

One Tube Does Not Fit All

Parent Experiences and Decision-Making for Choosing a Nasogastric Tube or Gastrostomy for Their Child During Allogeneic Bone Marrow Transplant

James Evans, MRes; Julie Lanigan, PhD; Dan Green, PhD; Graeme O'Connor, PhD; Faith Gibson, PhD

Background: Children undergoing bone marrow transplant (BMT) are at risk of developing malnutrition. A feeding tube becomes a requirement for most children to meet their nutritional and medication requirements. Two tubes are typically used: nasogastric tube (NGT) or gastrostomy. At the UK center where this study took place, parents are offered a choice between these tubes.

Objective: This qualitative data collection in a mixed methods study explored why parents choose either tube and their experiences of using it.

Methods: Parents participated in 2 semistructured interviews. First, on admission to explore why they chose either tube. Second, 1–2 months postdischarge to explore their experience of using the tube. Interviews took place over 18 months. Transcripts were thematically analyzed.

Results: Sixteen parents whose child had an NGT, 17 a gastrostomy, were interviewed. Choice was experienced across a continuum of difficulty and freedom. Many parents deferred to the expertise of professionals; others felt they were the experts in their child. Influential factors in decision-making included expected duration of need, the child's age and activity, cosmetic differences, balancing gastrostomy surgery against NGT dislodgement, lay advice, healthcare professionals' recommendations and prior tube feeding experiences.

Conclusions: Parents valued choice appreciating 1 feeding tube might not suit every child.

Implications for Practice: Choice of a gastrostomy or NGT should be offered to children prior to BMT.

What is Foundational: Parents navigate a complex decision-making process when choosing a feeding tube for their child. Healthcare professionals can facilitate informed decision-making through collaborative discussions, inclusion of peer support, and provision of balanced information.

Keywords: Bone marrow transplant, Decision-making, Experiences, Gastrostomy, Nasogastric tube, Pediatrics, Thematic analysis

The conditioning regimens used during allogeneic bone marrow transplant (BMT) frequently lead to mucositis and gastrointestinal toxicity including vomiting and diarrhea.¹ These factors compromise children's oral intake putting them at risk of malnutrition following BMT.² Malnutrition in children receiving a BMT has been associated with early mortality and graft-versus-host disease.³ Nutrition support becomes a requirement for most children to minimize the risk of these deleterious outcomes.⁴

Author Affiliations: Dietetics Department, Great Ormond Street Hospital for Children, London, UK (James Evans and Graeme O'Connor); University College London Great Ormond Street Institute of Child Health, London, UK (James Evans and Julie Lanigan); College of Health and Life Science, Aston University, Birmingham, UK (Dan Green); School of Health Sciences, University of Surrey, Guildford, UK (Faith Gibson); and Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID), Great Ormond Street Hospital for Children, London, UK (Faith Gibson).

The authors have no conflicts of interest to disclose.

Evans has received funding from the National Institute for Health and Care Research (NIHR) (grant number NIHR300554) and the NIHR Great Ormond Street Hospital Biomedical Research Centre (grant number NIHR-INF-0041).

Correspondence: James Evans, MRes, Dietetics Department, Great Ormond Street Hospital for Children, London, WC1N 3JH, UK (james.evans.20@ucl.ac.uk).

Copyright © 2024 The Authors. Published by Wolters Kluwer Health, Inc. on behalf of Cancer Care Research Online. All rights reserved. This is an open access article distributed under the Creative Commons Attribution License 4.0 (CCBY), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Cancer Care Research Online (2024) 4:e052

Received: 10 September 2023; Accepted 4 December 2023

Published online 6 February 2024

DOI: 10.1097/CR9.000000000000052

Enteral rather than parenteral nutrition is the recommended first-line intervention.⁵ A nasogastric tube (NGT) is the mainstay to provide this.⁶ However, they are susceptible to complications including dislodgement, irritation with mucositis, and refusal by children and parents.⁷ Gastrostomies are an alternative route used widely with children.⁸ At the UK center where this study took place, parents are offered a choice of a gastrostomy or NGT for their child prior to admission for BMT. A recent systematic review in pediatric cancer/BMT concluded that whilst gastrostomy complications occur frequently they are mostly minor and easily treated.⁹ Despite this, gastrostomy use is less common in BMT due to risks with surgery and infectious complications, but healthcare professionals want to use them more in practice.⁶ They are preferential over NGTs when long-term enteral nutrition is required, as has been shown up to 6 months post-BMT.² Studies in pediatric BMT have shown preferential outcomes associated with gastrostomies, rather than NGTs, including less use of parenteral nutrition,¹⁰ lower transplant-related mortality, and better 5-year overall survival.¹¹ However, these studies are observational and retrospective.

During patient and public involvement to develop this study parents spoke of the challenges they faced when choosing a feeding tube for their child. They reported that hearing the experiences and decision-making of other families would have helped them when choosing a tube for their child.¹² This consequently informed the focus of this study. A nonsystematic literature search of databases including Medline, Embase, and Cinahl, using keywords "bone marrow transplant," "pediatric," "decision-making," "experience," "nutrition support," and "enteral nutrition," with no date restrictions, was undertaken. Few studies were identified that qualitatively explored parent experiences of using their child's feeding tube during BMT. Several studies have explored parental perceptions of NGTs in children undergoing

cancer treatment, including BMT, using qualitative interviews¹³ and surveys.^{14,15} However, no studies were found that addressed the decision-making process for choosing a feeding tube. Parents have reported positive outcomes of NGTs including improvement in their child’s nutritional status and reduced family conflict at mealtimes with less pressure on the child to eat.¹³ Negative perceptions included discomfort¹³ and a detrimental impact on body image.^{14,15} Sixty-eight percent (21/31)¹⁴ and 59% (16/27)¹⁵ of parents preferred parenteral nutrition for their child to avoid these issues. Qualitative studies regarding gastrostomies have primarily been in pediatric neurodisability. In this context gastrostomies are usually placed permanently due to irreversible feeding difficulties¹⁶ rather than as a temporary measure as during BMT. A systematic review explored parent’s decision-making around gastrostomy feeding for their child with neurodisability.¹⁶ Eleven studies were included which found parent decision-making around gastrostomy placement was characterized by decisional conflict, anxiety, and resistance. Gastrostomy placement represented a loss of normality, a sign of disability and decline in their child’s condition, yet following placement, parents reported positive experiences, including removal of pressure associated with eating and perceived improvements in their child’s quality of life. Negative experiences included restricted ability to go out and time needed for gastrostomy care. However, comprehensive reporting across included studies (assessed using the consolidated criteria for reporting qualitative studies, COREQ¹⁷) was variable. Whilst all studies reported decision-making, in over half of them it was not the focus. Most studies also conducted interviews at 1-time point and in variable durations from the intervention. This limited the ability to understand the evolving experiences of parents. The aim of this study was to explore parent experiences of using their child’s NGT or gastrostomy during BMT and the surrounding decision-making process for choosing either tube.

Methods

Study Design

This study was undertaken within the context of a convergent mixed methods study¹⁸ investigating outcomes and experiences of gastrostomy feeding in pediatric BMT (registered at ClinicalTrials.gov NCT04804631). The quantitative component included a cohort study comparing outcomes of children fed via gastrostomy versus NGT.² This qualitative component ran concurrently to the cohort study (Figure 1). It used the interpretivist/constructivist paradigm which accepts reality and knowledge are socially constructed by individuals, leading to multiple realities and perspectives built out of each individual’s unique life experiences.¹⁹ This paradigm was chosen as it traces back to phenomenology which describes the meaning and significance of experiences, and the aim of this study was to explore parent experiences of using their child’s tube and their decision-making process.

Sample, Recruitment and Setting

This study took place at a single pediatric BMT center in the UK. Parents whose child was part of the cohort study were recruited between April 2021 and April 2022 during the family’s usual consultations with the BMT multidisciplinary team (MDT) before the child’s admission for allogeneic BMT. Parents whose child received first-line parenteral nutrition (not the standard nutrition support pathway of the center) and chimeric antigen receptor T-cell therapy (different modality to allogeneic BMT), were excluded. Hospital interpreters were available for parents whose first language was not English. In total, 33 parents were interviewed, 16 whose child had an NGT, 17 a gastrostomy. Parents provided written informed consent prior to participation. The study was approved by Newcastle and North Tyneside 2 Research Ethics Committee (IRAS number 281830).

