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Fear, isolation and the importance of support: A qualitative study of parents' experiences of feeding a child born with esophageal atresia

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ABSTRACT

Objective: Feeding and swallowing difficulties in children are increasing due to improved survival rates of children with complex medical conditions. Despite being common complications of esophageal atresia (EA), EA related feeding difficulties have received little attention in research. Establishing positive feeding interactions and practices are important for child health and development, and for parental and child mental health. The current study aimed to investigate the parental experiences of feeding a child born with EA.

Methods: An international online survey was developed and disseminated to parents of children born with EA, aged 0–12 years, in collaboration with a patient charity for EA. Reflexive Thematic Analysis was used to analyze the qualitative survey responses.

Results: 176 participants were included in the qualitative sample from a larger international online survey study, chosen by a process of selective coding. Three themes were constructed during the analysis: 1) Anxiety, trauma and loss; 2) Isolated and unsupported; and 3) Supported. The results indicated that parents of children born with EA experienced significant anxiety related to their child's swallowing and feeding difficulties and traumatic experiences during feeding, and that these led to parents feeling a sense of loss and sadness. It was also found that support, or a lack of support, within parents' social environment might mediate parental experiences of child's feeding difficulties.

Conclusions: This study highlighted the importance of support for parents of children born with EA, and suggested a need for improved guidance for feeding and swallowing difficulties.

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Introduction

Esophageal atresia (EA) and Tracheoesophageal fistula (TEF) are rare congenital malformations of the esophagus, affecting globally approximately 1 in 4100 births (Roberts et al., 2016). More complex presentations include a long gap EA, and additional anomalies, such as VACTERL association, in which at least two associated anomalies (vertebral defects, anal atresia, cardiac defects, tracheoesophageal fistula, renal anomalies, and limb abnormalities) are present (Raam et al., 2011; Séguier-Lipszyc et al., 2005). EA/TEF require neonatal surgical repair to enable oral feeding (Roberts et al., 2016). Although, corrective surgery aims to minimize postoperative complications, feeding and swallowing difficulties and poor growth remain common (Conforti et al., 2015; Menzies et al., 2017). EA related chronic morbidity, such as dysphasia, respiratory complications and gastroesophageal reflux,

often continue beyond pediatric care, impacting quality of life and mental health across the life-span (Gibree et al., 2017; Mikkelsen et al., 2022; Rabone & Wallace, 2021). Despite being common complications of EA, feeding difficulties have received little attention in research (Conforti et al., 2015). Given the increased incidence of feeding and swallowing related problems due to the improved survival rates of children with complex medical conditions (Sdravou et al., 2020), the current study has relevance across pediatric healthcare.

Research has differentiated between feeding and swallowing disorders (Conforti et al., 2015), but in practice, it is often difficult to separate these two. A number of EA related feeding problems can influence the child's ability and willingness to eat (Ramsay & Birnbaum, 2013). These include slow eating, oral aversion, food refusal, dysphagia, coughing, choking, or vomiting during meals (Puntis et al., 1990). The estimated prevalence of feeding or swallowing difficulties in children born with EA/TEF varies between 28 and 75%, depending on criteria used to assess presence of feeding and swallowing difficulty (e.g. Faugli et al., 2009; Mahoney & Rosen, 2017; Menzies et al., 2017). Research has also shown that whilst feeding difficulties in patients with

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typical EA might be mild, patients with more complex EA tend to experience significant feeding difficulties (Baird et al., 2015).

Possible causes for feeding and swallowing difficulties are likely to be multifactorial and interacting, including abnormal functioning of the esophagus, such as gastroesophageal reflux, esophageal dysmotility or narrowing (Mahoney & Rosen, 2016; Ramsay & Birnbaum, 2013); psychological trauma related to aversive and intrusive oral events (Pham et al., 2021); parental factors, such as parental age, educational level and employment status (Sdravou et al., 2020); and feeding practices (Greer et al., 2008). Current recommendations highlight the need for early intervention and a specialist multidisciplinary team approach (Mahoney & Rosen, 2016; Menzies et al., 2017; Ramsay & Birnbaum, 2013). Research has, however, suggested that EA related feeding difficulties are often unrecognized, under-treated and under-reported (Baird et al., 2015; Rozensztrauch et al., 2020).

