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Title: Dietitians' perceptions and experience of blenderised feeds for paediatric tube-feeding

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ABSTRACT

Objective: There is an emerging interest in the use of blenderised food for tube-feeding (BFTF). This survey explored paediatric dietitians' perceptions and experiences of BFTF use.

Design: A web-based questionnaire was distributed to the Paediatric Group of the British Dietetic Association. The survey captured dietitians' personal opinions and experience supporting children on BFTF, and the perceptions of carers.

Results: Of the 77 respondents, 19 were aware of professional guidelines and 63 had never received training on BFTF. Thirty-four wouldn't recommend BFTF and 11 would advise against its use; yet 43 would recommend it to supplement commercial feeds. Fifty-seven would change their perception about BFTF if there were evidence based guidelines. Forty-four would feel confident to support a patient using BFTF. Forty-three had previous experience supporting a patient with BFTF. The main concerns perceived by dietitians, pertinent to the use of BFTF, were nutritional inadequacy (n=71), tube blockages (n=64) and increased infection risk (n=59) but these were significantly higher than those experienced by themselves in clinical practice ($p < 0.001$ for all three). A reduction in reflux and vomiting and increased carer involvement were the main perceived and observed benefits by both dietitians and carers.

Conclusion: The use of these feeds for tube-fed children is increasingly being seen as a viable choice. Dietitians experienced significantly fewer issues with the use of BFTF in clinical practice compared with their self-reported apprehensions in the survey. Well controlled studies are now needed to objectively assess the benefits, risks, costs and practicality of BFTF.

INTRODUCTION

More than 1,300 children are tube-fed at home in the United Kingdom (1). While most of these children will use commercial formulae, there is an increasing interest by health professionals and carers in the use of blenderised food for tube-feeding (BFTF) (2, 3). Recently, the British Dietetic Association (BDA) issued a policy statement, advising its members that BFTF is not recommended (4). Similarly, the European Society for Paediatric Gastroenterology, Hepatology and Nutrition also advised against the use of BFTF, citing as reasons the risks of contamination and nutritional inadequacy (5).

There is little good quality evidence as to the benefits or risks of BFTF, with very few studies reporting on patients' clinical outcomes (6-9) (Table 1). Previous research has reported discrepancies between the estimated and analysed nutritional content of BFTF (10-14) and a recent study, comparing the effect of changing clinical practice from BFTF to commercial formulae for tube feeding, found a significant reduction in the occurrence of infectious complications (6). An observational study in children after fundoplication surgery suggested that tube blockages were not an issue when a wide bore feeding tube was used, and carers reported a decrease in retching and gagging symptoms using BFTF (15) (Table 1).

As parents and carers of children on long-term tube-feeding become more interested in the use of BFTF and treatment moves to a more personalised, patient-centred approach, health professionals responsible for the management of such children will most likely become a source of information and advice. This study evaluated the current perceptions, experiences and training of paediatric UK dietitians in the use of BFTF and presents recommendations for future research.

METHODS

A web-based questionnaire survey was distributed to the members (n~400) of the Paediatric Group of the British Dietetic Association. As no pre-existing questionnaire was available, a questionnaire (available from authors on request) was compiled by academics in clinical nutrition and senior paediatric dietitians from the children's hospitals in Glasgow and Aberdeen, UK, considering relevant literature. The questionnaire was split into four thematic domains:

1. Dietitians' professional role and practice setting.
2. Dietitians' perception of BFTF, including training and clinical care pathways in place for use of BFTF.
3. Dietitians' experiences with patients using BFTF, including issues and benefits observed.
4. Perceptions of patients and their carers on the use of BFTF, as reported by the dietitians.

There were 35 questions, including open-ended questions for respondents' personal comments. The questionnaire's content validity, readability and ease-of-use were additionally assessed by postgraduate nutrition students. Two reminders were sent; after 21 days and two months. After consultation with the local NHS Research Ethics Committee, it was decided that ethical approval was not required for this staff-based survey, as institutional approval would suffice. A prize draw of £100 in shopping vouchers was offered to encourage completion in those participants who supplied an email address; otherwise, the survey was anonymous.

Statistical analysis

Summary statistics are presented as counts and frequencies. Significant differences ($p < 0.05$) in categorical data were assessed by cross-tabulating and performing a binomial McNemar's chi-square test using SPSS v21.

RESULTS

Respondent characteristics

The survey was launched in June 2014 and 83 respondents completed the survey. Incomplete questionnaires (n=6) were removed from analysis. The majority of the dietitians worked in district general hospitals and 30% had more than 50% of paediatric patients on tube-feeding in their current clinical caseload (Table 2).

