

How Avoidable are Hospitalizations for Children With Medical Complexity? Understanding Parent Perspectives

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ABSTRACT

OBJECTIVE: Children with medical complexity (CMC) are a small group that utilizes large amounts of health care resources. Although parents are the primary healthcare decision-makers for their children, little is known from their perspective about why CMC are hospitalized. We sought to understand what parents think about factors leading to hospitalization and whether any recent hospitalizations might have been avoidable.

METHODS: We conducted qualitative, semistructured interviews with 35 parents of hospitalized CMC who receive care in the Pediatric Medical Home Program, a complex care program at University of California, Los Angeles. Interviews were conducted in English and in Spanish, audio-recorded, transcribed and translated, then coded in ATLAS.ti (Scientific Software Development GmbH, Berlin, Germany) for qualitative analysis. We sorted qualitative codes into groups with shared concepts, to generate emergent themes.

RESULTS: Parents described their experiences leading up to their children's hospitalization, but no one suggested that

the hospitalization was potentially avoidable. Most parents perceived their children as having higher susceptibility because of underlying conditions, perceived the symptoms they observed as high-risk, and described seeking emergent care only when they no longer were comfortable at home. Decisions about where to seek care were influenced by health care system factors such as accessibility and continuity of care. Most parents expressed a desire to learn more about their children's conditions and how best to care for them at home.

CONCLUSIONS: Parents of CMC believe that hospitalizations are largely unavoidable because of higher susceptibility and higher risk. Increasing parents' self-efficacy in caring for children at home might influence their decisions to seek emergent care.

KEYWORDS: children with medical complexity; hospital utilization; parent perspectives; qualitative research

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WHAT'S NEW

Despite increasing interest in reducing hospitalizations for children with medical complexity, relatively little is known from the parent perspective. Understanding parents' perceptions about whether hospitalizations are avoidable might help shape future interventions aimed at parents to reduce hospitalizations for children with medical complexity.

CHILDREN WITH MEDICAL complexity (CMC) have been defined as a subset of children with special health care needs who often have multiple, complex chronic medical conditions and major functional limitations.^{1,2} Although CMC represent a small proportion of all children,^{3,4} they account for disproportionately high health care costs,

driven largely by high utilization of hospital care.^{5,6} Previous studies have shown that CMC are hospitalized for a variety of reasons, but common conditions among hospitalized CMC include neurologic impairment, dependence upon medical devices such as gastrostomy and tracheostomy tubes, and respiratory concerns.^{7,8}

Avoiding hospitalization is a complicated issue for all children, with research focused primarily on early readmissions^{9,10} or “ambulatory care–sensitive conditions” such as asthma, for which timely and appropriate ambulatory care might be associated with reduced need for hospitalization.^{11,12} Previous work has characterized factors associated with hospitalizations or Emergency Department (ED) visits that might have been avoidable, but these studies do not focus on CMC.^{11–15} Furthermore, avoidance of hospitalizations for CMC

likely differs from children in general,¹⁶ in part because of high-risk medical conditions and increased susceptibility to serious illnesses. The emergence of pediatric complex care programs that improve quality and coordination of care for CMC,^{17–20} are credited with reductions in hospitalizations.²¹ Despite these efforts, evidence gaps remain and there is no clear consensus about whether most hospitalizations (including readmissions) among CMC are avoidable.²²

Understanding parent perspectives is essential to the study of CMC hospital utilization because parents are often the primary decision-makers regarding when to seek help. Conceptual frameworks describing personal health behaviors and utilization of health care services, in the context of health care systems and sociodemographic factors, have been widely used to help understand how patients and families make decisions about when and how to access care.^{23,24} There has been limited research, however, on caregiver perspectives or applying these conceptual models to hospital use among CMC. We are aware of only 1 previous study that has used formal qualitative methods to examine parent perspectives on risk and protective factors associated with hospitalizations among CMC, and only 8 patients were included.²⁵

