





## Feeding after congenital heart surgery: a mixed-methods study of the caregiver experience

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## Original Article

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**Abstract**

**Objectives:** Feeding difficulties after congenital heart surgery are a common concern for caregivers of children with CHD. Insight into the intricacies of their experience is lacking. With a better understanding, healthcare providers can continue to optimize the approach and support mechanisms for these families. This study will explore the psychosocial impacts on caregivers, define barriers to care, and identify areas to improve their care. **Study Design:** This mixed-methods study combined semi-structured interviews with surveys. Purposive sampling targeted caregivers of a child who underwent heart surgery and was discharged with alternative enteral feeding access. A hybrid inductive-deductive methodology was used to analyse interview transcripts. Survey scores were compared to interview content for concordance. **Results:** Fifteen interviews were conducted with socio-demographically diverse caregivers. Feeding difficulties were often identified as their greatest challenge, with the laborious feeding schedule, sleep deprivation, and tube management being common contributors. Most caregivers described feeling overwhelmed and worried. Time-intensive feeding schedules and lack of appropriate childcare options precluded caregivers' ability to work. Barriers to care included imperfect feeding education, proximity of specialist clinics, and issues with medical supply companies. Caregiver proposals for improved care addressed easing the transition home, improving emotional support mechanisms, and intensifying feeding therapy for expedited tube removal. **Conclusion:** This study describes the psychosocial toll on the caregiver, typical barriers to care, and ideas for improved provision of care. These themes and ideas can be used to advance the family-centered approach to feeding difficulties after heart surgery.

Each year in the United States, roughly 40,000 children are born with CHD and approximately one-third of those children will eventually undergo corrective surgery.<sup>1</sup> While children and their caregivers experience many challenges after congenital heart surgery, feeding difficulties are exceptionally common.<sup>2</sup> Feeding difficulties are often multifactorial and may be related to the sequelae of CHD, surgical complications, effects of prolonged hospitalisation, associated comorbidities, or many other factors.<sup>3</sup> Roughly half of infants who undergo heart surgery in the first month of life will require alternative enteral feeding strategies at the time of their hospital discharge to achieve adequate nutrition and growth goals.<sup>1,2,4–6</sup> Unsurprisingly, feeding difficulties have often been identified by families as the leading cause of non-cardiac morbidity in the early post-operative period and a significant source of caregiver stress.<sup>7–9</sup> Parents have described feeding a medically complex child after heart surgery to be a time-consuming and anxiety-inducing endeavour.<sup>8–10</sup> Providing adequate education and support for caregivers is one avenue to not only improve post-operative nutrition and growth of the child but also mitigate parental stress.<sup>10</sup>

While several studies<sup>7,9,11</sup> have sought to describe the overall experience of caregivers after hospital discharge, few have been dedicated to the specific topic of managing feeding difficulties. As such, insight into the magnitude of the impact that feeding challenges can have on a caregiver's well-being is lacking.<sup>1,7,9</sup> Further investigation into this unique experience could inform strategies to help these families cope with and overcome the challenges associated with feeding a child after heart surgery and possibly mitigate long-term detrimental outcomes (e.g., feeding tube dependence).<sup>8,9</sup> Perspectives gained through this study will serve as the first stage of a larger study intended to develop and pilot test a specific intervention strategy for families managing feeding difficulties after heart surgery.

### Specific Aims:

1. What is the impact (physical/emotional/financial) of caring for a child with feeding difficulties?
2. What barriers are faced (personal/system-based) when managing the child's feeding difficulties?
3. What do caregivers identify as beneficial support mechanisms within the healthcare system and beyond?
4. What is the ideal healthcare delivery system from the caregiver's perspective?

## Materials and methods

### Study design

This mixed-methods study combined a phenomenological qualitative method via caregiver interviews with qualitative survey responses. Through semi-structured interviews, researchers explored predefined topics while allowing the caregiver to elaborate and generate ideas throughout the discussion. All interviews were conducted via telephone to reduce the burden of time and travel on the caregiver and to allow equal access to participants residing far from our institution. Caregivers were interviewed within four months of hospital discharge following congenital heart surgery. At the time of the interview, caregivers completed the Feeding/Swallowing Impact Survey, a validated instrument that measures the impact of feeding/swallowing disorders on the caregiver's health-related quality of life.<sup>12</sup>

### Participant recruitment

Purposive sampling recruited caregivers of children treated at a tertiary care children's hospital. Eligible participants were selected from the institution's cardiothoracic surgery patient discharge log. Inclusion criteria included: primary caregiver of a child  $\leq 18$  years of age who underwent congenital heart surgery, was discharged home with alternative enteral feeding access (nasogastric, nasojejunal, or gastrostomy tube) between April and October 2022, and who continued to have alternative feeding access at the time of study enrolment. Eligible participants were contacted by phone by the trained research coordinator (SM) within 4 months of hospital discharge and invited to participate. Participant enrolment occurred from May to December 2022. At the time of initial contact, the research coordinator discussed the study's specific aims and the voluntary nature of participation, and informed consent was obtained verbally.

