

Exploring parental thoughts and clinical experiences on blended food in a paediatric population, a qualitative study

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Abstract

Background: There's a growing interest in blended food (BF) as an alternative to commercial food (CF) for tube-fed children. Thus, we investigated parental and medical experiences with BF as an option for tube feeding in children

Methods: In this cross-sectional study, all patients were already using BF, chosen by parents. In March 2022, all patients using BF provided consent and completed a questionnaire assessing their experiences. Medical data were collected retrospectively from patient charts, including biometric changes, dietary adjustments, and nutritional status. A non-validated parent satisfaction score was computed from 17 questions, rated on a scale from one to five. A score of ≥ 51 points, indicating an average score of > 3 per question, was deemed indicative of a positive parental experience with BF.

Results: Nine children receiving BF were identified (median age: 4.7 years; weight: 14.9 kg; 66% male). All parents were satisfied with BF, reflected in the parent satisfaction score. Parents cited reduced feeding-related discomforts as the main reason for switching to BF. Weight ($+0.3$ SD) and length ($+0.5$ SD) showed positive changes. None discontinued BF, though modifications were made for five patients by the dietician. Nutritional deficiencies, mainly iron with or without zinc deficiency, were observed in four patients, with uncertain onset due to lack of pre-BF laboratory testing.

Conclusions: In this small BF cohort overseen by an experienced multidisciplinary team, BF was well tolerated, resulting in high parental satisfaction and maintaining good nutritional status. (*Acta gastroenterol. belg.*, 2024, 87, 241-254.

Keywords: blended food, blended diets, tube feeding.

Introduction

Children with chronic diseases and/or persistent feeding or swallowing difficulties often require additional nutritional support through a gastrostomy (1,2). Historically, blended food (BF) was the sole form of tube feeding before 1970, when advances in enteral nutrition led to the commercialization of tube feeding (3,4,5). Nowadays, commercial food (CF) is the standard offered to these tube-fed children, although BF is gaining recognition and being promoted by some parents.

BF involves the process of liquefying home-cooked food into a smooth puree-like consistency, often using a blender machine (6). Since 1970, BF has gradually been supplanted by CF, with the aim of reducing the risks associated with tube feeding, such as the heightened risk of morbidity (including diarrhoea, potential bacterial contamination with pathogenic bacteria as BF is not pasteurized, and pneumonia) or even increased mortality (3-5).

Studies conducted in Brazil, Saudi Arabia, and the Philippines have demonstrated the growth of pathogenic bacteria in samples from BF diets in hospital settings (7,8,9). Conversely, multiple studies in the paediatric population (6,12-24) have shown no signs of BF-related sepsis or death. Johnson et al. also demonstrated that with a safe food handling protocol, no pathogenic bacteria were cultured in samples of paediatric BF diets (10).

Another advantage of CF is its balanced composition regarding calories, macro- and micronutrients, promoting stable growth. Analysis conducted by dietitians on BF diets revealed a nutritional composition ranging from normal to higher levels, with increased calories, proteins, micronutrients, and reduced carbohydrates compared to CF diets (12,15,18,21,23,24). To sustain growth, BF necessitated 1.3 to 1.5 times more calories than CF with uncertain explanation (23). Given the limited experience in transitioning children from CF to BF, guidance from an experienced dietitian specializing in BF is recommended (25,26).

Society's recent focus on natural foods or specific diets, such as vegan or gluten-free options, has renewed interest in BF diets (4,5). In paediatrics, BF is significantly correlated with reduced tube-feeding intolerance and can serve as a transition to oral intake, fostering a sense of nurturing and care among parents. It gives parents an increased sense of normalization and to empowerment (17). Switching from CF to BF also leads to improvements in gastrointestinal (GI) complaints, including vomiting, gagging/retching, constipation, and diarrhoea (4,11-23). Children on BF diets exhibit a more diverse gut microbiome, associated with positive health outcomes (23,27,28,29). Additionally, parents report enhancements in emotional health, sleep quality, and physical well-being in their children (16,17,23).

In our tertiary hospital, we manage medically complex children already utilizing BF, overseen by our team comprising an experienced paediatric gastroenterologist and a dietitian. Given the rising interest in BF diets among our population, we sought to explore parental

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motivations for switching and their experiences with the BF diet, along with assessing clinical outcomes such as GI complaints, growth evolution, and nutritional deficiencies. Another objective of this study is to develop a departmental protocol to guide the transition to BF diets and propose a follow-up plan.

