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Determinants in parents' decision to use blended diets with gastrostomy-fed children and young people: A mixed methods study

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Background

Children fed via a gastrostomy are provided with commercial produced formula feeds. They are not offered blended diet (BD) as an alternative, and it is not formally supported in the UK due to concerns regarding nutritional content, contamination and tube blockages. Despite this increasing numbers of families are opting to use BD.

Objective

To discover why parents opt to use of BD with their children and young people who are fed via gastrostomy.

Method

This mixed methods study comprised a qualitative phase of 18 in-depth interviews with parents who were using BD with their child. The quantitative phase comprised a survey of 208 parents, 140 of whom used BD and 68 did not use BD.

Results

The in-depth interviews identified four overarching themes that influenced parents' decision to use BD; loss, conflict, empowerment and quality of life. Responses from the survey revealed differences between those who did and did not use BD in levels of self-efficacy, views about formula feeds, rating of their child's health and stools.

Conclusion

Concerns about formula feeds and less perceived need for it are key determiners in parents' decision to use BD. These views are influenced by

social constructs and individual beliefs and circumstances. Those using BD were more likely to rate their child's stools as being normal and rated their child's health more highly than those not using BD.

Key Words: *Blended diet, gastrostomy, enteral feeding, parental attitudes, well-being, mixed methodology*

Introduction

Blended diets (BD) comprise everyday family meals or other foods blended to a smooth consistency and then passed down a feeding tube. Coad et al (1) recognised that the use of BD has gained momentum despite the availability of commercially prepared and nutritionally complete enteral formulas. The use of BD is controversial with many parents extolling its virtues whilst dietitians and other healthcare professionals (HCP) may advise against its use.

It is acknowledged that there is a lack of understanding about why BD is used, and previous studies have focussed on potential challenges and benefits of BD. (1)(2)

Parental decision to use BD may be influenced by society's views on feeding and food: a study exploring women's attempts to construe their world of looking after and feeding their disabled child concluded that narratives around normalisation are embedded within women's accounts of feeding (3). Similarly the use of BD may support parents' construct of normality. Parents in the study also referred to 'props or cues' of disability including wheelchairs and tube feeding, it may be hypothesised that the use of BD goes some way to reducing the 'cue' of disability around feeding. Another study investigating perceived food-associated health risks amongst the general population (4), found respondents were more concerned with 'modern risks' such as food additives than traditional risks such as bacterial contamination and spoilage. These concerns about additives may reflect those of parents regarding commercially produced formula feeds.

UK Government policies of patient choice and empowerment (5), may also have influenced parents' decision to use BD. A study found that facilitating meaningful choice led to improved engagement and well-being amongst breastfeeding mothers (6).

The aim of this research was to understand what factors contribute to parents' decision to use BD, using in depth interviews and a survey.

Method

A mixed methods two-phase exploratory design was used, with the results of the qualitative phase being used to inform the content of the quantitative

phase. This design provides a more complete understanding of social experiences in little-researched areas (7).

University Research Ethics Committee granted ethical approval was granted for both phases of the project (LCRD.20.26.05).

Qualitative Phase Method

A phenomenological inductive approach was adopted to gain an understanding of the lived experiences of the participants (8).

Participants were parents of a child or young person who was fed via a gastrostomy using a BD. Full inclusion and exclusion criteria are provided in supplementary materials 1. There were 18 participants, recruited through snowball sampling; a technique used when research involves recruiting participants from a very specific population by word of mouth or via networks such as parent support groups (9). All participants were mothers of children and young people aged between 3 and 19 years of age. All children were using BD, 10 exclusively.

Participants were able to choose face to face, online or telephone interviews. Table 1 provides details regarding participants, their child, recruitment method and interview medium.

