

Original Article

The parental experience and perceptions of blenderized tube feeding for children with medical complexity

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Abstract

Objectives: Parents of children with medical complexity are often expected to implement complicated plans of care, such as enteral tube feeding, to support the health of their child. Enteral feeding can have psychosocial implications for the parent, child, and family. Blenderized tube feeding (BTF) refers to the administration of pureed food and drinks through a feeding tube. Little is known regarding parents' experiences with BTF. Therefore, the purpose of this qualitative study was to understand the lived experience of BTF from the parent's perspective.

Methods: This qualitative study was a grounded theory analysis utilizing semi-structured interviews of parents who provided at least 50% of their child's diet through BTF. Participants were recruited using purposive sampling from the Complex Care Program at a tertiary care paediatric centre. Interviews were conducted until thematic saturation was achieved. Themes were identified using constant comparative analysis of transcribed interviews.

Results: Parents (n=10) felt that BTF positively affected the experience of tube feeding and enhanced their child's health and wellbeing. Parents described BTF as a means of self-empowerment and a mechanism to normalize feeding and care for the entire family. Despite reporting BTF as more time consuming than formula feeding, all parents were satisfied with having made the change, and planned on continuing the diet.

Conclusion: BTFs can improve the experience of tube feeding and positively address some of the negative psychosocial implications of enteral tube feeding, providing a sense of normalcy and control for parents caring for a child with medical complexity.

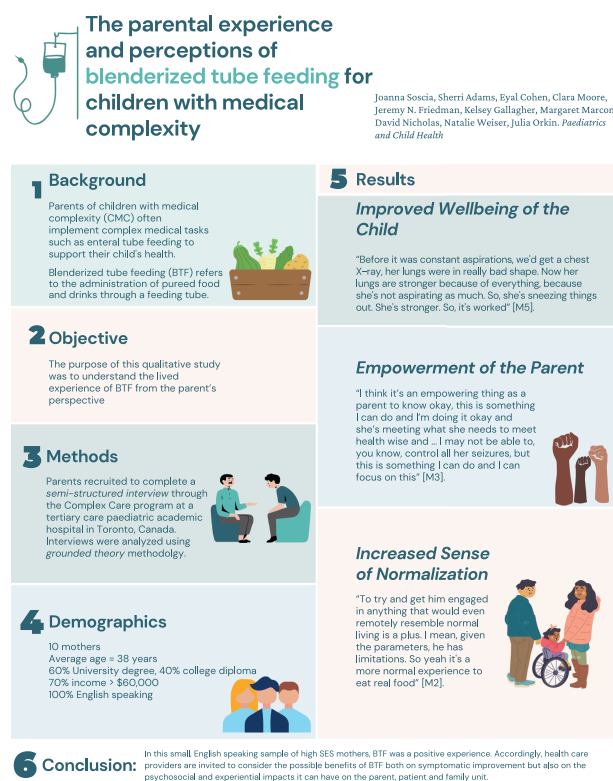
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Graphical Abstract



Keywords: Blended diet; Blenderized tube feeding; Children with medical complexity; Enteral feeding

Children with medical complexity (CMC) have multisystem chronic health conditions, medical fragility, significant functional impairment, and frequently rely on one or more medical technologies (1). The majority of these children experience feeding difficulties and require enteral feeding tubes for nutritional supplementation (2,3). Traditionally, commercially prepared formulas have been used; however, there has recently been increased interest and demand for blenderized diets (4–6). Blenderized tube feeding (BTF) is the administration of pureed foods and drinks through a feeding tube. The motivation to administer BTF is multifactorial, but has been reported to be driven by caregiver desire to provide more whole food, manage feeding intolerance and improve oral intake (7,8).

Possible benefits of BTF include increased satisfaction with tube feeding and improved symptom management particularly as it relates to gastrointestinal symptoms such as vomiting, gagging, and retching (7–11). However, there is a significant time investment (6) and possible cost associated with the required supplies to provide BTF. Increased costs can be related to food, supplies, and other out of pocket expenses that may not be covered by health insurance. Administration of BTF also requires

comprehensive education regarding preparation, food safety, and administration (9,12–14). Since the nutritional content of BTF varies (12,13), support by a dietitian and close follow up is necessary (13,15).

The purpose of this study was to understand the lived experience of parents of CMC who provided BTF and the impact on the family as a whole.