Methods

Study population and study design

In this cross-sectional and retrospective study, we extended invitations to all parents of children aged 0-17 years who had been using BF for more than three months and were under follow-up care in March 2022 at our University Hospital. Invitations were sent out via letter and telephonic consultation. Tube feeding was required to be either exclusively BF or a combination of BF and CF. At that time, our hospital did not have a standard departmental protocol with defined criteria for guiding the switch to BF. The decision to switch to BF prior to our study had been driven by parents. BF was defined as any food administered via a feeding tube that was not water, medication, or commercial formula. Patients receiving BF via tube feeding and still having some oral intake were eligible for inclusion in the study.

At our centre, BF was not initiated under the following conditions: (1) age less than 4 months (as infants receive fully infant formula or breastfeeding), (2) the use of a nasogastric tube due to the higher risk of tube blockage with BF, (3) the presence of severe immunological deficiencies due to the threat of severe food-borne infections, and (4) the presence of severe digestive comorbidities with a high risk of nutritional deficiencies (such as intestinal failure or within the first three months after major gastrointestinal surgery). All parents using BF at our centre received standard guidance from an experienced dietitian, which included dietary information on germ-free and hygienic cooking methods, balanced meal composition, and information on caloric intake.

All participating parents were asked to complete a questionnaire. The parental questionnaire was based on previous studies that had surveyed parents of children fed on BF. We translated and back-translated validated questionnaires, adding some extra questions developed by the study team to address specific interests. The questionnaire comprised multiple-choice, scaled, and a few open-ended questions. Parental judgment was chosen as a surrogate for their child's experiences due to age restrictions or intellectual disability preventing the expression of their opinions. The survey consisted of 54 questions and took approximately 45 minutes to complete. These questions assessed the impact on the physical and emotional well-being of patients, including effects on GI complaints, behavioural changes, energy balance, overall happiness, financial aspects, preparation methods, time investment, and the perceived benefits and disadvantages of BF.

Additionally, the treating gastroenterologist and dietitian completed a questionnaire for each child to evaluate their nutritional health status, changes in medication, and growth assessment. The estimated time required to complete the survey was a maximum of 15 minutes.

Patients' characteristics were retrieved retrospectively from medical records, including demographic data, primary diagnosis, psychomotor development, age at the start of tube feeding, age at gastrostomy insertion, age at the start of BF, medication changes, and any earlier nutritional deficiencies. Growth was evaluated by the treating physician per patient, comparing weight, height, and weight for height as age- and gender-adjusted standard deviation scores (SDS; z-scores) according to Belgian growth charts (30). Data from the last growth value when still on CF and the last growth value on BF were collected.

After obtaining additional parental consent, blood samples were analysed for full blood count, electrolytes, kidney and liver function, vitamin A/E/D, copper and zinc, and iron status to assess nutritional status and possible deficiencies. Iron deficiency was defined as ferritin <20 µg/L and anaemia when haemoglobin was below age-specific reference ranges. For zinc, vitamin A and E, age-specific reference ranges were used. Vitamin D deficiency was defined as vitamin D <20 ng/mL. If available, these results were compared to previous blood samples when children were on CF.

Approval was granted by the ethics committee of our university hospital (Approval No: MP017965, date 24-08-2021), and the study was conducted in accordance with Good Clinical Practice guidelines. All parents provided informed consent before any study procedures and assessments were performed.

Endpoints

The primary outcome of the study was to assess parental satisfaction. A score was calculated based on cumulative responses to 17 questions, rated on a scale from one to five, regarding their agreement with statements related to parental experiences and their child's symptoms. The minimum and maximum achievable scores were 17 and 85 points, respectively. A score of 51 points or higher, indicating an average score of more than three points per question, was considered indicative of a positive change following the switch to BF.

A secondary objective of the study was to evaluate whether BF could serve as an alternative feeding option to CF in our cohort. The appropriateness of BF was assessed across four different categories: weight and length evolution before the initiation of BF and at the last follow-up visit, potential presence of nutritional deficiencies, need for alterations in the blended diet by the dietitian, and requirement for changes in medication. A change in weight standard deviation of more than one SD was considered clinically relevant.

Statistics and analysis

Analyses were conducted using Excel. Continuous variables are reported as medians with interquartile ranges [IQR], while categorical variables are presented as frequencies and percentages.

Results

Patient characteristics

In our centre, a total of nine children were identified as being on BF in March 2022. All of them provided informed consent to participate in the study. They had a median age of 4.7 years (age: 2.5-13.5 years), with a median weight of 14.9 kg (range: 8.6-35.3 kg), and a median weight for height of -1.7 SD (range: -3.9 SD to -0.4 SD) at inclusion. Most of the participants (n=6;

66.7%) were male. A summary of baseline characteristics is presented in Table 1. The transition to BF occurred at a median age of 29 months (range: 4-45 months), with all decisions to switch to BF being parent-driven. At the time of patient selection, the median duration of BF usage among the cohort was 28 months (range: 7-109 months). At inclusion, five children were exclusively on a BF diet, while four children were on a combination of BF and CF. Additionally, five children were receiving some oral intake in addition to tube feeding.