Selection of Feeding Tube

During preadmission consultations families are provided with nutritional counseling from clinical nurse specialists, dieticians and medical consultants. It is during these meetings that families are offered the choice of a prophylactic gastrostomy placed prior to admission, or an NGT placed during admission, as has been standard practice at the center for years. To assist in this process parents are provided with verbal and written information delivered by experienced members of the MDT. Information provided outlines the pros and cons of gastrostomies and NGTs. Parents decide which tube is most suitable for their child in collaboration with the MDT.

Data Collection

Parents participated in 2 face-to-face, semistructured interviews. The same parent, designated the “main caregiver” who would be primarily present throughout the child’s admission, was interviewed at each time point. First interview, within 1–2 days of their child’s admission for BMT, conducted in their own room on the ward, to explore why they chose a gastrostomy or NGT. The decision regarding which tube to use was made in the month preceding admission. Therefore, conducting the interview at this time was close to when the decision was made. Second interview, 1–2 months following their child’s discharge, was conducted in a private room in the BMT clinic. This interview explored parent experiences of using either tube during admission and at home postdischarge and comparison of their expectations having gone through BMT when compared to the start. Throughout admission families were met weekly by the lead researcher to discuss generally about their tube, build rapport, and establish trust so parents felt comfortable sharing their experiences.²⁰ Field notes were made in a reflexive diary following these discussions, recording anything notable parents said that could be explored during their second interview. Rapport built during admission was maintained following discharge through ongoing phone, email, or face-to-face contact in the clinic.

Interview structure was based on separate topic guides for each interview, informed by the literature,^{13,14,21–23} project advisory group, a survey of UK BMT healthcare professionals’ perceptions toward gastrostomies⁵ and discussion amongst the research team. Topics discussed during interviews and the rationale for their inclusion are shown in Table 1. Most questions were open with prompts used as needed. Scope was provided for parents to raise unanticipated issues with flexibility built into the topic guide to follow such leads. Interviews were conducted by the lead researcher and, with permission, audio recorded.

Data Analysis

Data were analyzed using reflexive thematic analysis²⁴ as the objective was to identify patterned meanings across the dataset.

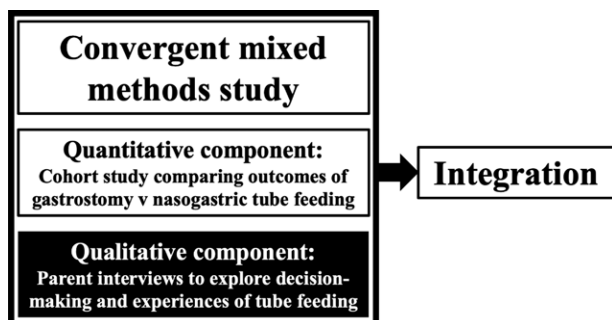


Figure 1. Positioning of this qualitative component in the convergent mixed methods study.

Downloaded from http://journals.lww.com/ccr/cancerresearchonline by BMDMfsePHKav1ZEoum11QINd4+kLLHEZ gbsIH04XMI0hCwCk1AWmVQpI0h7HD33D00Dr7ITV5FAcQ3VC1y0abgQZXdGj2MwIZle= on 02/16/2024

Table 1.
Topic Guides for Both Interviews With Rationale for Topics

Question	Rationale
<p>First interview (on admission)</p> <p>Tell me who talked to you about tube feeding and what were you told about it?</p> <p>Were you offered the choice of feeding tubes?</p> <p>If yes:</p> <p> Why did you choose your tube?</p> <p> What was it like making the choice?</p> <p>If no:</p> <p> Would you have liked the choice?</p> <p>Was your child involved in discussions?</p> <p>Who do you think had the final decision on the choice of tube?</p> <p>Were you given enough time to consider you options?</p> <p>Information:</p> <p>Were you given enough information?</p> <p>Is there anything you would have liked more information on or anything else that would have helped?</p> <p>Expectations:</p> <p>How do you think the tube will help?</p> <p>How long do you think the tube will be needed?</p> <p>What concerns do you have about the tube?</p> <p>How do you feel about using and looking after the tube?</p>	<p>To understand which clinicians give advice on tube feeding, timing of discussions, reasons clinicians gave as the rationale for a feeding tube and parent's understanding of this</p> <p>To establish whether all families were offered the choice or not</p> <p>To identify the rationale for choosing either tube</p> <p>To explore the experience of the decision-making process</p> <p>To explore reasons choice was not offered, if families would have liked it and how choice could be implemented in the future</p> <p>To establish the degree of child involvement in decision-making</p> <p>To understand parent's perception of who was ultimately responsible for the choice of tube</p> <p>To see if parents felt rushed or pressured in making their choice</p> <p>To explore parent's perceptions of the quality, detail and format of information provided and whether this was sufficient to enable them to make an informed choice</p> <p>To understand parent's expectations of various issues relating to the tube</p>
Question	Rationale
<p>Second interview (postdischarge)</p> <p>What was the tube used for during admission and at home and how have you found using it?</p> <p>What was it like to look after and maintain the tube?</p> <p>What's been good about the tube?</p> <p>What problems happened with the tube, how did they get fixed and how did they make you feel?</p> <p>Did anything happen with the tube, or did you learn anything about it, that no 1 told you?</p> <p>What support have you had with the tube and how have you found it?</p> <p>Was having the tube like you thought it would be?</p> <p>If you could go back to the start of transplant, would you still have chosen the same tube and why?</p> <p>Should the choice of tubes be offered to families and why?</p> <p>What would you say to other families about tube feeding?</p>	<p>To understand what the tubes were used for throughout transplant, the practicalities of using them and how this fitted into daily routine</p> <p>To explore the input needed to care for the tube and potential burden</p> <p>To evaluate any positive impact the tube had on any aspect of life</p> <p>To explore the range of tube complications that occurred, what was required to remedy the complication and the impact this had on parent's experience</p> <p>To understand if there was anything missing from standard information provided about tube feeding that could be used to improve education in the future</p> <p>To understand what support structures were in place for parents and whether these were sufficient</p> <p>To compare whether expectations from the first interview were met after having had experience using the tube throughout transplant</p> <p>To explore if, having gone through the transplant and having used the tube, parents would have changed their mind or not</p> <p>To explore whether families feel this choice should be part of standard practice or not and their rationale</p> <p>To summarize parent's feelings around their experiences of tube feeding which could be used to help families in the future</p>

Phase 1 involved data familiarization. Recordings were transcribed verbatim and uploaded to NVivo (Version 1.7.1)²⁵ for management. Thoughts and impressions were noted whilst reading transcripts, alternating between a parent whose child had an NGT and gastrostomy to give opposing views and challenge thinking. A parent's first interview transcript was read prior to their second so important points could be explored further. Phase 2 generated inductive codes. Sections of data were labeled that captured meaning relevant to the study aim. Phase 3 combined relevant codes into groups based on shared meaning. Mind maps were used to visually represent data with possible relationships between codes, overarching and subthemes, which culminated in a collection of candidate themes. Phase 4 reviewed candidate themes to ensure they were identifiably different, that data cohered meaningfully around each, and there were sufficient data to support each theme. Phase 5 defined and named overarching themes with further refinement undertaken to identify subthemes. Phase 6 involved writing the report. Progress with analysis was discussed during monthly meetings with the research team to refine coding and theme development.

Trustworthiness of the data was evaluated using 4 criteria: credibility, transferability, dependability and conformability.²⁶ Throughout this study a reflexive diary and field notes were kept.

Peer scrutiny through monthly meetings with the research team built dependability and conformability in the data. Credibility was promoted through triangulation; comparison of field notes and the reflexive diary to interview transcripts and discussion of findings with the research team. Detailed descriptions of the research process and findings will aid others in their judgment of the transferability to other populations and settings.

