

BMJ Open What are parents' perceptions related to barriers in diagnosing swallowing dysfunction in children? A grounded theory approach

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ABSTRACT

Objectives Swallowing dysfunction (SwD) is under-reported in otherwise healthy infants and toddlers (OHITs). The identification of parental perceptions of factors that may hinder the diagnosis could help clinicians manage these children in a more expeditious manner. This study investigated the barriers to diagnosing SwD, as reported by the families.

Design Grounded theory study.

Setting This study was performed in a tertiary care paediatric centre in Canada.

Participants Parents of OHITs were recruited using purposeful sampling.

Intervention We used detailed, semistructured, in-person interviews and the audiotapes and transcriptions were thematically analysed. From the parental insights, we built a framework composed of three themes of barriers.

Result Ten parents of OHITs with SwD were interviewed. The children presented with recurrent coughing, choking, cold-like symptoms, recurring/consistent illnesses and feeding difficulties. They were managed with multiple rounds of antibiotics and diagnosed with allergies, asthma or recurrent viral infections before considering SwD. The three emerging themes are false beliefs about SwD among parents and some physicians, parent-related barriers and physician-related barriers. These barriers had severely impacted the parents, impairing work productivity and leading to work-related reprimands and changes in the family dynamics.

Conclusion This study suggests that there are several barriers that face the parents of OHITs when seeking a diagnosis of SwD and initiating appropriate management. These barriers likely interact with one another and amplify their effects on the family and the child. A common denominator is a lack of education regarding SwD, its clinical manifestations and the available expertise to manage this condition.

INTRODUCTION

Dysphagia is a common condition that affects children. Bhattacharyya analysed data collected from the national health survey and estimated that approximately half a million children are affected by dysphagia annually in the USA.¹ Despite the methodological shortcomings of that report, it provided an important indicator

Strengths and limitations of this study

- As paediatric swallowing dysfunction is under-reported, this study tried to get the parents' perspective in experience to understand the reason behind it.
- Data obtained through an hour-long of a semistructured interview with each participant, which transcribed verbatim and verified by the participants.
- The result was verified by another group of participants to certify the experience.
- This was a single care centre study and might not be generalised on other cohorts as the included participants were parents of otherwise healthy infants and toddlers with swallowing dysfunction, who were from the province of Alberta in Canada.
- Using a purposeful sampling technique provided rich data to understand the barriers to detecting swallowing dysfunction in our cohort of interest; however, it constrains the generalisation to other cohorts.

of the burden of this condition. Dysphagia is especially frequent in children of certain high-risk populations, such as those with neurological, genetic and anatomical defects, reaching 85% in some.^{2,3} Oropharyngeal dysphagia, also known as swallowing dysfunction (SwD), has been increasingly studied in the otolaryngological field. Our interest has focused on otherwise healthy infants and toddlers (OHITs), that is, those aged 2 years or younger who have no neurological or syndromic diagnosis. We believe this cohort is an understudied and under-represented population. Our literature search revealed that SwD affects between 13.35% and 74.85% of the OHIT cohort in relevant reports,⁴⁻⁸ despite the absence of well-designed epidemiological studies. This is partly due to the absence of a valid screening test.

A diagnosis of SwD is established by video-fluoroscopic swallowing studies (VFSS) and functional endoscopic evaluation of swallowing (FEES).^{9,10} Although these are the

reference standard tests for SwD, they inherently suffer from important drawbacks. These include radiation exposure, the requirement for experienced personnel with specialised training, and the intrusiveness and discomfort of the process itself.¹¹ Alternative tools have been sought, for example, ultrasonography, auscultation, but none have been proven accurate or valid for regular clinical utility. Patient-reported outcomes (PROs) have recently been demonstrated to have clinical utility to replace or supplement traditional endpoints (such as in osteoarthritis) and satisfy the interests of the patients or proxy.^{12 13}

We designed a mixed-method research project to develop and validate a PRO tool for SwD in OHITs. A common narrative consistently emerged during the initial qualitative phase and while interviewing the parents. This narrative expresses a negative experience while achieving the diagnosis.