Parental questionnaire

One parent (BF09) provided informed consent for data analysis but did not participate in the questionnaire. Therefore, questionnaire data were based on the remaining eight participants.

Table 1. — Patient characteristics

Patient	Gender (M/F)	Age at inclusion (years / months)	Underlying medical conditions	Psychomotor development	Reason feeding issues	Age start BF (years/ months)	Duration use BF (years/ months)	Some peroral intake	Only BF/ combination of BF and CF
01	M	4y	Prematurity (24 weeks), SIP requiring GI stomata	Delayed psychomotor development	Oral aversion, restrictive oral intake	2y5m	1y	Yes	BF
02	M	5y7m	Prematurity (33 weeks), CHD, severe GERD with GI stomata and Nissen operation	Delayed psychomotor development	Severe GERD	2y4m	2y11m	No	BF
03	M	13y2m	NAI with bilateral subdural hematoma	Severe intellectual and motor disability (spastic quadriplegia)	Unsafe swallowing	3y9m	9y1m	No	BF and CF
04	M	4y5m	Noonan syndrome, cardiopathy (DORV/AVSD)	Delayed psychomotor development	Oral aversion and restrictive caloric intake	1y7m	2y6m	No	BF
05	F	3y	Genetic syndrome (Chr. 17 deletion) causing microcephaly, deafness	Delayed psychomotor development	Restrictive caloric intake	4m	2y4m	Yes	BF
06	M	3y2m	Prematurity (26 weeks)	normal	Oral aversion	10m	1y7m	No	BF and CF
07	F	4y4m	Cerebral palsy (COL4A1 mutation)	Severe intellectual and motor disability	Persistent vomiting and restrictive oral intake	2y5m	7m	Yes	BF
08*	F	2y2m	Prematurity (27 weeks), ADPKD	normal	Restrictive oral intake	*	*	Yes	BF and CF
09	M	5y1m	Selective eating pattern and oral aversion without underlying diagnosis	Normal	Oral aversion	3y4m	4y	Yes	BF and CF

Legenda: SIP (spontaneous intestinal perforation), GERD (gastro-oesophageal reflux disease), CHD (congenital hernia diaphragmatic), NAI (non-accidental injury), ADPKD (autosomal dominant poly-cystic kidney disease). *This patient started on BF before being referred to our hospital.

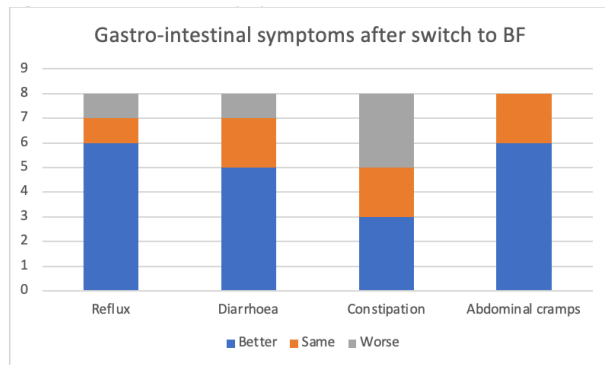


Figure 1 — Gastro-intestinal symptoms.

The primary reasons cited for switching to blended food, according to the parent questionnaire, were a reduction in feeding-related discomforts (n=8). Parents reported fewer signs of reflux (n=6), reduced incidence of diarrhoea (n=5), and fewer instances of abdominal cramps (n=6), as depicted in Figure 1. Additionally, constipation either emerged or worsened in some children (n=3). Parents observed positive changes in their child's mental well-being (n=8), noting improvements in their appearance (n=8), happiness (n=6), and energy levels (n=6). Other motivations that contributed to switching to BF was the ability to participate in family mealtimes (n=5), provide self-made pureed meals (n=6), and establishing a structured daytime feeding routine (n=3). A final benefit noted was an enhanced sense of self-confidence among parents (n=7). All parents expressed

satisfaction with their child receiving blended food and none considered reverting to exclusively commercial formulas. When queried, all parents indicated they would recommend blended food to other parents of children requiring tube feeding.

Preparation time ranged from 30 minutes to two hours per day (n=7), with some parents occasionally requiring more than two hours per day (n=1). Preparation time was identified as the primary disadvantage (n=6), with some parents suggesting meal preparation in advance as a time-saving solution (n=7). All parents needed to purchase special equipment, such as blenders and storage containers, with a median cost of 200 euros (range 20-650 euros) in total. Most parents reported that the average cost of producing blended food was not higher than commercially available products (n=5). Parents typically spent between 200-400 euros per month on preparing blended food. However, all parents stated that the financial investments did not outweigh the advantages.