The relationship between child's feeding difficulties and parental mental health is likely to be complex (Cullinane & Novak, 2013). Research has found that parental feeding concerns are often related to EA complications (Arslan et al., 2020), and that these often continue throughout the early years, even without a severe feeding difficulty (Menzies & Hughes, 2020). Choking and food bolus impaction have been reported as the most common parental concern around feeding, although choking after a lodged food bolus in the esophagus is unlikely to cause asphyxia and will most commonly be resolved with reassurance and a drink (Menzies & Hughes, 2020). It is evident that feeding difficulties can cause anxiety in parents, yet, they may be offered little useful advice or support on how to deal with worrying situations such as a child choking on food (Morton et al., 2019; ten Kate et al., 2021). Similar findings have been found in the wider pediatric literature; for example, a recent study found that parents' perception of threat around their child's food allergies predicted parents' psychological outcomes (Roberts et al., 2021).

Research has demonstrated that pediatric feeding problems can cause significant distress in patients (Baird et al., 2015; Greer et al., 2008), leading to feeling isolated, "different", anxious and depressed (Rozensztrauch et al., 2020; Wallace et al., 2021). Further, child's feeding difficulties can be experienced by parents as overwhelming and frustrating, particularly when other family members might not be able to or willing to help (Ramsay & Birnbaum, 2013). Furthermore, child's problematic feeding can become the central focus of family life, resulting in family tension and stressful mealtimes (Dellenmark-Blom et al., 2016; Menzies et al., 2017). This can lead to parents feeling misunderstood by others, adding to their burden and sense of responsibility (Morton et al., 2019).

Parental feeding practices are important as they can both contribute to the development and maintenance of the feeding problems, and also, help to facilitate problem solving and resolution (Mitchell et al., 2013; Sdravou et al., 2020). Parental mental health and feeding difficulties can also negatively impact child health and development, and parent-child relationships (Baird et al., 2015; Ramsay & Birnbaum, 2013; Vänskä et al., 2017). It has been found that parents might respond to feeding difficulties by using maladaptive feeding practices such as control, coercion, distraction strategies, bribery, and physical intervention (Sdravou et al., 2020), and that parental stress and frustration can lead to increased stress and avoidance in the child (Greer et al., 2008). Further, previous research has shown that challenges to accessing specialist feeding support can add to parents' frustrations (Morton et al., 2019).

The current study forms a part of a larger international online survey study, with a cross-sectional, explorative mixed method research design, investigating the psychological impact of EA on families. Findings from an earlier, quantitative study suggested that increased levels of anxiety and depression in parents of children born with EA/TEF may be associated with child's feeding problems and with parental factors such as younger age, caring stress, perceived lack of support and financial concerns (Wallace et al., 2021). The current study aimed to further investigate the parents' experiences of feeding a child born with EA

using qualitative methods. This more in depth analysis aimed to improve understanding of the psychological impact of feeding difficulties on parents as a response to the growing relevance and need (Conforti et al., 2015; Sdravou et al., 2020; Wallace et al., 2021).

Methods

Participants

This qualitative study included 176 participants, chosen by the process of selective coding from a total of 215 participants who filled in an online survey and met the inclusion criteria. Exclusion criteria included survey responses where the participant indicated that they had not attempted oral feeding of their child or did not mention feeding at all ($n = 39$). The sample size falls within the upper range for qualitative survey studies (Braun & Clarke, 2020). Parents of children born with EA were able to take part in the online survey, if their child with EA was 0–12 year old, if they had an access to a computer, and if they had sufficient English language skills to provide written answers to survey questions. Most surveys were submitted from the United Kingdom ($n = 134$, 76%), whilst 18 (10%) came from Oceania, 11 (6%) from both European Union and North America, and 2 (1%) from Africa. From these, 169 (96%) participants were mothers and eight were fathers. Most parents were aged 30–39 years ($n = 108$, 61%), whereas 44 (25%) were over 40 years, and 24 (14%) were 18–29 years. Parent-reported age for their child born with EA, varied between 1 and 12 years ($M = 4.28$, $SD = 2.66$). Parents described their child's EA as "EA/TEF" ($n = 93$, 53%) or as "EA/TEF with additional complications", such as VACTERL or a long gap presentation ($n = 83$, 47%). (See Wallace et al., 2021 for the development and further details of the survey).