The purpose of our study was to understand perspectives of parents of CMC enrolled in the Pediatric Medical Home Program (PMHP), a complex care program at University of California, Los Angeles (UCLA), about their decisions to bring their children in for acute care encounters that ultimately led to hospitalizations. Our goal was to identify potentially modifiable factors, to support development of future interventions to reduce overall hospital use, while acknowledging that many hospitalizations might not be avoidable. This qualitative study is part of a larger, ongoing project aimed at reducing hospitalizations among CMC. With the growth of complex care programs across the country, this study provides a unique perspective with important implications for improved systems of care.

METHODS

DESCRIPTION OF UCLA'S PMHP

The PMHP at UCLA provides primary care for CMC, with an emphasis on continuity of care and care coordination. On the basis of the American Academy of Pediatrics' principles of a high-quality medical home,²⁶ the PMHP at UCLA was launched in 2003 to deliver accessible, family-centered, continuous, comprehensive, coordinated, and culturally effective care to CMC from predominantly low-income communities. The program is staffed by a nurse practitioner, 3 to 4 full-time, bilingual care coordinators (called "family liaisons"), and general pediatrics faculty who supervise pediatrics residents assigned to specific families in their continuity clinics. A more detailed description of the PMHP services is available elsewhere.¹⁹ Services of the PMHP include interpreter services, appointment and procedure coordination, durable medical equipment and insurance authorization, and communication with community resources. Enrollment criteria

include having chronic conditions that make patients eligible for 2 distinct subspecialty care centers, as defined by California's Title V program for children with special health care needs (California Children's Services) in which all patients were enrolled.

At the time of this study, the PMHP had 180 patients enrolled, with a mean age of 7.4 years, 47% female, 78% Hispanic, 63% from Spanish-speaking households, and 100% publicly insured (3% with supplemental commercial insurance). The cohort had a wide array of primary diagnoses, including seizure disorders (42%), and use of medical technology (gastrostomy tubes, 53%; tracheostomies, 17%; and ventriculoperitoneal shunts, 12%). The initial PMHP cohort experienced a 50% decrease in the number of ED visits after enrollment,¹⁹ while achieving high parent satisfaction, particularly among Spanish-speaking families.²⁰

DESCRIPTION OF SAMPLE AND STUDY PROCEDURES

We conducted semistructured, qualitative interviews with 35 parents of hospitalized PMHP patients during their inpatient stays. Eligible interview participants were identified by reviewing the hospital census daily to find PMHP patients with an acute, unscheduled admission within the previous 24 hours. There were 8 families who declined to participate in the study (participation rate, 81%). These CMC, not represented in the study, were similar to the study participants in terms of severity of their underlying illnesses and health care utilization. Interviews were conducted between June 2013 and March 2014, at the Mattel Children's Hospital at UCLA. The interview guide asked parents to describe their experiences leading up to their children's current hospitalizations as well as hospitalizations in the past 12 months, and to reflect upon whether any of those circumstances might have been avoidable or what might be done differently in future situations. The interview guide was developed by the research team and then refined after the first several interviews, for clarity and completeness.

This study was approved by the UCLA institutional review board. After obtaining informed consent, interviews were conducted with parents in private rooms and audio-recorded. A bilingual and bicultural interviewer, not involved in delivering clinical care, led all interviews in either English or Spanish. A trained research assistant took notes and monitored the recording process at each interview. Recordings were transcribed and translated into English as necessary. Translations were completed by trained, bilingual research associates and checked for accuracy by a bilingual project manager. Recruitment of parents and interviews continued until we reached thematic saturation, meaning that no new information was being uncovered from additional interviews.

In addition to the qualitative interview data, we collected basic demographic information from each participant (such as self-reported race or ethnicity), and reviewed the medical records of patients after discharge, to gather basic clinical information (patient's age, use of medical devices at baseline, admission to the intensive care unit, and length of the index hospitalization).

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