Some parents (n = 2) reported that gastrostomy blockages occurred more frequently (approximately once per month). They resolved this issue by flushing the tube with water. Additionally, one parent mentioned that they needed to replace the extension set once, but the button itself remained intact.

A parental satisfaction score was calculated (see Table 2), incorporating all the aforementioned factors. All parents scored between 51 and 80 points with a median of 65.5 points.

Table 2. — Parent satisfaction score (scale 1-5, totally disagree, totally agree)

Participant	01	02	03	04	05	06	07	08	Average
I am overall satisfied with switching to BF	5	4	5	5	4	4	5	4	4,5
Child looks healthier	4	5	5	5	4	4	5	5	4,6
Child is happier	4	5	5	3	3	4	5	4	4,1
Less reflux symptoms	2	3	5	4	5	4	5	5	4,1
Less diarrhoea	4	4	5	2	4	3	3	4	3,6
Less constipation	2	4	4	3	2	3	4	2	3
Less abdominal cramps	4	4	4	3	4	3	5	4	3,9
Tube is less blocked	1	3	3	2	2	3	3	2	2,4
Feeding times is more a family moment	4	3	5	2	2	1	4	4	3,1
Feeding times is more fun	3	4	5	2	2	1	4	4	3,1
Family is more coherent	3	3	5	3	2	2	3	4	3,1
Only few problems in preparation of BF	4	4	5	3	4	2	2	5	3,6
Only fed problems in administering BF	4	2	4	4	4	1	4	4	3,4
BF is better than CF	5	5	5	4	4	4	5	5	4,6
The financial investment is worth it	5	5	5	5	4	4	5	5	4,8
The extra costs of preparation are worth it	5	4	5	5	4	4	3	4	4,3
The time preparation is worth it	5	5	5	4	4	4	5	4	4,5
Total	64	67	80	59	58	51	70	69	3,8

BF as alternative for CF

Medical Progress: Medication Adjustments and Gastrointestinal Infections

All patients underwent changes in their medication regimens based on the gastrointestinal complaints experienced by the children. Anti-acid medications (PPIs, H₂-receptor antagonists) were continued in three children, initiated in three children, and discontinued in two children. Prokinetics and anti-nausea agents (such as erythromycin, metoclopramide, domperidone) were discontinued in four patients, initiated in two patients, and continued in one patient. Laxatives were continued in two patients and initiated in four patients.

No food-borne gastrointestinal infections or instances of sepsis were reported following the transition to blended food.

Anthropometric progress on Blended Food

Six patients exhibited positive changes in standard deviation for weight (Figure 2), indicating an improvement in weight evolution on blended food, with an average growth of +0.3 SD for age. No patient experienced a decrease of more than 1 SD in weight evolution after the transition to blended food, with the maximum decrease observed in one patient being -0.9 SD. The remaining two patients experienced decreases of -0.1 and -0.2 SD, respectively. Length growth showed an average increase of +0.5 SD, with two patients showing a decline on the growth chart, with a maximum decrease of -0.6 SD (Figure 3). One of these two patients also exhibited a decline in weight.

Dietary Considerations

Follow-up and guidance by a dietitian were tailored to each patient's individual needs. On average, patients had contact with the dietitian approximately once per month. Six patients required increased frequency of contact compared to when they were on commercial formulas. In five patients, dietary adjustments were made, such as increasing protein or fibre intake, enhancing fluid intake, or implementing hypercaloric feeding to optimize weight gain.

Biochemical considerations

Blood test results were available for six patients before transitioning to blended food. Four of them had iron deficiency anaemia, which was corrected in three patients before the commencement of blended food. Vitamin status and trace elements were not assessed while patients were on commercial formulas, as this was not part of the standard protocol.

In our cohort, six parents consented to blood analysis while their children were on blended food, with one

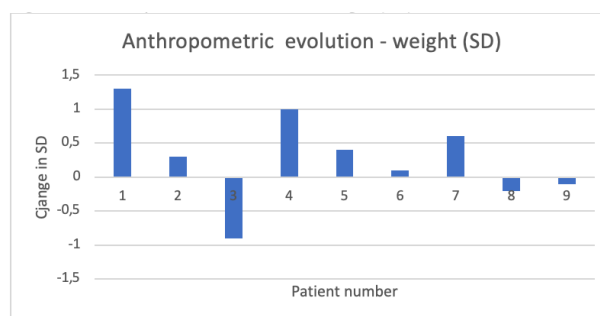


Figure 2. — Anthropometric evolution – weight (SD).