There are some reports on the experiences of parents of children with dysphagia and feeding problems in the literature. Hewetson and Singh published a phenomenological report that described the lived experiences of seven parents who had children (mean age 80 months, range 36–156 months) with feeding and swallowing problems.¹⁴ They reported that these parents endured two independent journeys. The first was the journey of deconstruction; here the parents faced dissipating life dreams, a continuum of life changes and a constant feeling of powerlessness. In the second journey, reconstruction, the parents approached life more realistically and became proactive information seekers to empower themselves.

Lutz undertook a study to comprehend the experiences of parents of neonatal and paediatric intensive care unit graduates with feeding problems using a convenience sample of 15 parents and ten healthcare providers.¹⁵ The salient themes identified through content analysis were: (1) diverse and fluctuating parental responses; (2) feeding as the focus; (3) isolation and disappointed expectations; (4) conflicting collaboration, perceptions and communication; and (5) barriers and challenges to accessing care.

However, none of these reports addressed the experiences of the parents of OHITs who were not yet diagnosed with SwD. They were based on experiences of high-risk populations (such as Down syndrome¹⁶) who already had been diagnosed with dysphagia and feeding problems¹⁷ and who were enrolled in special feeding programmes.

Here, we report our findings that point to barriers to the diagnosis of SwD in OHITs.

METHOD

The grounded theory was chosen as an overarching theoretical approach because we sought an exploratory theory that was environmentally sensitive to the social processes and would assist in understanding their relations.^{18 19} Purposeful sampling was used to obtain rich data that contained parental insights into their children's

experience. We included parents of OHITs who were not diagnosed with named syndromes, neurological or genetic disorders, or exhibited dysmorphic features. The parents were identified from the database of the multidisciplinary Aspiration and Aerodigestive Clinic at the Stollery Children's Hospital at the recommendation of the treating speech-language pathologist based on the parents' potential willingness to participate in such a study, and their comprehension of English language. A semi-structured interview was selected for data collection.

Twenty-one eligible parents were identified and approached to query participation in the study. Eighteen of them agreed, whereas three of them declined due to conflict of data collection time with other commitments related to personal or work-related reasons. After an initial approach to solicit participation, written informed consent was obtained from each participant after one of the investigators explained the aims, related potential risks and the benefits. A second consent was obtained from the participants who were willing to provide helpful related material (eg, videos, blogs and pictures). Also, the anonymity of the participants was maintained throughout the study phases by using unique identifying numbers.

A guideline was designed to navigate the interview. This guideline contained eight open-ended questions (online supplemental file 1). It was built through a multistep process that started with a literature search for validated questionnaires designed to assess swallowing in children. Based on the literature, commonly used questions were compiled to formulate the first draft. This draft was honed in a meeting session by two paediatric experts, an otolaryngologist and a speech-language pathologist; these individuals led the multidisciplinary clinic. The draft interview guideline was further refined and revised with the help of a panel of independent qualitative method experts over another meeting session.

This interview guide was flexibly used during the interviews. A prompting technique was used to explore fuzzy information expressed by the participants in addition to active listening (ie, summarising and restating what the participant had said). These interviews were performed by a single interviewer and ranged from 45 min to 1 hour and were audiorecorded and transcribed verbatim. Interviewees had no previous encounter with the interviewer. Other than the interviewer and the interviewee, no other participants attended the interview. The interviewer was a recent graduate of Medicine who received 2 years clinical experience in the field of Otolaryngology-Head and Neck surgery and was completing his postgraduate degree. Also, he was trained by an expert in Qualitative Research on techniques of performing a proper interview. The interviewer introduced himself to the parents as a master's degree candidate who had no role or influence on the management of their children.

Once the investigators noted the emergence of a consistent experience of obstacles to establishing a diagnosis and its impact on the life of the parents and children, this information was further analysed.

We employed the six-step thematic analysis technique proposed by Braun and Clerk.²⁰ This technique was a sequential process that included data familiarisation, the production of codes and the generation, reviewing, defining and naming of themes. The research team members started to familiarise themselves with the data by repeatedly reading the first three transcripts. Next, they generated codes and themes independently from each other. Multiple meetings were devoted to cross-check the codes and the emerging themes. The remaining transcripts were then analysed by the interviewer, followed by random checks by the team members. Finally, the resulting framework and related quotes were sent back to three participants for cross-checking and collecting their feedbacks.

