The experience of caregivers of children with medical complexity receiving blenderized tube feeding: a qualitative study

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Background
- Children with medical complexity (CMC) often rely on enteral feeding tubes for nutritional supplementation.
- There is an increasing interest and demand by caregivers to offer blenderized tube feeds (BTF) as an alternative to formula.
- Feeding is associated with values and beliefs, affects the parent-child relationship and has social implications.
- Tube feeding can result in a loss of normalcy, stigmatization and affect relationships.
- There is no research to date on the experience of caregivers who provide BTF.

Objectives
This qualitative research study aimed to describe:
1. Caregiver satisfaction with BTF
2. The feasibility/usability of BTF including preparation, sanitization, storage and administration of feeds.
3. Caregiver perceptions of benefits and challenges of BTF.

Methods
Qualitative research study using a grounded theory approach.

Setting & Sample
- 10 English speaking mothers of 11 CMC followed in the Complex Care clinic.
- Child received at least 50% of their diet through BTF for a minimum of three month before participating in this study.
- 1/10 child no longer received blend feeds.
- G tube fed.

Data Collection
- Open-ended, semi-structured interview.
- Interviews lasted between 60 and 90 minutes.
- Ethics approval from the Hospital for Sick Children Research Ethics Board.
- Written consent was attained.

Analysis
- Interviews were audio-recorded and transcribed verbatim
- Interviews and data analysis took place concurrently
- A coding tree consisting of codes and sub-codes was developed iteratively
- To ensure reliability, transcripts were coded individually and two researchers met to compare, and discuss to arrive at a consensus
- Data analysis was followed by both member checking and peer debriefing.

Results
All caregivers expressed high level of satisfaction with BTF and desire to continue the use.

Usability and Feasibility related to:
1. Content: initial challenges determining what to feed to provide balanced, healthy diet and appropriate consistency to be able to syringe into tube.
2. Preparation: more planning and prep compared to formula.
3. Administration: shorter bolus feeds, no need for pump but frequent syringe breakdown issues.

Conclusions
- Caregivers are highly satisfied with BTF in CMC.
- Tube fed CMC have complex and high care needs that put strain on the caregiver, affect relationships and normal family dynamics/activities.
- BTF can potentially change the experience and meaning of tube feeding through normalization, empowerment and improved wellbeing of the child.

3 Emerging Themes

Wellbeing of the child
- Greater sense of overall improved health in child.
- More enjoyable meal times and interest in food.
- More time to engage in other activities.
- More time with family and overall social inclusion.

“...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.”

“I didn’t realize how much of difficulty it was having her attached to something and then when we switched over it was like oh my goodness, I can take her out and roll her and move her places and it was so much quicker because it was a syringe.”

Empowerment
- Sense of control over one aspect of the child’s care.
- Control over food choices, meal planning and feeding schedules.

“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.”

“...It’s a huge thing as a parent knowing I get a choice in what she’s eating and seeing the benefits of it. The emotional connection is huge. I know that this is the best thing for her.”

Normalization of family and life
- Caregivers stated that BTF made their family activities (particularly meal times) feel more “normal.”
- BTF de-medicalizes the family’s everyday life giving an increased sense of normalcy.

“Connecting better at family time and meal time and getting back what a normal family’s all about. Everything’s a medical issue and to be able to do normal stuff has been a huge benefit to the family.”

“The way I see it is she’s got a lot of issues already, medical issues, I’m trying to give her the most normal kind of life I can give her and I want her to have the same things that we have.”

References
3. Mahant S, Friedman J.M., Connolly B, Cohen E., Pentiuk M, MD, FRCP, FRCP, Friedman Jeremy, MD, MSc, FRCP, Gallagher Kelsey, RD, Marcon Peggy, MD, FRCP, Nicolas, David, PhD, RSW, Orkin Julia, MD, FRCP.

Changing the meaning of tube feeding

Normalisation

Wellbeing

Empowerment

Meaning of Tube Feeding

Stigmatization/Social Isolation

Disruption to relationships

Process of caregiver and administering blenderized tube feeds

Increased sense of normalization

Improved wellbeing of the child

Empowerment of the caregiver

Meaning of Tube Feeding

Blenderized Tube Feeding

Normalisation

Wellbeing

Empowerment

Figure 1