ID	Parent Age	Parent education	Household income	Age of child	Diagnosis	Age at gastrostomy	Reason for gastrostomy	Reason for BD	Source of Recruitment	Interview Medium
P1	46+	Degree	£76+	14y	Neuro-degenerative disorder	12y	Unsafe swallow	Formula intolerance and vomit	School	Phone
P2	36-45	Degree	£36-50K	3y 8m	Cerebral Palsy	2y 2m	Faltering growth / aspiration	Parental preference	Internet	Online
P3	36-45	Degree	£26-35K	6y	Undiagnosed	12m	Faltering growth	Formula intolerance	Internet	Online
P4	36-45	Degree	£26-35K	13y	Neuro-muscular disorder	9Y	Unsafe swallow	Formula intolerance	Internet	Online
P5	36-45	Degree	£36-50K	7y	Premature	3y	Faltering growth	Bowel movements	Facebook	Phone
P6	36-45	Degree	£51-75k	7y	ASD	1y 9m	Faltering growth	Formula intolerance	Word of mouth	Face:face
P7	26-35	A Level	<£25k	19y	Cerebral Palsy	7y	Faltering growth	Formula intolerance	Facebook	Phone
P8	36-45	Post grad	£36-50K	8y	Cerebral Palsy	5m	Faltering growth	Formula intolerance and reflux	Facebook	Phone
P9	36-45	Degree	£51-75k	3y	Posterior fossa tumour	1y 3m	No swallow	Bowel movements	Internet	Online
P10	46+	A Level	£51-75k	5y	Genetic syndrome	2y	Faltering growth	Reflux and bowel movements	Facebook	Online
P11	26-35	A Level	<£25k	10y	Learning difficulties	6m	Unsafe swallow	Formula intolerance	Hospice /School	Online
P12	26-35	Degree	<£25k	10y	Cerebral Palsy	3y 6m	Fundiplo-cation	Bowel movements	Internet	Phone
P13	36-45	A Level	£26-35K	3y 6m	Genetic syndrome	7m	Faltering growth	Reflux	Hospice	Online
P14	46+	Degree	£76+	3y	Genetic syndrome	4m	Fundiplo-cation/ Reflux	Bowel movements	Facebook	Online
P15	26-35	GCSE	<£25k	9y	Genetic syndrome	8y	Delayed swallow	Parental preference	Hospice	Phone
P16	36-45	Post grad	<£25k	5y 8m	Premature	8 m	Faltering growth	Formula intolerance	Facebook	Phone
P17	46+	Post grad	£76+	3y	Genetic syndrome	6m	Unsafe swallow	Formula intolerance and reflux	Word of mouth	Online
P18	36-45	Degree	£51-75k	12y	Genetic syndrome	1y 4m	Faltering growth	Formula intolerance	Word of mouth	Face:face

Table 1: Demographics of the 18 participants and clinical characteristics of their children

Semi-structured interviews were used to collect the data. An interview guide was developed based upon clinical experience, discussions with other HCPs and a review of the current literature regarding feeding, gastrostomy, disability and BD (see supplementary material 2). This provided the researcher with prompts and ensured all areas of interest were covered during each interview. Interviews ranged from 30 minutes and 90 minutes, all were audio recorded and transcribed by the researcher.

Reflective thematic analysis (10) was used to analyse the data. Coding decisions and a reflective diary were shared and discussed with the co-authors, and the analysis was shared with participants to check it was

representative of their views. Data coding was carried out using Nvivo for Mac version 11.

Qualitative Phase Results

The themes and subthemes from data analysis are shown in Table 2 below

Theme	Subthemes
Loss	Control
	Validation
Conflict	Sources of conflict
	Impact of conflict
	Dealing with conflict
Empowerment	Questioning
	Persistence
	Innovation
	Iatrogenics
Quality of Life	Choice
	Well being

Table 2: Themes and Subthemes from thematic analysis

Loss

Some parents expressed a loss of control when their child initially had their gastrostomy, which was particularly intense if the child had previously eaten orally. P1

“It [feeding] almost became a care thing rather than an enjoyable pleasurable social thing and um I just thought that’s quite sad really.... And I felt in my heart that he was missing out.”