Results

Parents whose child was participating in the ongoing cohort study² were interviewed consecutively with none refusing participation (Figure 2). Data saturation, determined through monthly discussions amongst the research team, was reached after interviewing the first 16 parents whose child had an NGT, 17 gastrostomy. Hence, not all parents whose child was involved in the cohort study were interviewed. A total of 66 interviews were undertaken each lasting 30–60 minutes. Demographics of the 33 parents and their children are shown in Table 2.

A wide range of codes were identified. Broad topics included: age of the child; impact of the tube on the child; a range of concepts surrounding choice and decision-making; healthcare professionals' advice; comfort of the tube; conflict; control; cosmetics of the tube; how the tube fitted into

Downloaded from http://journals.lww.com/cancerresearchonline by BHD/MSF/PHK/v1/2Eoum/1QIN/4+kLLHEZ/gbsIHo4XMI0hCwWCX1AWmVQpI00rHD3I3D00dR7/7V5F4C13VC1y0abgQZXdgGj2MwIZIeI= on 02/16/2024

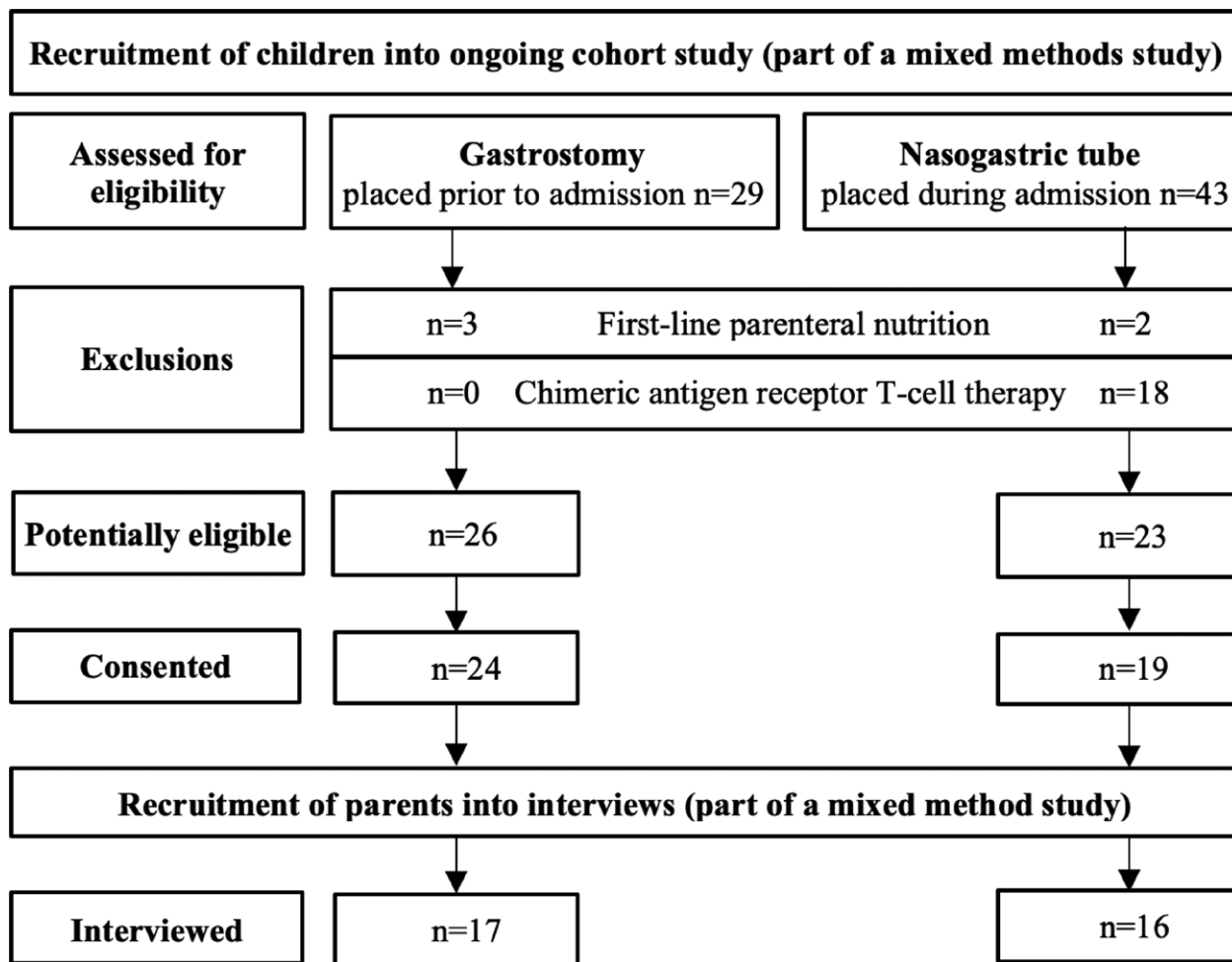


Figure 2. Recruitment of parents into the interviews.

daily life; expectations on a range of issues; experts; information needs; priority of tube feeding; lay advice; medications; a range of topics related to use of the NGT/gastrostomy; impact of the tube on the parents; prior experiences, and; reassurance. Two mind maps were initially produced outlining the core concepts being explored: experiences of tube feeding and influential factors in decision-making. Codes with similar meanings within each concept were merged and possible relationships between codes regarding both experiences of tube feeding and decision-making were combined (Figure 3). From this map 6 candidate themes were identified (Figure 4). On reviewing these themes, 1, “Choice was characterized by spectrums and scales” was felt to be too broad with potential for containing 2 themes. The final iteration split this theme into 2 with the “scales” part given its own theme, “A delicate decisional balance,” which contained sufficient evidence to be an individual theme. Each theme was then given its final name. Thematic analysis identified 7 overarching themes that captured parents’ decision-making and experiences of using their child’s feeding tube (Figure 5).

Choice was Characterized Across a Continuum

Offering choice of tubes has been standard institutional practice for years, but despite this, multiple factors influenced whether choice was offered or not. Among parents whose child had an NGT, 56% (9/16) reported not being given a choice, whereas all those who had a gastrostomy were. Some were not offered choice as their child was already tube-fed at home before admission. Others were having chemotherapy prior to BMT restricting time for neutrophil cell count recovery to allow safe surgery for gastrostomy placement:

Had the meeting, had the chemo, then we were here. There hasn’t been a long enough gap to even consider getting that gastrostomy fitted. (Mother of child with an NGT)

Difficulty and freedom of choice were also experienced across a continuum. Some parents found choice easy going with their gut reaction. Others found it difficult and were skeptical they had made the correct choice. Some tried to make the best choice they could, but felt it was a “best-guess” given the longevity of BMT and the uncertainty of all that could happen. Some parents were given complete autonomy to choose, others felt healthcare professionals from the BMT MDT told them which tube to have. Even if parents were given a choice, some felt it was beyond their capability to make it and deferred to the expertise of these experienced healthcare professionals. However, some had the confidence to go against professional recommendations and make the choice they felt was best for their child:

Everybody in the local hospital telling me gastrostomy is best. But at the end of the day I was like, “No, I don’t want it” ... I know my child better than everybody else. (Mother of child with an NGT)

Information and Prior Experience Underpinned Choice but Varied

Information from various sources and prior tube feeding experiences acted as cornerstones of decision-making. For some families the child had previously been tube-fed. However, most (61%, 20/33) had no such experience to draw upon which complicated decision-making:

Downloaded from http://journals.lww.com/cancerresearchonline by BMDMfsePHKav1ZEoum1IQINda+kLLHEZ gbsIH04XMI0hCwCk1AWmYQpI00rHD3I3D00dRv17TSFACI3VC1y0abgqZXd9Gj2mWIZleI= on 02/16/2024