### Data collection

Socio-demographic data were obtained through review of the electronic health record and/or caregiver self-reporting. Caregiver socio-demographics included caregiver role, preferred language, and distance from residence to the tertiary care hospital. Children's demographics included age and method of feeding at time of discharge, insurance status, parent-reported race, and medical comorbidities.

Interviews were conducted by one of two female researchers (EW & CP) trained in qualitative research and interview techniques. Interviewers were uninvolved in the patient's medical care to reduce researcher bias and encourage caregiver candour. Caregivers requiring language translation services were interviewed by a professional translator. Prior to beginning the interview, caregivers were reminded of the study aims, verbal

consent for an audio-recorded interview was confirmed and the interviewers administered the Feeding/Swallowing Impact Survey. Interview duration was  $<60$  minutes. Interviewers used a semi-structured interview guide (Supplementary Figure S1) developed by Nikhila Raol that underwent pilot testing in simulated interviews and subsequent refinement throughout the study. Interviewers recorded field notes during and after interviews. Audio recordings of the interviews were transcribed verbatim using Descript, a professional transcription software (Descript, Inc. Version 52.1.0, 2022). Auto-generated transcripts were manually compared to the audio files, edited for textual accuracy, and anonymized through the removal of patient identifiers. Participant enrolment concluded upon achievement of thematic saturation, defined by the point at which new interviews failed to generate novel codes or information and future interviews would be unlikely to yield new themes.<sup>13</sup>

### Analysis

Qualitative data analysis was performed using a hybrid of inductive and deductive methods to honour the study's specific aims while allowing for a broad exploration of topics. Interview transcripts were coded and queried using NVivo, a software designed to facilitate the management and analysis of qualitative data (QRS NVivo Version 12, 2019). Using consensus coding, an initial sample of three interviews was inductively coded by three separate analysts who worked independently (EW, CP, SM). Each individual coder developed their own unique codes and codebook. After a rigorous team review of the three codebooks, it was determined there was strong inter-coder consistency across the codebooks. Despite minor differences in code nomenclature, all three codebooks had similar patterns and overarching themes. A composite codebook was created by EW and approved by the team. The three initial interviews underwent consensus coding again, with deductive coding done individually by one of two analysts (EW or CP) using the composite codebook. The coding was compared using Nvivo Coding Comparison Queries, in which the percentage agreement of the codes between the two coders ranged from 80.0–100%. This demonstrated strong inter-coder agreement. Of the remaining interviews, four randomly selected interviews underwent consensus coding by two separate analysts, and their codes were again queried in Nvivo to ensure continued concordance between the analysts. The remainder of the interviews underwent split coding by a single coder, which was reviewed by other authors to ensure the coding stayed true to the codebook. The codebook was a dynamic document that was updated and refined to accommodate additional codes and themes identified in successive interviews. The team frequently returned to the transcripts for content familiarisation. At adjudication meetings that occurred at various time points throughout the project, transcript coding and thematic analysis were reviewed by the entire research team and colleagues outside the project to confirm consistency and check biases. Any discrepancies were discussed by the team and adjudicated by NR. Quantitative analysis of survey responses was performed through Nvivo queries and Microsoft Excel (version 16.71).

## Results

### Descriptive

In total, 22 eligible families were contacted for study enrolment, of which 21 families agreed to enrol in the study. Of the 21 families

enrolled, 15 families were successfully interviewed. Three families could not be reached after consenting, two families' children no longer had feeding difficulties at the time of interview, and one family's child expired prior to the scheduled interview. Of the 15 interviews, two were conducted with mother-father dyads and 13 were with the mother alone, for a total of 17 caregivers interviewed. The families were socio-demographically diverse (Table 1). The average age of the child at the time of discharge was 3.5 months (range = 0.75–8 months). Interviews were conducted an average of 66 days after hospital discharge (range = 36–136 days).

### Part I: qualitative

The data are presented in four broad categories, with corresponding themes that emerged from the data (Fig. 1). These include (1) psychosocial impact on caregivers; (2) barriers to care; (3) support mechanisms for caregivers; and (4) change proposals for ideal health care delivery. Major themes, subthemes, codes, and representative quotations for each category are presented in Table 2. Themes are further discussed below.

