



Medical foster care for children with chronic critical illness: Identifying strengths and challenges



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A B S T R A C T

Objectives: A growing population of children has chronic critical illness (CCI), defined as children with complex and chronic medical conditions who require repeated and prolonged ICU hospitalizations. Some of these children are unable to be cared for by their parents and are placed in medical foster care (MFC). We sought to better understand the potential strengths and challenges of MFC as a placement setting for children with CCI.

Methods: As part of a larger study exploring barriers to care for children with CCI, we conducted semi-structured interviews with healthcare professionals (inpatient; outpatient; home care; foster care) with extensive CCI experience. The subset of questions related to MFC was included in this analysis. Participants were recruited from 5 metropolitan areas across the US.

Results: Content analysis of 44 participant transcripts revealed the following themes: 1) why CCI children enter MFC; 2) transition from hospital into MFC; 3) potential strengths and 4) potential challenges of MFC for CCI children. Complicated hospitalizations commonly precede entrance into MFC for children with CCI, a transition complicated by delays in identifying need for MFC, limited MFC availability, and discharge training of foster parents. MFC strengths included quality MFC caregivers, MFC system supports, and a home environment. Challenges included separation from biological family, fragmented medical care, decision-making, variable quality, and transitioning out of MFC.

Conclusion: The advantages of MFC for CCI children can be potentially improved through intentional child welfare and health care system collaboration, protocols for hospital-to-MFC transitions, consistent medical homes, alternative medical decision-making policies, greater MFC availability, and broader biological family supports.

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1. Introduction

Children with medical complexity are those with chronic and severe health conditions, functional limitations, and high health care needs and utilization (Cohen, Kuo, Agrawal, et al., 2011). Over the past two decades, increasing numbers of children survive acute and chronic

Abbreviations: CCI, chronic critical illness; FC, foster care; MFC, medical foster care

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illnesses but remain dependent on multiple medications and medical technologies (Cohen et al., 2011; Kahn, Le, Angus, et al., 2015). These children represent the sickest of those with medical complexity, and are considered “chronically critically ill” (CCI) (Shapiro, Henderson, Hutton, and Boss, 2017). They have repeated and prolonged hospitalizations and require close outpatient supervision and intensive home care. When the daily care needs of a child with CCI exceed parental abilities or resources, the child may be placed into out-of-home care through the child welfare system (Seltzer, Henderson, and Boss, 2015).

There are over 437,000 children in foster care, on any given day, in the United States (Children's Bureau, 2017). The American Academy of Pediatrics estimates that 10% of children in foster care are medically complex or fragile (American Academy of Pediatrics, n.d.-a). This is disproportionately high compared to the < 1% of children with medical complexity in the general US population (Kuo, Cohen, Agrawal, Berry, and Casey, 2011). Unfortunately, current data does not tell us the prevalence within foster care of the subset of children with CCI. Due to state variation in classification, determination, and reporting of child welfare placements based on medical needs, it is difficult to reliably track children with CCI in the variety of foster care placement types (i.e., medical foster care (MFC), basic foster care, kinship care, group homes, institutions) (DeVooght & Blazey, 2012; Williams, Seltzer, and Boss, 2017). At the national level, foster care outcomes collected through the Adoption and Foster Care Analysis and Reporting System do not specify placements due to medical need or even distinguish MFC as a unique placement type (Children's Bureau, 2017).

MFC is designed to be a specialized placement setting within the child welfare system that provides medical care and supervision for children with complex medical conditions (Seltzer et al., 2015). MFC parents typically receive additional training, supports, and higher reimbursement than basic foster parents to help them provide care for children with intensive medical needs (Seltzer et al., 2015). While previous work has documented high healthcare needs and unmet healthcare issues within the general foster care population (Council On Foster Care, 2015; Mekonnen, Noonan, and Rubin, 2009; Steenbakkers, Van Der Steen, and Grietens, 2018; Takayama, Wolfe, and Coulter, 1998), little is known about how MFC might address the healthcare needs of the very complex CCI population. There has been some exploration of the foster parent experience in caring for children with medical complexity (Brown and Rodger, 2009; Greiner, Ross, Brown, Beal, and Sherman, 2015; Lauver, 2008; Lauver, 2010), but data are sparse regarding the interaction of children in MFC with the healthcare system. Because these contacts are frequent for children with CCI, healthcare professionals can offer valuable insights regarding the impact of MFC on medical care for these children. We designed this exploratory study of the potential strengths and challenges of MFC for children with CCI as a first step in identifying potential targets for interventions, policies, and research in optimizing the care of this vulnerable population.