During the analysis, the team members mainly focused on the experiences of the participants with diagnosing SwD in their child, but they were also open to any new themes that emerged during the analysis process. Refining, testing and retesting of the emerging themes was undertaken until they achieved the best fit for the data.^{8,9} Data saturation was ensured when no extra relevant information emerged in the last interview.¹⁰ As data collection and analysis were performed simultaneously, the tenth interview did not produce any new area that required further exploration, accordingly data saturation was achieved.

Research reflexivity, as defined by Ahern,²¹ is the recognition of personal preconceptions and feelings and thinking critically about them in relation to the research being conducted.¹¹ This was practiced by keeping a journal of the thoughts, feelings, and emotions to minimise researcher bias and improve the overall outcome.

All interviews were recorded using a Philips Voice-Tracer (type: DVT6010, Korea). The transcription and analysis were carried out using Microsoft Word Office 2019.

Patient and public involvement

Patient and public were not involved in designing this study. However, they helped in triangulating the results.

RESULT

Saturation of ideas was achieved after interviewing ten parents. Four parents were referred to the multidisciplinary swallowing clinic by general paediatricians and six by emergency physicians. The median age of the children at diagnosis was 4.5 months (range of 1–23 months). They had been previously diagnosed with gastro-oesophageal reflux disease, asthma and/or acute bronchiolitis. All of these children were diagnosed with SwD by FEES or VFSS and were managed by the multidisciplinary team using feeding modifications, injection laryngoplasty or endoscopic repairs of type one laryngeal clefts (table 1).

Table 1 Demographics of the participants

Participant demographics	
No of interviewed parents	10 mothers
Parental education	<ul style="list-style-type: none"> ▶ Secondary school (N=1) ▶ Undergraduate degree (N=7) ▶ Postgraduate degree (N=2)
Parents with a health-related job	Two of them: <ul style="list-style-type: none"> ▶ Nursing ▶ Adult occupational therapist
Ethnicity of the parents	All of them were Canadian. <ul style="list-style-type: none"> ▶ Arabic origin (N=1) ▶ African origin (N=2) ▶ Caucasian (N=7)
No of children	14
Median diagnosis age in months (IQR)	4.5 (6)
Male:female ratio of the children	6:08

All families perceived that the diagnosis of SwD could have been reached or entertained earlier. They recounted many stories that demonstrated several elements leading to this belief. The three themes that emerged at the end of the analysis were: (1) fallacies or false beliefs about SwD, (2) parent-related barriers and (3) healthcare-related barriers. Figure 1 shows the main themes.

Fallacies about SwD

The parents of OHITs expressed four erroneous beliefs related to SwD. These beliefs were described as: (1) Cough is not a worrying symptom; (2) The presence of normal vital signs (ie, temperature, heart rate, respiratory rate, oxygen saturation) is reassuring; (3) Achieving proper milestones and gaining weight rule out a concerning health issue and (4) These infants and toddlers are still growing and acquiring their swallowing skills and pace. Interestingly, according to the parental reports, some of these beliefs were shared by some paediatricians. Table 2 contains examples of these erroneous beliefs.

Parental-related barriers

Barriers related to the parents were linked to two central ideas. They pertained to a lack of knowledge about SwD and the presence of psychosocial stressors affecting them. The presence of previous experience with the condition helped one parent to seek medical attention for her infant earlier than for the older child. However, most of the parents expressed a major burden of stress that affected their life quality and judgement. Table 3 shows excerpts of the parental accounts.

