



## Original Article

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**Abstract**

Dysphagia is common in children with CHDs, resulting in multiple stressors for their caregivers including having a child with a serious medical condition and coping with their child's feeding needs. However, relatively little is known about caregivers' perceptions and experiences of the burden of care and support needs for their child with a CHD and dysphagia in low-middle income contexts. This qualitative study investigated the burden of care and support needs identified by parents of children with CHDs and dysphagia in a single centre in South Africa. Semi-structured interviews took place in a tertiary hospital with seven mothers of children with CHDs and dysphagia, followed by content analysis. Participants described four main impacts of their child's condition, which included worry, the burden of caregiving, emotional responses, and acceptance and coping. The participants were well-supported by speech-language therapists and dietitians, but suggestions for additional support included support groups and using mobile messaging apps for communication with peers and professionals. The study has important implications for understanding challenges faced by caregivers of children with complex needs in low-middle income settings and will be useful to inform and improve holistic healthcare practice for families of children with CHDs and dysphagia.

Feeding and swallowing disorders, hereafter referred to as dysphagia, are common in infants and children with CHDs, with the highest reported prevalence in neonates (83%)<sup>1</sup> and young infants (84%).<sup>2</sup> Dysphagia may contribute to respiratory illness, poor weight gain, longer hospital stays, and increased stress for caregivers.<sup>3</sup> The stress experienced by caregivers is related to their concerns about the safety of their child's swallowing and the increased risk of illness; nutritional concerns; the impact of dysphagia on the family; increased demands of caretaking related to time, physical well-being, and specific activities related to feeding; financial strain; and social isolation.<sup>4–7</sup>

Increased stress and reduced quality of life for caregivers of infants and children with CHD are well described.<sup>8–13</sup> Parents of children with CHD report higher levels of stress than caregivers of healthy children and children with other chronic medical conditions,<sup>14</sup> and lower quality of life than parents of children with other medical conditions.<sup>9</sup> Caregivers of infants and children with CHD and dysphagia carry a double burden of stress—the stress associated with having a child with a serious medical condition, and the stress of caring for a child with dysphagia. Dysphagia has been described as the greatest stressor for parents caring for their child with CHD after surgery and discharge from hospital, and has been reported as a greater concern than cardiac-specific issues by some parents.<sup>15</sup>

Caregivers' quality of life is affected by the demands of caregiving on physical health and psychological well-being, social isolation, financial difficulties, and family functioning.<sup>9,16–17</sup> The time needed to care for a child with a chronic medical condition results in physical stress for the caregiver (e.g., inadequate sleep) and impacts relationships within the family and in social relationships. Financial strain may occur because of expenses related to healthcare and difficulties retaining employment while caring full-time for a child with a chronic medical condition.<sup>9,16</sup> Furthermore, healthcare models have changed, and healthcare professionals expect parents to take more responsibility in caring for their child with chronic medical issues at home.<sup>14</sup> Thus, parents' coping strategies influence their own quality of life and their ability to fulfil caring requirements for their child.

Healthcare professionals need to assess and support parents' coping as part of comprehensive family-centred care to ensure the best outcome for the child and family. Understanding their child's medical condition and becoming an expert on their child has been reported as an important coping mechanism for parents of children with CHD and/or dysphagia.<sup>7,10,11,18</sup> Other coping resources include peer-to-peer support, family, social support, spirituality, and clear communication with the healthcare professional team, and for those with dysphagia, having a plan to address their child's feeding difficulties.<sup>7,18</sup> Individuals use different approaches to

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respond to stress, and strategies for coping may be problem- or emotion-focused.<sup>19</sup> Problem-focused coping strategies include finding practical solutions, such as making changes to the physical environment, obtaining more information or researching solutions, and trialling practical options. Emotion-focused strategies involve adapting perspectives, having discussions, and building relationships.<sup>11</sup>

In low-middle income contexts, relatively little is known about caregivers' perceptions and experiences of the burden of care and support needs for their child with CHD and dysphagia. This information is vital to inform and improve holistic healthcare practice. Thus, this study aimed to describe the burden of care and support needs identified by parents of children with CHD and dysphagia in a single centre in South Africa.

## Materials and methods

### Study design

A qualitative design was used involving semi-structured interviews with parents of children with CHD and dysphagia to explore their self-identified burden of care and support needs, and their suggestions for the type of support that would be helpful for parents. Semi-structured interviews allowed the researchers to guide the discussion using main questions and probes, while also documenting additional information volunteered by participants.