Table 2.
Demographics of Parents and Their Children

Parent Demographics	Gastrostomy (n = 17)	Nasogastric Tube (n = 16)	P value
Age (years), median (IQR)	38 (32–41)	36 (32–38)	.459a
Female, n (%)	15 (88)	12 (75)	.398b
Ethnicity, n (%)			.340b
White	14 (82)	9 (56)	
Non-White	3 (18)	7 (44)	
English speakers, n (%)	16 (94)	15 (94)	>.999b
Time of second interview			
Days post-BMT, median (IQR)	61 (48–75)	48 (35–64)	.157a
Offered choice of tubes, n (%)	17 (100)	9 (56)	<.001b
Prior tube feeding experience, n (%)	6 (35)	7 (44)	.393c
Child characteristics			
Nonmalignant disease, n (%)	16 (94)	9 (56)	.017b
Having first BMT, n (%)	15 (88)	15 (94)	>.999b
Stem cell source, n (%)			
Bone marrow	9 (53)	9 (56)	.849c
Peripheral blood	8 (47)	2 (13)	.057b
Cord	0 (0)	5 (31)	.018b
Donor, n (%)			
Matched unrelated donor	9 (53)	5 (31)	.208c
Matched sibling donor	5 (29)	3 (19)	.688b
Mismatched unrelated donor	3 (18)	3 (19)	>.999b
Cord blood	0 (0)	5 (31)	.018b
Conditioning regimen, n (%)			.438b
Myeloablative	11 (65)	13 (81)	
Reduced intensity	6 (35)	3 (19)	

P < .05 are bold.
Abbreviations: BMT, bone marrow transplant; IQR, interquartile range.
Comparison using:
aMann–Whitney U test.
bFisher exact.
cχ².

By the time we realized he’s not going to tolerate the NGT he was in the middle of chemo. We couldn’t get the gastrostomy for weeks ... I never knew an NGT or a gastrostomy, and by the time you’ve made these decisions and you know it’s the wrong 1, you can’t change it. (Mother of child who initially had an NGT but required a gastrostomy after BMT)

Parents received information from healthcare professionals during preadmission consultations, which was often sufficient to facilitate decision-making, but parents often wanted more detailed information. As this study took place during the COVID-19 pandemic many preadmission consultations were switched from face-to-face to video consultations. Whilst parents often felt in-person meetings provided the opportunity for a more complete exchange of information, they accepted this compromise to ensure the safety of their child:

I would have liked more information face-to-face. We didn’t get it because of COVID. With the difficulties getting an immunodeficient child in during a pandemic, I was anxious about bringing her in. (Mother of a child with a gastrostomy)

In addition to professional advice parents valued and actively sought out lay information from family, friends, online sources, and social media, to help decision-making. This lived experience offered something beyond the information provided by healthcare professionals. Many parents were cautious about online advice tending to go for what they deemed trustworthy sources:

We are constantly looking for BMT ... online, Google, mostly NHS (National Health Service) though because we know the source is genuine. (Father of a child with an NGT)

Conflict

A subtheme of conflict was present. Lay and professional advice was often conflicting depending on personal experiences. This led to parents receiving different opinions which caused confusion. Some felt a conflict of interest regarding who the tube would be most useful for biased recommendations. This complicated decision-making and illuminated a hierarchy of whose advice parents most valued:

The doctor thought NGT would be better, nurse gastrostomy ... you don’t know the right thing to do ... You want to listen to the doctor ... the nurse is giving you the advice because it’s easier for them. (Father of a child with a gastrostomy)

One area of conflict unique to families who had an NGT concerned the priority given to tube feeding by healthcare professionals. During preadmission consultations, some parents felt healthcare professionals emphasized a tube “might,” rather than “will,” be needed. Inevitably, during BMT all children did need

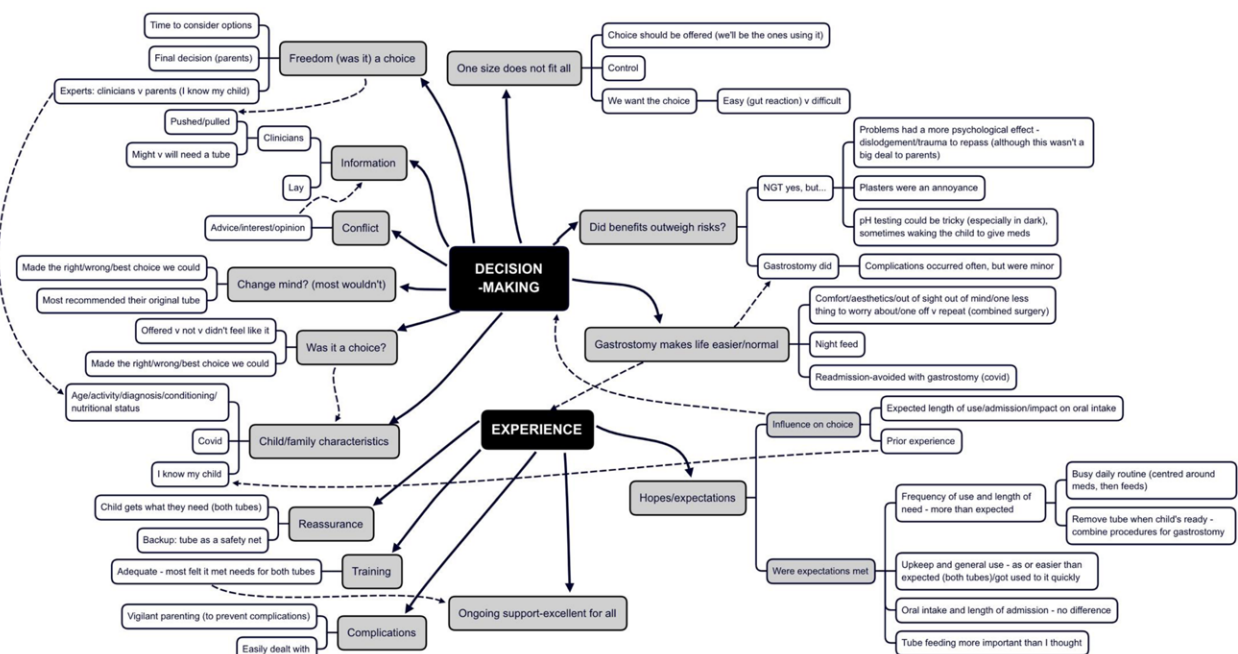


Figure 3. Combining inductive codes for parent decision-making and experiences of using their child’s tube. NGT indicates nasogastric tube.

Downloaded from http://journals.lww.com/cancerresearchonline by BMDMfsePHKav1ZEoum1IQINda+kLLHEZ gbsIH04XM0hCwvCX1AVwN1QpI00rHD3I3D00dR717V5F4C13VC1y0abgqZXd9Gj2mWIZleI= on 02/16/2024