Procedure

The study employed a patient-led approach to its design, data collection and data analysis. The lead investigator had personal investment in the research topic through having "lived-body experience" (Braun & Clarke, 2020) of the research topic as an adult survivor of EA. The ethical approval for the study was obtained from the University of Bath Psychology Research Ethics Committee.

An online survey was developed using Qualtrics software. It included 1) demographic questions; 2) quantitative measures for anxiety, depression, and care-related quality of life (reported in Wallace et al., 2021); and 3) eight qualitative open-ended questions for collecting participant-generated textual data. Online survey methods provided a flexible way for accessing qualitative data (Braun et al., 2021), which is particularly useful for research in a rare disease population. Participants were recruited through EA patient social network sites with the help of a patient charity for EA. A digital advertisement with a link to the online survey was posted on the patient charity's website and on private social network sites for EA 8 times over a 4-month period. Participants were asked their consent at the beginning of the survey, and they were informed of the lead researcher's "insider" status (Braun & Clarke, 2020), as an adult born with EA, during the data collection.

Materials

The qualitative survey questions (see Table 1) were designed to be open and broad to generate rich data on the issues around psychological wellbeing and family impacts of EA with an understanding that every family's experience is different. Participants were encouraged to write about their experiences without a word limit, in as many or few words as they would like. The lead researcher also used previous literature on the impact of child's physical health condition, her own lived-body experience of EA, as well as her clinical experience of working with children and families affected by complex health conditions, to guide the development of survey questions.

Table 1
Qualitative online survey questions.

Data analysis

The data set analyzed in this study was selected from the entire qualitative survey data ($N = 97,072$ words) by performing a selective coding process (Braun & Clarke, 2020). This data reduction process involved identifying and selecting instances where participants talked about experiences, feelings or thoughts related to orally feeding their child (see Table 2). This process was done semantically, paying attention to any feeding or eating related words or situations. The selective coding resulted in a data set containing 30,056 words in total from 176 participants. The range of words for each participant in the final data set varied between 26 and 964 words ($M = 171$).

The data was analyzed using reflexive Thematic Analysis, utilizing a six-stage process described by (Braun and Clarke, 2006; Braun & Clarke, 2019) to identify reoccurring themes across the data set. Thematic analysis was considered suitably flexible and accommodating to the online survey data, which can be “reduced” or summarized compared to face-to-face interview data (Braun et al., 2021). Flexibility of thematic analysis allowed for a theory-driven analysis as the researcher was particularly interested in the detailed analysis of parents' experiences, feelings and thoughts around their child's feeding or eating, from a theoretical preconception that child's feeding problems might be associated with parents' psychological wellbeing (Wallace et al., 2021). Through this approach, the researcher aimed to develop a deeper insight and expanded understanding (Braun & Clarke, 2006) into parents' experiences of children's EA related feeding difficulties.

The thematic analysis was conducted using critical realist epistemology, conceptualizing participants' experiences and meanings in a straightforward way and focusing on “individual psychologies” (Braun & Clarke, 2006), but also acknowledging that experiences, feelings and thoughts are socially constructed through language and in relation to other people. The codes and themes were identified and interpreted at the semantic level, focusing on the explicit meanings of what participants said (Braun & Clarke, 2006; Braun & Clarke, 2013). The

Table 2
Process of selective coding and data reduction.

	Participants (n)	Words (n)
Entire data set	215	97,072
Participants removed no oral feeding attempted or mentioned	39	8360
Textual data removed instances of not talking about feeding or eating		58,656
Final data set	176	30,056

researcher's influence on the coding and analysis process was acknowledged. To ensure reflexivity, the researcher mapped out their own contextual personal and professional background, including the “insider” status; experience of parenting; social characteristics such as gender, ethnicity, and social class (Palaganas et al., 2017) as well as professional training and experience. Keeping a reflective diary and frequent discussions with supervisors helped with remaining reflexive throughout the analysis process.