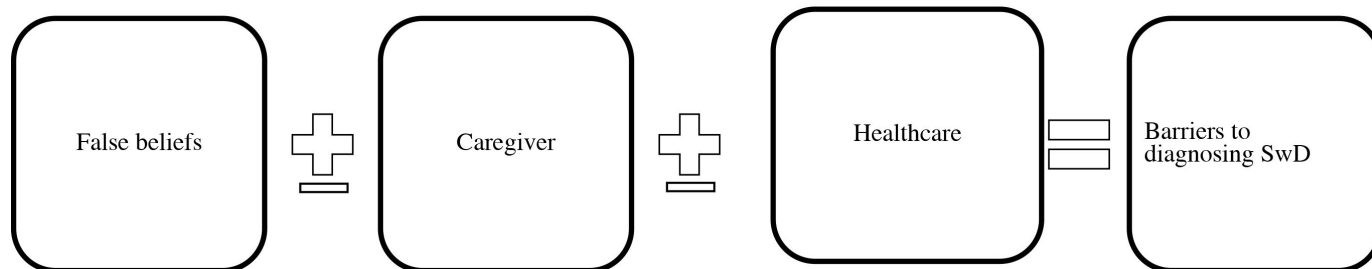


Figure 1 shows the barrier framework from emerging themes. It illustrates how intricate could be the impact of barriers on diagnosing swallowing dysfunction in the otherwise healthy cohort. These barriers could happen together in some cases or as a single theme to hinder the diagnosis. SwD, swallowing dysfunction.

Healthcare-related barriers

Healthcare-related barriers revolved around interacting with non-empathetic healthcare workers who would second guess or dismiss the parental reports or require proof of symptoms. As these hindrances prevented them from receiving care, parents of the affected OHITs were forced to improvise to convince the healthcare workers and obtain a referral to specialists. Some resorted to video and audio recording of the experiences to convince the healthcare professionals. Others educated themselves and tried different delivery systems to alleviate the symptoms (different

types of nipples that control the flow). A selection of parental quotes are presented in [table 4](#).

DISCUSSION

This study provides insights about the barriers that hindered the diagnosis of SwD in OHITs, according to the parental reports. These barriers were streamlined and fitted into a model that has three themes, namely, fallacies about SwD in OHITs, parent-related barriers and clinician-related barriers. The study also demonstrates the complex interactions between the themes, where each

Table 2 Fallacies regarding SwD

Theme 1: fallacies regarding SwD

Cough is not a worrying symptom.	<p>Family:</p> <ul style="list-style-type: none"> ▶ ‘She was coughing every time when she was feeding. But what my mother-in-law would do is to follow old wives’ tales when a child is choking, and blow in their face to shock them out of it’ (3rd interview). ▶ ‘Can we feed in here just so you can see?’ And she [pediatrician] said, ‘Yep, we’ll feed.’ And she did cough. If my memory serves me, I don’t think we did anything about it.’ (2nd interview). <p>Physician:</p> <ul style="list-style-type: none"> ▶ ‘...I remember that her pediatrician said that if she is still coughing then she is still clearing stuff’ (1st interview). ▶ ‘They cough a lot. And they would just say, ‘Yes, it’s normal, all, but you know, they need to get out all that stuff that’s in’ (4th interview). ▶ ‘I noticed that something was just weird with their feedings, and then lots of coughing in the beginning. And there was lots of reassurance from the nurses and stuffs that it would go away.’ (7th interview).
Proper progression of milestones and weight gain means the child is healthy.	<ul style="list-style-type: none"> ▶ ‘She was gaining weight at a good steady pace. Um, and she was hitting all of her milestones on time. So, I thought that Oh, she is fine, she is fine (laughs)’ (1st interview). ▶ ‘... The weight gain was always good. I felt like if you looked at them, you’d never think anything was ever a problem, because their weight was great. They’re gaining a good weight.’ (6th interview).
Normal vital signs are reassuring.	<ul style="list-style-type: none"> ▶ ‘She wasn’t desaturating [decreased oxygen level in the blood], which is why I had such a huge struggle getting people to believe me that there was a problem’ (9th interview). ▶ ‘...so, I think that is why nobody had any concerns, because the monitors were not beeping’ (7th interview). ▶ ‘I mean, her oxygen saturation was always good.’ (3rd interview).
Children need time to acquire feeding skills.	<ul style="list-style-type: none"> ▶ ‘You try to give a child a little bit of time to adjust to their feeding mechanism [i.e. breast or bottle feeding].’ (8th interview). ▶ ‘She is just drinking too fast. So, we just need to interrupt her, sit her up...’ (9th interview). ▶ ‘Oh, this happens. She just needs to grow and learn.’ (3rd interview).

SwD, swallowing dysfunction.