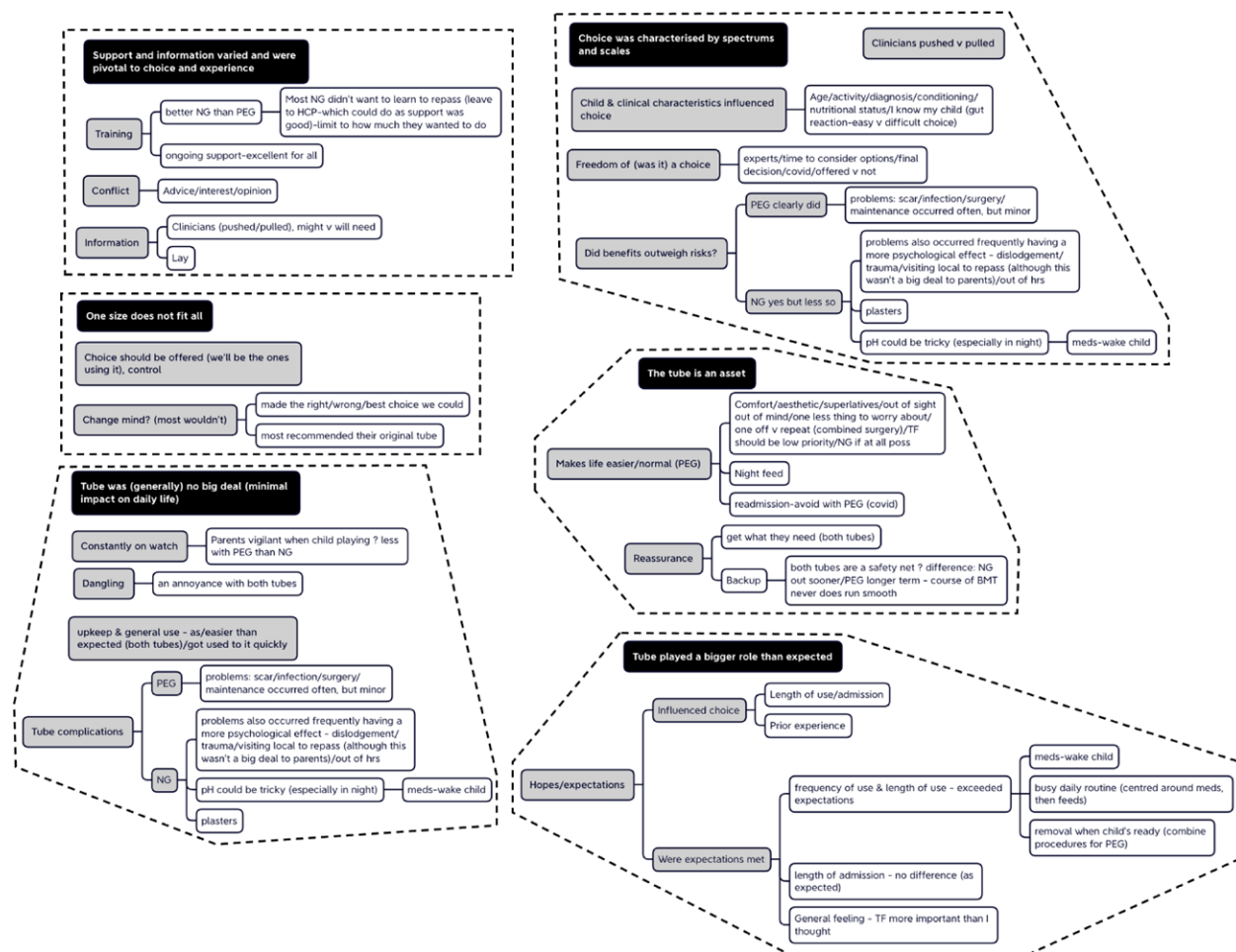


Figure 4. Mind map showing 6 candidate themes. HCP indicates healthcare professional; NG, nasogastric tube; PEG, percutaneous endoscopic gastrostomy; TF, tube feeding.

a tube and an NGT was placed. Parents felt they were given misleading information, which affected decision-making and felt advice should stress a tube “will” be needed:

It was, “You might need it,” but if you’re told, “He will have to have it,” you can decide which one ... if they had said, “This will happen” that would help make that decision. (Mother of child with an NGT)

A Delicate Decisional Balance

Parents delicately weighed up multiple factors that filtered into their decision-making before making their choice. If parents anticipated the tube to be needed short-term, they would choose an NGT, long-term a gastrostomy. If children were old enough to understand why a tube was needed and therefore were not going to pull out an NGT, parents tended to prefer this over a gastrostomy. If a child was very active and more likely to dislodge an NGT, a gastrostomy was often preferred:

He’s an outdoorsy boy. Constantly on his bike, he climbs, he rides. It needed to be something concealed. The NGT was going to be pulled out constantly. (Mother of child with a gastrostomy)

Cosmetic differences between tubes also played heavily into choice. If parents were concerned about attention from the visibility of NGTs, feeling it was a constant reminder of their child’s illness, they often chose a gastrostomy:

Because of the tube on her face I experienced a lot of looks, the attention bothers me. I don’t want to explain to strangers what we’re going through. I liked the gastrostomy because it’s hidden. (Mother of child who initially had an NGT but required a gastrostomy after BMT)

The most contentious dilemma in this theme was the balancing between the risk of gastrostomy surgery against NGT dislodgement and replacement. Some parents were accepting of surgery, feeling it was a risk worth taking, often justified as a “one-off” procedure, allowing them to focus on more important aspects of BMT. It would then be fixed in place avoiding the stress of potentially “repeated” NGT replacement. Many children had their gastrostomy placed in combination with another procedure, such as central line insertion, which minimized the risk and often influenced choice:

We went for it (gastrostomy) because we got given the option of having it the same time as his line. If it was a separate procedure we would have said, “No.” We didn’t want to put him through the risk. (Father of a child with a gastrostomy)

One Size Does Not Fit All

Parents universally agreed choice of tubes should be offered. They appreciated NGTs, as the current mainstay, might not be tolerated by every child given their different personalities and characteristics:

Every child is different ... you know your child best, what they can handle and how you feel about having it done. I do think it should be a choice. (Mother of child with a gastrostomy)

Parents also acknowledged that as they will be the ones using the tube, not healthcare professionals, their preferences and confidence in using the tube should be considered through offering choice. A sense of control provided through choice was also welcome in BMT; a situation that felt out of parents’ control:

Downloaded from http://journals.lww.com/cancerresearchonline by BMDMFEPHKAV1ZE0UM11QIN4+KLLHEZ gbs1H04XM00hCwWCX1AWmVQp100rHD313D00dRr71VSFAcR3VC1y0abgQZXdGj21MwIZleI= on 02/16/2024

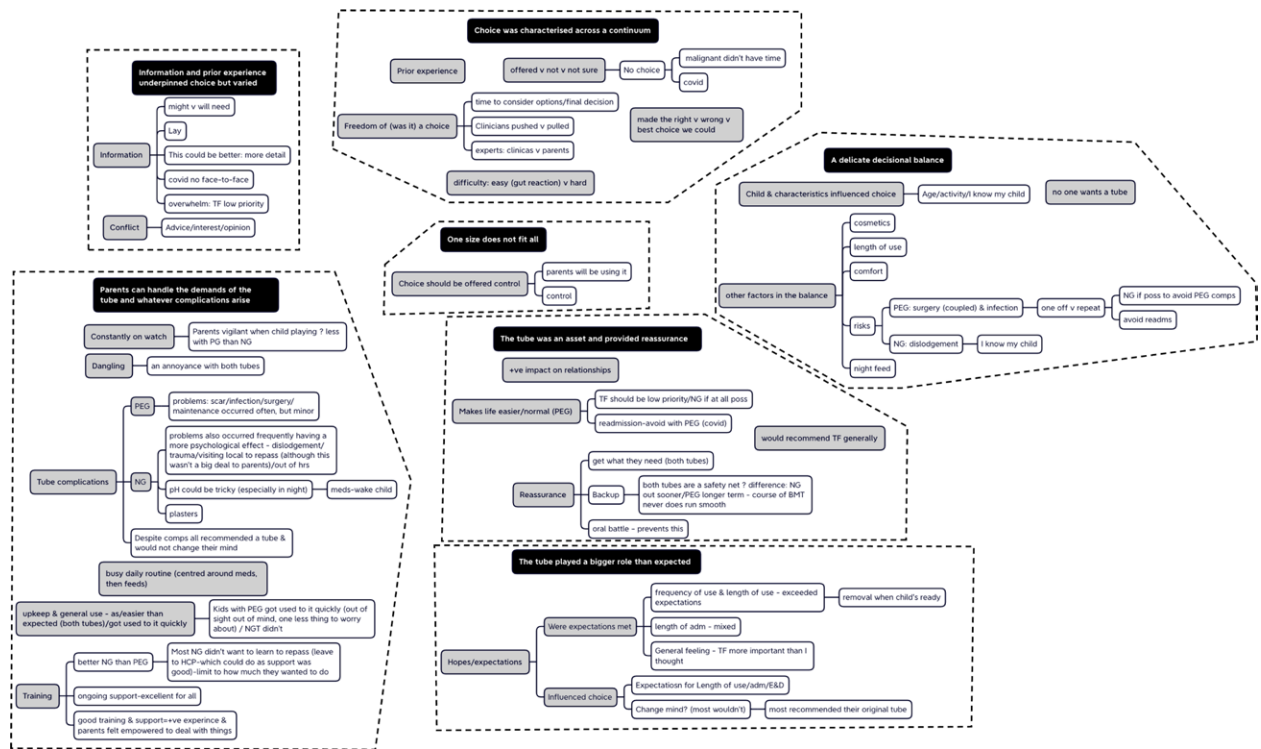


Figure 5. Mind map showing 7 overarching themes. NG indicates nasogastric tube; PEG, percutaneous endoscopic gastrostomy; TF, tube feeding.