METHODS

Study design

This qualitative study comprised individual interviews of parents who chose to provide BTF to their child. Study design was based on a grounded theory approach. The purpose of grounded theory is to understand participant experience and use these experiences to generate a theory (16,17). We aimed to determine a detailed understanding by gathering family-oriented information from the lived experience of the individual and family (18).

Research ethics board approval was obtained. Parents were recruited to participate through the Complex Care program at

a tertiary care paediatric academic hospital in Toronto, Canada. Health care providers within the Complex Care program were provided with presentations, recruitment posters and email flyers to determine eligible participants. Participants eligible for recruitment included parents (English and non-English speaking) who self-identified as being the main caregiver involved in providing BTF to their child. Their children must have received at least 50% of their daily calories through BTF by gastrostomy tube for a minimum of 3 months before participating in this study, including children who were started on BTF, met this threshold, but had then discontinued BTF. Purposive sampling was used in an attempt to gain representation from participants of varied backgrounds and experiences (both positive and negative) with BTF (19). Those who met the inclusion criteria were identified and recruitment was subsequently prioritized based on parent background and experience. Twelve parents of CMC were deemed eligible for recruitment.

Data collection

Potential participants (n=12) were sent a letter by a familiar health care provider introducing the study; this was followed by a telephone call from a research coordinator. Written, voluntary consent was provided prior to study enrolment.

Participants completed a demographic survey and participated in an in-depth semi-structured interview conducted at a time and place convenient for the parents. Interviews were conducted by a study investigator (NW) with doctoral training in qualitative interviewing. The interview guide was developed through literature review and consultation with experts in the areas of paediatric medicine, gastroenterology, social work, dietetics, and qualitative methodology. In accordance with grounded theory methods, the interview guide was modified following the first two interviews as data were analyzed and emerging codes and categories were identified (see [Supplementary Appendix 1](#) for final interview guides) to ensure in-depth exploration of desired areas (16,18,20). Interviews lasted between 60 and 90 minutes. Following 10 interviews, recruitment was closed as thematic saturation had been achieved (21). Interviews were audio-recorded and transcribed verbatim.

Data analysis

A qualitative data management and analysis software (NVivo 10) (22) was used to support data analysis. Interviews and data analysis took place concurrently as the grounded theory approach integrates 'constant comparative analysis' throughout data collection (19). To ensure inter-rater reliability, the transcripts were coded individually by three research team members (JS, JO, and NW). Codes were compared and reviewed until consensus was achieved and a coding tree consisting of codes

and sub-codes was developed and agreed upon by the multiple analysts. Data analysis reflected three stages: (1) open coding: initial codes were developed and refined through review of the transcripts; (2) axial coding: categories and relationships that developed from open coding were noted; and (3) selective coding: a conceptual model was created through the connections between central themes. In keeping with grounded theory, conceptual themes and analytic constructions were developed and revised through inductive analysis (16,18).

Inter-rater reliability, member checking, and peer debriefing (20,23) were undertaken to demonstrate methodologic rigor. Member checking was completed with four of the participants to ensure that findings resonated with participants' experiences of BTF. Peer debriefing was completed with experts in the field of paediatric medicine and nutrition support to confirm findings that resonated with their clinical expertise.

RESULTS

Participants consisted of 10 mothers of 11 children with medical complexity, no fathers agreed to participate ([Supplementary Appendix 2](#)). Half of the participants (n=5) heard about the diet through social networks, other parents and peer supports. Others (n=5) were introduced to the idea by one of their health care providers. Participants conveyed a range of reasons for initiating BTF, predominately reflecting a desire to move away from commercially prepared formula in order to change the experience of feeding, provide a more natural or healthy alternative form of nutrition, and/or symptom management ([Table 1](#)).

All participants made the decision to initiate BTF in collaboration with their clinical team. Many participants chose to initiate BTF in order to make the experience of feeding more enjoyable for their child and improve the management of symptoms related to feeding intolerance, gastroesophageal reflux, and aspiration pneumonias. Several felt that formula was unnatural and unhealthy and that BTF was a less invasive alternative to other suggested treatments including surgical interventions such as a Nissen Fundoplication for severe gastroesophageal reflux disease.