P4 recalled a conversation with her dietitian, which highlights the loss of control.

“He said to me ‘as soon as you’ve got a tube, we’re [dietitians] in control’”.

Parents sought proxy measures of normal parenting practices as a means of regaining a sense of control. Thirteen participants compared the introduction of BD to weaning, and used the terminology associated with weaning

.. introduce one food at a time like you're supposed to wean babies. (P18)

Several parents also expressed a loss of self-validation as capable parents,

and even those who were confident in their use of BD felt they were being judged as P6 explained

Weighing, counting things out so that when the dietitian asked for the food diary I could say to her- you know there were 27 leaves of spinach went in ... X many grams of things, because I was just so determined that I had to do it from a nutritional point of view

Conflict

Several parents described how their decision to use BD had led to conflict and feelings of frustration and isolation.

And it's frustrating that I had to do it on my own, not only completely on my own but against the entire medical establishment. (P18)

There was an acceptance from parents that BD led to greater financial and time costs with the purchase of blenders and preparing the meals. However, discussions around this also led to conflict.

One of them [HCP] was saying you do realise the cost implications of blending food are more than us providing you with milk and I said well that's ludicrous – you don't have a child and not expect to feed it! (P4)

Parents dealt with this conflict in different ways; some became secretive.

I thought if I told anybody I would get into trouble so very quietly at home I would not give him his formula at home and he would have just like some fruit and vegetables. (P12)

Others compromised; P15's child attended school part time as the school would not give her daughter a BD and P5 allowed her child formula feeds at school – saying it was 'less complicated'.

P10 showed conciliation as she spoke about how she wished that she could just get advice from her dietitian, but empathised with the dilemma of dietitians.

Their hands are tied, and some of them will go a little bit further than I guess they are supposed to because perhaps they believe in it as well though they are not able to say.

Empowerment

Parents were able to address problems as they became more confident. P12 described how she dealt with her son's constipation.

So I thought well if it was any of my other children I would just up the fruit and vegetables why can't I do that with xxx? So without really officially telling anyone I gave it a go.

The majority of parents expressed concerns regarding iatrogenic effects of formula – causing their child to vomit, and others described their concern over the content of formula feeds.

They[staff at the hospital] were very proud of the fact that it was made in the lab, never been near a cow and all these sorts of things you know. For me I found that quite difficult because I just don't feel that is very natural. (P13)

Some parents felt the use of formula feeds was over-medicalising their child.

The milk to me felt artificial it was something that she needed when she was very poorly. I completely understood that I had no problems with her having it then but as it became more apparent that it was going to be longer term, I just wanted something that seemed more normal.(P9)

Parents were determined in their quest to use BD.

All the way I have been very much an advocate of xxx's health and if I don't think something is right I will stand up and I'll say no matter who I am talking to.(P10)

Although participants sought information about BD, they found little or no specific advice regarding BD from healthcare professionals. Instead they turned to the Internet with frequent reference to the Blended Diet UK Facebook group as a source of information and support. The irony of this situation was expressed by P12.

I think there's definitely a place for social media but it shouldn't be the first line of "I'm not going to tell my dietician but you know, can you strangers on the internet help me decide what to feed my child"?

Quality of life

This theme explored the relationship between BD and the quality of life of the whole family, encompassing issues of choice and well-being.

In making the decision to use BD, parents appeared to embrace a new normality. P10 described how she felt the offer of BD could help parents come to terms with the need for a gastrostomy.

But if somebody had said to me I know this is really difficult but at the moment she's just not getting enough nutrition, now you'll be able to cook a healthy meal, just pop that in the blender and then you'll know she's well fed and she's not hungry. I would have felt differently.

The integral relationship between social interactions, mealtimes and food was seen as a further aspect of well-being.