2. Participants and methods

This qualitative study is part of a larger study exploring barriers to care for children with CCI, defined here as “children with complex and chronic medical conditions who require repeated and prolonged ICU hospitalizations.” (Seltzer et al., 2015). Between 12/15–3/16 we conducted in-person and telephone semi-structured interviews with participants from 5 metropolitan areas (Seattle, WA, Houston, TX, Jackson, MS, Baltimore, MD, and Philadelphia, PA). Diverse professional stakeholders were recruited via purposive and snowball sampling, a sampling approach used for populations that do not form distinct groups, such as CCI professionals (Goodman, 1961). Initial recruitment started with professionals known by the authors for their CCI expertise. These participants were asked to recommend other professionals who they knew to have important CCI experiences. Professional recruitment was continued until there was representation of participants with a diversity

Table 1
Foster Care-Related Questions from CCI Stakeholder Interview Guide.

Question for every CCI stakeholder:
1) Can you tell me about any experiences you might have had regarding children with chronic critical illness in foster care?
Additional questions for stakeholders with specific foster care expertise:
2) What are some of the primary reasons why these children enter foster care?
3) What are the challenges of caring for children with chronic critical illness within the foster care system?
4) What are the barriers to discharging these children from the hospital to foster care? What about the barriers to then keeping them out of the hospital?
5) What can you tell us about how medical care is coordinated for these children? How are medical records maintained and shared?
6) What training is provided to foster parents to care for these children? In your experience, has this training been sufficient?
7) What are the placement options for children with chronic critical illness in foster care? What are the pros and cons of each option?
8) How are medical decisions made for children with chronic critical illness in foster care?
9) Who usually takes part in these conversations involving medical decisions and goals of care? Who do you think should take part in such discussions?
10) What do you with the healthcare team knew about caring for children with chronic critical illness in foster care?
11) What do you see as important interactions between the legal system and medical foster care for children like this?

of roles related to CCI care.

Given the lack of existing survey instruments relevant to pediatric CCI, we designed our survey based on literature review and consultation with various clinicians providing pediatric CCI care. A priori questions that targeted foster care issues relevant to children with CCI were included in the survey. All participants were asked to describe their experiences regarding foster care (FC) for children with CCI; participants who indicated substantial FC expertise (e.g., clinician in foster care clinic, nurse who is former foster parent) were then asked an additional 10 questions (Table 1). We included in the analysis all interview content related to FC or MFC for children with CCI. All interviews were conducted by one of the authors (EPW) and were audio-taped and transcribed.

Additional study methods and details of content analysis have been published previously (Boss, Williams, Henderson, et al., 2017). Conventional content analysis was applied to the interview transcripts (Hsieh and Shannon, 2005). Each author individually reviewed and assigned codes to the transcribed interviews. The authors then jointly reviewed codes and grouped codes into code families and then themes. One author (RB) used the master codebook to review all transcripts; coding discrepancies were resolved through discussion with the larger group. This study was approved by the Johns Hopkins Institutional Review Board. Informed consent was obtained.

3. Results

We interviewed 44 professionals, including 23 physicians, 15 nurses, 4 social workers, 1 lawyer, and 1 healthcare administrator (Table 2). All 44 professionals had prior experiences with foster care for children with medical needs; 5 professionals identified as having extensive foster care expertise, characterized as current/ prior

Table 2
Participant characteristics.

Primary role	Metropolitan area				
	Baltimore	Jackson	Philadelphia	Houston	Seattle
Physician	5	5	5	3	5
Nurse/NP	6	2	4	3	–
Social worker	1	3	–	–	–
Other	1	1	–	–	–
Total (n)	13	11	9	6	5

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