I like that it was our decision. It made us have control over the situation that's out of our control. Everything that's going on I can't do anything about ... to give you choice, that bit of control, it's nice. (Mother of child with a gastrostomy)

The Tube Played a Bigger Role Than Expected

There was a shift in parents' appreciation of the importance of a feeding tube between their first and second interviews. Initially, a tube was considered a minor part of the process with more serious issues dominating parents' thoughts. But with hindsight, many altered their view giving greater importance to the tube:

At the beginning I didn't give the tube as much thought as I should have. I didn't consider it a big part of her treatment and it is, it's huge. (Mother of child with an NGT)

Parents often expected the negative impact of conditioning on their child's oral intake to be less extensive, and consequently a tube not to be required for a prolonged period, nor utilized very frequently following BMT. There was a change in parents' opinions when these issues were discussed during their second interview, having lived through their child's BMT and realized their nutritional and medication requirements. The day-to-day frequency with which tubes needed to be used and their length of requirement exceeded original expectations. Parents came to accept the tube would be removed "when their child was ready":

At the beginning I would have loved the gastrostomy removed as soon as possible. Now I've changed my mind completely because he's taking so many meds ... until he stops taking medication it has to stay. (Mother of child with a gastrostomy)

However, despite a shift in expectations most parents would not have changed their original choice feeling they still chose the best option. No parents regretted their decision to have a gastrostomy. For 4 children NGT feeding failed and they needed a reactive gastrostomy to enable safe discharge. These parents would have changed their minds:

Knowing what we experienced we'd go for the gastrostomy. I wouldn't even discuss the NGT. The gastrostomy's been more convenient and (child's) happier, more comfortable. If we were in

a situation where he needed a tube again, I would go straight for the gastrostomy. (Mother of child who initially had an NGT but required a gastrostomy after BMT)

The Tube was an Asset and Provided Reassurance

Parents came to appreciate their tube was an asset, reassuring them that regardless of how unwell their child was, and unable to take anything orally, they could receive their nutritional requirements, and most importantly to them their medicines, to facilitate recovery. For many families getting their child to take anything orally was a battle, negatively impacting family relationships. The tube ameliorated this. Parents viewed the tube as such an asset that all recommended a tube to families going through BMT. It was often described as making life easier allowing parents to focus on more important aspects of BMT:

The NGT makes my life so much easier. I know she's getting the exact dose the doctors have prescribed. I know she's getting the calories the dietician wants ... when she doesn't want to feed, I can give the feed through the tube. It gives you time to focus on what's really needed. (Mother of child with an NGT)

Both tubes were viewed as a "backup" when the child was unable to consume nutrition and medicines orally. This concept is especially pertinent given the post-BMT journey is rarely smooth due to the ever-present risk of complications and fluctuations in oral intake:

When we got home I wasn't having to give feeds ... but when he became unwell he wasn't eating. If he'd had the NGT we might have taken it out and struggled ... being home has opened my eyes to the peaks and troughs you go through ... once he'd started eating and drinking, I thought he'd be fine. (Mother of child with a gastrostomy)

Parents Can Handle the Demands of the Tube and Whatever Complications Arise

Parents had responsibility for the significant burden of post-BMT care of their child, including significant feeding and medication regimens:

Downloaded from http://journals.lww.com/cancerresearchonline by BHDJMF5EPHKAV1ZEoum1IQINda+kLLHEZ gbsH04XM00hCwWCX1AWnVQpI0qRH3D00dR7ITV5FAQ3VC1y0abgQZXdgGj2IMwIZleI= on 02/16/2024

He has his first meds at 7 then 12, 3, 5, then 10 ... In the morning he has 5 medicines then at 12 he has 4, sometimes 5 as well, then at 3 he has 2, then at 5 he has 3 again, then at 10 he has 5 or 6. Feeds he has 4 times a day at 6, 12, then 6 and 12 again. (Mother of child with an NGT)

But regardless of how much parents had to use the tube and deal with complications, they could handle it. Complications did occur frequently with both tubes. Whilst these caused some inconvenience, including interruptions to tube feeding, missing medications and temporary stress to the family, they were mostly minor, easily managed and quickly remedied. Parents showed great resilience when dealing with objective differences between tubes. Many with a gastrostomy felt cleaning and maintenance were not labor-intensive or complex and slotted easily into their daily routine:

It's just his bath routine, simple. He'll have a bath, I'd dry his gastrostomy. I don't find it much work. It's new, something I haven't had experience with. It did feel hard at first but after a few weeks it wasn't scary. (Mother of child with a gastrostomy)

Most parents found checking the position of their child's NGT in their stomach generally quite easy. However, this process became more complicated when giving the first and last medicines of the day when their child was asleep and they could not turn on the bedroom light and hence easily see the color of the pH strip to confirm correct positioning. Dislodgement and NGT replacement were frequently encountered and often described as being "traumatic." Some families had to travel to their local hospital (a distance from the BMT center) to get another placed and motivate their child to allow replacement:

I took him to our local hospital, it was the evening, he needed his ciclosporin, wouldn't take it orally. It was stressful, more complicated than I anticipated. He was upset and you need to "gee him up" to have another NGT put in. (Mother of child with an NGT)

Despite these complications, most parents would, again, not have changed their original choice. Support from acute and community teams throughout BMT was universally praised and an important factor in parents' mostly positive experiences of tube feeding. Most parents also received comprehensive training on either tube, which empowered them to feel competent in dealing with frequent use and complications that arose.

Discussion

Patient-centered care and involvement in decision-making can bring substantial responsibility to patients. Despite the potential affliction of choice, all parents felt it should be offered and welcomed inclusion in decision-making. Being presented with a choice of tubes has been shown to promote a positive experience among adults with head and neck cancer.²⁷ Choice and involvement in decision-making for all parents whose child had a gastrostomy provided ownership during their child's BMT and contributed to high levels of acceptance. Conversely, some parents whose child had an NGT were not offered a choice due to receiving chemotherapy prior to BMT where gastrostomy placement requires careful planning around neutrophil count recovery. Thus, equality of opportunity was not always present.

Despite wanting choice, parents had different preferences for their involvement in it. Some deferred to the expertise of healthcare professionals, others felt they were the experts in their child. Trusting themselves was key to decision-making for gastrostomy placement for mothers of children with neurodisability.²² Healthcare professionals and patients are experts in their own fields. Through a culture of sharing power and responsibility, both must respect the others' expertise.²⁸ Healthcare professionals should make recommendations for which tube they feel is best in any situation, but information needs to be balanced. Collaborative discussion is required to reach a mutually agreeable decision. For some parents it was questionable how

collaborative choice was. Some felt they were told which tube to have, others reported having complete autonomy. Mothers of children with neurodisability have reported experiences of gastrostomy placement ranging from coercion to no, limited or true choice.²² Contrary to a systematic review exploring attitudes to gastrostomy feeding in adults, which found insufficient time contributed to lack of choice,²⁹ most parents in this study felt they had sufficient time to consider their options and, ultimately, the choice was theirs. Healthcare professionals' advice was always valued. However, absence of a decision-making framework within BMT meant it was often conflicting which complicated choice. Parents experienced conflicting advice, specifically that an NGT "might" versus "will" be needed. Discordant perceptions regarding enteral nutrition between healthcare professionals and parents in children's cancer care have been reported.¹³ Education is needed to ensure families are appropriately informed to aid understanding and decision-making.^{27,30} A framework to aid decisions around gastrostomy placement has been produced in pediatric neurodisability, which supports consistent advice and shared decision-making.³¹ A framework to guide decision-making in BMT is needed.