Guidelines and training on BFTF

A fifth of dietitians (n=19/77) were aware of professional guidelines on BFTF. Four of these referenced the BDA policy statement (4) and five the Parenteral and Enteral Nutrition Group risk assessment template (16). Most dietitians (n=63) stated that they had never received any professional training on BFTF.

Dietitians' perceptions on the use of BFTF

Thirty-four respondents (44%) said they would not generally recommend BFTF and 11 (14%) would advise against it. Two participants (3%) said they would strongly recommend it and 24 (31%) might do so. However, when respondents were asked if they would recommend BFTF to supplement feeding with a commercial formula, 43 (56%) agreed that they might consider BFTF; 18 of these (42%) had previously stated that they would not generally recommend or would advise against BFTF.

Over half (n=44/77) said they would feel very or quite confident to support a patient using BFTF. The proportion of respondents who stated that they would change their perception of BFTF if there was an evidence base or guidelines was high (n=57/77); thirty-four of these had previously stated that they would not recommend BFTF. A small number of

dietitians had previously recommended BFTF (n=10/77), or this was recommended to them or their patient by another member of their clinical team (n=14/77).

Dietitians' experience of use and carers' interest in BFTF

Forty-three respondents had previous or current experience with BFTF. Of those, 40 reported a total of 93 patients (median=2, min-max: 1-10) who had ever used BFTF. The most common route of BFTF was via gastrostomy button (n=34) or tube (n=31). Most of the respondents who supported these patients reported that they would provide some advice on meal planning and preparation techniques (n=34/43); four respondents (9%) said they provided formal training to carers. Of the 43 respondents who had supported a patient using BFTF, 34 had never received any training.

Fifty nine (77%) of the respondents had discussed the use of BFTF with a patient or carer. The perceptions of patients and carers, as reported by the survey respondents (n=59), indicated that over half expressed a positive view of BFTF (n=30/59), with some others expressing mixed opinions (n=23/59).

Dietitians' and carers' perceptions of issues and benefits of BFTF

The main issues expected by dietitians, pertinent to the use of BFTF, were nutritional inadequacy, tube blockages and increased infection risk. However, nutritional inadequacy (p<0.001), adverse nutritional outcomes such as failure to thrive (p<0.001) and weight loss (p=0.004) were also not as commonly seen in practice as expected (Figure 1). Similarly, fewer dietitians or carers than expected had experienced infections (p<0.001) or tube blockages (p<0.001). Five dietitians reported significant adverse effects in some patients using BFTF (Figure 1).

In contrast, the main benefit of BFTF expected by dietitians was increased carer involvement in the feeding of the child, which concurred with that observed by carers ($p=0.4$). A physical benefit anticipated was decrease in reflux and vomiting symptoms, which coincided with the observations of dietitians in clinical practice ($p=0.1$) and with carers' reports ($p=0.8$) (Figure 1).

DISCUSSION

In this survey, the number of dietitians reported as having had clinical experience of BFTF was modest, but more than three quarters had received enquiries from carers about this practice. These findings mirror the rising interest from carers of tube-fed children, and a pressing need and professional duty for dietitians to be able to offer informed advice.

While most dietitians would not recommend BFTF, a majority would be prepared to support a patient using BFTF, more so if used as a complement to commercial feeds. Reluctance to recommend BFTF may indicate lack of training or confidence to support patients who opt to use this mode of feeding, or a cautious attitude from health professionals to implement interventions for which no evidence-based guidelines exist or management pathways are available. Several dietitians indicated that availability of evidence-based guidelines might change their view on the use of BFTF, e.g. *“I would feel confident supporting someone wanting a blended diet if there were adequate evidence-based guidelines in place”*. Recently, the Paediatric Enteral Nutrition Group (PENG) of the BDA has produced a risk assessment template to facilitate safe practice for nutrition support staff with a duty of care to patients using BFTF (16), and a toolkit has been launched by the BDA (17).

Nutritional inadequacy was seen as a potential risk by almost all of the respondents, but this was not often evident in their clinical practice. This is in agreement with the findings of observational studies of patients using BFTF (3, 7, 9, 18), but in contrast to laboratory-based studies where nutritional content of feeds was analysed (10-14, 19) (Table 1). Well-controlled interventional studies with robust assessment of nutritional outcomes are needed to assess the impact of BFTF compared to standard commercial formulae (20).

More than three-quarters of the survey respondents felt that risk of infections might be an issue with BFTF, but this was rarely observed in clinical practice. While there is a risk of

contamination from use of raw food ingredients (21) (Table 1), careful risk assessment of handling practices should mitigate contamination risk substantially (21, 22).

