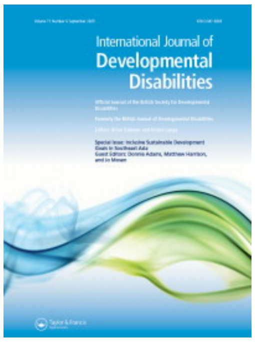

International Journal of Developmental Disabilities

ISSN: 2047-3869 (Print) 2047-3877 (Online) Journal homepage: www.tandfonline.com/journals/yjdd20

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To cite this article: Laura K. Hielscher, Karen Irvine, Amanda Ludlow, Samantha Rogers, Nicola Enoch & Silvana E. Mengoni (23 Aug 2025): Mothers’ experiences of nasogastric tube feeding for young children with Down syndrome, International Journal of Developmental Disabilities, DOI: 10.1080/20473869.2025.2539236

To link to this article: https://doi.org/10.1080/20473869.2025.2539236

INTERNATIONAL JOURNAL OF DEVELOPMENTAL DISABILITIES
https://doi.org/10.1080/20473869.2025.2539236

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Mothers' experiences of nasogastric tube feeding for young children with Down syndrome

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ABSTRACT

Objectives: Evidence suggests that nasogastric (NG) feeding tubes are frequently used for infants with Down syndrome. Despite caregivers being an essential resource, relatively little is known regarding their perspectives of NG tube feeding and its impact for children with Down syndrome. Therefore, this study aimed to expand on the research to understand perspectives of mothers of young children with Down syndrome to inform how best to support them.
Methods: Fourteen mothers of children with Down syndrome (*mean age* = 39.43 years, *SD* = 5.96 years) took part in virtual semi-structured interviews to explore how NG feeding tubes are being used for young children with Down syndrome, including exploring decision-making processes, exit-planning, and the impact on oral feeding, eating, and drinking.
Results: Reflexive thematic analysis resulted in three core themes. Mothers had clear feeding goals which were often required to be put aside during periods of acute illness. Where mothers were not able to meet their breastfeeding goals, they experienced feelings of grief. Once NG tubes were in place, mothers struggled with a lack of support and exit-planning, meaning that their child was dependent on the NG tube far longer than initially anticipated, with mothers reporting significant psychosocial and emotional challenges.
Conclusions: Specialist practical support for breast feeding (including for infants that are fed *via* NG tube), that is targeted to children with Down syndrome is crucial to parents. Structured NG tube exit planning is essential in reducing parental anxieties and preventing feeding tube dependency.

ARTICLE HISTORY
Received 28 November 2024
Accepted 21 July 2025

KEYWORDS
Down syndrome; tube feeding; support; infants; parent/carers, eating

Introduction

Children with Down syndrome, a genetic condition leading to intellectual disability, are more likely to require the use of nasogastric (NG) tubes to provide them vital nutritional benefits, due to being more prone to feeding difficulties, congenital heart defects and prematurity (Bergström et al. 2016; Kamity et al. 2021). Although feeding tubes have a life sustaining function, the negative impacts on feeding development have been widely documented and are considered to have a particularly profound effect on children with Down syndrome, who are already reported to have more feeding and oral motor difficulties (Agostini et al. 2021; Hielscher et al. 2023) including oral-motor delays and challenges with chewing and swallowing (Anil et al. 2019; Roccatello et al. 2021).

It is estimated that between 13% and 50% of children with Down syndrome will need to be fed *via* NG tube in the first three months of life (Lewis and Kritzinger, 2004; Williams et al. 2022). This is often due to feeding difficulties, such as some infants and children with Down syndrome presenting with hypotonia (low muscle tone), poor lip seal, difficulty sucking and an inefficient swallow (Agostini et al. 2021). Therefore, short-term NG tube feeding can provide vital nutritional benefits, prevent malnutrition and faltered growth for unwell infants, whilst minimising the energy expenditure needed to feed (Bliss 2024; Krom et al. 2019; Mason et al. 2005).

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/20473869.2025.2539236.

Studies exploring the prolonged use of NG tubes in pre-term infants have identified significant negative impacts on feeding development; including difficulty co-ordinating sucking, swallowing (Shiao et al. 1995; Reilly et al. 1995), along with resistance to transition from tube feeding to oral feeding, delayed development of oral motor, chewing and swallowing abilities, food refusal and intolerance of a variety of food textures and tastes (Mason et al. 2005; Strologo et al. 1997). NG tubes also have the disadvantage in becoming misplaced and entering the lungs, leading to respiratory problems (Williams et al. 2019), as well as contributing to unwanted side effects such as vomiting, gagging and reduced appetite (Krom et al. 2017).