Feasibility of BTF

Feasibility and challenges of BTF were related to issues with the blend content, preparation, administration, and costs. Participants described increased planning and preparation with BTF compared to their previous experiences with formula feeding as well as increased challenges providing BTF during hospital stays or at school due to limited resources and awareness of BTF. Some participants mentioned that because BTF is not paid for by health insurance plans and commercial formula is covered, the out of pocket expenses for food and equipment (syringes) were greater.

Table 1. Reasons for starting BTF

Theme	Parents' comments
Modification of feeding experience	<p>"He experiences this in a very different way than how we experience eating, so trying to make it as pleasurable for him in whatever way we can. So I'm hopeful that blenderized food is more enjoyable than formula" [M2].</p> <p>"I don't anticipate him taking his whole meal orally any time soon, but we were hopeful we would get to that point where he could start eating orally, again, a more normal experience" [M2].</p> <p>"We decided to do it because we want her to like experience - like even though she can't taste it, at the same time, you know, we can give her a little bite, you know, whatever she's going to get and so we give her by mouth like which is a little bit to taste" [M4].</p>
Healthy and natural option	<p>"And just because he's disabled doesn't mean that he shouldn't eat normal, healthy food, and beyond a premade formula with words I can't even pronounce. And something that can sit on the shelf for like three years. To me, that's pretty gross to put into my child's body" [M6].</p> <p>"It's not normal for it [the body] to be processing and breaking down formula. It's just not the right way to do it. So it just made sense to give her what her body needs, which is nutrients, like, food, like, a balanced diet like we would have" [M5].</p> <p>"We never really wanted our kid to be on formula, it's a very unnatural thing. If you look at the ingredients... I wouldn't put that in my body, never mind a child's. So we're happy that we could find an alternative" [M8].</p>
Symptom management	<p>"I thought well maybe they would be able to handle a bit something heavier. And that's when I said, you know what, I'm willing to try something different because what we're doing is obviously not working" [M10].</p> <p>"At that point in time he was still vomiting pretty frequently so we were trying to see if this [BTF] would help with the vomiting" [M2].</p> <p>"So just coping with that [aspirations] and then looking at other options and how do we prevent her illnesses and that was the thought of blended food, it's going to sit in her gut and weighed down and then less to liquid to reflux so we had nothing to lose. This was the easiest thing before we looked at surgery and other options" [M3].</p> <p>"I realized; some foods are bothering him more than the others. So, seeing that every formula I tried seemed to have these negative effects on him, I knew I wanted to go back to food, because I've seen him happy and healthy on it" [M6].</p>

*BTF Blenderized tube feeding.***Experience with and perceived impact of BTF**

All participants expressed a high level of satisfaction with BTF and desired to continue the diet. One family discontinued BTF because the child had frequent hospitalizations and the diet was not feasible due to medical instability, however they were keen to restart BTF. Participants explained that any challenges associated with BTF were mitigated by the benefits they witnessed in improvements to their child's overall health and wellbeing.

Central themes and outcomes of implementing BTF emerged as: (1) improved wellbeing of the child; (2) empowerment

of the parent; and (3) an increased sense of normalization (Table 2).

Improved wellbeing of the child

From an overall health and symptom perspective, parents felt that their child was thriving on BTF compared to formula feeding. This was manifested as increased growth, improved feeding tolerance, and fewer symptoms of gastroesophageal reflux and/or vomiting. Participants perceived these factors led to fewer hospitalizations for feeding-related issues or aspiration pneumonia. Further, feeding and mealtimes were felt to be

Table 2. Central themes

Theme	Parents' comments	
Improved Wellbeing of the Child	Physical Wellbeing "I think she's stronger, she physically looks healthier and I know nutrition in the formulas, it's all synthetic. It's not the same. So for somebody meeting my kid, she looks perfectly happy. They don't get that sense there's something wrong because she's just so healthy. She eats very well, she's not even that skinny. So I would attribute it to that [BTF] and she doesn't get sick often" [M8]. "[child] has more hair. Her skin colour is better. She doesn't have that sick look to her. She has more energy, a lot more energy" [M10]. "Before it was constant aspirations, we'd get a chest X-ray, her lungs were in really bad shape. Now her lungs are stronger because of everything, because she's not aspirating as much. So, she's sneezing things out. She's stronger. So, it's worked" [M5].	
	Social Wellbeing "Before she gets four feeds a day and each feed lasts up to two hours and during that time we can't really do much with her because she's hooked up to the pump. But now with the blenderized feed it takes a half hour max and even while we're feeding her she can do other things" [M4]. "To have her at the table tasting things while she's getting tube fed, yeah, it was a - it's a bigger deal than I thought it was as a family to do that and she can be part of the dinner table instead of sitting somewhere where she needs to be tube fed, you know, in her bed or whatever" [M3]. "It's got to have some huge impact, that they're part of the family, they're joining in, they're not segregated in doing something different than anyone else, that they're like everyone else" [M5].	
	Empowerment of Parents	"I think it's an empowering thing as a parent to know okay, this is something I can do and I'm doing it okay and she's meeting what she needs to meet health wise and ... I may not be able to, you know, control all her seizures, but this is something I can do and I can focus on this" [M3]. "Just like my other children, I get to decide what they eat and what's healthy for them and it's even easier because it goes right through a tube so she can't complain. But I think that is a huge thing as a parent is knowing I get a choice in what she's eating and how she's eating it and seeing the benefits of it. Again, talking about the emotional connection is huge. Like I know that this is the best thing for her regardless of what anyone else kind of thinks" [M3]. "When I was giving him formula [I feel] guilty inside that we are eating [solid food] and he's not taking. So when he will be able to take the food like we are taking? So it was guilted me, now I am satisfied" [M9].
		Increased Sense of Normalization "To try and get him engaged in anything that would even remotely resemble normal living is a plus. I mean, given the parameters, he has limitations. So yeah it's a more normal experience to eat real food" [M2]. "It feels like, you know, now to be kind of in a normal relationship because now I have to make her food and she's going to eat. Not like before I just, you know, like plug into her milk ... It just did not feel normal like at all like, you know, that she's away over there and then her sister's eating at the table" [M4]. "At least they're having some semblance of normalcy in their life, right, and they're able to participate with what their family is having" [M5]. "For us as a family connecting better during family time and meal time is getting back what a normal family's all about and I think that's so hard when we spend so many years here and everything's seen as medical. Everything's a medical issue and a medical problem and to be able to do stuff for [child] where it's become more normal has been a huge benefit to the family" [M3].

BTF Blenderized tube feeding.

more enjoyable for the child with a more active interest in food, and some were more accepting of eating orally. Social inclusivity improved as participants explained that their child had

more time with family in and outside of mealtimes. Less feeding equipment and shorter feeding times allowed more time to engage in other activities.

Empowerment of the parent

Participants described BTF as an empowering experience. Unlike many other aspects of their child's condition and care needs, they could independently make decisions about the child's feeding and diet. Participants also felt that by providing BTF they were personally contributing to positive outcomes for their child and they had regained an aspect of their parenting role that was lost with formula feeding and caring for a child with medical complexity. Finally, feelings of guilt related to tube feeding were relieved by the ability to provide tube feeds that consisted of natural, whole foods and/or the same foods as the rest of their family.

Increased sense of normalization

Participants discussed family eating patterns and perceived relationship changes that occurred as a result of transitioning to BTF. Participants felt that BTF helped siblings and peers relate better to their child. They also felt that the use of BTF shifted the dynamics of the family unit at mealtimes to a more positive and interactive experience. Common descriptions of mealtimes involved the child eating the same food at the same time as the rest of the family, thus resembling more typical eating habits and behaviours. Ultimately, participants noted their pleasure in having one aspect of their very medically driven life resemble normal living.

DISCUSSION

This study explored the lived experience of parents who chose to provide BTF to CMC. Our study complements the findings by Phillips (2019) who performed qualitative interviews with six mothers whose children received BTF (24). Participants in our study had varied reasons for beginning BTF, and despite feasibility challenges, they preferred BTF to conventional formula feeding. Participants who chose to initiate BTF felt that BTF improved their child's health and wellbeing, helped them feel empowered and increased normalization surrounding the care of their child. Challenges associated with BTF included increased time for preparation and administration, difficulty travelling, and associated costs. Barriers to initiating BTF may be related to parental capacity or appropriate funding options. Many families cannot afford BTF or choose not to initiate BTF for other reasons; therefore, our results do not represent these varied perspectives. Despite these limitations, we believe that our findings offer important considerations and implications for family-centred care for CMC and call for improved resources to ensure equitable access to BTF.

