

# The Experiences and Unmet Needs of Caregivers of Children with Medical Complexities - A Qualitative Study

Children's Healthcare, Illness, Legacy, & Loss Lab Directed By Dr. Jessika Boles  
Presenters: Vanessa Torano, Nora Wang

## Introduction

Children with medical complexity are children that have “severe and pervasive” medical needs (Edelstein et. al., 2016). Medical advancements have allowed for children with medical complexities to receive most of their daily care needs at home. This has created new challenges for caregivers as they strive to meet the medical, social, emotional, and financial needs of their child. The aim of our study is to understand the specific challenges and unmet needs of caregivers of children with medical complexity.

## Research Questions

1. How do parent/caregivers describe their experiences with caring for a child with medical complexity?
2. What challenges and unmet needs do parent/caregivers of a child with medical complexity identify?

## Literature Review

- Prior studies have maintained that caregivers of children with medical complexity are facing a greater burden of care than healthcare teams and the general public. They have substantial responsibilities that have a significant impact on their family and daily life. (Page et al., 2020)
- A recent study that conducted in-depth interviews with parents of children with medical complexity stated that accessibility barriers impaired care delivery at home and directly impacted children's participation in family life. (Black et al., 2022)
- Being a chronic need for children with medical complexity, pediatric home health care influences the family's physical, mental, and financial well-being. In addition, parents often need to fight for services and make out-of-pocket payments. (Boss et al., 2019)
- Based on the 2016-2017 National Survey of Children's Health, parents of children with medical complexity were at higher risks of poor or fair mental health than parents of children with non-complex special health needs and of children without special health needs. (Bayer et al., 2021)
- Communication challenges in the care of children with medical complexity were widely reported in prior studies. Technological and organizational barriers in the health care system, inadequate access to health information, and poor collaboration in care are among the most prominent challenges. (Adams et al., 2021)

## Results

Themes	Sub-themes
Being a caregiver of children with medical complexities involves many responsibilities.	<p>Around the clock monitoring of the child, including appointment/medication management, schooling, and observations at night.</p> <p>Physically moving the child.</p> <p>· <i>“It's hot, yes, yes, and it's a lot of effort...when I push her I'm pushing about 100 pounds up the hill, a steep hill. And that is exhausting. (laughs)”</i></p> <p>Feeding the child and making food and formula.</p> <p>Understanding and speaking for the child.</p>
Caregivers face a lack of respite care and skilled supports.	<p>Respite care is generally difficult to find.</p> <p>Skilled and timely supports are lacking, especially home nursing care.</p>
Caregivers struggle with financial strains and high costs of care.	<p>Complex care is very expensive and can be financially devastating to caregivers.</p> <p>· <i>“Every single day I'll go to the mailbox and I'll be terrified I'm going to get a letter stating that I'm going to lose money, or I owe money.”</i></p> <p>A lot of things necessary for the family are not covered by the insurance and caregivers have to look for other funding sources.</p> <p>· <i>“I do think she needs equipment. We were looking at this sleeping system...It's 5,000 dollars. I can't, we can't do that. It's not covered by insurance.”</i></p> <p>Negotiating bills or services involves considerable difficulties.</p> <p>Traveling long distance causes greater financial burden in addition to being time- and energy- consuming for both the child and the caregiver.</p>
Caregivers face challenges with mental health and wellbeing.	<p>Caregivers find it difficult to fit into a group and opportunities to connect with other caregivers who understand are limited.</p> <p>Caregivers commonly feel anxious or worried about the child's integration into “normative” contexts like school and peer groups.</p> <p>Caregivers have to cope with multiple stressors.</p> <p>· <i>“I read something on Facebook once that said never let the storms of your life get your kids wet, and I cried I cried over that for I don't know probably half the day because I've tried to stretch out and bring an umbrella to protect my kids, but my kids are drenched.”</i></p>
Transitions are stressful for children with medical complexities and their families.	<p>Transitions to adult care can be unpredictable and require considerable effort and attention.</p> <p>Transitions between home, school, and healthcare institutions are lengthy and stressful.</p>
Communication across teams within the healthcare system is lacking.	<p>While care coordination—especially between different healthcare providers—is urgently needed, it is critically lacking for families.</p> <p>· <i>“...twenty specialties and you got a juggle how are they communicating with each other and you have to remember all the details to share and every appointment.”</i></p> <p>It is hard for caregivers to get agreement across teams on a clear care plan due to a lack of communication.</p>
Caregivers are learning to be an advocate.	<p>Many caregivers are advocating 24/7 for their child on their own.</p> <p>· <i>“That's one of the hardest things about being a mom of a kid that's got complex medical needs is that you have to learn how to advocate because if I didn't advocate, I don't know where we would be.”</i></p> <p>More physical inclusivity is pressingly needed, as advocated by many caregivers.</p>
Purposefully inclusive environments for children with medical complexities are needed.	<p>Caregivers believe that child needs more opportunities for peer interaction and socialization activities.</p> <p>Social or school environments that prevent discrimination and stigmatization and provide adequate care for the child are desirable.</p>
Caregivers have a strong need for connections and community.	<p>Caregivers genuinely wish to connect with and learn from others with similar experience, while such communities or groups are often hard to find.</p> <p>· <i>“...much easier to just sort of talk to someone who has done it, that sort of community is harder to come by.”</i></p>
COVID has generally made things harder for families.	<p>Less staff were able to help during COVID, which could be both inconvenient and risky for the child.</p> <p>COVID has caused delays in care and a lack of acute care resources.</p> <p>COVID has led to more time in isolation or quarantine and less access to resources.</p>

## Demographic Table

Table 1. Participant demographics.

Variables	Variables	Frequency	Percentage (%)
<b>Age</b>	Less than 20	0	0.0
	20 to 29 years	0	0.0
	30 to 39 years	9	47.4
	40 to 49 years	8	42.1
	50 years or older	2	10.5
<b>Race</b>	White	17	89.5
	Hispanic or Latino	0	10.5
	Black/African American	2	0.0
	Native American	0	0.0
	Asian/Pacific Islander	0	0.0
	Other	0	0.0
<b>Gender</b>	Female	18	94.7
	Male	1	5.3
	Other	0	0.0
	Prefer not to say	0	0.0
<b>Education</b>	Less than high school	0	0
	HS Diploma GED or	0	0
	Some college < 2yrs	3	15.8
	Associate's Degree	3	15.8
	Technical training	1	5.3
	Bachelor's Degree	8	42.1
	Graduate Degree	4	21.1
Post-graduate degree	0	0.0	
<b>Child's Age</b>	0 to 3 years	4	21.1
	3 to 6 years	7	36.8
	6 to 9 years	1	5.3
	9 to 12 years	2	10.5
	12-15 years	4	21.1
	15-18 years	1	5.3

## Methods

**Participants:** The study consisted of 19 parent/caregivers of children under age 25 who receive care in the complex care clinic at Monroe Carell Jr. Children's Hospital at Vanderbilt.

**Procedure:** Each participant completed a demographic survey and an in depth interview regarding their experience as a caregiver to a child with medical complexity

**Analysis:** The interview data was analyzed using an inductive coding approach. Each transcript was independently coded by two members of the research team

## Discussion & Future Directions

The results demonstrate that there are many challenges faced by parent/caregivers of children with medical complexity. It is important to understand and lessen these challenges because they may increase risk of burnout, mental health issues, substance abuse, and suicidality for parent/caregivers which can have negative ramifications for the family unit and the child with medical complexity (Cardenas et. al, 2022). To combat these effects, efforts can be made to increase inclusivity of public spaces, increase mental health supports of caregivers, and increase accessibility to informational resources across caregivers of children with medical complexity.