Along with the direct impact on feeding, the use of NG tube feeding has also been shown to have profound psychosocial impacts on parents and the families. For example, together with its impact on the parent-child bond (Serjeant & Tighe, 2022), parents also worry about their child becoming dependent on the NG tube, and struggle to juggle the practical demands of NG tube feeding and tube weaning with family life (Serjeant & Tighe, 2022; Syrmis et al. 2019; Wright et al. 2024). Moreover, recurrent negative facial and oral experiences such as repeated tube insertion, choking, vomiting and gagging can lead to the development of oral aversions whereby infants refuse to have anything in or near the mouth, making feeding and eating very difficult to manage (Hawdon et al. 2000; Mathisen et al. 1999). These psychosocial impacts are likely to be particularly pertinent for families of children with Down syndrome, who already report high levels of stress around feeding (Brantley et al. 2023).

To facilitate timely weaning from NG tubes, it is recommended that exit plans are documented when NG tubes are first placed (Tilyard et al. 2020), that feeding goals are set and the use of the NG tube is reviewed at regular intervals (Syrmis et al. 2019; Remijn et al. 2022). However, there is evidence to suggest exit plans are not effectively and routinely used within some health care settings, inclusive of those in the UK (Syrmis et al. 2019, 2020), with prolonged use of NG tubes associated with feeding tube dependency and oral aversions (Tilyard et al. 2020).

Given, children with Down syndrome frequently experience feeding difficulties and are also often reliant on NG tubes for nutrition, there is a need to understand the unique obstacles in transitioning to oral nutrition (Pahsini et al. 2025). Therefore, the present study aimed to explore parents' experiences of NG feeding tubes for their young children with Down syndrome in the United Kingdom (UK), including a) the tube-feeding journey for the family b) the impact that parents feel NG tubes have on feeding, eating, and drinking development.

Materials and methods

Research design

As an exploratory study, a qualitative reflexive thematic analysis was used to explore mothers' experiences of NG tube use, their concerns and reflections and to identify common themes amongst mothers' experiences.

Participants

A convenience sampling method was used to recruit 14 mothers of 15 children with Down syndrome (Mother 14 had two children with Down syndrome). To be eligible for inclusion in the study, participants must have been UK-based parents of a child with Down syndrome who may have been currently fed *via* NG tube, or the tube use may have occurred within the last five years. There was no restriction on the minimum duration of NG tube feeding required.

Demographic details of mothers and children are shown in Tables 1 and 2. Seven of the 15 children with Down syndrome (47%) were born prematurely, at less than 37 wk' gestation (22-42 wk. $M = 35.23$ wk) weighing between 1.4-3.7 kg. Ten (67%) of the children had some kind of cardiac anomaly at birth.

It is necessary to note that, for the majority of mothers, it was not possible to recall a specific and discrete length of time that the NG tube was in use. For example, in some cases the tube would be removed and then a period of sickness would cause eating to regress, and so the tube would need to be

Table 1. Sample characteristics.

	Mean (SD)/N (%)
Child's age	40.8 months (19.7 months)
Child age range	7-67 months
Mother's age	39.43 years (5.96 years)
Mother age range	30-50 years
Mother and child dyad ethnicity:	
White British	12 (80)
Other white	2 (13)
Mixed	1 (7)
First time mothers	6 (43)
Gestation at birth	35.23 weeks (19.71 weeks)
Gestation at birth range	22-42 weeks
Premature	7 (47)
Weight at birth	2.68 kg (0.78kg)
Weight at birth range	1.4-3.7 kg
Timing of Down syndrome diagnosis:	
Pre-natal	5 (33)
Post-natal	8 (53)
Given high chance then confirmed post-natally	2 (13)

Table 2. Characteristics of individual participants and their children.