It felt quite divisive because we used to have family meals, and xxx would be on a pump and we would be at the table and actually we felt really awkward eating in front of him, it felt cruel because we knew that he'd be thinking well why can't I have that? ... by doing something like the blended diet we could actually open his whole world up. (P1)

Parental stress was another dimension of well-being that was impacted on by BD. Participants described how using BD had led to a reduction in stress for parents of children who were part oral and part tube fed.

I'm not too fussed about pushing the oral thing because I know that she is getting a good balanced diet and I would rather push the other things rather than worrying too much about her eating orally. (P14)

Finally parents highlighted the physical benefits of BD to their child

She took a massive leap in development and I think it's just because she wasn't feeling sick all the time. (P17)

It was like magic. And his bowels improved and his vomiting stopped and his reflux reduced. (P1)

Quantitative Phase Method

A survey was developed based upon the literature regarding BD and the findings of the thematic analysis, and used a combination of validated instruments, and statements rated on Likert scales. The survey took approximately 20 minutes to complete.

The survey was open to all families who had a child or young person with a gastrostomy. It was advertised via a range of networks (see supplementary materials 3). There were 208 respondents, 140 of whom used BD and 68 did not. The unequal group size may be attributed to self-selection bias. The only missing data were for 5 children in the 'age at gastrostomy insertion'. The survey was open for 6 weeks.

The survey was developed and piloted with families who participated in the interviews. Content validity was obtained by sharing it with a community paediatrician, a consultant in paediatric neurodisability and a dietitian. The survey was available online, by email or post, and 207 were completed online, and one via email. Consent was implied through participation (11).

The survey sections included General Self Efficacy rating (12) Beliefs about Medicines Questionnaire (BMQ) (13), Bristol Stool chart rating (14), parent rating of their child's health and quality of life, (see supplementary materials

4).

Data was analysed using SPSS v21 for Mac. A priori value of $p < .05$ was used to indicate statistical significance.

Quantitative Phase Results

There were no statistically significant differences between the two cohorts – those who used did not use BD (Formula users) and those who did (Blended Users) regarding the demographics in Table 3 below

		Formula Users		Blended Users	
		Count	%	Count	%
Parental age group	16-25 years	3	4.4%	6	4.3%
	26-35 years	17	25.0%	41	29.3%
	36-45 years	25	36.8%	64	45.7%
	46+ years	23	33.8%	29	20.7%
Education	Up to GCSE O level	12	17.6%	19	13.6%
	Up to A level	16	23.5%	40	28.6%
	Degree	21	30.9%	43	30.7%
	Post Grad	17	25.0%	29	20.7%
	Other	2	2.9%	9	6.4%
Household Income	£25k	19	27.9%	46	32.9%
	£26 -35k	10	14.7%	28	20.0%
	36-50k	12	17.6%	25	17.9%
	£51-75k	18	26.5%	29	20.7%
	£76+k	9	13.2%	12	8.6%
Sex	Male	6	8.8%	6	4.3%
	Female	62	91.2%	134	95.7%
Ethnicity	White English/Welsh/ Scottish/Northern Irish	57	83.8%	112	80.0%
	Any Other white background	9	13.2%	17	12.1%
	Any other Asian background	1	1.5%	3	2.1%
	White Irish	0	0.0%	4	2.9%
	Any other ethnic group	1	1.5%	2	1.4%
	Any other mixed /multiple ethnic group	0	0.0%	2	1.4%
	Mixed Multiple Ethnic White	0	0.0%	1	0.7%
	Diagnosis	Cerebral Palsy	17	25%	51

	Genetic	19	27.9%	45	32.1%
	Epilepsy	4	5.9%	3	2.1%
	Structural	4	5.9%	12	8.6%
	Physiological	3	4.4%	1	0.7%
	Other	12	14.6%	20	14.3%
	ARFID*/Faltering growth	9	13.2%	8	5.7%
Any food orally	No	33	48.5%	56	40%
	Yes	35	51.5%	84	60%
*ARFID = Avoidant restrictive food intake disorder					

Table 3: Demographics and information relating to participants in questionnaire

Parents who used BD had significantly higher levels of self-efficacy when data was analysed using an independent t-test on the composite self-efficacy score.