Our study supports previous literature on BTF showing high levels of satisfaction (7–9,24). All 10 participants were interested in continuing BTF, including the one participant whose child had discontinued BTF. BTF emerged as a modality that

positively changed their experience and perception of tube feeding (Supplementary Appendix 3).

Participants viewed their child's growth, feeding tolerance, and overall health to have improved because of BTF. These perceptions have been supported in previous research (4,7,9,24,25). Most notably, parents of children on BTF reported decreased feeding intolerance symptoms and increased growth goal achievement (7) and following children's transition to BTF, the prevalence of vomiting decreased and bacterial diversity in the stool increased significantly (8).

The ability to gain control over one aspect of their child's care that was not entirely driven by a medical team or medical plan of care was important to many participants. Typically feeding tubes result in dependency on health care providers (26) and CMC have highly prescribed plans of care. Therefore, parents rarely have the opportunity to make independent decisions about their child's care. A novel finding of this study is that after obtaining guidance regarding appropriate and adequate nutrition from their medical team, participants felt empowered by their ability to determine what their child was fed as BTF allows parents to adjust feeds based on their child's unique needs (4). As a parent, the ability to actively engage in decision-making appears to allow for an improved sense of empowerment in a world of uncertainty and medical predominance.

Normalization was another important factor related to BTF, perhaps amplified because families of CMC are continually faced with deviation from common norms. The values and beliefs associated with eating by mouth significantly impact parents and have profound meaning beyond supporting adequate growth and nutrition (27). Eating by mouth is often viewed as one of the only remaining normal activities in which a child with neurological impairment can engage (28). Therefore, there is a perceived loss of normalcy associated with tube feeding (26,28–30). Tube feeding is also felt to change the mother–child relationship, as defined by sociocultural perceptions of good mothering (11,12,28–30). For many families, there is a perception that tube feeding is abnormal, emphasizes the child's disability or illness, (31) and negatively impacts mealtime interactions (26). In contrast, participants in this study associated BTF with a sense of personal fulfillment in their parenting role around feeding. They reported an increased sense of normalcy as preparing and providing tube feeds that constitutionally resemble 'real food' seemed to contribute to a sense of integrating the child into normal family behaviour and routines, thus fostering a desired sense of social inclusion and engagement in everyday life. Participants also felt that BTF helped siblings and peers relate better to their child. These results are supported by previous literature that found BTF may provide greater social benefits, enhance the child–parent relationship and allow families to be more engaged in tube feeding (24,32,33). Ultimately

our findings demonstrate that BTF changes family dynamics around meal time and can lead to improved social integration for their child and family.

Our findings highlight the parental perception, feasibility, and perceived positive effect on many aspects of life such as enjoyment of feeding, normalcy, and feeding as a social process. These findings amplify the consideration of BTF when supporting families around decision making for enteral tube insertion. They offer salient considerations for discussion such as parents' sense of normalcy, social inclusion, and expectations of feeding (8).

Given the small sample from one clinical program, generalizability is a limitation. In addition, despite extensively attempting to include non-English speaking parents, we were not able to recruit any. Further, participants were women from predominantly well-educated, high-income families. Therefore, our study sample may lack diverse population distinctions, which could have a bearing on perspectives or experiences of participants. Lastly, our study recruited parents who had already made the decision to start BTF, which may have trended toward more positive feelings about BTF than would be posited by those not choosing for this option. Future research should examine the perceptions of BTF of families from lower socioeconomic backgrounds and explore reasons why some families choose not to initiate BTF. This research would help to identify specific barriers to BTF such as cost, belief systems, or trust in Western medicine.

CONCLUSION

The study has explored the role of BTF as an option to improve the parent caregiving experience. The study offers a range of benefits such as enhanced parental empowerment and normalization in the context of a life and care processes that were otherwise largely prescribed and medically driven. In this small, English speaking sample of high SES mothers, the experience of BTF was seen as extremely positive, and outweighed associated enhanced caregiving tasks. Accordingly, health care providers are invited to consider the possible benefits of BTF on symptomatic improvement but also on the psychosocial and experiential impacts it can have on the parent, patient, and family unit.

SUPPLEMENTARY DATA

Supplementary data are available at *Paediatrics & Child Health* Online.

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