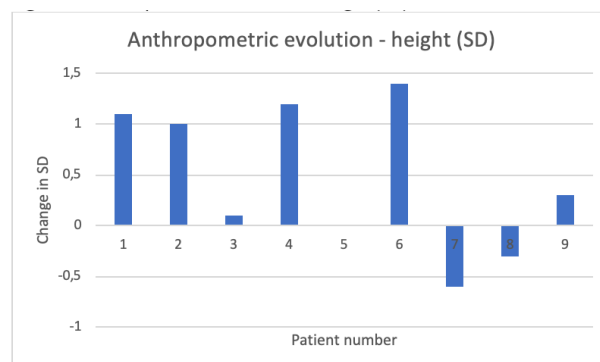


Figure 3. — Anthropometric evolution – length (SD).

patient having no previous blood analysis. All patients had been on a blended food diet for at least six months, with three on a blended food-only diet and three on a combination of blended food and commercial formulas. Three parents declined blood analysis to assess nutritional status due to past difficulties with venous access in their children. Among the analysed patients, four showed no deficiencies. One patient on a blended food-only diet presented with iron deficiency anaemia, which was already present during the commercial formula phase, and two patients had zinc deficiency (one on a blended food-only diet and one on a combination diet). Blood samples were not obtained at the time of dietary transition from commercial formulas to blended food.

Discussion

Blended food (BF) has gained popularity as an alternative for chronic tube feeding in children. In our cohort, BF appears to be a suitable option for selected patients when guided by an experienced nutritional team. Parental satisfaction was high, consistent with previous research (4,5,11-14,16-19,21-23). BF was deemed appropriate based on anthropometric progress, biochemical values, and dietary factors.

Most parents reported improvements in GI complaints under BF, including reduced gagging, reflux, diarrhoea, and abdominal cramps. However, constipation increased in some cases. Four out of nine patients experienced more complaints of constipation, but all of them were easily managed with the increase of water consumption, the addition of fibers and the start of macrogol. This

contrasts with earlier research, in which an improvement or no change of stool frequency and consistency was seen (4,11-14,21-23) and the same evolution was seen in research of Batsis et al (13). This effect might be explained by the different types of recipes, since small changes had a positive effect on stool frequency and consistency. Collaboration of dieticians can lead to better understanding of problems that can rise with BF.

Interestingly, in our cohort, three patients were prescribed proton pump inhibitors (PPIs) following the introduction of BF, despite only one parent reporting an increase in reflux symptoms in the questionnaire. The initiation of PPIs suggests a potential rise in gastro-esophageal reflux symptoms. These findings appear to contradict earlier studies, which observed a decrease in GERD (11-14,21-23). One hypothesis is that our cohort may have been affected by more severe underlying conditions, such as neurological or gastrointestinal motility issues, independently contributing to a higher prevalence of reflux symptoms. However, it's important to note that earlier research did not thoroughly describe patient characteristics, making direct comparisons challenging. Additionally, it's noteworthy that the decision to start anti-acid medications in our cohort was based on clinical observations rather than objective measures like gastroscopy or 24-hour pH monitoring.

The most significant drawbacks of BF, as mentioned in the literature, include the time-consuming preparation process, the risk of foodborne infections, potential tube blockages, and financial considerations (6). Our study also highlighted preparation time as the primary disadvantage, although it did not outweigh the benefits of BF over reverting to regular CF.

Consistent with previous research, no instances of foodborne gastrointestinal infections were reported after transitioning to BF over a period of combined 18 patients' years, indicating the effectiveness of proper education on germ-free cooking for parents (23). Moreover, emerging evidence suggests a link between BF and increased bacterial diversity, which is associated with improved health outcomes, particularly in adults (23,29). This suggests that BF may contribute to a healthier gut environment and may explain the beneficial effect on overall wellbeing (16,17).

While tube blockages were occasionally encountered in our population, they were generally easy to resolve. Regarding financial costs, a comparison between CF and BF in Belgium suggests a similar balance. In Belgium, CF is not fully reimbursed, with monthly costs ranging from 190 to 350 euros, comparable to the average expenses of 200 to 400 euros for preparing BF. This finding aligns with the BLEND study, where 66% of caregivers found BF to be equally affordable as CF. However, it's essential to consider indirect costs associated with BF, such as the need for a blender, which can add to the overall expense (23).

Three children in our cohort required hypercaloric feeding while using blended tube feeding to improve

weight gain. Anthropometric measurements remained stable or even improved under BF, even among children not on hypercaloric feeding. Previous research has suggested a 30-50% increase in caloric intake to sustain growth, although the exact reason remains unclear. (25,26). A larger cohort would be necessary to conduct a thorough comparison with these findings.