Variable		<u>BD</u> (n=140)	<u>Formula</u> (n=68)	<u>t-value</u>	<u>Prob.</u>	<u>Effect size</u> (Hedge's g)
Self Efficacy	Median	38.81	30.96	3.09	.002	.5

Table 4: Self efficacy levels of BD users and Non users (Formula)

The BMQ found parents who used BD were more likely to believe medicines in general are overused. The BMQ, found a significantly higher level of perceived need for formula feeds amongst those parents who did not use BD. Conversely, it showed higher levels of concerns about formula feeds amongst the parents who were using BD

Variable		<u>BD</u> (n=140)	<u>Formula</u> (n=68)	<u>U-value</u>	<u>Probability</u>	<u>Effect size</u> (Cohen's)
BMQ Overuse	Median	114	85	3456	<.001	.05
BMQ Need	Median	79	157	1224	<.001	.37
BMQ Concern	Median	125	62	1888	<.001	.24

Table 5: BMQ results of BD users and non users (Formula) – Mann Whitney U test

There was a positive correlation between ‘normal’ stool rating (15) and the use of BD , which was statistically significant using Chi Square ($X^2(1) = 3.81$, $p = .05$) The effect size was small ($\phi = .14$). These results suggest that children having BD are more likely to have stools in the normal range when compared with those not having BD.

Parents rated their child’s health and quality of life on a 5-point scale ranging from poor (rated 1) to excellent (rated 5).

Variable		<u>BD</u> (n=140)	<u>Formula</u> (n=68)	<u>t</u> <u>value</u>	<u>Probabilit</u> <u>y</u>	<u>Effect size</u> <u>(Hedge’s g)</u>
Health	M	3.25	2.87	3.09	.002	.5
	SD	(1.62)	(4.07)			
Quality of Life	M	3.65	3.36	-1.89	<.06	NA
	SD	(0.97)	(1.1)			

Table 6: Health and quality of life responses of BD users and non users (Formula)

Parents who used BD were more likely rate their child’s health higher than those not using BD. There was no statistically significant difference between the two cohorts in terms of quality of life rating.

Statistically significant variables were further analysed using binary logistic regression. The model explained 54.7% (Nagelkerke R^2) of the variance in BD use and correctly classified 81.7% of cases. The strongest predictor was BMQ concerns (odds ratio 2.3), suggesting that parents who used BD were over twice as likely to express concerns about the use of formula than those who did not. Conversely, the odds ratio for BMQ needs was .32 suggesting that parents who used BD were a third less likely to see the need to use of formula feeds compared to those who did not.

Discussion

The themes of loss, conflict, empowerment and quality of life from the quantitative phase were further explored in the questionnaire through measures of self-efficacy, beliefs about medicines and indicators of health and wellbeing. Some parents when describing their experiences with BD

used the analogy of a journey. They first spoke of their sense of loss. Loss of a child who could be fed or eat orally, and loss of their self-image of a capable parent and an overall loss of control about what was going on in their lives. This loss of control led to conflict between families, HCPs and schools. As parents dealt with this conflict they appeared to become more confident and empowered, seeking ways to establish the use of BD in their child's daily life to improve the overall quality of life for their child and family.

The feelings of loss expressed by mothers appear to be influenced by food discourses in society, such as the suggestion that home cooked food is good and additives and processed food are bad (16). The perception amongst parents having to use formula feeds was that they were giving feeds that were indicators of poor nutrition, may well contribute to feelings of parenting failure and loss of identity as a capable parent.

The conflicts and disagreements described by parents were also described in research by Cowpe et al (17) who found parents would seek solutions and 'take matters into their own hands'. Participants felt there was a greater level of perceived versus actual risk in using BD, a finding also noted amongst dietitians in a study by Armstrong et al (18).