To ensure good quality of the analysis process, the researcher followed the 15-point checklist for quality criteria for thematic analysis, described by Braun & Clarke (2006), and standards for Reporting Qualitative Research guidelines (O'Brien et al., 2014). Furthermore, the researchers employed techniques of “member checking” and “triangulation”, which are suitable techniques for ensuring quality in qualitative research (Braun & Clarke, 2020). The process of member checking included presenting and discussing the initial themes with six parents of children born with EA in an online Microsoft Teams meeting and reflecting on the relevance and “fit” of the model to the parents' own experience. The process of triangulation involved discussing the model in supervision and checking whether it fitted with the theoretical underpinnings of the analysis, through the lenses of persons with training and experience in health psychology but no personal experience of EA. Based on the feedback, the researcher was able to refine the thematic map and themes descriptions.

The six-stages of thematic analysis included the processes of familiarization, generating initial codes, and generating, reviewing and defining themes. During these steps, the researcher exported the textual survey data from Qualtrics into a Microsoft Word document and immersed themselves in the data, reading it several times. Notes were written on the side of the printed Word document, identifying the researcher's initial thoughts and interests. These were drawn into visual maps, which were shared and discussed in supervision. Complete coding process involved working systematically through the data set by reading through the text and identifying features of data by manually writing down “codes” on index cards with a reference number referring to specific segments in the data set. The reference numbers included the following information: 1) parental role ($M =$ mother; $F =$ father; 2) participant number; 3) parental age group ($1 = 18-29$ years, $2 = 30-39$ years, or $3 = 40+$); 4) child's illness severity group ($1 =$ EA/TEF, or $2 =$ EA/TEF with additional complications); and 5) line numbers. The codes were identified in relation to the theory-driven question: “How do parents talk about their experiences, feelings and thoughts about their child's feeding or eating in the context of EA?”

Following the process of initial coding, the memory cards were carefully examined and similar codes were collated into piles. An initial thematic map was developed with simple theme descriptions and reflections on relationships between themes. The initial themes were then refined and some themes were combined, separated or discarded. The data extracts were collated for each theme, and themes were examined in relation to their coherency and internal consistency (Braun & Clarke, 2006). When the thematic map with data extracts “made sense”, the final themes were analyzed in relation to previous literature. The final thematic map with theme descriptions was developed, and vivid and compelling data extracts were chosen to illustrate the essence of each theme.

Results

This paper reports findings from the qualitative part of the survey, whilst the quantitative results were reported in Wallace et al. (2021). During the qualitative analysis, three themes were generated: 1) Anxiety, trauma and loss; 2) Isolated and unsupported; and 3) Supported. Please see Table 3 below for themes and subthemes with data extracts.

Table 3

The three themes and subthemes identified in relation to the research question.

Themes	Subthemes	Data extract example
1. Anxiety, trauma and loss	1.1. Fear of feeding and choking	"It was terrifying. [...] I was so scared she would get stuck and choke." (M14/3/1)
	1.2. Traumatic experiences during feeding	"Every feeding time I was mentally getting ready to go to hospital." (M151/2/1)
	1.3. Loss and sadness	"I found seeing other children his age eating normally, I found it quite emotional and sad." (M92/2/2)
2. Isolated and unsupported	2.1. Lack of understanding	"It felt like no one knew what to do [...] There was a lot of conflicting advice from each professional." (M7/2/1)
	2.2. Loneliness	"I felt completely alone with very little information and support." (M63/2/1)
3. Supported	3.1. Supported by information	"The TOFS leaflets were really helpful in explaining the condition to nursery." (M32/3/2)
	3.2. Supported by others	"The SALT team was an absolute godsend offering us a wealth of advise on techniques to help him clear his throat." (M102/2/2)
	3.3. Developing resilience	"I would not change him for anything that has happened as it has taught me to never take anything for granted." (M42/1/1)

Theme 1: Anxiety, trauma and loss

Many participants talked about anxiety and fear, often related to EA complications such as swallowing difficulties, choking and medical emergencies. Understandably, these experiences led to some parents feeling a sense of loss and sadness about their child's feeding difficulties.

Fear of feeding and choking

Participants described their anxiety in several ways: feeling fear and constant worry, feeling frightened, overwhelmed, scared or petrified. They talked about their child gagging, choking, having "stickies" and food getting stuck in the esophagus. These experiences contributed to worry about choking, making it harder to relax during feeding situations. The following quotes illustrate the emotional impact of choking: "He choked all the time. I became a nervous wreck." (M27/2/2); "It's really scary and upsetting seeing your baby choking" (M19/1/2). Some mothers talked about the impact of choking episodes on the family, "She [sibling] gets very scared when he [child born with EA] has a choking episode and always leaves the room." (M18/1/2); "He [child born with EA] often chokes which makes us on edge and stressed at every meal time." (M86/1/2). Many participants also talked about the lack of advice they had received about managing choking episodes: 'I don't remember ever being told what to do when he choked the first time and when it did happen it was horrific for both of us.' (8/2/1).

Traumatic experiences during feeding

A small number of participants described experiences of having to call an ambulance or resuscitating their child born with EA. Understandably, these experiences contributed to mothers feeling anxious and upset. One mother said, "I have nightmares about things that have happened. I find it hard to talk to people about it without getting upset." (M42/1/1). Another mother explained, "The whole weaning experience was traumatic for me, constant worry of choking, of having to resuscitate him etc. I was petrified inside." (M128/2/1). Participants also described worrying about what might happen and fearing the worst:

The weaning stage was the scariest and most stressful years of my life. My son repeatedly choked and I had to call ambulances a few times. I thought he was dead a few times too. [...] I felt weighed down and depressed and constantly focusing on if my son may choke or die. (M7/2/1).

Loss and sadness

This subtheme captures the feelings of loss of sadness. Mothers described feeling sad when comparing their experiences to others. Some mothers talked about feeling guilty about the lost opportunities: "[Not being able to breastfeed her] was hard for me because I felt that I had failed her. I did feel like her 'baby-hood' if you will, was stolen from her and I." (M172/1/1). Participants described feeling low and putting pressure on themselves: "The pressure I put on myself was immense. [...] I remember sobbing on my husband as he [child born

with EA] couldn't eat crisps like other children in my postnatal group." (M116/3/2). One father talked about how feeling low had impacted on his parenting,

I'm more "snappy" and angry. I often fly off the handle and swear more, which is distressing for me, especially when I swear in front of my children. I take far less pleasure in anything that I do, and often find being a parent a chore and a bind. (F118/3/1).

Theme 2: Isolated and unsupported

This theme captured how parents' social environment, and a lack of understanding and support from others, contributed to parents feeling isolated and unsupported.

Lack of understanding

This subtheme described difficulties participants faced trying to explain EA to others, whilst struggling to understand it themselves. One mother explained, "The main challenges were working out what was 'normal baby weaning behavior' and what was TEF/EA related." (M4/2/1). Many participants talked about the lack of information they received from healthcare professionals and having to educate themselves about EA: "Health visitors and doctors knew very little about what to recommend. I had to research myself online for ways to progress." (M26/2/2).

Many parents reported having a poor relationship with different healthcare professionals. One mother explained, "I found that medical professionals didn't always listen to our worries or observations. [...] and made me feel insignificant." (M22/2/2). Poor relationship with child's day-care or education setting was often related to the lack of understanding of EA and the child's needs. One mother explained, "We really struggled with nursery as the teacher just didn't understand her problems and would give food she knew she couldn't manage." (M29/2/2).

Participants also faced a lack of understanding about their child's unusual cough in public. One father explained, "It is hard sometimes explaining her cough is nothing to be worried about." (F37/3/2). Some participants felt judged by others: "I found that people commented and judged me a lot by being out with my son. People were very quick to say that they thought he should be at home as he sounded very poorly." (M115/3/2).

Loneliness

Many participants talked about difficulties relating to others and feeling isolated. One mother explained, "Small talk about babies and having children with friends and family was non-existent as I could not relate to the normal 'problems' people have." (M128/2/1). Some mothers described challenges on their relationships: "He [partner] doesn't have to see the baby choking with water or spitting the food all over. He doesn't need to clean his high chair, the walls, the floor [...]. And then he comes home and ask why I'm tired." (M158/2/2).

Some participants talked about having a conflict with their in-laws over their child's eating:

My in laws did and still think we are exaggerating our son's condition and they see him as ok as it is not obvious from the outside. We have fallen out many times as they have given my child unsafe foods to eat. (M124/2/2).

Many parents also explained that family and friends were not willing to help with childcare due to feeding difficulties: "The hard thing was the sole responsibility: no one else would ever feed her or look after her without me as the choking frightened them." (M75/3/1).

Theme 3: Supported

The third theme illustrated how the parents' social environment provided resources and support, helping parents to develop resilience.

Supported by information

Many participants explained that information and support provided by an EA patient charity, including books, information leaflets and guidance, had been helpful. One mother reflected on the benefits of having access to information and peer support: "The Facebook TEF support group was a lifeline during this time! So many food suggestions and encouragement was given." (M4/2/1). However, one mother noted potential risks of parents relying on peer groups for medical advice: "Facebook support groups are very helpful, but can be worrying to see parents asking advice on clear respiratory distress on the internet rather than calling 999 or GP." (M60/2/1).

Supported by others

Participants talked about the importance of support from family and friends. One mother talked about developing confidence in leaving her son with family: "Our family has been really supportive. [...] We are scared to leave him with family for feeds, but we have left him twice now." (M47/2/1). Some participants also talked about the importance of support from their partner: "My husband's support and understanding was amazing and being fully on the same page has helped us all to get through this stage." (M151/2/1).

Many participants talked about support from healthcare professionals, including speech and language therapists (SALT), GPs, pediatric consultants, nurses, health visitors, and dieticians. One mother explained the impact of a speech and language therapist on her mental health,

I spent large parts of the day alone with baby and facing the fear of feeding [...] without much support. Getting a SALT on board at this stage was probably more important for my mental welfare at this time than she realized. (M76/3/1).

Some participants talked about building relationships with healthcare professionals: "All our consultants have been amazing. GP surgery to start with were hard as they hadn't heard of TEF/EA, but now we have a fantastic relationship with them and they know my daughter very well." (M75/3/1). Participants also talked about the importance of nursery and school being accommodating and understanding. One mother explained, "They [nursery] understood my son's condition and were understanding towards my anxieties [...] and happy to be guided by me." (M7/2/1). Some parents gained confidence in feeding with the help of nursery: "My child starting nursery helped [as] they had the confidence to try new foods under advice from feeding specialist where I didn't always have this." (M10/2/1).

Developing resilience

This subtheme illustrated personal growth and resilience parents developed through their difficult experiences. Many described feeling grateful and developing compassion and patience: "Grateful for all who cared for and fixed our child." (M22/2/2); "He has taught me a great deal about compassion and patience, and I certainly am stronger

since becoming his mom." (M148/2/1). Another mother explained, "Having a child with EA has helped to make me a better, more relaxed mother. Having feared that I was going to lose her, I now cherish every minute." (M45/2/1).

Some mothers also reflected back on their coping during stressful situations: "I still remember the first time in early days of weaning her choking on food and I surprised myself with how calm I stayed." (M29/2/2). Two fathers reflected back on their experiences and described their feelings towards their sons: "I am so very proud of my son. He has a special throat. But he also has a very special nature due to the exposure to all the great people that have helped him along the way." (F36/2/1);

I would not change him for the world! He has made me a much stronger person and even though I feel like I'm failing a lot of the time, I know deep down I can carry on, because I have him, and he has me! (F21/2/2).

Discussion

The strengths of this study were its patient-led approach, and providing an in depth analysis of parents' multifaceted experiences of EA related feeding difficulties. The study demonstrated that online survey methods can be particularly useful for research in a rare disease population, enabling a large sample and providing rich data for qualitative data analysis (Braun et al., 2021). Due to increased incidence of feeding and swallowing related problems (Sdravou et al., 2020), the current study has relevance across pediatric healthcare.

The current study found that parents experienced significant anxiety around feeding their child born with EA, and that this anxiety was related to swallowing difficulties, choking and traumatic feeding experiences, and led to parents feeling a sense of loss and sadness. Parents' social environment both provided resources and support, helping parents to develop resilience, but also contributed to parents feeling unsupported and isolated. This unique finding highlighted the importance of support within the parents' social environment, which might mediate parental experiences of child's feeding difficulties.

Parents' experiences of anxiety around feeding and choking is consistent with previous research, which found that parents' most common concern was choking and food impaction (Menzies & Hughes, 2020). Parental anxiety about feeding was often intense and it impacted on feeding practices and confidence to try new foods. Similar findings have been found in the wider pediatric literature, which highlighted the importance of parents' perceived threat around food allergies as a predictor of psychological outcomes (Roberts et al., 2021). In line with previous research, feeding difficulties had an impact on family meal-times, social relationships, and available social support (Dellenmark-Blom et al., 2016; Menzies et al., 2017). At times, feeding difficulties contributed to parents feeling a sense of loss and sadness about their children being different to other children (Rozensztrauch et al., 2020), which impacted on their parenting and feeding practices (Sdravou et al., 2020). This is particularly important as parental wellbeing and mental health can have an impact not only on feeding difficulties themselves, but also on general child wellbeing, health and development (Greer et al., 2008; Mahoney & Rosen, 2017; Vänskä et al., 2017).

Like in previous research, this study found that child's EA related feeding difficulties resulted in parents feeling isolated and unsupported (Baird et al., 2015; Rozensztrauch et al., 2020). Parents were often faced with a lack of understanding about EA related swallowing and feeding difficulties by healthcare professionals, teachers, friends and family, and general public. Similar to what has been found elsewhere, this often led to parents feeling frustrated, judged, and misunderstood, adding to the isolation and sense of responsibility (Morton et al., 2019). It was also commonly reported that family members were not able to or willing to help due to risks during feeding. This significantly reduced the available support for parents adding to their burden (Morton et al., 2019).

The current study highlighted the importance of support in helping parents to navigate through the complex task of feeding a child born with EA. Interestingly, this was experienced as a learning process for everyone involved. The study found that parents, family and friends, as well as healthcare professionals and teachers needed to learn new skills and develop confidence in feeding a child born with EA. Information and peer support is particularly important in providing necessary help and guidance for both families affected by rare diseases. Parents valued support from a patient charity, including books, information leaflets, and peer support online groups. The findings noted, however, that without specialist training, it can be difficult to recognize difficulties that require medical intervention, indicating the importance of patient charities working together with healthcare professionals. In line with previous research, support from others helped parents to cope with child's feeding difficulties, and parents were able to reflect on developing resilience through their difficult experiences (Morton et al., 2019).

Practice implications

The findings of the current study suggest that information and support for EA related feeding difficulties is needed, and that patient voice is important in developing guidance for rare diseases. This study recommends a guidance for EA related feeding difficulties to include: 1) Information about what to expect when feeding a child born with EA; 2) First aid skills and safe feeding practices; 3) Guidance on how to deal with food sticking in child's esophagus; and 4) Guidance on how to recognize and cope with uncomfortable emotions and difficult feelings during feeding.

Study limitations

The limitations of the current study included uneven gender distribution of the sample, which is one of the common challenges for online survey designs and using social media networks for participant recruitment (Thornton et al., 2016). Another limitation related to not measuring the severity of feeding difficulties. The large sample of the current study included, however, a wide variety of feeding difficulties described by participants, suggesting that the findings are relevant across different levels of feeding difficulties. Also, previous research has suggested that parental responses to child's medical problems might be experienced subjectively (Menzies & Hughes, 2020; Roberts et al., 2021). The large sample could have enabled investigation of how parent and child characteristics were linked to the main themes, but this study focused on generating broader themes around parents' multifaceted experiences of child's feeding difficulties. Looking at contextual details in relation to the findings, such as parental and child characteristics, provide potential directions for future research. Also, the findings suggested that parents develop resilience whilst caring for a child born with EA. The future research might investigate how the resilience develops and how healthcare professionals could support this.

Conclusions

Feeding and swallowing difficulties in children are increasing due to improved survival rates of children with complex medical conditions. The current study found that parents of children born with EA experienced anxiety related to their child's feeding difficulties and traumatic experiences during feeding and that these led to parents feeling a sense of loss and sadness. A unique finding highlighted the importance of support within parents' social environment, which might mediate parental experiences of child's feeding difficulties. The study made suggestions for guidance on EA related feeding difficulties and for future research.

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CRediT authorship contribution statement

Vuokko Wallace: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Writing – review & editing, Visualization. **Kirsi Honkalampi:** Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision. **Maija Korhonen:** Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision.

Declaration of Competing Interest

The authors declare that they have no conflict of interests.

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