Caring For Children in State Custody: Recommendations for Hospital-Based Teams

Emily Rothenberg; Megan Wiebe, M.Ed., CCLS; Jessika Boles, Ph.D., CCLS

Introduction

- Nationally there are over 400,000 children in foster care each year. A significant portion of these children will be hospitalized during their time in out of home care.
- Although it is known that nearly 6 million children in the United States are hospitalized each year, current data does not track the incidence or outcomes of hospitalization for children in temporary or long-term state custody.
- It is known that roughly half of all children in foster care have a chronic health condition and there are 20,000 to 40,000 children in medical foster care each year.
- Hospitalization is developmentally and psychosocially challenging for children of all backgrounds and abilities, but hospitalized children in state custody are at a higher risk of developing pediatric medical traumatic stress and struggling with their medical experience because they have likely experienced numerous traumas prior to the current healthcare encounter.

PROBLEM: To date, there is almost nothing known about the experiences of hospitalized children in state custody.

PURPOSE: Therefore, the purpose of this study is to understand the needs and experiences of hospitalized children in state custody through provider perspectives, thereby allowing the identification and implementation of interventions to promote adaptive coping efforts and resilience in this at-risk population.

Methods

- Twenty-five healthcare providers at an academic children's hospital in the Southeastern United States completed an in-depth semi-structured interview about their experiences caring for hospitalized children in state custody.
- Participants were recruited via a hospital-wide research Listserv.
- All interviews were audio-recorded and transcribed, and they underwent thematic analysis using an inductive, line-by-line approach by three members of the research team.
- The intercoder reliability rate was 84.3% agreement.

Participant Demographics

Table 1. *Participant demographics.*

Variables	Variables	Frequency	Percentage (%)
Occupation	Nurse	8	32.0
	Physician	5	20.0
	Social Worker	5	20.0
	Child Life Specialist	3	12.0
	Nurse Practitioner	1	4.0
	Pediatric Audiologist	1	4.0
	Registered Dietician	1	4.0
	Patient Teacher	1	4.0
Sex	Woman	25	100.0
	Man	0	0.0