Ethics approval was obtained from the University of Cape Town Faculty of Health Sciences' Human Research Ethics Committee (HREC: 038/2019) and permission was obtained from the necessary hospital committees and departments to conduct the study. Participants provided their informed written consent prior to the interviews.

### Participants and setting

Purposive sampling was used to identify potential participants from the Cardiology and Speech-Language Therapy department records at a tertiary hospital in the Western Cape, South Africa. Parents of children aged two to four years with CHD and a history of dysphagia documented before the age of 2 years were invited to participate. The children were being managed at the research site and the families were invited to participate when they attended follow-up appointments at the hospital.

Spoken and written information regarding the study was provided in the parents' preferred language of English, Afrikaans, or isiXhosa, the predominant languages of the region. The final sample included seven participants who met the inclusion criteria and provided informed consent.

### Data collection

The semi-structured interview guide included questions related to the following main themes: description of the child's dysphagia and the impact of dysphagia on the caregiver and family; intervention provided to the child and the caregiver's involvement in the intervention; support provided to the caregiver with regard to dysphagia; support needs that parents experienced and that may have impacted on their ability to cope with their child's dysphagia; and recommendations by the caregiver regarding support that they would have appreciated and, therefore, suggest be included as part of family-centred care for infants and children with CHD in future.

The interview questions were translated into Afrikaans and isiXhosa by first-language speakers, followed by back

translation by additional first-language speakers. Interviews were conducted in participants' preferred languages by members of the research team, and took place at the hospital, with an average duration of 40 minutes per interview. Each participant was assigned a unique ID number to ensure anonymity, and all data were securely stored.

The audio-recorded interviews were transcribed verbatim, and where necessary translated into English for further analysis. Trustworthiness was addressed through member checking immediately post-interview by summarising the main points; written notes and consultation with the research team regarding the coding; and theoretical triangulation through consulting available literature.

### Data analysis

Content analysis followed the steps described by Elo and Kyngäs<sup>20</sup> and Erlingsson and Brysiewicz.<sup>21</sup> The transcribed interviews were read multiple times so that the primary investigator was immersed in and familiar with the content. Coding was completed by identifying meaning units, condensing the meaning units, and then grouping them into codes. The codes were grouped into categories and subcategories to provide information to address the research aim.

## Results

Seven caregiver participants, all mothers, were interviewed: three Afrikaans-speaking, three isiXhosa-speaking, and one English-speaking. The participants demonstrated a clear understanding of their child's dysphagia and the intervention provided. Table 1 provides a summary of the participants' descriptions of their child's dysphagia, mostly related to aspiration risk and poor growth, with the associated interventions. All participants identified the speech-language therapist and dietician as the professionals providing ongoing intervention for their child's dysphagia.

Participants described the impact of their child's dysphagia on themselves and their families, and the support they received. The following subcategories were identified: "worry," "burden of care," "emotional responses," and "acceptance and coping." The mothers reported that while they accepted and coped with their child's dysphagia, they also experienced the impact of these difficulties, which resulted in worry about their child's health, safety, and general well-being; an increased burden of care, particularly for the primary caregiver; and emotional responses.

The intervention and support participants received were described in terms of the following subcategories: "profession-specific intervention"; "access to professionals"; "information and training"; "support"; and the "caregiver as a team member." Profession-specific intervention focused on speech-language therapy and dietetic intervention related to managing the dysphagia at home while reviewing and revising management strategies as the child's abilities changed. Participants were able to access professionals through in-person consultations and telephonic contact. Most participants indicated that they had received professional support, and two mentioned support from family members, specifically in caring for their child's special feeding needs. The participants received information and training about their child's dysphagia and management and had opportunities to ask questions and receive more information. They felt part of the team and were able to contribute to decision-making regarding their child's dysphagia.

**Table 1.** Summary of participants

Participant	Feeding-related difficulty described by caregiver	Intervention described by caregiver	Healthcare professionals involved with feeding intervention
A01	Aspiration of liquids: <i>"If he coughs . . . then it's going to the lungs. So the runny food that he eats, it doesn't go to the stomach, it goes to the lungs."</i>	Gastrostomy (for liquids)  Thickened feeds orally <i>"Then they . . . put in the 'pipe'. Then through the PEG I had to give him milk. Milk goes in, medicine, just those two go down. His food may not be um runny . . . he can eat, solids . . . His food must be . . . thick."</i>	SLT
A02	Aspiration of liquids: <i>"She may not have milk because she coughs . . . yes, it goes down the wrong place and can [cause] lung infections."</i>	Gastrostomy (for liquids)  Eats solids <i>"After the PEG now they try to take her off it . . . she's already on the PEG for 2 years. Now they are struggling to get her off the PEG, but she eats properly."</i>	SLT & dietician
A03	Aspiration of liquids: <i>"Any other liquid goes to his lungs . . . they took him for a barium swallow and . . . saw that it goes to his lungs."</i>	Thickened feeds <i>"So I must thicken his milk and his food with porridge because he swallows it. And water is the only thing he can drink now . . ."</i>	SLT & dietician
E01	Poor weight gain: <i>"She was feeding but she was not gaining weight."</i>	Gastrostomy and oral feeds <i>"So that's when they put the PEG in. But now she is swallowing and the weight – she is gaining a little bit."</i>	SLT & dietician
X01	Aspiration: <i>"Before the operation there were difficulties with feeding so when I gave the child the breast he was [aspirating]."</i>	Gastrostomy and oral feeds <i>"Now that they have done the operation [gastrostomy] the child has no difficulties."</i>	SLT & dietician
X02	Coughing with feeds (aspiration) and reflux: <i>"The difficulty he had was coughing when he is eating and the food kept coming up when [he] was eating."</i>	Thickened feeds <i>"Then it was suggested that we try to mix milk with porridge and that was a better way for the child to eat. So the child now could swallow and the food was not coming back up."</i>	SLT & dietician
X03	Aspiration of liquids: <i>"He couldn't drink liquids. He couldn't drink water and milk. It was difficult. Immediately when he drinks, he would cough. He would cough until he gets chest infections . . . food is going through the wrong pipe."</i>	Gastrostomy – not successful  NGT long term and solids orally <i>"They inserted a PEG but still the PEG was not working but they kept trying. Then they inserted a (NG) tube here (pointing) so that the food goes straight to his stomach not to his lungs."</i>	Nurses, SW, Doctors, SLT & dietician

NGT = nasogastric tube; PEG = percutaneous endoscopic gastrostomy; SLT = speech-language therapist; SW = social worker.

These results are summarised in Table 2.

Participants shared suggestions for additional support they would have liked to receive. Only one participant volunteered a suggestion—that of having a “caregiving break,” although she also said she probably would not want to be away from her child if given that opportunity. Participants were provided with suggestions for additional support options, such as support groups, individual consultation sessions, virtual support, psychological counselling, and education, information and training. All the participants who responded to this question (6/7) indicated that they would have liked a parent support group facilitated by a speech-language therapist, and ongoing individual face-to-face sessions with the speech-language therapist. Many liked the idea of a parent WhatsApp group or mobile app for messaging the speech-language therapist. However, they did not want the messaging to replace the in-person engagement, but rather as an additional option for “back-up” support.

X01: *I always attend a face-to-face support group but I am happy for the WhatsApp one but I don't want to totally rely on that. I want them to see how the child is improving. Looking at the child is not enough. I don't have a scale at home so . . . maybe the child is dropping [weight]. They will see when the weight is dropping.*

Another participant explained that having contact with other parents through an in-person facilitated parent support group and a WhatsApp group with other parents would have been helpful:

X02: *It is something I didn't get but if it was there I would have chosen it because I had a feeling like I was the only one having a child with this problem. If I had met other parents I would have known that there are other parents with kids with the same problem and I would have seen the way they feed their kids. When you are alone, [you are] overthinking but when you are chatting to other parents on WhatsApp you stop thinking. I would choose WhatsApp and face-to-face.*

Another participant explained the benefit of being able to check in via WhatsApp when resources are limited.