The lack of information and support about BD was also described in other studies with half of parents saying they did not have adequate information about BD (19) and others having to find out for themselves about BD (20). Physical improvements parents attributed to BD including reduction in vomiting, improved anthropometric measures and bowel movements have been documented in other studies (21)(20)(22). Improved concentration and 'happiness' was also attributed to BD as well as more inclusive less stressful family mealtimes. Increases in health related quality of life and higher levels of parental self efficacy were noted in studies when parents proactively improved mealtimes and created a more nurturing environment (23)(24).

The most statistically significant difference between parents who did and did not use BD was the response to the Beliefs about Medicine Questionnaire (BMQ). The BMQ is derived from the Necessity-Concerns Framework (25) which suggests an individual's actions are influenced by the balance of their perceived need for a medication (in this study, the formula feed) versus their concerns about adverse consequences, and that the relationship between

needs and concerns can predict an outcome. The correlation between participants' beliefs regarding needs and concerns of formula feed and the use of BD indicate that parents who use BD have more concerns about formula feeds, relative to their perceived need for formula feeds. High levels of concerns and low levels of perceived need are associated with low levels of adherence to medications and may explain why these parents chose to stop using formula feeds.(26)

Bandura (27) described self efficacy – ones belief in their ability to cope with a given situation based on the skills they have and the circumstances they face. It is not possible to determine if higher levels of self-efficacy amongst BD users served as a driver to try BD, or conversely, whether self-efficacy increased through the experiences of using BD. However, studies have shown that increased self-efficacy in a mother's sense of her parenting efficacy can improve outcomes for their child. (28)(29)(30)

In relation to the Bristol stool ratings, although the statistical effect size was small, the significance to families was great, with parents from the interviews describing how improved stooling had facilitated toilet training and reduced the amount of soiled clothing and bedding that they had to wash.

Finally, the finding that quality of life ratings were similar for the two groups, and may indicate formula feeds suits some families better, and serves as a reminder that parents who opt to use formula feeds should not be vilified or made to feel guilty as was found with in a study of mothers who chose not to breastfeed. (31) The higher health rating for those who were using BD may be due to the improvements mentioned in the interviews or may indicate parents using BD over-estimating the benefits in anticipation that it may lead to BD being offered as an alternative to formula feeds.

There were some limitations in the study. Parents not using BD were not interviewed as it was felt ethically and morally wrong to introduce the idea of BD to families when it is often not supported by HCPs. Only mothers opted to participate in the interviews; further research may consider purposeful sampling to gather the views of fathers. Self-selection of participants for both interviews and the survey may lead to overrepresentation bias of unsatisfied families seeking changes (32). During some interviews parents commented on the impact of BD on weight and growth, however anthropometric data was

not collected. Finally, the survey allowed respondents to remain anonymous, which meant it was not possible to verify their credentials.

Conclusion

Amongst the most significant findings of this research are that parents who opt to use BD saw less need for formula feeds and expressed more concerns about its use. Parents who used BD also had higher levels of self-efficacy. With regards to the impact of BD on their child, parents who use BD report their children have more normal stools.

Results indicate that parents appreciate the freedom of choice offered by BD as well as the benefits it they perceive it offers their children and the whole family. As the use of BD becomes more widespread(1) a greater understanding of these factors is required to enable HCPs to work with families to develop and implement the most appropriate feeding plans for their children. The perspective of parents and some HCPs may be opposing, with parents viewing BD as the best way to feed their child and some HCPs viewing it as a risky and inappropriate means of feeding(18). Listening to and attempting to understand the views of parents who want to use BD seems to be a means of bridging the gap, and enabling HCPs and parents to journey together to learn and understand more about the benefits and challenges of BD.

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Authorship statement

All authors contributed to the study design and production of the manuscript.

Declaration of competing interest

The authors declare no conflict of interest

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