Feeding tube blockages are considered likely to be more of an issue with BFTF than with commercial formulae but respondents and carers alike reported fewer instances of equipment failure than expected, concurring with previous reports (6, 15) (Table 1). Degradation of feeding sets by food components could potentially occur and the Enteral Plastics Safety Group in UK have issued a statement advising against the use of feeds other than those medically approved (23).

A decrease in reflux and vomiting symptoms was a perceived and actual benefit of BFTF over commercial formulae in this survey. This finding is in accordance with previous research in children after fundoplication surgery (Table 1) and may be due to the higher viscosity of BFTF, which slows gastric emptying and thus alleviates dumping syndrome symptoms (15), although this benefit may depend each time on the composition of the individual BFTF preparation.

Increased carer involvement, and integration of the tube-fed child into family mealtimes, was an important reason families chose to utilise BFTF, as was also supported by comments made by the respondents e.g. *“Having foods the rest of the family are having is important”*. Several respondents commented on the need for a degree of awareness and motivation on the part of the patient’s family, as the additional preparation involved could increase the burden of tube-feeding on carers (24).

Although the response rate to this survey is modest, it is likely that people who did not respond were less likely to have come across BFTF, or felt it was not relevant to their practice. This may also mean that the dietitians who completed this survey were those most likely to have experienced a query about, or use of, BFTF; this is reflected by their long

median length of work experience in clinical dietetics. As a result, the actual prevalence of BFTF use, a secondary outcome in this survey, may have been overestimated. However, the high proportion of respondents who had professional experience in supporting a patient with BFTF allowed a comparison of personal perceptions with professional experience.

There are several caveats; the data reported are cross-sectional, and based on recall. No data were gathered on length of use of BFTF or practices employed. Similarly, we explored patient and carer perceptions, from data reported by the dietitians supporting the families. Future studies should directly explore patients' and carers' perception on the use of BFTF.

CONCLUSION

Use of BFTF is increasingly being seen as a viable choice by carers of children on long-term tube-feeding. The findings of this survey represent dietitians' personal opinions and experience of the use of BFTF. There is now an urgent need for well-conducted controlled trials to evaluate the use of BFTF and explore the risks, benefits and costs associated with their use. Such research will provide the basis for evidence-based recommendations.

Contributorship Statement

JA carried out the majority of research activities and statistical analysis and drafted the manuscript. EB, HD, KR designed the study and advised on the survey questionnaire. KG designed and coordinated the study, revised the first draft, offered advice on data analysis. ALL authors approved the final draft for submission.

Competing Interests

KG received speaker's fees from Nutricia and a research grant from Nestle

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Data Sharing Statement

Data may be available on request from the authors.

WHAT IS ALREADY KNOWN

- The use of blenderised food is reportedly increasing among paediatric patients on tube-feeding.
- There is little high quality evidence on the effectiveness and risks of use of blenderised food for tube-feeding.

WHAT THIS STUDY ADDS

- The majority of dietitians are unaware of professional guidelines and most had never received training on blenderised food for tube-feeding.
- Most would not generally recommend blenderised food for tube-feeding but more than half of them would recommend it to supplement commercial feeds.
- Main concerns perceived by dietitians were nutritional inadequacy, tube blockages and increased infection risk but these perceptions were significantly higher than those experienced in clinical practice.

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Table 1: Evidence table of studies on the effect of BFTF for tube-feeding on infection risk, nutritional adequacy and clinical outcomes

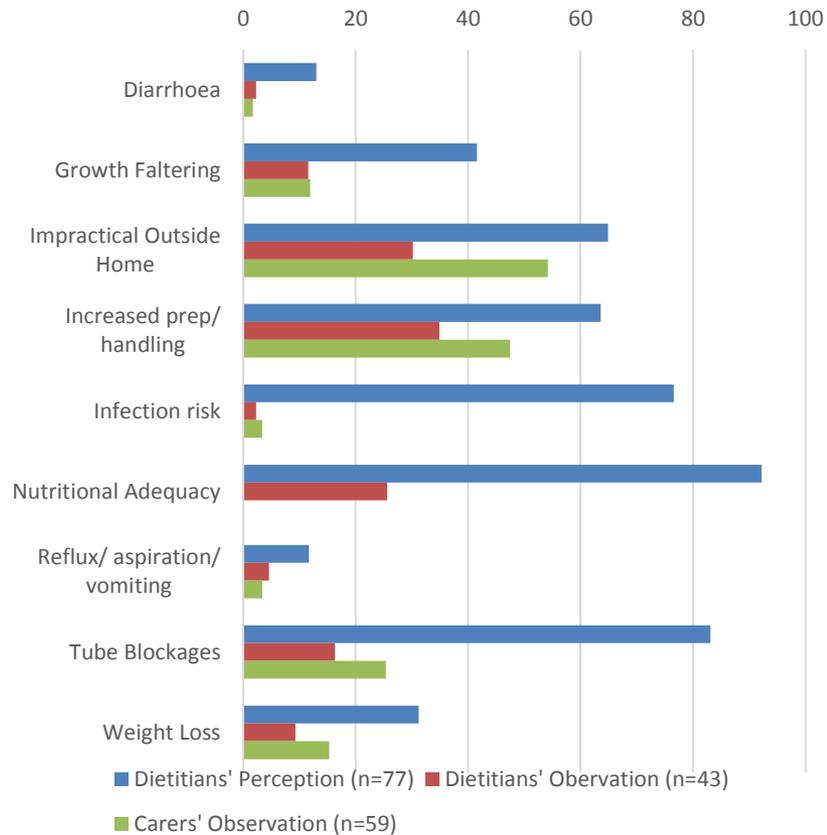
Author/Year	Study Setting	Intervention	Patient Outcomes	Results/Comments
Hurt et al., 2016(3)	54 outpatients on home enteral nutrition; USA	Self-reported reasons and benefits of BFTF use compared to commercial formulae alone	Self-reported gastrointestinal symptoms, weight loss and signs of infection such as fever or nausea.	Reasons for use: more natural, eating like rest of family. Fewer gastrointestinal symptoms compared to those using commercial formulae.
Klek et al., 2014 (6)	142 children in community; Poland	Transition from BFTF to commercial formula (CF) & training/support at point of change	Biochemistry; anthropometry; incidence of infections; number of admissions; length of hospital stay and health costs; data collection retrospectively (BFTF) and prospectively (CF)	Risk of infections, length of hospital stay, number of admission and health costs all decreased significantly on CF; BMI significantly increased
Pentiuk et al., 2011(15)	33 children with post-fundoplication surgery in community; USA	Individually prescribed BFTF using commercial infant foods and according to child's requirements	Anthropometry; carer self-reported gastrointestinal outcomes	29 children gained weight during follow-up; carers reported some decrease in retching and gagging and increased oral intake.
Santos and Morais, 2009 (7)	30 severely disabled children on home enteral nutrition; Brazil	Milk-based and soup-based BFTF	Proportion of stunted/ underweight/ obese children; chemical analyses of BFTF and comparison with prescribed requirements	Stunting increased by 23%; underweight decreased 10% over mean 14-month follow-up; milk based feeds nutritionally more adequate than soup-based BFTF.
Tanchoco et al., 2001 (9)	13 patients with COPD; RCT in hospital; Philippines	BFTF compared with CF for 2 weeks; BFTF more calories than CF	Anthropometry; biochemistry; pulmonary function	No significant differences in outcomes between the two groups
Bailey et al., 1982 (18)	5 hospitalised burn patients >12 y; no control; USA	High calorie, high protein BFTF with supplemental vitamins and minerals, in addition to normal diet	Weight loss; wound sepsis	No statistics given on outcomes; author reported prevention of significant weight loss; dietary analysis of BFTF showed good nutritional adequacy
Kendell et al., 1982 (8)	24 adult hospitalised surgical patients; US	BFTF alone compared with BFTF & nutritional supplement	Dietary intake assessment; biochemistry, anthropometry at 1, 3 and 6 weeks post-operatively;	Mid-arm muscle circumference decreased in unsupplemented group; supplemented patients had a higher protein & energy intakes

Table 2: Respondent characteristics

	Respondents <i>(n = 77)</i>	%
Setting*		
<i>District Gen. Hospital</i>	35	46
<i>Tertiary Hospital</i>	21	27
<i>Community</i>	32	42
<i>Other</i>	3	4
<i>Primary Care</i>	1	1
Region*		
<i>England</i>	59	77
<i>Scotland</i>	15	20
<i>Wales</i>	3	4
<i>Northern Ireland</i>	1	1
Clinical experience, median (IQR) years	16 (10 - 25)	
Paediatric experience, median (IQR) years	10 (5 - 20)	
Proportion of current caseload on tube-feeding		
<i>>50%</i>	23	30
<i>21-50%</i>	18	23
<i>11-20%</i>	14	18
<i>6-10%</i>	15	20
<i>1-5%</i>	7	9

* = multiple responses allowed, some respondents worked in more than one setting or region; IQR = inter-quartile range

Issues



Benefits