**Table 2.** Summary of findings: impact of dysphagia and support

CATEGORY	SUB-CATEGORY	CODES	QUOTE	
Impact of dysphagia	Worry	Worried about weight; have to watch	PS1E01: "I was only worried because she was not gaining weight." PS1X03: "I had to make sure I look after him so that they don't feed him."	
	Burden of care	Others won't feed; no-one else can help; can't work; can't do normal things; problem with childcare (siblings)	PS1A01: "At the crèche [nursery] they can't feed him ... they don't want to work with the 'pipe' [PEG]." PS1A02: "Nobody wants to look after her because she's got the thing [PEG] in." PS1X01: "[I] wish to live like other mothers ... to go and do shopping but you can't do that." PS1A01: "My problem was I had another one [child] ... how must I look after my other one?"	
	Emotional response	Upset about PEG; negative impact on family	PS1A02: "I was very upset that they put it in because then I left my work to do the 'issue' [PEG]." PS1X02: "We are not okay at home when the child is not eating."	
	Acceptance and coping	Coped with feeding difficulty; patience for improvement	PS1A01: "We handled it alright." PS1A03: "I didn't have a problem thickening his food." PS1X01: "We ... hold on until he grows up."	
	Intervention and support	Profession-specific intervention	SLT; Dietician Review/revise intervention; reinforce intervention advice; thickened feeds; monthly feed supplies	PS1A03: "The dietician and the speech therapist because I see both and that helped me." PS1E01: "Then every month I'm coming here to see them and ... then they say we must change the feed ... [we] must do this and that."
		Access (to professionals)	Come in; Phone; follow-up; contact numbers	PS1A02: "They will give me advice about what to do ... (they) say 'come to me' and then we talk; there's always help when I come to [hospital's name]" PS1X02: "When I come for follow up appointments I was able to talk to them about anything. I also had their contact numbers."
Information and training		Feeding information and advice; food advice; training for feeding; receive information [feeding]	PS1X01: "They were giving me advice on which food is appropriate." PS1E01: "They show me how to do everything. How to feed her through the PEG, and ... how to feed her with the mouth." PS1X03: "They would show me how to hold him because he is not like other kids. So, I was always there."	
Support		Felt supported [by healthcare professionals]; can ask questions; encouraged to ask; limited family support	PS1A03: "They supported me ... if I maybe had a problem then the dietician said I can phone if I'm worried." PS1X02: "I was asking questions and they would answer me. I mustn't keep quiet when I see something happening." PS1A01: "My mother spent more time at the hospital because I still had a little one at home."	
Caregiver as team member		Involved in decisions; intervention options discussed; included in intervention	PS1E01: "They explain to me everything ... how this thing is going to help and then I understand and ... agree with them to put the PEG in." PS1X02: "I was taking part because I wanted to make the right decisions for my child."	

PEG = percutaneous endoscopic gastrostomy; SLT = speech-language therapist.

*E01: I would like to talk to them on WhatsApp ... Sometimes I don't have money to come here for transport ... I'd like both [face-to-face and telephonic/ WhatsApp check-in].*

## Discussion

Worry and anxiety contribute to increased stress for caregivers, and together with the burden of care, lead to reduced quality of life for caregivers of chronically ill children.<sup>9,14</sup> These findings also apply to caregivers of children with CHD and dysphagia,<sup>22,23</sup> and are supported by our findings in the South African context. Caring for

a child with CHD and dysphagia places parents under significant stress. They care for a child with a serious medical condition, and in addition, cope with the challenges of dysphagia. It is critically important to identify ways to support caregivers, both in general and in the South African context in particular. Our findings detail the impact of dysphagia in children with CHD on caregivers, including worry, burden of care, emotional impact, and acceptance and coping.

Anxiety about their child's weight gain and the risk of swallowing safely was a common theme. The strong link between weight gain and feeding means weight gain is often considered a measure of successful feeding. Parents consider feeding their

responsibility, and inadequate weight gain can lead to feelings of incompetence.<sup>15</sup> Weight gain is often especially emphasised for infants and children with CHD because of the need to gain weight for future surgeries. Caregivers worry about their child's swallowing safety, which may lead them to become hyper-vigilant—as noted by a participant who reported having to constantly watch her child. This hypervigilance is not unique to caregivers of children with dysphagia and has also been reported as a coping mechanism for parents of children with CHD.<sup>10</sup>

The constant caregiving responsibility was identified as a main contributor to the burden of care experienced by participants. A lack of help with caring for their child, and specifically for assisting with feeding, was highlighted. This burden has been noted in other studies of children with dysphagia<sup>6,24,25</sup> and gastrostomies.<sup>23</sup> Not being able to share the caregiving burden is common in the care of children with chronic illness, and the primary caregiver—typically the mother—often carries this load alone.<sup>4</sup> In addition to the physical and emotional toll of caring for a child with chronic illness, primary caregivers' lives are impacted by reduced work and social opportunities, and the impact on the rest of the family.<sup>4,26</sup>

Parents of children with dysphagia experience emotions related to their child's feeding difficulties and the associated interventions, such as tube feeding,<sup>15,27</sup> feelings of inadequacy associated with their child's feeding difficulties,<sup>28,29</sup> and the negative impact of the dysphagia on the family.<sup>23</sup> These feelings were clearly articulated by the participants in this study, notably by one participant who gave up work to care for her child following gastrostomy tube placement. Participants also reported that others were not willing or able to feed the child or that they did not trust others to do so. The emotional impact of the child's feeding difficulties was felt by the entire family.

The participants considered that they were able to cope with their child's feeding difficulties and the intervention strategies they needed to implement to manage the dysphagia. This suggests they use a problem-focused approach to coping with the practical aspects of their child's feeding difficulty<sup>11,18</sup> by implementing intervention strategies recommended by their healthcare professional. Participants reported acceptance of the current situation and hope for change in the future, indicating that they also engaged in emotion-focused coping strategies by adopting a positive outlook.<sup>4,11</sup> Acceptance of a child's feeding difficulties is considered a facilitator for improved outcomes for the child.<sup>26</sup>

Caregivers reported that intervention from healthcare professionals and easy access to those professionals contributed to their coping, along with information and training, and professional and informal support. Caregiver stress associated with dysphagia may be reduced, and outcomes improved, by having access to knowledgeable healthcare professionals and receiving intervention for dysphagia from them (with a clear feeding plan).<sup>25,26,29</sup> The participants in this study all reported access to the relevant healthcare professionals both in-person and by telephone, and the clinicians evaluated the child's progress and intervention at every visit, fostering feelings of progress. The participants also felt part of the decision-making team and comfortable asking questions, essential aspects for optimising the care for children with dysphagia. Having a clear understanding of the child's medical condition and the interventions provided has been identified as a coping strategy for parents of chronically ill children, reducing caregiver stress.<sup>11,18</sup>

The participants in our study received information and training regarding dysphagia and intervention strategies from their treating healthcare professionals. Nonetheless, the use of

additional resources, such as videos that caregivers can watch again at home and share with other family members as suggested by Neille and Selikson,<sup>30</sup> may enhance caregiver support in the future. Pars and Soyer<sup>27</sup> demonstrated a reduction in caregiver stress after completing a training programme for home gastrostomy feeding before discharge from hospital.

Support from family and social networks benefits caregivers and can reduce their feelings of stress and isolation.<sup>10,11,26,30</sup> These aspects seemed limited in our participants' experience, with only two reporting support from close family members (husband and mother, respectively). This was surprising given that family and community support are generally considered integral to child-rearing in the (South) African context.<sup>31</sup>

Linking with parents of children with the same difficulties as a form of peer-to-peer support has been reported as beneficial in studies of caregivers of children with CHD and caregivers of children with dysphagia.<sup>4,11,18,22,25,26</sup> When asked about additional support that they would have liked, our participants reported that they would have valued a facilitated parent support group where they could share their experiences with other caregivers facing similar difficulties. Current research and feedback from participants suggest that this intervention should be implemented as standard of care. The participants considered that access to healthcare professionals and other parents via a mobile format, such as WhatsApp, would be "nice to have." They did not want this support to replace the face-to-face consultations with professionals, but felt it would be an additional valuable support. In-person consultations with healthcare professionals were seen as reassuring and beneficial, despite the cost to attend such sessions—a relevant point to note in low-middle income settings.

WhatsApp groups or other forms of social media and messaging hold great potential for facilitating communication between healthcare professionals and parents. However, speech-language therapists and dieticians already face heavy workloads and may struggle to be available at all times in these forums. It would be important, if such approaches are adopted, to ensure that clear boundaries and expectations exist for all parties. Ultimately healthcare professionals may encourage more experienced parents to drive such initiatives and support newer members of the group, stepping back to facilitate peer-to-peer support and only getting involved when specifically called upon.

This is the first study to explore caregiver perceptions, challenges, and experiences in caring for children with dysphagia and CHD in the South African context. Although many of the findings are similar to those of other studies that have described the impact of dysphagia on caregivers and families, the insights gained from our sample are important for understanding caregiver needs of a specific population in a particular setting, and for service planning and development. At the same time, the study was limited by the small sample of participants at one hospital in South Africa, and thus, generalisation of the findings to caregivers in other settings should be made with caution.

## Conclusion

The participants in this study provided their perspectives on the impact of their child's dysphagia, the support they received, and additional support that they felt would have been helpful. Results were similar to previous reports in different settings. Caring for a child with CHD and dysphagia has a great impact on families. The mothers in this study described their experiences of worry, emotional responses, acceptance and coping, and their

considerable burden of care. Alongside these challenges, they felt well-supported and included by the healthcare team and that they had sufficient access to healthcare professionals. Caregivers appreciated face-to-face consultations with healthcare professionals but also highlighted the potential value of a parent peer-support group and app-based messaging groups to help reduce stress and improve caregiver coping skills and quality of life.

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**Ethical standards.** The authors assert that all procedures contributing to this work comply with the ethical standards of the Helsinki Declaration, as revised in 2013. Ethics approval was obtained from the University of Cape Town Faculty of Health Sciences' Human Research Ethics Committee (HREC: 038/2019) and permission was obtained from the necessary hospital committees and departments to conduct the study.

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