Table 3 Parent-related barriers

Theme 2: parental barriers

Lack of education or prior experience	<ul style="list-style-type: none"> ▶ ‘What took so long was for us to figure out that something was actually going on with her and connecting the dots that there could be a swallowing issue even though she was growing and gaining weight. And at most, she would catch a cold or something, but the assumption was she just caught a cold because she has an older brother going to school and coming home. And he would catch a cold and she would show symptoms. It’s hard to pinpoint what, um, what the cause was.’ (6th interview). ▶ ‘I realized that maybe something was happening with her too. Yeah. It was a lack of knowledge’ (3rd interview).
Psychosocial distress	<ul style="list-style-type: none"> ▶ ‘She called me and said ‘what are you doing?’ I said I’m looking for a bridge. I’m done. I do not want to do anything anymore.’ (7th interview). ▶ ‘I wasn’t working. I mean, with three kids. I mean, two were babies and they’re both coughing and there was just no sleep at all.’ (5th interview). ▶ ‘We were housebound everyone for two months. My son wasn’t allowed to go to playgroup or school anymore. I wouldn’t go anywhere. When my husband came home, he wasn’t allowed to touch her. I made him take a shower, and I made him put on stupid hand sanitizer. I made people wear masks when they came to my house because I didn’t know what else to do.’ (6th interview).

one acts as a barrier by itself or by amplifying one or more of the others in the model. For example, the healthcare provider may have erroneous beliefs that enforce those of the parent. Similarly, parental stress can weaken their stance and self-confidence and embolden an uninformed healthcare provider to ignore the complaints related to the child.

To our knowledge, this is the first report on the barriers to diagnosing SwD in this group of children. Most of the relevant available literature addresses the barriers or needs of parents of either older children (>2 years), those with complex health problems (such as cerebral palsy) or both,^{22–25} and all of these studies were conducted in populations that already had a confirmed diagnosis.

Each part of our model contains distinct entities. Some of these entities are in agreement with previous reports, while others are unique to the current study. One of the previously reported entities is the fact that parents spotted

the clinical presentations of the condition in their infants and toddlers.¹⁴ However, the parents did not have the ability to connect the dots and formulate a reason to seek an urgent medical consultation, which was also reported in Heweston and Singh’s study.¹⁴ In the end, they believed it was a result of their insufficient understanding of SwD.^{15 22 24}

Parental beliefs about the condition were found to play a role in hindering SwD diagnosis. Mikhail interviewed 100 Hispanic women who had at least one child younger than 5 years to investigate beliefs about specific health etiologies (such as fever, cough and conjunctivitis).²⁶ Eighty per cent of the interviewed parents believed that cough is caused by an imbalance between hot and cold environments. Traditional or home remedies (such as increased fluid intake, the use of a humidifier, and the application of a grounded coffee poultice on the soles of feet) were performed by 41% of the parents to manage the cough.²⁶

Table 4 Healthcare-related barriers

Theme 3: healthcare personnel-related barriers

Healthcare providers ignore what parents say and do not consider SwD.	<ul style="list-style-type: none"> ▶ ‘Well, I just got dismissed. Like I seriously went through three pediatricians and, uh, the last one that I went to that did the referral, she was dismissive of me as well.’ (3rd interview). ▶ ‘I will vent about it. Like my biggest peeve with our medical system is a dismissive attitude towards either a mom or a nurse who knows better than a doctor. It is a problem.’ (2nd interview).
The physician agrees to refer only after the problem is demonstrated or witnessed.	<ul style="list-style-type: none"> ▶ ‘I said ‘If you give me a chance, I will prove it to you.’ She said ‘Okay.’ She was like ‘how are you planning on proving it?’ I said well, I have three different flows and fluid consistencies. I want you to watch her drinking. I will start with the slowest flow with the thickest consistency, and you tell me. I had a nectar thick mango juice through the slow flow bottle. She watched what was happening. She was like ‘yeah, she needs swallowing assessments.’ (1st interview). ▶ ‘Anyway, so it was tough. It was tough getting that referral. It was tough trying to speak to the pediatrician about all these symptoms.’ (9th interview). ▶ ‘It was actually that night, I went to the emergency at the Stollery Children’s Hospital and I said I am at my wit’s end. I am not sleeping. I do not know what to do. So, it was actually, I believe if my memory serves me, the emergency that referred us.’ (2nd interview).