Prior tube feeding experiences and information from various sources were pillars of decision-making. Another study found mothers negotiated decision-making around gastrostomy placement for their child with neurodisability by reflecting on personal experiences.²² Absence of tube feeding experience has also influenced parents' perceptions in a children's cancer study where parents perceived NGTs to be invasive and painful.¹⁴ Families with no prior experience were clearly disadvantaged in this study. Lay advice is crucial in providing first-hand experience. Studies have reported peer support in head and neck cancer to provide emotional comfort and better coping with treatment.^{27,32} The importance of peer support should be recognized by healthcare professionals and implemented into decision-making. Online information was frequently used to guide choice. Reassuringly parents tended towards trustworthy sources, as shown in a study following a child's cancer diagnosis, where parents preferred information from professionals, rather than online, where information was deemed untrustworthy.³³ Given the widespread availability of online information, research is needed to understand its impact on patients' experiences, empowerment and interactions with healthcare professionals.

Adult cancer studies have found reluctance, anxiety, and fear toward gastrostomy^{27,34,35} and NGT insertion.^{13,27,36} Parents were initially apprehensive about the need for a tube, but through proactive counseling, spread over numerous meetings to avoid information overload, there was quick acceptance 1 would be needed. Preadmission counseling is crucial to prepare families for tube feeding,¹⁵ especially given resistance to tube placement³⁷ and preference for parenteral nutrition^{14,15} have been found. On accepting the need for a tube, parents delicately balanced their risks before making their choice. The primary conflict here regarded the risk of gastrostomy surgery versus NGT dislodgement. For those choosing a gastrostomy, the surgical risks were justified through one-off placement, often combined with another procedure to mitigate risk, and the gastrostomy fixed in place which eliminated potential repeated "trauma" of NGT dislodgement, an emotion expressed regarding NGTs elsewhere.³⁸ However, for many parents the risk of surgery was unjustifiable. Longevity of the tube was another important factor in decision-making. Parents' attitudes toward this changed over the study, shifting from originally wanting either tube short-term, as in adult cancer studies,^{27,35} to accepting removal when their child was ready. However, parents wanted to avoid permanent tube dependence. This is rarely required post-BMT. Most children were planned to have their tubes removed in the coming months. Hence, decision-making is often in the context of temporary rather than permanent needs as in children with neurodisability.^{31,38} Whilst prophylactic placement is a risk if not used, this was never the case; both tubes were used more frequently and required for longer than parents expected, despite comprehensive pre-BMT counseling to manage expectations.

On initiation of tube feeding parents rarely expressed feelings of failure, as in adult cancer care,^{27,35,39} only relief a tube was present; as felt by parents of children with gastrostomies but not undergoing BMT.^{21,38} Parents recognized their tube was an asset, reassuring them their child could receive the necessary nutrition and medicines to protect against malnutrition and post-BMT complications. Rather than a burden, both tubes were highly valued, reduced anxiety and burden of treatment, as found in adult^{27,30,34,35} and pediatric cancer studies.¹³ Medications were parents' top priority; children rarely took them orally. Hence, tubes were predominantly used to administer these. Nevertheless, the importance of nutrition was recognized, likely due to comprehensive counseling and dietetic input. The prioritization of medicines may be because the consequences of not taking them are more immediately apparent, and potentially life-threatening, compared to those of malnutrition which can take longer to materialize.⁴⁰

Both tubes were not without their challenges. Other studies in adult cancer care have reported daily use of either tube being a burden, negatively impacting daily life, and restricting social activities.^{27,34,35} Curiously, there was rarely a feeling the tube, per se, restricted daily activities, but that life was impacted more by demands of post-BMT care, including intensive medicine and feeding regimens and avoiding crowded areas to minimize infection risk. In fact, both tubes facilitated parents in providing daily care to aid their child's recovery. These tasks were usually managed between a family dynamic of 2 parents who worked together delegating tasks accordingly. Whilst not specifically questioned, few parents mentioned involvement of wider family/friends as support networks. Adult cancer patients have shown reluctance to ask for support to avoid passing burdens and maintain control over their lives.²⁷

Regarding gastrostomies, parent perspectives have included negative impacts on family life and restricted ability to socialize.²¹ In this study parents reported gastrostomy use to be easily managed, experiencing mostly minor issues. However, even when major complications, such as infections, occasionally arose, parents seemed unperturbed. It would be intriguing to compare the opinions of healthcare professionals on these issues. Another pediatric cancer study found similar perspectives of NGT feeding between parents and healthcare professionals on positive (weight gain, reduced anxiety) and negative (discomfort, appearance) factors.¹³

Gastrostomies objectively seemed less burdensome to daily life through avoidance of NGT dislodgement and pH testing. Their discreetness allows patients to live a normal life, particularly undertaking social activities.^{27,41} Social stigma with NGTs is a barrier to use amongst adolescents^{14,38} and was a factor in parents' decision-making. Parents spoke of the unwanted attention brought about by their child's NGT, which have been reported as a visible sign of disability.³⁸ Yet subjectively, despite these inconveniences, parents showed great resilience, accepting the NGT as part of their child's recovery and doing whatever was needed to remedy complications. Many parents felt the pros of NGTs outweighed those of gastrostomies, and ultimately an NGT was right for their child. However, they appreciated that NGTs might not be acceptable for all children and that gastrostomies might suit others better. An individual approach to decision-making is required.³⁵ Sadly, several parents expressed regret when NGT feeding failed and reactive gastrostomies were needed. Many of these had no prior tube feeding experience. An NGT trial to explore acceptability before BMT might have avoided this additional stress.

Limitations and Future Research

Interviews did not capture parent experiences regarding their child's feeding tube in their entirety. Experiences regarding surgical removal of the gastrostomy and removal of a child's NGT would have provided further insight. Parental involvement in deciding feeding regimens and their impact on daily life was

also not explored. The lead researcher's personal biases, opinions, and experience working with this population may have influenced analysis, but were acknowledged through reflexivity.

Further research is needed to explore the opinions of healthcare professionals toward NGTs and gastrostomies, including the full range of interactions regarding tube feeding, from the information exchange prior to BMT, to managing tube feeding throughout BMT admission and beyond. Interviews should include a range of healthcare professionals who are the decision-makers regarding tube feeding to obtain a range of opinions. Hearing the child's voice regarding their experiences of tube feeding also needs important consideration. Interviews with children were part of this study and will be reported separately.

Implications for Practice

All parents interviewed felt a choice of feeding tubes should be offered, including those who did not want a gastrostomy for their child. This aligns with clinicians' opinions from our previous UK survey.⁶ There was widespread acknowledgment that NGTs, as the current mainstay, might not suit all children and gastrostomies might be preferential for some. Therefore, choice of a gastrostomy or NGT should be offered to children prior to BMT. Themes identified during this study will better inform healthcare professionals regarding parent's decision-making process, factors that are important to them regarding their choice, and their experience of managing their child's tube. Healthcare professionals will consequently be able to better help parents navigate this complex decision-making process, to weigh up their options, and make a truly informed choice through collaborative, family-centered discussions and provision of balanced information highlighting the pros and cons of either tube. Given that parents highly valued recommendations from other families, inclusion of peer support structures may be beneficial to some families in their decision-making. For families who are unsure an NGT will be tolerated, a trial to assess tolerance prior to admission may be a useful implication for practice. This could avoid the unnecessary stress of failure with NGT feeding during the BMT admission and likely need for reactive gastrostomy placement following BMT, and thus prolonging admission during what is already a difficult period for families.

Conclusions

Choice and involvement in decision-making were highly valued with an appreciation 1 tube might not suit all children. Both tubes exceeded initial expectations for frequency of use and longevity and came to be seen as an asset, reassuring parents their child could receive everything they needed. Parents showed resilience in the face of frequent complications. Few would have changed their original decision feeling they made the right choice. An individual, family-centered approach, with shared decision-making between families and healthcare professionals, underpinned by MDT advice, peer support, and consideration of families' prior experiences, is key to navigating this complex decision-making process.