The retrospective nature of our study made assessing nutritional deficiencies challenging, as there was no standardized follow-up, and not all patients had repeated blood samples under CF and BF. However, it's noteworthy that iron deficiency anaemia was observed in both CF and BF cases, underscoring the importance of regular monitoring of biochemical values in every tube-fed child, regardless of the feeding method. When preparing BF at home, the precise macro- and micronutrient content remains unknown. Often, BF is deficient in calories, carbohydrates, proteins, and fats (12). However, the BLEND study and an analysis by Hron et al. demonstrated that participants receiving BF had similar, if not greater, micronutrient intake compared to those receiving CF (21,23).

Our study combined the perspectives of parents, physicians, and dieticians, along with retrospective patient chart reviews, to propose guidance for using BF. Unfortunately, we were constrained by a small cohort that had transitioned to BF. All decisions to switch to BF were driven by parents, introducing a significant bias in our parent satisfaction questionnaire. Although we aimed to understand the motivations for switching to BF and the challenges encountered, as well as to assess long-term enthusiasm, the reliance on parent-driven decisions limits the generalizability of our findings. Additionally, the lack of blood results for all patients, taken at different time points during CF, creates uncertainty about when nutritional deficiencies may have occurred. Consequently, we cannot conclusively determine whether nutritional deficiencies occur more frequently with a BF diet. Larger, multi-centre prospective trials involving paediatric populations are warranted, with a focus on analysing children initially on CF and later transitioning to BF, while paying specific attention to the nutrient content of BF.

Our findings align with a recent position paper from the ESPGHAN committee, which suggests that BF can serve as an alternative to CF in children following a thorough risk assessment and with regular follow-up by paediatric dieticians and healthcare professionals (6). Building on this guidance and our own experience, we have developed a protocol to guide the use of BF in paediatric patients (see Figure 4) (6). Exclusion criteria include the use of a nasogastric tube (due to increased risk of tube blockage), severe immunodeficiency (due to the risk of food-borne infections), and severe digestive comorbidities with a high risk of nutritional deficiencies. Switching to BF should only be conducted in a tertiary referral centre, where multidisciplinary follow-up with a paediatric gastroenterologist and a dietician experienced

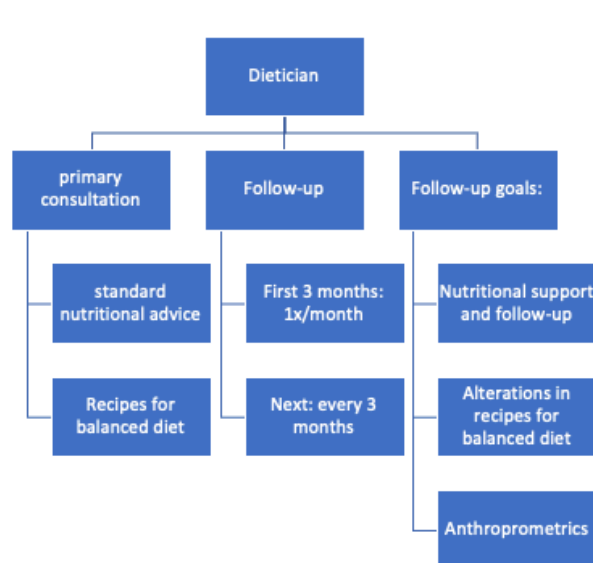


Figure A. — Dietary support.

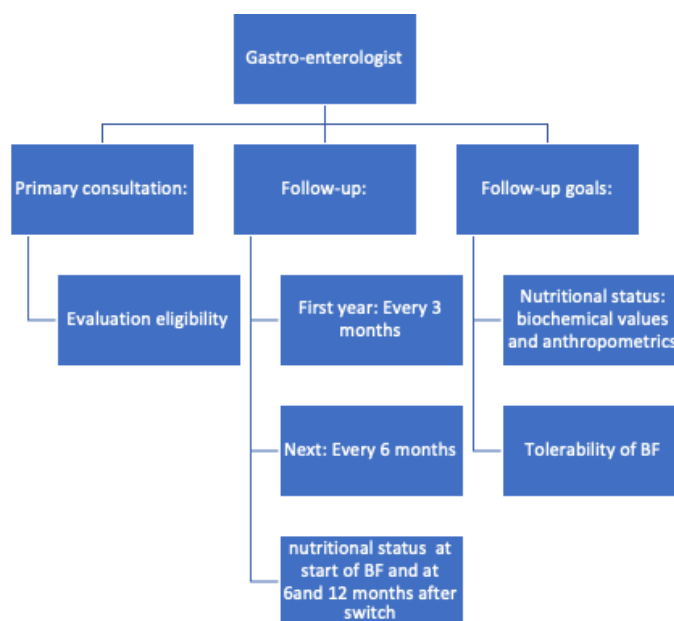


Figure A. — Medical support.