Participant	First time mother?	Child gender	Child ethnicity	Child gestational age at birth (weeks)	Child weight at birth (kg)	Timing of Down syndrome diagnosis	Child age (months)	Co-morbid diagnoses of the child
Mother 1	Yes	Male	White British	33	3.7	Pre-natal	57	Hypothyroidism Gastro-oesophageal reflux disease Unsafe swallow Chronic lung disease
Mother 2	No	Male	Other White	29	1.4	Post-natal	52	Congenital heart disease
Mother 3	No	Female	White British	37	3.7	Pre-natal	30	Congenital heart disease Hirschsprung's disease Laryngomalacia
Mother 4	No	Male	Mixed	22	2	Post-natal	18	Congenital Heart Disease Hypothyroidism Hypogonadism
Mother 5	No	Female	White British	38	2.6	Pre-natal	27	Congenital heart disease
Mother 6	Yes	Male	White British	37	2.9	Pre-natal	59	Hirschprung's Disease Obstructive sleep apnoea
Mother 7	No	Female	White British	33	2.5	Given high chance, confirmed post-natally	67	Congenital heart disease Global Developmental Delay Hypotonia Hearing loss
Mother 8	Yes	Male	Mexican and British	34.5	1.9	Post-natal	60	
Mother 9	No	Female	White British	41.9	3.3	Post-natal	37	Congenital heart disease Hypothyroidism Hypotonia
Mother 10	No	Male	White British	39.9	3.2	Post-natal	31	Congenital heart disease
Mother 11	No	Male	White British	33	2	Given high chance, confirmed post-natally	26	Congenital heart disease Adrenal insufficiency Infantile spasms Visual impairment Hearing impairment
Mother 12	Yes	Female	White British	31	1.5	Pre-natal	7	Congenital heart disease
Mother 13	Yes	Female	White British	39	3.3	Post-natal	67	
Mother 14	Yes	Male	White British	42	3.5	Post-natal	55	Congenital heart disease Hearing impairment Visual impairment
Mother 14	No	Female	White British	39	2.7	Post-natal	19	Congenital heart disease Duodenal webbing repair

reinserted. This experience was common, and where it happened repeatedly, mothers struggled to say exactly how long the tube had been fitted. Due to this complexity, it was not possible to include NG tube duration for participants in Tables 1 and 2.

Interview

The semi-structured interview guide was developed by the research team considering issues raised in the literature. NE also contributed her expertise as a parent of young person with Down syndrome and as CEO of Positive About Down Syndrome. An additional parent of a young person with Down syndrome who has professional experience in health and education for young children with Down syndrome reviewed the questions for relevance and accessibility. The interview guide utilised set questions with specific prompts and follow up questions (for full interview guide see supplementary materials). Mothers were asked about their experiences feeding in hospital shortly after birth, the challenges associated with NG tube use and the perceived impact of NG tube use on later eating, speech and language development. All interviews concluded with asking parents whether they would like to add anything more.

Data collection

To recruit participants, information about the study was shared *via* websites and social media groups (including infant feeding and mother and baby support groups used by mothers of infants with Down syndrome) and *via* existing contacts with relevant local professional and support organisations and groups. Parents were invited to contact the research team *via* email to express their interest in study participation, or to get further information. Parents were then sent a web link to access a digital participant information sheet, consent form and demographic questions (hosted by Qualtrics). The researcher then contacted the participant to arrange a time and date to conduct the interview *via* Zoom. Interviews were undertaken and recorded using Zoom, and then an audio file was extracted from the interview recording. MS Word online was then used to create a transcript of each of the interviews and for manually coded. Interviews lasted between 42:21 min and 1:20:58 ($M = 55{:}15$ min, $SD = 6{:}07$ min). Following the interview, participants were given the opportunity to share further information, thanked for their time and given a debrief sheet.

Ethical considerations

Ethical approval to conduct the study was granted by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (approved protocol number: acLMS/PGT/UH/05175(1)). Participants were provided with written information before interviews to allow them to fully understand the nature of the interview, and the topics that discussions might include. Before interviews commenced, participants were informed that if at any point they felt they wanted to pause or stop the interview, this was encouraged, and they need only to inform the interviewer. Recordings were downloaded directly to researchers' university OneDrive and password protected. Recordings were deleted following transcription, pseudonyms applied, and all identifiable features removed. Debrief information, which included signposting to relevant sources of support, was provided to participants after interviews.

Data analysis

The data analysis process was informed by Braun and Clarke's (Braun and Clarke 2006, 2019) six-step process for conducting reflexive thematic analysis. The lead author read transcripts and listened to interview audio recordings several times to ensure familiarity with the dataset. Coding of the transcripts was then carried out manually using Microsoft Word. Both semantic (e.g. descriptions of events) and latent (e.g. reflections on the emotional impact of challenges faced) codes were used, and comments and initial interpretations were also noted. Initial themes were then generated using the codes. Initially, three transcripts were coded by the primary author and the themes were checked by two members of the research team to ensure coherence, consistency, and clarity. Following this internal consistency process, the primary coder coded the remaining transcripts.

Main themes were developed followed by subthemes. These were reviewed and refined following discussions with the wider research team. Themes were then compared with direct quotes from the transcripts, to ensure they were supported by and rooted in the data and that theoretical sufficiency (Dey, 1999) was reached i.e. where all the code categories were the ones the data itself suggested. Themes were then written up into a narrative account and continued to be refined throughout this stage.

Member checks were conducted to ensure rigour and credibility. All participants were given access to the finalised themes and supporting quotes to check the analysis was representative of their experience and provided their approval with no changes requested (O'Brien et al. 2014). The first author, who had experience working and carrying out research with families with Down syndrome, conducted all of the interviews. By centring the research from a phenomenological approach, it provided an understanding to the researcher on the retrospective reports and lived experiences of the mothers.

Results

Analysis of the interviews resulted in three main themes: 1) Adjusted expectations, 2) The pervasive impact of the NG tube and 3) Finding our own way. The relationships between main themes and their subthemes are outlined in Figure 1.

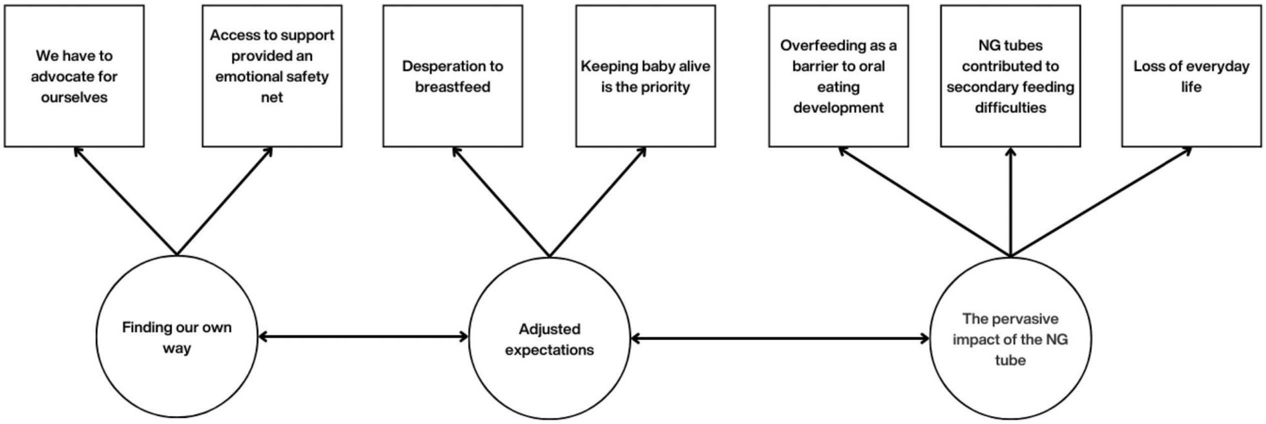

Figure 1. Relationships between main themes and their sub-themes.

Theme 1 - adjusted expectations

Many of the mothers had to shift their expectations and make sacrifices to manage competing priorities around baby's health needs, and their own desires for feeding.

Keeping baby alive is the priority

There was often no discussion regarding the initial insertion of the NG tube, it was something which just appeared, '*it didn't feel like there was any real choice. They would just do stuff and then tell you about it or not tell you about it, and then you'd have to ask*' (Mother 14). Mothers put their own desires around how they'd like to feed their child aside, '*When he was first born the main thing was to keep him alive*' (Mother 2), and they put their faith in the decision-making of the health professionals who were supporting them. '*They didn't tell me they put it [NG tube] in, but it was obviously done for the right reasons*' (Mother 6).

Desperation to breastfeed:

Mothers often commented on how important it was to them to be able to breastfeed their child. Where there were initial struggles establishing breastfeeding, (e.g. due to challenges around baby's suck and swallow, or very tired, floppy babies) mothers were proactive and persevered to eventually establish breastfeeding. '*I guess as she got stronger, trying to offer her the boob each time and then top up with the NG… I was clear that I intended to exclusively breast feed, I felt quite strongly about it*' (Mother 13).

Mothers reported concerns about baby losing their ability to suck or latch effectively due to not feeding orally, and were desperate to promote this and increase their chances of eventually being able to breastfeed their child:

> Once I knew I was going home, I asked to speak to a speech and language therapist…, about what I can do next to help her not lose her sucking reflex and help her latch. (Mother 3)

Often mothers poured their energy into expressing breastmilk, a small thing they could control during an uncertain and scary period. However, for some, expressing was incredibly challenging, '*It's at that point now where I don't know if I've got it in me, because I think back to all the pumping and everything that I did, it was really difficult*' (Mother 12).

Some mothers were able to initiate breastfeeding their child, but health and subsequent NG insertion meant that they were pressured to stop, against their wishes. '*I wanted to breastfeed, it never happened. I'm still sad about that*' (Mother 12).

> His cardiologist was concerned, he obviously needs to reach his optimum weight for his operation and the sooner he reaches that weight, the sooner he can have his operation and the better that will be for him. They wanted to put him on a feeding plan, and told me basically you can't breastfeed him anymore… I felt quite pressured to not breastfeed him. (Mother 10)

Theme 2 - the pervasive impact of the NG tube

Challenges associated with having the NG tube were far reaching and affected mothers, their child and family life as whole.

Overfeeding as a barrier to oral eating development

For many mothers, the regular NG feeding schedule and their child's resulting constant satiety hindered the development of their child's oral feeding. Where tube feeds were given at regular, frequent intervals, children were not experiencing physical sensations of hunger. Parents felt strongly that attempting to orally feed a child who was not hungry was akin to fighting a losing battle. '*I feel like she was always overfed, so why would she make the effort for anything else when she was full up all the time?*' (Mother 9). As such, children experienced delays developing their oral motor skills and this increased the length of time that the the NG tube was required. '*One of the other things that we needed to try was to try and get him moving stuff around his mouth because he just didn't have the control, the oral skills to eat because he'd never had to do it*' (Mother 1).

Many mothers felt that health professionals prioritised weight goals over feeding skills: '*You definitely felt that the emphasis was just on getting the calories in rather than giving her exposure to encourage her to feed*' (Mother 9).

In some cases, mothers felt that their child was pushed to a higher than necessary weight, which hindered other developmental milestones such as gross motor skills. '*I think he was overfed… he was just on these eight feeds a day… and he was just a little roly poly, bless him. And I know that that will have impacted his development as well*' (Mother 10).

NG tubes contributed to secondary feeding difficulties

The presence of the NG tube had a wider impact on children's feeding than just hunger. Mothers commented that their child developed oral aversions and would refuse anything in their mouth. '*It got to a point when he was about 7 wk old where he just started gagging. Like any time that the bottle teat would be near his mouth, he would just start gagging*' (Mother 10).

Furthermore, having the NG tube in place caused significant difficulties with reflux and vomiting.

> His reflux was horrendous. So, we would tube feed him, then we would have to keep him upright for half an hour, he couldn't go on his belly. Any kind of movement he would projectile vomit it up and then it would be awful. (Mother 4)

Vomiting made it very challenging for mothers to ensure their children were reaching nutrition goals. '*It got to the point where she would vomit on every NG feed*' (Mother 14).

Loss of everyday life

The presence of the NG tube placed many practical limitations upon everyday life. '*I felt at one point that it was going to be quite impossible when we came home*' (Mother 1). As a result, parents often felt they were confined to their home in the early days. '*Certainly, for the first few months it felt like we were stuck in the house because trying to tube feed when you are new to it and taking all the stuff you need*' (Mother 9).

Even once they became more familiar with the NG tube, typical family experiences such as holidays, included extra challenges.

> It really is difficult when you're going anywhere to make sure that everything's there and then fighting with airports because you have to bring this milk and they see all this medical equipment. (Mother 7)

Additionally, constant fears around their child pulling out their NG tube made it very difficult for mothers to do day-to-day things with their child, such as driving in the car. '*He was constantly ripping it out. I don't know how I didn't crash the car, really. Driving around with him in the car, in his car seat, in the back*' (Mother 1)

Many mothers were reluctant to insert their child's NG tube themselves but found it equally hard to bear when health professionals were inserting the NG tube.

> We were constantly going to the hospital. Inserting the tube was horrible, horrible… we were thinking what's the point of this? This is making everyone's life hell. (Mother 5)

The presence of the NG tube complicated vital aspects of family life, such as sibling relationships.

> And for her sister… one of my phrases that's out my mouth all the time is 'watch her tube' (Mother 9)

Furthermore, typical experiences which should be enjoyable for a young child can instead be fraught with worry and distress.

> We've been in soft play, the last time it happened, the little girl, I would say she was around four and she pulled it right off her face. And the duoderm that holds that on literally it takes a layer of skin off. It was horrific, the screams of her was awful…. And it was kind of bleeding a wee bit. (Mother 7)

Simultaneously, mothers worried about their child's social integration amongst their peers. They were aware that the NG tube made their child look different and struggled explaining it to younger children. '*The sticker is really obvious and it is the one thing little kids ask me about. 'Why has he got a plaster on his face? What has happened to (child)'s face?*" (Mother 11).

Mothers aspired towards eating and drinking experiences that they considered to be 'normal', such as family mealtimes. Eating and drinking orally were seen as universal, enjoyable experiences that they did not want their child to miss out on. '*I want her to enjoy life and enjoy eating and drinking. I don't want her to rely on having top ups*. (Mother 3).

Theme 3 - finding our own way

This theme highlights the inconsistency in feeding support access across the sample, and how mothers responded to this.

We have to advocate for ourselves

It was felt that the NG tube was sometimes used as a 'sticking plaster' and that inserting an NG tube was a default, automatic choice for children with Down syndrome.

> I just felt like we weren't properly informed, and it was a little bit like she has Down syndrome, she has a heart problem, it's the same for everyone. (Mother 5).

It was also felt that health professionals did not fully inform parents about the use of the NG tube, the process involved, and the risks associated with it.

> We weren't properly informed about everything that is involved with the entire tube, all the risks. We were never told about the aversion, for example. (Mother 5)

Once NG tubes were *in situ*, many mothers were shocked that information and support for a structured removal was not available. '*But there's just no obvious pathway… there doesn't seem to be any NHS process that we're aware of that weans a child from a tube*' (Mother 9). Mothers tried everything they could to develop their child's oral feeding in order to move away from needing the tube, but without a structured and progressive plan, this sometimes hindered more than helped.

> I think we tried so many things because we were desperate, and he then gradually got more aversive. So actually, I think if we'd have had like a structured approach to trying different things, yeah, maybe he would have come off it quicker. (Mother 11).

Where mothers could not access structured support to wean their child from the NG tube *via* the NHS, they sometimes sought out expensive overseas programmes that specialised in this. '*We started researching private programs that we could get to, and so we found Graz and we found one in the US called Growing Independent Eaters*' (Mother 4).

Mothers were frustrated by the inconsistency in the advice given to them and found the support varied significantly.

> He got sent to [different hospital] and there the team were horrified that he was still on the NG tube, and they were basically like if you lived in [different city], this wouldn't have happened. (Mother 4)

Trying to access appropriate support was a huge burden on parents who were already managing a very challenging situation. '*The following up because they've (health professionals) not done this, they haven't done that. They've not referred you to this person. It's just huge. It's a full-time job*' (Mother 1).

When mothers could access support, they often felt that it was insufficient for needs because it was at a low frequency or delivered by a professional who was not a specialist in Down syndrome.

> I don't think he saw speech and language until he was six months old. There was nothing in the early months at all. (Mother 14).

> I think it might have been nice to speak to someone who actually was an expert in kids with Down syndrome and their feeding as opposed to well-meaning but uninformed general hospital staff… this is the most common chromosomal difference, why are there not loads of experts? (Mother 13)

Access to support provided an emotional safety net

When mothers' support needs were met, the impact it had on them was akin to having a safety net whilst navigating this unexpected world

> She was like, to be honest, I don't think there's any point putting it back in for now… there's always someone on hand 24/7 if you need somebody, just ring the team and we'll come and put it back in. (Mother 6 describing a conversation with a nurse after her child pulled out his NG tube)

Furthermore, mothers spoke very highly of healthcare professionals who they felt understood their feeding goals and were actively supporting them to achieve this.

> The nurses were brilliant, they were really amazing, very promotive of trying to breastfeed. So, although they really helped me with the bottle feeding, because they knew I wanted to breastfeed and they wanted to support that, I think he was 5 weeks old and we introduced trying to let him suck as well. So, he was nasogastric and bottle and breast (fed) at one point. (Mother 8)

During long hospital stays, mothers were desperate to go home and establish some sort of family life and move towards normality. Where this was understood and supported by health professionals, it gave them hope.

> A different doctor came… and I remember him being on the rounds one day and usually they just sort of sit there and talk over my head and he was the first person to look at us and say 'what is keeping this baby here?' [in hospital]… .The road to home happened so suddenly, and I credit it all to this doctor… He was amazing. (Mother 12)

Additionally, mothers highlighted that access to appropriate and accurate information he empowered them and meant that they were less reliant on health professionals.

> When we arrived [at hospital], we were given a folder which had all the information that we could ever want in it, and it had all the information on NG tubes and oxygen and everything so that if we didn't want to go and ask someone, it was in there which was fantastic. (Mother 12)

Mothers were also reliant on online support groups, charities and other parents within the Down syndrome community. Mother 7 wondered how she would have coped were this not available to her: '*I think I would have been at a real loss; I probably got more advice from them than I did from health professionals*'.

Resilience and perseverance are essential to get off the tube

Working towards completely oral eating and drinking to allow removal of the NG tube was a long process with many steps forwards and backwards.

> I'm not sure exactly how many months, but it definitely took months of encouragement and perseverance every day of going through everything to see what does she really like? (Mother 7).

Fears around choking sometimes led to mothers limiting the types of food they offered their children, which could in turn hinder the development of their child's eating skills. *'Initially those kinds of things he choked on, and I just couldn't cope. I couldn't just try it again'* (Mother 8).

Mothers commented on the pressure they put on themselves to get their child off the NG tube, and how difficult it was to persevere when things were not going according to plan.

> I remember speaking to the neonatal dietician. Once I got home, she called me to follow up on something and she made some comment about, we would have expected him to be off of the NG by now. But because he's not, I've got to transfer you to the community dietitian service and that really upset me. I felt like I'd failed because I hadn't managed to get him off the NG tube. (Mother 14)

Discussion

The research sought to explore the experiences of mothers in the UK whose children with Down syndrome had been fed using NG tubes, and its impact on feeding, eating, and drinking development. The findings emphasised the emotionally challenging and often tumultuous journey faced by the parents of young children with Down syndrome who were fed *via* NG tube. For example, mothers often did not feel included or heard regarding their child's feeding and were not always supported to meet their own breastfeeding goals. Additionally, they worried about their child becoming dependent on the NG tube, and felt the tube hindered the development of oral eating skills. When at home, juggling the practicalities of NG tube feeding alongside the demands of everyday life, was articulated as being not only an unexpected challenge but one that came with a lack of preparedness.

Mothers in this study reported feelings of grief, anger and loss when they wished to breastfeed but were unable to. Previous research has shown that mothers who are unable to meet their breastfeeding goals will often experience significant negative psychosocial impacts, including feelings of grief, anger, and loss, particularly when they lack practical and emotional adequate support (Brown, 2018; Brown and Shenker 2021). This distress is especially pertinent where infants are born premature, or are unwell at birth, as mothers feel that breastfeeding is a way that they can protect their infants (Lööf-Johanson, Foldevi, and Rudebeck 2013). For mothers of infants with Down syndrome, breastfeeding is often a key goal yet breastfeeding support quality and access is highly variable, and does not always meet mothers' needs (Cartwright and Boath, 2018; Colón et al. 2009; Hielscher et al. 2024).

Mothers in the present study did not feel included or informed about decisions around their child's feeding, reporting a distinct lack of information about the potential negative impacts of NG tube feeding such as the development of oral aversions and/or oral motor delays, and problems with vomiting and gagging. This mirrors findings from families of children without Down syndrome (Steward et al. 2020; Syrmis et al. 2019; Syrmis et al. 2020). Even when parents were given information handouts about NG tube feeding, this failed to include the significant social or emotional challenges that often arise (Townsley and Robinson, 1999), demonstrating the need for integrated mental health support for parents of infants and children who are experiencing feeding difficulties and/or being fed *via* NG tube (Woolf-King et al. 2017; Wright et al. 2024).

Mothers also blamed the lack of appropriate information around the use of the NG tubes as having contributed to their children's feeding difficulties. For example, when the NG tube is *in situ*, oral stimulation is necessary to prevent the development of oral aversion and subsequent tube dependency (Senez et al. 1996). When infants who do not receive oral nutrition or stimulation in the first three months of life have been shown to have reduced tolerance to oral sensations (Scarborough, 2002). However, in the present study, many of the mothers were not aware of the need for oral stimulation and consequently failed to offer it leading to a sense they had inadvertently hindered their child's eating development, as well as contributing to oral aversions and prolonged use of NG tubes.

In addition, mothers argued that a consequence to their child not being fed orally early in life, meant that their children had missed out on the development of oral muscle strength and oral motor control, something which is already noted as being delayed in children with Down syndrome (Kumin, 2015). As such, children struggled to establish effective sucking, chewing and swallowing. This in turn limited the types of food and drink they believed their child could safely consume. Additionally, fears regarding an unsafe swallow, limited the types and textures of food that mothers offered their child, which may hinder the development of eating skills further due to a lack of exposure to challenging food textures (Cochran et al. 2022; Reilly et al. 1995).

The practical demands of NG tube feeding were also raised as an issue for the families, making day to day life feel complicated and impossible, with NG insertion itself noted as being incredibly traumatic, whether done by mothers themselves or by the health professionals. Taken together with existing research, the findings demonstrates the need for in-hospital education and training to equip parents to manage NG tube feeding when leaving hospital, and to prepare for the impact it may have on their day-to-day lives, such as managing the uncertainty and unpredictability that came with feeding problems, NG tube use and weaning (Serjeant & Tighe, 2022; Syrmis et al. 2019; Wright et al. 2024).

In line with previous research, mothers reported a distinct lack of planning regarding NG tube removal (Syrmis et al. 2020; Tilyard et al. 2020), despite recommendations that a review date be documented upon insertion and regularly reviewed on an ongoing basis by a multidisciplinary team (Dunitz-Scheer et al. 2009; Tilyard et al. 2020; Trabi et al. 2010). In this scenario, an absence of concrete plan for tube weaning may exacerbate parents' concerns about their child becoming dependent on the feeding tube long-term. However, in pre-term children, education and targeted tube weaning goals have been shown to reduce parental anxiety regarding tube feeding dependency (Slater et al. 2021; Wright et al. 2024).

Currently, there is a lack of research around the outcomes of tube weaning protocols specifically for children with Down syndrome, although a recent study suggests that the Graz model could be effective as a rapid tube-weaning protocol for tube-dependent children with Down syndrome (Pahsini et al. 2025). The Graz model tailors enteral nutritional input, so children could have the opportunity to feel hungry and aims to increase a child's autonomy in feeding (Dunitz-Scheer et al. 2009; Pahsini et al. 2025). Having such a protocol would also provide the structured guidance that the mothers in the current study had raised as a necessary requirement.

This study was one of the first to explore parental experiences of NG tube feeding for young children with Down syndrome, appearing to reflect NHS services throughout the UK. Despite this, there are a few limitations to note. Only mothers volunteered to participate in the study- a phenomenon previously documented within parenting and feeding research (Docherty and Dimond, 2018; Mengoni et al. 2025). As such, further research which explores the unique paternal experience would be of value, particularly given that whole family dynamics are impacted when a child is fed *via* NG tube (Wright et al. 2024). Moreover, within the participant sample, many mothers described their ethnicity as White British, so the study findings may not accurately represent the experiences of individuals from minority groups who have been reported to face additional barriers when accessing quality maternity care (Obionu et al. 2023).

Conclusion and recommendations

In summary, the current findings emphasise the importance of quality breastfeeding support that is targeted towards mothers of infants with Down syndrome, addressing the challenges faced by those whose child is fed *via* NG tube. Breastfeeding was recognised as a high priority, and mothers wanted specialist practical support targeted to children with Down syndrome, prioritising attempts at oral feeding. This is important, as research has shown success at reaching these goals when mothers of infants with Down syndrome are provided with timely and effective breastfeeding support (Sooben 2012, Zhen et al. 2021).

Parents wanted to have access to information about NG feeding tubes, including associated risks, practicalities and the potential psychosocial impact. Structured NG tube exit planning was highlighted as crucial to reduce parental anxieties and prevent feeding tube dependency. As was, exit plans encompassing specific timelines and goals, including preventive action that aims to avoid loss of sucking reflex and development of oral aversions were also warranted. Taking this into consideration, it is suggested that future research could explore the suitability of existing tube-weaning protocols (e.g. the Graz tube weaning protocol, Dunitz-Scheer et al. 2009) for use with infants and children with Down syndrome specifically, and the feasibility of employing them within NHS services.

Acknowledgements

Thank you to all of the participants who took part, and to Positive about Down Syndrome, the Down Syndrome Association, Sandra Redman and Barnet Integrated Group for Down Syndrome, for their assistance with recruitment for this study.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by a PhD Studentship from the University of Hertfordshire.

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Data availability statement

Data available on request.

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