Acknowledgments

The authors thank the National Institute for Health and Care Research (NIHR) for funding this research and the parents who generously shared their time and experiences during their participation in this study.

References

1. Fuji S, Einsele H, Savani BN, et al. Systematic nutritional support in allogeneic hematopoietic stem cell transplant recipients. *Biol Blood Marrow Transplant.* 2015;21(10):1707–1713.

2. Evans J, Green D, Gibson F, et al. Complications and outcomes of gastrostomy versus nasogastric tube feeding in paediatric allogeneic bone marrow transplant: a prospective cohort study. *Clin Nutr ESPEN*. 2023;55:58–70.
3. Kerby EH, Li Y, Getz KD, et al. Nutritional risk factors predict severe acute graft-versus-host disease and early mortality in pediatric allogeneic hematopoietic stem cell transplantation. *Pediatr Blood Cancer*. 2017;65(2):1–9.
4. Zama D, Gori D, Muratore E, et al. Enteral versus parenteral nutrition as nutritional support after allogeneic haematopoietic stem cell transplantation: a systematic review and meta-analysis. *Transplant Cell Ther*. 2021;27(2):180.e1–180.e8.
5. Muscaritoli M, Arends J, Bachmann P, et al. ESPEN practical guideline: clinical nutrition in cancer. *Clin Nutr*. 2021;40(5):2898–2913.
6. Evans J, Green D, Connor GO, et al. Nutritional support practices and opinions toward gastrostomy use in pediatric bone marrow transplant centers: a national survey. *Nutrition*. 2022;95:1–8.
7. Trehan A, Viani K, da Cruz LB, et al. The importance of enteral nutrition to prevent or treat undernutrition in children undergoing treatment for cancer. *Pediatr Blood Cancer*. 2020;67(S3):1–8.
8. Townley A, Wincentak J, Krog K, et al. Paediatric gastrostomy stoma complications and treatments: a rapid scoping review. *J Clin Nurs*. 2017;27(7-8):1369–1380.
9. Evans J, Gardiner B, Green D, et al. Systematic review of gastrostomy complications and outcomes in pediatric cancer and bone marrow transplant. *Nutr Clin Pract*. 2021; 27;36(6):1–13.
10. Evans J, Needle JJ, Hirani SP. Early outcomes of gastrostomy feeding in paediatric allogeneic bone marrow transplantation: a retrospective cohort study. *Clin Nutr ESPEN*. 2019;31:71–79.
11. Kairiene I, Vaisvilas M, Vasciunaite A, et al. Impact of percutaneous endoscopic gastrostomy on pediatric bone marrow transplantation outcomes: retrospective single-center cohort study. *JPEN J Parenter Enteral Nutr*. 2023;47(3):390–398.
12. Evans J. How patients can enhance research into feeding children during bone marrow transplantation. *Nurs Child Young People*. 2019;31(4):19–19.
13. Cohen J, Wakefield CE, Tapsell LC, et al. Parent, patient and health professional perspectives regarding enteral nutrition in paediatric oncology. *Nutr Diet*. 2017;74(5):476–487.
14. Williams-Hooker R, Adams M, Havrilla D, et al. Caregiver and health care provider preferences of nutritional support in a hematopoietic stem cell transplant unit. *Pediatr Blood Cancer*. 2015;62(8):1473–1476.
15. Montgomery K, Belongia M, Mulberry MH, et al. Perceptions of nutrition support in pediatric oncology patients and parents. *J Pediatr Oncol Nurs*. 2013;30(2):90–98.
16. Mahant S, Jovcevska V, Cohen E. Decision-making around gastrostomy-feeding in children with neurologic disabilities. *Pediatrics*. 2011;127(6):e1471–e1481.
17. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357.
18. Plano Clark V. Meaningful integration within mixed methods studies: identifying why, what, when, and how. *Contemp Educ Psychol*. 2019;57:106–111.
19. Mackenzie N, Knipe S. Research dilemmas: paradigms, methods and methodology. *Issues Educ Res*. 2006;16(2):1–13.
20. DiCicco-Bloom B, Crabtree BF. The qualitative research interview. *Med Educ*. 2006;40(4):314–321.
21. Brotherton AM, Abbott J, Aggett PJ. The impact of percutaneous endoscopic gastrostomy feeding in children; the parental perspective. *Child Care Health Dev*. 2007;33(5):539–546.
22. Brotherton A, Abbott J. Mothers' process of decision making for gastrostomy placement. *Qual Health Res*. 2012;22(5):587–594.
23. Gibson F, Shipway L, Barry A, et al. What's it like when you find eating difficult: children's and parents' experiences of food intake. *Cancer Nurs*. 2012;35(4):265–277.
24. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77–101.
25. QSR International Pty Ltd. *NVivo*; Published online 2022.
26. Lincoln Y, Guba E. *Naturalistic Inquiry*. Sage; 1985.
27. Williams GF, White H, Sen M, et al. Patients' experience of enteral feeding following (chemo) radiotherapy for head and neck cancer: a qualitative study. *Clin Nutr*. 2019;38(3):1382–1389.
28. Kennedy I. Patients are experts in their own field. *BMJ*. 2003;326(7402):1276–1277.
29. Jaafar MH, Mahadeva S, Morgan K, et al. Systematic review of qualitative and quantitative studies on attitudes and barriers to percutaneous endoscopic gastrostomy feeding. *Clin Nutr*. 2016;35(6):1226–1235.
30. White S, Brereton L. Examining the role of patient values in decisions about long-term enteral feeding: a qualitative study. *Clin Nutr*. 2018;37(3):1046–1052.
31. Mahant S, Cohen E, Nelson KE, et al. Decision-making around gastrostomy tube feeding in children with neurologic impairment: engaging effectively with families. *Paediatr Child Health*. 2018;23(3):209–213.
32. Egestad H. The significance of fellow patients for head and neck cancer patients in the radiation treatment period. *Eur J Oncol Nurs*. 2013;17(5):618–624.
33. Gage EA, Panagakis C. The devil you know: parents seeking information online for paediatric cancer. *Social Health Illn*. 2012;34(3):444–458.
34. Kwong JPY, Stokes EJ, Posluns EC, et al. The experiences of patients with advanced head and neck cancer with a percutaneous endoscopic gastrostomy tube: a qualitative descriptive study. *Nutr Clin Pract*. 2014;29(4):526–533.
35. Hazzard E, Gulliver S, Walton K, et al. The patient experience of having a feeding tube during treatment for head and neck cancer: a systematic literature review. *Clin Nutr ESPEN*. 2019;33:66–85.
36. Ehrsson YT, Sundberg K, Laurell G, et al. Head and neck cancer patients' perceptions of quality of life and how it is affected by the disease and enteral tube feeding during treatment. *Ups J Med Sci*. 2015;120(4):280–289.
37. Montgomery K, Belongia M, Schulta C, et al. Health care providers' perceptions of nutrition support in pediatric oncology and hematopoietic stem cell transplant patients. *J Pediatr Oncol Nurs*. 2016;33(4):265–272.
38. Mårtensson U, Cederlund M, Jenholt Nollbris M, et al. Experiences before and after nasogastric and gastrostomy tube insertion with emphasis on mealtimes: a case study of an adolescent with cerebral palsy. *Int J Qual Stud Health Well-being*. 2021;16(1):1–13.
39. Alberda C, Alvdj-Korenic T, Mayan M, et al. Nutrition care in patients with head and neck or esophageal cancer: the patient perspective. *Nutr Clin Pract*. 2017;32(5):664–674.
40. Viani K, Trehan A, Manzoli B, et al. Assessment of nutritional status in children with cancer: a narrative review. *Pediatr Blood Cancer*. 2020;67(S3):1–9.
41. Corry J, Poon W, McPhee N, et al. Randomized study of percutaneous endoscopic gastrostomy versus nasogastric tubes for enteral feeding in head and neck cancer patients treated with (chemo)radiation. *J Med Imaging Radiat Oncol*. 2008;52(5):503–510.