Figure 4. — Follow-up scheme for switching CF to BF

Legenda figure A and B display 2 approaches that need to be followed simultaneously. Figure A illustrates that during the initial appointment guiding the transition to BF, standard advice regarding germ-free and hygienic cooking methods, balanced meal composition, caloric intake requirements, and basic recipes can be provided. Follow-up assessments of anthropometrics and BF composition, including potential adjustments, should occur monthly during the first three months, followed by regular checks every three months if stability is maintained. Figure B outlines the medical support process, beginning with the evaluation of eligibility for BF during the first appointment using criteria outlined in the BLEND position paper. Nutritional status assessments, encompassing anthropometric measurements and biochemical analyses (including full blood count, electrolytes, kidney and liver function, vitamin A/E/D, copper and zinc, and iron status), should be conducted at the outset and at 6 and 12 months post-transition. Evaluation of BF tolerability, involving assessment of its impact on GI complaints and any necessary medication adjustments, should be performed every three months during the first year, followed by assessments every six months thereafter.

in BF is available, given the limited experience in this area. The dietician's role involves guiding parents by providing examples of suitable diets, ensuring children receive a balanced diet, addressing practical concerns, and offering advice on hypercaloric feeding if there is a decline in growth anthropometrics. Therefore, we recommend monthly contact with the dietician during the first three months after the transition to BF, followed by quarterly appointments for the remainder of the first year. The treating physician's main responsibility is to evaluate anthropometric measurements, GI complaints, and nutritional deficiencies during quarterly visits, with blood analyses conducted just before the transition to BF and at 6 and 12 months post-transition.

Conclusion

Our study confirms that transitioning to BF results in heightened parental satisfaction and improved physical and emotional well-being in children. Moreover, it underscores that BF can serve as a suitable alternative to CF. Effective guidance by a medical team experienced in BF is essential for the success of this transition.

Conflicts of interest

The authors declare no conflicts of interest.

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Appendix 1. — Questionnaire for the parents

Dear parent,

Hereby you receive a questionnaire about the use and about your experiences of blended food. There are multiple choice questions, where you can indicate multiple options for some questions (this will be specified). For some questions there is an option to give your own answer, please stay as short and concise as possible. Thank you again for participating and filling in the questionnaire.

General information:

Name of the patient:

gender of the child:

- Boy
- Girl

Age of the child

- ... year (if >1 y)
- ... months (if < 1y)

How old was your child with the start of nasogastric tube feeding

- ... year (if >1 y)
- ... months (if < 1y)

How old was your child with the start of blended food?

- ... year (if >1 y)
- ... months (if < 1y)

How long have you been using blended food

- < 1y
- 1-3y
- >3y

How did you discover the use of blended food as alternative or as combination with commercially available tube feeding?

- via internet
- via friends/family
- via my treating doctor
- via my treating dietician
- via my treating logopaedic
- via my treating psychotherapist
- via patient groups / gatherings
- other:

Which sources of information do you use to gather your information (you can indicate more than one option)

- internet
- dietician
- patient organisations
- literature
- other

Time investment, preparation and administration:

How many hours per day do you spend on preparing blended food

- 0-1 hrs
- 1-2 hrs
- 2-3 hrs
- 3-4 hrs
- more then 4 hours/day

Do you prepare food for multiple days

- yes
- no

If yes: what did you buy?

If yes: can you give an estimation of the budget of your expenses?

If yes, did the health insurance repay any of the invested money?

Can you give an estimation of your weekly budget on the preparation of blended food?

- 0-50 euro/week
- 50-100 euro/week
- 100-150 euro/week
- > 150 euro/week

Does the health insurance repay any of this money?

- Yes
- no

Is the cost of blended food higher then the cost of commercially available tube feeding?

- yes
- no

If yes, can you give an estimation of the price difference on a monthly base?

Growth data:

Are/were there problems with growth (both height growth and weight gain) when using commercially available tube feeding?

- Yes
- No

Have there been any problems with the growth (both height growth and weight gain) of your child since the start of blended food?

- Yes
- No

Were there nutrient deficiencies (e.g. vitamins or iron) when using commercially available tube feeding?

- Yes
- No

Are there nutrient deficiencies (e.g. vitamins or iron) when using blended food?

- Yes
- No

If you answered yes to the above question, do you use dietary supplements or vitamins for this?

- Yes
- No

If you answered yes, which supplements do you use?

Personal aspects

What's the main reason you switched to blended food? You may indicate multiple options.

- To reduce digestive discomfort (such reflux, gagging, vomiting, cramping, bloating, constipation, diarrhea)
- To be able to give home-made food
- To allow my child to participate in feeding moments with the family
- Other:

What is the biggest advantage for you about using blended food? You may indicate multiple options.