SwD, swallowing dysfunction.



In our study, parents reported that coughing or choking was addressed by startling the infant or by changing the feeding position. These practices could be explained by a lack of education and not having previous experience with SwD, as reported by most of our interviewed parents. This lack of knowledge drove parents to proactively seek out information either through searching for answers from other sources or through a trial and error approach, as demonstrated in this work and by others.^{14 15 22 24 27}

The parents consulted healthcare professionals only after they had gone through a 'wait and see' period and used all advice from close family and friends. Some reports described parents thinking that healthcare professionals were 'in over their heads' or 'did not seem to know a lot about it.'^{14 22} Some parents consulted several physicians without receiving a convincing or good explanation for the problem.²² In our study, the healthcare professionals expressed erroneous beliefs to the parents or provided baseless reassurance to them, as reported by the parents.¹⁴ Therefore, there is a pressing need to educate parents and primary healthcare workers about the prevalence, presentation, and management of SwD.

Anxiety and psychosocial stress were reported by most of the participants. This could be explained by the parental uncertainty of diagnosis, by dealing with day-to-day feeding and swallowing issues, and by the difficulties encountered to access information (ie, difficulty in obtaining information or receiving insufficient or inaccurate advice).^{22 24 25 28} In addition, lack of sleep and limited personal time could have amplified parental anxiety and stress. One of the parents whom we interviewed frankly stated '...no sleep at all,' which was also reported in the Estrem *et al* study.²⁹ Some parents thought they neglected their own health to mitigate the day-to-day swallowing issues and to coordinate hospital visits and referrals.²⁸ It appears that acknowledging their strain and efforts and providing these parents with support is urgently needed.

The presence of an OHIT with SwD changed the family dynamic from several points of view. First, it restricted the family freedom to eat outside the home, as found by Estrem *et al*.²⁹ We found that it restricted family leisure time either by limiting their pursuit of hobbies or preventing travelling or social interaction during holidays.^{14 15} These changes complicated the family dynamics and made the parents further prone to developing conflicts in their relationships and also contributed to health deterioration;^{14 15} these circumstances might indirectly impact the child's health.

Parents reported that a negative or dismissive attitude of healthcare professionals was one of the contributors to their stress. In Cowpe *et al* one parent reported that 'More the medical side than the community side have no respect for what the parents have to say... it is quite nice when you find people who actually listen.'²² Being dismissed was one of the findings of the current report and has also been reported in other studies.^{14 15} Parents are happy to work and learn together with a healthcare professional who has the ability to admit a scarcity of knowledge about the condition.^{23 30} If the healthcare

worker is not comfortable managing the case, providing access to specialist care would greatly help the parents.

Finally, we would like to further discuss the interviews that were conducted over the course of our study. A couple of the parents broke down and wept. They recounted their stories of helping other families who were in the same situation. They also expressed that they would do anything possible to prevent seeing others from going down the same path.²⁹ One of the parents began to post daily information on social media about her infant in an effort to motivate her followers and friends to read about the condition. Collaboration between the care providers and families is needed to address this condition and improve the provided care.

The present study has some limitations. Due to the nature of the qualitative approach, the results cannot be completely generalised, although all of the participants expressed a struggle in one or more domains of the model. A quantitative study to assess this framework and its validity is needed. Additionally, this framework was based on the insight of parents without incorporating the opinions of the healthcare professionals, which would likely further characterise the phenomena. The purposeful sampling of the participants provided rich information about the experiences of families. However, these parents already had access to a specialty clinic or had begun a management plan, and we did not consider sociodemographic differences. Including caregivers of the affected children from the community may have provided a different dimension. Lastly, we have limited our conclusions to the cohort of interest (OHITs diagnosed with SwD), but we cannot confirm that these barriers are specific to them.

To conclude, there are multidimensional barriers to achieving a diagnosis of SwD in OHITs. These barriers are erroneous beliefs about SwD, parent-related barriers and clinician-related barriers. A critical factor that might enhance the presence of these barriers is a lack of knowledge and education about SwD in the general population and in community healthcare workers. Further research is required to assess these barriers and to verify their impact on the management of this condition.

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