#### Psychosocial impact on caregivers

A major theme that emerged from the discussions was the emotional toll experienced by caregivers. Caregivers shared a multitude of emotions (Table 2), but most reported feeling overwhelmed and worried. Parents often felt overwhelmed by the demands of caring for their child, noting sleep deprivation and a time-intensive feeding schedule as common contributing factors. Additionally, most caregivers described feeling regularly overcome with worry. These worries most frequently included the current and future health of their child, the adequacy with which they were managing their child's feeding difficulties, and an overall feeling of uncertainty. In reference to the emotional distress they experienced, caregivers frequently desired increased mental health support and resources from their child's healthcare team.

Though caregivers had many concerns about their child's overall care, feeding difficulties were frequently cited as the most challenging aspect of care. Feeding tube specific concerns, including learning how to manage and replace a feeding tube at home, were common themes. Other common themes included fears that their child was not receiving adequate nutrition, breathing concerns while feeding, loss of feeding skills, development of oral aversion, and a desire for their child to feed like a "normal" baby.

In many cases, the impact of feeding difficulties affected not only the caregivers but the entire family. When caregivers had other children at home, they reported difficulty managing their child's feeding problems while also tending to the siblings. Protective factors when caring for multiple children at home included having a partner or extended family to assist in the care of other children.

Many caregivers commented that the demands of their child's time-intensive feeding schedule necessitated extended time away from work with consequent financial strain. While some families were able to share childcare with nearby extended families, others struggled to find childcare that could accommodate their child's complex needs.

#### Barriers to care

Caregivers experienced many barriers when managing their child's feeding, both at a personal level and at the level of the healthcare system (Table 2). While most parents expressed

**Table 1.** Caregiver and child demographic data.

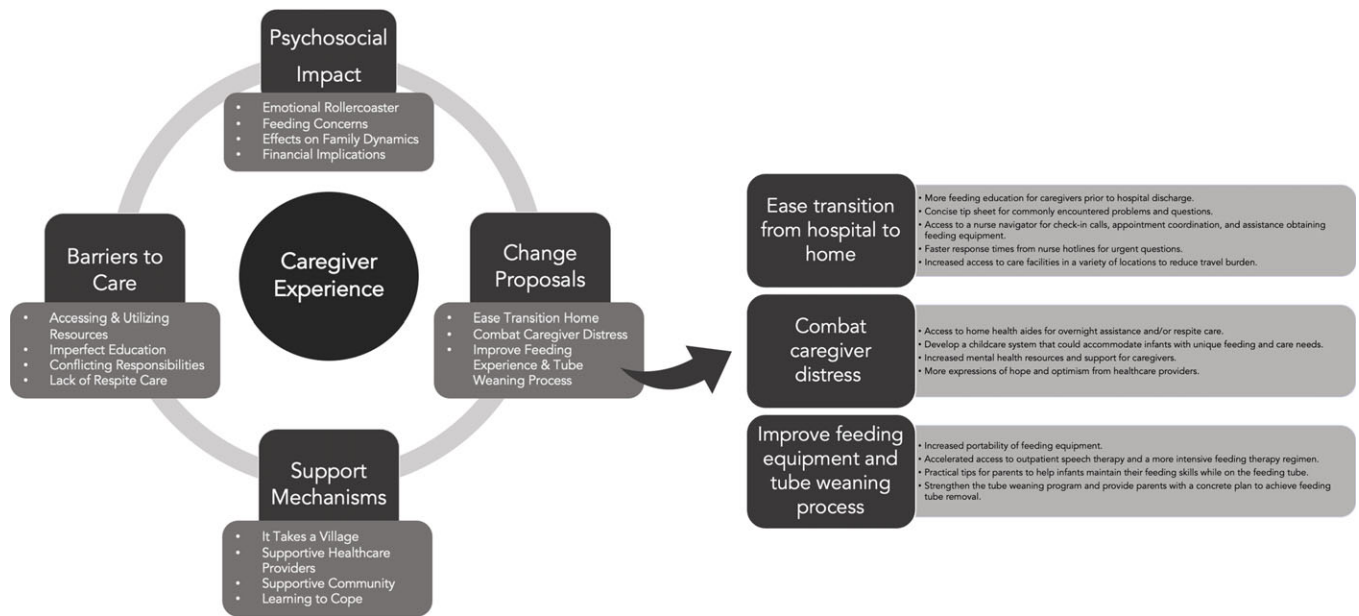
Caregiver demographics		N = 17 (%)
Role		
Mother		15 (88.2)
Father		2 (11.8)
Preferred language		
English		15 (88.2)
Spanish		2 (11.8)
Distance from residence to tertiary hospital (miles)		
<20		5 (29.4)
21–100		9 (53.0)
>100		3 (17.6)
Child demographics		N = 15 (%)
Age at time of discharge (months)		
<2		4 (26.7)
2–4		7 (46.6)
>4		4 (26.7)
Method of feeding at discharge		
NG / NJ tube		10 (66.7)
Gastrostomy tube		5 (33.3)
Enrolled in feeding therapy		
Yes		12 (80.0)
No		3 (20.0)
Insurance coverage		
Private		2 (13.3)
State-sponsored		13 (86.7)
Race		
Asian / Pacific Islander		1 (6.7)
Black or African American		3 (20.0)
Hispanic or Latino		5 (33.3)
White		4 (26.7)
Multiracial		2 (13.3)
Cardiac Abnormality <sup>Δ</sup>		
Cyanotic heart disease		12 (80.0)
Acyanotic heart disease		3 (20.0)
Single ventricle defect		1 (6.7)
Medical Comorbidity(-ies) <sup>Δ</sup>		
Preterm birth (<37 weeks)		4 (26.7)
Chromosomal disorder		7 (47.0)
GERD		4 (26.7)
Upper airway disease <sup>+</sup>		2 (13.3)
Lower airway disease <sup>*</sup>		2 (13.3)

GERD=gastroesophageal reflux disease; NG=nasogastric; NJ=nasojunal.

<sup>Δ</sup>child may have more than one condition.

<sup>+</sup>e.g., laryngomalacia and subglottic stenosis.

<sup>\*</sup>e.g., pulmonary hypertension and chronic lung disease.



**Figure 1.** Major themes, subthemes, and change proposals that emerged from the interviews.

appreciation for the healthcare providers that taught them how to manage their child’s feeding issues, many still felt apprehensive about their level of education in the early period after hospital discharge.

Some parents noted feeling a disconnect with their child’s providers, feeling as if they were not on the same page about their child’s care. At times, this interfered with getting their child appointments with specialists. Other times, parents were left wanting more from their providers.

Barriers to care exist at the level of the healthcare system as well. Some caregivers noted issues with insurance covering specific providers or essential feeding equipment, all of which interfered with providing the best care for their child. Numerous parents expressed frustration with the medical supply companies, recounting frequent struggles to get the correct supplies at the correct time. Another common sentiment was the lack of specialists located near the family’s residence. Multiple families reported travelling more than an hour to get their children to their various weekly appointments.

*Support mechanisms*

When describing the emotional impact and complex care requirements of their children, caregivers commonly identified various support mechanisms that were essential to their success (Table 2). These mechanisms fall into three general types: community support; support from healthcare providers; and supporting oneself through coping mechanisms. One common remark was that caring for a medically complex child “takes a village” that requires support from families, communities, and parent-support groups. Many caregivers also expressed gratitude for their healthcare providers who offered medical advice, guidance, care coordination, and emotional support. Finally, caregivers shared their personal methods of coping and how they learned to care for themselves during a stressful time. Common coping mechanisms included journaling, professional counselling, prayer, and finding comfort in knowledge through education about their child’s illness.

*Change proposals for ideal healthcare delivery*

Caregivers provided many ideas to improve their experience of managing their child’s feeding difficulties. Proposals addressed three key areas for improvement: easing their transition home, combatting caregiver distress, and improving the tube weaning process (Fig. 1).

*Part II: qualitative*

The Feeding/Swallowing Impact Survey scores were collected from 14 of the 15 interviews; the survey was not completed at the time of one interview in error and subsequent attempts to reach the caregiver were unsuccessful. The caregivers’ subsection and total scores were dichotomised to two groups, low (n = 7) or high (n = 7), whether the score was less than or greater than the median score.

Select demographic variables were associated with a higher total survey score (Fig. 2). Caregivers more likely to be in the high score group included those whose children were discharged at age <2 months or with a nasogastric tube. The caregiver’s preferred language, distance from hospital, or insurance type did not appear to influence score group distribution.

The frequency of specific codes used during an interview was compared to the associated total survey score (Fig. 2). Codes that were associated with a low total survey score included access to community and familial support, care coordination, parent-support groups, and speech therapy. The low score group had fewer codes associated with negative emotions (e.g., fearful, helpless) and more codes associated with positive emotions (e.g., hopeful, managing well).

The frequency of codes used during an interview was then compared to the Feeding/Swallowing Impact Survey subsection score to assess for concordance. For the survey subsection that assesses “carrying out daily activities,” codes that related to strain on their familial, job-related, and financial responsibilities were seen more frequently in the high subsection score group. For the subsection that assessed “problems worrying,” the high and low score groups had a similar number of codes related to caregiver



**Table 2.** Major themes of interview content.

What is the impact (physical/emotional/financial) of caring for a child with feeding difficulties?			
Theme	Subtheme	Codes	Representative Quote(s)
Emotional rollercoaster ride	Caregivers often felt emotionally overwhelmed	<ul style="list-style-type: none"> <li>Sleep deprived</li> <li>Traumatized</li> <li>Helpless</li> <li>Sad</li> </ul>	<p>"I was doing all the feedings the way they scheduled them. And I did everything they told me to do. And still, sometimes we would go and he didn't gain any weight and then, how else are you gonna feel? Again, sleep deprived, already stressed out, paranoid that something bad is gonna happen to your baby and now you feel like a failure." (C05)</p> <p>"It's a wild Rollercoaster ride for anybody. I mean, that's one of those things that we've been dealing with for a couple months and I'm still gonna try to figure it out. Other than that, I just take it day by day." (C14)</p>
	Paranoia regarding child's current and future health	<ul style="list-style-type: none"> <li>Uncertainty</li> <li>Desire for normalcy</li> </ul>	"It really is an unknown time of when your baby will eventually wanna eat my mouth. Cuz you know, it's all dependent on them. And I just . . . It's a hard life, being a tube baby. Like for us, two parents, like trying to always . . . our life is just different for sure." (C12)
	Over time, parents adjusted to a new normal	<ul style="list-style-type: none"> <li>Managing well</li> <li>Hopeful</li> </ul>	"I've adjusted pretty well. Within the first month of bringing him home, I had things kind of down pat, so I felt comfortable enough to even teach family members and those that would want to learn about his feedings." (C08)
Feeding-related concerns		<ul style="list-style-type: none"> <li>Managing/replacing feeding tube at home</li> <li>Respiratory concerns (breathing/choking)</li> <li>Inadequate nutrition</li> <li>Loss of feeding skills/oral aversion</li> </ul>	<p>"I think on some level he just knows that whether he makes this effort to try to eat or not, he still is gonna get fed. So he just doesn't." (C05)</p> <p>"I feel like she's gonna remember now because she's so smart and intelligent. She's two months now. So it's like when she was a newborn, it wasn't that bad. When they did the NG tube, she cried for two seconds. But now it's like she's crying and she's feeling it like she knows what's going on. And it's just traumatizing to know what a baby has to go through." (C07)</p>
	Effects on the family dynamic	Managing the child's health had effects on the entire family unit	<ul style="list-style-type: none"> <li>Relationship conflict</li> <li>Toll on family member(s)</li> </ul>
Financial implications	Demands of caring for child resulting in financial struggles and/or loss of work or pay	<ul style="list-style-type: none"> <li>Financial stability</li> <li>Financial strain</li> <li>Job security</li> </ul>	"We have been experiencing a lot of financial issues because most of these appointments and doctors are 30 minutes away. The closest is 25 minutes away, and gas . . . we have to pay for gas and food. And it has taken a big toll on our financial aspect." (C10)
What barriers are faced (personal/system-based) when managing the child's feeding difficulties?			
Accessing care and utilising resources	Barriers at the caregiver level	<ul style="list-style-type: none"> <li>Lack of caregiver education</li> <li>Parent-provider disconnect</li> </ul>	<p>"Sometimes I feel like I don't know what to say or maybe the questions I ask are dumb (. . .) The first time I went to speech therapy, I just had a mental breakdown that day because I felt like they made me feel like I've known this my whole life and like I'm stupid for asking questions or for not knowing where to go." (C10)</p> <p>"I would tell my husband, I was like, 'You know what? I can't do this. I'd rather her stay in the hospital knowing that they're doing a good job with her than taking her home.' And what if I'm gonna do something wrong to her and then we have to bring her back to the hospital?" (C13)</p>
	Barriers at the healthcare system	<ul style="list-style-type: none"> <li>Insurance issues</li> <li>Feeding supplies issues</li> <li>Proximity of care</li> <li>Scheduling appointments</li> </ul>	"All her appointments were an hour and 10 minutes away (. . .) So at that point, I was going to Savannah at least twice a week in the beginning until the appointments started to spread out (. . .) And then having to stop in the middle of the road because her feeding needed to start and starting that feeding with her tube and pulling over if it was finished and the machine was beeping. So it was a lot of stuff entailed with that. And then, I did this all by myself." (C10)
	Providing care for child required significant time and energy	Caring for child impacting the caregiver's ability to maintain other roles/responsibilities	<ul style="list-style-type: none"> <li>Conflicting responsibilities (work, school, other children)</li> </ul>

(Continued)

Table 2. (Continued)

What barriers are faced (personal/system-based) when managing the child's feeding difficulties?			
	Time-intensive feeding schedule impacts daily life	<ul style="list-style-type: none"> <li>Feeding schedule</li> </ul>	<p>hit all his growth markers, so that way I feel comfortable to continue school." (C08)</p> <p>"At the beginning, he was being fed every three hours. Plus, I was pumping breast milk, feeding him every three hours. So just the feeding and the pumping took up about two hours worth of time. So then there's only one hour in between." (C05)</p>
Child's feeding difficulties require the care of a skilled caregiver	Lack of appropriate childcare options	<ul style="list-style-type: none"> <li>Fear of leaving child with others</li> </ul>	<p>"What daycare am I gonna trust to manage his 15 doses of medication, make sure he gets fed exactly on schedule? Because you can't be late when it's every three hours because it takes like an hour for the feeding to go through the tube and then an hour to pump. You know what I mean? If you get off schedule, you end up missing some of his food and then he doesn't get the nutrition. What daycare does that? There's no way they would be able to keep up. You'd have to get like a personal, like one-on-one nanny or something, which is also super expensive. So if I had been working outside the home, there's no way I would've been able to have a job." (C05)</p>
What do caregivers identify as beneficial support mechanisms within the healthcare system and beyond?			
It takes a village	Familial and community support are essential	<ul style="list-style-type: none"> <li>Familial support</li> <li>Community support</li> <li>Parent-support groups</li> </ul>	<p>"We did train my mom and my dad. They would come over here, give us a break on night shift. They would take care of her when we were extremely exhausted. His cousin that lives about the next neighborhood down, she's helped tremendously with her. And basically, those are our go-to's when we absolutely needed something." (C09)</p>
Support from healthcare providers		<ul style="list-style-type: none"> <li>Advice</li> <li>Care coordination</li> <li>Appreciation for providers</li> </ul>	<p>"They took care of my son in ways that I would've never imagined. They treated him just like how I treat him and loved him just the same way and the fact that they don't even know me. They made me feel so welcomed and so comfortable with leaving my child with them, you know?" (C08)</p>
Learning to cope and care for oneself		<ul style="list-style-type: none"> <li>Coping mechanisms</li> <li>Comfort in knowledge</li> </ul>	<p>"I would say I cope in terms of just like praying and writing down how I feel. Just a journal and kind of going from that point. And being very self-aware of just everything and allowing myself to feel emotions." (C08)</p>

worry and anxiety. Finally, for the subsection that assesses "problems feeding my child," the two score groups had a similar number of codes that related to caregiver education.

### Discussion

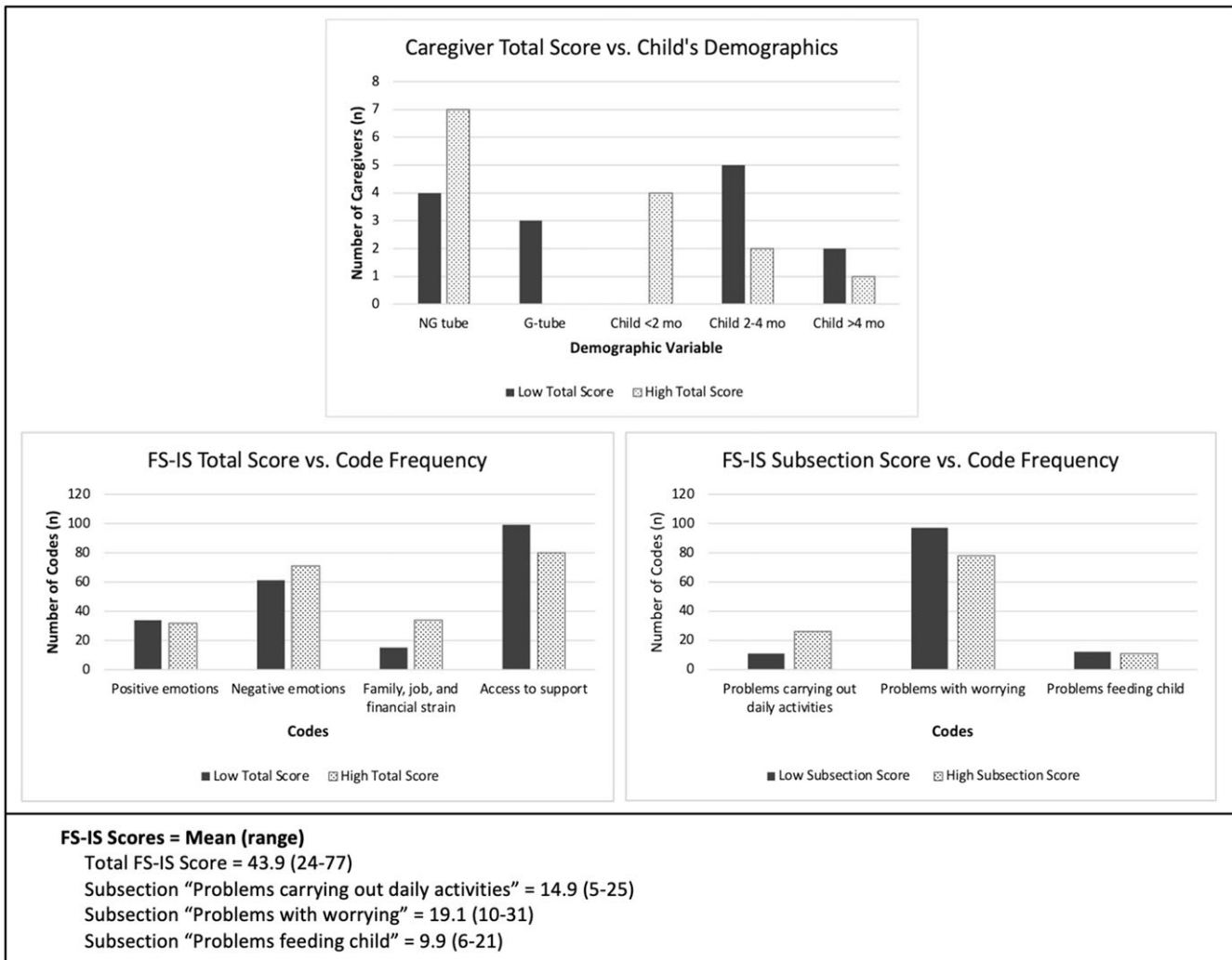
This mixed-methods study aimed to further elucidate the caregiver experience of managing a child's feeding difficulties after heart surgery. Consistent with previous studies,<sup>7-9</sup> the parents in this study regularly reported that managing their child's feeding was one of the most arduous aspects of their child's care. Specifically, these caregivers shared important insights regarding the psychosocial impacts, barriers to care, and crucial support mechanisms.

Caregivers in this study emphasised the psychosocial impact of managing their child's feeding difficulties. The emotional toll of feeling constantly worried, uncertain, and sleep-deprived was a common theme in this group of caregivers. Parents of children with CHD are at an increased risk for developing mental health problems, especially in the immediate post-operative period.<sup>14</sup> Many parents in this study expressed a desire for improved access to mental health support to cope with the emotional stress. Woolf-King et al. reported that parents and providers felt that integration of mental health services into the child's cardiac care would be a valuable tool to support both children and parents.<sup>11</sup> Our caregivers offered further suggestions to reduce the physical

and emotional stress. They advocated for better access to home health aides and respite care, both of which are unmet needs identified by many families of children with special health care requirements.<sup>15</sup> Increasing access to such resources would benefit these caregivers who work tirelessly to support their children.

Identifying those caregivers who are at highest risk for negative mental health effects could help healthcare providers recognise when to offer supplemental resources. Survey tools such as the Feeding/Swallowing Impact Survey are a quick and simple method to identify such caregivers. This study found that caregivers who took home a child younger than two months or a child with a nasogastric tube had higher Feeding/Swallowing Impact Survey scores, suggesting that these caregivers' health-related quality of life was impacted to a greater degree. While all caregivers in this sample struggled with worry, regardless of their Feeding/Swallowing Impact Survey score, those with higher scores utilised and desired professional mental health resources at a higher rate than those with low scores. This suggests that this specific survey may assist in risk-stratifying caregivers, but further investigation into a more comprehensive screening tool that identifies those in need of additional resources would be valuable.

Because feeding difficulties are one the greatest sources of stress for caregivers of children with CHD,<sup>7-9</sup> ensuring that parents are equipped to manage their child's feeding at home is essential. Parents in this study often felt apprehensive about feeding their children in the early period after hospital discharge. They



**Figure 2.** Comparison of caregiver Feeding/Swallowing Impact Survey (FS-IS) score groups (high or low) to specific variables. *Top:* Caregiver total score distribution per child demographic variables. *Bottom left:* Comparison of total Feeding/Swallowing Impact Survey score to frequency of codes in interview transcripts. *Bottom right:* Comparison of Feeding/Swallowing Impact Survey subsection score to frequency of codes in interview transcripts.

expressed a desire for more in-hospital education to ease their transition to home. The greatest areas of uncertainty involved the process of replacing the feeding tube, handling urgent feeding questions, and best practices to advance the feeding skills of their child. Those parents who recounted robust education from providers prior to hospital discharge felt the most comfortable with feeding once home, but many still experienced some anxiety early on. Previous studies report similar findings, with parents feeling universal discomfort with feeding tubes at home, despite skills training during hospital admission.<sup>7,16</sup> Creating stronger skills training for parents while their child is in the hospital would be a worthwhile venture.

Augmenting parental education was one of many change proposals suggested by this group of caregivers. Several proposals addressed logistical improvements, such as increased portability of feeding equipment and increased access to care for those living far from the tertiary care hospital. Healthcare providers may consider utilising Telehealth strategies for on-demand access to educational resources or live chats with healthcare providers. Such strategies have been shown to not only reduce parental anxiety and

depression<sup>17</sup> but also improve parental care ability and nutritional status of the child after hospital discharge following congenital heart surgery.<sup>18</sup>

Satisfactory nutrition and growth are enduring issues for many children with CHD. Children < 2 years old with CHD are at an increased risk of acute and chronic malnutrition.<sup>19</sup> Maurer et al. found that 22% of children who underwent neonatal congenital heart surgery met criteria for a feeding disorder at 2 years of age.<sup>20</sup> Many of our caregivers feared that their child would develop long-term dependence on a feeding tube. Oftentimes, these parents reported that the lack of a concrete plan for tube weaning after discharge contributed to this fear. Slater and colleagues reported that when parents are given early tube weaning goals and education, they had lower levels of anxiety.<sup>21</sup> Development of tube weaning programmes involving a multidisciplinary approach with early intervention from feeding therapists is recommended to accomplish safe and swift feeding tube removal.<sup>21</sup> Moreover, standardised nutritional programmes with outpatient surveillance and interventions have been shown to improve growth patterns in CHD infants to resemble growth of

healthy infants.<sup>22</sup> Offering parents strong nutritional programmes and a plan for tube removal after discharge could help alleviate the stress of uncertainty on caregivers while improving the child's nutritional outcome.

There are several limitations of this study to consider when interpreting the findings. All participants were selected from a single academic institution that utilises a multidisciplinary approach to feeding difficulties, limiting the generalizability of the average caregiver experience across institutions. Caregivers were interviewed soon after hospital discharge, so their concerns, anxieties, and barriers may change once they are further from hospital discharge. All but two interviews were conducted with only the mother present, which may limit the breadth of perspectives obtained. While this sample was demographically diverse, further investigation into the experience of fathers and parents with different geographics, cultural backgrounds, and family structures is important. Caregivers included in this study may have self-selected as caregivers possessing the emotional bandwidth to share their experience, thus limiting the breadth of experiences obtained. Though caregiver candour was encouraged, some caregivers may have been hesitant to admit the severity of the impact. As such, this sample could underestimate the severity of the impact felt by all caregivers. Within this type of qualitative research, the process of coding and thematic analysis is susceptible to subjectivity. However, every effort was made by the entire research team to reduce subjectivity of individual team members. This sample was relatively small but was consistent with a systematic review demonstrating that thematic saturation is often obtained after 9–17 interviews.<sup>13</sup>

## Conclusions

This investigation of the caregiver experience offers valuable insights into the specific psychosocial challenges faced by this group and provides actionable ideas for improved provision of care. These caregivers reported that managing a child's feeding difficulties after heart surgery can be a challenging and overwhelming task that requires significant dedication of time, patience, emotional resilience, and support from one's community and healthcare team. The knowledge gleaned from the accounts of these caregivers can be used to advance the family-centred, multidisciplinary approach to feeding difficulties after heart surgery that minimises caregiver burden. While this study focuses on a paediatric cardiology patient population, many of the findings may be applicable to caregivers managing feeding difficulties in other patient populations. Future directions for this study include developing and pilot testing a single-centre, multidisciplinary management intervention for post-congenital heart surgery feeding difficulties. Outcome measures will include assessing feasibility and fidelity of the intervention, caregiver survey scores, and healthcare utilisation.

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**Competing interests.** None.

**Ethical standard.** The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by Children's Healthcare of Atlanta's Institutional Review Board.

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