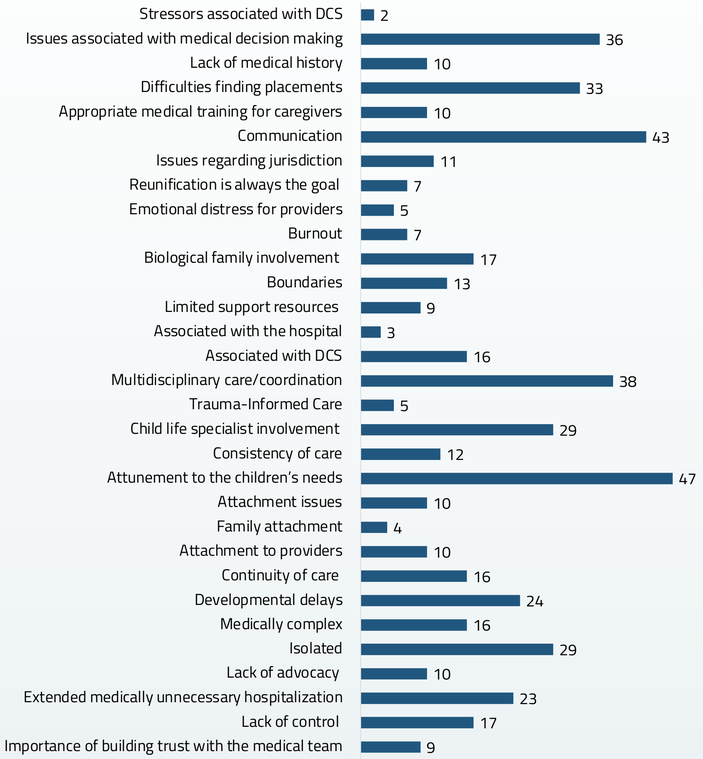
Note. N = 25

Results

Table 2. *Themes*

PROVIDER EXPERIENCES AND NEEDS	
Theme 1: Stressors associated with DCS ▪ Issues associated with medical decision making ▪ Lack of medical history ▪ Difficulties finding placements ▪ Appropriate medical training for caregivers ▪ Communication ▪ Issues regarding jurisdiction ▪ Reunification is always the goal	**Issues associated with medical decision making:** *"Sometimes children are in foster care and their parents still have medical decision making which can be very difficult. We have to reach out to the parent first, and if they are not available then we reach out to the Department of Children's Services nurse for consent. Sometimes that can be a significant delay of care."* (12) **Lack of medical history:** *"It's not uncommon to ask a question about a child with a complex medical history—you know, a long-time history—and for the parent or caregiver to say, 'Well I don't know, they just came to my house last week.'"* (8)
Theme 2: Emotional distress for providers ▪ Burnout ▪ Biological family involvement ▪ Boundaries	**Boundaries:** *"Another very memorable thing about their [child in DCS custody] specific situation was a respiratory therapist at that hospital ended up becoming their foster placement. And that was really interesting just to see from a boundary perspective how she became their foster mom, and as they prepared to discharge with her, how her boundaries looked with them [hospital staff]. She was no longer obviously their respiratory therapist that they were working with, but other staff members' boundaries shifted as it became their friend's foster kid rather than the patient they were treating. Then, even after discharge, they became a patient that we often got updates on because everyone knew the foster mom that they were living with."* (2)
Theme 3: Limited support resources ▪ Associated with the hospital ▪ Associated with DCS	**Associated with DCS:** *"It was really hard; there was a lot of back and forth between what the child needed and what could be provided. So, as a hospital and healthcare team we might say the child needs XYZ, but the DCS caseworker would say we can only offer AB and C. So, we could identify their needs, but we couldn't always meet them because they were in DCS custody or there were decisions that needed to be made quickly."* (31)
Theme 4: Multidisciplinary care/coordination ▪ Trauma-Informed Care ▪ Child life specialist involvement ▪ Consistency of care	**Trauma-Informed Care:** *"We take a trauma-informed approach with all of the patients, but more so with the kids in state custody."* (11) **Child life specialist involvement:** *"I [child life specialist] provided a lot of support and normalization in the hospital environment, creating some structure and routine for him while he was here."* (5)
Theme 5: Attunement to the children's needs	*"When we're not attuned to what a child needs and we're not willing to remove ourselves from the situation and pay attention to them, that can be retraumatizing. The last thing a child [in state custody] in that vulnerable state needs to be is retraumatized "* (32)
PATIENT EXPERIENCES AND NEEDS	
Theme 6: Attachment issues ▪ Family attachment ▪ Attachment to providers ▪ Continuity of care	**Family attachment:** *"I could tell that there was already bonding in place with the foster care child and his new foster family. He was already calling her mom and had been in her custody for just a few days. So, I could see that he was making progress, especially in a situation where he was medically complex…and being uprooted and moved from one foster home to another."* (15)
Theme 7: Developmental delays	*"We know children in foster care experience developmental differences, disorders, and delays for a wide variety of reasons that I'm sure are more complicated than I can understand."* (8)
Theme 8: Medically complex	*"I can think of several cases where the scenario was kind of the same: the child was medically complex and wasn't able to be cared for at home, and they were in the hospital with a foster family waiting to take them home. They had to wait on the DCS system to have all the right things in place for that child just to be discharged and sent home with his foster family."* (17)
Theme 9: Isolated ▪ Lack of advocacy	**Isolated:** *"They're in the most restricted environment that they could be in because they aren't with family or friends. They're in a hospital which is isolating, and they may not have people visiting them."* (16)
Theme 10: Extended medically unnecessary hospitalization	*"I've had kids that get admitted to the ER because they're in state's custody, and they don't technically have a reason to be admitted, it's just a situational issue…If they are admitted, they're there for a prolonged period of time even though they may be medically stable. They're just waiting for a proper placement by the state, which is ultimately not good for them."* (33)
Theme 11: Lack of control	*"Physically, there is just the lack of choice of where they can go, and what they can do, and who they can be with."* (9)
Theme 12: Importance of building trust with the medical team	*"If you say you're going to come back, come back. Predictability. Building trust in all those things that you would want to do outside the hospital, but especially in the hospital to help them see that there is that kind of consistency."* (9)

Figure 1: **Themes by Frequency of Mention**



Discussion and Implications

- Participants identified a variety of themes related to their experiences caring for hospitalized children in state custody, as well as perceived needs for themselves and their patients.
- Twelve themes were organized into two categories: (1) Provider Experiences and Needs, and (2) Patient Experiences and Needs.
- The most prevalent themes in order of decreasing frequency of participant mention were (1) attunement to the children's needs, (2) communication, (3) multidisciplinary care/coordination, (4) issues associated with medical decision making, and (5) difficulties finding placements.

Given these findings, the practical implications of this study are:

1. **Training:** Enhanced training for staff on the psychosocial and behavioral needs of children in DCS custody is necessary to better understand and meet the needs of this population.
2. **Resources:** As facilities seem to lack sufficient resources, it is essential for them to form partnerships with government agencies and other institutions; this will help them secure additional resources, utilize them more effectively, and better advocate for this population.
3. **Protocols:** Facilities should create and implement best practices protocols to better improve in communication and decision making for this population.