- Since using blended food, my child is generally happier
- Since using blended food, my child suffers less from digestive discomfort
- Since the use of blended food, eating is more of a family moment
- Since using blended food, I feel that I am feeding my child in a healthier way

- since the use of blended food I have the feeling I can care for my child in a better way
- other:

Would you recommend it to other caregivers/ parents with children with gastrostomy?

- Yes
- No

Do you notice a change in your child's physical health?

- Yes
- No

If so, what change did you notice in your child's physical health? (You may specify multiple options.)

- More energy
- Less gagging/ vomiting
- Better stool production or less cramps
- Behavioural change
- Other:

What do you think is the biggest disadvantage of blended food?

- A lot of time in preparation
- Blockage of tube
- Financial aspects where blended food is more expensive
- It has not had the hoped-for effect
- Other:

Have you ever thought to (partially) stop blended food?

- Yes
- No

If so, why?

For the following statements, please indicate the box where your opinion is most in line (you may only indicate 1 box).

	Completely disagree	disagree	No opinion	agree	Completely agree
I am satisfied with the use of blended food					
In my opinion, my child looks generally healthier since the use of blended food					
In my opinion my child is happier since the use of blended food					
Since switching to blended food my child has less gagging, vomiting or reflux					
Since switching to blended food my child has less diarrhea					
Since switching to blended food my child has less obstipation					
Since switching to blended food my child has less cramps					
Since switching to blended food I have less problems of tube blockage					
Since switching to blended food eating moments are more a family moment					
Since switching to blended food eating moments are more fun					
Since switching to blended food my family has become more close					

I have little problems with preparing blended food					
I have little problems administering blended food					
In my opinion blended food is better than commercially available tube feeding					
I think my purchased material for blended food is worth the investment					
I think the possible additional cost of blended food is worth the investment					
I think the time I spend making blended food is worth the time					

What did start of blended food do to you as a parent(s)?

- Made you feel better about yourself as a parent
- Made you feel less about yourself as a parent
- It had no impact on me as a parent

What did starting up with blended food for the family do (indicate the most appropriate option)?

- It has brought the family closer together
- It has driven the family further apart
- It had no impact on the family

Appendix 2. — Questionnaire for the dietician

How was the use of blended food introduced to this patient?

- The patient was already using blended food at my first contact moment
- I have advised the patient, after agreement if the medical team, to switch to blended food
- The request for switching to blended food came from parents and not from the nutritional support team (doctor / dietician / speech therapist / psychologist)

How many contact moments are there with the patient?

- 1 x / week
- < 1 x / week
- < 1x / month

Have you had more contact with healthcare providers / parents since the start of blended food from the patient?

- Yes
- No

These contact moments mainly take place via:

- Mail
- Phone
- Physical contact moment via consultation
- Other:

Where can you find recipes / usage tips that you can recommend to the patient?

- Via the internet
- Through conferences
- Through contact with other dietitians
- Other:

Since the use of blended food, have there been more concerns about the nutritional status of the child than with the use of tube feeding?

- Yes
- No

If so, nutritional status concerns include:

- Vitamin deficiency / nutritional element deficiency
- Problem regarding weight evolution and/or height evolution
- Other:

I have recommended that the following products can be used to enrich blended food:

.....

Have there been more gastrointestinal discomforts since using blended food?

- Yes
- No

Do you think it is nutritionally safe for the child to use blended food?

- Yes
- No

Are you satisfied with using blended food for this child?

- Yes
- No

Do you think it would be better for the child to switch back to tube feeding?

- Yes
- No

Appendix 3. — Questionnaire for the physician

Patient Name:

How was the use of blended food introduced to this patient?

- The patient was already using blended food at my first contact moment
- I have advised the patient, after agreement of the nutritional support team, to switch to blended food
- The request for switching to blended food came from parents and not from the nutritional support team (doctor / dietician / speech therapist / psychologist)

How many contact moments are there with the patient?

- >1x/month
- Every 1-3 months
- Every 3-6 months
- Annually

These contact moments mainly take place via:

- Mail
- Phone
- Physical contact moment with consultation
- Other:

Have you had more contact with healthcare providers / parents since the start of blended food from the patient?

- Yes
- No

Has there been a shortage of certain nutrients or vitamins since the start of blended food?

- Yes
- No

If so, nutritional status concerns include:

- A vitamin deficiency / nutritional element deficiency

- A problem regarding weight evolution and/or height evolution
- Other:

Has there been good weight and height evolution since the start of blended food?

- Yes
- No

Have there been any medication changes since the start of blended food?

- Yes
- No

Has the use of blended food led to less medication use by the child?

- Yes
- No

Do you consider it medically safe to use blended food for this child?

- Yes
- No

Since the start of blended food, have you considered switching back to commercially prepared tube feeding?

- Yes
- No
- If you answered yes to the above question, please briefly explain the reason: