

**An Investigation Into Factors That Affect  
The Decision Of Parents To Use  
Blended Diets With Their  
Gastrostomy-fed Children**

A thesis submitted for the degree of Doctor of Philosophy  
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**Declaration**

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Confirm that the work presented in this thesis is my own.  
Where information has been derived from other sources,  
I confirm that this has been so indicated in the thesis.

Signature..... Date.....

## **Abstract**

Children who are unable to swallow safely, have gastric problems or neurological difficulties may require tube feeding via a gastrostomy to meet their nutritional requirements. Usually commercial formula feeds are used however, more families are opting to use blended diets (BD), which may consist of everyday family meals or other foods blended to a smooth consistency and then passed down the feeding tube. The overall impact of BD is not fully understood and there are varying views amongst professionals involved in the care of those using them.

The aim of this research is to identify the reasons for and implications of using BD, and establish whether there are any differences between parents who do and do not use BD, and the outcomes for children and young people who do and do not use BD.

A mixed methodology is used in the research, with three phases, the first two being qualitative using thematic analysis with data collected from in-depth interviews and blog posts. The information from phases one and two informed the content of the survey used in phase three. The third phase of the research is the quantitative phase. A survey was distributed to families who were and were not using BD. This enabled the researcher to gauge the prevalence of the viewpoints/ themes from the interviews, and to compare views and characteristics of those who were and were not using BD.

The qualitative phase revealed a mismatch between the priorities and perceptions of families and clinicians, which was also identified in the literature. The quantitative phase indicates that parents who opt to use BD have a significantly higher level of concerns about commercial formula and see less need for it. Both phases provided anecdotal evidence suggesting BD have physiological benefits to the children and young people using them. These data are parent-reported, and larger scale studies, with more objective outcome measures are now required.

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## **Impact Statement**

The use of blended diets (BD) by parents of gastrostomy-fed children is not currently sanctioned by the NHS, and yet an increasing number of parents are opting to use a blended diet.

The research reveals that parents of children with complex needs have high levels of self-efficacy. With this attribute comes a sense of empowerment and parents will strive to do what they believe to be best for their child even if this view does not align with the views of experts. The mixed methodology used in the study, and early engagement and on-going involvement of parents in the research has ensured its relevance to a current and growing area of challenge within the healthcare.

This research highlights the consequences of healthcare professionals failing to proactively engage with parents, listening to their beliefs, concerns and wishes with regard to blended diets. Without this there is a danger that parents will make choices in the absence of full and unbiased information. The research shows that the Internet and social media are being used as a source of information in the absence of information from healthcare professionals. Whilst the Internet's potential as a means of both empowering and informing parents is illustrated, the research also highlights the risk that parents may be misinformed or that information they discover maybe inaccurate or even damaging to their child's individual health needs.

The research provides quantitative data that indicates that there are benefits gained from using blended diets, and these initial findings may be used as a platform from which to develop further larger scale studies.

The research has the potential to lead to financial savings to the NHS if less formula feed is prescribed. It will also support the NHS vision of patient-centred care, choice and empowering patients with long-term conditions to take a greater role in the self-management of their conditions.

The research has generated widespread interest and the project has been presented internationally. The research findings has the potential to initiate changes in clinical guidelines regarding the use of blended diets, and ultimately to facilitate greater choice in the foods that can be given to children and young people who are fed via a gastrostomy.

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## **Chapter 1 Introduction**

This chapter introduces the topic of blended diet (BD), and its importance. It states the research aim, questions and objectives prior to providing context in the form of the researcher narrative and philosophical, theoretical and methodological foundations. It concludes by setting this complex and multifaceted area in the context of feeding development, food psychology, feeding difficulties and other theoretical and models perspectives relating to the BD.

### **1.0 Background to the study**

Children, who are unable to swallow safely, have gastric problems or neurological difficulties may be unable to gain sufficient calories and nutrients by oral intake alone. Such children may require tube feeding via a gastrostomy<sup>1</sup> to meet their nutritional requirements. Commercially prepared formula feeds are usually used to feed these children. However, more families are opting to use blended diets. Blended diets (BD) are diets made from everyday family meals or food that is blended to a smooth consistency and then passed down the feeding tube into the stomach.

The use of BD is an area of controversy. Many parents extol the virtues of BD whilst dietitians and other healthcare professionals may be unsupportive and advise against the practice. The British Dietetic Association policy statement (2013) does not recommend the administration of liquidised food via enteral feeding due to the risks such as nutritional inadequacy and tube blockage. Escuro (2014) however has acknowledged that the use of BD has gained momentum despite the availability of commercially prepared and nutritionally complete enteral formulas.

### **1.1 Research aim, questions and objectives**

This research aims to identify the reasons for and implications of using BD, and establish whether there are any differences between parents who do and do not use BD, and the outcomes for children and young people who do and do not use blended diet, by answering the following research questions –

What are the reasons for and implications of using BD?

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<sup>1</sup> A gastrostomy is a surgical opening through the abdomen into the stomach, which allows a person to be fed directly into their stomach, bypassing the mouth and throat.

Are there differences in demographics and beliefs of parents who do and do not use BD?

Do parents who do and do not use BD report differences in terms of health, well-being and stool quality in their children and young people?

The researcher has identified the following objectives, which will need to be met in order to answer the research questions.

I. To identify and explore the reasons that parents opt to use BD, (and to establish if different reasons are identified by data gathered from blogs as opposed to in-depth interviews);

II. To identify perceived benefits using BD;

III. To identify any challenges with regard to the use of BD;

IV. To assess whether differences exist regarding demographics and beliefs between parents who do and do not use BD;

V. To assess whether parents who use BD rate their children's health and quality of life higher than those who did not;

VI. To assess the impact of BD on stools

Objectives I., II., III., will be achieved in phases 1 and 2, whilst objectives IV., V., VI., will be achieved in phase 3.

## **1.2 Importance**

This research is being carried out in the context of an increase in the use of tube feeding, financial constraints, views of families and national policy.

Sharma et al. (2012) report that over the past 20 years the prevalence of gastrostomy feeding in the population of children with neurodevelopmental disorders increased from 5% to 14%. This increase reflects both the increasing number of children with a neuro-disability and the advances made over the last 20 years in gastrostomy feeding compared to non-gastrostomy feeding including better overall health and improved weight gain. Similarly the British Artificial Nutrition Survey (BANS) Report (Smith et al., 2011) examined figures relating to the amount of formula feeds being prescribed to children. Between 2005 and 2010 there was an estimated 40% increase (11,800 to 17,000) in children who required tube feeding within the UK.



A 2009 NICE report on medicines adherence found that approximately half of medications prescribed for long-term conditions were not taken as directed. The report added that adherence presumes an agreement between HCP and patient about the HCP's recommendation, (which may not be the case with formula feeds). If the NICE findings are applied to formula feeds, which are a form of prescribed medicine, this represents a significant waste of resources to the NHS. Estimates put the cost of enteral feeding for a gastrostomy fed patient at between £20 and £45 per day (Holmes, 2013; Wright, 2013).

Studies such as those by Meral and Fidan (2015) and Petersen et al. (2006) investigated feeding difficulties in specific cohorts of children. The studies also shed light on the impact that feeding difficulties have on children and their families. Much of this impact relates to quality of life, and emotional and psychosocial well-being. Meral and Fidan found that high levels of feeding problems correlated with a decreased quality of life while Peterson et al.'s study reported that families generally had a negative response to gastrostomies.

NHS policies such as the 'Choice Framework' (2016), describe the mandate for providing patient choice. 'Liberating the NHS: No Decision About Me Without Me' (2012) emphasises the determination to place the patient at the centre of decision-making and 'New Care Models: empowering patients and communities' (Jones, 2015) highlights the resolve to develop approaches that facilitate self-management and personalised care. True adoption and implementation of such policies should facilitate the potential of parents to be able to use BD to feed their children if that is what the parents themselves want.

### **1.3 Researcher's Narrative**

The Scottish Executive defined the role of an Allied Health Professional (AHP) as preventing dependency, facilitating independence and supporting individuals and their families to live healthy fulfilling lives (The Scottish Government, 2012).

As a speech and language therapist with over 25 years of experience as a clinician and manager I am aware of the importance and value of holistic, patient-centred care. By working with families to understand their priorities and goals, I have been able to provide services that meet their needs rather than services into which families

have to fit. Whilst working in the field of paediatric dysphagia<sup>2</sup>, I became increasingly aware of the complex psychosocial issues faced by families whose children required a gastrostomy. My clinical practice was revealing a conflict between clinicians and families born out of a disparity between their respective priorities. I wanted to understand more about what I was witnessing –that is parents opting to use BD - a feeding method that cost them more in time and money and that was not advocated by clinicians. I was aware of ethical dilemmas faced by clinicians. For example parents would confide in their speech and language therapist that they were using BD but did not want to tell their dietitian.

I began to explore external factors that may help to explain the use of BD, such as social media and influence from the USA, with some evangelical proponents of BD. I also considered how the guidance from British Dietetic Association not to use BD directly contradicted the NHS drive towards patient choice, person centred care and self-management.

More recently as a commissioner for children's community services, my belief in the need for co-production of services was reiterated, alongside the need to commission cost effective services within a defined financial budget.

Now, as a researcher I am aware of how my background, beliefs and values influence my choice of methodology and interpretation of the data I have compiled. As the researcher I was careful to keep my views as neutral as possible, and to use open questions, in order to reduce the risk of participants changing their responses to conform with what they perceived to be the research goals.

## **1.4 Philosophical, Theoretical and Methodological Narrative**

### **1.4.1 Philosophical Foundations**

This study draws on epistemology, a branch of philosophy that investigates the origin, nature, methods and limits of human knowledge, and on social ontology as it is concerned with the social reality of the participants (Howitt & Cramer, 2011). The research uses a constructivism paradigm, that is there is no single reality, and reality is socially constructed by people according to their individual perceptions. Axiology,

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<sup>2</sup> Dysphagia refers to a difficulty in swallowing

the study of values, is an important concept as it contributes to the understanding of influences of society and medicine on participants in relation to their decision to use BDs. The use of BD is a controversial area (Coad et al., 2016). In using BD, parents are acting against the advice of health professionals and in some instances evidencing how they perceive formula feeds to be harming their children. This research is concerned with the study of human behaviour in relation to the use of BD. The philosophical perspective of existentialism provides a context for the study. Proponents of existentialism include the German philosophers Martin Heidegger and Edmund Husserl. Existentialism emphasises the existence of the individual to define their own meanings within life and to attempt to make rational decisions in what can be an irrational world; it is about acknowledging that there is no 'handbook' to making sense of the world (Winston, 2015). Instead individuals must use their freedom of choice to make decisions for themselves; it is this decision-making and the rationale behind it that is to be investigated in relation to the use of BD.

#### **1.4.2 Theoretical Framework**

The complexity of the motivations behind parent's decisions to use blended diet cannot be fully explained by any one single theory. Abraham, Sheeran, & Johnston, (1998) suggested that a range of overlapping theoretical models can provide insight into behaviours around health. Several theoretical frameworks have influenced this study, however there are three key overarching models social cognition theory, self-determination theory and self-regulation theory.

Social cognition theory, suggested that a portion of a person's knowledge acquisition is related to how they relate to and observe others within social interactions and experiences. Self-efficacy was developed by Bandura (1977), and was part of his social cognition theory. Self-efficacy involves a complex interface between knowledge and beliefs, social environment and behaviour. Those with high levels of self-efficacy (i.e. who believe that they can perform well) are more likely to see difficult tasks as challenges to be mastered rather than avoided. Bandura cited four sources of self-efficacy as mastery of experiences, verbal persuasion, affective state and vicarious experience. It is likely that increased self-efficacy may be evident in parents who succeed in using BD with their child, whilst the accompanying positivity

they experience as they become more proficient in their use of BD improves their affective state.

Self-determination theory (SDT) (Ryan & Deci, 2000), is a framework that facilitates the study of human motivation and personality. SDT emphasises the importance of the motivations behind choices and actions, and explains how these actions pertain to -

I. Relatedness, being the desire to interact with, be connected to, and experience caring for other people;

II. Autonomy, being the sense of free will when doing something based on one's own interests and values; and

III. Competence, being the desire to control and master the environment and outcome.

The motivations of those parents who use BD will be considered in relation to these three basic human needs.

Relatedness may be used to explain the decision of a parent to use BD. The ability to feed and nurture their child with real food rather than a prescribed formula feed meets the need of a parent to care for their child. Autonomy enables a parent to decide what they believe to be best for their child, thus opting to use BD fulfils this need. The actions of parents surrounding BD are likely to be influenced by emotions of guilt about not being able to feed their own child orally, and the subsequent need for a gastrostomy. Grief over the loss of the 'normal' child and their perceived inability to feed their child normally challenges a parent's perception of competence. It is important to contextualize the psychological meaning of feeding within the sociocultural context. Having a gastrostomy will have challenged the parents' internalised representation of social norms around nurturing and feeding their child. According to SDT, being told to feed a child with a prescribed formula feed would be experienced as controlling rather than autonomous, and as a result, could undermine a parent's behavioural regulation and motivation (Ryan & Deci, 2000). In contrast, autonomously derived goals such as 'being able to feed my child with real food' better reflects a parent's sense of volition and personal importance. Such an intrinsically motivating act would result in better behavioural participation (Ryan & Deci, 2000).

Self-regulation theory describes how an individual controls what they think, do and say in order to be the person they want to be. There are four components of self-regulation (i) standards of desirable behaviour, (ii) motivation to meet those standards, (iii) monitoring of situation and thoughts that proceed breaking the standards and (iv) willpower to control urges using inner strength (Baumeister & Vohs, 2007). The self-regulatory theory in the context of health beliefs suggests that when a person perceives a threat to health they may develop two parallel, yet interrelated, representations of the stimulus: cognitive and emotional. Health behaviours are shaped by either or both of these representations (Leventhal, Leventhal, & Contrada, 1998). This may suggest that for parents who view formula feeds as a threat to their child's health, their decision to use BD may be influenced at a cognitive and emotional level. Similarly the Health Belief Model (HBM) (Rosenstock 1974) assumes that people are generally rational in their thoughts and actions. It suggests that people will take the best health-supporting action if they feel that it is possible to address a negative health issue, they believe that taking the proposed action will be effective in addressing the issue; and they feel able to take the proposed action.

These theoretical perspectives will be considered in greater detail and applied to the discussions in chapter 9.

#### **1.4.3 Methodological framework**

The roots of the study are in phenomenology as it concerns an attempt to understand the parent's lived experience of blended tube feeding.

Human behaviour cannot always be predicted or controlled by scientific method and distilled to quantifiable data and logic. Why would parents reject an easily administered, nutritionally complete feed, which is free on the NHS in favour of a regime that involves going against medical advice, costs them more in terms of monetary value and preparation time and does not give the assurance of being nutritionally complete? Positivist methods of scientific research cannot grasp the subjective emotive nature of feeding. Phenomenology addresses the concept that a person's life-world shapes the interpretation of an experience.

A mixed methodology is used in this study. Tashakkori and Teddlie (2003) suggest that qualitative and quantitative research can be viewed as being on a continuum.

Denzin (1988) contends that mixing the two approaches enhances the validity and reliability of a study. Coleman (1990) suggests that mixed methodology provides a more complete understanding of social experiences by using a qualitative approach to look in-depth at themes in relation to their impact on individuals, and a quantitative approach to look at the prevalence of these overarching themes and any significant correlations between themes. In this study, the in-depth knowledge of social contexts acquired through qualitative research is used to inform the design of survey questions i.e. the information from interviews and blog analysis informed the content of the questionnaire in phase three.

In this research, phases one and two will have a constructivist paradigm using qualitative research methods, and phase three will take a positivist view and use quantitative methodology. A positivism paradigm relating to quantitative studies contrasts with the constructivist paradigm of qualitative studies. Positivism may be viewed as the world of testing hypotheses and one in which researchers exist apart from their data (Cupchik, 2001). Conversely constructivism views reality as subjective and experiential and the researcher interprets the responses of the participants (Guba & Lincoln, 1994).

This three-phased research study will create an understanding of the multifaceted reasons that underpin how a parent's decision to use BD will be achieved.

### **1.5 Blended Diet: Setting the scene**

To recap, the aim of the research is to identify the reasons for and implications of using BD, and establish whether there are any differences between parents who do and do not use BD, and the outcomes for children and young people who do and do not use blended diet, There are a myriad of factors that may relate to the use of BD. Following a brief introduction to BD this section will provide context by presenting the myriad of issues, regarding normal feeding development, psychosocial elements of food, and feeding difficulties all of which may influence parents' decisions to use BD. The section will conclude with an overview of theoretical frameworks that may assist in understanding parents' decision to use BD.

### 1.5.1 Blended Diet

BD is defined as the administration of blended foods and liquids directly into the stomach via the patient's feeding tube. Historically, these types of enteral formulas have been called 'blended diet', 'blenderized feeding', 'blended formula', or 'homemade blended formula' (Escuro, 2014). The British Dietetic Association (2013) refers to BD as 'liquidised food via enteral tubes'. For some, BD may be deemed as only blending family foods and giving no commercial formula, whilst others may combine the use of blended family foods and commercial formula.

The widespread use of commercially produced formula feeds grew dramatically in the 1970s with the development of more disease specific formulas (Dudrick & Palesty, 2011). At the turn of the century it was suggested that *"commercial feeds have virtually eliminated blenderized feedings in the developed nations of North America and Europe"* (Sullivan et al., 2001, p.271).

However, patient groups and some clinicians have begun to question the effect of the use of formula feeds on the gastrointestinal system and the physical and psychosocial health and well-being of patients (Hurt et al., 2015; Johnson et al., 2013; Bobo, 2016). Brown (2014) stated that commercially produced formulas do not contain the range of components such as antioxidants and bioflavonoids. Such components cannot be added to commercial formulas due to legislation restrictions and a lack of knowledge around safe levels of usage. In Canada, Siden et al. (2009) found increasing intolerance to formula feeds amongst a population of children with life limiting conditions. Although it is acknowledged that such children may have particularly complex medical needs that could impact on their tolerance levels, other studies with broader cohorts of children have also reported issues around intolerance on formula feeds (Johnson et al., 2015). These studies which questioned aspects of formula feeds have in turn led to an upsurge in the use of BD (Coad et al., 2016).

In 2013 the British Dietetic Association (BDA) issued a policy statement; its first recommendation was *"At the present time, The British Dietetic Association (BDA) does **not** recommend the administration of liquidised food via enteral feeding tube due to the risk to nutritional adequacy."* (British Dietetic Association, 2013, p.3)

However, the BDA recommendations go on to discuss how to manage situations in which the patient (or parent) wishes to use BD. The BDA has produced a risk

assessment template and professional guidelines to support the dietitian in such circumstances. It should be noted that the Royal College of Speech and Language Therapists have not produced guidelines or a policy statement regarding BD.

Gaps in the evidence base regarding the impact of BD on the health and well-being of the children who receive them and upon the carers who feed the children were reiterated Coad et al. (2016). Similarly, the nutritional implications of BD are not fully understood and there is a mixed consensus regarding the use of BD amongst professionals involved in the care of those receiving it. Chapter 2 will provide a comprehensive review of the literature regarding BD using a peer reviewed scoping review written by the researcher.

### **1.5.2 Feeding Development**

Few people would disagree that feeding is a fundamental and natural part of bonding. Feldman et al. (2013) studied the impact of early skin-to-skin care on aspects of child development over a 10-year period. The study concluded that a child's physiological regulation, executive functioning and behavioural control may be shaped by early maternal–infant contact. High levels of parental self-efficacy are associated with improved feeding (Danaher,, Fredericks, Bryson and Agrad 2011). Similarly Swanson et al., (2012) in an investigation into feeding preterm babies suggested that mothers who are successful in engaging with their babies in early feeding behaviours may also be more able to develop other general maternal self-efficacy behaviours, and failure to do so could lower self-confidence and increase psychological distress.

Swanson et al.'s findings have parallels with findings that may be expected in mothers of children who are gastrostomy fed, such as loss of autonomy, and a searching for normality. Swanson also described the importance of providing breast milk for increasing maternal confidence. Again clear parallels could be drawn with mothers who opt for BD as it enables them to make meals for their tube-dependent child. They also found that women actively constructed opportunities to develop ownership, control, and confidence in relation to interactions with their baby; again clear parallels with mothers opting for BD as the act of choosing and preparing the ingredients of the BD provides them with ownership and control of their child's



feeding. The positive experiences described by mothers included love and contentment when they could provide breast milk which in turn served as self-validation, a part of self-efficacy. Again mothers who can prepare their own BD may experience this self-validation. Mothers in the study sought new skills around tube feeding and other skills required to look after their pre-term baby that also reinforced self-efficacy through mastery of knowledge and skills. Mastery of knowledge and skills is achieved by mothers who opt for BD as they are able to feed their child with food that they have prepared and in addition may see physical improvements in their child such as the reduction in gagging and constipation cited in the study by Pentiuik et al. (2011). In Swanson's study emotional and technical support from staff facilitated the development of self-efficacy. However, negative comments concerning expressing milk and inconsistent advice were both cited as being detrimental to self-efficacy. Anecdotal evidence from conversations with parents who have opted for BD and from social media BD support groups indicate that mothers who opt to use BD face both negative comments and inconsistent advice from some professionals involved in their child's care. The study concluded that behavioural change techniques could be used to improve maternal self-efficacy.

Maibach and Murphy (1995) consider self-efficacy in relation to health promotion, and suggest that commitment, resourcefulness and perseverance is required to achieve success. Albarran and Reich (2014) cite numerous studies that have found mothers with higher self-efficacy positively influence their child's development. Albarran and Reich go on to surmise that increasing a mother's knowledge about child development in turn increases their self-efficacy for parenting, which may ultimately improve outcomes for the child. Machalicek et al. (2015) also suggested that improving parental optimism and self-efficacy in their ability to meet their child's needs, improved outcomes for both parents and the child.

Thus if as Swanson et al. propose, that behavioural change techniques can improve self-efficacy, and as Albarran and Reich and Machalicek et al. suggest, maternal self-efficacy can improve outcomes for a child, the research project will explore whether there are any correlations between levels of self-efficacy and parents' decision to opt to use BD.

The importance of mothers talking to their child was reiterated in a study by Radesky et al. (2015). The study investigated the impact of parents using mobile devices during mealtimes. Radesky et al. found that mothers who used mobile devices initiated fewer verbal and non-verbal interactions and provided less encouragement for their child to eat. This relationship was strongest during parent–child interactions during eating in particular, showing a protective effect on child health outcomes, which have been attributed to the positive family communication, and emotional connection that mealtime routines allow. The relevance of this study was associated with numerous studies (Spagnola, 2007; Snow, 2006; Hale, Berger, & Le Bourgeois, 2011; Muniz et al., 2014) that have linked involvement in family routines such as mealtimes, story time and reading to improved cognitive outcomes and social emotional health.

Fiese et al. (2012) conducted research around the importance of mealtimes in terms of understanding childhood obesity. They acknowledged that the fact that families eat together cannot explain why shared family mealtimes appear to protect children from unhealthy weight gain. They also acknowledged that the effects of shared family mealtimes are complex and must take into account the socioeconomic and cultural context. However, Fiese et al. did find that families with a child of a healthy weight spent more time on engagement during meals and considered mealtimes important compared with families who had an overweight child.

The findings of the above studies illustrate the complex issues surrounding the development of feeding and eating that goes beyond the physiological need for nutrition, and in turn may have some bearing on the decision of parents to use BD.

### **1.5.3 Psychosocial Aspects of Food**

There is more to food and eating than satiation of biological needs. Social, cultural, historical, economic and political factors affect how we perceive food and eating. Germov (1997) suggests that an increase in the availability and variety of foods has led to anxiety and confusion, with food customs and traditions being eroded. He also describes contradictory discourses around food; of oral pleasure and satiety versus displeasure through feelings of bloatedness and indigestion from overeating. Similarly, the paradox of health versus illness, where food can be a source of energy and well-being but can also lead to ill-health through obesity, and poor nutrition.

Germov also discusses the interface between food and women. Citing research into domestic violence, it was found that incidents often took place at meal times due to perceived failure of the 'woman's role' of feeding her family. He also suggests women's eating patterns are viewed as a public issue, with an image of slimness as desirable being created by the media. Germov goes on to suggest that denying oneself food is seen as a good trait in a woman. More recently, a small study of 50 women in the US found that eating food that was perceived as unhealthy increased body image dissatisfaction. The degree of dissatisfaction was greater for those defined as restrained eaters i.e. who were concerned about their weight and shape (Hayes et al., 2011). Further burden has been put on women with the childhood obesity agenda, where the media often present obese children as victims of poor parenting particularly by the mother (Zivokic & Warin, 2010).

The final aspect of food psychology considers the notion of food risk. These risks can be considered as traditional (contamination, food poisoning etc.) and modern (food additives, pesticides etc.). A study investigated personal characteristics associated with perceived food associated health risks (Buchler, 2010). It was found that respondents were more concerned with modern risks such as food additives, with women, individuals with a higher education and older people being more highly represented in this belief. They concluded that their findings supported the suggestion that different groups hold different concepts of risk. This is a concept that will be explored in further detail in chapter 9.

This section has used the literature to illustrate the complexity of physical and social aspects of feeding and food within the general population. The multiple food discourses may leave individuals at the 'best of times' feeling overwhelmed and confused. When these food discourses are applied to feeding a child with complex needs the feelings may be magnified for a parent not able to feed their child as they would like or as expectations demand leading to a loss of self belief and guilt.

#### **1.5.4 Feeding Difficulties**

This section will consider prevalence, parental perceptions and impacts of issues relating to feeding and eating difficulties, and may in turn provide some insight into the motives of parents who opt for BD.

#### **1.5.4.1 Prevalence of feeding difficulties**

Over the last 20 years the prevalence of gastrostomy feeding in the population of children with neurodevelopmental disorders increased from 5 to 14% (Sharma et al., 2012). The British Artificial Nutrition Survey (BANS) report collected this data until 2011 but has not done since as fewer establishments returned figures meaning accurate data could not be compiled (Smith et al., 2011). Sharma et al.'s findings appear to reflect both the increasing number of children with a neuro-disability and the benefits of gastrostomy feeding such as better overall health and improved weight gain. Rogers (2004) reported that children with severe cerebral palsy who are fed orally have a slower rate of weight gain and a higher prevalence of growth failure compared with children fed via a gastrostomy.

#### **1.5.4.2 Parental perceptions and beliefs around feeding difficulties**

Cowpe et al. (2014) asked the parents of children with dysphagia about their views of their child's multidisciplinary feeding team (MDT). All 14 interviewees wanted to be involved in their child's care through working closely with the MDT. The study also highlighted the importance of holistic child centred care to families, and the negative effect on their quality of life and well-being when it is absent. Negative experiences included parents feeling that they were not being listened to and professionals having different priorities to them. An example of this was the strong focus on health and risk versus the parent's perceived priority of quality of life and emotional well-being. Positive experiences were cited when parents had good quality information, which facilitated informed decision-making. These findings will be taken into account by the researcher when devising the interview guidance schedule.

Non-compliance with swallowing recommendations is a well-documented phenomenon. In a study by King and Ligman (2011) actual patient non-compliance was found to be much higher than the estimations given by speech and language therapists. Reasons for non-compliance included dissatisfaction with modified food consistencies and taking a 'calculated risk' regarding the consequences of not following recommendations. These reasons could equally be applied to behaviours of parents who opt for BD; they may be dissatisfied with the formula feeds and take a calculated risk regarding the impact of not using a 'nutritionally complete' feed.

Colodny (2005) suggested that because dysphagia can lead to a sense of loss of control, non-compliance might serve as a coping mechanism for some patients. In the case of parents opting for BD, non-compliance with 'prescribed' formula feeds may be viewed as a way of regaining some sense of control with feeding their child.

A study was carried out to explore women's attempts to construe their world of looking after and feeding their disabled child. The study concluded that narratives around normalisation are embedded within women's accounts of feeding (Craig & Scambler, 2006). The study also described how a parent's notion of 'good mothering' has to be reconstructed with regard to feeding when a child requires a gastrostomy. This may suggest that the use of BD helps support parents' construct of normalisation. Parents in the study also referred to 'props or cues' of disability including wheelchairs and tube feeding. Again, it may be hypothesised that the use of BD goes some way to reducing the 'cue' of disability around feeding.

#### ***1.5.4.3 Effects of feeding difficulties***

Heyman et al. (2004) looked at the economic and psychological costs faced by the parents of children with chronic disorders. In the study 50 children were fed via a gastrostomy while the remaining 51 were not. The study found that children fed via gastrostomy required twice as much care time compared with those without a gastrostomy. However, there was no difference between the groups in measures of depressive mood or quality of life. It is widely acknowledged that the preparation of BD is more time-consuming than using commercially produced formula feed.

Several studies looking at feeding difficulties in specific cohorts of children shed light on the impact of these difficulties on both children and their families. Many of these impacts relate to quality of life, and emotional and psychosocial well-being.

Carter et al. (2013) examined the impact of having a child with Potocki-Lupski syndrome. Potocki-Lupski syndrome is a relatively recently identified genetic syndrome that has a wide range of implications on health, including feeding difficulties, motor delay, cardiac anomalies, cognitive impairments, communication difficulties and autism. At the time of the study there were less than 100 diagnosed cases worldwide 58 of whom were contacted to be part of the study, and 29 (53%) participated. The study examined the impact of these health issues on the stress and well-being of parents. When compared to children with no feeding difficulties, the

study found that regardless of severity, feeding difficulties led to decreased scores in the dimensions of daily activities, family relationships and overall family functioning. This finding was in part attributed to the extra time required to feed a child with feeding difficulties, whether related to oro-motor skills (i.e. taking longer to be fed) or to the management of tube feeding such as checking pH levels before giving nasogastric feeds.

A study by Meral and Fidan (2015) investigated the impact of feeding difficulties in children with autistic spectrum disorders on health related quality of life (HRQoL). They found higher levels of feeding and mealtime problems to be predictive of a decreased HRQoL. However, the use of feeding strategies to address feeding and mealtime issues leads to an increased HRQoL. It should be noted that the study did not attempt to discover if the feeding strategies were effective, instead emphasizing the importance of the proactive use of strategies. This notion will be further explored in the section covering self-management. Their conclusion that feeding problems are predictive of the quality of life and that enhancing parental practices may improve the quality of life, may also be true that ameliorating a parents' control with regard to tube feeding (by use of BD) may improve the QoL rating.

Another group of children who are likely to experience feeding difficulties are those with cerebral palsy. An understanding of parents' perceptions of gastrostomy feeding may shed some light on the selection of BD. Petersen et al. (2006) undertook a study using a qualitative methodology to examine parental perceptions of feeding and adherence to feeding recommendations. In the study, 26 parents of children with cerebral palsy and gastrostomy-fed were interviewed. Of the 26 participants, 18 had a negative response to the suggestion of a gastrostomy for their child. Negative statements about the gastrostomy included it being seen as "unnatural" or as an "additional disability". The study also reported that many parents were more reluctant to let their child have a gastrostomy (a relatively short, safe and reversible operation) compared with having a more invasive irreversible operation. Although not explored in detail, 14 parents reported putting food and drink down their child's tube in addition to the prescribed formula. Nine parents had been told that their child should not have any food orally, however, five of them admitted to giving some food orally. One mother said "*I may stick mashed potato in her mouth. Just a little taste so she won't*

*feel left out*". The same study also reported themes around the nurturing experience associated with feeding, and the use of a gastrostomy was seen as a 'failure of the caregiver' to provide this. Another theme identified related to the pleasure of eating. Parents saw the provision of food to their children as being extremely important. 50% of the parents who were able to give their child some food orally reported that, despite their child being distressed during feeding, they continued to give food orally. This illustrates the significance of food and feeding on parental behaviours, and in turn may be significant for understanding more about the reasons why parents opt for BD.

### **1.5.5 Theoretical and conceptual perspectives**

Section 1.4.2 presented the three main theories, which shaped the research (Horne et al, 1999). Formula feeds are a form of prescribed medicine and may be perceived to contain unnatural chemicals. A further point of interest was that Horne found that negative views of medication focused on potential harmful effects rather than a lack of efficacy or benefit. Again with regard to commercial formula feeds discussion has tended to focus on the negative effects rather than questioning whether the feeds were beneficial.

Horne (2006) describes the subtle differences between the terms compliance, adherence and concordance. He suggests compliance describes the extent to which the patient acts in accordance with the HCP. Adherence also takes into consideration the will of the patient to behave in accordance with the HCP, and implies the need for some level of agreement from the patient. Finally concordance refers to a consultation between HCP and the patient and implies an ethos of a shared decision-making. Horne suggests that most people are non-adherent at times, and Porteous et al. (2010) suggest that beliefs about medicines are most likely to be associated with intentional non-adherence (i.e. choosing not to adhere to advice).

Horne's work illustrates the importance of practitioners considering the beliefs and concerns of patients (including parents), and perhaps attempting to address negative views about interventions such as the use of formula feeds. As Horne and Clatworthy (2010) indicated there is a range of ways patients' behaviour can differ

from recommendations, which in turn may impact on clinical outcomes.1.5.5.3 Self-management, and the deficit model

There is no agreed definition of self-management, but it can be described as a means of facilitating individuals to learn more about their long-term condition and in turn to enable them to make more informed decisions that will maintain or improve their health (Barlow et al., 2002). Self-management is based upon the assumption that an individual's own priorities/aims/goals are what are most likely to motivate them to change their behaviour (Lonsdale et al., 2012). A systematic review of 184 studies of self-management in long-term health conditions found that the use of self-management could improve the efficiency of health services without compromising patient health outcomes (Panagioti et al., 2014).

In 2000 the NHS plan suggested that the association between the NHS as an organisation and patients was too hierarchical and patriarchal and that it still reflected its original values of the 1940s (Department of Health, 2000). An early version of self-management was the expert patient programme in the NHS (Department of Health, 1996). This grew from a realisation that a purely technical, biomedical approach to health care was not effective, and acknowledged the need to take a phenomenological approach in order to appreciate the impact of an individual's social circumstances. The Government's consultation exercise published by the Department of Health "No decision about me without me" gave further credence to patient led policies and self-management (Department of Health, 2012).

The deficit model blames public scepticism or hostility towards science and technology on the public's lack of knowledge about science and research and suggests that experts must 'put this right' (Ko, 2016). This is contrary to the concept of self-management, and Latour (1988) criticised the deficit model, and suggested that the public were becoming more proactive, generating their own priorities; "*The patients did not wait for results to trickle down into their daily lives. They took over. They tailored a science policy adjusted to what they perceived as their needs.*" (Latour, 1998, p.208)

Parents who opt to use BD are challenging the deficit model theory, indeed they may have a greater knowledge and understanding of the issues and any risks involved in BD than some health professionals. Evidence suggests that the growth in the uptake



of BD has been fuelled by the use of the Internet and social media, as parents self-manage their children's feeding (Coad et al., 2016).

#### ***1.5.5.4 Models of Disability***

Retief and Letšosa (2018) describe three main (Shakespeare, 2002) ability and their origins. The oldest model of disability, the 'Religious model' was founded upon moral or religious beliefs. The model regarded disability as a punishment from God for a sin committed by the person or their parents or relatives. This led to individuals and entire families being ostracised by their communities. Around the mid 1800s the 'Medical model' began to grow in prominence. In this model disability is viewed as a defect or failure within an individual, and seeks to cure or rehabilitate the person, and that disability is deemed as a 'personal tragedy' and the person and their families may be pitied. Retief and Letšosa suggest that in this model there is a negative connotation to disability and people with a disability deviate from the norm and need to be fixed. The third model they described was the 'Social model', which is attributed to disability activists in the 1960s and 70s in response to the inadequacies of the medical model. The social model suggests that society disables individuals with impairments, and that rather than trying to cure the impairments society should adapt to accommodate people with impairments. A study into parents' attitudes to inclusive education revealed how their attitudes to education were influenced by models of disability (Runswick-Cole, 2008). In-depth interviews were carried out with 24 parents who were contacted through voluntary organisations involved in supporting parents with aspects of the special educational needs system in England. The study suggested that parents who chose inclusive mainstream schools identified with the social model of disability – with the onus being on schools and society to remove the barriers to their child. These parents were also found to be more sceptical about professional opinions about their child, and placed more value on their own parental knowledge of their child. Conversely, parents who opted for special schools favoured a medical model – putting high value on specialist knowledge and resources aimed at providing rehabilitation and potentially curing their child. The study concludes that at times parents' perspectives are inconsistent and that they are driven by pragmatism to engage with different models for different reasons. Parents who decide to use BD may favour the social model of disability; the certainty they place on knowing what is

best for their child and the rejection of professional expertise is reminiscent of the views expressed by parents who opt for mainstream schooling.

The impression that parents identify with different models of disability at different phases of their child's life was described in a qualitative anthropological study of mothers of babies and young children diagnosed with disability (Landsman, 2005). The study found that initially mothers primarily conform to the medical model embracing rehabilitation goals aimed at making their child more normal. Some begin to question the accuracy of the medical model, particularly when their child exceeds levels predicted by doctors or when they are given contradictory prognoses. When talking of the future they take the stance of the social model – with thoughts about how the world will treat their child, and they feel that it is not their child's impairment but the attitudes of society that is the biggest barrier to their child's happiness and development. The studies by Landsman (2005) and Runswick-Cole (2008) illustrate that the dichotomy between the medical (impairment) and social (disability) models may no longer be sophisticated enough to reflect disabled people's experiences (Shakespeare, 2002).

#### ***1.5.5.5 Normalisation***

Behaviour is determined in part through ideologies based on a combination of beliefs, attitudes and interpretation of reality resulting from one's experiences and knowledge and values. Wolfensbeger (1972) suggested that society viewed deviance from what was considered to be the norm in a negative light. Terms such as a vegetative state may be construed as seeing a patient as more vegetable like than human (von Wild, 2012). Wolfensbeger suggests normalisation means enabling a person to live in a way that is as culturally normal or typical as possible for a person with similar cultural characteristics, age and gender. These concepts resonate with models of disability, and chapter 9 will consider in more detail how the use of BD can be construed as a means of normalisation.

### **1.6 Summary**

There are ten chapters in this thesis. Chapter 1 introduced the topic of BD and its importance and provided context in the form of the researcher narrative and philosophical, theoretical and methodological foundations. Following the section

outlining the research aim, questions and objectives a broad overview of literature relevant to this complex topic presented. Chapter 2 comprises the previously published scoping review of BD. Chapter 3 presents the research question, rationale and methodology for the in-depth interviews with chapter 4 presenting the results. Chapter 5 and chapter 6 present the methodology and results of the blog analysis respectively. Chapter 7 presents the methodology for the quantitative phase of the research, with chapter 8 providing the results. Chapter 9 provides a forum for the discussion and triangulation of the findings from the qualitative and quantitative phases. Chapter 9 also discusses the limitations of this research and offers recommendations for clinical practise and further research, and the thesis closes with the conclusion in chapter 10.

## **Chapter 2 Scoping Review of Blended Diet**

### **2.0 Introduction**

Scoping reviews may consist of a brief listing of articles on the topic in question or a more comprehensive breakdown of articles in which information/data from the articles are charted and collated into a report. Although the methodology of scoping reviews is imprecisely defined, they are particularly suited to summarising and disseminating researching findings and identifying gaps in literature in areas which are complex or poorly defined. (Arksey & O'Malley, 2005)

Whereas systematic reviews clearly seek to address a well-defined question, taking into account the type of study designs that may be appropriate to the question, and assessing the quality of the studies, scoping reviews tend to have a broadly defined topic area and include studies with a wide range of designs. The quality of the studies is not generally considered. However, a review of scoping reviews proposed recommendations to enhance consistency of methodology and provide some form of quality assessment of articles included in the review (Pham et al., 2014). Therefore this review will provide an overview of the research, summarising the findings, assessing the quality of the studies and identifying gaps in the evidence base.

The research question for the scoping review is “What is known from the existing literature about the use of blended diets by parents to feed their gastrostomy-fed children and young people”?

### **2.1 Method**

#### **2.1.1 Search Strategy and data synthesis**

Searches were carried out using Pubmed, PsycINFO, Scopus, Embase, AMED and CINAHL. All articles published in peer-reviewed journals up until October 2016 were considered for inclusion in the study. Grey literature (such as unvalidated posts on the internet) was not included.

The keywords and Medical Subject Headings (MeSH) used were: “blended diet OR blenderized diet OR liquidised diet OR homemade diet OR pureed diet” AND “gastrostomy”. Initially a search on child\* OR infant OR paediatric OR pediatric was added to the first search but it narrowed the field to the extent that no matches were found so it was removed. However, the studies included are relevant to the

paediatric population. Details of the search strategy can be found in below in Figure 2-1

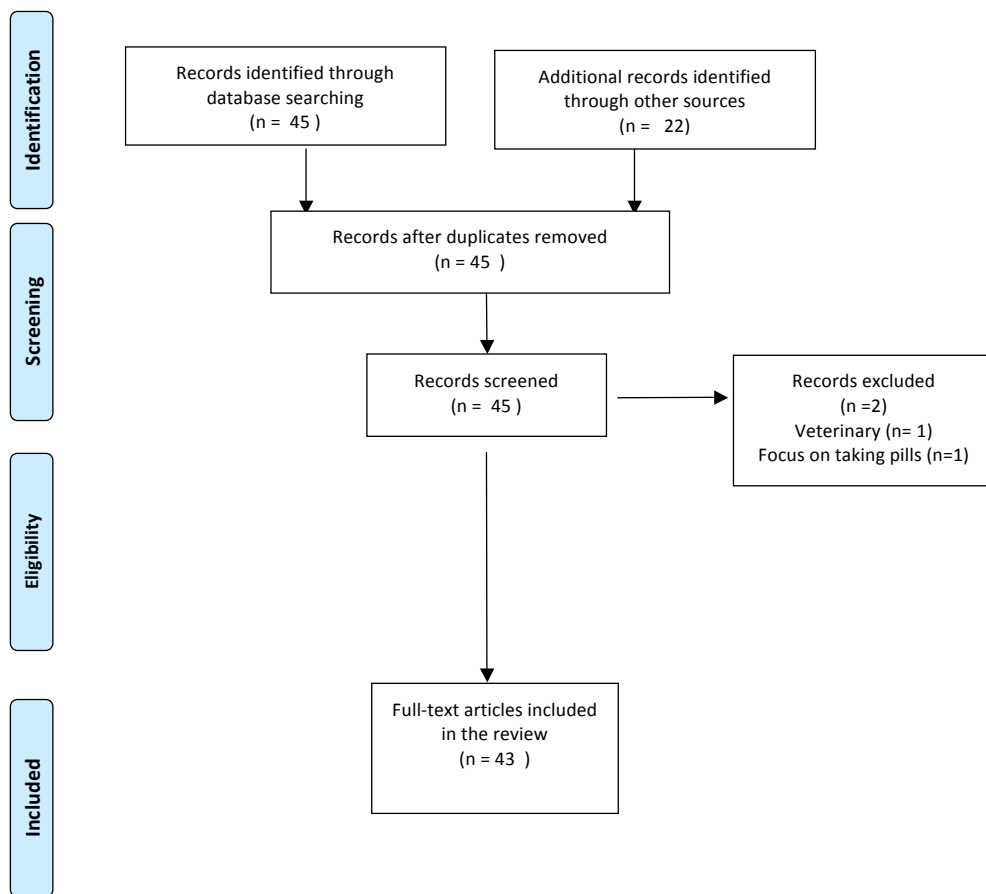


Figure 2-1 Scoping review search strategy

In addition to the database search, to gain a comprehensive picture of the literature, a search of specific journals in the field of gastrostomy feeding, nutrition and paediatrics was undertaken. A total of 43 articles met the inclusion criteria

### **2.1.2 Definition and inclusion/exclusion criteria**

The review included studies that evaluated any aspect of blended diets with gastrostomy feeding in children. It should be acknowledged that only 17 of the papers focussed specifically on children. However, the finding of all the papers included (such as those investigating nutritional content or contamination issues) were applicable to children. The search identified studies that reported on pureed and blended diets that were fed orally as opposed to via a gastrostomy; these were not included in the study. Discussion/ reviews, educational papers, poster presentations and new research articles from peer-reviewed journals were included.

### **2.1.3 Quality Assessment**

Although scoping reviews do not necessarily consider the quality of the articles included, due to the concerns expressed by researchers a quality rating was used in this scoping review (Pham et al., 2014).

A range of tools were considered including the Consolidated criteria for reporting qualitative research (COREQ), the PRISMA, the CASP Qualitative research checklist. However, the methodological checklist published in the UK by the National Institute for Clinical Excellence (NICE) guidelines manual (2009) was selected as a basis for assessing the quality of the studies. Although intended for use with qualitative studies, 8 of the 14 criteria were applicable to qualitative and quantitative research and review papers.

The following eight quality criteria were selected. One point was awarded for each criterion, providing a total quality score for each paper.

1. Is the approach appropriate for the stated purpose of the paper?
2. Is the study clear in what it seeks to do?
3. Is the method of data collection appropriate and clearly described?
4. Are the methods reliable; could the study be replicated?
5. Is the data analysis sufficiently rigorous for the purpose of the paper?

6. Are the findings convincing, clearly presented, referenced and discussed?
7. Are the findings relevant to the aims of the study?
8. Are the conclusions adequate?

In order to enhance the level of rigour of the ratings, a second researcher also rated the quality of 11 of the 43 papers. Both ratings were then compared. There was a high level of agreement in 91% of papers, defined as being rated the same level or one point different. The second researcher also categorised each paper by type of study and methodology, and there was 100% agreement. Nineteen of the papers were categorised as discussion/review papers, four as education (i.e. providing systematic instruction) and 20 as new research. The quality ratings can be found in Appendix 1 Table 1.

#### **2.1.4 Analysis methodology**

Content analysis, a means of making inferences by objectively and systematically identifying specified characteristics (Vaismoradi, Turunen, & Bondas, 2013), was used to provide an overview of the articles. In this paper specified characteristics are themes, both deductive and inductive in nature. Deductive in that the authors are aware of key issues regarding blended diet and can specify themes that are likely to be present, and inductive in that other more latent themes may be discovered within a document. Listed below are deductive themes that formed the basis of the framework onto which the articles were charted.

- Nutrition
- Contamination
- Equipment
- Medical/well-being
- Patient experience
- Carer experience
- Clinician experience

## **2.2 Search results and analysis of themes**

For each of the papers included in the scoping review, data relating to year, country and areas of focus have been summarised in Appendix 1 Table 2. Four of the papers were published before 2000, but the majority (27) were published after 2013, 27 of the papers were from the USA, 37 had an area of focus on nutrition and contamination, 16 on equipment, 13 on clinicians' experience, 24 on patient/carer experience and 17 on medical/well-being.

A summary of the aims and findings of each of the papers, can be found in Appendix 1 Table 3, and the sections below provides the results of the content analysis.

### **2.2.1 Nutritional value**

Several papers ( Felicio, Pinto, Pinto, & Ferreira da Silva, 2012; Escuro & Hummell 2016; Campbell, 2006; Heimberger, 1985; Machado de Sousa, Rodrigues Ferreira, & Madalozzo Schieferdecker, 2014; Waitzberg et al., 2013) investigated the nutritional content both of commercial feeds and blended diet. A cross-sectional study of 64 children who were enterally fed with commercial formulas reported that 94% were deficient in at least one micronutrient (Boullata et al.2017). Conversely other researchers reported on a case of a child receiving a blended diet who went on to be diagnosed with scurvy due to a lack of vitamin C (Jonkers-Schuitema, 2009). Both studies concluded that close monitoring of a diet's nutritional content was important whether it was a formula or blended diet. An investigation of the fibre content of commercial enteral feeds highlighted concerns about mineral retention in fibre used in formula and other effects of formula fibre including bloating, gas and cramps(Santos & Morais, 2009). More recently researchers suggested that a blended diet may improve stooling patterns by incorporating complex whole food nutrients and varying types and quantities of fibres and fats (Gottrand et al., 2013). A study investigating properties of commercial formulas found that they did not have the necessary bacteria found in a normal diet that help maintain normal gut function, and that antioxidants and bioflavonoids required for long term prevention of disease were also absent (O'Hara, 2015).



## **2.2.2 Contamination concerns**

Several papers in the review focused upon issues concerning contamination of blended diet. (Fredstrom et al., 1991; Samela, Mokha, Emerick, & Davidovics, 2016; Sullivan et al., 2001). . The studies were carried out in hospital settings. One such study in the Philippines analysed 96 samples of blended diets from four hospitals and found 100% had unacceptably high levels of bacterial contamination, compared to 33% of commercial formula (reconstituted powder form). They concluded that commercial feeds from prefilled or closed systems are safest in terms of microbial contamination (Sullivan et al., 2001). Another also concluded that closed system (i.e. ready prepared formula) were safest in terms of levels of contamination, whilst acknowledging that there was “ample opportunity” for commercial products to become contaminated in a hospital environment (Samela et al., 2016).

## **2.2.3 Equipment**

The effect of blended diet on feeding equipment (tubes, connectors, pumps) was examined (Anderson et al., 1984; Brown, Roehl, & Betz, 2014; Vermilyea & Goh, 2016). One reported that the viscosity of blended diet might render it unsuitable for infusion through feeding tubes (Brown et al., 2014). As a result of 33 patient incidents involving oral medicines being incorrectly delivered intravenously the EnFit<sup>®</sup> system was introduced. This system improved patient safety by ensuring that an enteral plastics device will only connect to another enteral device and cannot be connected to an intravenous device (Jalali, Sabzghabae, Badri, Soltani, & Reza, 2009). However, the EnFit<sup>®</sup> design may negatively impact patients, as the force required to dispense a blended diet is higher than the previously used syringes (Anderson et al., 1984). Studies report that there is an increased risk of feeding tubes becoming blocked by blended diet, and that the bore of the feeding tube should be no less than French -14 (a measure of the internal diameter of the tube). However, one study found that none of the five different handmade formulas tested in their study blocked tubes of 10-French (Machado de Sousa et al., 2014). None of the papers in this study presented evidence that blended diet caused more blockages than formula feeds. Indeed an increased occurrence of tube occlusion was reported when patients changed from blended diet to commercial feeds which

they surmised was 'probably due' to the lack of experience of families in using reconstituted powder commercial feeds (Sullivan, Sorreda-Esguerra, Platon, & Castro, 2004)<sup>1</sup>. A discussion paper suggested that care for the gastrostomy site is the same whether using blended diet or formula but suggest that the extension tubing may need to be changed more frequently although no studies have been carried out to prove or disprove this (Hurt, Miller, Patel, Codner, & Mundi, 2016).

#### **2.2.4 Medical/well-being**

There have been no clinical trials to determine the impact of blended diet on specific parameters such as height or weight, but studies have considered broader aspects of well-being such as a reduction in retching (Pentiuk et al 2011). In a discussion paper it was suggested that complications and risks might occur as a result of discovering previously unknown food allergies, gastrointestinal challenges or of parent error in food preparation, such as insufficient calories or fluids (Peggi Guenter and Beth Lyman, 2016).

Numerous papers describe benefits of blended diet including increased tolerance of feeds, reduction of constipation, and retching and decreased oral feeding aversion (M. Gottrand et al., 2013; Johnson et al., 2013; Mundi, Epp, & Hurt, 2016; Guenter & Lyman, 2016; Pentiuik et al., 2011; Thomas, 2016). One such study suggested that the viscosity of blended diet may reduce the rate of gastric emptying and that gastrointestinal motility may be positively influenced by blended diet (Pentiuk et al., 2011b). A single case study described the case of a 5-year old boy who had a gastrostomy and fundoplication at 8-months due to failure to thrive. The boy did not tolerate formula feeds and instances of vomiting, retching and constipation gradually increased accompanied by poor growth. On the advice of a friend the boy's mother tried putting small amounts of puree and fruit juices down his tube, and he then exhibited no signs of gastrointestinal discomfort and his growth improved (Johnson et al., 2013).

## **2.2.5 Views of patients, carers and clinicians**

### **2.2.5.1 Patient experience**

Papers in the scoping review discuss the clinical impact and well-being of patients using blended diet such as the intimacy of the feeding act between a child and parent, and the importance of providing a tube-fed child with the same meal as others in the family (Hurt et al., 2016). They also explain how using blended food can enable children who are able to have some oral intake to receive the same food by mouth as by the gastrostomy. The Graz clinic in Austria also recommends that parents use blended tube feeds when under-going tube weaning (Holland, 2014). A negative effect of the new EnFit® tubing on patients' well-being was that they make it more difficult for patients to vent their gastrostomy i.e. to stop uncomfortable build up of gas (Anderson et al., 1984). A study of 33 children who had a gastrostomy with fundoplication described improvements following the introduction of blended diet. In the study by Pentuik et al. (2011) more than half of the children experienced a significant reduction (76-100%) in gagging and retching. A study of 10 children with intestinal failure was carried out to investigate the effect of using blended diet. They found that 90% of the nine children who successfully transitioned to blended diet showed an improvement in diarrhoea and inconsistent stooling, and prescribed supplementary fibres were able to be discontinued in 100% of the children who transitioned to blended diet (Gottrand et al., 2013).

### **2.2.5.2 Carer experience**

Carers' views focused on the need for information/knowledge, the psychosocial impact and more overt practical implications.

Mundi et al (2016) describes how the use of a blended diet can enable parents to take a more involved role in providing food for their child. The need to ensure parental education, and a parental desire for more information regarding preparation and nutritional content on blended diet, and the cost implications in terms of time and equipment is also highlighted by Guenter and Lyman (2016) .

The psychosocial importance of blended diet was illustrated by Brown (2014), describing how a UK hospice enabled children to have a blended diet based upon its

policy of respecting parental wishes and replicating home conditions as far as possible. As blended diet can be prepared by using family foods, it can lead to the restoration of the psychosocial aspects of feeding, enabling the tube fed patient to be included in family meals. Conversely, another paper reported that parental satisfaction with blended diet was 'exceptionally high', primarily due to the decrease in retching and gagging. Although not mentioned by parents, the authors acknowledged that the use of blended diet may add time pressures in terms of preparation (Pentiuk et al 2011). A study in which self-reported parental satisfaction with blended diet was 'excellent', illustrated their findings with examples of parents spending less time on changing and washing as their child's stooling improved which in turn enabled them to work on toilet training that improved their self-esteem (Gottrand et al., 2013).

#### ***2.2.5.3 Clinicians' experience***

The review revealed a diversity of experience and opinion regarding blended diet, with a lack of overall consensus. Perceptions and reality did not always match. One study reported that in practice dietitians found there were fewer problems than they had predicted when families used blended diet. It was also found that despite concerns regarding tube blockage and infection more than 50% of dietitians who responded would recommend blended diet to supplement commercial formula (Klek et al., 2011). A survey carried out to assess attitudes and experiences of registered dietitians regarding blended diet revealed that 70.2% indicated that parental request was the main reason for using blended diet, and 22.9% cited tube-feeding intolerance as the main reason. Positive outcomes were reported by 76.9% of respondents including less feeding intolerance, improved growth and oral intake (Novak, Wilson, Ausderau, & Cullinane, 2009). The paper also examined differences in relation to the experience of the dietitians. More experienced dietitians were less likely to be familiar with blended diet and wanted no more information about it, whereas less experienced dietitians tended to be more familiar with it and wanted more information. Anecdotally one dietitian with many years experience reported that tube-feeding intolerance was unheard of in her practice prior to the introduction of commercial formulas.

Another dietitian in the same study reported that in her experience families who undertook to use blended diet on their own had poor outcomes. This opinion is further supported in a paper that reported on a case of a child developing scurvy as a result of being fed a nutritionally inadequate blended diet (Santos & Morais, 2009). A discussion paper summarised the issues facing clinicians, acknowledging that there are many websites and social media devoted to the promotion of blended diet, and clinicians working with tube fed children are likely to be asked about the use of blended diet. The paper recommends that clinicians increase their knowledge of and familiarity with blended diet so that they feel more comfortable when discussing its use with patients (Nowak-Cooperman & Quinn-Shea, 2013).

## **2.3 Other Themes**

The themes in the previous section related to the safety of blended diet, in terms of contamination, equipment and nutrition, and to the opinions of practitioners, carers and patients. This section highlights more latent overarching themes.

### **2.3.1 Uncertainty**

This was found to permeate several of the studies, and perhaps reflects the lack of evidence. For example uncertainty about the potential impact of allergies,(Ryan T. Hurt et al., 2016) the effect of using pumps for blended diets, and using blended diets for jejunostomy fed patients (Nowak-Cooperman & Quinn-Shea, 2013). Further uncertainty comes from the fact that commercial formulas are exempt from labelling and health claim regulations in the US, and can be used in patient care without undergoing efficacy trials (Escuro & Hummell 2016)

### **2.3.2 Choice and Compromise**

In order to enable viable patient choice there is inevitably a need to compromise;

*“The best candidate would be a family who has considered the pros and cons of a blenderized diet”*(Hurt et al., 2016 p22) The same study mentions that parents may be forced to compromise, and use a combination of blended diet and formula if schools will not allow staff to feed a child using a blended diet in school.

### 2.3.3 Edification

This theme relates to both carers and clinicians. Clinicians need to consider the carer's preferences and level of health literacy (Seche & Brady 2014) and to increase their knowledge and understanding of blended diet (Anderson et al., 1984). Guenter and Lyman (2016) created a clinical decision-making tree to aid practitioners in their clinical practice. Gottrand et al (2013) acknowledged that carers must also be aware of the potential risks relating to inadequate nutrient intake. This lack of knowledge or awareness highlights the need for further research into blended diet.

## 2.4 Discussion

Researchers and practitioners alike acknowledge the paucity of research related to blended diets (Coad et al., 2016). As far back as 1985 it was stated "*there is no documented advantage of blenderised 'normal food' over formulas compounded from individual nutrients*" (Douglas C. Heimberger, 1985 p64). Despite dietitians and manufacturers knowing the exact constituents of formula feeds, a question that was not addressed in any of the papers was that of knowing exactly what is absorbed by a patient. There is also debate about whether there are some micronutrients that cannot be provided by commercial feeds (Boullata et al., 2017).

There still remains a lack of evidence regarding the incidence of tube blockages with blended diet and whether there are groups of patients who have less negative symptoms such as gagging and retching when using blended diet. Other research questions concern whether blended diet can lead to a reduction in medications required for constipation (Guenter & Lyman, 2016), and whether there is an improvement in health status when a child is fed a blended diet (Thomas 2016).

The need for increased knowledge about blended diets was a recurring theme, with studies highlighting the importance of clinicians considering the carer's/family's food preferences and health literacy when contemplating the introduction of a blended diet (Seche, G., 2014), and recommending that clinicians increase their knowledge of issues relating to blended diets in order to be able to provide appropriate care (Brown 2014).

Further empirical research regarding the overall impact of blended diets will increase the evidence base. This increased knowledge may provide clinicians and families

alike with the resources upon which to discuss the potential use of blended diets with individuals and thus to make informed choices. We have reported that 37 of the 43 papers in the review examined issues related to contamination and nutrition, whereas only 17 considered those related to the medical/well-being of patients. This, and the acknowledgement that many families are turning to social media for support and information, (Hurt et al., 2015) may imply that there is a mismatch between the priorities of patients /carers and those of clinicians/researchers. The importance of involving patients in their care is reiterated by both research evidence and Government policy (Mascarenhas, Meyers, & Konek, 2008); researchers should consider greater patient participation and focus when developing research questions.

## **2.5 Limitations of the review**

Scoping reviews are a relatively new way of synthesizing research evidence. There is still considerable debate about the methodology, particularly with regards to quality assessment of the evidence. The authors noted in excess of ten articles in non peer-reviewed publications regarding the use of blended diets but these were not included. There are also active online groups that generate regular debate regarding the use of blended diets both in the USA and in the UK, with membership of over 2200 and 1600 respectively.

It is also acknowledged that reviews can only consider the evidence at a single point in time, and that new papers may have been missed by setting end date parameters. Similarly, papers may have been missed through selecting certain databases for the search.

## **2.6 Conclusion**

This scoping review provides an overview of the literature regarding the use of blended diet. Data from papers were charted and emerging themes were described. By providing a degree of quality evaluation of the studies and synthesis of the findings it is anticipated that the review may be of use to policymakers, and to those carrying out or commissioning research.

Regardless of the views and recommendations of clinicians, it is evident that some families are using blended diets. Overall, the review revealed a picture of divergent opinions, a patient/carer led move towards the use of blended diets and a lack of evidence to refute or substantiate opinions and anecdotal evidence as to the impact of blended diet on the nutritional, clinical and psychosocial well being of patients and their families.



## **Chapter 3 Phase One In-depth interviews: Methodology**

### **3.0 Introduction**

This chapter will address the research question ‘what are the reasons for and implications of using BD’? The objectives are to identify and explore the reasons that parents opt to use BD, to identify perceived benefits of using BD and to identify any challenges with regard to the use of BD. This phase will take a qualitative approach, using in-depth interviews with parents who use BD with their children and young people. Thematic analysis will be used to analyse the results. The philosophical approach and proposed research design will first be outlined, the next section describes the pilot study, followed by the main study. The findings will be discussed and limitations of the study presented in the final section of the chapter.

### **3.1 Philosophical Approach**

This study will adopt a phenomenological approach. Prior to the emergence of social science, the more traditional scientific quantitative methodologies struggled to capture the subjective nature of human experience. Littlejohn and Foss (2009) describe phenomenology as “the philosophical tradition that seeks to understand the world through directly experiencing the phenomena.” Similarly, Denscombe (2010) describes a phenomenon as something that humans directly experience through their senses but may not be fully analysed or explained. Husserl (2001) described phenomenology as a means of understanding how people describe experiences, thoughts, emotions and perceptions. Phenomenology takes an inductive approach in order to gain an understanding of lived experiences (van Manen, 1997). It is important to recognise that the whole may be different to the sum of its parts (Omeray, 1983). Therefore the researcher must acquire a clear understanding of these lived experiences in order to develop initial themes that combine to form meaning to the narrative of the participants. Phenomenology is particularly relevant to this research question as by focusing on the narrative account of individuals it gives voice to the parents, which may later be used in healthcare decision-making.

A phenomenological approach will:

- I. provide the researcher with the rigorous and unbiased study of things as they appear to the participants, thus providing insight into the way people experience phenomena (in this case the use of BD);
- II. provide a view on human behaviour that cannot always be predicted, controlled by scientific method and quantifiable data and logic. For example, why would parents reject a prescribed easily administered nutritionally complete feed which is free on the NHS in favour of a regime that involves going against medical advice, costs more in terms of food and preparation time and does not give the assurance of being nutritionally complete? Quantitative methods of scientific research cannot grasp the subjective emotive nature of feeding; and
- III. explore how the concepts of each participant's life world shapes the interpretation of their experiences.

The adoption of a research philosophy is influenced by the nature of the research question, and the researcher's view of knowledge and how it is developed. In order to adopt the most appropriate philosophical approach it is important to have an understanding of epistemology, ontology and axiology, and how each of these ways of thinking contribute to the philosophical approach.

Epistemology investigates the origin and nature of human knowledge. Interpretivism suggests that the researcher believes that there are multiple realities, and that both social action and inaction has meaning that is interpreted by the researcher. In order to make sense of these realities the researcher must build a rapport with the participants. Weber (1968) used the term *verstehen*, to describe this notion of 'putting yourself in their shoes' to see the world from the viewpoint of the participant. Actions result from the way we all make our own meanings, and although an individual's actions may be shaped by their interactions with external forces, the actions are not a direct result of them. The essence of interpretivism is encapsulated in the quotation, "*If men define situations as real, they are real in their consequences*".(Thomas and Thomas, 1928, p.572)

Ontology considers the nature of the social context, and if the social world is external to social actors or something that people construct (Bryman, 2004). To illustrate the notion of ontology, consider the analogy of a car; although parts of a car such as the

engine or brakes can be seen, they are no more real than concepts such as speed or acceleration. This concept of reality is particularly important in the field of BD, where physical or physiological changes that can be measured or seen maybe considered more real than a concept such as well-being or quality of life. The ontological orientation of this research is that of constructivism; suggesting that an individual's knowledge and reality are the result of social relationships and cultures. Riegler (2012) refers to constructivism as the way an individual experiences reality and that it is actively constructed and that the researcher plays a role in this.

Axiology, the study of values was described as being about "*what human states are to be valued simply because of what they are*" (Heron & Reason, 1997, p.287).

It is an important concept as it contributes to the understanding of the influence of the researcher. My values and opinions as the researcher regarding BD, medicine, disability, etc. will inevitably influence the research. Axiology enables me to acknowledge these values rather than trying to eliminate or neutralise them. As a speech and language therapist I value the importance of listening, and as a clinician I am aware of my professional responsibilities and duty of care. As an individual I value choice and self-determination. All these factors have shaped my research at every point from the initial choice of subject to the final write up.

### **3.2 Research Design**

The research design is key to ensuring that the evidence obtained effectively addresses the research problem. Phases one and two of the study used qualitative methodology. Qualitative research is appropriate when there is a lack of research into the area. This is in contrast to a situation where quantitative methodology may be more appropriate, such situations being where there is already a significant amount of information that can be used to derive and test hypotheses (Howitt & Cramer, 2011).

There is little research with regard to the question of why parents opt to use BD. The research that has been carried out in regards to BD relates more to concerns regarding quantifiable areas such as contamination, nutritional sufficiency and tube blockage. Indeed the British Dietetic Association Policy Statement on BD asserts that one of the purposes of the policy is to "*help patients/carers to understand the concerns of their dietetic practitioner*" (British Dietetic Association, 2013, p.1). The

remit does not extend to seeking the views of parents as to why they are opting to use BD. Similarly a scoping review of studies into BD revealed that 37 of the 43 studies included in the review had a focus on nutritional content and contamination (Breaks et al., 2018). It may therefore be concluded that there is a significant lack of research in the area and that the qualitative approach in this study is appropriate.

This study will focus on learning about the experiences of parents regarding feeding and their use of BD. Pring (2005) suggested that a qualitative approach is appropriate in order to explore an individual's personal experience or to examine complex behaviours.

### **3.3 Pilot study**

A pilot study was carried out to establish whether all of the components of the main study would work together, and to assist in answering the research question. The pilot enabled the researcher to confront potential challenges that may have jeopardised the integrity of the main study including overall acceptability and feasibility, practicalities regarding interviews, the use of resources and other unpredicted or unforeseen challenges. At the end of the process each of the participants was asked to provide feedback about the length of the interview, convenience, whether there was anything that made them feel uncomfortable, and any other suggestions or comments they had. This feedback was incorporated into the main study.

The pilot consisted of in-depth interviews with two participants. The interviews were then transcribed and analysed using thematic analysis (Braun & Clarke, 2014).

The key components considered in the pilot study concerned-

- I. Use of face to face versus Skype/phone interviews;
- II. Suitability of interview guide and demographics;
- III. Suitability of analysis tool; and
- IV. Personal skills development;

#### **3.3.1 Use of face-to-face interviews versus Skype/phone interviews**

The interview of one of the participants in the pilot took place in their home face-to-face. The other interview with the second participant was carried out using Skype. There are a number of factors in relation to technology, ethics, and rapport that need

to be considered when using Skype as a medium for interviewing. Some of these are advantageous while others may be viewed as disadvantages. An advantage of Skype is that participants from a wider geographical location can be included more readily, although it excludes participants who are unable to access Skype. Another advantage of Skype is that it is more time effective than face-to-face interviews, which was one of the reasons the participant opted for Skype as they were able to carry out the interview from their place of work at a pre-agreed time. During the pilot, the quality of the Skype connection was excellent, although it is acknowledged that connectivity problems can occur. To minimise the risk of connectivity problems the researcher ensured that the most up to date software was used and ensured that it was possible to switch to an audio-only 'channel' in the event of video connectivity issues as this can help improve audio quality. Although telephone contact was not selected by either participant it was offered in the main study, as studies have shown that telephone interviews may be preferable when interviewees are discussing sensitive subjects or when they may feel shame or guilt (Chapple, 2013; Heath, Williamson, Williams, & Harcourt, 2018). Whilst it was acknowledged that telephone interviews preclude the ability to observe non verbal communication, it was felt that offering choice of interview medium would increase participant recruitment and enable the participants to select the interview channel that best suited them.,

The researcher emailed the participant the information and consent forms (2 and 3). The consent form was then completed by the participant, scanned and returned by email. The Skype participant only needed to provide their Skype contact details as opposed to their home address, which may be preferable for some participants. Similarly, it is acknowledged that participants using Skype can more easily terminate the interview if they wish to for any reason without the potential embarrassment or awkwardness that may occur if they wished to end a face-to-face interview. As the audio recorder was not visible to the participant on the screen, the researcher reminded the participant that the interview would be recorded and gained verbal consent that they were happy for the recorder to be used (in addition to the earlier written consent that they were happy for the recorder to be used). Deakin and Wakefield (2014) presented an article describing the experience of PhD researchers using Skype interviews in which they acknowledged that it might be more difficult to

build a rapport using Skype compared with a face-to-face interview. The researcher had a telephone conversation (to briefly explain the research project) with the participant, which helped develop a rapport between the interviewer and participant. The Skype call lasted 49 minutes. This was the length of the entire call and included introductions, rapport building and concluding remarks; the interview lasted just under 40 minutes. In contrast the researcher spent two hours with the participant in the face-to-face interview, with the interview lasting approximately 90 minutes. It should be noted that the Skype participant was taking time out of work to be interviewed so this may also have impacted on the length of time taken rather than being directly related to the interview medium. The participant in the Skype interview also emailed the researcher two days after the interview with some additional comments that had not been covered in the interview. Again, this cannot definitively be attributed to the interviewing medium. The quality of both recordings was good and enabled transcription.

### **3.3.2 Suitability of interview guide and demographics**

The interview guide is a means of ensuring the conversation with the interviewee covers specific topics identified by the researcher that will assist in answering the research questions. Areas contained within the guide were also informed by the literature review, for example the impact on time management described by Heyman et al. (2004).

Braun and Clarke (2014) also suggest that the interview guide assists with building trust and rapport. In developing the guide the researcher also considered the potential flow or order of the conversation. The researcher began by asking the parent “Could you start by telling me about your child – their personality, likes and dislikes and their needs? I’d like to have a ‘picture’ of the child we are talking about.” This broad opening question allowed the parents to settle and to talk about their lived experiences with their own child. The next prompt was to explore their child’s feeding development. However, with both participants, once they began talking about their respective child they covered this area without further prompt. The interview guide was ordered to flow in such a way as to help the parent feel at ease. First, talking about their child, then discussing their feeding and the practical issues relating to BD, before moving on to discuss their beliefs, concerns and self-efficacy. The interview

then considered in more depth the impact of BD on the quality of life of the entire family and the specific impact on the child using the diet. Finally, the researcher provided a brief summary of areas that had been discussed and asked the participant if there was anything else they wanted to add or discuss more generally. Using the guide ensured that key areas were covered in all of the interviews. The guide also ensured that there was enough flexibility to allow the interviewer to probe parents' statements more fully, ask questions in the language that the respondents were using themselves and to follow up any new information uncovered.

The demographic data predominantly used tick box options for answers. The researcher took the decision to gather the data at the end of the interview when more of a rapport had been developed. This also gave the researcher the opportunity to clarify specific areas that had been discussed in the interview such as the date of the gastrostomy.

### **3.3.3 Suitability of analysis tool**

Prior to starting the pilot the researcher had concluded that thematic analysis would be used to analyse the data. However, it had not been decided which Computer-Assisted Qualitative Data Analysis Software (CAQDAS) was to be used. At its most basic level CAQDAS allows a researcher to code text on a computer screen, and retrieve all sequences of text related to a particular theme. There is no single gold standard CAQDAS. In 2004 Bryman suggested that there was 'no industry leader', and as recently as 2014 Braun and Clarke state that there is a range of programs available. The researcher read reviews and trialled three programmes - (i) Nvivo for Mac, (ii) Quirkos and (iii) an app based solution called Saturateapp. Nvivo had the greatest range of features but the researcher acknowledges that any CAQDAS is just a tool, and as such does not negate the need for the researcher to understand and be competent in the whole process of thematic analysis.

### **3.3.4 Personal skills development**

The researcher has in-depth knowledge regarding communication and conversation but it was necessary to attune these skills for research interviews. Dickson-Swift, James, Kippen, and Liamputtong (2007) describe some of the issues faced by researchers undertaking qualitative health research and stated that the relationship

between the researcher and participant should not be hierarchical. Building a rapport with the participant can facilitate the necessary trust and respect required for an effective interview. A strong rapport with the participant may also lead to a greater level of disclosure by them. Self-disclosure by the researcher may also serve to develop rapport. The researcher explained her background profession as a speech and language therapist and interest in the topic of BD. The researcher did not explicitly state whether or not she was in agreed with the use of BD.

### **3.4 Participant selection**

#### **3.4.1 Sampling strategy**

When carrying out research it is generally not possible to gain the opinions of the total population, as they are normally too large. Further, in the case of BD there is also a lack of certainty as to who constitutes the total population. In sampling researchers select a proportion of individuals with the expectation that they are representative of the overall population, whilst acknowledging that the results from the sample population will not be exactly representative of those of the overall population. Two types of error are introduced by sampling; (i) random error and (ii) systematic error. Random error can be reduced by increasing sample size. Systematic error can be reduced by careful design of the sampling procedure. To reduce sampling error, participants should be randomly selected so that chance alone determines who will be included. This removes the possibility of selection bias with each individual having a known probability of selection so that statistics can be applied to the results. Such selection processes would achieve a probability sample (Byrman, 2004).

However, in the field of qualitative research random sampling is not always feasible or appropriate, and qualitative sampling does not claim to be representative of, nor generalizable to, the whole population of interest (Ritchie, Lewis, & Nicholls, 2013). A study into the factors influencing participant recruitment for medical research in the NHS by Newington and Metcalfe, (2014) cited trust as a factor that influenced the decision of potential participants. Studies cited in the literature review, King and Ligman, (2011); Petersen, Kedia, Davis, Newman, and Temple, (2006) and the researcher's clinical practice revealed covert use of BD and a lack of trust between



some families and members of the NHS feeding teams regarding BD. The decision was therefore made not to recruit via the NHS. This decision influenced the selection of sampling method.

### **3.4.2 Method of approach**

Participants were recruited through snowball sampling. This technique is used when research involves recruiting participants from a very specific population by word of mouth or similar networks (Patton, 2002). The researcher was aware of a range of networks using BD such as social media, family support organisations, special schools and hospices, It was therefore deemed that recruitment via snowball sampling was most appropriate. Consequently families were recruited via:

- I. Social media – such as BD Facebook groups;
- II. Special schools;
- III. Parent support organisations; and
- IV. Hospices.

Participants were initially approached by email or telephone (see Figure 4-3 for details)

### **3.4.3 Sample Size**

The sample size required for a qualitative study is a topic of much discussion. Guest (2006) considers this in terms of the purpose of the data collected suggesting *“if the goal is to describe a shared perception, belief, or behaviour among a relatively homogeneous group, then a sample of twelve will likely be sufficient.”* (Guest, 2006, p.76).

The sample size required relates to the research question, the nature of phenomena being explored, and the need to be able to create a convincing analytical narrative from the data obtained. Patton (2002) suggests that a small sample size facilitates the collection of rich, deep information about the phenomena under investigation. The concept of saturation was described by Bowen (2008) as being the point at which no further additional novel or relevant information appears to emerge. Once this point is reached no further interviews are carried out. More recently Saunders et al. (2018) suggested that the model of saturation should be consistent with the research question, theoretical position and analytic framework. The model of data

saturation was applied by the researcher. The inductive thematic saturation model was also considered. This model of saturation relates to the emergence of new codes or themes so saturation focuses on the analysis stage. The term code saturation, is used to refer to the situation when no new codes are identified and the codebook stabilises (Hennink, Kaiser, & Marconi, 2017). Having reviewed the literature, it was anticipated that between 15 and 20 interviews would be required to reach saturation and fully answer the research question.

#### **3.4.4 Inclusion criteria**

- I. The parents' child should be over the age of 12 months and under the age of 25 years in line with legislation contained in the 2014 Children and Families Act concerning children and young people with special educational needs and disability. This age range also reflects research which suggested that the brain continues to develop into the mid-20s (Johnson & Blum, 2010);
- II. Able to take part in the interview in English; and
- III. Be the parent of the child or young person, or other relative with full parental responsibility.

#### **3.4.5 Exclusion criteria**

- I. Children with a gastrostomy but who are undergoing chemotherapy. It is considered by the researcher that the burden placed upon families in this particular situation would be too great;
- II. Parents/carers who require an interpreter will not be included in the study due to the time and cost that would be incurred in order to accommodate them. Further, the parents may also feel less able to communicate openly and honestly with the researcher through a third party; and
- III. Primary carer who is a foster carer or corporate parent (i.e. a looked after child) as they are not likely to have the same decision-making 'freedoms' as a birth parent or adoptive parent.

18 participants were interviewed, 2 of whom had been interviewed as part of the pilot study. The decision was made to include these participants as the sampling and methodology was the same in the main study as it used the same methodology (Thabane et al., 2010). There were four other potential interviewees who contacted

me to request the participant information. Two agreed to participate after they had received information, but subsequently decided they were unable to participate; one due to “illness and family pressures” and the other due to “illness and life just being too hectic”. The other two potential interviewees did not respond after they received the participant information.

### **3.5 Data Collection**

Focus groups were considered as potential methods of data collection as well as in-depth interviews.

In-depth interviews provide the participant with the opportunity to discuss issues important to them with regard to the research area. Such interviews also allow the participants to reveal their own perspectives, attitudes and beliefs.

Focus groups are a means of rapidly stimulating discussions and gaining rich data from a range of participants. Focus groups are frequently used in health related discussions particularly with topics that may prove difficult to talk about on a one-to-one basis. Focus groups must be carefully managed to ensure that a particular participant's viewpoint does not dominate the discussion at the detriment of the wider discussion. The possibility of harmonisation of views must also be considered (Acocella, 2012; Robinson, 1999). The lives of families of children with multiple needs, particularly those who are gastrostomy-fed are often busy and complex. It was possible that these parents may not be able to commit to a focus group. Similarly if parents had needed to cancel attendance at a focus group at short notice this would impact on the viability i.e. lack of critical mass.

In order to minimise participant burden, the researcher decided that in depth interviews would be used, with parents being offered interviews by Skype, phone or face to face at a location of their choice. Daytime, evening and weekend time slots were available. Prior to the interview parents received the information leaflet and consent form.

Of the 18 participants who took part in the research interviews, two opted for face to face interviews whilst eight opted for Skype interviews, and eight for phone interviews. The Skype link did not work fully for participant four's interview so audio only was used. One of the parents who opted for Skype admitted that they had never used it before, saying she was 'not techno savvy'.

Deakin and Wakefield (2014) found that interviewees who said they did not have time to be interviewed face-to-face were willing to participate when interviews were offered via Skype. In the first week of interviews, three of the families had to reschedule the Skype calls due to their respective children being ill. All participants rescheduled the Skype calls and participated in the study. This illustrates the decision not to use focus groups was justified, and parents reported that rescheduling online was less stressful and meant they did not 'just try and cope' and carry on with the interview.

All interviews were recorded using a Olympus VN-741PC MP3 Digital Voice Recorder. Initial contact with participants took place between 2<sup>nd</sup> February 2017 and 28<sup>th</sup> March 2017. Interviews were carried out between 6<sup>th</sup> February 2017 and 25<sup>th</sup> May 2017. It should be noted that all but one of the interviews were carried out before the end of April but the participant who was interviewed in May needed to postpone on multiple occasions due to illness (this was in addition to the three parents mentioned above who had to reschedule in the first week). The duration of the interviews ranged from 29 minutes to 1 hour and 52 minutes. Demographic details were taken at the end of the interviews and after the interview was finished the researcher made brief notes / pen sketches of the participant and child to aid recall.

An interview guide was developed, (see appendix 2) which provided the researcher with prompts and ensured all areas of interest were covered during the interview. The theoretical perspective provided by the self determination theory was used to inform the guide as the research sought to understand the motivations behind choices and actions, and explains how these actions of the parents.

The interviews comprised a combination of open and closed questions. At the start of the interview the researcher explained the broad aim of the research (participants had by this stage already received the information leaflet and consent form). The confidentiality of the interview was also reiterated. Next an open-ended question was posed; *"Could you tell me a little bit about your child so that I can try and get to know them a little as an individual - a bit about their personality likes and dislikes that kind of thing?"* This question was intended to put participants at their ease. Participants then continued to talk about feeding and gastrostomy and BD, developing their own narrative with minimal further direct questioning from the researcher.

Recordings were made of all interviews, and the researcher ensured Skype and phone interviewees were reminded of the recorder as they were not able to see it.

### **3.6 Data Analysis**

A number of different forms of data analysis can be used with qualitative research. Before adopting Thematic Analysis (Braun & Clarke, 2014) the researcher considered alternatives. In addition to thematic analysis, content analysis and discourse analysis were both considered as potential methods. Content analysis can be viewed as being more quantitative in nature, taking a more deductive approach. Critics suggest by converting qualitative into quantitative data based on frequency researchers may overlook potentially important themes and insights. (Kracauer, 1952). Discourse analysis considers how words or phrases may be used to convey meaning, and can critics suggest that there is a tendency to focus more on how things were said, including turn taking within conversations rather than what was said (Schiffrin, Tannen, & Hamilton, 2008). For the purpose of this study, the researcher decided that the priority was to identify the actual views and experiences of the participants rather than focusing on the discourse. Thematic analysis was selected over content and discourse as it offered a more inductive approach than content and as the interviews were not primarily discursive. The following section outlines the full rationale for the use of thematic analysis.

### **3.7 Characteristics of Thematic Analysis**

This section discusses four features of thematic analysis (TA), which made it particularly suitable for this research. Firstly, TA uses an inductive approach. As the researcher, my analysis was informed by the responses of the participants, not by preconceived hypotheses. However, it is important to acknowledge that general areas to explore were included in the interview guide to ensure they were covered whilst maintaining open questions to allow participants to discuss matters important to them. Secondly TA uses no preconceived categories, and it is important to ensure that data collection questions do not just become themes. Instead themes are the result of analysis of the data and patterns within it. Thirdly TA helps to highlight similarities and differences across the data set and identify trends or patterns. Some

of these trends and patterns could become the basis for phase three, the quantitative survey that will be distributed to a much greater number of participants. Finally, the qualitative analysis produced from the data set could be used to inform policy. This is particularly pertinent in the domain of BD where there is a lack of evidence and a conflict between legislation and parental preference.

Figure 3-1 below provides an overview of the advantages and disadvantages of TA.

<b>Advantages</b>	<b>Disadvantages</b>
Flexible	Flexibility can lead to inconsistency
Accessible	Lack of substantial literature on thematic analysis (compared to grounded theory for example) leaves it vulnerable to accusations of lack of rigour
Not theory driven so can be used with inductive approach	Deriving themes from research data can lead to a lack of coherence
Can generate unanticipated insights through social and psychological interpretation of the data	When there is a mismatch between data and analytical claims it is not possible to consider alternative interpretation of the data

**Figure 3-1 Advantages and Disadvantages of Thematic Analysis**

Applied TA was described as “*a type of inductive analysis of qualitative data that can involve multiple analytic techniques*” (Guest et al., 2011, p.4).

The six steps of TA (which include the preparation and analysis of the data) were described by Braun and Clarke, and are explained below in the context of the BD research. The Nvivo for Mac (version 11) programme that was used in the pilot study was also used in the main study.

## I. Familiarisation with data

This step involved listening to each of the recordings and then each one was transcribed verbatim by the researcher into a Microsoft Word document which was then uploaded to Nvivo for Mac. Patterns and trends within the data were actively considered when listening to and transcribing the recordings. The recordings were captured using QuickTime Player, enabling easy stop/start, rewind/forward and time stamps, which were incorporated into the transcription to facilitate the identification of key sections of text. During the transcription process, the researcher noted any early ideas and thoughts. A brief 'pen sketch' of each of the participants was also created as an aide memoire.

## II. Generating initial codes

From reading and rereading the data, preliminary features were noted and coded. These codes were data driven i.e. derived from the data. As an inductive analysis was being undertaken, line-by-line coding was used and all the data was assigned to relevant codes with some extracts being allocated to more than one code. As codes were created, they were defined and (on Nvivo) initial consideration was given to ordering the codes into meaningful groups, which ultimately provided the basis of the themes. Codes, subcodes and their definitions can be found in appendix 3.

## III. Searching for themes

Step three marked the start of the interpretive analysis. Codes were collated into themes and some subthemes. At this stage the themes were predominantly descriptive. The subthemes were attached to themes in the form of child nodes in Nvivo. Some data did not appear to fit in any of the codes so were placed in a miscellaneous code for later consideration. The relationship between codes, subthemes and themes was borne in mind in this and future stages.

## IV. Reviewing themes

At this stage the descriptive themes were reviewed and became more interpretive in nature. For example the original theme of 'doing my best' became part of a theme concerned with innovation, and the initial theme of paternalism was reframed as part of the overall theme of conflict.

Data were re-read to check they were representative of the themes, and in turn that the themes were appropriate in the context of the entire data set. In order to ensure coherence between the themes a thematic 'map' was generated (appendix 4).

#### V. Defining and naming themes

This final stage of refinement aims to identify the essence of each theme (Braun & Clarke, 2006, p.92). It involved defining the themes, identifying the story that each theme told in relation to the research question, and explaining how the themes related to each other. It was at this stage that data in the miscellaneous category was finally reviewed and incorporated into a theme. For example, one participant described how their family had stopped going to a coffee shop with their gastrostomy-fed child because they felt guilty. On reflection it was understood and interpreted as belonging to the theme of loss.

#### VI. Producing the report

Producing the final report involved distilling complicated data from life stories into a cohesive, concise and compelling document. Extracts from the data set were used to make the report more vivid and persuasive. The final report had to ensure the reader was convinced of the credibility (i.e. the degree to which the researcher's interpretation reflects and represents that of the participants) In addition, the report must be representative of the evidence from the literature review and perhaps most importantly effectively address the research question.

### **3.8 Research Ethics**

The UCL Division of Psychology and Language Science Departmental Ethics Committee granted ethical approval of the project (LCRD.20.26.05). The project was registered with the UCL Data Protection Officer (No. Z6364106/2016/08/14). As the study included lone working the researcher and supervisor carried out the Division of Psychology and Language Science Experimenter Safety Risk Assessment.

The storage and transfer of electronic data and hard copy documents was carried out in accordance with the UCL guidelines. As previously discussed, potential participants were also given information sheets and consent forms (See appendix 5 and 6). The right to withdraw at any time was specified in the information and consent forms.



Within the positivist paradigm of quantitative research the researcher is viewed as an external observer who objectively examines a range of phenomena displayed by the participants. In contrast, the qualitative researcher and participant share a more equal role where the division between the two is blurred (Gergen & Gergen, 2000). This can lead to ethical dilemmas and tensions. Karnieli-miller (2009) described how the participant's right to a significant role in the research can lead to the denial of the researcher's intellectual and academic freedom. As the researcher, I was conscious that participants could view my research as an opportunity to publicise their cause and promote the use of BD. It was therefore imperative to maintain neutrality whilst engendering an informal, non-hierarchical environment together with a sense of empathy with the participants to facilitate the sharing of their experiences and beliefs. The researcher provided verbal assurances to the participants that the study would not be detrimental to their child's care or their relationship with their HCPs. As the researcher only knew one of the participants (via a parent support group) the risk of insider bias was considered to be low (Creswell, 2009) and there was no explicit power relationship. However, participants were made aware of my background as a healthcare professional so it was possible that they may have provided responses that they thought were desirable to me, i.e. the Hawthorne effect.

All participants were assigned a coded identity number and the names of their children were changed. The use of direct quotes from participants could potentially lead to the identification of settings and individuals. For this reason the names of hospitals, schools and names of HCPs were anonymised.

Although the research was non invasive and participants were adults, in-depth discussions may cause some degree of stress and anxiety for some participants. It was anticipated that discussing sensitive issues such as conflict or occasions when their child was seriously ill could cause a degree of stress and anxiety for some participants. To mitigate this, the researcher remained sensitive to signals of possible distress. On one occasion, a mother became distressed when she described a life-threatening incident involving her child. As a result, the researcher paused the interview and offered to discontinue or reschedule it. When conducting research with members of the public, adverse reactions occasionally occur. For example a previously undisclosed or unknown mental health problem may become

apparent. In such circumstances the researcher would have provided signposting to other sources of help, and asked permission to inform the participants' GP to ensure timely and appropriate support was received.

### **3.9 Research Quality**

Quantitative research is often viewed as being objective and systematic, through using numerical data and describing and determining relationships between variables. Some debates continue concerning the 'worthiness' of qualitative research. This section presents other studies that support the use and value of qualitative research.

Firestone (1987) suggested that qualitative and quantitative approaches should not be viewed as antithetical. Instead, he argued that the different kinds of information could be used to triangulate, thus providing greater confidence in the researcher's conclusion. Indeed, interviews may uncover a number of different perspectives given their subjective nature, with each interview conveying an account from the perspective of the specific interviewee. However, Webb and Stimson, (1975) cautioned about the potential mismatch between what various interviewees say and do with their actual beliefs and actions. Confounders such as the Hawthorne effect must also be acknowledged. Shenton suggested *"The trustworthiness of qualitative research generally is often questioned by positivists, perhaps because their concepts of validity and reliability cannot be addressed in the same way in naturalistic work"* (Shenton, 2004, p.63)

However, Guba, (1981) devised a framework to ensure the rigor of qualitative research addressing 4 key issues; credibility, transferability, dependability and confirmability.

Guba and Lincoln (1994) refer to concept of trustworthiness as a means of assessing the quality of qualitative research. Figure 3-2 below describes the concept in more detail. The study employed this notion of trustworthiness to assure the quality of the research.

<b>Element of Trustworthiness</b>	<b>Correlation with quantitative measure</b>	<b>Description</b>
Credibility	Internal validity	The degree to which the researcher's interpretation reflects the participants' social world.
Transferability	External validity	The extent to which the rich data collected can be transferred to other situations
Dependability	Reliability	The level of audit rigour, as judged by peer audit of records including field notes and data analysis decisions
Confirmability	Objectivity	The degree to which the researcher has kept their own values and beliefs from overtly influencing their work

**Figure 3-2 Elements of trustworthiness**

The question of inter-rater reliability remains a concern in qualitative research. Campbell, Quincy, Osseman, and Pedersen, (2013) suggested that inter-rater reliability should aim to ensure the codes of a knowledgeable coder would likely be reproduced by a similarly knowledgeable coder. The study highlighted the tendency to produce large numbers of codes especially when there are high levels of transcripts (a total of more than 500 pages of text in the study), and the greater the number of codes the greater the potential for coding errors. The option of merging or removing unreliable codes and recoding and repeating the process until an acceptable level of reliability is achieved would be a potential way to improve the rigor of the research (Hruschka et al., 2004). It should be mentioned that there is not a consensus amongst academics as to what constitutes an acceptable level of numerical agreement. Hodson (1999) considers 79% to be a 'relatively high degree of reliability whereas Fahy (2001) provides a range from 70% (acceptable) to 94% (exceptional). This notion could be considered similar to that of confidence levels. Another method of establishing validity was described by King, Desmarais, Lindsay,

Piérart, & Tétreault (2014) in which coders showed their interpretations to some of the therapists who had taken part in the study for comment. This peer examination of categories gained mutual confirmation from researchers from different backgrounds. However, there is still potential for poor intercoder reliability. A study by Garrison, Cleveland-Innes, Koole, and Kappelman (2006) reported that coders initially achieved a relatively low level (43%) of intercoder reliability. Following the negotiated agreement method, the reliability was raised to 80%. Personal dynamics have the potential to influence the negotiation process – especially if the one coder is significantly more experienced or senior than the other. Finally, the view of Yardley (2000) was that inter-rater reliability as a means of checking objectivity of a coding system is meaningless, arguing that codes are shaped by the purpose and perspective of those who create them.

For the purpose of this study, all data were coded by the researcher alone. However, coding decisions were and a reflective diary were shared and discussed with the supervisory team to ensure dependability. A degree of dependability was also afforded by the use of Nvivo to document the development and definitions of themes and subthemes. Credibility was checked by the researcher sharing a draft of the thematic analysis report with five of the participants to confirm it reflected their views. One responded by saying *“I think the themes are a really good description of the tube feeding and BD ‘journey’ that I’ve been on. So I felt like I identified with most of what was written to be honest”*

### **3.10 Conclusion**

In conclusion, this chapter presented a description of and the rationale behind the philosophical approach adopted. It went on to describe the research approach and design including a section on the pilot study and the data collection and analysis. Lastly ethical considerations and research quality issues were presented in the final two sections. Results from the in-depth interviews will be presented in the next chapter.

## Chapter 4 Phase One In-depth interviews: Results

### 4.0 Introduction

Following analysis of the data, four overarching themes were identified. The first theme is entitled loss. In this early stage parents are coming to terms with issues of loss. Loss of the 'normal' child, of a 'normal' life, of their own sense of who they are i.e. a parent who is able to take care of and nurture their child. Gradually they begin to find ways to take control and to cope with the sense of loss. However, this can lead to conflict; the second overarching theme. Within this theme there are subthemes of fear and uncertainty, mistrust and paternalism.

The subtheme 'dealing with conflict' appears to serve as a conduit between theme two - conflict and theme three – empowerment, with both healthcare professionals and families making compromises. Families are able to move away from the cycle of conflict towards a more constructive solution focussed state. Although not necessarily a simple sequential journey, and the earlier themes of loss and conflict are still to an extent present, this third theme sees parents change and become more empowered and confident.

The fourth and final theme can also be viewed as the ultimate goal for parents. The theme is titled quality of life. This encompasses the well-being of the child and family, choice, balance and acceptance of a different concept of normality. This new normal may not reflect that which the parents had envisaged for themselves, their child and their family but it is one with which they feel comfortable and which they accept.

Appendix 6 illustrates the codes and subcodes with a definition. Figure 4-1 below provides an overview of how the codes related to the final overarching theme.

Overarching theme	Associated codes
Loss	Emotion, nurturing, nutrition, parental belief, self-efficacy
Conflict	Compromise, conflict, schools etc., parental belief
Empowerment	Financial, information and discovery, questioning, parental belief, self-efficacy, support, trial and error
Quality of Life	Child's well-being, choice, family, medicalisation, normalisation, nutrition, parental belief

Figure 4-1 Overarching themes and associated codes

Four overarching themes were generated from the codes. Data coded under ‘emotion, nurturing, nutrition, parental belief and self-efficacy’ related to the theme of loss. Data coded under ‘compromise, conflict, parental belief and schools’ related to the theme of conflict. Data coded under ‘financial, information and discovery, questioning, parental belief, self-efficacy, support and trial and error’ related to the theme of empowerment. Finally data coded under ‘child’s well-being, choice, communication, family, medicalisation, normalisation, nutrition, and parental belief’ related to the theme of quality of life. Figure 4-2 below summarises the themes and subthemes.

Theme number	Title of theme	Subthemes
1	Loss	Control
		Validation
2	Conflict	Sources of conflict
		Impact of conflict
		Dealing with conflict
3	Empowerment	Questioning
		Persistence
		Innovation
		Iatrogenics
4	Quality of Life	Choice
		Well being

Figure 4-2 Overview of themes and subthemes

#### 4.1 Description of sample

All participants were mothers and three had adopted the child who was using the BD. All the adoptive parents also had their own birth children. The age of the children ranged from 3years to 19 years of age. The age at which the child had had their gastrostomy inserted ranged from 4 months to 12 years of age. Each participant was given a unique identifier (Px). Figure 4-3 below summarises characteristics of the sample.

ID	Parent Age	Parent Education	Income	Age of Child	Diagnosis	Age at gastrostomy	Reason for gastrostomy	Reason for BD	Source of Recruitment	Interview Medium
P1	46+	Degree	£76+	14y	Neurodegenerative disorder	12y	Unsafe swallow	Formula intolerance and vomit	School	Phone
P2	36-45	Degree	£36-50K	3y 8m	Cerebral Palsy and epilepsy	2y 2m	FTT / aspiration	Reflux and bowel movements	Internet	Skype
P3	36-45	Degree	£26-35K	6y	Undiagnosed	12m	FTT	Formula intolerance	Internet	Skype
P4	36-45	Degree	£26-35K	13y	Neuromuscular disorder	9y	Unsafe swallow	Bowel movements	Internet	Skype
P5	36-45	Degree	£36-50K	7y	Premature	3y	FTT	Reflux	Facebook	Phone
P6	36-45	Degree	£51-75k	7y	ASD (premature)	1y 9m	FTT	Bowel movements	Word of mouth	Face:face
P7	26-35	A Level	<£25k	19y	Cerebral Palsy	7y	FTT	Parental preference	Facebook	Phone
P8	36-45	Post grad	£36-50K	8y	Cerebral Palsy and epilepsy	5m	FTT	Formula intolerance	Facebook	Phone
P9	36-45	Degree	£51-75k	3y	Posterior fossa tumour	1y 3m	No swallow	Parental preference	Internet	Skype
P10	46+	A Level	£51-75k	5y	Neurofibromytosis 1	2y	FTT	Formula intolerance	Facebook	Skype
P11	26-35	A Level	<£25k	10y	Profound multiple learning difficulties	6m	Unsafe swallow	Formula intolerance	Hospice/school	Skype
P12	26-35	Degree	<£25k	10y	Cerebral Palsy and hydrocephalus	3y 6m	Fundiplocation	Bowel movements	Internet	Phone
P13	36-45	A Level	£26-35K	3y 6m	Joubert's syndrome	7m	FTT	Formula intolerance	Hospice	Phone
P14	46+	Degree	£76+	3y	Kabuki Syndrome	4m	Fundoplication Reflux life threatening event	Formula intolerance	Facebook	Skype
P15	26-35	GCSE	<£25k	9y	Down Syndrome and epilepsy	8y	Delayed swallow	Formula intolerance and reflux	Hospice	Phone
P16	36-45	Post grad	<£25k	5y 8m	Inability to thrive	8 m	FTT	Bowel movements	Facebook	Phone
P17	46+	Post grad	£76+	3y	Costello syndrome	6m	Unsafe swallow	Formula intolerance and reflux	Word of mouth	Skype
P18	36-45	Degree	£51-75k	12y	Noonan's syndrome	1y 4m	FTT	Formula intolerance	Word of mouth	Face:face

Figure 4-3 Characteristics of interviewees

The following sections in this chapter will analyse each of the themes in more depth, and provide extracts to illustrate and support the interpretation of each theme.

## 4.2 Theme 1: Loss

The first theme describes the loss faced by parents. The concept of loss for parents was multifaceted. Parents of newborn babies faced the loss of the 'perfect' infant that they had been anticipating for the past nine months. For parents of older children with degenerative conditions or acute trauma it was defined by the loss of the child they had known. Parents also faced a loss of their own sense of identity, of control,

of independence and confidence. Figure 4-4 below shows the theme of loss and the subthemes.

Theme 1	Subthemes
Loss	Control
	Validation

Figure 4-4 The theme and subthemes of loss

#### 4.2.1 Control

Participants described a wide range of emotional responses to control and to the loss of control. The following extract from P1 illustrates her sense of loss when her son was no longer able to eat. It also illustrates how using BD gave back some sense of control, and that in turn alleviated some of her emotional distress.

*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 and I thought we really, you know he's losing so much already, yet by doing something like the blended diet we could actually open his whole world up.*

There was a sense that once a child was using a gastrostomy to feed, the parent's role in managing and controlling their well-being with regards to eating was forfeited. P4 described a conversation she had with her dietitian who highlighted this shift on the locus of control.

*He [the dietitian] said to me 'we let children eat McDonalds everyday for a meal you know – all the meals everyday and we don't worry about what their intake is just because they're eating, but he said as soon as you've got a tube, we're [dietitians] in control. And it's crazy' – which it is.*

Parents appeared to seek proxy measures of normal parenting practises as a means of regaining a sense of control. Thirteen of the participants compared the introduction of BD to weaning, and used the terminology associated with weaning when talking about how they had introduced BD. For example -

*.. introduce one food at a time like you're supposed to wean babies. (P18)*  
*...and if you child's never eaten then you do need to follow the path of weaning like you would a baby. (P3)*



P2 compared introducing BD to weaning her other children (who did not have additional needs).

*Well a bit like when you're weaning your baby I chose when I weaned my babies, to make my own food and to do baby led weaning.*

P9 acknowledged the importance of having some control/influence in her daughter's care. Her daughter had been diagnosed with a brain tumour at 10 months of age. The extract below illustrates the fundamental impact of loss of control and how the use of BD addressed, and brought some resolution to the situation.

*But because xxx was so poorly and there was no control in anything I could do for her, you know my baby at 10 months old everything was suddenly taken off me and I didn't feed her I couldn't do anything for a long long time. And I think, I will be honest and this is with my personality a big bit was control. I think it was getting control back of looking after my little girl. And by me choosing and me deciding what she was going to eat gave me a bit of control and made me feel like I was looking after her again.*

Similarly P8 described how the sense of failure that she experienced when she was unable to breastfeed her second child was overcome by the successful introduction of BD.

*You see I got the chance to breastfeed my daughter and that was fantastic you know. I didn't get to do that with him and that whole feeding and nurturing I -I mean I don't want to be sexist but I as a mother that is such a big thing a big thing. And when I finally got it [BD] right for him it was brilliant.*

#### **4.2.2. Validation**

Parents described the impact of the loss of validation in their ability to care for their child as they believed they should.

P13 recalled how she felt that she was not being listened to or taken seriously by doctors. Her son was having episodes where he stopped breathing, but they had not been witnessed by anyone else.

*I had spoken to a load of doctors and they kept saying he is fine -you know - that I have got a problem.*

Parents talked about how they felt their child's weight gain was viewed as a measure of their parenting skills particularly when they were using BD. However, they also

acknowledged both the importance of weight gain and the difficulty of sustained weight gain.

In this extract P13 describes a visit to her gastroenterologist.

*I think it was in the October that we went up to xxx hospital for a review. They weighed him and they said he was (unclear) kg and I was literally oh my god! this is amazing like you know we had been trying so hard.*

The pleasure and excitement from this parent illustrates how emotive this area is, and the final phrase 'we had been trying so hard' provides validation to her use of BD.

Another parent, P16 described her early experience of using BD with regards to weight gain.

*The first 2 weeks that I did that [BD] she lost a bit of weight so I panicked a bit - that wasn't nice .... I asked the other mums 'what am I doing wrong'?*

In this extract the emotional impact of weight loss on a parent is shown. Her immediate reaction is to blame herself.

Similarly P4 recalled her decision to use formula feeds in an attempt to improve her son's weight gain, which had been faltering for some time.

*We tried feeding him formula overnight to try and gain some weight and it was such an epic failure.*

Again this sense of failure is inextricably linked to the belief that parents are judged (or indeed judge themselves) in terms of their ability to feed their child, and for the child to gain weight.

The fact that weight gain was a highly emotive area for parents may account to some extent for the perception that it was being used as a measure of their ability to feed their child appropriately; and in turn they were being criticised by HCPs. P10 recalled a conversation she had with her dietitian prior to starting BD. The dietitian said-

*You will really struggle to get her to gain weight because you have to water it down so much to get it through the tube.*

Weight loss or poor weight gain in a child on BD was seen as vindication of the view of the HCPs that BD was not an appropriate means of feeding. Parents were aware of the nutritional needs of their children but there was an undercurrent of anxiety about being criticised for poor weight gain as P12 described.

*At the moment he needs to put on a bit of weight so I am being a bit more heavy-handed with the cream and the oil and the avocado things that I know are high in calories.*

Parents who were confident in their use of BD still felt they were being judged in terms of their ability to provide a balanced diet. P6 explained.

*And literally weighing counting things out so that when the dietician asked for 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, whereas now it's much more from a nurture point of view.*

### **4.3 Theme 2: Conflict**

During the interviews participants spoke openly about how their decision to use BD had led to conflict. In this section the sources and causes of conflict will be discussed. It will also report on the impact of this conflict and finally describe how participants deal with conflict.

<b>Theme 2</b>	<b>Subthemes</b>
Conflict	Sources and causes of conflict
	Impact of conflict
	Dealing with conflict

**Figure 4-5 The theme and subthemes of conflict**

Data were coded from all participants relating to the theme of conflict, although the degree to which they felt conflict was variable as was the impact upon the participants. Some dealt with the conflict by becoming secretive but others sought compromise

#### **4.3.1 Sources and causes of conflict**

Parents faced conflict resulting from a range of factors including differences of opinion, inflexibility, mistrust and paternalism.

The first source of conflict to be discussed will be that of the 'establishment'. This was a rather nebulous concept, viewed as 'fighting the system' as opposed to conflict

with individual practitioners. Participants described conflicts and disagreements with their local teams, with their schools and local authorities, which they regarded as inflexible and not family-centred.

P18's exasperation with the establishment is illustrated in the following extract.

*He was at a special school with a nursing centre with this insane situation where nurses are not allowed to put anything but formula so the nurses had to train the TA to feed him.*

Participants described their concern and mistrust of the pharmaceutical companies that provide formula feeds and tubing for their gastrostomy fed children. Participants questioned the motives of these companies and stated why they believed that these companies may be putting profit before the best interests of patients. Others questioned the costs to the NHS and were frustrated that they were able to have expensive formula feeds but could not have alternatives such as coconut milk on prescription. P 13 said -

*The NHS is shooting itself in the foot.*

P18 talked about her experience of a Facebook group in the USA, where formula is not always covered by insurance, where families were supported in their use of BD.

*So, as a result of that hospitals were and I think continue to be very supportive in terms of putting together a kind of quick and dirty recipe of real food that you can put in a blender and put down the tube. So, I knew a number of families that did that.*

Families provided examples of a paternalistic establishment, which was contrary to their views of patient centred care. P10 recalled a conversation she had with the surgeon who had inserted her child's gastrostomy.

*I'd initially asked whether or not I could give her real food. You know could I blend soups for her and things like that and he said we couldn't do that. We never actually asked the gastroenterologist because it just sort of ended that conversation you take that as it is don't you? And it ended there really.*

Contradictory advice and behaviour from HCPs was another source of conflict. A mother described how her dietitian mentioned the issue of food hygiene as a concern around BD. P18

*I said would you like me to get a food hygiene certificate? No no that would be excessive [mum laughs] it's so full of contradictions.*

One parent explained that her child's neurologist, gastroenterologist and respiratory consultant were all supportive of the use of BD but her dietitian was not. Similarly P10 experienced contradictory rules; when her daughter was an inpatient she was allowed to bring in her blend but there was no fridge in which to store it. She concluded -

*It's funny with health and safety rules when you come in when you're coming to hospital and it was really really difficult to find a fridge!*

### **4.3.2 Impact of Conflict**

This section will consider the overt manifestations of conflict; feeling judged and deskilled, fearful and uncertain, isolated, secretive and frustrated. The first impact to be considered is judgement, which encompasses judgement by others and by themselves, which led to inner conflict.

P18 recalled a conversation that took place with her son's dietitian several years after she had first started using BD.

*For that period I was feeling very much under scrutiny ... there was this kind of conversation of you are lacking so much in common sense that I feel very much victimised.*

Participants also spoke of how they had judged themselves. P10 described the sense of self-doubt when she was at a low emotional ebb and feeling alone, and there was a sense that she had nowhere to turn.

*It is a very very isolating and quite slow process because you've got to get through quite a few emotional hurdles as well. You know am I doing the right thing .. because there's literally there's nothing anybody can do to help.*

P10 described the powerful emotional struggle that parents go through regarding their feelings of self-judgement at the loss of their ability to feed their child when a gastrostomy is required.

*As parents we are made to nurture aren't we, and feeding is a huge part of that. And so the feeding tube felt alien to what you are hardwired to believe in and to do, that it was a really really agonisingly difficult decision.*

Her heightened awareness of her inability to feed her child in the way that she wanted was reinforced by the credence placed on eating by society, making her sense of inadequacy even greater.

*And feeding is everywhere, and I sort of noticed I noticed more so when xxx didn't eat, how much feeding takes a part of your life because when I knew she wasn't able to eat it was everywhere.*

This self-judgement bordered on guilt for P16. She described a time when she read about the contents of formula feed.

*I had a look at the ingredients of formula I gave her and found myself thinking why didn't I look at the ingredients before - it didn't occur to me to think what I was putting inside her 4 years ago ... there is a sense of guilt definitely because why didn't I as a mother think about that.*

Parents alluded to a sense of deskilling that occurred when they were told that their child needed to be tube fed. This feeling was reinforced by the unfamiliarity of the situation and by Healthcare Professionals (HCPs) using clinical terms. P8 described her feelings.

*You are very frightened a lot of the time because it is all medical procedures you know it is not your world necessarily that you're walking into.*

This notion of deskilling had a benign quality; HCPs and others did not appear aware of the impact they were having on parents. However, there was a sense that the attempts or wishes of parents were being undermined by a lack of engagement and discussion prior to decisions being taken. P5 described her feelings about the insertion of a nasogastric tube (NG tube) saying -

*I was really against it, but she felt her concerns were not addressed before the NG tube was placed.*

Another parent, P8 recounted how she felt undermined during sessions with a speech and language therapist.

*I had several sessions where we used to go to try and get him to try things orally, but I was so nervous about doing it under the watchful gaze of the speech therapist it kind of put me off the whole thing, you know I was distraught by it really.*

Parents described how use of formula had become the norm, and how its use had disempowered/deskkilled parents around feeding their child. P10 -

*If people were feeding the children prior to its [formula] actually coming in, it [BD] must have been okay and now it [formula] has just become the norm and nobody knows any different we follow like sheep.*

The preceding examples of deskilling or disempowering parents resonate with the notion described in the literature review of a mismatch of priorities as perceived by families and HCPs. This final extract from P18 illustrates the point.

*Doctors will tell you it [BD] is so much work and wouldn't it be easier to give him formula; yes practically it would be easier but I wouldn't be his mum anymore and that's really huge.*

Participants described uncertainty resulting from acting against medical advice. P10 -

*It is a really big step because you are doing something that somebody is telling you not to do.*

For other participants, their actions led to them feeling fearful of what would happen to them if HCPs became aware that they were using BD. P12

*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.*

A feeling of isolation resulted from conflict for some participants. P10 had decided to go ahead and start using BD despite being told not to do so by her child's HCPs and recalled how she felt at the time.

*And when you're taking something like that into your own hands and it is your child it is quite difficult so yes it is very very, at the moment while there is no recognition of it being option for people quite an isolating process to go down.*

This sense of isolation was combined with frustration for P18 who described a lack of engagement when she wanted help with producing a blend that would be suitable for her son.

*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.*

Parents also voiced their frustration at the lack of engagement from schools, and tried to understand the reasons for it, citing lack of confidence, time constraints, worry about setting a precedence. P1 -

*I wonder whether they are worried about opening the floodgates, because I think there are quite a few other parents who want to do it, and the school are going woow!*

Some parents who faced conflict with their HCP described how their experiences led them to become secretive about what they were doing. The covert use of BD stemmed in part from the knowledge that they were opting to feed their child in a way that was not supported by HCPs and despite their belief in the benefits of BD, little was really known or understood about potential pros and cons of BD. P12 spoke about a conversation she had had with other parents at her child's school who were using BD.

*We have all felt like if you tell anyone you might get into trouble...and that very first dietician that we had discussed it with was just so horrified you know it put me off I didn't tell anybody else long time I thought that if that is not acceptable I will get into trouble if I do that.*

#### **4.3.3 Dealing with Conflict**

Parents and practitioners alike dealt with conflict differently. Parents appeared to become acclimatised to confrontations in their lives. Some parents became more resilient and as a result coped better with the challenges of using BD, and found ways to avoid potential confrontations. P7 described an encounter with her dietician.

*So I sort of said I was giving him this the breakfast ... she wrote it all down and I think she just assumed what I was talking about was what I was feeding orally. Like I say we've not had too much of a battle and I think having a young man with his needs for 19 years you grow quite a thick skin.*

For other parents secrecy was used as a means of avoiding conflict. P15-

*We didn't tell the professionals what we were doing. I kind of knew that they probably wouldn't be that happy and I know they don't really approve of it generally. ...you do feel like you're doing it behind their back little bit because you know they don't approve of it.*



The language used by participants implied parents were fearful about how HPCs would react if they became aware that they were using BD. Phrases such as –

*'I just started quietly', 'I kept it incredibly quiet that I did it',  
I told no one', 'someone caught me doing it', it sort of leaked out – I didn't say  
that was what I was doing, It feels like you're doing a slightly naughty slightly  
underhand, I thought if I told anybody I would get into trouble.*

The frustration around the impact of the perceived need for secrecy was conveyed by P12 in the following extract; when asked where she went for advice she like others frequently consulted social media support groups.

*But it shouldn't be the first line of "I am not going to tell my dietician but" you  
know can you strangers on the Internet help me decide what to feed my child?*

Parents provided examples of how they were able to deal with conflict with the help of members of their child's HCP team – particularly when cross agency solutions were sought. P10's child was due to start at a mainstream school where they had little experience of dealing with children with special needs, such as gastrostomies and were reluctant to agree to feeding using BD.

*So her consultant wrote a letter, which got us beyond that red tape. And then I  
went in and taught the teaching assistant how to, how to feed, stayed with  
them for two or three weeks just until they felt happy.*

Thus this parent had worked with her hospital consultant and her child's school in order to find resolution or a mutually agreeable arrangement.

In this final extract describes how the dietitian compromised when faced with a parents' refusal to switch her child back to formula feeds. P11-

*But I knew it (formula) was wrong. So by this time I was able to say there was  
absolutely no way I'm going to be putting him back on that milk. So she[the  
dietitian] kinda knew then that she had to work with me or lose me. And she  
was ever so good then.*

Parents described situations where they knowingly agreed to a course of action in order to avoid further conflict or as a means of resolving a situation from which they could see no other alternative. P2 had given up battling with the local school regarding feeding her child BD because the family were due to move to a different area.

*We did try asking the school I tried for about the year we've been trying and then we when we knew for definite that we were moving away we decided that it wasn't worth the battle.*

On another occasion in order to be discharged from hospital the same parent explained her rationale for giving her child formula instead of BD.

*We just wanted to get out of hospital as quickly as possible so we just agreed.*

*We put some formula down and didn't bother trying to have the [conversation].*

P15 described how her decision to use BD had meant that her daughter could not be fed at school and therefore was only attending on a part time basis.

*No they won't give it to her there so she only actually does part time ... so she doesn't actually need food when she is there.*

P5 decided to give her daughter BD at home and formula at school in order to avoid potential difficulties.

*I felt like by doing it that way we weren't going to have to involve the school in delivering it . And it was going to be less complicated for us.*

P5 negotiated with HCPs to avoid escalation of conflict, and to achieve a mutually acceptable plan.

*Our dietitian was very cautious about it but we were very open with her and said you know we do this with or without you we'd rather do it with you so that we can actually see what the benefits are and be able to tweak it with your approval. We took the decision to only do a partially blended diet because we sensed that our dietitian was able to support us better that way than going fully.*

Conciliation describes the way in which some parents sought to understand the actions and views of others. Parents, who although they passionately believed in BD tried to understand the views of those who were not advocating or indeed preventing its use.

P12 provided a possible explanation for the stance of her local hospice where her child received respite.

*There's not much incentive for places like the hospice to take any ownership and get it sorted out their end. They are quite happy opening a bag of feed and sticking him on it – it's a lot simpler.*

P5 described her interactions with her dietitian, again showing her attempt to make sense of her dietitian’s stance.

*I maybe didn't expect her to be totally supportive but she was she was just cautious with the (unclear) and she just wanted to make sure everything had been risk assessed and she came out to visit and talked about food hygiene and things like that which I was totally fine with because I understood that that was part of her job.*

Similarly P10 spoke about how she wished that she could just get advice from her dietitian, but empathised with their dilemma.

*..they can't, 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.*

These extracts illustrate a more positive and conciliatory viewpoint, which enables parents to create less antagonistic relationships with those involved in their child’s healthcare and everyday life, and in so doing enable parents to become more proactive and innovative.

#### **4.4 Theme 3: Empowerment**

This theme explores the way in which families deal with the process of learning about BD, and what it means for them and their child – practically, psychologically and emotionally. The subthemes of questioning, persistence and innovation will be explained and exemplified using extracts from the data.

Theme 3	Subthemes
Empowerment	Questioning
	Persistence
	Innovation
	iatrogenics

Figure 4-6 The theme and subthemes of empowerment

##### **4.4.1 Questioning**

Parents questioned the status quo with regards to the formula feeds their gastrostomy-fed child was being given. As they questioned practice, they sought and discovered an alternative – BD. However, as BD is not officially recognised or

endorsed by HCPs parents had to seek information and then through a process of trial and error they discovered how to use BD.

Participants recounted why they originally started questioning the use of formula and investigating BD. For some it was because they could see that their child was not doing well with formula feeds, describing frequent vomiting and problems with bowel movements. P12 explained how when using the formula feed her son had become very constipated. The laxative that she had used ceased to be effective, and rather than adding more laxatives she reflected upon how she would deal with constipation in her other children

*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 quietly just started.*

Other parents described their concern over the content of formula feeds, they questioned the use of additives and felt it to be unnatural P13-

*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.*

Similarly, some parents felt the use of formula feeds was over-medicalising their child and queried the rationale for formula feeds as P9 described.

*The milk to me felt artificial it was something that she she needed when she was very poorly I completely understood that I had no 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 I just wanted something that seemed more normal.*

In general the participants were not anti-medicine per se, but as P9 said she felt as though her daughter's formula was something she needed when she was 'poorly' not as a long term solution. For other families their motivation to use BD was more related to their desire to simply give their child normal food, and they questioned why formula feeds were used. This was particularly the case when the child or young person with the gastrostomy had previously eaten normal food, but because of an inability to eat sufficient food or an unsafe swallow they had required a gastrostomy. Others also questioned the rationale of giving children and young people a diet of just milk.

*I don't know how you would feel if you were just having milk all the time', Well I wouldn't want to be on a ready meal for the rest of my life.*

The brother of one of the young people had tried the formula and told his mum P7

*It feels awful in my stomach'. There's something in that milk that just doesn't agree with him, and I would just be interested for somebody to drink that milk and have it for at least three or four months.*

P4 was perplexed by the practice of providing formula feeds and questioned why BD was not offered as a matter of course.

*You know why don't they wean tube fed babies onto real food rather than just giving the milk all the time?*

P8 was baffled by the status quo around tube feeding.

*If the milk [formula feed], causing them to vomit what if they tried a blended diet and it stopped vomiting. So I don't understand why that hasn't been tried or there is more sort of research into it.*

Similarly P6 recounted how friends she spoke to were often surprised to learn that BD were not the norm for gastrostomy fed children.

These extracts illustrate how a variety of reasons motivated parents to find an alternative to formula feed.

At the same time as parents began to question the use of formulas, they also began to seek information about alternatives. Although there were a variety of ways in which parents found out about BD, the Internet was most commonly cited. The overwhelming majority of references to Facebook concerned support information and discovery. Some parents describe logging on initially as passive observers and learning more about BD without actually participating online in conversations or posting. Parents viewed social media and Facebook groups as both a source of information and support. P8 was asked where she was getting support.

*'Online – other parents that is where the support has always come from. The people who are in our situation are the ones that have offered the best support'.*

P6 described the unconditional support parents gave each other via online groups as well as sharing the practice of BD.

*I used to chop and change between the 2 groups. As soon as you saw someone on the tube feeding group saying oh I'm really struggling with my child's having awful reflux and I don't really know what to do there would be a swathe of people coming in saying 'go to the blended diet group - go to the blended diet group' - just read up and have a think and you know it is worth a go.*

P8 and several other participants bemoaned the lack of information available from HCPs and also highlighted their lack of knowledge about the existence of BD. P8 said-

*Some are quite surprised, others are just like okay and just write it down and just take it as fine, whatever but some have been like what really!*

P12 made an interesting observation.

*It was completely unheard of, unless you spoke to nurses who had been there for quite a long time, and they said 'well in the old days we didn't have formula feed – we used to just blend up some chicken and shove it down – that's all there was.*

Some parents found out about BD from relatives, whilst others were informed by friends who often were using BD with their own children. Others brought a book written by an adult BD user. Families described being asked by their child's school to talk to other parents who were considering BD. Others such as P15 used a more eclectic approach.

*We go to xxx for respite. So I had sort of heard people talking about it ... I did a bit of reading up ... I kinda discussed it with a few friends.*

Many of the participants talked about the lack of information and support for families and many had filled this void by providing other families with information and support, primarily on line but also via other networks or even just through arranging to meet up for a coffee and a chat.

#### **4.4.2 Persistence**

The subtheme of persistence was eloquently captured in the extract from P10 who was referring to the lack of information about BD.

*I do think, as well unless you know somebody you have got to go looking for it, and if you're not going to go looking for something for your child you'll never know that it exists.*

Parental persistence was not confined to BD. P10 described her tenacity when attempting to wean her daughter.

*She didn't wean she wouldn't take anything we literally tried everything. Absolutely every different kind of food you could imagine we gave it to her- we did games, we would give it to her every way you could imagine she wouldn't take it.*

Another dimension of persistence was self-belief. P1, whose son had a sudden onset unsafe swallow described her transition from a state of panic to one of self-belief.

*When we first started to embark on it and we were really looking at all the different minerals and vitamins I thought my god if I didn't if I didn't have xxx [family's support worker] there's no way I would be able to do this and then we kind of became very pragmatic about it and once we'd taken all the fear and scientific element out of it, and thought actually all he needs to do is to have the same meal as everyone else, coz if he was a normal 14-year-old.*

P11's persistence was attributed in part to her positive experience with a hospital consultant.

*Wonderful man. Because really .. I knew I had him on board it gave me the courage.[to keep using BD] Yeah. They fully fully understood and fully tried to work with me. As I say we were working against the climate of not being supported at the time.*

This extract illustrates the value of shared decision making and patient centred care to this parent.

Determination appeared as a trait in parents that resulted from their belief that they had to advocate for their child. This was true of parents of children of all ages. P10-

*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.*

Similarly P4 said -

*I'm one of those mums that carries on and on and on until I get what I want unfortunately – I mean it's not unfortunate for xxx but, but he's only got me to fight for him.*

Trial and error was a dimension of both persistence and innovation, and its exploration will be at the end of this section of persistence and lead into the section on innovation.

Parents experimented to find the best way to make BD work for their child. Trial and error relates to various aspects of BD; foods, equipment and decision-making and reveals parental positivity and pride.

Parents in general had little or no specific advice regarding BD. Many participants, to help them determine the sorts of food they should put into a blend and the consistency of the blend used a combined approach of trial and error and common sense, as the following extract from P10 illustrates.

*Now I take it for granted what I put in there and what the consistency is but at the start you just think right well how do I start this where do I go? What goes in? You know what do you blend up what's the consistency? What's the volume how do I know if there's enough fat in for my child, and quite often a child with a feeding tube is not their only problem, see you don't want to introduce another one.*

P17 described the process of ensuring her daughter's nutritional and calorific needs were met.

*First I started off counting every calorie and putting everything into 'my fitness Pal. I was doing it but I was finding that within error I was putting in the same amount of duocal in most days. ...and it all works itself out -sometimes it's higher one day in calories and other times it's not.*

This extract reveals as she grew in confidence she became more relaxed about feeding her child (self-efficacy mastery of new skills).

Parents described how they had to use trial and error when their children were unwell or not thriving and they were not receiving help or support from their HCPs. P10 talked about when her daughter was constipated.



*So I thought well I'll get a pouch of Ella's kitchen and see what happens. So I gave prune juice and that seemed to help that - you know there's no guidelines.*

Parents also reported about the impact of equipment and the control it gave them as P11 recalled.

*It all took off the minute I got the Vitmix. Everything was different then.*

#### **4.4.3 Innovation**

Innovation can be defined as the introduction of new things, ways of doing things or new ideas (Oxford English Dictionary, 2018). The use of BD gave parents a new sense of freedom. They spoke about how they felt less restrained and more in control than they had when using formula feeds. As the extract below from P12 illustrates parents' innovation, using their in depth intuitive understanding of their child to design and implement feeding regimes.

*I am less, you know, not worrying about the calories I think you do just get good at adjusting what you're giving to them. Like I know at breakfast he can tolerate quite a lot whereas after school he might not want as much. Whereas with formula well you're like it's 4 o'clock say you have got to have 200 ml whatever your day has been like or however you're feeling.*

P10 believed that parents needed a certain degree of confidence and resilience and determination if they were to undertake BD. She described a conversation with another parent who felt she would not be able to cope with giving BD to her son.

*Unless you feel confident enough and it really is a big step because you're doing something that somebody is telling them not to do. And you're already usually in quite challenging emotional position if your child has got additional needs.*

As parents became more expert in their child's care, they became more innovative in finding potential solutions to obstacles that they faced. Although parents saw themselves as experts in the needs of their own child, they acknowledged the importance of the therapeutic relationship and that they would benefit from advice and support from their HCPs. In the following extract P18 describes the support she felt would suit her.

*What I wanted from the relationship was somebody to talk to somebody to bounce ideas off someone you know I can phone up and say can I just tell you what I've done today and the dietician will say yes that's absolutely fine or maybe you might want to do this instead.*

Parents found innovative practical solutions such as dehydrating blends so that the family could go on a camping holiday. Another parent described how she had adapted a backpack for her son's feeding pump that he used at school and commented that '*it gives him a huge amount of freedom*'. Others talked about how they had worked out which type of blender best suited their needs.

Parents understood the importance of evidence to the medical world. They were keen to share their new evidence of the impact of BD, sometimes as a means of helping people understand their decision to use BD. The following extract from a conversation between P1 and her sister who was questioning why P1 was using BD illustrates this.

*SISTER: I don't understand surely it is the same why are you putting yourself through a lot of effort for something that there isn't any benefit of.*

*P1: But I think once you explain to people,... Or if I have been able to say well actually I have been able to take him off all of his laxatives and I think they see his energy levels they're seeing my energy levels because you sleep better you know it has been a gradual changing of the beliefs of everybody.*

Parents were also innovative in their use of Apps. In addition to providing a source of advice in the absence of support and guidance from dietitians, Apps also served as a means of evidencing the parent's understanding of and providing their child with a diet that was both nutritionally balanced and met their calorific requirements. P17 used an App to help plan her daughter's meals, which she took to show her dietitian.

*I would always go in with my example meals a spread sheet of her feeding plan. Example meals to see how I get to the 1.5 kcals per ml, .. .And any print out that I've had from my Fitness Pal app to show macronutrients and micronutrients..*

#### **4.4.4 Iatrogenics**

Participants evidenced how they believed formula feed was causing their child harm. Iatrogenics, is defined as being an illness caused by medical examination and

treatment (Oxford English Dictionary, 2018). Participants described how they believed that formula feeds were causing symptoms such as vomiting and diarrhoea in their gastrostomy-fed children. Participants viewed formula feeds as unnatural. In general participants acknowledged the value and need of their children regarding medications - however they perceived that formula feeds rather than benefiting their children were actually harmful.

Parents found it difficult to align or incorporate the use of formula into their schema of good nutrition. P10 -

*It seems to defy logic and common sense when we know that real nutrition non-processed food is what helps us as people to then recommend that a child with additional needs medically - you give processed food, it seems to defy logic.*

P16 explained the impact of her daughter having to have formula feed whilst at nursery.

*So we gave her some formula and she got extremely sick that evening and very sick the following day so at Nursery I said that we are not feeding her any more until we can get blended diet at the Nursery.*

P7 recounted an occasion when her son who was 11-year-old had reacted to being given formula. The family were on holiday and his mother was giving him BD for breakfast and supper and was giving him a formula feed at lunchtime when they were out and about. She described how her son got really upset, she said that she had been aware for a while that he wasn't comfortable with formula feed but on this particular occasion she said he got really stressed.

*And being on holiday there was lots of time so we got the old communication book out and he was very clear that it [formula feed] gave him tummy ache, and he didn't like it and he didn't want it.*

P7 had described how her 19-year-old son was able to detect whether his mother had used formula in his BD.

*For a while I did try using it [formula] as fluid you know to keep up the calorie content but he knew when I done it even if he wasn't there he knew.*

These extracts from P16, and P7 illustrate how parents gave examples of 'evidence' to support the use of BD and to highlight their concerns about formula feeds.

Others described the positive consequences of using BD. P4-

*Oh its had a massive impact its stopped vomiting – there’s no vomiting, whereas before it was constant on formula, which has massive knock on effects as well with his condition because it sort of makes him lose strength, it triggers dystonia, pain –it’s not just you know it’s not just vomiting.*

This extract illustrates how the parent is keen to share the overall benefits of BD to her child. Other parents also described how they were able to reduce the medications needed by their child when they used BD compared to when they used formula feeds.

This section has provided extracts to illustrate how the use of and beliefs about BD empowered parents to use BD, to experiment with BD, to evidence its benefits and to question the effects of formula feed.

#### **4.5 Theme 4: Our Quality of Life**

This theme explores the relationship between the use of BD and the quality of life of the whole family. It encompasses issues of choice and well-being. Families describe the values that are important to them and how these are reflected in their choices and the decisions that they make. Well-being is a concept that transcends more than just that of their gastrostomy fed child, and incorporates practicalities of everyday family life.

<b>Theme 4</b>	<b>Subthemes</b>
Our Quality of Life	Choice
	Well-being

Figure 4-7 The theme and subthemes of quality of life

##### **4.5.1 Choice**

Participants explained the importance of being able to make choices. There was an appreciation that on occasions they made difficult decisions that under different circumstances they would not have had to make. For example P13 recalled her reaction to being told her son required a gastrostomy, and how her husband supported her and helped her to see the benefits of the gastrostomy.

*I was very much against it. I said this is ridiculous my son doesn't need tubes. So my husband was great he said 'if we can take his feeding away and help him then hopefully he can learn to hold his head up and sit up and all those kinds of things.' So he had a really open mind it was very good".*

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 to feed their child via 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 be able to give her a healthy meal and know that she's well fed and she's not hungry. I would have felt differently.*

This view was shared by P12, who went on to suggest that parents whose children had previously been eating family foods orally were particularly prone to reservations about formula feeds;

*I think psychologically tube feeding is difficult for lots of people but I think we could make it easier if we made it seem more normal. They are supposed to be on this formula whereas actually if you said to families they can still eat what you're eating, still eat with you, you can just put it down the tube. Formula should be the last resort especially when a child is already orally eating and then we want to supplement that why do they automatically get given formula. I think it is one of the things that puts people off a tube ... is not necessarily the tube aspect, .. but then they are going to get given that stuff [formula]when actually they are eating age-appropriate meals.*

Parents expressed how they valued the way BD and tube feeding in general had given their child motivation to make meaningful choices. P3 described how when her son was on formula she felt she had to ensure he had the full, predetermined quantity. However, since being on BD she accepts that some days he will be hungrier than others.

*And he's in full charge of how much blend he get and so when he wants more he'll grab the syringe and try and put it down himself, and when he's had enough he'll push the syringe away.*

P4 described how her 13-year-old son (who is partly oral and partly tube fed) would rather go hungry than have a formula feed, so he used to say he wasn't hungry.

*he was refusing [formula] feeds because he knew how ill it made him feel.*

Since starting BD P4 said he likes going shopping.

*he'll choose food to eat but he hardly ever eats it [orally]... he'll say oh will you blend it for me?*

P5 also describes how her daughter is able to choose for herself how much food she had orally.

*So if she's got tired of eating a roast chicken and there's still gravy and things she'll go. Can I get that as a smoothie? So that's personal favourite and she'll ask for that one!*

P13 provides a quote that encapsulates how important it is for families to be given choices and the role that BD plays in providing families with an alternative form of food.

*I think like you say it is the choice I don't think it works every family at all and I don't think it will work every child I just think that being given the choice to make your own decision.*

#### **4.5.2 Well-being**

During the initial stages of thematic analysis this code was divided into different aspects of wellbeing; developmental, physical, psychological and diagnosis or condition. However, throughout the course of the interviews it became apparent that well-being was a fundamental concern of parents, and that it was not necessarily seen as an entity to be subdivided and classified. The opening question of the interviews was "Could you tell me about your child so I can get a picture of who they are as a person"?

This led to parents presenting their child as an individual not a list of diagnoses or difficulties, and they took the opportunity to talk about their child's personality.

*She is a very cheeky little girl, lots of character, she loves reading and she likes playing with her dolls. She likes arguing with her sister! (P14)*

*He's an 'outdoorsy' the type of person really. He uses a wheelchair full-time - but he likes to be – it's a powered wheelchair – so he likes to be bombing around as fast as he can. Basically he's a typical boy. (P4)*

*She's the most caring little girl you could come across. (P10)*

Parents describe their child in the language of normality whilst not ignoring or denying their disability; they view their child foremost as a child not a child with a disability.

Arguably the most overt element of well-being was that of physical well-being. Parents described the negative impact of formula feeds on their child's physical health, whilst describing positive changes in physical health following the introduction of BD.

Whilst it should be acknowledged that parents, who believe that BD is good for their child, might over attribute positive changes to BD, there were numerous claims made about how BD had improved physical health. Some participants stressed that the changes were noted and commented upon by others who were unaware of the introduction of BD. These parents were pre-empting those who may suggest that 'evidence' of health improvements was anecdotal and possibly related to a subconscious desire for BD to be better than formula feeds for their child. The following data extracts contain examples of objective and subjective improvements described by parents.

P1 was asked whether BD had led to a reduction in vomiting, she replied -

*Oh it did. So I mean at that point it stopped it was like magic. And his bowels improved and his vomiting stopped and his reflux reduced. Yeh - they were very noticeable things. In fact his hair has changed -his hair has gone really curly and do you know funnily enough I haven't thought to coincide the two, but he used to have quite straight hair but it has gone really curly in the last two years and his hair and nails - they grow so fast.*

One of the more overt physical impacts of BD was improved bowel function. P5 described the issue they faced.

*We struggled and struggled and struggled with trying to toilet train her and gain control of her bowels. So the biggest impact for her has been her bowel control and her bowel movements are much much more normal now. So that's been a massive thing in terms of being able to go out and about without her being embarrassed about having to do very messy changes.*

This extract from P17 illustrates the differences she noticed in her child, which in essence she attributed to her child feeling well.

*It wasn't instantaneous it was over about 3 or 4 weeks so she went from vomiting 7 or 8 times a day to just nothing. And also her personality changed she took a massive leap in development and I think it's just because she wasn't feeling sick all the time.*

The following extracts provide examples of improvements that are more objective in that others noticed them, who were unaware of the child's feeding regime.

P7 described how her hairdresser had noticed a change.

*She didn't really know anything about how he was fed because I used to turn up at the hairdressers with him and she commented on probably I think after we've been on blended for quite a while about how much better his hair condition was.*

P3 recounted how her son's teacher's noted his change in behaviour and motivation.

*They use workstations like they do for autistic children and he's pushing the other children out the way so he can get in and he can do it! Before he used to shut his eyes so that he didn't have to do anything.*

Another facet of well-being was the impact on communication. Communication serves a number of purposes, it is important for social and cognitive development, and is used to express feelings, to influence, and to make choices. There were three areas in which communication had impacted on well-being.

Firstly P13 described how the use of BD lead to increased opportunities to communicate.

*Yeah so xxx loves it, and he enjoys it he asks for it even now he will go over and get his lunch box when he wants a feed when you put it onto a spoon he doesn't want it on a spoon and he wants it in his tube so that is quite nice actually to see that he wants to be fed because it is never ever actually done that before.*

Secondly it led to increased motivation to communicate. P10 described how her daughter enjoys guessing what her mother has added to her blend by the colours, and she went on to say -



*If I have cooked some beetroot she will say 'wow is that for my dinner?' so you know there is actually a real positive to it.*

P7's 19-year-old son had used his eye gaze technology to communicate his opinion on formula.

*My young man can be very expressive for somebody who is non-verbal (mum laughs). The dietitian was absolutely clear about what his views on the subject were!*

Thirdly, it increased communication opportunities between parents and their child as P1 describes below.

*I need to keep an eye on his reaction and his body language to make sure he's not sort of getting uncomfortable or 'regurgity', and all of that. Yes and I talk to him and actually because he's learning to use an eye gaze as well and we've been transferring the symbols on we've now figured out when he is full and we ask him have you had enough? And he tells us now that he is full.*

These extracts illustrate how communication around aspects of BD has led to improved well-being of the child or young person. The parents also seemed to appreciate this increase in communication, and its overall impact.

P1 describes the psychological impact of increased communicative intent that stemmed from BD.

*I think what it (BD) did do it inclined him to make more of an effort to communicate, he felt better, as I say he had become quite withdrawn, it was really quite hard work and some days he just really chose not to engage at all which was just so unlike him because he'd always been very engaging and happy and giggly.... it brought it all back to life.*

Parental stress was another dimension of well-being that surfaced from the data. Parental stress is frequently observed in relation to feeding and eating difficulties. In a study by Peterson et al. (2004) parental stress was greater in parents of children with feeding tubes than children with other chronic illnesses such as diabetes. Participants described how using BD had led to a reduction in stress for parents of children who were part oral and part tube fed. P14 -

*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 like her*

*speech and work on that rather than worrying too much about her eating orally.*

Douglas (2002) described how parents of children with eating difficulties lose confidence in their ability to feed their child.

P16 illustrated how BD had reduced her anxiety regarding her daughter's eating.

*The blended diet allows me not to worry about how much she is eating because whatever she doesn't eat I put through the tube.*

Whilst P12 was clear and confident about her rationale for using the tube to 'top up' oral intake.

*She's eating puréed meal anyway when she gets tired why can't you just put that down the tube? and we [p12 and her partner] sort of decided actually you know we really strongly believe in this together and I think that gave us, gave us the confidence to start.*

Thus the use of BD appears to enable parents to re-evaluate their expectations around the need for oral intake thus reducing their anxiety levels and in so doing creating a more positive eating /mealtime experience.

The overall psychosocial aspects of eating were important to participants, not just about nurturing children. P6 spoke about a gastrostomy-fed adult.

*For many people it's a big social thing. And you're there with a bottle of gunk I'm gonna pour down while everyone else is tucking in to a lovely dinner - it's not the same is it - it's not the same.*

The use of words such as 'gunk' illustrate how emotive this topic is and provides more insight into why parents opt for BD. P6 also questioned the impact of a milk based diet on the normal population.

*How many people go on those milkshake diets, and they can't take it because it's just slopping around inside you -well that's what you're asking someone to have just because they can't chew and swallow?*

The integral relationship between social interactions, mealtimes and food was illustrated in the following extract from a conversation with P1. Food and eating had been an important part of family life prior to her son having a gastrostomy. The following extract provides insight into the impact on the whole family.

*Emotionally and psychologically I think he just didn't seem particularly happy um and food – it almost became a care thing rather than an enjoyable pleasurable social thing... All of a sudden you just felt actually it felt quite divisive because we used to have family meals, and xxx would be on a pump [feeding pump used to give formula feed] and we would be at the table and actually we felt, we felt really awkward eating in front of him, just didn't feel comfortable, coz it was almost like, it was almost like it felt cruel because we knew that he will be thinking well why can't I have that?*

P1 went on to describe how the introduction of BD alleviated some of the emotional distress for both her and her son.

*And I felt in my heart that he was missing out and I thought we really, you know he's losing so much already, yet by doing something like the blended diet we could actually open his whole world up.*

Participants recounted how the use of BD became the 'norm', integrated into their everyday family life and spoke about the practicalities of blending.

P12 described how the entire process of BD was assimilated into family life.

*Sometimes they [siblings] will help blend up things for him. xxx sits at the table with the rest of us, and he eats the same as the rest of us. The other children think of it more as – well xxx has got the same as us, they are more interested in what he is eating, they want to help you know plunge the syringe it is a real family thing.*

Participants recognised that the use of BD does have obstacles. The preparation of the BD was acknowledged to be time consuming, and added an extra worry. P12 -

*It adds another element to the whole day obviously I have always got on the back of my mind what are you going to have for tea? Can you eat what the rest of us are going to have? I will occasionally do a big cook up and make sure he has got a freezer full of suitable meals.*

Several participants also commented on the costs associated with BD. P12 explained-

*It has been it has been more expensive - there was a £500 blender that was needed for a start. We started off with just like a stick blender and then I would have to strain it make sure there's no lumps. Then I decided right if we*

*are really going for this and I want to give things like nuts I need a whizzy blender so there was that expense.*

Conversely P4 described a conversation she had with her dietitian that illustrates that parents were not concerned about the everyday costs of feeding a child.

*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!*

However, families also recounted the benefits of BD for their everyday life; P5

*We were able to go to places and just order some soup and shove it down her tube.*

P8 said -

*When we go out we just blend it say for example a sandwich cut up and some fruit and we put it in a cool bag and we take it with us and feed him when he's out and about with us. So it has made a massive difference.*

Participants described how they managed BD on family holidays – some dehydrated blends whilst others ensured that the places they stayed had the facilities required.

P14 described how they made things work for their family holiday.

*It is always interesting going on an aeroplane with your 2 litres of puréed food it does seem to upset security a bit! But you know we manage we've been abroad we just take the blender with us and we do it while we are there.*

#### **4.6 Discussion**

This section will provide a summary of findings and brief analysis of how each of the key themes relate to the theoretical models and other research. Further discussion, elaboration and triangulation of the findings of all three phases of the research will be in chapter 9.

Parents experienced loss in a number of areas. For example loss of their identity as a competent parent, who should be able to feed and nurture their child and loss of their 'normal' child. These in turn led to emotions of guilt and isolation from 'mainstream' society. Loss of control occurred as a result of paternalistic attitudes and behaviours experienced by some participants from HCPs, with families recounting HCPs questioning whether they were aware of the cost and time implications of BD.

Conflicts between HCPs and parents led to a reduction in self-efficacy. Parents recounted negative comments and inconsistent advice from HCP both of which were found to be detrimental to self-efficacy (Swanson et al., 2012). Inner conflict and feelings of inadequacy expressed by parents were also detrimental to self-efficacy. A mismatch of perspectives and priorities described in the paper by Cowpe et al. (2014) was apparent in confrontations described between HCPs and parents. In some instances this was due to differing priorities; the desire to have a blended family meal versus the desire to provide a feed of known calorific and nutrient content. This was also viewed as HCPs being paternalistic by some families who expressed resentment at not being trusted to feed their child 'correctly'. The self-regulation theory can be used to understand that parents' willpower and inner strength enabled them to face such challenging situations.

The theme of empowerment can be understood in terms of self-efficacy with the desire to master new skills providing some explanation as to why parents spent time on the Internet searching for information about how best to feed their child with BD. Similarly vicarious experience, another facet of self-efficacy was reinforced when parents went onto the BD Facebook group and read about the successes of other parents. Self-efficacy increases a person's willingness to question and experiment (Ormrod, 2008); a factor which was exemplified in the questioning subtheme when parents were seen to challenge professional advice and also within the subtheme of innovation when parents experimented using trial and error to discover the best way to implement BD for themselves, their child and their whole family.

Likewise, asking questions, seeking information and support are examples of self-determination; that is the intrinsic motivation to make choices and control our lives in order to achieve our goals

The fourth theme was entitled quality of life. Parents' desire for their children to live as normal a life as possible may be at odds with the use of formula feed, especially for those who have previously eaten 'normal' food. Indeed Horne (2006) acknowledges that most people do not indiscriminately follow recommendations, rather they make judgements as to whether recommendations and advice fit with their personal beliefs and act in the light of that judgement, which aligns with the necessity concerns framework. Shapiro, (1988) suggests that one of the most

important actions to facilitate normal family dynamics is to remove the child with the disability from the centre of the attention. It is possible that by using BD parents are facilitating this as well as developing bonds between the child and their siblings as P 12 described.

*The fact that he sits at the table with the rest of us, and he eats the same as the rest of us have got– the other children think of it more as – well xxx has got the same as us, they are more interested in what he is eating, they want to help you know plunge the syringe it is a real family thing.*

Parents' beliefs and actions regarding quality of life can also be examined through the lens of normality and models of disability. Parents expressed their feelings of loss of a normal child, and this was particularly acute when a child had previously been able to eat family meals. The use of BD appeared to reinstate a sense of normality to meals. Families appeared to equate formula feeds with a medical model of disability, viewing the formula as something to fix their child's disability. However, they appeared to view BD through the lens of a social model of disability, describing how using BD enabled them to be more spontaneous – for example knowing that if they were out for the day they would be able to buy their child soup or a smoothie rather than having to take the formula with them. So by removing the social barrier of formula feed, families enable their child to engage in mainstream activities.

The complex interaction of the themes identified from analysis of the in-depth interviews will be examined in more detail and in the light of the findings from the other phases of the research in chapter 9.

#### **4.7 Limitations**

Although the researcher endeavoured to design and construct a robust qualitative study, it is acknowledged that there were limitations that should be considered when interpreting the findings.

Firstly while the principles of trustworthiness were adhered to in the analysis and interpretation of the data, it must be acknowledged that as the researcher my approach to coding and interpretation are influenced by my values, beliefs and experiences. The use of a second coder could have addressed this issue to an extent. However, in the light of Yardley's (2000) work which suggested inter-rater

reliability as a means of checking objectivity was meaningless as interpretations are so shaped and influenced by the individual researcher, the decision was made not to use a second coder. This may be viewed as a weakness of the study. However, the researcher did share the analysis with participants to check it was representative of their views.

For the interviews participants were self-selecting and may have attracted parents who were least satisfied with formula feeds (Thune-Boyle I., Wilcock J., 2013). It is also possible that participants may have over-attributed benefits of BD if they viewed the study as a means of raising profile of BD and ultimately gaining acceptance of BD amongst HCP. As issues in the interview included past events, recall bias is a possible limitation.

No fathers were interviewed and it is possible that they would have different perspectives and experiences; future studies could purposefully sample fathers to address this issue.

Another limitation was that there were no non-English speakers interviewed. In addition to the logistical challenges it was felt that speaking through a third party (ie using an interpreter) may mean some parents were reticent to speak openly about their views and about their use of BD. Future research could consider using multilingual interviewers to address this (Berman & Tyyskä, 2010). In addition certain aspects relating to differing cultural practices regarding feeding may have been missed by restricting potential interviewees to English speakers.

When carrying out interviews by phone there is no non verbal communication and it is difficult to understand or interpret pauses. However, on balance the offer of a range of interview mediums was considered to outweigh this limitation.

A final limitation was that the researcher did not interview parents of children who were not using BD. The researcher faced a difficult decision, but concluded that it would not be ethical to introduce parents to a form of feeding which is not sanctioned nor recommended. In the light of increasing debate and the NIHR –funded research if the research was to be restarted at this time a different decision may have been reached.

## 4.8 Conclusion

This thematic analysis provides some insights and explanations as to why parents opt for BD. The analysis reveals an often challenging and complex picture with a range of positive outcomes being attributed to BD, not just by the parents themselves but also by others who are part of their child's everyday life.

The implications for overall development are transparent – better physical health leading to improved motor developmental which in turn have led to improved sleep patterns and concentration and learning at school.

Although a range of improvements – both objective and subjective have been cited and attributed to BD, further rigorous research is required to determine the part played by BD in these improvements. This final extract below from P8 encapsulates the impact of BD on quality of life.

*In terms of the feeding - well it's completely changed it it's completely changed our lives because we are not stressed about feeding him anymore we are not getting upset because we are not thinking oh God we're gonna have to give him this milk again and he's going to throw up and umm just made everything, that bit of life easier.*



## **Chapter 5 Phase Two Blog Analysis: Methodology**

### **5.0 Introduction**

Phase two is seeks to answer the same research question as phase one, the in-depth interviews namely 'what are the reasons for and implications of using BD'?. However, different issues may be exposed due to the different sources of data and data maybe more candid (Eastham, 2011), so a supplementary questions is 'are different reasons for and implications of using BD are identified by data gathered from blogs as opposed to in-depth interviews'?

Both parents and professionals report that social media has played a part in the spread of interest in BD (Coad et al., 2016). This phase examines blogs, which are part of social media, and will aim to establish if different reasons for and implications of BD use are identified by data gathered from blogs as opposed to in-depth interviews

There has been an upsurge in the number of research studies investigating the use and impact of social media and healthcare in the past decade (Jones & Alony, 2008; Lee, 2015; Rothman et al., 2015). Blogging provides a means of self-expression, social contact and academic knowledge and interest (Jones & Alony, 2008). Parents access the Internet for additional information about chronic diseases (Paterson et al., 2013). Online resources, including advice from peers are a significant source of health information (Fox, 2011).

Blogs can be used to substantiate concepts identified through interviews (Acaster & Wild, 2009; Yen et al., 2013). Winkler et al. (2014) suggest that unsolicited first person narratives in the form of blogs offer a novel and rich source of data to examine how stroke and aphasia affect the carer and their relationship with the person with aphasia. It was anticipated that the blogs would provide a more holistic view of the lives of families using BD, as blogs were generally about life with a child with complex needs not specifically about BD. In contrast, the participants in the interviews were aware that BD was the focus of the research.

The motivations of blogging amongst patients with chronic pain or illness were studied by Ressler et al. (2012). Parallels between chronic pain and illness can be drawn with parents of children using BD, many of whom have chronic conditions often associated with pain. The paper found that those bloggers who took part were

predominantly female (81.8%). This resonates with the BD research in which a female wrote 100% of the blogs. Ressler et al concluded that initiating and maintaining blogs created an opportunity to make meaning of and gain insight into their situation, which in turn provided a sense of purpose and understanding about the illness as well as decreasing sense of isolation. Again this resonates with the BD bloggers who share their narrative around their experience of BD.

### **5.1 Theoretical Perspectives**

Three theoretical perspectives underpin this section of the research.

Firstly social representation theory (SRT) explains how representations of an issue emerge in society and go on to legitimise particular thoughts and practices regarding issues such as health and disability (Moscovici & Zavalloni, 1969). This legitimisation may be more apparent with the relative anonymous environment of blogs. SRT emphasises that beliefs and practices about health wellbeing and illness are 'intersubjectively negotiated'. SRT has resonance with needs and concerns framework which is part of the overarching theoretical framework of the entire research project (Horne et al., 1999).

The second perspective is that of the social norms theory (Perkins, 2002). Social norms theory suggests that human behaviour is shaped by moral obligations and social behaviour rules that are shared by specific groups. These norms can be either descriptive or injunctive. Thus if families go onto the BD website and read about families with whom they identify (parents of children with complex needs who are gastrostomy fed), opting to try BD can create or consolidate the social norm.

The third theoretical perspective is that of agenda setting theory (McCombs & Shaw, 1993). People acquire cues to the relative importance of various topics based on the emphasis given to them in media. If social media selectively amplifies these messages they can be far reaching. However, extensive sharing of inaccurate or 'fake news' can provide undue prominence to potential harmful ideas on social media. This is an important consideration in the realms of BD as families turn to social media for advice in the absence of advice from health professionals.

## **5.2 Research Design**

The purpose of this phase was to obtain a rich and meaningful understanding of the bloggers' own experiences and perspectives on BD. In contrast to phase one the experiences and perspectives from blogs are unsolicited. This non-reactive data (i.e. data without interaction with the researcher) was obtained from public blog sites. As with phase one, thematic analysis will be used to analyse the data from the blogs. Firmin et al. (2016) used a mixed methodological approach to compare correlations between findings from thematic analysis and The Linguistic Inquiry Word Count (LIWC) with interview data. Significant correlations were found and Firmin et al. concluded that this mixed methodological approach could enhance the rigor of thematic analysis, and potentially inform new areas for investigation.

### **5.2.1 Sampling Strategy**

There is little consensus, and relatively few qualitative studies that use blogs as a data source. In order to inform the sampling strategy the researcher reviewed a range of peer-reviewed articles that used qualitative analysis of blogs (Elliott, Squire, & O'Connell, 2017; Garbett, Harcourt, & Buchanan, 2017; Keelan, Pavri, Balakrishnan, & Wilson, 2010). In these studies the research question influenced the sampling strategy. Some used country-specific sampling, others gender-specific. For the BD research, the researcher used topic-specific sampling as this enables blogs from the people using BD to be targeted.

Two searches were carried out. Firstly a specific blog search engine, 'Twingley' was selected. Twingley provides the facility to search on precise terms, to select a language and timeframe. All the blogs that contained the term 'blended diet' from the past three months were retrieved. The second search used a generic search engine Google, which was rated the most popular search engine in the world in 2017 with an estimated 89% of the market share (Reliablesoft.net, 2017) and therefore likely to be the search engine that a parent searching for BD blogs would use. All posts were found in the first seven pages of the Google search, pages eight, nine and ten had no hits so no further pages were searched, again trying to replicate how a parent would be likely to search.

Figure 5-1 below summaries the search strategy used.

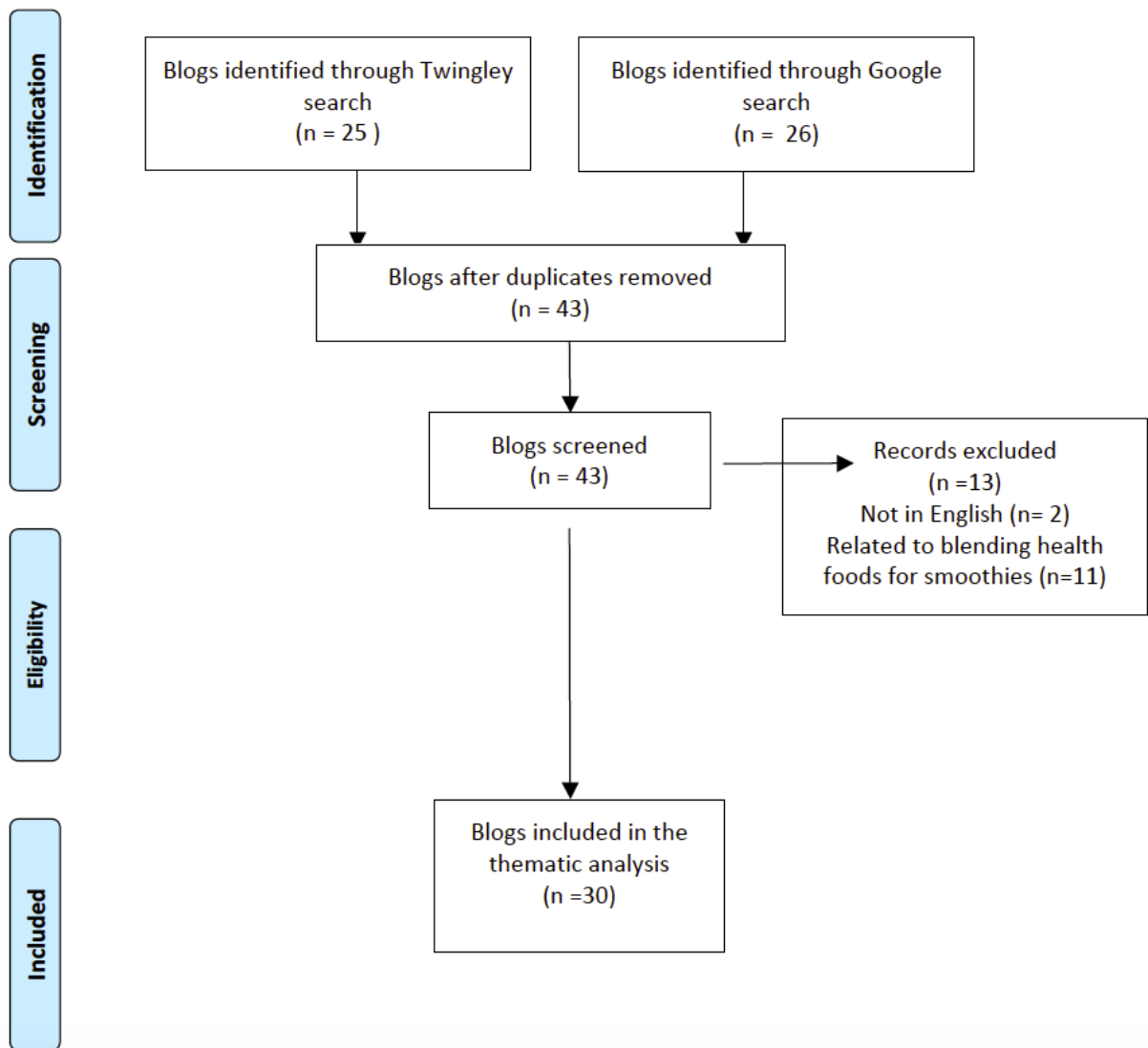


Figure 5-1 Search strategy for blogs

### 5.2.2 Inclusion Criteria

The following inclusion criteria were used.

- I. Only blogs that were written in English were included
- II. Blogs had to be published publicly available and were easily accessible via Internet search without a password or special access
- III. Blogs had to be unsolicited. This was to ensure that bloggers did not skew their blogs to their perception of what they thought I as the researcher wanted to hear. It also ensured that blogs were not written with the purpose of influencing the research

IV. Bloggers had to have been active in the past 3 months

As the purpose of the blog analysis was to gain the perspective of parents who were using BD the following exclusion criteria were established

I. Blogs written by healthcare professionals

II. Blogs written by organisations

III. Blogs written solely to provide information in the absence of personal perspectives.

IV. On blog sites that allowed comments, these comments were not analysed as it was not always apparent who they were written by and also they could have been viewed as being solicited i.e. the blogger had asked for opinion or response.

## **5.4 Data Analysis**

The posts from both the Twingley and Google searches were given unique identifiers to ensure anonymity and were then imported into NVivo and to LIWC for analysis.

### **5.4.1 Thematic Analysis**

All blog posts were imported into NVivo for analysis. Thematic analysis was used to analyse the data (Braun & Clarke, 2014).

The six steps of thematic analysis (which include the preparation and analysis of the data) were described by Braun and Clarke, and are explained below in the context of the BD research -

I. Familiarisation with data

All the posts were read online to ensure they met the inclusion and exclusion criteria. Posts were then copied into Microsoft Word documents and any comments, photographs and images were removed. As described in 3.4, the researcher noted down initial impressions, ideas and thoughts at this stage that also acted as an aide memoire. Then each data set was imported into Nvivo.

II. Generating initial codes

From reading and rereading the data, preliminary features were noted and coded. These codes were data driven i.e. derived from the data. As an inductive analysis was being undertaken, line-by-line coding was used and all the data was assigned to relevant codes with some extracts being allocated to more than one code. As codes

were created, they were defined. It is acknowledged by the researcher that there will have been a degree of contamination of thoughts from the analysis of phase one the in-depth interviews. However, there were also codes for the blog analysis that were not in the in-depth interviews analysis (see appendix 3 for lists of codes and their definitions for in-depth interview and blog analyses).

### III. Searching for themes

Step three marked the start of the interpretive analysis. Codes were collated into themes and some subthemes. At this stage the themes were predominantly descriptive. The relationship between codes, subthemes, and themes was borne in mind in this and future stages. Figure 5-2 below illustrates the final themes and the corresponding codes.

Overarching theme	Associated codes
Loss	In charge/control, medicalisation, nurturing, parental feelings and beliefs, real food
Conflict	Appointments, blogging/soapbox, conflict/mismatch, the establishment
Empowerment	Blogging/soapbox, equipment/cost, in charge/control, support, establishment
Quality of Life	Appointments, chores, equipment/cost, family life, medicalisation, oral, real food, religion, sleep, vomit, well-being

Figure 5-2 Overarching themes and associated codes - blogs

### IV. Reviewing themes

At this stage the descriptive themes were reviewed and became more interpretive in nature. In order to ensure coherence between the themes a thematic ‘map’ was generated.

### V. Defining and naming themes

This stage involved defining the themes, identifying the story each theme told in relation to the research question, and explaining how the themes related to each other. The themes, from the blogs shared similarities with those from the interview analysis, however, the focus of some of the themes varied. For example in the analysis of the blog data the theme of ‘Our quality of life’ emphasised the impact on the entire family as opposed to focusing more on the child who had the BD. These differences will be explored further in chapter 9.

### VI. Producing the report

For the final report complicated data from life stories was incorporated into a cohesive, concise and compelling document, with extracts to make the report more vivid, persuasive and credible. The report must be representative of the evidence from the literature review and perhaps most importantly it addresses the research question.

#### **5.4.2 Linguistic Analysis**

All data sets were analysed using the Linguistic Inquiry Word Count (LIWC) Software (Tausczik & Pennebaker, 2010). LIWC provides a range of data as defined below

Word Count = raw number of words within the data set.

Words per Sentence = mean number of words per sentence within each data set.

Percentage of total words = this provides the percentage of words within a predefined category such as positive emotion or biological processes.

Analytical thinking = defined as the degree to which formal, logical, hierarchical thinking patterns are used. Thus a low number in this dimension would reflect a more narrative focusing on the here and now.

Clout = defined as the relative social status, confidence, or leadership that people display. It does not necessarily reflect power (which reflects people's attention to or awareness of relative status in a social setting).

Authenticity = this reflects the degree to which a person exposes themselves as humble or vulnerable

Tone = the higher the number the more positive the tone is deemed to be, with a number below 50 implying a more negative overall tone.

All data was analysed by LIWC and then imported into an excel spreadsheet for further analysis in relation to BD specifically.

#### **5.5 Research Ethics**

The UCL Division of Psychology and Language Science Departmental Ethics Committee granted ethical approval of the project (LCRD.20.26.05), and the project was registered with the UCL Data Protection Officer (No. Z6364106/2016/08/14). There has been and continues to be a great deal of discussion about the ethics of using data from online sources for research.

Perhaps the most fundamental question is do researchers need consent when using data from blogs? Although there is no clear agreement the researcher took guidance from the British Psychological Society (Hewson et al., 2013) in addition to consensus views and other parameters used by other researchers. These included only selecting publicly accessible blogs that did not require password access, and excluding any that mentioned specific privacy terms.

Another consideration was whether the scholarly activity of bloggers meant that their work should be credited. However there is a tension between this and maintaining the anonymity of the bloggers. Another tension that exists is that although the blogs are accessible to the public, it could be argued that their purpose is not for academic research. Seale et al. (2010) took the view that posts in the public domain do not require informed consent or ethical review to be included in research. A comparison has been drawn between the use of blog data as being the equivalent of analysing readers' letters in newspapers. von Benzon (2018) urged ethicists to reconsider the paternalistic image of blog writers as being potentially vulnerable and naïve, and instead to reframe them as informed agents to enable researchers and policy makers access to the data they provide.

In order to seek informed consent i.e. make knowledgeable decision about whether or not participate, a researcher would have to reach out into the communities which they are researching, by contacting bloggers directly or through social media such as Facebook. This may immediately change the behaviour of those blogging as they will be aware that their posts may be used in research and act or speak differently thus losing the unique uninhibited unsolicited quality of the data.

Blog hosts provide privacy statements for potential bloggers that they must sign up to when setting up a Blog. Such policies give credence to the suggestion that posts are in the public domain. For example Tumblr states "*The content you create on Tumblr is, by default, public. This means that anyone can see it, and that search engines can index it.*" (Tumblr, 2017).

Similarly Facebook provides a simple table showing what can be seen in public, closed and secret groups as shown below in Figure 5-3.



	<b>Public</b>	<b>Closed</b>	<b>Secret</b>
Who can see the group's name?	Anyone	Anyone	Current and former members
Who can see the group description?	Anyone	Anyone	Current and former members
Who can see your membership in the group?	People on Facebook	Current members	Current members
Who can see what members post in the group?	Anyone	<i>Current members</i>	Current members
Who can find the group in Facebook search?	People on Facebook	People on Facebook	Current members
Who can request to join?	People on Facebook	People on Facebook	Former members
Who can see stories about the group on Facebook (ex: News Feed and search)?	People on Facebook	Current members	Current members
Who can see admins and moderators in the group?	People on Facebook	People on Facebook	Current members

**Figure 5-3 Facebook privacy settings**

Having given due consideration to the evidence and taking into account the degree of uncertainty regarding consent and ethical issues surrounding internet-based research the researcher applied the following standards:

- I. Posts will only be sourced from sites that are available to the general public;
- II. Each blog will be reviewed to identify any conditions/ expectation of privacy (eg a privacy tab or specific terms and conditions); and
- III. No individual identifiable information will be disclosed.

## **5.6 Research Quality**

Hank (2013) considered the use of scholar blogs. In the research 153 tenured academic scholars from the fields of history, economics, law, biology, chemistry, and

physics were asked about their views on the attributes and functions of blogs. Of the 153 respondents, 60% felt blogs improved research quality across a range of parameters including research quality by providing an opportunity to creatively share and explore new ideas.

Just as the use of blogs as data sources in research is a relatively new phenomenon, so is the use of software packages as a means of enhancing rigor and supporting more traditional qualitative analysis. The rationale for the use of LIWC will now be considered in more detail.

Within this research the use of thematic analysis and LIWC software served to maximise the strength of both approaches by triangulating the findings from both approaches, thus enhancing the rigor of the research. LIWC can be viewed as a tool to support objective analysis of texts (i.e. blog posts), whilst the thematic analysis provides a means of discovering more subtle nuanced findings. A second researcher independently coding samples of the data can enhance the rigor of coding for thematic analysis. LIWC provides an additional means to enhance rigor by substantiating themes identified by the thematic analysis. For example the theme of well-being was substantiated by the high percentage of 'biological process' words. LIWC data also served to highlight potential areas for further investigation such as the reasons for the discrepancy between actual and predicted levels of authenticity. Finally, an exploratory study with schizophrenic patients by Minor et al. (2015) using LIWC found that clinical variables were significantly predicted by the word use categories within LIWC. The use of anger words that were categorised as negative emotion predicted symptoms of depression illustrating how LIWC software in conjunction with thematic analysis has been used to improve the quality of research.

## **5.7 Conclusion**

This chapter presented a rationale for the use of blogs as a data source, an overview of pertinent theoretical perspectives that informed the decision, and described the research approach and design, and the data collection and analysis. The section on ethics provided an overview of considerations surrounding the use of blogs for research and highlighted the lack of consensus amongst researchers. The section concerning research quality issues describes factors that were taken into account to

strengthen the quality of the research. Results from the blog analysis will be presented in the next chapter.

## Chapter 6 Phase Two Blog Analysis: Results

### 6.0 Introduction

This chapter will present the results of the thematic analysis and the linguistic analysis from the blog post data.

The themes from the blogs resonated with those identified in the thematic analysis of the in depth interviews. Blogs provided more of a narrative, and bloggers used posts as an opportunity to share experiences or emotions. Stronger, less guarded and more visceral language was used including swear words and shouting (signified by the use of capital letters). Bloggers recounted conversations they had with HCPs within the posts, as the extract copied directly from a blog in Figure 6-1 illustrates.

I had my share of “how about if the tube gets blocked” (I have a good blender thank you very much) to “are you sure you will be able meet xxx’s nutritional needs if she is not on medical formula?” (Errr, yes. Have you seen what is in the crap you are proposing that I feed my child?)

Figure 6-1 Conversation between parent and HCP

The use of sarcasm illustrates the frustration felt by the blogger here.

Thus although blogs do not necessarily reveal different themes this form of data provides an additional dimension that may be suppressed by participants who are being directly interviewed by the researcher. For example, social conventions and concerns that a participant may jeopardise their child’s care or not be taken seriously if they swear or openly condemn practises of HCPs may impact on the way they express themselves.

There was little difference found between posts from each of the two search strategies (i.e. the search using the specific blog search engine Twingley and the one using Google).

## 6.1 Characteristics of the Bloggers and Blogs

The blogs in the study were personal blogs, (i.e. contain personal opinions as opposed to ‘official’ content). They did not provide full demographic details, however some characteristics were identified, namely who wrote the blog, the country of origin (although not possible to determine for 14 of the blogs), use of images and whether there was a link to a social media platform (Facebook or Twitter). The information is shown in Figure 6-2 below. It was not possible to check if there were links to social media for B22 and B25 as the blogs had been removed from the internet – an action that will be discussed in the limitations section of this chapter.

Identifier	Author	Images	Country	Twitter	Facebook
B1	Mother	y	UK	y	y
B2	Mother	n	US	y	y
B3	Mother	n	US	y	y
B4	Mother	n	US	y	y
B5	Mother	y	US	n	n
B6	Mother	y	UK	n	n
B7	Mother	y	US	y	y
B8	Mother	y	US	n	y
B9	Mother	y	US	n	n
B10	Mother	y	Unknown	y	y
B11	Mother	y	US	y	y
B12	Mother	y	US	y	y
B13	Mother	y	Unknown	y	y
B14	Mother	y	Unknown	n	y
B15	Mother	y	Unknown	y	y
B16	Mother	y	Unknown	n	n
B17	Mother	y	US	y	Y
B18	Mother	y	US	y	y
B19	Mother	y	Unknown	y	Y
B20	Mother	y	Unknown	y	y
B21	Mother	n	Unknown	y	Y
B22	Mother	y	Unknown	?	?
B23	Mother	y	UK	y	y
B24	Mother	y	Unknown	y	y
B25	Mother	y	Unknown	?	?
B26	Mother	y	Unknown	n	n
B27	Mother	y	Unknown	y	y
B28	Mother	y	UK	y	y
B29	Mother	y	Unknown	n	n
B30	Mother	y	US	y	y

Figure 6-2 Characteristics of bloggers and blogs

## 6.2 Theme 1: Loss

The concept of loss was multifaceted, and within the blogs the subtheme of a loss of control was most apparent. However, the subthemes of judgement, and loss of validation were also evident in the blog posts.

An extract from B1 illustrates the loss of control that parents experienced – in this case the control over how to feed her child.

*I am absolutely convinced that the blended diet is the right thing for her, but I was getting worried that if she didn't gain weight soon the medical people might make me switch back to the evil junk formula.*

Despite the mother's conviction she was doing what was right for her child she was still aware of how ultimately the final decision over how her child was fed laid with the HCPs.

There was a belief that weight gain was being used to judge parents - a proxy measure of parental competence, and with feelings of self-doubt were engendered.  
B12

*xxx's next appointment was with his gastroenterologist. This is the appt. that I always fret over because it's the one that they always are on me about his size, weight and what I feed him.*

When children were ill parents described a loss of control and an acute sense of helplessness. B11's emotive and poetic prose illustrates her anguish at seeing her daughter unwell, and the importance of being able to feed

*"A fever is an expression of inner rage." ~Julia Roberts*

*..xxx was raging last night! Poor sweet girl couldn't keep her blends down yesterday morning, so we switched to pedialyte and that helped. We'll slowly reintroduce blends today.*

In the following extract the inability of a mother to breastfeed her baby culminates in a sense of loss of control and loss of self-validation of herself as a mother able to nurture and feed her child. She blamed herself for not being able to breastfeed, rather than viewing it as something her baby was not able to do. The neonatologist has stressed the importance of breastfeeding, likening it to a medicine for a premature infant, which increased her sense of culpability B19

*A pretty strong guilt trip, but it also gave me something to focus on that I could do for her when I felt otherwise helpless.*

Bloggers described how organised they had to be in order to cope with day to day life bringing up a child with complex needs. They expressed frustration at the loss of control brought about by last minute changes. B11

*Ugh! Why do people change plans? Just stick with the plan folks. My schedule is clear, I'm ready to go and now this. Surprise! It's all for the best, really. Just me and my color coded outlook scheduled life trying to keep all the balls in the air.*

### **6.3 Theme 2: Conflict**

The theme of conflict spanned 'sources of conflict' and 'consequences of conflict'. As with the data from the in-depth interviews conflict often arose between parents and HCPs or with a more nebulous concept of 'the establishment'. However, in contrast to the interviews, the delivery and language used to express frustration and anger was less reserved and more visceral. Whether this reflects a subtle difference in the theme or the medium of the data will be discussed in more detail in chapter 7.

In the following extract B3 describes an encounter with a phlebotomist. The conflict appears to have arisen from a culmination of factors rather than one single event.

*Phlebotomist wants us in the chair. I say no. She says she prefers the chair. I say that I prefer the bed. She says babies kick too much on the bed. I tell her I could give a sh\*t less if he kicks her in the face because I'm really tired of arguing with everyone at this place today. Did you totally believe me? No, I did not say that. I said in a voice only slightly less grumpy than the one I pulled out for the boy phlebotomist, "He does better in the bed so unless you're not able to do it with him on the bed at ALL, that's what we'd strongly prefer to do." "oh, ok, fine." THANK YOU. Male phlebotomist says it sounds like we've had a stressful day. I laughed the bitter laugh of the woman who should own a t shirt saying something like "NOT IN THE MOOD FOR ANY CRAP TODAY, PLEASE KEEP BACK AT LEAST 5 FEET." I apologized and said that nothing seems to have gone right so far today and everyone's trying to blame us and I'm just grumpy and tired of arguing with people.*

Blog posts provided an opportunity for the bloggers to describe situations that had led to conflict. In some cases such as the one in the extract below, these arose from a lack of understanding of the needs of families with children with complex needs and systemic failures in terms of appointment slots. B3's son had multiple appointments with a range of specialists, which is not uncommon for children with complex needs. In the extract below B3 had just had an ultrasound

*Left there finally at 10:15. (Our first doctor appt with GI was for 10. Let's note that this was NOT MY FAULT.)*

*Check in at clinic at 10:20. Yes, I stopped to pee.*

*Evidently, what I SHOULD have done was leave ultrasound at 9:40 (note: before we even got started) so that I wouldn't be late for our check in time in the clinic. I certainly should not have taken time to pee. SO, we checked in, with the gal who checked us in telling us that a) we were late and b) we had missed an 8:00 appointment. No, I said, the 8:00 appt got rescheduled. No, she said, it didn't. Well, I said, the latest phone call I received, and the information in his MyChart, says otherwise.*

In addition to the use of capital letters, a convention that signifies shouting, B3's frustration is also shown through irony 'yes I stopped to pee'.

As well as frustration conflict also resulted in some parents feeling isolated. B19 wrote

*Blenderized diet is kind of on the fringe as far as tube feeding goes. The standard medical advice is to feed tube fed commercial formula. And it is hard to go against the status quo.*

Differences of opinion were another source of conflict, as the extract below from B2 illustrates. She was using breast milk to feed her baby but her HCPs wanted her to use formula.

*I have fought to keep her on 100% mamas milk.... It makes me sad that even when a child is growing well and thriving, the medical professionals would push for formula additives.*

This extract illustrates what some parents view as the medicalisation of tube fed babies. This concept is further explored in the theme of quality of life, in the context



of enabling children to reach their potential in as normal as possible way – without over medicalisation.

There were many examples of situations when parents felt they were battling with the establishment, and with contradictory messages. In the extract below B1 recounts the difficulty getting nursery staff trained to feed her child

*The community nurses train key workers at nursery on how to feed her with formula but won't sign people off to feed the blended food. I can't believe what I'm up against just to give xxx real food. Imagine if things were reversed and I suggested to a friend that they should just feed their 3-year old formula because they don't eat a very balanced diet. They'd be horrified!*

She highlights what she sees as an obvious illogical stance when she compares dietary advice for oral versus tube fed children (i.e. the former should have a wide variety of foods and the latter just formula).

Parents describe conflict with the HCP over the use of BD both as individuals and also the system. B28 wrote

*As soon as I started mentioning the words blended and diet I got the distinct feeling I was not going to be making friends amongst the xxx's dieticians. But overall I think I got off lightly – I have heard of parents who have had their dieticians threatening to report them to social services and for their kids to be taken into care if they insist on feeding them real food instead of medical formula.*

For some bloggers it appeared more comfortable or safer to condemn faceless bureaucracy or the establishment, rather than individual HCPs with whom they have to interact concerning their child's care.

As with participants from the in-depth interviews, some bloggers believed that the formula was causing their child harm, and this led to conflict between the parents and HCPs. B21

*We weren't supported by her doctors. I repeatedly said I thought the formula was causing her vomiting. They disagreed. The only solution they suggested was to do a Nissen surgery .... When we refused to do the surgery, they tried to coerce us into it, by saying they wouldn't write any more prescriptions for her if I continued to refuse.*

Although the blog post did not provide details of the outcome of this situation, others who also faced conflict gave a fuller account of how they dealt with it. B3 cited an incidence of inflexibility not directly related to BD but regarding the scheduling of appointments.

*It's one of those things, they want to see us in person to discuss results, so even after the results come back, we'll have to wait until we can get out there for an appointment.*

This extract shows the parent on the brink of passive acceptance – reducing autonomy and increasing paternalism. In contrast the same parent shows characteristics of passive resistance.

*Our nutritionist found a recipe online that I wasn't thrilled with, but had agreed to, but we've never tried it.*

The parent agreed with the HCP to try the recipe, but then chose not to do so. What led the blogger to behave in this manner will be discussed in more detail in chapter 9, whether it was passive resistance, a means of keeping a better relationship with HCPs, or just evaluating what the parent considered to be best for their child.

Appeasement can be defined as giving into demands in order to preserve peace. This was used by bloggers to deal with conflict, as illustrated in the following extract from B4, recounting a conversation with the dietician.

*She still wanted us to give him Peptamen Jr overnight for calcium and sodium. I agreed to this in the short-term, but my goal is to get him off Peptamen Junior completely by the end of the year. No child or adult should have to be fed while they are sleeping.*

There were also incidences of compromise as a means of dealing with conflict; B13 described a discussion with her daughter's HCPs regarding her nutritional intake.

*They felt that at least they knew how many calories were going in. This is a common concern of medical professionals, which is why I eventually modified the blenderized diet in a way that would make xxx's medical team happy by creating a recipe that provided consistent calories and fluid volumes.*

To conclude this theme a more positive outcome of conflict will be considered. B1 described a situation in which staff in her daughter's nursery were willing to feed her but the community nurses would not provide training.

*The nursery are happy to give her the blended food but the difficulty is in getting them adequately trained. I've had to help write a risk assessment for feeding her, write a protocol for feeding her and then I'll have to sign a disclaimer to say the food I have prepared meets food hygiene standards and is prepared to the correct consistency and viscosity.*

When parents feel more empowered the level or intensity of conflict with the establishment is reduced. In the above extract although the parent describes a level of frustration about having to sign a disclaimer and help write the risk assessment there appears to be a little animosity towards the establishment or the healthcare professionals supporting her child.

#### **6.4 Theme 3: Empowerment**

The phrase 'knowledge is power' is widely attributed to Frances Bacon in his book 'Meditationes Sacrae and Human Philosophy' (1597). B2 used much of a post to list and explain the content of Pediasure, which is one of the leading brands of formula foods in order to give parents knowledge.

*If you've read through this site, you are probably aware that I do not plan to feed xxx formulas. Just because she has a feeding tube, doesn't mean she should exist on a diet of corn syrup and vitamins.*

Elements of empowerment include having access to information, knowledge and resources, decision-making power, options from which to choose, whilst being assertive, feeling part of a group, in control, and able to effect change (Chamberlin 1997). B13's blog provides advice and knowledge intended to empower readers

*If you sense your doctor and/or dietitian may need persuading I suggest you start by doing a bit of research, come up with a [BD] formula recipe based on the caloric intake your child is currently on and put it in writing so they can look at it.*

B29's post illustrates how discovering about BD and the online community had made her feel part of a group or community and in turn more empowered to use BD.

*So I did what has helped me through so many challenges as a special needs parent, and that is to search the Internet to see what other moms and dads are doing and learn from them. While searching for a solution, I came across forums and groups and websites dedicated to parents feeding their children,*

*through their g tube, real food that had been all blended up. The idea was so foreign to me, no doctors had ever suggested it as a solution, but after reading about other parents' success with it I was hooked on the idea.*

On a more practical level bloggers frequently posted about the importance of planning, with regard to control and empowerment, often borne of necessity. For example getting family members to look after siblings in order to attend hospital appointments. Bloggers described precise organisation prior to going on holidays to ensure their child could continue to have BD. Figure 6-3 is an extract taken directly from a blog by B5.

The supplies I have for the trip (not including foods and water):

- Syringes
- Bolus extension(s)
- 3 Small (up to 16 oz) pourable containers with closable spout lids
- Rectangular Rubbermaid container with lid that syringes will fit in
- Gallon ziplock bags

Figure 6-3 Illustration of a blogger's post

Assertiveness was shown by B1. Her daughter appeared to have lost weight, but rather than accepting what she said,

*I was gutted. I then asked if they could measure her on the scales that you sit down on as these were the ones she was measured on before, thankfully they showed her weighing at 9.65kgs. I was much happier with that.*

Despite her confidence in asking if her daughter could be reweighed, the use of words 'gutted', 'thankfully' and 'happier' underline the strong emotions associated with weight gain.

### 6.4.1 Questioning

B28 questioned the status quo, using humour when she posted about her rationale for not wanting to use formula feeds

*My reasoning was that I cannot believe there is a magic liquid that fully provides all our nutritional needs (though a good red wine comes close. I am now talking from personal experience). Why would all health professionals otherwise bang on about varied diet and eating your veggies to us mouth eaters?*

Despite using a light-hearted tone, she still makes a serious point.

Bloggers described how they sought information, believing that there was a better alternative to formula feeds. B4

*I knew that we had to make a change, and I started talking to friends with children that were g-tube fed. I knew there had to be a better alternative to the formula. As I talked to more parents, I learned about blended diets. I had known they existed, but I had no idea how I would implement this at home.*

This extract demonstrates how B4 experienced feelings of both certainty ('I knew') and uncertainty ('I had no idea') regarding BD. B3 wrote about her deliberations as to whether to try a drug to help manage her son's reflux-

*There is one drug (it's actually an allergy med) that is used for slow emptying as well as an appetite stimulant that he thought might be useful. We're currently pondering whether to give that a try. Hey, once you've got 10 prescriptions, what's one more, right?*

Again there is not a clear-cut choice for the parent. This concept of choice will be explored further in the discussions in chapter 9.

Bloggers posted about how they had found out about BD. B12 described how she had seen a documentary about a child with complex needs who had a BD, which made her question the status quo and consider the possibility of using it with her son. In the extract below B17 described using the Internet to seek answers to her questions.

*Wary of more surgeries that may or may not work, I did some Internet sleuthing and came upon the blenderized diet (which also may or may not work).*

The post highlights the uncertainty faced by parents who opt for BD.

B18's blog questions the perception that BD increases the risk of infection, which was an area of debate amongst dietitians (Armstrong, Buchanan, Duncan, Ross, & Gerasimidis, 2017).

*Real food is not sterile. I know parents of other children my child's age, including children with complex medical histories, that eat by mouth. No one is telling them not to feed their child food because of the risk of foodborne illness. Even when I change my child's g-tube, it does not have to be done under sterile conditions. If a g-tube itself does not need to be sterile, why would the food that passes through it need to be? I will practice the same food safety practices that I use for myself and my family members. To my knowledge, I have never poisoned anyone. Therefore, I feel confident I will not poison my tubie [gastrostomy-fed] child.*

Bloggers use rhetorical questions to provide support to others, often by sharing information and opinions. B18 wrote,

*Something being easier does not make it the right choice. Would you feed your child nothing but Pediasure for years simply because it is easier? Why not? If it is not good enough for your orally fed child, why is it good enough for my tubie child?*

Bloggers use their posts as a means of sharing their beliefs in a more forthright manner, whilst still offering other parents support and encouragement. In the initial analysis some data was coded as 'soapbox', defined by the researcher as sharing experiences and offering support, often with a campaigning tone. The following extract from B18 illustrates this.

*If the fact that you need no one's permission is good enough for you, then, you can skip the rest of this section. However, there is a decent possibility you will be met with great resistance by at least one medical professional involved in your child's care. And if you choose to pursue a conversation with this person about BD, you will probably be offered one or more arguments. Below, you will find a list of common arguments and answers to these arguments developed not only by me, but by tubie BD mamas around the world.*

B19 offers support but is careful to express her comments as a veiled warning, first advising parents to work with their HCP, and then pointing out that the HCPs may not be well informed or entirely unprejudiced

*There's no one right way to do it, and you should obviously consult with your own medical team before starting it for yourself or your child. Unfortunately, a lot of medical practices are ill informed about the benefits of BD, and commercial formula is big business in our country.*

Other bloggers were less subtle. B18 referred to a frequently cited study into the benefits of BD by Pentiuk, O'Flaherty, Santoro, Willging, and Kaul (2011), and went on to advocate for further research into the area with the caveat.

*And these investigations should not be conducted by those profiting enormous sums of money from the sale of enteral formulas.*

As with participants in the interviews, the Internet provided bloggers with information that they were not given by their HCPs. This resonates with the findings of Fox (2011) that online resources, including advice from peers are a significant source of health information. B19 wrote

*Luckily we found a dietician in the Fall of 2012 through our equipment supplier. I only learned from their website that they offered dietician services, but I'm so glad I found that because the local feeding clinic dietitians were neither well-versed in nor supportive of a BD.*

In addition to supporting other parents, posts were used to empower them, as illustrated by B25's post

*We're here to give you a starting point and the resources you need to make an informed decision about blending.*

B25 continues the post by explaining about and listing potential ingredients for BD, concluding by reminding the reader,

*You are in control of the ingredients.*

B17 uses her blog to lobby for BD to be offered as an option, or an alternative to formula.

*We recognize that the blenderized diet is not for all children and that not everyone with severe GI problems will react in this way. However, I fully*

*believe that it should be an option made available by the medical community to parents as a treatment option.*

### **6.4.2 Innovation**

To recap from chapter 4, the verb to innovate is defined as “*To make changes in something established, especially by introducing new methods, ideas or products*” (Oxford English Dictionary, 2018).

Examples of innovation in the blogs often related to generating and trying new BD recipes. B20, B13 and B15 all used their posts to share innovative recipes they had devised and B22 described how she developed a nutritionally balanced base BD recipe to which families could add foods of their choice. Similarly B3 described how her innovative actions were at the point when she was at her wit’s end with no solutions or suggestions being offered from her HCPs

*yes I’m at the point where I’ll try random things*

B9 wrote one of the benefits of being innovative with regards to her daughter’s feeding regime, and the introduction of BD was

*It helped our daughter grow and get stronger*

This section has provided examples of how bloggers have questioned the status quo, shared their knowledge and experiences, and found new ways to support other parents. The cause and effect of these actions are that parents become more empowered; a concept that will be explored in more detail in section 9.3.5.

### **6.5 Theme 4: Quality of Life**

The intrinsic importance of BD to families’ quality of life is illustrated in the extract below from B21 when she compares it to other major life events

*There are certain dates in your life you will never forget. September 7, 2009 is one of those dates for me. It was not the day I became a nurse. It was not my wedding day either. It was the day I took a leap of faith that literally changed our lives. It is the day we took our first step out of our feeding disorder hell, the day we ditched formula, and started my daughter on a blended diet. Changing from formula to blended food may not sound all that momentous, but once you know how much it changed our lives for the better, you might understand why it is so significant to me.*



In contrast B4 described her son's poor quality of life after he had his gastrostomy and began using formula feeds.

*My son had eaten regular food for three years, and I was distraught that we would have to give him formula in his tube. We stuck in the formula game for over a year, but over time his weight stalled and the amount of gas the formula created in his stomach made it difficult for him to breathe. I cannot count the number of times that I looked over to see his lips a shade of blue and watch him gasping for air. I was venting his g-tube up to 30 times a day on the worst days.*

Similarly B29 wrote

*We just didn't feel that it was ok or normal for xxx to spend his days with his formula coming back after almost every single feed. He was so uncomfortable, so small, and cleaning it up all the time was dreadful.*

The negative physical impact on the children is clear, in addition to the psychological distress of the mother's at seeing their child unwell and not being able to nurture and care for them as they wished; B4 using the word '*distraught*' and B29 describing her child as '*so uncomfortable, so small*'.

Although parents are ostensibly blogging about BD's benefits, it is in the context of the overall needs and well-being of their child; B6.

*I'm doing everything I can with him each day- all the physio exercises we're advised to do, taster sessions, sensory play, time to make sounds together, teaching him a few signs, seeking out helpful equipment and plenty of trips out to nice places and fun with friends too.*

Quality of life for the child and family is enhanced by an acceptance of the situation in which they find themselves and by being appreciative of the present moment. B10

*Tube feeding is definitely a different world than we had ever experienced with our first 8 children. It has a steep learning curve, but hopefully one we are staying ahead of as best we can. We are grateful that this one 'small' adjustment [BD] has allowed xxx to grow and thrive and let his heart and body work easier when his heart defect already makes things hard enough. We do not know how long this stage will last for xxx, but step by step and day by day it continues to be a great adventure we will enjoy with him.*

The same blogger also illustrated how acts of kindness from HCPs can contribute to an improved quality of life.

*We are not sure of the name of the woman who drew his blood, but 'Mama D' was able to pull it off without xxx breaking into tears. She entertained and distracted him while holding his arm still and getting the needle into the vein on the first try. She even sang.*

Simplifying and normalising the way bloggers fed their child also led to an improved quality of life. B12 wrote,

*The best part of blending xxx's food is it almost feels normal. I can make his food and pack his lunch like all the other moms.*

This again shows the positive impact on the mother's self-esteem and the desire to be normal; normal being what is built from beliefs experiences perceptions and social rules and customs. B21 simplified and normalised the process of tube feeding.

*Think of the blender as doing the chewing, and the G tube as doing the swallowing. We should stop thinking of G tube feeding as a medical procedure, and realize it is just an alternative way of eating.*

Another blogger B25 used humour and a pseudo headline as a means of making the point that using BD is common sense and simple.

*Are you relying on formula to feed your daughter through her G-Tube? Have you heard about a healthy alternative called a "blended" or "blenderized" diet? Here's the scoop: A blended diet is simply taking everyday foods and blending them so they can be given through a feeding tube.*

Bloggers depicted a sense of realism and acceptance regarding quality of life. In the extract below the mother, B4 had listed an array of improvements in her child since she's started using BD including more energy, better skin colour and a happy disposition. She concluded by saying -

*His quality of life is my primary concern as his mother. He has many incurable diseases, but I can control what I feed him. I can help his digestion by eliminating synthetic formula from his diet.*

BD improves the quality of life of the child and enables his mother to feel that she can provide for and nurture her son despite the constraints imposed upon them by her son's complex needs. This sense of control and choice is reiterated by B3

*I don't start feeding him via his tube until noon because I like to give him some empty-stomach time to feel hunger and to help stimulate him to eat orally.*

This mother has made a conscious decision even though she goes on to say that it now means she cannot get all his food in during the day so has to have some feed overnight. The priorities of HCPs may not match those of parents and they may advise stopping overnight feeds (Cowpe, Hanson, & Smith, 2014).

Extracts from B8 and B1 show that they have made a conscious choice to use BD and are using it with full knowledge of all it entails,

*To save me time in the morning I do a lot of prep in the evening before bed. It does take a lot of work to make sure your family is healthy and fed. (B8)*

*That's one con of the blended diet. It takes one hell of a lot more effort to plan and prepare three meals a day that are balanced and have enough calories than it does to pour some prescription formula down her. It is worth every single second of extra work. (B1)*

B13 also explained her rationale for choosing BD; it reveals a combination of beliefs about the benefits of real food and the potential to alleviate the reflux experienced by her child.

*This was the main motivation behind why I went to all the extra trouble, there is just no way any canned formula is as good as the real thing. An additional motivator was that I hoped the BD would control reflux.*

Bloggers highlighted the importance of family with regards to quality of life, both in terms of family members and of family activities and routines.

For some, family outings revolved around hospital appointments – parents accompanying the child whilst siblings were looked after by another carer often a grandparent, B10

*The rest of the kids had a great day as well. They were still chatting excitedly about the events of yesterday with grandma and grandpa this morning.*

Within the blogs the role of the grandparent was both practically and emotionally supportive.

B1 wrote

*Thank goodness for Glamorous Grammy and Patient Pops or I wouldn't have a minute.*

B11 wrote

*Grandma is freezing apples picked from Papa's apple trees this fall. (For xxx's blended diet).*

B10 also showed how they made decisions that worked for their family's circumstances

*We got xxx's food prescription changed over to a food based 'formula' for his tube. We will still be blending most of his food, but it gives us more wiggle room when we are running short on time or have to be away from home.*

Travel was a topic that featured in many blogs, with many sharing practical advice that would make journeys easier such as taking stick blenders, and recipes for blends that are easy to feed whilst travelling. B1 recounted an incident on a day out at a museum, in which she uses humour to share and normalise or downplay the event.

*The one low point of the trip was when she puked up her lunchtime blend in the cafe area. However, it is a lot easier to be discreet with a blended projectile vomit as it doesn't quite have the same reach as milk does!*

## 6.6 Linguistic Analysis

The Linguistic Inquiry and Word Count (LIWC) is an online text analysis application. The latest version LIWC 2015 was developed by Pennebaker, Booth, Boyd and Francis (2015). The application analyses texts and counts percentage of words that reflect parameters such as emotion, thinking styles, and parts of speech. LIWC derived norms based on analysis of six data sources; blogs, expressive writing, novels, natural speech, the New York Times and Twitter. The number of words from each source is shown in Figure 6-4 below

Source	Blogs	Expressive writing	Novels	Natural speech	New York Times	Twitter
Total words	119,449,058	2,526,709	57,467,183	2,566,446	26,007,632	23,172,994

Figure 6-4 Number of words included by data source

The LIWC dictionary comprises approximately 6,400 words, and an average of 83.37% of words in the BD blogs were coded (i.e. contained in the dictionary) compared with an average of 85.79% of the words from the LIWC blog data.

This section will present differences between the BD blog data, and the LIWC norms will be presented in summary variables and linguistic domains.

LIWC analyses four summary variables, and provides a score for each variable ranging from 0 (very low) to 100 (very high). The first variable is analytical thinking, it reflects the degree to which formal logical, and hierarchical thinking is used as opposed to informal, personal, and narrative.

The second variable is clout, and a high number in this variable would imply the data is authoritative with high levels of expertise and confidence.

Authenticity is the third variable, and relates to the level to which the data is honest, personal, humble and vulnerable. .

Finally the fourth variable, emotional tone combines both positive and negative sentiments, and the more positive the tone the higher the number, with numbers below 50 indicating an overall negative tone.

	Analytic	Clout	Authentic	Tone
Overall LIWC norms	56.34	57.95	49.17	54.22
LIWC blogs	49.89	47.87	60.93	54.50
Blended diet blogs	63.30	71.14	22.21	67.76

**Figure 6-5 Comparison of LIWC variables**

The high analytic score for the BD blogs suggests that the bloggers have formal logical, and hierarchical thinking. The high score for clout reflects a high level of expertise and confidence. The comparatively low score for authenticity implies the BD bloggers' posts may be more guarded and detached, portraying them as less humble or vulnerable. The high score for tone suggests that the BD bloggers were more positive in the tone of their posts.

The LIWC software uses a dictionary of words that are hierarchically arranged so for example the word 'ate' belongs to the ingestion category, which in turn is a subset of the 'biological processes' category. It will also appear in the verb category. Key categories of vocabulary were also analysed in the BD blogs and then compared to the LIWC data and are shown in Figure 6-6 below.

	Positive emotion	Negative emotion	Social processes	Family	Biological processes	Health	Ingestion
Overall LIWC norms	3.67	1.84	9.74	0.44	2.03	0.59	0.57
LIWC blogs	3.66	2.06	8.95	0.46	2.16	0.61	0.54
Blended diet blogs	3.26	0.96	9.91	0.63	6.61	2.17	4.28

Figure 6-6 Comparison of percentage of words categorised in LIWC norms and BD blogs

The percentage of negative emotion words (such as hurt and nasty) in the BD blogs was lower than both the overall LIWC norms and that of LIWC blogs. The percentage of positive emotion words in the BD blogs was also less, although a less significant difference. The BD blogs have a higher percentage of social process and family words. Biological process words and the subsets of health and ingestion show the largest difference between BD blogs and the overall LIWC norms and that of LIWC blogs, and the family category that is a subset of social processes reflects the importance of family as mentioned in the thematic analysis. The implications of these results are explored in more detail in chapter 9 section 9.5.2.2.

## 6.7 Discussion

This section will briefly discuss the main themes identified through the thematic and linguistic analysis of the blog data. Further triangulation and in depth discussion of the findings from all three phases will be in chapter 9.

Bloggers described how some HCPs made them feel guilty or inadequate (section 6.1). The research by Forbat, Teuten, & Barclay (2015) suggests that conflict can result from of a deterioration of trust and was characterised by entrenchment of arguments and avoidance; this was evidenced by B18 and B19 (section 6.4.1 p126-7).

As mentioned in section 6.3, the tone of the blogs was more visceral than that of the interviews. This may be explained by the anonymity of blogs, but also because the

blogs were recounting raw feelings experienced in the 'heat of the moment', and perhaps served as a means for parents to vent their frustration (Pedersen, 2010).

The agenda setting theory (McCombs & Shaw, 1993), suggests that the relative importance of a topic is influenced by the emphasis given to the topic in the media. The frequent 'soapboxing' of BD's benefits by bloggers may therefore suggest that its relative importance is amplified through social media.

Similarly positive feedback from others who read blogs means that the bloggers' intrinsic motivation to continue with diet is increased. This is in contrast to negative feedback from some HCPs, which in fact decreases intrinsic motivation. The use of blogs increases the opportunity for bloggers to interact with and be connected to others who experience the same situation of caring for children with complex needs. This social affiliation is a key element of self-regulation. Self-regulation theory also explains parents' use of impulse control when faced with challenges from healthcare professionals.

Self-determination theory suggests that competency relatedness and autonomy are driven by needs and motivations. Parental competence is negatively impacted upon when they perceive their parenting is being criticised or comments are made that are at odds with their health beliefs. The manner in which parents deal with these conflicts can be explained by the findings of Thiots (2014) regarding how parents react to stigma; i.e they challenge it or deflect it. Bloggers tended to recount incidents of challenging more frequently than deflecting, however it is not possible to determine whether this truly reflected their actions or was subject to a degree of recall bias.

The act of questioning (a subtheme of empowerment) resonates with the findings of Maurer et al (2012) who suggested parents use questioning because they do not feel involved in decisions about their child's feeding. Challenge behaviours described by Manago, Davis, and Goar (2017) are also a facet of questioning.

The quality of life theme reflected parents desire to make their lives as normal as possible as Conrad (1987) described, making comparisons with normalisation. B12 wrote '*The best part of blending xxx's food, it almost feels "normal"*'.

Parents' mastery of new skills as well as the vicarious joy of sharing success of

others serves to increase levels of self-efficacy amongst the bloggers.

Findings from the LIWC analysis indicates that this computer based analysis, though more quantitative than thematic analysis, is able to support findings from the thematic analysis. This was also found in a study by Firmin et al. (2016) using LIWC to analyse transcribed narratives of a cohort of 46 patients with schizophrenia. Firmin et al found clinical presentation was predicted by word use categories, for example anger words, a subcategory of negative emotion words were predictive of the presence of greater severity of symptoms. Unsurprisingly, from the blogs data LIWC revealed higher percentages of words relating to biological processes, health and ingestion than general blogs. Similarly higher percentages of family and social words were also noted, which reflects aspects of the theme of quality of life and the value bloggers placed upon family support (as illustrated by B1, B10 and B11 on pages 133-134). However caution is required when interpreting the LIWC data. For example the use of sarcasm and irony may lead to inaccurate coding of words – particularly over attributing positive emotion words such as *'super excited'* referring to stooling B22 and B24 who wrote *'I am BAD at having an actual recipe so I apologize for that!'* when she was actually proud of how good she was at having recipes for BD.

## **6.8 Limitations**

There are a number of limitations with regards to this study specifically and to studies in general that use blog data.

A lack of demographic information meant that it was not possible to determine the location of the bloggers. It is therefore not possible to determine whether there are different issues surrounding the use of BD in different countries. For example is there a different view of BD in countries where formula feeds must be paid for, and poorer families may therefore be forced to use a BD?

It is possible that the physical act of writing a blog can have an impact upon a person's feelings and views relative to a 'non-blogger', Stockton (2014) found an increase in post-traumatic growth in trauma sufferers who explicitly wrote about their feelings and opinions. So generalisation of views expressed in the blogs cannot necessarily be generalised to non-bloggers.



The motivation of bloggers for writing their blog cannot be determined. There is a potential for bloggers to use their blog as a soapbox to promote their individual views with the intention of changing the opinions of others.

The potential benefit of blogs over interviews is that the former provides an individual with more freedom to truly express themselves than they would have in an interview situation with a researcher. Conversely the lack of interaction means that it is not possible to seek clarification about potentially ambiguous blogs.

Another limitation of the study is that although the selection process is clearly documented, the ownership remains with the blogger who can decide to stop and /or delete the blog preventing replication of the research. Deletion of two of the blogs used in the study meant that it was not possible to go back to check on any details and meant that there was data missing from the figure showing characteristics of the blogs i.e. whether or not the blogs offered links to other social media platforms such as Twitter and Facebook.

As with the in-depth interview analysis, there was no second data coder for the blog analysis, but use of the LIWC tool did provide an element of triangulation.

As with the interviews, it was mothers who wrote all of the blogs; more purposeful sampling in future research could ensure the views of fathers were also captured.

The increasing availability of secondary data from blogs offers a voice and platform for bloggers to share and publicise their views more widely and publicly, However it should be acknowledged that they were unlikely to have been intended as a potential research data source, and as such efforts should be made to contact the author to seek permission and to acknowledge their contributions within the references.

## **6.9 Conclusion**

Overall the thematic analysis of the blogs exposed similar themes to those found in the in-depth interviews, but there was a difference in the tone of the interviewees and bloggers. The LIWC analysis carried out on the BD blog data provided a degree of triangulation but its findings must be interpreted with caution, as there were some anomalies between norms from the LIWC blog data and that of the BD blogs.

## Chapter 7 Phase Three Questionnaire: Methodology

### 7.0 Research Approach

Little is known about the potential benefits and disadvantages of BD with no published studies comparing outcomes from using BD with formula feeds. An advantage of mixed methodology research in little-researched areas is that qualitative data can be used to inform the content of the quantitative phase, with questionnaires presenting the constructs identified in a simple and contextualised style (Harris & Brown, 2010).

The first two phases, the in-depth interviews and blogs took a qualitative approach and were exploratory. These phases sought to gain insight and identify themes by obtaining data from individuals who were knowledgeable or experienced in using BD. Phase three takes a quantitative approach using a questionnaire to collate and describe information about those who do and do not use BD. This will include demographic information about the parents, their beliefs about medicines, perceived levels of self efficacy and information about their child's diagnosis, well-being and their feeding practices.

The research questions to be addressed by phase 3 of the research are –

I. Are there differences in demographics and beliefs between parents who do and do not use BD?

II. Do parents who do and do not use BD report differences in terms of health, well-being and stool quality in their children and young people?

Five hypotheses will be tested; each one has been developed in relation to the theoretical concepts and findings from the qualitative phases of the study.

The self-regulatory model suggests people incorporate their views about medicines into their constructs about the world in which they live (Leventhal, Leventhal, & Contrada, 1998). For example non-adherence to advice or medicines may be involuntary or unintentional—that patients forget, but it could equally be intentional - based on personal beliefs about their 'illness' and possible risks from the treatment and with perceived need of the treatment. With regard to (BD) if parents' constructs of feeding and nurturing their child conflict with the notion of using a prescribed formula feed they are likely to be intentionally non-adherent. Constructs relating to adherence can be evaluated using the Beliefs about Medicines Questionnaire

(Horne, Weinman, & Hankins, 1999). This is a tool that assesses an individual's cognitive representations of medicines in terms of their beliefs about necessity for and concerns about medicines, their potential harm and overuse. The tool has been adapted for use with a range of chronic conditions and has been used to study parents beliefs associated with adherence among children (Miner, Alexander, Ewing, & Gerace, 2013; Schoeler et al., 2014).

The first hypothesis for the study is that **parents who opted to use BD would have high levels of concerns about formula feed and low levels of belief in the need for it.**

The second is that **parents who used BD would feel that medicines were harmful and overused.**

The third hypothesis is that **parents who opted to use BD would have higher levels of self-efficacy.** Self-efficacy is a key component of behaviour change and is linked with control and self-confidence (Bandura, 1977). Responses from in depth interviews of parents using blended diet suggest constructs of control and loss are challenged when their children require gastrostomies. The decision of parents to use BD suggests they may use this as a way of gaining control and increasing self-confidence *"I feel like we have become Mum and Dad again whereas I felt like I had become a carer or his nurse"*.

The fourth hypothesis is that **children who are being fed using BD would have more normal bowel movements.** The rationale for this hypothesis is derived from the theme 'our quality of life' which contains dimensions relating to bowel movements and constipation. Similarly research into BD such as the study by Pentiuik, O'Flaherty, Santoro, Willging, and Kaul, (2011), described anecdotal improvements in bowel function, but these improvements were not measured.

The fifth hypothesis is that **perceived levels of health and quality of life would be greater for those children using BD.** The rationale for this hypothesis is derived from Issues relating to parental perspectives regarding the impact of BD on well-being and health were highlighted within the theme 'our quality of life'. A parent said *"And also her personality changed she took a massive leap in development and I think it's just because she wasn't feeling sick all the time"*.

## **7.1 Study Design**

The UCL Division of Psychology and Language Science Departmental Ethics Committee granted ethical approval of the project (LCRD.20.26.05). The project was registered with the UCL Data Protection Officer (No. Z6364106/2016/08/14).

### **7.1.1 Background**

Considering all aspects of the survey process or a total survey design approach ensures data collected can be used to answer the research question (Sue & Ritter, 2017). Themes and information from the first two phases, in conjunction with evidence from the literature review informed the content of the questionnaire in phase three. For example the feeding statements (see Figure 8-7) were derived from statements made by participants during the interviews and also reflect the sentiments of the some of the blogs. The literature around the Necessity Concerns framework led to the inclusion of the Beliefs about Medicines Questionnaire. A pilot study was carried out prior to the main study, which was designed to check acceptability in terms of accessing the questionnaire, time to complete and also to offer parents the opportunity to give any other feedback and suggestions.

### **7.1.2 Pilot Study**

Eight parents volunteered to pilot the questionnaire. The questionnaire comprised the following sections which are described in more detail in section 7.1.3.1-7.1.3.8.

Section 1 Demographics

Section 2 Feeding statements

Section 3 BMQ specific

Section 4 BMQ general

Section 5 Self-efficacy scale

Section 6 Bristol stool chart

Section 7 Pediatric Quality of Life Inventory (PedsQoL) Gastrointestinal module

Section 8 Blended diet questions (for BD users only)

The questionnaire was created in Google forms, which meant it could be completed on smartphones, tablets or computers. Feedback was sought regarding; how long the survey took to complete, any technical problems accessing or completing the form, anything they felt uncomfortable or difficult to answer, any questions that were

unclear or ambiguous and any other comments. The parents were also asked if there were any other issues they thought should be included or emphasised within the questionnaire.

Feedback suggested clarifying that the word 'child' referred to all children and young people at the start of the questionnaire. The length taken was approximately 20-30 minutes and this was considered to be on the upper limit of an acceptable time.

The pilot survey included the PedsQoL Gastrointestinal module, a comprehensive validated scale with statements covering a range of gastrointestinal conditions including reflux, constipation, stomach pain and vomiting (Varni, Kay, Limbers, Franciosi, & Pohl, 2012). It can be child self-reported or parent proxy-reported, with respondents required to select an option from a five-point scale - *never, almost never, sometimes, often, almost always*. However, pilot participants reported that they were unable to respond meaningfully to some of the statements. For example in the problems with diarrhoea section a parent was unable to respond to the statement *'has poop accidents in his/her underwear'* as their child was still in nappies. Another parent found it frustrating when faced with statements beginning with *'feels like'* such as *'feels like throwing up'*. The parent commented, *"that's one of the hardest things about tube feeding I find – that you don't know how they are feeling/what's wrong because they can't tell you"*.

Parents suggested having a 'don't know' option in the responses. The final version of the questionnaire did not include the PedsQoL Gastrointestinal module as some questions made parents feel uncomfortable, some they felt they could not answer, and as the measurement was validated it could not be amended. The researcher also reflected that the length of the module placed unnecessary burden on the participants and may lead to lower levels of completion.

A statement about sleep was also removed from the final questionnaire. Although improvements in sleep patterns had been mentioned in both the in-depth interviews and blogs, pilot participants felt that there were too many other variables that impacted on sleep besides the use of BD.

On the recommendation of two parents, the initial instructions were amended to inform participants that the survey could not be saved partway through. The demographic information was moved to the final section of the survey as it was

suggested that participants might have felt more commitment or willingness to invest time to the survey having understood more about its purpose and therefore complete the demographics.

Some adjustments were made to ensure questions were in a logical order and used unambiguous, plain non-emotive language. The final amendment was that the sections were numbered so that participants knew how much of the questionnaire they had completed, with online form providing a 'percentage completed' progress bar. Content validity was obtained by sharing the questionnaire with three colleagues; a paediatrician, a consultant in paediatric neurodisability and a dietitian.

### **7.1.3 Questionnaire design and content**

A quality criteria checklist was used when designing the questionnaire (Boynton & Greenhalgh, 2004). The questionnaire consisted of eight sections, one of which was completed only by families who were using BD. Standardised scales of self-efficacy, alongside questions regarding perceptions about gastrostomies and feeding, that arose from the in-depth interviews, were included. Participants were asked to provide demographic information including their child's date of birth and age of their child when they had their gastrostomy, their diagnosis and whether or not their child had any food orally. Some questions had the option to add free text, however, wherever possible single response questions were used in order to facilitate analysis (Boynton & Greenhalgh, 2004). The questionnaire used skip logic so respondents were taken to the BD section contingent on their response to certain questions. In addition to reducing the burden of survey completing on respondents, skip logic used in online surveys may also improve the quality of the data from respondents as it prevents them from selecting an option merely because it enables them to skip portions of the survey (Johnson, 2016). A red asterisk identified mandatory questions, and progression through the questionnaire was prevented until all mandatory questions were answered. These ensured participants did not omit responses and therefore improved the quality of the data collected for analysis (see appendix 7 for full questionnaire).

No enticements or rewards were offered for completing the survey other than the option to receive an update on the project. The introductory paragraph provided details of the purpose of the study, who was eligible to take part and an

approximation of the time it would take to complete. It provided assurances of anonymity and ethical approval, a contact in case of query. Although anonymity was assured the end of section 8 the demographics did contain a section for contact details if parents wanted to be informed of results from the study; 61 of the 208 participants opted to be informed.

The survey was made available online via Google forms, via email and by post. The anonymity afforded by a web-based survey was an important factor in determining the survey design, potentially increasing the likelihood of participation. Only one of the 208 responses was not via the web, it was via email. A paper version was offered in the flyers sent to special schools and support groups, hospices etc. (see appendix 8 for full list). The survey was open from 10<sup>th</sup> February to 31<sup>st</sup> March 2018, a period that covered both term time and school holidays. The questionnaire also used three previously validated instruments, the Beliefs about Medicine Questionnaire (Horne, Weinman, & Hankins, 1999), the Bristol Stool Scale (Lewis and Heaton, 1997) and the General Self Efficacy Scale (Schwarzer & Jerusalem, 1995). The benefit of using validated instruments is that they have been tested and can be assumed to be accurate and support the research methodology (Jones, Baxter, & Khanduja, 2013). There were 8 sections in the questionnaire (see appendix 7) -

Section 1 feeding statements

Section 2 BMQ specific

Section 3 BMQ general

Section 4 Self-efficacy scale

Section 5 Bristol stool chart

Section 6 Health, quality of life

Section 7 Blended diet questions (for BD users only)

Section 8 Demographics

#### ***7.1.3.1 Section 1: feeding statements***

In section 1 eight statements derived from the in-depth interviews, were rated using a 5-point Likert scale (Strongly Disagree (1) to Strongly Agree(5)). The questions aimed to (i) assess if the views and themes from the in-depth interviews were reflected in the larger sample and (ii) if there were differences between those who did

and did not use BD (iii) if any of the questions were predictive of BD use. Figure 7-1 below presents the statements and the themes/ subthemes to which they relate.

<b>Statement</b>	<b>Related theme/subtheme</b>
1. I feel involved in my child's feeding.	Loss and control
2. A more flexible approach to feeding my child would suit me better.	Innovation and choice
3. Formula feeds are the best way to be sure my child has the calories and nutrients he/she needs.	Conflict and questioning
4. The food my child is given improves his/her quality of life.	Quality of life and well-being
5. Feeding my child is stressful.	Validation and persistence
6. I feel that my child receives the help and support with feeding that I want for him/her.	Conflict and its impact
7. My child is usually well.	Well-being
8. I know what is best for my child with regard to feeding.	Questioning and empowerment

Figure 7-1 Feeding statements and themes/subthemes

### **7.1.3.2 Section: 2 BMQ specific**

The Beliefs about Medicine Questionnaire (BMQ) has two parts, the BMQ *specific* and the BMQ *general*, each part can be used individually or together. Both parts were used in this research. The BMQ *specific* consists of 10 items, five of which assess views about necessities of medication (formula feed in the context of this research) and five assess concerns. Each statement is rated on a 5-point Likert scale (Strongly Disagree (1) to Strongly Agree (5)). Individual items relating to necessity and concern are computed to provide a needs score and a concerns score for each participant. High levels of concern and low levels of necessity were associated with non-adherence to medication (Conn, Halterman, & Fisher, 2005).



### **7.1.3.3 Section 3: BMQ general**

The BMQ *general* consists of eight items, five of which assess views about harm and three about overuse of medicines in general, and also uses the 5-point Likert scale. Individual items relating to harm and overuse are computed to provide a harm score and an overuse score for each participant.

Both of the BMQ scales were derived from a pool of items representing commonly held beliefs about medication using exploratory Principal Component Analysis (PCA). Confirmatory factor analysis verified the factor structure, and stability across illness groups was checked with exploratory PCA. Validity of separating specific and general beliefs about medications was checked. Criterion validity and discriminant validity were checked. Internal consistency of each BMQ scale was evaluated with Cronbach's Alpha and confirmed satisfactory internal consistency for each scale. Test retest reliability was checked with Spearman correlations (Horne 1997).

### **7.1.3.4 Section 4: The general self-efficacy scale**

The General Self-Efficacy Scale is a 10-item scale that assesses a participants' belief in their ability to cope with demanding situations, and that their actions are responsible for successful outcomes. A 4-point Likert scale is used (Not true at all to Exactly true). A composite self-efficacy score is obtained by adding all ratings together and dividing by 10. Concurrent and prognostic validity of general perceived self-efficacy was checked in relation to constructs including depression, anxiety optimism and self-esteem. Correlations were tested with other personality traits including extraversion and neuroticism, hope for success and fear of failure. All correlations were significant (Schwarzer, R., & Jerusalem, 1995)

### **7.1.3.5 Section 5: The Bristol Stool Chart**

Improvements in bowel movements following the introduction of BD were cited both in the literature review, (Samela, Mokha, Emerick, & Davidovics, 2016), and by participants in the in-depth interviews (see section 4.4.2). The Bristol Stool Scale (BSS) uses a 7-point ordinal scale to describe the stool ranging from the hardest (Type 1) to the softest (Type 7) (see appendix 9). Type 3, 4 and 5 are considered as normal stools. Participants select the type that best describes their child's stool acknowledging that there will be some variation. The BSS provides a means of

identifying any differences in the quality of the stool of those who do and do not use BD. A reliability study found that 86 volunteers were able to classify a total of 977 out of a possible 1204 (81%) stool models correctly. (Blake, Raker, & Whelan, 2016).

#### **7.1.3.6 Section 6: Health, quality of life and gastrostomy**

This section had asked parents to rate their child's health over the past month on 5 point scale – excellent, very good, good, fair, poor. In the analysis these were given a numerical value of 1(poor) to 5 (excellent). The same scoring was applied to the question of how parents rated their child's quality of life – i.e. excellent to poor. This section also asked parents the date of birth of their child, their diagnosis or problem, the reason and date of the gastrostomy, whether their child had any food orally and if they used the gastrostomy to administer medicines. The final question 'do you or have you in the past fed your child with anything other than formula feeds via their gastrostomy?' used skip logic to determine if participants were directed to the blended diets section or to the demographics section.

#### **7.1.3.7 Section 7: Blended diet**

This section asked parents who were or had been using BD about how long they had been using BD, the reasons for using BD, the types of food and whether or not they used any formula feed.

#### **7.1.3.8 Section 8: Further information**

This section gathered demographic information – ethnicity, sex, age group, household income and education level. There was also the opportunity for participants to leave contact details if they wanted to be kept informed of the research project.

## **7.2 Sample**

As BD is not an officially recognised means of feeding gastrostomy-fed children and young people there is no accurate estimate of the number of users. Due to the parent's secrecy and their mistrust of healthcare professionals surrounding the use of BD (as identified from thematic analysis of the in-depth interviews) an estimation of families who may be using BD is not possible. Even anecdotal reports from informal conversations with colleagues suggested wide variations, with one dietitian knowing

of one family on her caseload using BD, whilst another had more than 10 families. Colleagues acknowledged that they were likely to have families on their caseload who were using BD that they were unaware of. Due to the secrecy and mistrust, the researcher decided not to use NHS clinics to recruit participants for this survey. For the same reasons it was not possible to estimate the likely number of respondents to the survey. Instead participants were sourced via Facebook groups for BD users, for children with gastrostomies and via Twitter. Twenty family support organisations, hospices and other non-statutory agencies and 13 special schools also agreed to publicise the survey to their membership, service users and parents. Some organisations advertised it electronically and others in printed newsletters. (See appendix 8)

The use of social media as a source of participants was supported by recent research. The use of BD has been driven by parents via the Internet (Coad et al., 2016; Thomas, 2017). Similarly a study in which patients were asked about their use of Internet found 68% used it for information about nutrition or diet, and 58% to investigate potential side effects of medications (Diaz et al., 2002). More recently a study in the US revealed that 80% of Internet users have looked online for information about a specific disease or treatment (Fox, 2011). Frequent use of the Internet was evident in the in-depth interviews with seventeen of the eighteen participants making reference to the Internet, Facebook or the websites. It is acknowledged that this may have contributed to self selection bias, and account for the unequal group size for BD users (n =140) versus BD non users (n=68).

There were 16 duplicate entries, these were identified by the researcher in the initial review of the data. One participant had entered the identical data nine times, eight of which were removed, another had entered identical data seven times , six of which were removed and another had entered identical data three times of which two were removed. All duplicates were removed before the data was entered into SPSS.

The only area with missing data in the survey was in the age of child when their gastrostomy was inserted. This was missing for five of the participants all of whom were in the BD users cohort.

### **7.3 Ethical Considerations**

In this section ethical dilemmas raised by investigating the use of BD as a topic and practical issues relating to the questionnaire design, distribution and collection will be discussed.

Parents who opt to use BD are rejecting medical advice and often have little or no support from HCPs, and may therefore be deemed a vulnerable group at risk of being stigmatised as non-compliant (Nordentoft & Kappel, 2011). The web-based questionnaire therefore afforded anonymity to parents who may otherwise have been reluctant to participate (Wright, 2005).

The majority of respondents (approximately two thirds) were users of BD, and one third were using formula feeds which is unlikely to be indicative of the proportions using BD across the population of gastrostomy-fed children as BD is not offered as an alternative to formula feeds in the UK. It was therefore important that the questionnaire did not unduly promote or publicise the use of BD or to imply that taking part in the research would increase the likelihood of BD being endorsed by healthcare professionals and the NHS in general.

Demographic information was restricted to areas relevant to the research, to reduce the time burden for respondents and to conform with data protection guidelines from UCL (in line with Data Protection Act, 1988) ensuring only relevant information is obtained and ensuring participant identifiable information is “treated with respect and used fairly and lawfully”.

Contact details of the researcher were provided at the beginning of the questionnaire in case of queries and a paper /email version was offered.

The use of online surveys poses an ethical dilemma in terms of obtaining informed consent. Informed consent requires the provision of an explanation of the aims of the study, and what it means for participants to take part such as the time commitment and confidentiality. Whitehead (2007) suggests that it is evidencing that the process of providing information to facilitate informed consent may be regarded as more important than obtaining a hard copy of a signed consent form.

Paper based consent forms were produced and sent to the organisations that publicised the questionnaire (see section 7.1). No participants requested the consent form directly from the researcher during the study. Consent was implied through

participation in accordance with research by McDermott and Roen (2011) who suggested that paper based consent was no more valid than online. If a participant did not complete and submit the survey no data from their partial submission was kept.

#### **7.4 Statistical Methods**

Both the research questions and the types of data determine the tests used to analyse data. The analysis of the data will be in the form of descriptive inferential statistics. Descriptive statistics will provide information on measures of central tendency (mean/median/mode) and variability in the form of standard deviation. Inferential statistics will be used to determine if there is a correlation between the independent variable and the use of BD and regression analysis will be used to model the impact of any variables found to be statistically significant.

All analyses will be performed using IBM SPSS Statistics software package Version 21 (for Mac). A priori value of  $p < .05$  will be used to indicate statistical significance. Thus if the  $p$ -value is less than or equal to the alpha ( $p < .05$ ), then the null hypothesis will be rejected, and the result is deemed statistically significant. If the  $p$ -value is greater than alpha ( $p > .05$ ), then the null hypothesis is not rejected, and the result is deemed not to be statistically significant.

Figure 7-2 below provides a summary of the demographics of the participants and their children. Chi-square will be used to test for relationships between categorical variables. The null hypothesis of the Chi-Square test is that no relationship exists between the variables i.e. they are independent. The assumptions for the use of Chi square is that the variables are categorical and that there is no relationship between the participants in either of the groups and that the sample size is sufficient to allow distribution to be valid (i.e. no more than 20% of cell have a value of less than 5). Where distribution is not valid the Fisher's exact test will be used (Field, 2011). A Mann Whitney U test will be carried out on the age of gastrostomy (a numeric discrete variable), as a 2-tailed independent t test could not be used as the assumptions of equal distribution required for independent t test was violated.

Figure 7-2 below provides a summary of the demographic data and intended statistical methods.

Demographic Variables	Data Source	Type of variable	Analysis planned
Age of parent	Parent	Categorical ordinal	Pearson Chi square
Sex	Parent	Categorical binary	Pearson Chi square
Ethnicity	Parent	Categorical nominal	Pearson Chi square
Education	Parent	Categorical ordinal	Pearson Chi square
Income	Parent	Categorical ordinal	Pearson Chi Square
Child's diagnosis	Parent	Categorical nominal	Pearson Chi square
Age at gastrostomy	Parent	Numeric discrete	Mann Whitney
Reason for gastrostomy	Parent	Categorical nominal	Pearson Chi square
Does your child have any food orally	Parent	Categorical binary	Pearson Chi square
Do you use the gastrostomy to administer medicines	Parent	Categorical nominal	Pearson Chi square

**Figure 7-2 Demographic data and intended method of analysis**

The five hypotheses stated at the beginning of chapter 7 will be tested using 2-tailed independent t tests when the data meets the equal variance assumptions required for the use of parametric tests. Where these assumptions are violated, Mann Whitney test (non-parametric) will be used. The assumptions for Mann Whitney are that the independent variable has two independent categorical groups and the dependent variables are ordinal or continuous. Results of the Bristol Stool Scale were categorised into two groups by the researcher (normal – levels 3,4,5 or not normal – levels 1,2,6,7). Thus with binary categorical independent and dependent variable Chi-square will be used. Figure 7-3 provides a summary of the measures used and intended statistical methods.

Measure	Data Source	Type of variable	Analysis planned
BMQ (specific) Needs /concern	Parent	Categorical ordinal	Independent 2 tailed t test
BMQ (general) Harm /overuse	Parent	Categorical ordinal	Mann Whitney
Feeding Statements	Parent	Categorical ordinal	Mann Whitney
Self Efficacy	Parent	Categorical ordinal	Independent 2 tailed t test
Bristol Stool Scale	Parent	Categorical ordinal	Pearson Chi square
Health	Parent	Categorical ordinal	Independent 2 tailed t test
Quality of Life	Parent	Categorical ordinal	Independent 2 tailed t test

**Figure 7-3 Measures and methods of analysis**

Finally regression analysis will be used to model the impact of any variables from the five hypotheses that were found to be statistically significant. Regression allows a

researcher to make statements about how well one or more independent variables will predict the value of a dependent variable.

Binary logistic regression is used because the outcome variable (BD user = 0/1) is binary. Independent variables are ordinal.

The following assumptions will be met:

- I. The dependent variable is categorical and dichotomous, taking one of two values that BD (i) user or (ii) not user;
- II. Independence of observations;
- III. No outliers;
- IV. Multicollinearity is avoided; and,
- V. The sample size is sufficiently large in relation to the number of events per variables (EPV)

## **7.5 Conclusion**

This chapter presented a rationale for the quantitative phase of the research, describing and justifying the research approach and design and statistical methods used. The importance of the pilot study was illustrated and the revisions made were outlined. The section on ethics highlighted the issues raised by the use of web-based questionnaires. Results from the questionnaire will be presented in the next chapter.

## Chapter 8 Phase Three Questionnaire: Results

### 8.0 Introduction

In this chapter the results from the questionnaire will be presented.

To recap, the research questions to be addressed by phase 3 of the research are –

I. Are there differences in demographics and beliefs between parents who do and do not use BD?

II. Do parents who do and do not use BD report differences in terms of health, well-being and stool quality in their children and young people?

The five hypotheses are listed below

I. Parents who opted to use BD have high levels of concerns about formula feed and low levels of belief about the need for it.

II. Parents who use BD feel that medicines are (i) harmful, (ii) overused

III. Parents who use BD have higher levels of self-efficacy than those not using BD.

IV. Children being fed using BD would have more normal bowel movements than those not having BD.

V. Parent-perceived levels of their child's (i) health and (ii) quality of life are greater for children using BD.

The questionnaire was available on a web-based platform from 10<sup>th</sup> February -1<sup>st</sup> April 2018. Paper and email versions were also made available during this period.

There were 208 participants only one of whom did not use the web-based version.

Of the 208 respondents 140 used BD and 68 did not.

The results were analysed using the IBM SPSS Statistics software package Version 21 (for Mac). The results are presented through descriptive, correlational and regression statistics.

In the first section (8.1) descriptive and correlational statistics are used to present and summarise the characteristics of the respondents. The purpose was to establish if there were differences between the two cohorts (i.e. those who did and did not use BD), and to establish whether there was a relationship between variables. The second section (8.2) focuses on areas relating to the respondents' child and their gastrostomy and feeding. The third section (8.3), presents the results from the feeding statements derived from the in-depth interviews. The fourth section (8.4) provides the results of the hypotheses testing, and the fifth section (8.5) uses logistic



regression statistics to explain the relationship between the dependent binary variable and, ordinal variables.

### 8.1 Summary of Demographics

Participants were asked to provide details of their age, level of education, income sex and ethnicity. In the first part of this section the data are presented, classified into two groups - those do not use BD (labelled Formula) and those who do, (labelled blended).

		BD user or not			
		Formula		Blended	
		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%
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	Any other Asian background	1	1.5%	3	2.1%
	Any other ethnic group	1	1.5%	2	1.4%
	Any other mixed/multiple ethnic group	0	0.0%	1	0.7%
	Any other white background	9	13.2%	17	12.1%
	Mixed Multiple Ethnic White	0	0.0%	1	0.7%
	White English / Welsh / Scottish / Northern Irish	57	83.8%	112	80.0%
	White Irish	0	0.0%	4	2.9%

Figure 8-1 Summary of demographics of participants

### **8.1.1 Age of parents**

Parents were asked to select their age bracket. A chi-square test was carried out to determine if there was an association between parental age and the use of BD. No significant association was found ( $X^2 (3) = 4.30, p = .23$ ). The results meant the null hypothesis is accepted and that there is no association between parental age and the use of BD. The results meant the null hypothesis cannot be rejected and that there is no association between parental age and the use of BD.

### **8.1.2 Education Level**

The education levels were primarily set according to the English education system; however, the phrase 'or equivalent' was used for GCSEs and A levels categories. The 'other' category responses included some 'college' and 'would not say'. If 'other' included nursing qualifications this was re-categorised as a degree. A chi-square test was carried out to determine if there was an association between education level and the use of BD. No significant association was found ( $X^2 (4) = 2.38, p = .67$ ). The results meant the null hypothesis cannot be rejected and that there is no association between education level and the use of BD.

### **8.1.3 Household income**

Income groups were in UK currency, so some knowledge of conversion rates would have been required for non-UK respondents. The cost of living relative to other countries relative income has not been taken into account. The relevance of this demographic was to ascertain any differences in incomes between the two groups. A chi-square test was carried out to determine if there was an association between household income and the use of BD. No significant association was found ( $X^2 (4) = 2.71, p = .61$ ). The results meant the null hypothesis cannot be rejected and that there is no association between household income and the use of BD.

### **8.1.4 Sex**

A total of 12 males completed the survey meaning that just 5.77% of respondents were male. The test of homogeneity found that more than 25% of cells had a count of less than 5 so a Fisher's exact test was used and a  $p = .34$ , meaning no significant association was found. The results meant the null hypothesis cannot be rejected and that there is no association between gender and the use of BD.

### **8.1.5 Ethnicity**

Respondents were asked to select the option that best described their ethnic group or background from a selection of 17. The majority of respondents (81.25%) in both groups were White, English/Welsh/Scottish/Northern Irish/British (80% of the cohort who used BD and 84% of the cohort who did not). This may be in part a cultural issue as research has shown that some ethnic groups are under-represented in response to health surveys (Gill & Redwood, 2013), or there may be fewer ethnic minority groups who have gastrostomies. There is no data available to support or refute this suggestion. Overall there was no statistically significant association between ethnicity and the use of BD as assessed by Fisher's exact test  $p = .74$

### **8.2 Child-related Issues**

This section reports on the child's diagnosis, age at placement of gastrostomy, oral intake and use of the gastrostomy for medicines. Reason(s) for gastrostomy placement are then presented.

The final part of this section presents results that only relate to those using BD; length of time on BD, reason for using BD and the types of food given via the gastrostomy.

The table below provides details of diagnosis, stool rating and whether or not the child has any food orally. The information is broken down into two groups – those who do or do not use blended diet (labelled as Blended and Formula respectively)

Diagnosis or problem		BD user or not			
		Formula		Blended	
		Count	%	Count	%
Diagnosis or problem	Cerebral Palsy	17	25.0%	51	36.4%
	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 FTT*	9	13.2%	8	5.7%
	Reflux				
Bristol stool chart rating	1.0	4	5.9%	3	2.1%
	2.0	2	2.9%	16	11.4%
	3.0	6	8.8%	28	20%
	4.0	19	27.9%	43	30.7%
	5.0	4	5.9%	12	8.6%
	6.0	21	30.9%	32	22.9%
	7.0	12	17.6%	6	4.3%
Does your child have any food orally	No	33	48.5%	56	40%
	Yes	35	51.5%	84	60%

**Figure 8-2 Child- related Demographics**

\* ARFID = Avoidant restrictive food intake disorder, FTT = failure to thrive

### 8.2.1 Diagnosis

Parents were asked to provide their child's diagnosis or describe their problems. The researcher categorised the responses into groups that were then reviewed by a consultant paediatrician. Several children had multiple diagnoses or problem types for example '*Quadriplegic cerebral palsy, epilepsy, registered blind, severe developmental delay*'. In such cases the first or main condition was categorised i.e. cerebral palsy. The category of genetic included syndromes such as Down, Rett and SWAN (not a diagnosis but commonly used to describe a child with a yet to be identified genetic condition). The structural category included spina bifida, congenital diaphragmatic hernia and tracheo-oesophageal fistula. The physiological category included allergies and kidney disease, and other included brain tumour and traumatic brain injury. The two largest groups were cerebral palsy with 25% of children who were not using BD and 36.4% of those who were using BD being placed within the

group, followed by 'genetic' with 27.9% and 32.1% respectively. Overall there was no statistically significant association between diagnosis and the use of BD as assessed by Fisher's exact test  $p = .08$ .

### **8.2.2 Age at placement of gastrostomy**

The age at which the child had their gastrostomy ranged from under one year to 21 years of age. The mean age for gastrostomy insertion was younger for those using BD ( $M = 2.70$ ,  $SD = 3.99$ ) and for those not using BD ( $M = 3.63$ ,  $SD = 5.13$ ). The distribution was skewed (towards the younger age range) so a Mann Whitney U test was carried out to determine if the differences between age of gastrostomy placement was statistically significant different. Differences were not found to be statistically significant  $U = 4264$ ,  $z = .85$ ,  $p = .40$ . For both groups the majority of gastrostomies were in place before the age of 4 years. The age was missing for five of the participants all of whom were in the BD users cohort. This was the only area with missing data in the survey.

### **8.2.3 Oral intake**

Parents were asked to indicate if their child had any food orally. Parents were not asked in any more detail about the amount or types of oral intake they had. 84 (60%) children who were using BD had some food orally in comparison to 35 (51%) of those who were not using BD. A chi-square test was carried out to determine if there was an association between oral intake and the use of BD. No significant association was found ( $\chi^2(1) = 1.36$ ,  $p = .24$ ).

### **8.2.4 Medicines**

Parents were asked if they gave their child medicines through their gastrostomy. 135 (96.4%) of those who were using BD and 68 (100%) who were not using BD reported that they did give medicines via the gastrostomy. Of the five parents who did not use the tube, four said their child did not require any medicine and one said they did not use the tube for medicine. The difference between the two groups was not statically significantly different as shown by Fisher's exact test  $p = .23$ .

### 8.2.5 Reason for gastrostomy

Parents were asked to provide the reason for their child's gastrostomy, and were able to select multiple reasons. Categories were derived from the reasons given by parents who participated in the in-depth interviews as well as those presented (unpublished) at the East of England Paediatrics Neurodisability Special Interest Group (Oct 2017).

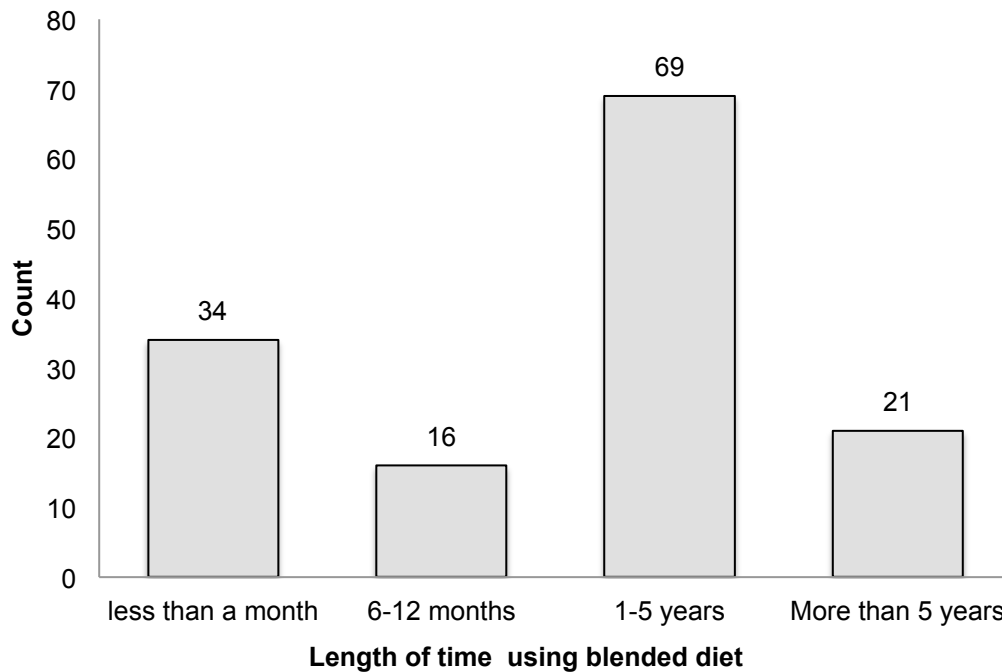
Figure 8-3 illustrates the reasons given for gastrostomy. All reasons were endorsed by at least 39 parents suggesting that the reasons were relevant to their experience. Most parents gave multiple reasons for their child's gastrostomy, with a total of 26 combinations of reasons. The reasons were further grouped and are shown in the table below, where n equals the number of times the reason was mentioned. Unsafe swallow was the most commonly cited reason for both those who did and did not use BD.

Reason for Gastrostomy	BD user or not	
	Formula (n)	Blended (n)
Failure to thrive	31	68
Gastro oesophageal reflux	17	52
Inadequate oral intake	28	65
Unsafe swallow	32	72
Other	10	20

Figure 8-3 Reason for gastrostomy

### 8.2.6 Length of time on blended diet

Skip logic was used within the questionnaire to present a set of questions only to respondents who were using BD. In this section the data relates only to those respondents who were using BD.



**Figure 8-4 Length of time using BD**

Parents were asked to indicate how long they had been giving their child BD. The largest single group (49%) consisted of those who had been using BD for more than a year but less than less than five years.

### **8.2.7 Reason(s) for using BD**

Parents were asked to state the reason they used BD, and were able to select multiple reasons. Figure 8-10 shows that the most frequently cited reason was 'parental preference' with 90 of the 140 parents selecting it, followed by 'did not tolerate formula' and 'bowel movement' both of which were cited 77 times.

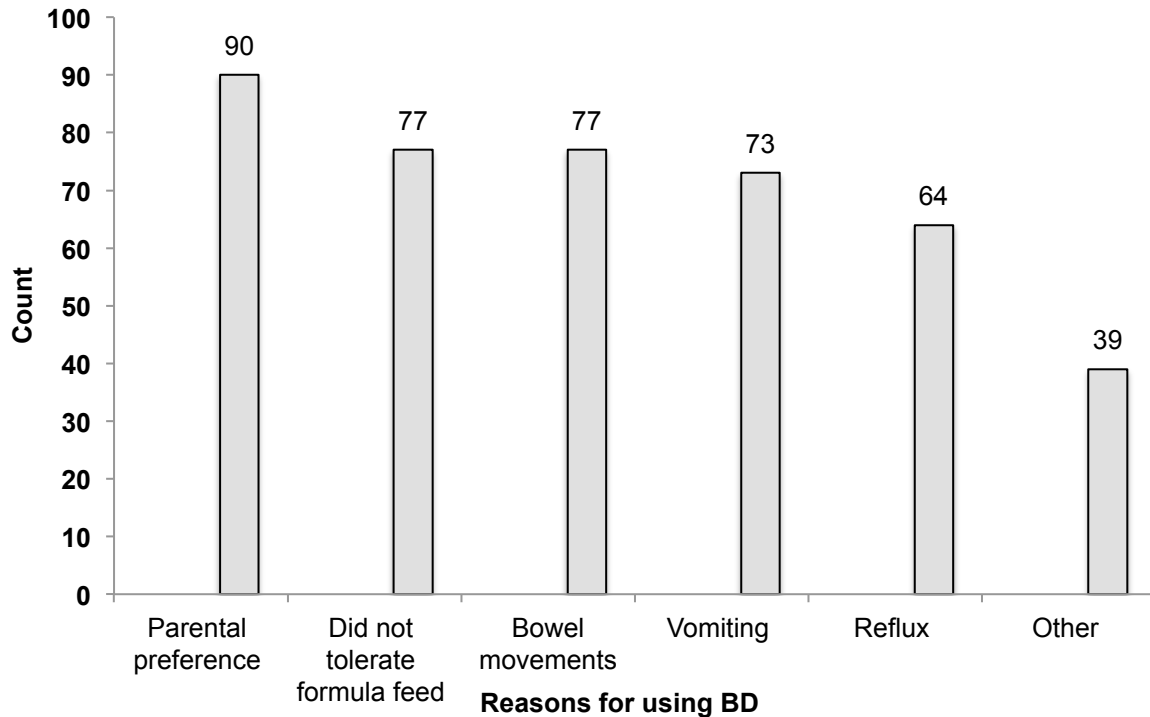


Figure 8-5 Reason for using BD

### 8.2.8 Types of food

Parents were asked to state the types of food that they gave to their child via the gastrostomy. The options were derived from the foods described by the parents in the in-depth interviews and from the blogs. Multiple options could be selected and if the 'other' option was selected parents used a free text field to describe this. Parents described using healthy ingredients such as fruit and vegetables, some mentioned selecting foods specifically to increase calorific intake and natural ingredients to aid digestion such as ginger and turmeric. Ketogenic diets were mentioned and one parent said they would blend restaurant food if they went out for dinner. Blended family meals were most cited (n=96) and 21 parents reported only giving this to their child. Food especially prepared for their child was second most cited (n=73) with 23 parents stating that they only used food especially prepared for their child.



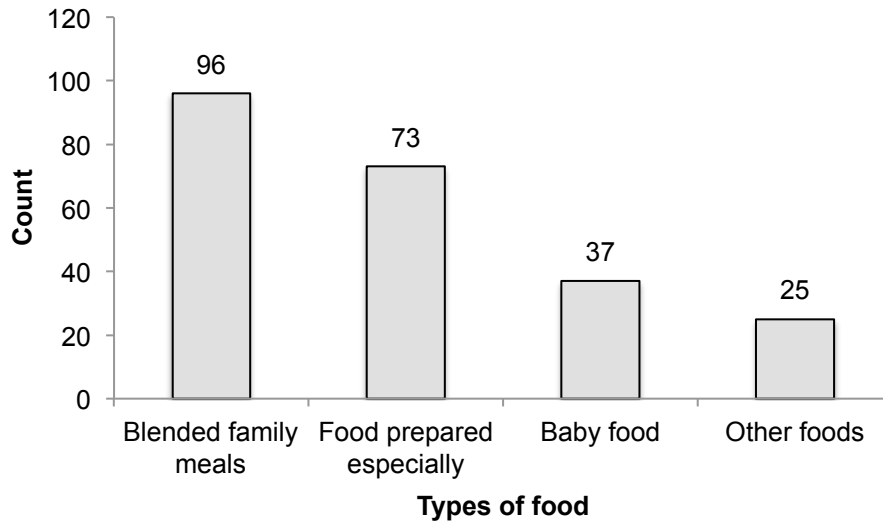


Figure 8-6 Types of food used for BD

### 8.3 Results from feeding questions

Figure 8-7 below lists the feeding statements. These statements were derived following the thematic analysis of the data from the in-depth interviews and blogs. Parents rated the statements as strongly disagree, disagree, neutral, agree and strongly agree, which were then coded from 1-5. The raw data which can be found in appendix 10, shows that BD non-users had a higher percentage of 'neutral' (3) ratings in comparison to the BD users in each of the questions.

Statement	Mann Whitney Results	Effect Size ( <i>r</i> )
1) I feel involved in my child's feeding.	$U = 3894, p = .01$	.18
2) A more flexible approach to feeding my child would suit me better.	$U = 3191, p < .001$	.28
3) Formula feeds are the best way to be sure my child has the calories and nutrients he/she needs.	$U = 1057, p < .001$	.66
4) The food my child is given improves his/her quality of life.	$U = 3620, p = .001$	.22
5) Feeding my child is stressful.	$U = 4345, p = .29$	N/A
6) I feel that my child receives the help and support with feeding that I want for him/her.	$U = 3842, p = .02$	.16
7) My child is usually well.	$U = 4082, p = .81$	N/A
8) I know what is best for my child with regard to feeding.	$U = 2580, p < .001$	.4

Figure 8-7 Feeding statements

Mann Whitney U indicated that statements 2,3,4,6,8 showed statistically significant differences in responses between those who did and did not use BD. Effect sizes were categorised according to Cohen's classification 0.1 (small), 0.3 (medium) and 0.5 and above (large) (Cohen, 1988).

## 8.4 Results of Hypothesis

In this section the results of each of the hypotheses will be presented. For clarity, the alternate hypothesis, as opposed to the null hypothesis is stated.

### 8.4.1 Parents who use BD have high levels of concerns about formula feed and low levels of belief about the need for it

The Beliefs about Medicines Questionnaire (BMQ) *specific* comprises of a set of belief statements, rated by participants that can be adapted according to the medication in question (Horne, Weinman, & Hankins, 1999). In this research the formula feed was the medication; an example being 'My child's health at present depends on their *formula feed*'. Five of the statements are used to determine a needs value (1,3,4,7,10) and five a concerns value 2,5,6,8,9). The statements are listed in figure 8-8 below.

---

BMQ 1	My child's health at present depends on their formula feed
BMQ 2	Having to use formula feed worries me
BMQ 3	My child's life would be impossible without formula feed
BMQ 4	Without formula feed my child would be very ill
BMQ 5	I sometimes worry about the long-term effects of formula feed
BMQ 6	My child's formula feed is a mystery to me
BMQ 7	My child's health in the future will depend on formula feed
BMQ 8	My child's formula feed disrupt their life
BMQ 9	I sometimes worry about my child becoming too dependent on formula feed
BMQ 10	My child's formula feed protects them from becoming worse

---

**Figure 8-8 Beliefs about Medicines (specific) Statements**

Answers ranged from strongly disagree (1) to strongly agree (5). It should be noted that the mode value for statements that reflected the perceived need for formula feeds amongst the BD users was 1 (strongly disagree).

The central tendency and standard deviations data for each of the statements is shown in figure 8-9 below.

BD user or not		BMQ1	BMQ2	BMQ3	BMQ4	BMQ5	BMQ6	BMQ7	BMQ8	BMQ9	BMQ10
	N	68	68	68	68	68	68	68	68	68	68
	Mean	3.74	2.37	3.91	3.82	2.81	2.49	3.66	2.66	2.46	3.91
Formula	Median	4.00	2.00	4.00	4.00	2.00	2.00	4.00	3.00	2.00	4.00
	Mode	4.00	2.00	4.00	5.00	2.00	2.00	4.00	2.00	2.00	4.00
	SD	1.24	1.11	1.08	1.18	1.31	1.09	1.13	1.22	1.27	.86
	N	140	140	140	140	140	140	140	140	140	140
	Mean	2.22	4.18	2.03	2.01	4.37	2.74	1.93	3.46	2.90	2.16
Blended	Median	2.00	5.00	1.00	1.00	5.00	3.00	1.00	3.00	3.00	2.00
	Mode	1.00	5.00	1.00	1.00	5.00	2.00	1.00	3.00	3.00	1.00
	SD	1.39	1.06	1.31	1.31	1.02	1.31	1.17	1.18	1.35	1.30

**Figure 8-9 Measures of central tendency for each BMQ specific statements**

The central tendency and standard deviations data for each the composite BMQ needs and concerns scores are shown in figure 8-10 below.

The results of the BMQ needs for the BD user and non BD user groups were compared using a Mann Whitney U. Results indicate a significantly higher level of perceived need for formula amongst those parents who did not use BD ( $Mdn = 157$ ) compared to those who did use BD ( $Mdn = 79$ ),  $U = 1224$ ,  $p < .001$ . The effect size was medium ( $r = .37$ ). Conversely, the BMQ concerns showed higher levels of concerns amongst the parents who were using BD than those who did not. ( $Mdn = 125$ ) compared to those who did use BD ( $Mdn = 62$ ),  $U = 1888$ ,  $p < .001$ . The effect size was small-medium ( $r = .24$ ).

BD user or not		BMQ Needs	BMQ Concerns
	N	<b>68.00</b>	<b>68.00</b>
	Mean	<b>3.81</b>	<b>2.56</b>
Formula	Median	<b>4.00</b>	<b>2.40</b>
	Mode	<b>4.20</b>	<b>2.00</b>
	Std. Deviation	<b>.83</b>	<b>.89</b>
	N	<b>140.00</b>	<b>140.00</b>
	Mean	<b>2.07</b>	<b>3.53</b>
Blended	Median	<b>1.80</b>	<b>3.60</b>
	Mode	<b>1.00</b>	<b>3.80</b>
	Std. Deviation	<b>1.14</b>	<b>.77</b>

**Figure 8-10 Measures of central tendency for BMQ needs and concerns**

### 8.4.2 Parents who use BD believe medicines are harmful and overused

The BMQ *general* measures the extent to which respondents believe doctors overuse medicines and the extent to which they perceive them as being fundamentally harmful (Horne et al., 1999). The scale comprises eight statements, five of which relate to perceived harm and three to overuse. Statements 1,4,7,8 related to beliefs about overuse and statements 2,3,5,6 related to beliefs about harm. The statements are listed in figure 8-11 below

BMQ 1	Doctors use too many medicines
BMQ 2	People who take medicines should stop their treatment for a while every now and then
BMQ 3	Most medicines are addictive
BMQ 4	Natural remedies are safer than medicines
BMQ 5	Medicines do more harm than good
BMQ 6	All medicines are poisons
BMQ 7	Doctors place too much trust on medicines
BMQ 8	If doctors had more time with patients they would prescribe fewer medicines

**Figure 8-11 Beliefs about Medicines (general) statements**

Answers ranged from strongly disagree (1) to strongly agree (5). The figure below illustrates the frequencies of responses. Figure 8-12 illustrates the central tendency and standard deviations data for each of the statements.

BD user or not		GBMQ1	GBMQ2	GBMQ3	GBMQ4	GBMQ5	GBMQ6	GBMQ7	GBMQ8
Formula	N	68	68	68	68	68	68	68	68
	Mean	2.69	2.03	2.24	2.32	1.94	1.54	2.21	2.63
	Median	3.00	2.00	2.00	2.00	2.00	1.00	2.00	2.50
	Mode	3.00	2.00	2.00	2.00	2.00	1.00	2.00	2.00
	Std. Deviation	.98	.91	.87	1.00	.75	.66	.84	.90
Blended	N	140	140	140	140	140	140	140	140
	Mean	3.18	2.19	2.39	2.43	2.08	1.71	2.74	3.01
	Median	3.00	2.00	2.00	3.00	2.00	1.50	3.00	3.00
	Mode	3.00	2.00	2.00	3.00	2.00	1.00	2.00	4.00
	Std. Deviation	1.08	.95	1.06	1.03	.83	.84	1.08	1.10

**Figure 8-12 Measures of central tendency for each BMQ general statement**

The results of the BMQ *general* from the parents who used BD and those who did not were compared using Mann Whitney U test. For the harm subscale results showed no statistically significant difference between the two groups BD  $U = 4126$ ,  $p = .12$ . The overuse subscale revealed that there was a statistically significant difference

between the two groups. Parents who used BD (*Mdn* = 114) compared to those who did use BD (*Mdn* = 85)  $U = 3456, p = .001$ . The effect size was small ( $r = .05$ ). This result suggests that parents who used BD were more likely to believe that medicines were overused.

BD user or not		BMQ Harm	BMQ Overuse
		<b>68.00</b>	<b>68.00</b>
	Mean	<b>1.55</b>	<b>1.97</b>
Formula	Median	<b>1.40</b>	<b>2.00</b>
	Mode	<b>1.40</b>	<b>2.00</b>
	Std. Deviation	<b>.49</b>	<b>.52</b>
		<b>140.00</b>	<b>140.00</b>
	Mean	<b>1.67</b>	<b>2.27</b>
Blended	Median	<b>1.60</b>	<b>2.20</b>
	Mode	<b>1.60</b>	<b>1.80</b>
	Std. Deviation	<b>.55</b>	<b>.67</b>

**Figure 8-13 Measures of central tendency for BMQ harm and overuse**

### **8.4.3 Parents who use BD will have higher levels of self-efficacy**

The self-efficacy scale assesses a respondent's ability to cope with and adapt to stressful life events (Schwarzer & Jerusalem, 1995). The 10 items are scored on a 4-point scale, giving a composite score ranging from 10 to 40, with the higher score indicating higher level of self-efficacy. The statements are in figure 8-14 below.

SE 1	I can always manage to solve difficult problems if I try hard enough
SE 2	If someone opposes me I can find the means and ways to get what I want
SE 3	It is easy for me to stick to my aims and accomplish my goals
SE 4	I am confident that I could deal efficiently with unexpected events
SE 5	Thanks to my resourcefulness I know how to handle unforeseen situations
SE 6	I can solve most problems if I invest the necessary effort
SE 7	I can remain calm when facing difficulties because I can rely on my coping abilities
SE 8	When I confronted with a problem I can usually find several solutions
SE 9	If I'm in trouble I can usually think the solution
SE 10	I can usually handle whatever comes my way

**Figure 8-14 Self-efficacy statements**

Figure 8-15 below shows the central tendency and standard deviations data for each of the statements for those who did and did not use BD.

BD user or not		SE1	SE2	SE3	SE4	SE5	SE6	SE7	SE8	SE9	SE10
Formula	N	68	68	68	68	68	68	68	68	68	68
	Mean	3.13	2.62	2.90	3.21	3.21	3.19	3.25	3.06	3.15	3.25
	Median	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00
	Mode	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00
	Std. Deviation	.64	.71	.63	.56	.48	.58	.58	.60	.53	.53
Blended	N	140	140	140	140	140	140	140	140	140	140
	Mean	3.31	2.96	3.14	3.40	3.36	3.39	3.32	3.29	3.28	3.37
	Median	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00
	Mode	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00	3.00
	Std. Deviation	.61	.69	.60	.56	.54	.54	.64	.55	.50	.54

**Figure 8-15 Measures of central tendency for each self-efficacy statement**

Using an independent t-test on the composite score, parents who used BD were shown to have significantly higher levels of self-efficacy ( $M = 32.81$ ,  $SD = 4.08$ ) compared to those who did not use BD ( $M = 30.96$ ,  $SD = 4.07$ )  $t(206) = 3.09$ ,  $p = .002$ . The effect size was medium (Hedge's  $g = .5$ ). The frequency data for the composite scores are shown in Figure 8-16 below.

Self efficacy score		
	N	<b>68.00</b>
	Mean	<b>30.96</b>
Formula	Median	<b>30.00</b>
	Mode	<b>30.00</b>
	Std. Deviation	<b>4.07</b>
	N	<b>140.00</b>
Blended	Mean	<b>32.81</b>
	Median	<b>32.00</b>
	Mode	<b>30.00</b>
	Std. Deviation	<b>4.08</b>

**Figure 8-16 Measures of central tendency for composite self-efficacy scores**

#### **8.4.4 More children who are having BD will have normal stools**

Parents were asked to rate their child's stools using the seven-point rating scale of the Bristol stool scale. A level of one or two is associated with constipation and six

and seven with diarrhoea. Levels three, four and five are considered normal (Chumpitazi et al., 2016). From the frequency table below it can be seen that although the mean for both groups of children were within the normal level, the mode level of children on BD was level four which is considered normal whereas for those who were not on BD the mode it was level six which is a level of diarrhoea.

	BD user or not				
	Formula		Blended		
	Count	%	Count	%	
	1.0	4	57.1%	3	42.9%
	2.0	2	11.1%	16	88.9%
	3.0	6	17.6%	28	82.4%
Bristol stool chart rating	4.0	19	30.6%	43	69.4%
	5.0	4	25.0%	12	75.0%
	6.0	21	39.6%	32	60.4%
	7.0	12	66.7%	6	33.3%
		Formula		Blended	
Mean		4.88		4.18	
Median		5.00		4.00	
Mode		6.00		4.00	
Std, Deviation		1.70		1.9	

**Figure 8-17 Bristol stool scale ratings and measures of central tendency data**

Figure 8-17 illustrates the range of values for both BD users and non-users, as rated by parents.

A Chi Square test was conducted to discover if there was a correlation between stool ratings and the use of BD. A significant association was found ( $\chi^2 (1) = 3.81, p = .05$ ). The effect size was small ( $\phi = .14$ ).

These results suggest that children having BD are more likely to have stools in the normal range as (defined in the Bristol stool chart) when compared with children who are not having BD.

## 8.4.5 Parents using BD rate their child's (i) health and (ii) quality of life higher than parents not using BD

### 8.4.5.1 Health rating

Parents were asked to rate their child's health over the past month on a 5-point scale ranging from poor (rated as 1) to excellent (rated as 5). Figure 8-18 below illustrates the distributions of rating by group, BD user of formula feed user, and mean, median, mode and standard deviation for each group.

		BD user or not			
		Formula		Blended	
		Count	%	Count	%
Health Rating	1 (Poor)	2	2.9%	18	12.9%
	2 (Fair)	23	33.8%	19	13.6%
	3 (Good)	26	38.2%	37	26.4%
	4 (Very good)	16	23.5%	42	30%
	5 (Excellent)	1	1.5%	24	17.1%
		Formula		Blended	
Mean		2.87		3.25	
Median		3.00		3.00	
Mode		3.00		4.00	
Std, Deviation		.86		1.26	

Figure 8-18 Parental rating of child's health and measures of central tendency data

A 2-tailed t-test was conducted and parents who used BD had a higher mean ( $M = 3.25$ ,  $SD = 1.62$ ) compared to those who did not use BD ( $M = 2.87$ ,  $SD = .86$ )  $t(206) = -2.259$ ,  $p < .03$ . The effect size was small – Hedge's  $g = .27$ . This result suggests that parents who used BD were more likely rate their child's health as being higher than those not using BD.

### 8.4.5.2 Quality of life rating

Parents were asked to rate their child's quality of life - their general well-being in terms of health, comfort and happiness. Responses were rated on a 5-point scale ranging from poor (rated as 1) to excellent (rated as 5). Figure 8-19 below illustrates the distribution and frequencies, rating by group, BD user or non-user.



		BD user or not			
		Formula		Blended	
		Count	%	Count	%
Quality of Life Rating	1 (Poor)	0	0%	7	5.0%
	2 (Fair)	16	23.5%	17	12.1%
	3 (Good)	20	29.4%	25	17.9%
	4 (Very good)	24	35.3%	60	42.9%
	5 (Excellent)	8	11.8%	31	22.1%
		Formula		Blended	
Mean		3.35		3.65	
Median		3.00		4.00	
Mode		4.00		4.00	
Std, Deviation		.97		1.11	

**Figure 8-19 Quality of life rating and measures of central tendency data**

Again, as with parental health rating the spread of ratings across all five levels is greater for BD users. None of the non BD users rated their child's quality of life as poor, whereas 5% of BD users selected this rating.

A 2-tailed t-test was conducted and parents who used BD rated their child's quality of life slightly higher with a mean ( $M = 3.65$ ,  $SD = .97$ ) compared to those who did not use BD ( $M = 3.36$ ,  $SD = 1.1$ ). However the difference was not significant  $t(206) = -1.89$ ,  $p < .06$ , indicating there is not a statistically significant difference in the quality of life ratings between the two groups.

## 8.5 Binary Logistic Regression analysis

Variables that were found to be statistically significant in the hypotheses testing were further analysed in a binary logistic regression analysis to see if they could predict which of the two categories (BD user or not) a participant was likely to belong. Simultaneous entry of all variable was used as the purpose of the model was more for exploration than hypothesis testing (Field, 2011).

### 8.5.1 Assumptions

This model was checked to ensure that all assumptions were met. The dependent variable is dichotomous. There are one or more independent variables. There are at least 15 cases per predictor variable (in the model there are 34 cases per predictor variable) (Field 2011). The Durbin-Watson statistic confirmed the independence of

the observations ( $d=1.9$ ) as an expected value of approximately 2 indicates assumptions of independence are met (Field 2011). There was no evidence of multicollinearity, with the Variation inflation factor (VIF) values ranging from 1 to 1.18 (well below 10) and the tolerance statistics are greater than 0.2 (Hair, Black, Babin & Anderson, 2014). Casewise diagnostics identified three cases with standardised residuals over 2.5 exceeding the expected 1% (Field, 2011). All Cooks distances were below 1, the centred leverage values were all within three times the size of the average leverage (0.09), and Mahalanobis Distance (maximum = 16.3) was acceptable given the sample size and number of predictor variables. It was therefore determined that the three outliers cases could be maintained in the model (Stevens, 2002).

### 8.5.2 Results

The sample size was 208. The model contained six independent variables (BMQ needs, BMQ concerns, BMQ overuse, self efficacy, stool rating and health).

The full model with all predictors was a statistically significant fit to the data ( $X^2(6, N=208) = 103.7, p<.001$ ) indicating that the model was able to distinguish between those who did and did not use BD.

	B	Wald	df	Sig.	Exp(B)	95% C.I. for EXP(B)	
						Lower	Upper
BMQ_N	-1.136	30.020	1	.000	.321	.214	.482
BMQ_C	.838	10.261	1	.001	2.311	1.384	3.857
GBMQ_O	-.171	.206	1	.650	.843	.404	1.761
SE average	.080	2.427	1	.119	1.083	.980	1.197
Normal stool	.312	.506	1	.477	1.366	.578	3.229
Health	.073	.129	1	.720	1.076	.721	1.607
Constant	-.993	.195	1	.659	.370		

Figure 8-20 Data from regression analysis

Figure 8-20 shows that only two predictors, BMQ needs and BMQ concerns contributed significantly to the model. The strongest predictor was BMQ concerns (odds ratio 2.3), suggesting that respondents who used BD were over twice as likely to express concerns about the use of formula compared to those who did not. Conversely, the odds ratio for BMQ needs was .32 suggesting that respondents who

used BD were .32 times less likely to see the need to use of formula compared to those who did not.

The model as a whole explained between 39.3% (Cox and Snell R square) and 54.7% (Nagelkerke R squared) of the variance in BD use and correctly classified 81.7% of cases. The initial null model with no variables categorised 67.3% correctly so the model with the addition of independent variables categorised an addition 14% correctly.

## **8.6 Discussion**

This section will provide a brief discussion on specific aspects of the quantitative phase of the research. Integration and triangulation of findings from all three phases and subsequent discussion is found in Chapter 9.

Much of the focus of the results section has been on the statistical significance of the findings. However, the concept of clinical significance must also be considered. Clinical significance can be viewed as the importance of a finding in relation to how it may impact on clinical practice or patients' lives. LeFort (1993) also discusses social validation as a means of evaluating clinical significance. Social validation argues that patients themselves and their carers are best positioned to determine clinical significance, and the importance of small but meaningful changes should not be overlooked. In relation to the Bristol stool ratings, BD users were statistically significantly more likely to rate their child's stool within the normal range. Although the effect size was small ( $\phi = 0.14$ ) the significance to families was great – with parents from the interviews describing how improved stooling had facilitated toilet training and a reduction in soiled clothing and bedding that resulted from improved stooling. Conversely the effect size of the statistically significant difference in self-efficacy between those who did and did not use BD was medium (Hedge's  $g = .5$ ), but the clinical significance may arguably be less important.

The significant correlation between participant's beliefs regarding needs and concerns of formula feed and the use of BD reiterated the concepts within the necessity concerns framework. That is, an individual's actions are influenced by the balance of their perceived need versus their concerns about adverse consequences (Horne and Clatworthy, 2010).

Similarly symbolic interactionism (Blumer 1969) suggests that the meanings a person attaches to symbols (words, objects, actions etc.) influence the way they act. This may explain why personal preference was cited 90 times as a reason for using BD; if parents attach negative views and concerns to formula feeds they are more likely to seek an alternative. This negative view of formula feeds may also have played a part in the choice of foods parents used in their child's blend. 90 parents indicated that they gave their child blended family meals and 73 that they prepared food especially for their child's blend. This resonates with some of today's food discourses - that home cooked food is good, and additives and processed food are bad (Warner 2017).

To recap, the BMQ has two sections – the *specific*, which asked questions directly related to the use of formula feeds, and the *general*, which sought beliefs about medicines in general. There was a statistically significant difference in the level of concerns about the potential harm of formula feed, with 88.6% of BD users agreeing or strongly agreeing with the statement 'I sometimes worry about the long term effects of using formula feeds'. However, there was no statistically significant difference in the views about harm from medicines in general between the two groups (as shown in the BMQ *general*). This could imply that BD users concerns were specific to the formula feeds, a view substantiated by interviewees who acknowledged their child's needs for some medicines, but did not want to over-medicalise their child or use them only when absolutely necessary. P12 said “*xxx still takes a lot of medication for his epilepsy and his bladder spasms and antibiotics you know things like that. I am not anti-medicines - I'm anti-medicine is where there is an alternative*”. This resonates with the suggestion that negative views of medication tended to focus on potential harmful effects rather than a lack of efficacy or benefit (Horne, Weinman, & Hankins, 1999).

Further analysis of the response to the feeding statements raises some issues that relate to choice, self-efficacy and quality of life. Of the BD users, 67.8% agreed or strongly agreed with Statement 2 '*A more flexible approach to feeding my child would suit me better*' as opposed to 45.6% of non-BD users. This resonates with the sub-themes of choice and control. Parents acknowledged that formula feeds were sometimes required but also wished to have the right to be able to decide what to

give their child at other times. P5 said “*So whilst xxx was in crisis state get the formula into her lets not faff about -let's do that and then once we kind of stabilized a little bit then we could look at the blended diet*”. Once parents took control, and began using BD, they were then also able to choose what they gave their child.

Feeding statement 4 states ‘*The food my child is given improves his/her quality of life*’. 86.5% of BD users agreed or strongly agreed with this statement as opposed to 78% of non-BD users, which was not statistically significant. Similarly, the overall quality of life rating for the two groups revealed no statistically significant difference. This finding should be further explored in future research to determine if there are families who would still opt for formula feeds even if BD was offered as an alternative, and reiterates the need to maintain equipoise when debating the pros and cons of BD.

For feeding statement 5 ‘*Feeding my child is stressful*’, there was no statistically significant difference between the two groups. Over a third of both BD users and non users agreed or strongly agreed with the statement with BD users having a slightly higher percentage 39.3% versus 35.2% for non BD users. This raises two issues, firstly the fact that over a third of all parents of gastrostomy fed children find feeding stressful, a concern that should be further examined by HCPs. Secondly that opting to use BD does not make feeding statistically significantly more stressful for parents, but perhaps what parents would like is for HCPs to understand and respect their perspectives and priorities around feeding (Cowpe, Hanson, & Smith, 2014). Of BD users, 93.6% agreed or strongly agreed with feeding statement 8 ‘*I know what is best for my child with regard to feeding*’, as opposed to 72% of those who did not use BD. This resonates with the levels of self-efficacy amongst the participants. Both BD users and non-users had higher than average levels of self-efficacy (Scholz, Doña, Sud, & Schwarzer, 2002), but the level amongst BD users were statistically significantly higher than that of non BD users. A question for future research could attempt to determine if this high level of self-efficacy was a driver for parents to try BD or has increased through the experiences of using BD.

The questionnaire revealed that out of the 204 children who required medication 203 (99%) were given their medicine via their gastrostomy. This widespread practice of administering a drug via a gastrostomy often contravenes the terms of the product

licence for both the drug and the tube (Bradnam & White, 2007). The issues raised by this practise are discussed in more detail in section 9.4.3.

## **8.7 Limitations**

Challenges associated with web-based questionnaires include ensuring a representative sample and measuring non-response rates (i.e. those who are aware of the questionnaire but opt not to respond). Sending the questionnaire directly to a predetermined number of families could address this but in this research this was not possible as there is no record of parents who are using BD. Self-selection bias is a limitation of the study. 140 BD users and only 68 non-users responded to the survey and yet it is likely that the majority of children and young people fed by gastrostomy are non-BD users. This may have been explained by BD users having a vested interest in the research project if they viewed it as a potential means of increasing the chances of BD becoming an acceptable form of feeding. Conversely, another potential issue caused by self-selection bias is that families who have tried BD and not found it beneficial may be less motivated to take part in the survey.

Dishonesty regarding answers and multiple survey submissions is a potential limitation. McInroy (2016) recommends asking some questions in several ways to assess for consistency of responses. Google forms contain a facility to collect email addresses which would enable a researcher to check for multiple submissions but this would then mean participants could not opt to remain anonymous.

The use of single questions rating health and quality of life was a limitation. Although feedback from the participants in the pilot about length of the survey led to the use of a single quality of life question, had a standardised rating been used more meaningful comparisons could have been made (see section 9.4). On reflection a rating scale based on the PedsQoL Gastrointestinal module would have provided ratings covering a range of relevant gastrointestinal conditions including reflux, constipation, stomach pain and vomiting even though previous feasibility, reliability and validity would be invalidated it could have provided a more holistic impression of the impact of BD on quality of life. Similarly, the quality of life and health ratings were arguably too similar, and had they been positioned separately within the survey they might have provided a greater insight in terms of reliability of response (Vicente & Reis 2010).

With regard to the BMQ *specific*, the cross sectional design of the questionnaire does not reveal whether concerns about formula feed led parents to use BD or whether the use of BD leads to greater concerns.

It is possible that the beliefs about formula feeds and BD of non-responders may be different from those of the participants. It would seem plausible that families who did not respond to or take part in the questionnaire may have held more neutral views.

The online survey did not provide an opportunity for non-BD users to write any other comments regarding their views on BD; again this was in part an ethical decision by the researcher, not wanting to draw them into a debate about something that is not approved or supported. It did however mean that there were potentially families who had used BD in the past and stopped, who were not able to share their views.

The web-based questionnaire meant that responses were international so it was not possible to determine UK based respondents and disaggregate any country specific information. A question asking about nationality and or country of residence could be used in any future web-based survey.

Another limitation was that there was no opportunity for families who did not speak English to access the survey or participate in the interviews. Although the ethnicity of the survey respondents was collected, it is not possible to determine whether families were resident in the UK, and therefore subject to NHS policies regarding BD. However, it was interesting to note that many blogs were not UK-based, but were still facing similar dilemmas with regard to the use of BD.

Participants in the survey were asked to provide their child's diagnosis or medical condition within a free text answer. The data provided were too diverse and it was difficult to make meaningful comparisons. Future research should consider providing a predefined set of conditions or diagnoses; however, careful consideration needs to be given to ensure the options are meaningful to parents. A recent study of paediatric enteral feeding in the Netherlands used the International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10 Version: 2016) to categorize medical conditions (Krom et al., 2019).

It was not possible from the data collected to determine whether having been previously orally fed had any impact on the use of BD; this would be an area to investigate in future research.

Another limitation of the survey was the grading of the time boundaries for length of time on BD, with 49% being in the 'more than one year and less than 5 years' bracket. More accurate data could have been obtained if the time brackets had been more graded.

Participants who completed the questionnaire could remain anonymous, however, there was an option to provide contact details in order to be informed of the outcome of the research. A more explicit statement stating that if parents did provide contact details these would be kept confidential by the researcher and not be shared would have provided additional assurance to participants.

Finally although consent was implied by the completion of the survey, a tick box could have been placed after the information about the survey for participants to confirm they had read, understood and consented to take part in the survey.

## **8.8 Conclusion**

The key results presented in this chapter have shown that demographics of age, income and education do not appear to correlate with the use of BD. Other results revealed correlations between factors such as stool type and health with the use of BD. Finally the BMQ needs and concerns scores were highly predictive of use or non-use of BD and correctly classified 84.6% of cases. Lower levels of BMQ need and higher levels of BMQ concerns were associated with an increased likelihood of using BD. Chapter 9 will discuss the implications of these findings.



## **Chapter 9 Discussion**

### **9.0 Introduction**

The purpose of the research was to understand why parents opt to use BD to feed their gastrostomy-fed children. A mixed methodology was used, and thematic analysis of data from interviews and blogs revealed a complex array of issues. The quantitative phase consisted of a questionnaire that was developed using information from the qualitative phase and other relevant studies.

In this chapter the main findings from the research will be summarised, and discussed in relation to the published literature and social theories, whilst considering potential explanations for, and the implications of the findings.

The four key themes from the qualitative analysis will serve as a framework for the discussion namely loss, conflict, empowerment and quality of life – will provide the framework. Parents in the interviews used the analogy of a journey when describing aspects of their experiences with BD. 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 parent and an overall loss of control about what was going on in their lives. This loss of control led to onto conflict between families and HCPs. Conflict will form the second area of discussion, and will examine how by dealing with or coming to terms with conflict, parents appear to transition to the third theme empowerment. Parents become more confident and empowered and seek ways to establish the use of BD in their child's daily life and to develop and share their experiences of BD with others. The fourth stage of this journey is encapsulated within the quality of life theme.

The chapter will also discuss social media and its use as a source of data and also its relevance to the research question.

There will be a critical review of the study including limitations, implications for clinical practise with recommendations for future research, and the chapter concludes with a personal reflection from the author.

### **9.1 Loss**

One of the most powerful emotions described by participants in the in-depth interview was that of loss. Losses included that of the 'normal' child and the life they had

anticipated, of their own self-identity as a parent and the loss of control over parts of their lives.

Some participants had older children without complex needs, so would have had experienced what they considered a normal family life prior to either their child becoming ill or the birth of their child with complex needs. Having had this experience of normal life appears to make its loss more distressing and lead to the re-emergence of some of the basic early maternal feeding and nurturing instincts. P10 said – ‘*As parents we are made to nurture ... you are hardwired to*’. Similarly P1, described her view of feeding him formula feeds as a ‘*care thing rather than an enjoyable pleasurable social thing*’.

The loss of an ideal, of a preconceived notion of family life and parenthood was another area parents described. Research into the effect of enteral feeding found parents who were unable to feed their child orally and felt their child was missing out on social activities associated with food suffered depression (Enrione, Thomlison, & Rubin, 2005). Parents in the interview expressed views about having to use formula feeds that were similar to those of parents describing their views regarding their child having to have a gastrostomy. It appears that the sense of a loss of control was apparent in both scenarios. Research reviewing psychosocial issues associated with gastrostomy insertion suggested parents viewed the gastrostomy as evidence of their failure to feed their child and that it was a source of disruption to maternal nurturing and bonding and that it denied their child the pleasure of oral eating (Sullivan, 2014). It appears having to give children formula feeds creates the same sense of loss of the ability, and perhaps the use of BD goes some way to alleviating this sense of loss and restoring their ability to feed and nurture their child.

Over the past two decades views regarding feeding, food and parenting have evolved from a relatively private culturally driven issue to one which involves increasing levels of public and political scrutiny and debate (Lee, Macvarish, & Bristow, 2010; Spector, 2015).

The effects on parents of the loss of validation in their ability to care for their child, as they believed they should were described in section 4.1.2. Mothers, faced with the loss of being able to feed their child normally, actively sought means of proving their ability to care for, feed and nurture their child. Weight gain was commonly viewed as

a proxy measure of parenting ability. A possible explanation for these views is that weight gain was an overt indicator of their ability to conform to the socially constructed norms of good motherhood - being able to ensure their child grows and thrives (Lupton, 2011).

Parallels with the breastfeeding agenda are evident, ironically the advice is the opposite when considering gastrostomy feeding (Fallon, Komninou, Bennett, Halford, & Harrold, 2017). Mothers are informed of the benefits and social desirability of breastfeeding as opposed to using formula feeds. However, mothers whose children need gastrostomies are informed that they should use formula feeds as opposed to ordinary fresh family foods. Just as breastfeeding has come to be embedded in the moral discourse as the definition of good motherhood in our society (Knaak, 2010), the use of formula feeds for gastrostomy-fed children appears to be viewed by HCPs in a similar manner. This was evidenced by P13 whose dietitian told her BD was not a good idea and was not recommended. This response may have served to reinforce the mother's perception that she was contravening the definitions of good motherhood; definitions, which Knaak suggests, are shaped by '*dominant expert guided scientific –medical discourses*' (Knaack, 2010, p.352).

Adverse experiences of guilt, blame and the need to defend their decision were found amongst women who chose to use formula feed rather than breastfeeding their babies (Fallon et al., 2017). Similarly parents who chose to use BD described how they faced disapproval from some HCPs and were challenged about their decision to use BD.

The feelings of loss expressed by mothers appear to be influenced by food discourses prevalent in current society. These include issues relating to food culture, demonising of certain foods and an increasing influence of government and health policy on our eating habits (Delormier, Frohlich, & Potvin, 2009; Germov, 1997; Lövestam, Orrevall, Koochek, & Andersson, 2016). The suggestion that home cooked food is good and additives and processed food are bad is one such discourse (Warner, 2017). The perception amongst parents having to use formula feeds for their gastrostomy-fed children, that they were only able to give feeds that were indicators of poor nutrition, may well contribute to feelings of parenting failure and loss of identity as a capable parent.

Risk is another element of parenting that has become the focus of public debate. With the suggestion that we live in a more risk aware and risk averse society in which mothers are charged with having to manage risks around the health of their family, parents may be judged as 'bad parents' if they do not manage risk well (Hoffman, 2010). As mentioned in section 9.5.1 children who are having BD often have multiple and complex needs, consequently parents are often carrying out medical procedures that involve risk on a daily basis. These may include, suctioning, changing tracheostomy tubes, stoma care and administration of oxygen for ventilated children. Parents who opted to use BD reported how they were told of the risks of using BD and frequently had to complete risk assessment documents with their dieticians, which highlighted that they were undertaking a practise that was not recommended and deemed unsafe (see Appendix 11 for risk assessment form). By enforcing the use of risk assessments HCPs may inadvertently be contributing further to parental feelings of loss of identity of a good parent. P18 said of the risk assessment,

*'It was very judgemental. It just blamed me for wanting to do something that was not considered the best thing and I didn't see how that was useful'.*

### **9.1.1 Summary**

This section has discussed the theme of loss and its effect on parents in relation to the use of BD in the context of a society that views feeding, parenting and risk as an area of public responsibility. Parents experience a loss of control and of their identity as a capable parent. The consequences of parents' attempts to regain some sense of control will be explored in the next section.

### **9.2 Conflict**

As the emotions and feelings of loss subside they appear to be replaced by conflict as parents begin to take control of the situation in which they find themselves.

Conflict was one of the overarching themes from the thematic analysis of the interviews and blogs. The issues of conflict faced by parents whose children require gastrostomy tube insertion may, in part, help to explain why parents opt to use BD. When considering the sources and impacts of conflict and how these are dealt with there appear to be three key interlinking factors; the shift in the locus of control, the challenging of professional integrity and the mismatch of opinions and priorities. The

impact of these factors will now be discussed, drawing on concepts of deficit model of science, government policy and models of disability.

### **9.2.1 Shift in the locus of control**

The narrative of the participants in the interviews revealed how the use of BD created a shift in the locus of control from the HCP to the families. When families started using BD, dietitians were no longer able to be certain of the nutritional content of the food that was being given, challenging their professional responsibilities. However, parents were aware of the importance of nutrition and took on the accountability of ensuring their child's nutritional needs were met; with parents reporting the use of Apps and careful weighing and measuring to ensure they met their child's nutritional requirements.

### **9.2.2 Challenging professional credibility/integrity**

Disagreements between dietitians and parents led to confrontations, this section will explore potential reasons for these conflicts. Firstly dietitians were generally the HCP with whom the parents had most frequent discussions regarding their child's feeding regime, which meant parents tended to vent their frustrations on them. Secondly dietitians were perceived to be the HCP who determined the formula their child was given, and so parents blamed them for the ill effects of the formula. Thirdly it was dietitians who, when families decided to use BD, were the HCP who would explain the potential risks and difficulties of BD, - again conflict arose as parents felt constrained and frustrated by the advice. The fourth factor relates to the issue of weight gain. As described in Section 9.1.1 parents felt weight gain was seen as a proxy measure of their parenting skills/ability to feed their child, and as the dietitian was usually the HCP who monitored weight gain parents tended to be defensive when interacting with them.

There are parallels here with the adversarial relationship that can develop between parents and a speech and language therapist (SLT) when a child's swallow is found to be unsafe and a gastrostomy is recommended. In this scenario it is the SLT who tends to be the HCP with whom the parents have the most contact and is seen to be the person who is determining how their child eats, in some instances stopping a parent doing something they construe as being central to being a good parent

(Wilken, 2012). It appears that HCPs may have an attitude of paternalism, which is at odds with the individualistic stance of the parents, driving both the shift in the locus of control and challenging professional integrity. This area was discussed in a paper that suggested the language used by HCPs such as 'my patient' and posters in hospital referring to 'our children' can appear paternalistic and undermine the family-centred approach, which HCPs purport to promote (Shields, 2016).

Conversely when the perspectives of parents and HCPs are more aligned conflict is reduced and relationships are more positive. Those parents in the study who reported positive relationships with their dietitians valued them, with P5 describing her dietitian as being supportive whilst cautious, and P12 saying her dietitian had been supportive whilst working within the clinical guidelines around BD.

The importance of relationships between HCPs and parents was highlighted in a study of coping strategies of mothers of children with feeding difficulties, that found mothers coped more effectively when they had formed better collaborative therapeutic relationships with HCPs involved in their child's care (Garro, 2004). Research into the therapeutic alliance suggests task alliance, takes a more contractual approach focussing on interventions and protocols, diagnosis and symptom management. Conversely personal alliance reflects the HCP's experience, and more intuitive interpersonal skills, and were found to be the strongest predictor of positive outcomes. The most effective therapeutic alliance results from a combination of the two areas (Green, 2009; Thompson, Bender, Lantry, & Flynn, 2007).

### **9.2.3 Mismatch of priorities and opinions**

Conrad (1987) suggested that there maybe a clash of perspectives with regards to dealing with illness, with the medical approach of focusing on biomedical control, whereas as patients focus on living as normal as life as possible. Conrad goes on to state that suboptimal outcomes result from ignoring each other's views.

HCPs appear to regard gastrostomy as a positive intervention that reduces risk of aspiration, of inadequate nutritional intake (Kurien, McAlindon, & Westaby, 2010). However, for some parents it was viewed as a sign of their failure to feed their child. Similarly, in the domain of BD, some parents may view the use of formula feeds as a sign of their inability to nourish their child. HCPs also emphasised the value of a gastrostomy as a means of reducing long and stressful mealtimes but Craig,

Scambler, and Spitz (2003) found that stressful feeding did not equate with acceptance of a gastrostomy. Participants in the in-depth interviews acknowledged the extra time it took to prepare blended meals for their children but regarded it more positively – food choice and preparation being equated as part of normal parenting. Although BD created additional work in terms of meal choice, the time required to prepare, blend and freeze meals in comparison to using formula feed, it was not viewed as any more burdensome than preparing and cooking food for the rest of the family. The comparison with siblings emphasised the normality BD brought with it to families as P12 said

*‘ I’m doing it really slowly and smoothly but it doesn’t take much longer than 15 minutes -when I look at the speed that my six year old eats it is about the same’.*

These findings again highlight how the paternalistic, benevolent stance of HCPs is misaligned with the individualistic approach of parents. As described in the results section, one parent reported how a dietitian had questioned whether she realised the cost implications of BD, telling her that it was more expensive than being provided with formula. The parent said she found such a statement ‘ludicrous’ adding that ‘you don’t have a child and not expect to feed it’.

Within the context of an acute tertiary hospital this notion of mismatch of opinions has been seen in recent high profile cases where clinicians have felt ceasing active treatment to be in a child’s best interest and parents have challenged this decision in the High Courts (Birchley, 2018). Some of the issues raised by these cases have led to debates about the role of the state versus the wishes of families; a subject that will be mentioned in section 9.2.4.

In addition to a mismatch of priorities and opinions parents also experienced mixed messages, with an apparent mismatch between intent and action amongst HCPs. Habermas (1987) proposed the concepts of ‘lifeworld’ and ‘system’. He suggests that ‘system’ comprises strategic objective structures, characterised by technical and scientific rationality as opposed to the more practical or negotiated rationality of ‘lifeworld’. Habermas proposed that reason should be sought through debate and mutual understanding free from the constraints of power and politics. However, he suggested that in the modern world ‘system’ is liable to encroach into ‘lifeworld’; a

concept, which he referred to as 'colonisation'. This colonisation of lifeworld often had a negative impact on families P8 -

*we were under a dietician and we were under the speech therapist, and we used to have to go to joint appointments with them both, we'd get weighed and height and you know we have the same conversation ... I dreaded those appointments'. She [the dietitian] felt the need to tweak things*

This extract illustrates how colonisation occurs as the scientific rationality (height and weight measurements) impedes the potential to focus conversations and discussions on the more practical aspects of the family's needs and wishes. This colonisation of the lifeworld was also evident in a study of dietitian's interactions with patients. The study cited the importance of holistic patient care and yet when describing the patient's problem they tended to focus on medico-technical and success-oriented 'system' at the expense of more subjective yet patient focused 'lifeworld' (Lövestam et al., 2016). Potential explanations may be that this is an unintended consequence of a target/ cost driven health service, which perhaps places emphasis on goals that are more objective. Similarly it could result from a need to prove professional credibility and visibility with other health professionals.

#### **9.2.4 The impact of deficit models of science, government policy and models of disability**

This section will explore how deficit models of science, government policy and models of disability impact on control, professional integrity and priorities.

##### **9.2.4.1 The deficit model of science**

The deficit model of science was a term coined by social scientists in the 1980s, which assumes public ignorance of science and that negative attitudes to aspects of science may be attributed to this lack of understanding (Ahteensuu, 2012). Opponents of this model called for upstream engagement of the public by involving members of the public who may have an interest but no specialist knowledge in setting research priorities (Wilsdon & Willis, 2004). Latour (1988) criticised the deficit model, and instead suggested that the public were becoming more proactive generating policy that they perceived to meet their needs. It is widely acknowledged that the driving force behind the call for BD to be allowed has been led by parents not



scientists or HCPs (Coad et al., 2016). Latour's perspective may explain the actions of families who started using BD, instead of waiting until they were given permission to do so by their HCPs.

Issues of compliance reiterate how the notion of the deficit model and paternalism perpetuate the mismatch of priorities and opinions of families with those of HCPs.

For some, the term compliance can be defined as acting in accordance with advice, but others view it as portraying paternalistic attitude by the HCP towards the patient (Aronson, 2007). Adherence is defined as 'persistence in practice' (Oxford English Dictionary, 2018). Studies have found that the more serious the disease the better the adherence, and also that adherence to regimes related to long-term conditions was poorer, suggesting persistence reduced with time (Hugtenburg, Timmers, Elders, Vervloet, & van Dijk, 2013). This resonates with the findings from the in-depth interviews. P9 whose 3-year old daughter had had a brain tumour as a baby explained how she understood the importance of the chemotherapy drugs (showing high adherence in serious disease) but said in relation to formula feed because the gastrostomy was becoming long-term she had the '*desire to start blending food*', rather than adhering to the expected routine of using formula feed (i.e. poor adherence with long-term conditions).

Data from the interviews shows that families were frustrated by what they regarded as a paternalistic attitude from HCPs who sought to ensure families complied with their advice even though it did not equate with the priorities and opinions of the families (see section 4.2.3).

#### **9.2.4.2 Government initiatives and health policies**

Government initiatives and health policies such as the Expert Patient Programme (Department of Health, 2001) and Liberating the NHS: No Decision About Me Without Me (Department of Health, 2012) aspire to empower patients to become active participants in their healthcare. The Expert Patient Programme had nine aims, including providing practical support for user-led programmes and promoting HCPs' knowledge and understanding of the benefits of these programmes for themselves as well as for patients. Participants in the interviews and blog posts imply that on occasions they felt that HCPs were actively discouraging these aims – P8 was warned by a nurse not to let another HCP know that they were using BD. Conversely

P7 whose son attended a mainstream school reported that they had never questioned the use of BD – the parent attributed this to schools very much viewing the parents as the expert in their child’s needs. The founding tenet of the policy No Decision About Me Without Me was that the ‘*patients are fully involved in decisions about their own care and treatment*’ (Department of Health, 2012, p.3). Like the Expert Patient Programme it also acknowledged the need to recognise that patients and HCPs are experts. The need for shared decision-making was stated in a Kings Fund report (Coulter & Collins, 2011), which also highlighted the need to ensure patients are provided with evidence and information about potential intervention options. Despite these Government initiatives, indications from the research data suggest that families are not involved in decision making about how to feed their gastrostomy fed child and no options to formula feeds are mentioned. Interestingly participants reported that they would have agreed to proceed with a gastrostomy sooner if BD had been presented to them as an alternative to formula feeds. P1–

*If if someone had said to us actually you would still be able to take xxx out, you could still buy him cake blend it up and give it to him, that kind of wouldn't have made it [the gastrostomy] feel like the end of the road it felt awful.*

This is particularly important in terms of children with neurodisability (the largest single cohort in the online survey) as the study by Sharma et al. (2012) reported significantly better weight gain in children who had their gastrostomy before 18 months of age. Similarly it may indicate that on balance the potential risks associated with the use of BD may be less harmful than the actual risks of aspiration and malnutrition resulting from delayed gastrostomy insertion. This is particularly pertinent in the light of recent research that found dieticians’ perception of risks associated with BD were greater than the actual risks (Armstrong, Buchanan, Duncan, Ross, & Gerasimidis, 2017).

#### **9.2.4.3 Models of disability**

Having considered the impact of deficit models of science and government policy, models of disability will now be explored to help explain findings from the research regarding the shift in the locus control, the perceived challenge, professional credibility and mismatch of opinions. Findings from the literature around stigma and disability, which may relate to the actions of parents who opt to use BD, will then be

explored. The medical model of disability emerged around the late nineteenth century, and viewed disability as a medical problem or defect within an individual that required curing or at least amelioration. It was expected that a person with a disability would take advantage of the services provided for them (Retief & Letšosa, 2018). In contrast, the social model of disability emerged in the 1960s and 1970s from disability activists who emphasised the social barriers that restrict a person's ability to engage in mainstream activities as opposed to the personal restrictions of impairment, and promotes a positive identity for disabled people (Oliver, 2013). The negative connotations around the medical model of disability described by Retief and Letšosa, that view disability as a personal tragedy appear to be refuted by those parents who opt to use BD. They do not concur with the medical model of a disability as being something that needs to be fixed, favouring instead the social model in which they adapt the environment (i.e. their food) to meet the needs of their child. P5 used the analogy of the blender as doing the job of the mouth and the tube functioning as the oesophagus.

However, critics of the social model of disability believe that it ignores the realities of impairment, and attempts to create an artificial distinction between impairment and disability, and is built upon assumptions of what it is like to experience impairment (Barnes & Mercer, 2010). Participants reflected this during the interviews. Some described HCPs making assumptions about what would be best for families with children with complex needs that appeared to be based on their assumptions of the impact of the child's impairment. The BD research took a phenomenological approach in the qualitative phase in order to mitigate this criticism by asking parents about their lived experiences. Participants felt HCPs did not understand their lives and therefore were unable to appreciate the factors that led them to use BD. Participants felt HCPs wanted to make parents' lives as easy as possible by minimising the burden of additional tasks and so assumed pre-made formula feeds would be most convenient. However, families did not view making the BDs as a burden rather it was seen as part of enabling their child to participate in family meals.

The ways in which parents reacted to conflicts may be understood more through the lens of stigma, and how individuals use different models of disability to deal with the

emotional and social consequences (Goffman, 1963). Parents of children with disability respond to stigma using strategies of challenges or deflections. Challenges 'push back' and confront, whilst deflections seek to minimise the impact of stigmatisation and maintain social order (Thoits, 2011). One might associate challenging strategies more with the social model of disability, which was born out of disability activists' response to the medical model. Deflection strategies may be more with the medical model, using diagnoses and the language of impairment to explain whilst maintaining social order. However this dichotomy does not appear to be so clearly defined. In a study of parents of children with disabilities by Manago, Davis, and Goar (2017) although this association was noted, parents were found to use both strategies when they framed disability in the medical or social model. Parents who opt to use BD may feel stigmatised and judged over their decision particularly by HCPs. Parents deal with this using deflection strategies, absorbing the associated social discomfort. For example a parent recounted how they agreed to give their child formula feed whilst in hospital due to nurses' disapproval of BD. Conversely bloggers frequently challenged the stigma and judgement of others about their use of BD. B19 wrote about a conversation with her dietitian when she asked her about the ingredients of the formula being recommended (appendix 13). Manago et al. suggests that parents draw on the social meanings of disability, and use deflection in order to achieve their ultimate goal of family well-being which is echoed by families who use BD in section 4.4.

To conclude this section on models of disability, it appears parents are challenging the medical interpretation of disability as impairment, instead focusing on the social model that reframes disability as an aspect of human diversity. There is some resonance here with those in the deaf community. Just as members of this community who use sign language and see themselves as belonging to a linguistic cultural group (Hoffman & Andrews, 2016), perhaps parents in the BD community view BDs and gastrostomies as just another way of eating- the blender taking on the role of chewing and the gastrostomy tube taking over from the oesophagus as a means of getting food into the stomach.

### 9.2.5 Impacts of conflict, and dealing with them

The impacts of conflict are far reaching and include lying and secrecy, which have negative consequences for both patients and HCPs. Traits of deceit are used by HCPs and patients and include distortion, evasion, fabrication and omission (Palmieri & Stern, 2009). Minimising or distorting the impact of fundoplication was mentioned by participants, who felt that their HCP had not explained the negative consequence of not being able to vomit to them - P14 describes the physical and emotional impact

*'but it is worse after the Fundo because you can't vomit -Yes it was awful- she would be sweating and retching'.*

Parents admitted to deceit in the form of omission and evasion – not telling their HCP they were using BD or in the case of P7 letting her dietitian assume the diet she was describing was given orally when in fact she was blending it and passing it through her son's gastrostomy.

Having discussed the impact of conflict, the final part of this section will illustrate the importance of addressing conflict. Forbat, Teuten, and Barclay (2015) proposed a model to describe levels of conflict. Mild conflict was characterised by poor communication including insensitive use of language and conflicting messages from HCPs. Moderate conflict came about as a result of a deterioration of trust and was characterised by entrenchment of arguments and avoidance. Finally at a level of severe conflict the child is no longer at the centre of discussions and the conflict is seen as central with media and legal involvement and in some cases physical and verbal abuse.

All three of these levels of conflict were apparent in data from interviews and blog analysis, with the more unrestrained visceral accounts being found on blog posts, (a phenomenon that is explored further in section 9.5.2). It is therefore important to acknowledge the de-escalation of conflict is possible by improved communication, patience and respect and by HCPs making time for difficult conversations. Parents who opt to use BD reported feeling unsupported, alienated, demoralised or confused, and would benefit from HCPs who show qualities of understanding and responsiveness whilst being confident, practical, sensitive and empowering (Fourie, 2009). Several studies have described the importance of a good therapeutic relationship, suggesting that the quality of communication impacted on the

engagement of the patient with the HCP, and that positive engagement led to better client outcomes (Elkin et al., 2014; King, Desmarais, Lindsay, Piérart, & Tétreault, 2014; Palmadottir, 2006).

### **9.2.6 Summary**

Parents deal with conflict in different ways, which relate to their beliefs, lived experiences, support networks and self-efficacy. Paternalistic attitudes appear to prevail amongst some HCPs that conflict with the stance of individualism favoured by parents. As parents gain more knowledge about BD, they confront the associated conflicts, and appear to become more confident in their decision to use BD. The next section will consider this transition from a state of conflict to one of empowerment.

## **9.3 Empowerment**

The act of parents questioning and seeking information about BD marked the transition from a state of conflict to one of empowerment and innovation.

### **9.3.1 Questioning**

The breadth and depth of questions raised by parents illustrated the strength of their desire to use BD, and the level of understanding they had achieved by this stage. It also illustrates their willingness to question the status quo, challenging the functionalist perspective of society and in so doing were taking on the perspective of conflict theorists in which more powerful members (in this case HCPs) impose order on the less powerful members of society (in this case parents). Parents questioned the rationale behind using formula feeds, the appropriateness of feeding children and young people a diet of milk as opposed to real food (especially when the child in question had been fully orally fed prior to the gastrostomy). They asked for evidence of tube blockages, of contamination and poor nutritional content of BD. They asked about why BD is not offered as an option, and they questioned the overall lack of support. Other questions concerned the chemical and sugar content of formula feeds, its impact on gut and bowel health and the cost of formula feeds to the NHS. A possible result of persistent questioning is that more research is being carried out into BD (Coad et al., 2016; Breaks et al., 2018), and the NIHR have commissioned research into BD (NIHR, 2017).

### 9.3.2 Characteristics and demographics of the parents

This section will discuss how the characteristics and demographics of the parents may have influenced their decision to use BD.

During the in-depth interviews parents were asked to consider whether they felt their friends and relatives were surprised by their decision to use BD. A number of parents said they thought others would not be surprised by the actions. When probed further the parents described themselves as being passionate (about BD), resilient, stubborn and proactive and aspired to make their child's life as normal as possible.

P8 described how she felt her decision to use BD had changed her from being-

*'terrified and frightened to question anything' to just 'running with it'.*

She did also acknowledge that perhaps she had always been a bit rebellious, and the trait was amplified by having to fight for her son's best interest. It was noted that there was almost no conflict between family members regarding the use of BD either in the interviews or the blogs. In the light of the high number of parents of children with complex needs whose relationship breaks down, this was somewhat surprising (Namkung et al., 2015.). Potential explanations may be that parents resolve was strengthened in the face of conflict with HCPs over their use of BD, or that the mothers who opted to use BD had such high levels of self-belief that they were not challenged by other family members.

A report into patient and family engagement found most patients wanted to be involved in decisions about their healthcare (Maurer, Dardess, Carman, Frazier, & Smeeding, 2012). The results from the questionnaire indicated that parents do tend to feel involved with their child's feeding. Although the parameter of involvement is not a direct comparison with shared decision-making it does provide some insight into this aspect of engagement and may be a useful basis upon which to further develop and improve engagement. The benefits of improved patient and family engagement are widely acknowledged and include increased satisfaction, trust, improved quality of life, reduced anxiety and better understanding of their own condition and personal requirements (Hamzehgardeshi & Hamzehgardeshi, 2014).

The report by Maurer et al. also found patients base their rating of the quality of a service not on clinical skills but instead on their interpersonal interactions with HCPs. The high levels of conflict revealed in the in-depth interviews and blogs suggest that

parents do not always feel their HCPs are responsive, empathetic and attuned to their needs.

Parents were asked to rate the extent to which they agreed or disagreed with the statement *'I feel that my child received the help and support with feeding that I want for him/her'*. Of the parents who used BD 37.9% disagreed or strongly disagreed with the statement as opposed to 11.8% of the non-BD users who disagreed, (none strongly disagreed with the statement). This disparity may indicate that engagement is poorer with parents who use BD, and as Hamzehgardeshi and Hamzehgardeshi (2014) suggested this may correlate with higher levels of mistrust, dissatisfaction and anxiety.

Parents were asked to rate the extent to which they agreed or disagreed with the statement *'I know what is best for my child with regard to feeding'*. The parents who used BD expressed higher levels of agreement than respondents who were not using BD. These results may reflect higher levels of self-confidence and self-belief amongst those who use BD, or that having carried out their own investigations into nutrition and feeding as part of their learning about BD, they feel they have gained the empirical knowledge about what is the best for their child with regard to feeding.

### **9.3.3 Demographic Variations**

As part of the survey demographic information was collected from the participants. These included gender, age, education level, household income and ethnicity. None were found to be statistically significant between the two cohorts of respondents i.e. BD users and non-users. However there were some notable observations. Males accounted for just 5.8% (n=12) of respondents, which may reflect the importance of feeding and nurturing to mothers or that society still views feeding as primarily being the role of a mother. Age did not correlate with BD usage but fewer parents in the 46 years and over age group are using BD than would be expected. This may be due to the fact that the children of these parents had been gastrostomy-fed for longer and were established on formula feeds before the increased interest in BD occurred, but data regarding age of the children was not obtained, which could have substantiated or refuted this. Maurer et al (2012) reported that younger females are most likely to want to be involved in health care decisions, which could also be an explanatory factor for these findings. Similarly a group of researchers looked at preferences



around participation in decision-making and concluded that whilst the majority of patients (96%) wanted to be offered choices, 52% still preferred to allow their doctor to make the final decision (Levinson, Kao, Kuby, & Thisted, 2004). However, women and those up to the age of 45 years were more likely to want an active role in decision-making.

Phase three of the research, the questionnaire was shared and publicised through a range of groups and organisations based in the UK, but the use of social media such as Twitter meant that there were respondents to the questionnaire from outside the UK. However, 87% of respondents were White English/Welsh/Scottish/Northern Irish/British. There were no respondents from any other British ethnic groups, meaning the responses were not representative of the UK's ethnic mix (Census, 2011). This may be in part a cultural issue as research has shown that some ethnic groups are under-represented in responses to health surveys (Gill & Redwood, 2013). Similarly immigrant families are more likely to respect and less likely to challenge people perceived as authority figures such as HCPs (Iruka, Curenton, & Eke, 2014). A study in the USA found that patients who required an interpreter made significantly fewer comments during medical consultations than English speakers (Maurer et al., 2012). These findings may imply this group of patients had a more paternalistic view of healthcare – the professional being the expert and were less empowered to question or discuss their care. In another study based in the USA Hispanic and African-Americans were more likely to want their doctor to make decisions (Levinson et al., 2004). Another possible explanation for the discrepancy in figures is that there may be fewer ethnic minority groups who have gastrostomies, although there are no data to support or refute this suggestion.

#### **9.3.4 Beliefs about medicines**

One defining difference between the two cohorts of respondents was the response to the Beliefs about Medicine Questionnaire (BMQ) *specific*. To recap the BMQ *specific* was developed by Horne, Weinman, and Hankins (1999) to assess cognitive representations of medication and consists of 10 statements that are rated using a 5-point Likert scale. The BMQ *specific* deepens understanding about how beliefs relate to patients' adherence to prescribed medications (i.e. formula feeds). Parents who opted to use BD expressed significantly higher levels of concern about formula

feeds and perceived less need for them than families who were not using BD. This outcome was predicated but the scale of the differences was large accounting for 68.8% of the variance (see section 8.5).

High levels of concerns and low levels of perceived need are associated with low levels of adherence to medications (Chapman, Horne, Chater, Hukins, & Smithson, 2014). It is of course important to maintain equipoise regarding the potential benefits and disadvantages of formula feeds, so if formula feeds are found to lead to better outcomes for some patient groups then it is important for HCPs to understand the concerns and beliefs of parents who may be reluctant to use formula in order to design interventions that address these concerns.

Participants also completed the BMQ *general*, which assesses views about harm, and overuse of medicines in general (Horne, Weinman, & Hankins, 1999). Neither group of parents considered medicines in general to be harmful. This resonates with the fact that many of these children have complex needs and require on-going medications, and only four (1.9%) of respondents to the survey stated that their child did not need any medication. Similarly during the in-depth interviews parents recounted instances where medications had saved their child's life, and also acknowledged that formula feeds do meet a need - P5 said

*'whilst xxx was in crisis state get the formula into her lets not fuff about'*

However, when asked about the overuse of medicines parents shared their belief that they harboured concerns about over use of drugs – P12

*'Experience tells me once you are on medicine it is quite hard to come off it- people are nervous about taking you off it'.*

Participants also reported that they felt using formula feeds was over-medicalising the normal human function of eating. These comments were reflected in the results of the BMQ *general* overuse rating. Those who were using BD were significantly more likely to believe that medicines in general are overused. The view that formula feeds are unnatural and contain high levels of chemicals was frequently shared during the interviews and on the blogs, with one post listing all the chemicals found on the label of the formula prescribed for their child (see appendix 12).

In the light of a study by Heller, Chapman, and Horne (2015) which found that individuals with more negative beliefs about medications were more prone to

misattribute symptoms and subsequently stop medication, it may be construed that parents who use BD maybe misattributing symptoms to formula feeds, but without further research it is not yet possible to refute or substantiate this.

The findings from the BMQ can be explained with reference to the self-regulatory model of health (described in chapter 2 section 6.10), which suggests that when a person perceives a threat to health they may develop cognitive and emotional representations of the threat (Leventhal, Leventhal, & Contrada, 1998). Application of the self-regulatory model would imply that adherence to a medicine will be more likely if taking that medicine makes 'common sense' and is congruent with personal beliefs. This poses the question that if parents' perception is that formula feed is unnatural and BD is more natural and closer to their construct of good nutrition could this be a factor in their opting for BD.

To summarise this section, it is apparent that there are a number of intrinsic factors that influence the decision of parents to use BD. However, although some factors appear to influence or predict the course of action more strongly, the complex interplay of human emotion and cognition and beliefs contribute to an individual's decision-making process.

### **9.3.5 Mapping theoretical perspectives to the use of BD**

The next section will discuss the interplay between the theoretical perspectives of self-efficacy, self-determination and self-regulation, and how they manifest in parents through questioning and persistence leading to empowerment and innovation.

Figure 9-1 below illustrates the relationship between theories of self-efficacy, self-determination and self-regulation and the actions of parents with regard to BD.

<b>Theory</b>	<b>Principle</b>	<b>Definition</b>	<b>Application to BD</b>
<b>Self Efficacy</b> the belief that you have the skills and capability to achieve something (Bandura, 1997)	Mastery of experience	Experience in overcoming obstacles	Implementation of BD leading to a reduction in vomiting and associated improved quality of life
	Verbal Persuasion	People influential in our life telling us we have the capability to succeed	Support from other parents within the 'BD community'
	Affective State	Emotional state influences our belief in ability to succeed	Joy, relief, happiness experienced by parents when describing the positive effects BD has had on their child
	Vicarious experience	Seeing people similar to ourselves succeed	Sharing success stories on blogs and other social media platforms such as Facebook
<b>Self Determination</b> intrinsic motivation to make choices and control our lives to achieve our goals (Ryan and Deci, 2000)	Competence	Ability to master skills and be effective	A parents' implementation of BD
	Autonomy	Belief that you are an agent of your own destiny	Using BD against professional advice
	Relatedness	Inclination to have a sense of belonging with others	Seeking out like-minded parents
<b>Self Regulation</b> the capacity to control thoughts and actions that govern behaviour (Leventhal, Nerenz and Steele, 1984)	Standards	The desired behaviours	Parents' belief that BD is best for their child
	Motivation	Drive to meet the standards	Finding out how to use BD including the pros and cons, the equipment and nutritional requirements
	Willpower	Internal strength	The ability of parents to face challenges from HCP, lack of information and support

Figure 9-1 Applications of Self Efficacy, Self Determination, and Self Regulation to BD

Self-efficacy involves a complex interface between knowledge, beliefs, social environment and behaviour. The value of BD with regard to parental self-efficacy was illustrated by P9 when recounting the impact of loss of control and the positive feeling associated with regaining of that control. She recalled how low she felt when she was no longer able to feed her daughter orally, and then the positive impact of BD, saying how it gave her some control back which in turn made her feel like she was able to look after her child again as she felt she should. Increasing self-efficacy in a mother's sense of her parenting efficacy can improve outcomes for their child. Albarran and Reich (2014) described how increasing a mother's knowledge and experience about a process led to increased level of maternal self-efficacy and improved outcomes for their child. So perhaps parents who gain knowledge and experience of BD increase their self-efficacy that in turn leads to better outcomes for their children.

This interface between knowledge, beliefs, social environment and behaviour was apparent in a study of self-efficacy in parents of children with type one diabetes, that found using an online web-based social support platform increased levels of self-efficacy amongst the parents (Merkel & Wright, 2012). Many of the components of the website are also found in Facebook groups used by parents using BD. These include providing a platform for families to interact and network, the sharing of positive outcomes and support between families. There are also similarities in the challenges and issues faced by parents of children with diabetes and those using BD, for example being overwhelmed by regimented demands of care management and a lifelong illness potentially riddled with serious complications.

Self-efficacy appears to be linked to the way in which parents advocate for their child. It is difficult to determine whether this perceived need to fight or advocate for their child has changed parents' level of self-efficacy or if parents already had high levels of self-efficacy that drove their actions. P10 said

*I have always been an advocate of xxx's health and if I don't think something is right I will stand up and say, no matter who I'm talking to*

However for others embarking on the use of BD, it appears to have altered their self-perception- P12 said

*As time went on I felt more and more confident.*

Similarly in the context of challenging professionals P13 's self-efficacy appears to have increased-

*'I am not one of those people who will [question professionals] oh well I say that I probably am now but I never be used to be'.*

From the data collected in the BD research it is not possible to determine whether higher levels of self-efficacy were the result of, or causal in, the decision to use BD. It does however appear that BD has been the catalyst for some parents to take more ownership of their child's overall health, with parents describing how they now question levels of medications, medical procedures and policies that affect their child. Given that individuals attempt to regulate their behaviour in order to achieve a desired outcome and have an intrinsic motivation to achieve their goals, self-regulation theory (Ryan & Deci, 2000) and self-determination theory (Leventhal, Nerenz, & Steele, 1984) may explain some of the behaviours seen in parents. Parents are highly motivated to achieve their goal of using BD with their child. The behaviours demonstrating this drive include questioning of the content and potentially harmful effects of formula feed, persistence to find out more about BD and how to implement it and challenging the status quo of using formula feeds. Similarly they draw on their willpower and internal strength at times of challenge, conflict and doubt. It is also important to consider how this strong desire may override self-restraint, and the potential consequences. P17's overwhelming desire to breastfeed her daughter, led to her ignoring those around her and perhaps even her own deep-down realisation that her daughter was not getting enough milk and becoming malnourished. This example shows the complex tensions between self-restraint, and an almost a primeval drive to nurture and do the best for one's child.

The idea that motivation exists for beneficial and adaptive reasons was described by Baumeister and Vohs (2007), who argued that the body's need for nutrients to survive motivates humans to find and eat food. Similarly they suggested the need to pass on genes motivates humans to protect their offspring. They also suggest that humans are motivated to seek social, group and cultural affiliations as these maintain human survival. When a motivational conflict occurs self-regulation is required. In the context of BD motivational conflicts were apparent when a parent's nurturing protective instinct led them to use BD in the face of socially and culturally accepted

norms of following advice from HCPs that they should not. It appears that the ways in which parents dealt with this conflict was influenced by a variety of factors. If the desire to use BD was associated more with parental preference than due to the child's intolerance of or physical reactions to formula feeds the social and cultural motivation to follow advice tended to be greater. P1 said-

*If he hadn't been really really sick, in all honesty we probably would have just carried on as we were [i.e. with formula feed].*

The place of compromise or reacting in a compliant manner in order to maintain social affiliations, or to avoid the conflict altogether as this quote from P14 illustrates

*I was always worried if she got taken into our local hospital ... the thought of [not being able to give] blended diet - I wouldn't take her there.*

Alternative actions included seeking out affiliations with like-minded social groups, and attempting to modify cultural norms (in this case the norm being following medical advice) by evidencing the benefits of the alternative such as less vomiting, more natural and lower costs for the NHS.

In the previous section the impact of stigma was discussed. If families who use BD are feeling stigmatised or disadvantaged, this may reduce their perceived need for self-regulation – the mind set being ‘if I am not accepted in this society, what is the impact of not conforming’ – is the net benefit of the intrinsic motivation to use BD greater than the extrinsic motivation to self-regulate to conform to social and cultural norms greater. This argument leads on to provide an explanation of the growing power of social media amongst parents who use BD (Coad et al., 2016). Social media provides social affiliation to like-minded families who may otherwise be isolated, and find it difficult to stand up to external pressures and need to conform. But is there a danger that these groups may artificially amplify the strong views and sentiments of pro BD families and construe them as the social norm. This danger has been evidenced in pro-anorexia (pro-ana) blogs where the most common theme was about maintaining eating disorders (Tong, Heinemann-LaFave, Jeon, Kolodziej-Smith, & Warshay, 2013), and increased use of pro-ana websites reinforces users' eating disordered identity (Tierney, 2006). The wider implications of social media are discussed more fully in section 9.5

### 9.3.6 Links between questioning, knowledge and empowerment

Having discussed the ways in which self-efficacy, self-regulation and self-determination theories can explain parents' behaviours, this section will consider the links between questioning and knowledge and empowerment.

Empowerment has been defined variously as; the belief that one has control over decisions, feelings of self efficacy and a sense of being powerful as opposed to having power (Kaminski, Kaufman, Graubarth, & Robins, 2000; Trummer, Mueller, Nowak, Stidl, & Pelikan, 2005.) The journey towards empowerment evolved from a sense of powerlessness (Kieffer, 1984). This was also noted by parents who reported a loss of control and finding themselves in an unfamiliar alien world (see section 9.4.4). Concerns also appear to precipitate the journey to empowerment, with parents questioning various aspects of formula feeds including cost to the NHS and content. As they begin to question and seek answers they become more knowledgeable about formula feeds, about alternatives and about their rights as parents. This results in a sense of empowerment, and this cyclical pattern enables them to continue to question and to gain knowledge and become more and more empowered, as shown in figure 9-2 below.

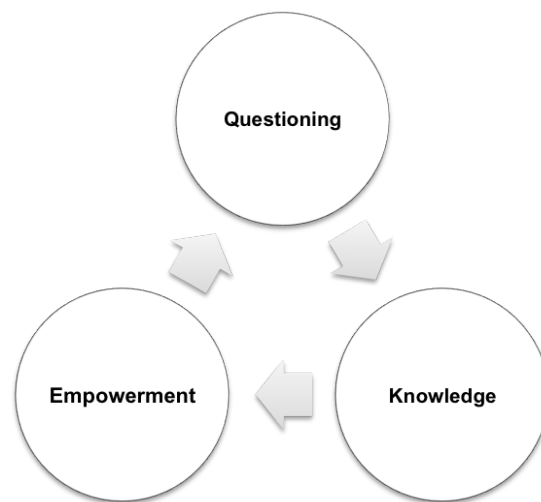
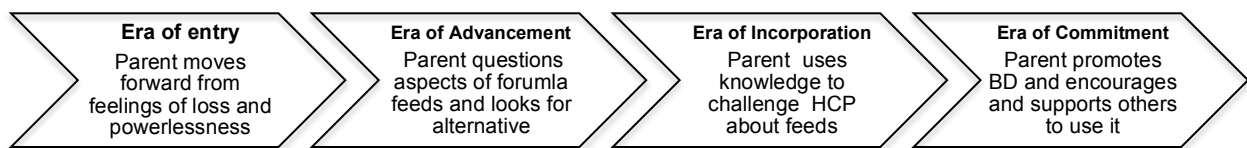


Figure 9-2 Model illustrating growth of empowerment

The above model differs in some respects from that proposed by Kieffer, who suggested a more linear model that included four stages. Firstly the Era of Entry when a person moves forward from the feeling of powerlessness. The second stage



is the Era of Advancement when the person develops more of an understanding of the situation including social and political issues, and this stage usually helped by a like-minded peer group. In the third stage, the Era of Incorporation a person begins to refine their strategic skills to confront institutional barriers. Finally in the fourth stage the Era of Commitment Kieffer states that a person typically starts to help others to develop their knowledge, skills and sense of empowerment. Figure 9-3 illustrates how parents who opt to use BD follow this model



**Figure 9-3 Application of Kieffer's stages of empowerment**

This shows how the process of empowerment as proposed by Kieffer can lead to challenges to HCPs current clinical practice and guidelines regarding BD.

Within the health context patient empowerment has focussed on enabling people with long-term conditions to change behaviours deemed desirable by HCPs to improve their health (Ben, Nibrass, Aoud, Ayed, & Aoud, 2017). However, in a broader social context, empowered individuals may be seen as having an understanding of options available to them and possessing the ability to play an active role in shaping their environment (Kaminski et al., 2000). This reveals an apparent mismatch between an empowered patient, versus patient empowerment, the former being an active process intrinsically driven by the individual, whilst the latter is a process driven by HCPs to change a patient's behaviour. Further insight into this issue is provided by Brown and Piper (1995), who describe patient empowerment in terms of enabling a person to take control over some of the factors affecting their health. However, they go on to question whether empowerment is actually being used as a form of social control, and whether desired health behaviours reflect the goals of HCPs and not necessarily those of the patient. Brown and Piper illustrate this using the example of health education regarding alcohol consumption. Whilst promoting a model of empowerment, a health educator may inadvertently undermine an individual's control, as their ultimate goal is to reduce the

patient's alcohol intake. Whereas it must be acknowledged that true empowerment may result in people still making unhealthy choices. In the case of BD whilst espousing good practice based on empowerment, patient centred care and choice, do some HCPs view their desired outcome as parents complying with the use of formula feeds?

### **9.3.7 Innovation as a manifestation of empowerment**

Empowerment positively correlates with innovative behaviours (Spreitzer,1995). Traits of an innovator include being open to experience, a generator of new ideas, being flexible and tolerant of ambiguity. Innovators see themselves as change seekers and risk-takers and tend to have high level of self-efficacy (Kwang & Rodrigues, 2002). These characteristics appear to be found within parents using BD. Innovation was a subtheme of trial and error in the thematic analysis of the interviews and blogs, sometimes borne out of a lack of information and support, with parents experimenting with different foods in the blend to enable them to find a combination that met nutritional needs and could be passed through the tube. Innovation also appeared to be the result of parents feeling backed into a corner, so parents needed to generate new ideas to deal with situations some of which involved an element of risk taking. For example a parent recounted being told they could not use the pump for BD so they adapted the feeding pump themselves so it worked with BD and enabled their child to continue to enjoy the freedom offered by pump feeds as well as having BD. So in the context of BD, innovation relates to parents finding ways to 'make things work' for their child and family, and the overarching driver of parental innovation appears to relate to the desire to improve their child's quality of life.

To conclude, there appears to be an inconsistency between the rhetoric of patient empowerment and its implication in practice. The paper by Brown and Piper (1995), described empowerment being used more as a means of social control, conversely Househ, Borycki, and Kushniruk (2014) provide examples of patients empowering themselves to take control of their health. Much of the literature regarding empowerment stems from research in the workplace, and parallels exist between the workplace and healthcare regarding empowerment. Empowerment can be viewed as a means of getting the best out of workers or patients for the good of the company or

health provider, but equally an empowered worker or patient may take on the role of an activist challenging the status quo (Kaminski et al., 2000).

### **9.3.8 Iatrogenics**

A fundamental and potentially serious aspect of questioning relates to parents' concerns about the iatrogenic effects of formula feeds.

The term iatrogenics was originally defined as illness caused by medical examination or treatment, but has been expanded to include not just illness caused by doctors but also by other HCP and carers and family members (Batavia, 2004). Research into iatrogenic illness in the elderly looked at risk factors, many of which are applicable to children and young people who are gastrostomy-fed. These include the requirement for multiple medications, multiple chronic conditions, multiple physicians involved in their care (Permpongkosol, 2011). Similarly Batavia found that iatrogenic illnesses in people with disabilities resulted from practitioners not fully appreciating their disability related needs.

In this section the suggestion from some parents that formula feeds have an iatrogenic effect will be discussed and contrasted with the concerns from HCP that non-compliance and the use of BD by family members may cause iatrogenic illness.

B13 described how her daughter went from vomiting several times a day, to no vomiting when she started her on BD. B21 described how when she added formula to her expressed breast milk under the direction of her doctors, her daughter would vomit and when she did not add formula she was fine. In addition to the physical impact of formula feeds parents seemed to perceive formula feeds as being bad for their children. Some parents described their child's formula feeds as being poison whilst others felt it did more harm than good. Similarly results from the survey showed that 75% of parents who were using BD agreed or strongly agreed with the statement '*Having to use formula feeds worries me*' as opposed to just 28% of those who were not using BD. Finally in addition to the evidence from parents, a paper cited the case of a patient who developed hypercalcemia whilst on a continuous formula feed. Once the Vitamin A associated with the hypercalcemia had been withdrawn the situation resolved (Bhalla, Ennis, & Ennis, 2005).

Conversely other evidence from the literature affirms the concerns of HCPs around the use of BD. A single case study described how a child had developed scurvy as a

result of inadequate nutrition in his BD (O'Hara, 2015), whilst others have expressed concerns over food safety and contamination leading to food poisoning (Walia, Van Hoorn, Edlbeck, & Feuling, 2016).

Finally it appears that some convergence may be emerging between parents and HCPs, as the dangers of mass medicalisation as polypharmacy induced iatrogenesis becomes more embedded in medical practice (Le Fanu, 2018). A belief shared by some parents - P8 stated,

*I just am always wary of how much medication he is getting and how much he actually needs. Don't get me wrong if he needs it he is having the medication.*

This notion of over medicalisation relates to the work of Lafont et al. (2011) who found over-dependence was a factor in iatrogenic disability. Similarly a study examining family stresses and family support factors concluded that in order to prevent iatrogenic disability, there should be detailed family-focused assessments based on the parents' perceptions and a clear understanding of the family routines (Jones, Angelo, & Kokoska, 1999). Such practise with families who wish to use BD would enable support to be offered that was sensitive to their beliefs, needs and desires.

### **9.3.9 Summary**

This section has shown how the negative confrontational state of parents described in section 9.2 transformed into a more positive proactive, innovative position, though some degree of tension between HCP and parents was still evident. The next section will consider how this transition has enabled parents to focus on attaining the best possible quality of life for their child and family and the part their decision to use BD has played in this.

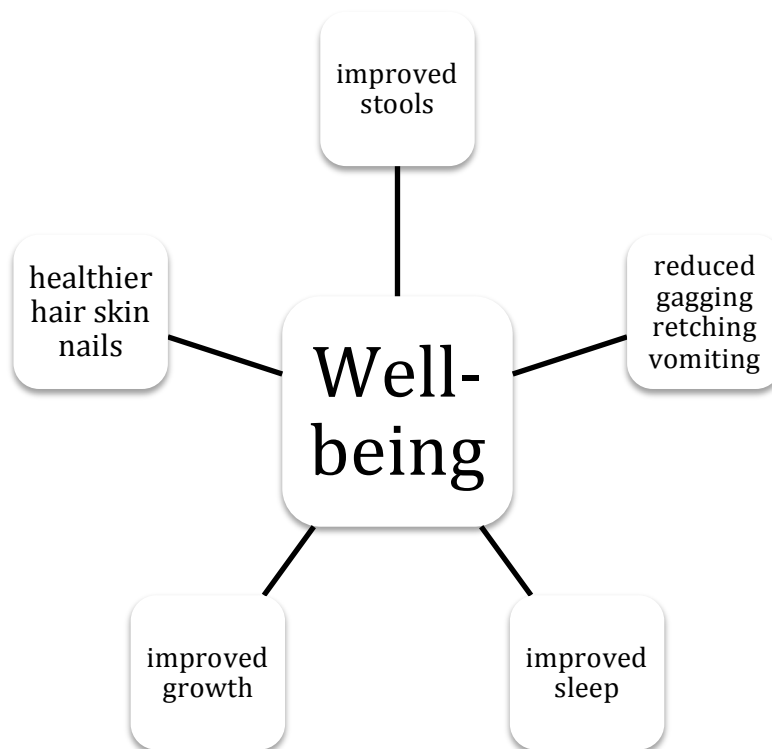
### **9.4 Quality of Life**

This section will encompass the topic of quality of life in its broadest sense, taking into factors that impact on well-being of the child and family including the sociology of food and mealtimes, communication, choice, risk and normalisation. Each section will consider how the use of BD may contribute an overall improvement in the quality of life of the whole family.

The results from the questionnaire found whilst there was no significant difference between the quality of life rating between those who did and did not use BD, parents who used BD rated their child's health significantly higher than parents who did not. It should be noted that over 75% of parents from both groups rated their child's quality of life as either good very good or excellent. This is contrary to findings by Loney, Thurston, Paul, Wong, and Browne (2010) who found parents rated their children with complex needs as having a lower quality of life. However, this may have been in part due to the more comprehensive rating scale used in that study. A potential explanation for the similarity of quality of life results in the BD research may be simply that the use of formula feeds suits some families better. The rating score may be oversimplified and therefore not actually reflect the complexities of quality of life judgements. The higher health rating for those who were using BD may be due to improvements in any of the areas shown in Figure 9-4 below, equally the results may reflect that parents using BD may over-estimate the benefits it offers if they felt the results may lead to BD being offered as an alternative to formula feeds. In future research should consider rating both scales before families start using BD and then again after it has been incorporated into the feeding routine.

#### **9.4.1 Physical well-being**

This section will initially consider the child's physical well-being using evidence from the literature and BD research data to consider possible explanations and implications. Figure 9-4 below provides an overview of the physical changes that impacted on their child's well-being that were identified by parents.



**Figure 9-4 Physical impacts of BD usage on wellbeing**

Bowel function appears to have been an important issue for parents. From qualitative (Pentiuk, O’Flaherty, Santoro, Willging, & Kaul, 2011) and quantitative data from the questionnaire in phase 3 of this research, there is evidence that the use of BD improves bowel movements. The quantitative data showed a positive correlation with BD and normal stools judged on the Bristol stool scale. However, it should be noted that the actual rating of stools is open to a degree of subjective interpretation, so there may have been some response bias i.e. parents who were pro BD over stating the impact of BD on their child’s stool consistency (Sedgwick, 2014).

In addition to the improved well-being of the child resulting from reduction in constipation this then had the effect of increasing appetite (Elsagh et al., 2016) and potentially weight gain. For P9 the improved stools, which had previously been very loose that meant she was now able to toilet- train her daughter. Similar benefits have been reported in the literature. Samela, Mokha, Emerick, and Davidovics (2016), noted that parents benefited from not having to spend time on washing soiled clothing and bedding when their children transitioned from formula to BD. The same study reported that the use of supplementary fibre could be stopped as stooling

improved in 90% of cases following the introduction of BD. The improvements in stools occurred within 2-3 days of being totally BD and continued when the children were followed up one year later. An improvement in bowel movement with less constipation was also cited by Pentiuk, et al. (2011) and Novak, Wilson, Ausderau, and Cullinane, (2009)

Constipation has also been linked to increased seizure activity in children with epilepsy. Experiments using mice showed that when constipation was induced by loperamide there was an increase in seizures (Moezi, Pirsalami, & Inaloo, 2015). A possible explanation (provided on the Epilepsy Research UK website) is that constipation leads to an accumulation of toxins within the body, which in turn triggers the seizures.

The mechanism or physiology behind improvements in stooling may be related to gut health, as the use of a single formula was found to lead to a reduction in the microbial diversity of enteric flora (Claesson et al., 2012). Samela et al (2016) also suggested possible mechanisms for improvement, including variation in fibre and fat types present in BD that would not occur with the use of a single formula feed. Interestingly, parents who used BD frequently questioned the wisdom and rationale of formula feeds - just having a single food - and suggested that if they gave their orally fed child a diet consisting of milk drinks alone they would be chastised.

A reduction in gagging, retching and vomiting was reported in several papers (Johnson, Spurlock, & Galloway, 2013; Pentiuk et al., 2011; Samela et al., 2016). Pentiuk et al. suggested that these effects may be attributed to the viscosity of BD reducing the rate of gastric emptying and improved gastrointestinal motility. This reduction in vomiting and retching seemed to be particularly important to parents who found it difficult to witness the distress caused to their child by retching and vomiting as P16 explained when contrasting life before and after BD.

*'We can go out more confidently because it's unlikely that she will vomit have this horrible retching where you have to drain her tummy in the middle of the street - vomit coming out of the syringe, your hands get dirty - you know it is not a quality of life to live like that'.*

Although there have not been any controlled studies that have directly investigated the effect of BD on weight gain, a single case study did describe how BD led to an

increase in growth (Johnson et al., 2013). The importance of weight gain and growth was highlighted in section 9.1.1 both in terms of the child's well-being, and on the parents, who often felt their parenting ability, and decision to use BD, was being judged in relation to their child's growth.

Sleep was another area some parents said improved when they used BD. A study found that when enteral feeds were given at the optimal time in relation to an individual's day–night patterns this had a positive impact on the immune response, possibly linked to the more normal rhythms of hormonal release (Sunderram, Sofou, Kamisoglu, Karantza, & Androulakis, 2014). The report concludes by stating that the impact of enteral nutrition on night/day cycle (sleep) needs further investigation.

Parents hypothesised that improvements in sleep may have been linked with having more energy and more normal mealtime routines or the reduction of the high corn syrup content found in formula feed.

Bloggers also emphasised how BD had indirectly led to improved sleep for them as parents as their children were waking less in the night, and no longer required night time feeds as BD had also increased volume tolerance (see appendix 14). The significance of sleep for parents was highlighted in a study into the effects of sleep deprivation on parents of children with complex needs (McCann, Bull, & Winzenberg, 2015). The study found a range of impacts including emotional and physical tiredness that in turn impacted on parents' ability to cope with their child's care needs during the day, their relationships and their ability to work.

The last physical benefit parents attributed to the use of BD, were improvements in their child's hair, skin and nails, with 12 out of the 18 participants in the in-depth interview and 15 out of the 30 bloggers mentioning improvement in these areas. P7 recalled how it was her son's hairdresser had commented on the condition of his hair, and she pointed out that the hairdresser knew nothing of the BD use so implied that it was an objective improvement not due to response bias (Sedgwick, 2014). Others reported family members commenting on how well their child looked and parents themselves mentioned having to cut nails more frequently. B25 attributed many of the physical benefits to better digestion with less bloating, constipation and reflux.

In summary, there are examples from both literature and parental reporting to suggest BD impacts positively on physical well-being. However, the precise



mechanism of these benefits is not understood, leaving room for speculation and doubt, and although these changes are generally acknowledged it is not possible to categorically attribute them directly to BD.

#### 9.4.2 General well-being

This section will present other components of well-being which were identified by parents during the interviews or in the blogs. Further consideration of these components may help identify how and why they are attributed to BD and indeed if there are any alternative explanations. Figure 9-5 below lists other cited benefits of BD.

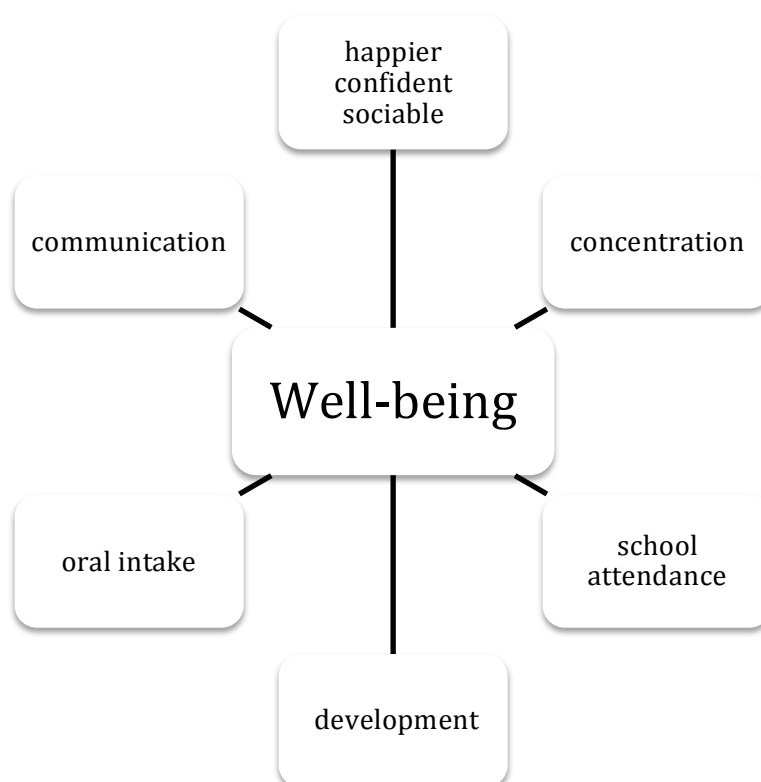


Figure 9-5 Areas of wellbeing improved by BD

##### 9.4.2.1 Happiness, concentration, school attendance and development

The first four areas will be collectively contemplated. Parents reported that children were happier, did better at school and made rapid developmental progress since they had been using BD. P16 described how prior to using BD her daughter felt sick and miserable and how since using BD she is happy and active.

The extract from B7 makes it clear that they attribute improved school attendance and performance to BD

*And now, he's back in school, LOVING it, and doing soooo much better. I just wish I'd figured out earlier that the formula was the issue.*

P17 reflected on the impact of BD-

*It wasn't instantaneous it was over about 3 or 4 weeks so she went from vomiting every time we fed her - 7 or 8 times a day to just nothing. And also her personality changed she took a massive leap in development and I think it's just because she wasn't feeling sick all the time.*

Whilst it is perfectly possible that these improvements were because the children were no longer feeling sick or vomiting, they could also be attributed in part to other factors. For example the more positive less stressful mealtimes, parents feeling more in control and having greater levels of self efficacy as a result of implementing BD. As the study found when parents were able to proactively address feeding and mealtime issues they increased levels of health-related quality of life for their child (Meral & Fidan, 2015). Similarly, higher levels of self-efficacy were strongly associated with a nurturing child-rearing environment and social, academic and psychological well-being (Jones & Prinz, 2005). Mothers with higher levels of self-efficacy also positively influenced their child's development and improved overall outcomes for both the parents and the child (Albarran & Reich, 2014; Machalicek, Lang, and Raulston, 2015). The parents who opted to use BD had significantly higher levels of self-efficacy when compared to the general population and to parents of gastrostomy-fed children who were not using BD.

#### **9.4.2.2 Increased oral intake**

A study of 33 children, which investigated the effect of BD, 57% of parents reported an increase in oral intake with the use of BD (Pentiuk et al., 2011). Similarly in the in-depth interviews, parents stated that one of the benefits of BD was that their child's oral intake increased, implying that they viewed oral intake as being beneficial to or desirable for their child. Two potential explanations for this will be considered. Firstly it may relate to the value parents placed on being able to eat food orally, and secondly they may ultimately wish to wean their child off the tube feeds.

The centrality of food procurement, preparation and mealtimes to family life as described by DeVault, (1991) may explain why parents viewed increased oral intake as contributing to their child's well-being. Likewise, although parents were using BD the symbolism of food as a means of bringing pleasure may be greater when it is visually more appealing (Chamberlain, 2004). The powerful influence of visual images of food has been described by Houston-Price, Butler, and Shiba (2009) and Spence, Okajima, Cheok, Petit, and Michel (2016) who demonstrated that eating behaviours could be modified through visual images. Similarly the production of food-shaped texture-modified diets by food manufacturers such as 'Apetito' also illustrates the importance of the visual appearance of food. Furthermore such food modifications were perceived more positively than pureed foods by family members (Keller, Chambers, & Niezgodna, 2012). This may suggest that although BD enabled parents to provide their child with the nutritious meal they chose, the appearance of a blend was not as acceptable as 'normal looking food'. Indeed P9 described the appearance of her child's blend -

*'it looks a concoction - it does look a bit of a grim colour'.*

Several parents highlighted the importance of presentation. P17 described putting food onto the plate to show her child what was going into his blend. P16, a mother of triplets, described serving three portions on three plates prior to blending one for her tube-fed daughter, and P10 recounted how her child was given a pudding at school which she could eat if she wanted to so she did not feel left out. So it appears that parents, despite using BD still place a high value on the ability to eat food orally.

The second factor that may contribute to the increase of oral intake being viewed as improving well-being or as a benefit of BD is the potential it offers to support tube weaning. Tube weaning is the process of moving a child from being fed by tube to being able to eat orally. Although there are no official figures to indicate what percentage of children who are tube-fed have the potential to achieve oral feeding, several participants in the in-depth interviews spoke of tube-weaning as an aspiration for their child.

Several studies refer to the use of BD by parents who were attempting to wean their child from tube to oral feeding (Edwards et al., 2016; Epp, Spurlock, Hurt, Johnson, & Mundi, 2017; Nowak-Cooperman & Quinn-Shea, 2013; Schauster & Dwyer, 1996).

The mechanism of this impact of BD on oral intake and the potential for tube weaning is not yet established or fully understood. Some examples of how parents facilitated increased oral intake will now be described and then potential explanations for how these may impact on oral intake will be explored.

P5 described how she hoped that by giving her daughter fruit or vegetable smoothies via her tube she may experience the flavours when she burped, in the hope that she would get used to *'the sensation of different foods in her tummy'*, which would encourage her to increase her oral intake. Parents also described how they would give their child meals on a plate initially but anything they did not eat they would then blend and pass down the tube. This had the effect of reducing the pressure on the child to eat all their meal orally and meant that they were able to experience pleasurable oral intake. This was particularly important for children who tired quickly when eating orally. Parents also acknowledged that having the option of blending anything their child did not eat reduced their own stress around feeding. P14 felt that reduction in her own concerns about encouraging her daughter to eat removed the focus on oral intake and then gradually her daughter chose to take more orally in her own time.

Sections 2.2 and 9.1.1 highlight the complex and value-laden issues surrounding food, mealtimes and eating. These psychological issues cannot be underestimated and the importance of psychological support and input when tube-weaning is evidenced by the staffing of a tube-weaning service which has high levels of input from both a clinical psychologist and psychology assistant (Wright, 2013). Another possible explanation for the apparent link between BD and increased oral intake is related to the reduction in constipation with the use of BD, as constipation can lead to a reduction in appetite and interest in food (Elawad & Sullivan, 2001). The reduction in reflux and other gastrointestinal symptoms noted by Pentiuk et al. (2011) may also be a factor. Improved appetite may also be stimulated by changes to the intestine's microbiota associated with BD (Gallagher et al., 2018). Finally, the use of BD may correlate positively with the importance of eating orally, in which case these parents may have been more motivated to increase oral intake with a view to tube-weaning.

#### **9.4.2.3 Communication and well-being**

Parents spoke of the benefits BD had on their child's communication and in turn on their well-being. Food is one of the earliest topics of childhood communication (Hart, 2004). The importance of communication around mealtimes was reported by Fiese, Hammons, and Grigsby-Toussaint (2012) who found a positive correlation between children with healthy weight and communication during mealtimes. A positive correlation between parent-child interactions during mealtimes and child health was also described by Radesky et al., (2015). As illustrated in figure 9-6 below, the use of BD gave children a reason to communicate; to ask for more, to refuse, to comment and to make choices.

<b>Participant</b>	<b>Function of communication</b>	<b>Example</b>
P10	Commenting	She'll say 'wow its pink'
P13	Requesting and showing preference/choice	Yeah so xxx loves it, and he enjoys it he asks for it even now he will go over and get his lunch box when he wants a feed when you put it onto a spoon he doesn't want it on a spoon and he wants it in his tube so that is quite nice actually to see that he wants to be fed because it is never ever actually done that before
	Sharing topics	I'll say to her you know we need to have our food now and so she she knows it's what's going to happen
P3	Requesting/ control	And he'll now grab my hand and he'll lead me to the kitchen to get his food. And he's in full charge of how much blend he gets and so when he wants more he'll grab the syringe and try and put it down himself, and when he's had enough he'll push the syringe away.
P7	Refusal /control	My young man can be very expressive for somebody who is non-verbal (mum laughs). The dietician was absolutely clear about what his views on the subject were. So we got the old communication book out and he was very clear that it [formula feed] gave him tummy ache, and he didn't like it and he didn't want it.
P9	Giving purpose and motivation to communicate	He's learning to use an eye gaze as well and we've been transferring the symbols on we've now figured out when he is full and we ask him have you had enough? And he tells us now that he is full because we were kind of going on and he was (mum makes groaning noise) full and we were carrying on and he was getting really bloated and uncomfortable.
P1	Motivation to interact	What it [BD] did do, it inclined him to make more of an effort to communicate, he felt better, as I say he had become quite withdrawn, it was really quite hard work and some days he just really chose not to engage at all
P1	Choice	When you've got people that are so limited around their own independent abilities it's lovely being able to give them .. choice, independence it's really nice to be able to do.

**Figure 9-6 Communication related to BD**

#### **9.4.2.4 Choice and Well-being**

A key reason to communicate is to indicate choice, as shown in the examples above. Choice can confer a sense of power and control; it can promote assertiveness and independence and can increase well-being (Dunlap et al., 1994; Knaak, 2010; Shevin & Klein, 2004). In this section the importance of choice for both parents and their children will be explored.

Parents, backed up by a wide range of studies into the effect of choice, acknowledge the importance of choice for their child with a disability. The importance of providing young people with a disability with choice was highlighted by Parsons and Reid (1990) who found that the food choices made by people with a disability were often not accurately predicted by their carers. Similarly providing meaningful choice can lead to improved engagement, and behaviour (Dunlap et al., 1994).

Another area of choice with principles applicable to BD is that of Gillick competence; defined as the ability of a child under 16 years to have the competence to consent to medical care and intervention (Griffith, 2015). It takes account of a young person's maturity, intelligence and gravity of the decision. It may therefore be considered that a child under 16 may be Gillick competent to opt to use BD. Conversely case law does exist in which two girls, aged 11 and 15, who were refusing the MMR vaccination were deemed not to be Gillick competent as the judge ruled that they had been unduly influenced by their mother's strong beliefs so their wish was overruled. Again there may be parallels here with BD; that young people could be unduly influenced by their parent's beliefs about the benefits of BD.

Although there are several examples of parents using BD to facilitate choice for their child, there may also be occasions when parental choice may be at odds with the child's choice particularly in terms of parents wanting to provide healthy meals and children preferring to eat the same as their peers. B18 said the BD her child has consists of whatever she chooses. B18 does not however, acknowledge this potential disparity when she goes on to highlight the mismatch between HCP and parental choice in the context of her HCP pointing out that formula feed is less work for parents as she wrote '*something being easier does not make it the right choice*'. It is also interesting to note that despite parents expressing annoyance about HCPs stressing the extra work BD creates, parents reported that they do frequently share

tips on ways of making things quicker, easier and more amenable to family life, and this was also noted in the blogs.

Parents did acknowledge that even within the BD community there are still differences of opinion, and that they do not all choose to feed their children in the same way as the extract from P18 illustrates

*'I know people on the [BD Facebook] site that will say oh she's not missing out on birthday cake, and blend the birthday cake up for them ... But you know we all feed our children what we choose'*

The consequences of a lack of choice was expressed by P6 whose son was not tolerating any of the formula feed he had been given,

*'we didn't feel like we had any other choice so we just struck out so there was no sort of advice or information'.*

The positive impact choice has on the well-being and independence of a young person with a disability was illustrated in the final two examples for P1 in Figure 9-6 above, and the sense of control and empowerment is illustrated by P4 whose teenage son had made a choice not to accept formula feed as it used to make him feel so unwell, and he would just say he was not hungry to avoid having a formula feed.

Making choices is an essential component of independence and for children and young people with complex needs and disabilities who are heavily reliant on others to assist them with Activities of Daily Living, the importance of being given the opportunity to make choices about their food cannot be underestimated. Similarly for parents, the significance of choice in their decision to use BD is encapsulated in the extract below from P13

*'I think .. it is the choice. I don't think it [BD] works every family at all and I don't think it will work every child, I just think that being given the choice to make your own decision'*

#### **9.4.3 Risk and quality of life**

The previous section considered choice as a factor in parents' decision to use BD. Choice is not without risk in many areas of life, and particularly regarding feeding (Krummrich, Kline, Krival, & Rubin, 2017; Lamantia et al., 2016). This section will consider how risk may influence a parent's decision to use BD.



Firstly it should be acknowledged that the word risk is not neutral and is often associated with socially undesirable behaviour and restrictions, and evokes feelings of guilt and anxiety and fear of getting things wrong (Lupton, 2011; Morgan, 2004). The term risk feeding is generally used to describe a situation in which a person continues to eat and drink orally despite the risks. A study of parents' perception of and adherence to feeding recommendations found parents continued to feed their child orally despite having been advised that it was not safe to do so (Petersen et al., 2006). In this instance it appears parents were balancing the risk of their child aspirating food, against their, (or their child's) desire to continue eating food orally. During the in-depth interviews parents reported that if BD had been mentioned as an option they would have agreed to a gastrostomy sooner. This poses a dilemma for HCPs who need to use their judgment to balance potential risks – would it be better for a family to be allowed to use BD than risk them continuing to feed their child orally? Similarly 99% of families whose children required medication reported that they always or sometimes use the gastrostomy to administer medicines. NICE guidelines accepts the practice and provides advice for HCPs even though it acknowledges that *“A very limited number of medicines are licensed for administration via enteral feeding devices and most administration of medicines via this route falls outside the product license for that medicine”* (NICE, 2015, p.21))

Ironically parents who had experienced tube blockages reported that medications had been the cause. It again appears that HCPs may be endorsing a practice that carries greater risk than the use of BD.

Families in the interviews and the blogs reported repeatedly being reminded of the potential risks of BD, namely tube blockage, food contamination, and inadequate nutritional intake. However, there is little relevant evidence to substantiate these concerns (Hurt et al., 2015), indeed a survey of dietitians reported that they experienced fewer issues in practice in comparison to their self-reported concerns, (Armstrong et al., 2017).

The impact of groups on risk is an important element to consider with regard to the use of BD. The Risky-Shift phenomenon describes how groups tend to accept higher levels of risk than individuals and that individuals shifted their stance to accept higher levels of risk after discussions with members of the group (Moscovici & Zavalloni,

1969). The mechanism of this shift may be that individuals sense some shared responsibility of the risk if taken by a group, or the particular group views the risk as more socially acceptable. The ramifications of this to parents who to use BD are significant as much of the spread of BD has come about through social media groups (Coad et al., 2016). The majority of parents interviewed were members of the Facebook BD group and indeed all but one of the respondents accessed the survey online, suggesting that they are active users of social media groups, and may influence or be influenced by the risky-shift phenomenon.

Finally, research from adult dysphagia may inform future practice. The FORWARD bundle (Feeding via the Oral Route With Acknowledged Risk of Deterioration) is a package of care developed to provide a more systematic, timely and patient-centred approach to the management of risk-feeding, including best interest discussions when agreeing feeding plans (Sommerville et al., 2017). The success of the package lies within the principles of good quality and consistent management with timely interdisciplinary communication and a logical reliable, consistent process, all of which could transfer to support and make safer the practice of BD.

#### **9.4.4 Normality and quality of life**

The concepts of medicalisation and normality are evident in section 9.2.4.3 around models of disability. In the context of the medical model of disability the vision of normality may involve 'fixing' the child or 'making them more normal'. However from a social model of disability perspective parents perceive the vision of normality as acceptance; and in the case of parents using BD acceptance of their choice of food appears to be a part of this.

This section will first discuss the concept of social markers of normality. It will then consider how normality is defined and construed and how opting to use BD helps parents to come to terms with and establish a new normality for their family life with a child who needs to be gastrostomy-fed.

Indicators of normality are socially constructed, and for babies and children include weight, eating and drinking and toilet-training. Consider the first questions to new parents 'Is it a boy or a girl and how much did they weigh'? Weight gain in babies continues to be measured and can be an area of great stress and anxiety for parents (Kaitz, Mankuta, Rokem, & Faraone, 2015). If their baby is not deemed to be gaining

sufficient weight they may feel judged by family members and HCPs. Similarly if an infant does not feed well or a toddler does not move on to solid foods at the expected time, parents may again face judgement from those around them. Finally toilet-training is an area for which society constructs perceived norms, and parents may feel judged according to whether or not they meet the perceived standards (van Nunen, Kaerts, Wyndaele, Vermandel, & Van Hal, 2015). These three areas, weight gain, feeding and eating and toilet training were all areas that parents in the interviews and blogs described how the use of BD related to normalising these three areas.

In the context of gastrostomy, normalisation and medicalisation may be viewed as different sides of the same coin. Medicalisation can be disconcerting for families, in part due to the fear of the unknown, an unfamiliar world of which they may be fearful, and from which they wish to distance their construct of normal everyday life. P8 said

*'it is all the world of doctors and hospitals; you do get frightened... a lot of the time because it is all medical procedures you know it is not your world necessarily that you're walking into'.*

The use of BD appears to serve as a means of regaining normality and disassociating themselves from the medicalisation of the feeding process, P5 said

*'I don't think it's quite as scary as seeing something that someone's blended going down her tube as it had if its pouring by the bottle hanging at the pump or whatever - that was very medical'.*

Parents want a normal life for their child, they are not denying their children's difficulties, instead they are making a positive choice to try and normalise life as much as possible as feeding is perceived as an area of that child's life that does not need to be medicalised. As food and feeding are so crucial / central to parenting the use of BD assists this normalisation.

An individual's representation of normal, is influenced by both descriptive norms, (for example *most children eat food*) and prescriptive norms i.e. the ideal (for example *children should eat food*). Descriptive and prescriptive norms are influenced by beliefs about how things tend to be or should be (Bear & Knobe, 2017). Bear and Knobe also suggest that what people consider as normal is in part determined by what is considered by them as ideal, combined with that they consider to be average.

So are families who use BD seeking an aspect of normalisation that they can attain, particularly when faced with so many other parts of their child's life, which they may view as abnormal and are unable to change? If parents of gastrostomy-fed children view the descriptive norm as feeding with formula food, but their ideal is to use BD, this may in part explain why 50% of families in the survey were still using some formula feeds.

Parents were also noted to favour the use of language associated with normal feeding and eating. For example they used the term weaning when describing how they first introduced BD. Similarly further analysis of the data from the interviews revealed that the word *food* tended to relate to issues of oral eating and weaning and about quantity and the nutritional quality of food, and tended to have a more positive, nurturing connotation. Conversely the word *feed* was used more in relation to the mechanics of gastrostomy feeding and the use of formula feeds and had a more negative connotation. It was striking to note that no one referred to formula feeds as 'food'.

Normalisation decrees that people with disabilities should experience norms and patterns in their daily lives as close as possible to those of mainstream society (Wolfensbeger, as cited in Horejsi, 1979). It should be noted that normalisation does not mean being normal, and attempts to undo physical or mental disability are not advocated. Normalisation suggests that individual growth and development involves making choices and taking risks. As with BD, it could be construed that parents, in order to promote the growth and development of their child are taking risks in using BD, and that this risk-taking behaviour is a dimension of normalisation. Horejsi (1979) suggests that normalisation ensures that all children and young people are engaged wherever possible in lifestyles that are culturally as normal as possible. Parents described how using BD afforded their children such opportunities.

Normalisation can relate to normal family life such going out together, for example some families mentioned that restaurants would blend meals for their child. Normalisation could also relate to mealtimes. For example one mother described how when giving formula feeds she always felt she had to give the full quantity regardless of how her child seemed to be. However with BD she knew that in the mornings her child tended to take more and other times less, so she would vary the

amounts across the day just as she did with her other children – again bringing normality to the situation. Another parent explained that by giving her child a packed lunch she could sit at the table in a mainstream school dining hall and either have food or just sit with her peers whilst they have their BD. Normalisation can also relate to hobbies or pastimes. One parent talked about how her daughter spent time cooking her feeds with her grandfather and highlighted that it meant she was eating the same food, but it was just going in in a different way. Finally the significance of the normalisation offered by BD was captured by P12 whose son was on a full BD –

*“You know I am secretly pleased when he comes home from school and he has got a bit of food on his trousers because that is totally what any 10 year old would do is come home with their dinner all down them- it is nice’.*

#### **9.4.5 Summary**

This section has considered how BD impacts on the quality of life of the child, parents and wider family. It considered how BD might improve the health and well-being of children who have BD, and concluded by exploring what the use of BD means in terms of choice, risk and normality.

#### **9.5 The Role of Social Media**

Phase 2 of the research involved the use of blogs from the internet as a data source in order to answer the research question; are different reasons for using BD identified by data gathered from blogs as opposed to in-depth interviews? Although the themes from both data sources showed little difference, this section will discuss how social media may relate to and impact upon parents’ decisions to use BD, and on their views and use of health and health services in general

The role of social media in the spread of the use of BD was widely acknowledged in the literature (Coad et al., 2016) and this was taken into account when designing the research, with the use of data from blogs and the online survey. Similarly there has been an increased awareness of the impact of social media and healthcare in the past decade (Rothman, Gnanaskathy, Wicks, & Papadopoulos, 2015; Ventola, 2014).

Therefore this section will address a supplementary research question *‘what role does social media play in the decision of parents to use blended diet’?*

This section will explain why and how social media has influenced and impacted upon the uptake and spread of BD.

### **9.5.1 Researcher's reflections on the use of blogs**

There were benefits and challenges to using data from blogs for thematic analysis. As there was no direct contact with the bloggers the researcher felt less empathy with them in comparison with interviewees, and it seemed that the interpretations in the thematic analysis were less nuanced in comparison to the data from the in-depth interviews. Similarly it was not possible to pose subsidiary questions so information was purely directed by bloggers. This was not an issue during the Skype in-depth interviews even when things did not go smoothly. Indeed technical adversity created a feeling of being 'in it together', and so seemed to lead to a greater sense of bonding and understanding between researcher and interviewee.

The relative anonymity of blogs meant that the researcher could not be certain that bloggers did not have malevolent intentions and skew data (Seale, Charteris-Black, MacFarlane, & McPherson, 2010).

The use of blogs mitigated against the Hawthorn effect i.e. changes in behaviour that result from being observed (Grainger, White, Morton, & Day, 2017). Similarly the use of blogs also mitigated against interviewer bias.

One final reflection concerns the accounts of parents' technical knowledge and expertise around medical procedures. Despite wanting to have normal lives, inevitably these families do become parent-medical experts in their child's needs. Parents were managing their children including tracheostomy, complex cardiac conditions, multiple drug regimes and placement of nasogastric tubes. It seems that it would be true to say that if parents can manage these procedures, perhaps they could be trusted and supported to feed their children the splendid diet without risks of blocking, poor nutrition or contamination. There seems to be contradictory or illogical practice - to expect ventilated children to be managed at home and in mainstream school but not to allow the use of BD.

### **9.5.2 Similarities and differences between blogs and interviews**

Themes across the blogs and interviews were generally similar; feeding in the overall context of the family, with sentiments of loss, a desire for control and influence amidst

conflict. Blogs substantiated concepts identified through interviews, which was also reported by Yen et al. (2013). The delivery of the themes was more visceral and unchecked in the blogs, and included expletives, whilst the interviewees were honest but measured. Blogs used words such as fight and struggle whereas interviewees used less emotive words such as conflict and compromise. This resonated with a study by Eastham (2011) who suggested that blogs are likely to expose more candid data.

Although the interviews took a phenomenological approach, the blogs could be deemed to be to provide a truly phenomenological account, as bloggers write of their views and experiences as they see it, and are not constrained by interviewer questions. This view is supported by Jones (2008) who suggested blogging provides a means of self-expression and provides social contact.

The content of the blogs appeared to be more spontaneous and reflective of the mood of the blogger at the time, some starting the blog with an apology for the interval since the last post saying they had been particularly busy that week for example. As a result, blogs are akin to other forms of human communication: they have evolved through convenience as opposed to by design. They offer an unstructured, organic and opportunistic means of communication (Williams & Jacobs, 2004), which again may imply that the content reflects lived experiences of the blogger.

#### ***9.5.2.1 Humour and visuals and religion***

The use of humour, visuals (e.g. pictures, photos, videos) and references to faith were evident in blogs but to a much lesser degree within interviews. The use of humour was much more evident in the blogs and was noted on 52 occasions across 20 blogs. Conversational humour includes, puns, witticisms, irony, teasing, banter, terms of endearment self-denigration and anecdotes (Demjen, 2018). Within blogs self-deprecating humour can draw attention to and therefore increase spread of the bloggers' message (Kanai, 2019). This was evident in posts that were used as a soapbox to share beliefs (see section 6.3). Irony relies on shared assumptions based on culture and experience (the notion of an 'in-joke'), and can enable a blogger to express opinions or attitudes implicitly, which may support BD bloggers who had concerns about negative repercussions from HCP regarding their BD usage.

In the light of the global status of blogs and indeed of BD, the function of humour as a means of bridging mental and intellectual distances of people of different backgrounds is particularly pertinent (Olsson, Backe, Sørensen, & Kock, 2002).

The use of visuals in BD blogs was significant with the majority of blogs containing them (appendix 15). Visuals were found to stimulate greater product interest, (Lin, Lu, & Wu, 2012.) and to enhance understanding and recall of information (Van Noort et al., 2011), both of which would serve to spread the message of BD. Mothers tend to show pictures of their children denoting happy times (Elliott, Squire, & O'Connell, 2017), however, when viewed in terms of symbolic interactionism (Blumer, 1969) Elliot's finding was not supported by this BD research. One parent showed a photo of her child purporting to be looking well due to BD, but from my perspective as a reader of the blog my interpretation of the meaning of looking well did not match that of the mother. The power of visuals and hyperlinks to spread a message and call for protests was recently seen in the case of the 'Charlie's Army' Facebook group, similarly religion had the effect of publicising the case as faith leaders and pro-life campaigners posted their views online (Das, 2018).

Religion or faith was mentioned in several blogs (appendix 15) but was only coded in relation to BD in three blogs. Research into the use of blogs with burn victims found that faith was expressed through a sense of gratitude for the things they can still do (Garbett et al., 2017). This was also evident in the BD blogs as well as requests for readers to pray for their child and thanks for prayers that they had received.

#### **9.5.2.2 Linguistic Inquiry and Word Count**

Analysis of the blogs using the LIWC software (see section 6.5) enabled comparisons to be drawn between the BD blogs and those used to produce normative data for LIWC (Tausczik & Pennebaker, 2010). BD bloggers tended to be analytical and authoritative and were affirmative of their stance with regard to BD and showed lower levels of humility and vulnerability, with an overall positive tone. Indeed a latent message from blogs was 'I am not an expert in medicine but I know what BD has done for my child'. These traits seem to match those respondents to the survey who used BD including high levels of self-efficacy and high levels of self-belief in response to the question '*I know what is best for my child with regards to feeding*'.



Analysis of word categories revealed higher levels of social words (i.e. related to family and friends), and higher levels of words associated with biological processes and health.

All these findings though predictable, do strengthen the premise that the themes from both blogs and interviews were similar, and substantiate the findings of Yen et al. (2013) that blogs substantiate concepts identified through interviews.

### **9.5.3 The impact of social media**

Even in the years prior to the Internet a shift from the paternalistic model of healthcare had begun, with '*an era of declining physician sovereignty and rising patient rights*' (Conrad, 1987, p.15). It is now estimated that in the Western world 80% of adults go online to seek health information (Grainger et al., 2017), so patients (and parents) have high levels of information about their condition, and views about treatment options. In a study that looked at reasons why patients used the internet for health information amongst the reasons listed were that they felt their doctor was not open to discussions of their suggestions and that their doctor did not understand their concerns (Diaz et al., 2002). It seems that parents who were using BD, whose perception was that BD is not allowed and discussions are closed down, shared these views. This was explained by P10 asked her gastroenterologist if she could try BD, and when he said no and she said '*it just ended – you take that as it is don't you*'. This also illustrates how the deficit model of science still prevails in some patient: HCP relationships which in turn may increase the likelihood of them turning to social media for support and information. Similarly although most mothers want information and advice it can sometimes be highly technical and confusing (Green & Florida, 2004). This may be the reason families seek information and advice from social media and FB groups formed of parents with whom they identify. So the Internet and social media has resulted in changes to decision-making powers fuelled by increased patient knowledge.

However, there is a real danger from non-expert stakeholders who may be charismatic self-appointed experts or 'celebrity bloggers' whose posts carry a lot of influence and have the potential to overshadow or marginalise the views of qualified experts (Warner, 2017). Within the health arena this populist rhetoric appears to be rejecting professional expertise and public institutions in favour of lay-expertise of the

ordinary patient (Das, 2018). Nevertheless, a participant in the in-depth interviews who thought it was wrong that parents were turning to social media and not their HCP for support expressed their concerns about this trend; 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"?'*

Closed Facebook groups may be heavily censored and only open to the like-minded, and as discussed in section 9.4.3 this group polarisation or risky-shift phenomenon can lead to individuals becoming less risk averse and potentially endangering their children.

It seems clear that HCPs now need to help distil information and provide high quality information regarding BD so parents can make informed decisions, and to ensure they are the 'informed masses not the misinformed masses' (Ko, 2016).

#### **9.5.4 Summary**

To conclude, it has been shown that blogs reiterate the findings of the interviews, and although they may be viewed as more authentic than interviews they can be used manipulatively.

Social media in general facilitates mass accessibility to information and engagement with the top three reasons for health related social media use being to increase knowledge, for social support and to exchange ideas (Antheunis, Tates, & Nieboer, 2013). It also has synergy with theories of individualism, with the moral worth of individual bloggers' perspectives being widely acknowledged, and social representation theory with the beliefs around BD being developed and shared via social media groups.

Finally blogs provide parents with a means of identifying with and connecting with other parents, as well as increasing their sense of purpose by helping others in similar situations. This sense of connection is particularly important for families of children with complex needs who are at risk of isolation (Ressler, Bradshaw, Gualtieri, & Chui, 2012).

## **9.6 Stakeholder perspectives**

This section will first describe the public and patient involvement (PPI) in the research project and then go on to consider how the perspectives of parents and other key stakeholders in the BD debate are shaped, in order to better understand their actions.

### **9.6.1 Patient and public involvement**

My acknowledgement for the need for patient and public involvement (PPI) was triggered when as a service manager for paediatric therapies I carried out an audit of the 'did not attend' (DNA) rates for paediatric therapy (physiotherapy, occupational therapy and speech and language therapy) appointments. When arranging appointments the physiotherapy service offered a choice of appointment slots via a phone call to the parent. The occupational therapy service called the family to inform them of their appointment time and the speech and language therapy service just sent a letter with the appointment time. Contrary to my expectation, the speech and language therapy service had the lowest DNA rates and physiotherapy the highest. My prediction was totally wrong, so needed to consider what other factors were 'at play'. This precipitated my realisation that truly listening to what parents and families say, rather than basing decisions on our assumptions was crucial.

There is ample evidence that illustrates the value of PPI across healthcare. Needham (2008) found that user involvement was able to "transform citizen attitudes in ways that improve service quality". Omeni et al (2014) found a number of benefits of user involvement in service design including improving the information and accessibility of services, improvements in the coordination of care and in the relationships between clinicians and those receiving treatment. Nicholls et al (2003), found that user involvement led to positive clinical outcomes, including improved self-esteem and confidence, and therapeutic benefits resulting from increased social interaction. Further evidence of the impact of user involvement is found in research into goal setting with patients with multiple conditions. Reuben and Tinetti (2012) reported instances of a reduction in resources required to manage patients with multiple chronic diseases when patient preferences were listened to and acted upon. Involving patients in research can improve the quality of the research in a number of ways. Patients can help define the research question and shape the research at an

early stage. Throughout the research they can also provide a unique perspective, they can comment on the language, content and acceptability of research tools such as questionnaires.

Because the use of BD is not advocated by HCPs I relied on personal contacts and word of mouth to establish contact with the two parents who agreed to pilot my in-depth interview. Several parents who were interviewed then offered to help in anyway they could with the research, and as a result a further 6 parents were recruited to what became a virtual group of parent advisors who helped to shape my research. Members of the group provided feedback on an early draft of the thematic analysis report section and piloted the questionnaire. In addition, they were kept informed of the progress of the research through 6 monthly update emails that I sent them. In terms of Arnstein's ladder of citizen participation (Arnstein, 2007) their inclusion varied between the levels of consultation and partnership. However, PPI for this research required a balance between over-burdening families and not letting their involvement become tokenistic.

The PPI in this research was both a strength, in that it was included but also a limitation as more formal PPI, and at an earlier stage would have enabled parents to shape overall the research. All parents in the virtual group were given regular updates and I plan to co-present the research to some groups with parents from the virtual group.

### **9.6.2 Parents**

Parents' perspectives are shaped by their values and beliefs. These in turn are shaped by those around them; their social and cultural groups, their experiences, by their family and their partners. They are also shaped by their beliefs around food and eating and about medicines and about disability and normality.

In chapter 4 the notion of BD representing a journey was raised. In some respects there are similarities with the grief cycle (Kübler-Ross & Kessler, 2005), which sees individuals move through the process at different rates, and not necessarily with a smooth progression. In some instances parents using BD also report a pendulum effect rather than a smooth progression referring to feelings of self-confidence one moment and self-doubt the next. However, there is still a sense that by opting to use

BD, parents are striving for something they believe to be best for their children whilst acknowledging that it would not be easy. If they failed, or BD was not found to be as good as formula feeds, parents put at risk their self-belief, their child's well-being and relationships with their family members and HCPs. Fear and uncertainty, self-belief and self doubt are feelings associated with having a child with complex needs rather than BD per se (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Enrione et al., 2005). So perhaps parents of children with a range of complex needs are on some sort of journey with similar elements or stages. Selective Dorsal Rhizotomy (SDR), a surgical procedure to reduce spasticity was widely shared and publicised by parents on social media. In a previous role as a commissioner, the researcher was aware of families who wanted to have SDR operations for their child experiencing conflict with their HCPs. A report suggested that potential benefits and adverse effects were not understood and some families in the UK resorted to crowd funding on Facebook in order to raise money to have the surgery in the USA (Crilly, 2012). In 2018 commissioners agreed that SDR should be provided on the NHS for a cohort of children with cerebral palsy (NHS England, 2018). The success of such high profile campaigns may inspire parents wanting to use BD to pursue their cause. The case of SDR raises the question as to whether the persistence and advocacy in campaigning provides some form of self-affirmation and a means of channelling the negative experiences associated with having a child with a disability into something more positive and potentially helps parents come to terms with their situation. This resonates with the discussion in section 9.3.4 as to whether having a child with complex needs is associated with higher levels of self-efficacy.

### **9.6.3 Professionals**

The perspectives of professionals have many similarities but are nuanced by their different roles and relationships with parents.

Medics' perspectives are shaped by their training, patient: medic relationship, by the media and expectations of society and by professional responsibilities. Perspectives are also influenced by their clinical evidence and guidelines and clinical experience that informs their judgement and by their own values and beliefs.

Dietitians' perspectives are shaped in a similar fashion to medics but nutrition is at the core of their profession and their professional guidelines specific to BD (British

Dietetic Association, 2013). Their views are shaped by professional ethos, mission and consensus, and their beliefs about risk, choice and empowerment.

School heads and governing bodies perspectives are informed by their responsibilities for the health and safety of children in their care as set out in the SEND legislation (DfE, 2015). They are also shaped by the financial resources, the national curriculum and by the levels of support and integration with local health service commissioners and providers.

Hospice staff are shaped by their ethos of enabling children and young people to live well and fully and to replicate home conditions in the hospice as far as possible (Brown, 2014).

#### **9.6.4 Summary**

This section has illustrated the complexity of the different factors that combine to shape the perspectives of those involved in the lives of children who are using BD. The theory of individualism can be used to help interpret the perspectives of parents, whereas medics, dietitians, schools and hospices take a more collectivism stance (Oliver & Evans, 2005), which results in the conflicting views and opinions around the use of BD.

#### **9.7 Limitations**

Limitations of this research will now be discussed, as well as the learning gained from them.

As mentioned in the limitations section at the end of chapter 4 parents who were not using BD were not interviewed. This was part of the ethical consideration. To mention or introduce the idea of BD to families who were not using it, and may not even be aware of its existence would I felt have been ethically and morally wrong. This is because there is no official support for BD, and indeed it is generally viewed by HCPs as not being an acceptable form of enteral feeding. The decision was further supported by a study by Hurt et al.(2015). In a prospective cross-sectional study (n = 54) of adults attending Home Enteral Nutrition follow up clinic, 58.3% of responded stated that they did not know about BD or how to prepare it as the reason for not using BD. However the lack of perspective from non BD users does mean that it is

not possible to determine if this is because they are satisfied with formula feeds or they just have not heard about BD.

Another limitation was that only mothers were interviewed and only mother's blogs are used, similarly 95% of respondents to the survey were female. This may indicate that fathers were less interested or felt feeding was not part of their domain of parenting responsibility. Future research should use purposeful sampling to ensure the views of fathers are gathered.

Although the research did not set out to seek views of children and young people, there was some indication that views of the parents were shared by the young people but without further research it is not possible to ascertain whether this is indeed the case. However future research should consider the views of children and young people as Dunn, Shields, Taylor, and Dodd, (2009) found that the views of children and young people with cerebral palsy showed significant disparity to that of their parents.

Another limitation of the research is that the views of HCPs around BD were not sought. Informally colleagues acknowledged that families were using BD and there were mixed opinions about the practise, as was reflected in the in-depth interviews and blogs. Although this was not part of the study, the inclusion of such views would have provided a richer and arguably more balanced picture.

Self-selection of participants for both interviews and the questionnaire is another potential limitation of the research. It is possible that parents who participated in the research wanted BD to be sanctioned as a viable alternative to formula feeds, and they may therefore have over exaggerated the benefits of using BD. Similarly self selection may mean that families who are disengaged with HCPs are not likely to participate.

As illustrated by the interviews the use of BD impacts upon all areas of a child's life – home, school, hospitals, holidays and outings. Future research could consider asking others involved in the child's everyday life about their opinions regarding the health and well-being following the initiation of BD.

## 9.8 Implications for Clinical Practice

The BD research has highlighted a fundamental tension between empowerment and self-management and actual clinical practice. This section will first reflect on some of the more philosophical issues raised by the use of BD and then move on to consider the application of the research findings within clinical practice.

### 9.8.1 A philosophical perspective

The move towards a less paternalistic NHS has been a long-term aspiration as can be appreciated by considering policy from the turn of the millennium.

Back in 2000 the NHS plan stated *“the relationship between service and patient is too hierarchical and paternalistic. It reflects the values of 1940s public services”* (Department of Health, 2000, section 2.33).

By the end of the first decade of the 21<sup>st</sup> century it seemed that little progress had been made; the leader of the Patients Association was quoted in the Guardian newspaper *“The NHS is still very paternalistic. There is a move away from that, but it's not happening fast enough”* (Murphey, September 2012).

At the beginning of 2019 the NHS continued to identify control and more personalised care for patients as one of its targets, and acknowledged that genuine partnerships that facilitate real choice will require professionals to work differently to engage with patients in decision-making around their health and well-being (The NHS Long Term Plan, 2019). However, tensions still arise when state power encroaches into the familial domestic arena, as was seen with the UK's vaccination programme (Bashford & Strange, 2007). Parallels can be seen between this area and that of feeding (of which BD is one aspect). Feeding, which had traditionally been considered a matter for families to determine, has become the focus of government policy with campaigns to tackle obesity and unhealthy eating (Coveney, 2009). So without patient engagement and involvement in decisions about their care, how can patient centred planning and self-management become a reality? With the demise of the deficit model (which suggested the public lacked knowledge about science and research and needed experts to inform them) a model of upstream engagement (involving members of the public who may have an interest but no specialist knowledge) came about (Wilsdon & Willis, 2004). The James Lind Alliance was established in 2004 to bring together patients, carers and clinicians to identify,



agree upon and prioritise the top 10 key research areas – or uncertainties about the effects of treatments. Funding from institutes such as the National Institute for Health Research (NIHR) is being linked to projects identified by the group. One of the topics raised regarding childhood disability in 2014 concerned the impact of BD versus formula feeds and in 2018 the NIHR commissioned research to consider this issue.

### **9.8.2 Application to clinical practice**

Moving forward with the assumptions that choice and patient involvement in decision-making become embedded in clinical practice, the implications for BD will now be considered. Parents reported that they did not have enough information about BD, so the use of patient decision aids (a form of guideline based on research evidence, to inform patients, which also help them think about the implications for different options for themselves) may be helpful. The aids were found to lead to greater knowledge, more accurate risk perceptions and greater participation in decision-making (Tevena et al., 2017); all of which parents in the BD research had expressed a desire for.

By using the research into patient safety and engagement carried out by Burrows, Walters and Duthie (2017), better relationships with those patients for whom BD may not be appropriate can be fostered. Similarly such research provides insights into reactions of parents regarding HCPs' concerns about the safety of BD. For example Burrows et al found that using the term *patient safety* was less meaningful than saying *your safety* and helped when patients appeared unable to process the reason for advice. This may be particularly relevant to highly emotive or confrontational situations between HCPs and parents such as those described in chapter 4. The importance of language or terminology in clinical practice was raised in section 9.2.5 suggesting insensitive use of language was a trigger factor in conflict. Similarly in section 9.4.4 the importance of using the language of normality was noted. A participant in the in-depth interview recounted a conversation with a HCP who 'proudly' told her how the formula feed was made in a laboratory and how incongruous with her own views that statement was. Koch-Weser, Dejong, and Rudd (2009) highlighted the effect of misinterpretation of medical terminology, and a distressing example from clinical practice being when a patient was told the 'disease

was progressing', having heard the term 'progressing' assumed that this was a positive outcome.

Another practical consideration concerns what happens when HCPs' goals are different from those of the parent (i.e. HCP wants formula feeds to be used and parents want to use BD). Research from the field of health visiting has helped to overcome barriers between health visitors and parents with regards to conflicting views around needs assessments (Cowley & Houston, 2004). Using the notion of participatory competence to enable health visitors to work with families in a more flexible way taking into consideration contextual and sociocultural issues, and validating parental perspectives.

There have been a number of studies into the impact of gastrostomies (Craig & Scambler, 2006; Gantasala, Sullivan, & Thomas, 2013; Martínez-Costa et al., 2011). It should be noted that parents who opted to use BD expressed similar feelings and emotions to those whose children require a gastrostomy. Findings from such research may be extrapolated to the area of BD in order to enable HCPs to better understand and support families.

With the increased use of gastrostomies and more children surviving into adulthood (Sharma, Williams, & Zaw, 2012), the need to invest in further research into the pros and cons of BD and formula feeding is becoming more apparent and acknowledgement of the expertise of parents in terms of their experiential knowledge of BD, would foster meaningful collaboration (Pomey, Ghadiri, Karaziivan, Fernandes, & Clavel, 2015).

Finally if future research concludes that BD is not a suitable alternative for some or all children, the BMQ will be a useful tool to assist HCPs to predict which families are more likely to be non-compliant with the use of formula feeds. The BMQ will facilitate better profiling and understanding of motivators and beliefs of parents, which in turn will enable more effective interventions to support all parents to be designed.

## **9.9 Future Research**

The increase in usage of BD appears to have driven a proliferation of research into issues relating to the potential risks and benefits of BD with 27 of the 43 studies in a scoping review of BD being published between 2013 and 2016 (Breaks et al., 2018).

Arguably the most fundamental question that needs to be addressed is whether the use of formula feeds is harmful for some children, and if it is not harmful whether BD leads to better outcomes for children and their families. Future longitudinal comparative research studies should monitor a range of outcomes pre BD and at intervals throughout the study such as comprehensive anthropometric data, quality of life ratings, for both parents and children and young people, school attendance levels and stooling patterns and gut function.

Future research should also include interviews with children and young people to determine whether or not they have the same views as their parents with regard to BD. This is especially important in the light of work by Dunn, Shields, Taylor, and Dodd, (2009) and Parsons and Reid (1990), who found discrepancies between the views of parents and carers and children and young people.

The Blended Diet UK Facebook group is a closed group for parents/carers, individuals and professionals with an interest in BD. It has provided a range of rich information and conversation about all aspects of BD, and as such would be a valuable source of data for further research. It would also enable further investigation into how agenda setting, social norms and self-regulation theories may impact parents' views on BD. However, this would present ethical and moral challenges, and the candid phenomenological nature of the posts may be affected as a result of the observer paradox (Labov, 1972). A possible compromise would be to seek permission for a retrospective analysis of the data

One additional aspect of BD that was mentioned in the interviews was cost, with some parents suggesting that the use of BD may represent savings to the NHS. In the event of both BD and formula feeds being found to be viable options cost alone should not determine whether BD or formula feeds are used. In 2013 a study estimated the annual cost of tube feeding a child to be £6,500 (Wright, 2013), but to date no studies of the costs of BD versus formula feeds have been undertaken. The potential of carrying out a comparative analysis of the costs of both methods of feeding was discussed in conversation between the researcher and Paul McCrone Professor of Health Economics at King's College London in 2018. Such a study would have to disentangle costs associated with equipment, dietitians funded by commercial companies etc.

Finally, even if it is assumed that BD does lead to better outcomes for children and young people, very little is currently understood about the mechanisms of these improvements. Pentiuk et al. (2011) hypothesised that the higher viscosity of BD leads to slower gastric emptying and that BD may stimulate a hormonal response that improves gastrointestinal motility. It has also been suggested that the bacteria found in foods used in BD, rather than being due to contamination are beneficial probiotics (Hurt et al., 2015). Future research should investigate whether there are physiological changes perhaps due to gut health that lead to improved bodily functions, physical health, development, cognition and well-being.

The possibility of the benefits being the result of a placebo effect cannot be ruled out. Parents have made a choice and are doing something that fits in with their constructs of good parenting and healthy eating and family life, which may in turn have a positive effect on self esteem, relationships, sleep, cognition and well-being.

#### **9.10 Personal reflection**

As a speech and language therapist working closely with dietitians, my early encounters with BD involved parents asking me not to tell the dietitian what they were feeding their child. This secrecy had the potential to undermine both multidisciplinary working and the therapeutic relationship between the parents and myself. I considered issues of behaviour change to improve adherence and compliance to clinical recommendations. However, I then began to examine the practice of using BD more closely and to consider the possibility that BD was a better form of feeding for some children and that formula feed was actually causing harmful side effects in others. The original research proposal was discussed with two parents who had experience of using BD, and throughout the project a group of parents have offered advice and comments on process, on the interviews and interview questions and on the content and usability of the online survey. Some parents were vehemently opposed to formula feed and there was the potential for them to regard my research as a means of promoting their views and adding more credibility to the use of BD. It was therefore important to maintain equipoise and not to condone or condemn either approach.

To finish on a note of caution, if BD is found to be better for some children but formula feed is not found to be harmful, it is important that parents who opt to use

formula feeds are not vilified or made to feel guilty as has happened to mothers who choose not to breastfeed (Knaak, 2010; Lagan, Health, Symon, & Dalzell, 2014).

At this stage it seems unlikely that one or other option will be right for all families, and the key message should be to ensure there is choice and support available to facilitate the best possible outcomes for children and their families.

## Chapter 10 Conclusion

This research used a mixed methodology approach to uncover a myriad of factors that influence parents' decision to use BD. As the use of BD becomes more widespread 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 findings of this research revealed four key points.

Firstly the children who are using BD often have very complex health needs and disabilities. This impacts on the whole family throughout their everyday life with frequent appointments and hospital admissions that may require practical and emotional support from extended family and friends. A range of social constructs including models of disability and individualism influences parents who use BD. Parents have to carry out a range of medical procedures at home to manage their child's condition. They appear to appreciate the freedom of choice offered by BD as well as the benefits they see that it has for their children.

Secondly the perspective of parents and some HCPs with regard to BD are often opposing, with parents viewing BD as the best way to feed their child and HCPs often viewing it as a risky and inappropriate means of feeding. Parents' views may be sanctioned or validated by society with the prevalence of healthy eating and choice discourses, however HCPs' views may be equally valid and are professionally sanctioned. This BD research has highlighted the importance of positive relationships between parents and HCPs and also the impact of poor relationships in terms of patient experience and outcomes. Listening to and attempting to understand the views of parents who want to use BD seems to be a means of bridging the gap between the priorities and opinions of HCPs and parents.

The third issue raised by this research concerns the benefits and threats posed by social media both for BD and wider health issues. Blogs can provide a rich accessible source of data for researchers and they can also provide parents with support and information. However, there is the potential for social media to misinform, and the dynamics of online groups may encourage risky behaviours. Parents stated that they wanted more information about BD and as more people turn to the internet for advice on health issues it would seem timely for HCPs to take

advantage of the potential for education and support that the internet and social media offer.

Finally this research confirmed the lack of evidence regarding potential benefits and challenges of BD. Evidence that does exist is often inconclusive or conflicting. Families and HCPs alike recognise the need for more evidence and the recent research commissioned by the NIHR is encouraging. The research did identify some predictors of BD use, the most powerful being from the Beliefs about Medicine Questionnaire, which showed a strong correlation between high levels of concerns about formula feeds and the use of BD.

To conclude, the importance of acknowledging that the way in which individuals live their lives and take decisions and make choices about health cannot be explained by knowledge alone. HCPs and parents should journey together to learn and understand more about the benefits and challenges of BD in order to align interventions with hopes, wishes and priorities.

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375-392.

## Appendix 1: Scoping Review Tables

**Table 1 Quality rating of the papers included in the review**

Title	Author	Year	1. Is the approach appropriate?	2. Is the study clear in what it seeks to do?	3. Is the method of data collection appropriate?	4. Are the methods reliable?	5. Is the data analysis sufficiently rigorous?	6. Are the findings convincing?	7. Are the findings relevant to the aims of the study?	8. Are the conclusions adequate?	Total Quality Score
Bacterial contamination of blenderized whole food and commercial enteral tube feedings in the Philippines.	Sullivan, M. et al	2001	Yes	Yes	Yes	No	Yes	No	Yes	Yes	6
The Use of Blenderized Tube Feedings	Novak, P. et al	2002	Yes	Yes	No	No	No	Yes	Yes	Yes	5
Nutritional analysis of blenderized enteral diets in the Philippines.	Sullivan, M.M. et al	2004	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Increased Force Required With Proposed Standardized Enteral Feed Connector in Blenderized Tube Feeding	Mundi, M	2014	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Blenderized Tube Feeding Use in Adult Home Enteral Nutrition Patients: A Cross-Sectional Study.	Hurt, R.T. et al.,	2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
ILSI Task Force on enteral nutrition; estimated composition and costs of blenderized diets	Waitzberg, D.L et al	2013	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	7
Blenderized Formula by Gastrostomy Tube.	Johnson, T.W et al	2013	Yes	No	Yes	Yes	No	Yes	Yes	Yes	6
Survey Study Assessing Attitudes and Experiences of Pediatric Registered Dietitians Regarding Blended Food by Gastrostomy Tube Feeding	Johnson, T.W et al	2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Caring for tube-fed children: A review of management, tube weaning, and emotional considerations	Edwards, S. et al.,	2016	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	7
Scurvy Related to the use of Homemade Tube Feeding Formula	O'Hara, C	2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	7
Basics in clinical nutrition: Diets for enteral nutrition. Home made diets.	Jonkers-Schuitema, C.F	2009	Yes	Yes	No	No	No	Yes	Yes	No	4
Universal Small Bore Connectors (ENFit) for Enteral Access: Implications for Clinical Practice	Hurt et al	2016	Yes	Yes	Yes	No	No	Yes	Yes	Yes	6
Use of Blenderized Tube Feeding in Adult and Pediatric Home Enteral Nutrition Patients	Epp L et al	2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Enteral Feedings in Children: Sorting Out Tubes, Buttons, and Formulas.	Vermilyea S et al	2016	Yes	Yes	No	No	Yes	Yes	Yes	No	5
Enteral Nutrition Formula Selection: Current Evidence and Implications for Practice	Brown B et al	2014	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	7
Finding the Balance: Oral Eating and Tube Feeding:	Nowak-Copperman et al	2013	Yes	Yes	Yes	Yes	No	Yes	Yes	No	6
Reit syndrome Questions and Answers	Seche G	2014	Yes	Yes	Yes	Yes	No	Yes	Yes	No	6
Pureed by gastrostomy tube diet improves gagging and retching in children with fundoplication	Pentiuk S et al	2011	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Reemergence of Blenderized Tube Feedings: Exploring the Evidence	Bobo E	2016	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	7
An Anthology of Advances in Enteral Tube Feeding.	Campbell S	2006	Yes	Yes	No	No	No	Yes	Yes	No	4
The Registered Dietitian Nutritionist's Guide to Homemade Tube Feeding	Walia C et al	2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Policy Statement Use of Liquidised Food with Enteral Feeding Tubes	British Dietetic Association	2013	Yes	Yes	No	Yes	No	No	Yes	Yes	5
Nutritional quality and osmolality of home-made enteral diets, and follow-up of growth of severely disabled children receiving home enteral nutrition therapy	Santos V et al	2009	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Commercial enteral formulas and nutrition support teams improve the outcome of home enteral tube feeding.	Klek S et al	2011	Yes	Yes	Yes	Yes	No	No	Yes	No	5
Transition to a Tube Feeding Formula With Real Food Ingredients in Pediatric Patients With Intestinal Failure	Samela K et al	2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Outpatient Nutrition Management of the Neurologically Impaired Child	Mascarenhas M et al	2008	Yes	No	Yes	Yes	Yes	Yes	Yes	No	6
Bacterial contamination of hospital - prepared enteral tube feeding formulas in Isfahan, Iran	Jalali M et al	2009	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Determination of the Fiber Content of Enteral Feedings	Fredstrom et al	1991	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Guidelines for Evaluating and Categorizing Enteral Feeding Formulas According to Therapeutic Equivalence	Heimberger D.C et al	1985	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	7
Bacterial Contamination of Tube-Feeding Formulas	Anderson K et al	1984	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Liquid Formulas for Oral and Tube Feeding	Shils M et al	1977	Yes	No	Yes	Yes	Yes	Yes	Yes	No	6
Blended Food for Enteral Feeding via a Gastrostomy	Brown S	2014	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	7
Deconstructing Pediatric Blenderized Tube Feeding Getting Started and Problem Solving Common Concerns	Zettel S	2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Food and nutritional safety of hospitalized patients under treatment with enteral nutrition therapy	Amaral Felisio B et al	2012	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Physicochemical and nutritional characteristics of handmade enteral diets	Machado de Sousa L et al	2014	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Home Enteral Nutrition: Updates, Trends, and Challenges	Martin, K. and Gardner, G	2017	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
Dietitians' perceptions and experience of blended feeds for paediatric tube-feeding	Armstrong J et al	2017	Yes	Yes	Yes	Yes	No	Yes	Yes	No	6
Blended foods for tube-fed children: a safe and realistic option? A rapid review of the evidence	Coad, J. et al.	2016	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	8
ASPEN Safe Practices for Enteral Nutrition Therapy	Boullata, J et al	2017	Yes	Yes	Yes	Yes	No	Yes	Yes	No	6
Enteral Formulas in Nutrition Support Practice: Is There a Better Choice for Your Patient?	Escuro A and Hummell A	2016	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	7
ENFit Enteral Nutrition Connectors: Benefits and Challenges	Guenter P and Lyman B	2016	Yes	Yes	No	No	No	Yes	Yes	No	4
Use of Liquidised Food Through Gastrostomy	Thiyagesh V and	2016	No	Yes	Yes	No	No	No	Yes	Yes	4
Blended diets - A challenge at the coal face!	Thomas S	2016	No	Yes	No	No	No	Yes	Yes	Yes	4

**Table 2 Summary of Characteristics of studies included in the review**

Title	Author	Year	Country	Type of paper	Methodology	Topic of focus of study					
						Nutrition/Contamination	Medical/Well-being	Equipment	Patient-carer experience	Clinician's experience	
Bacterial contamination of blenderized whole food and commercial enteral tube feedings in the Philippines.	Sullivan, M. et al	2001	Philippines	NR	Quan	Yes	No	Yes	No	No	
The Use of Blenderized Tube Feedings	Novak, P. et al	2002	USA	Dx/Rw	N/C	No	Yes	Yes	Yes	Yes	
Nutritional analysis of blenderized enteral diets in the Philippines.	Sullivan, M.M. et al	2004	Philippines	NR	Quan	Yes	Yes	Yes	No	No	
Increased Force Required With Proposed Standardized Enteral Feed Connector in Blenderized Tube Feeding	Mundi, M	2014	USA	NR	Quan	Yes	No	Yes	No	No	
Blenderized Tube Feeding Use in Adult Home Enteral Nutrition Patients: A Cross-Sectional Study.	Hurt, R.T. et al.,	2015	USA Czech	NR	Quan	Yes	No	No	Yes	No	
ILSI Task Force on enteral nutrition; estimated composition and costs of blenderized diets	Waitzberg, D.L et al	2013	Brazil	NR	Quan	Yes	No	No	No	No	
Blenderized Formula by Gastrostomy Tube.	Johnson, T.W et al	2013	USA	Dx/Rw	N/C	Yes	Yes	No	Yes	Yes	
Survey Study Assessing Attitudes and Experiences of Pediatric Registered Dietitians Regarding Blended Food by Gastrostomy Tube Feeding	Johnson, T.W et al	2015	USA	NR	Mixed	No	No	No	No	Yes	
Caring for tube-fed children: A review of management, tube weaning, and emotional considerations	Edwards, S. et al.,	2016	USA	Dx/Rw	N/C	Yes	Yes	Yes	Yes	Yes	
Scurvy Related to the use of Homemade Tube Feeding Formula	O'Hara, C	2015	USA	Dx/Rw	N/C	Yes	Yes	No	Yes	No	
Basics in clinical nutrition: Diets for enteral nutrition. Home made diets.	Jonkers-Schuitema, C.F	2009	Netherlands	Edn	N/C	Yes	No	No	No	No	
Universal Small Bore Connectors (ENFit) for Enteral Access: Implications for Clinical Practice	Hurt et al	2016	USA	Dx/Rw	N/C	No	Yes	Yes	Yes	No	
Use of Blenderized Tube Feeding in Adult and Pediatric Home Enteral Nutrition Patients	Epp L et al	2016	USA	NR	Mixed	Yes	No	No	Yes	No	
Enteral Feedings in Children: Sorting Out Tubes, Buttons, and Formulas.	Vermilyea S et al	2016	USA	Dx/Rw	N/C	Yes	Yes	Yes	No	No	
Enteral Nutrition Formula Selection: Current Evidence and Implications for Practice	Brown B et al	2014	USA	Dx /Rw	N/C	Yes	Yes	No	No	No	
Finding the Balance: Oral Eating and Tube Feeding:	Nowak-Copperman et al	2013	USA	Dx/Rw	N/C	No	No	No	Yes	No	
Rett syndrome Questions and Answers	Seche G	2014	USA	Dx/Rw	N/C	Yes	No	No	Yes	Yes	
Pureed by gastrostomy tube diet improves gagging and retching in children with fundoplication	Pentluk S et al	2011	USA	NR	Qual	Yes	Yes	No	Yes	No	
Reemergence of Blenderized Tube Feedings: Exploring the Evidence	Bobo E	2016	USA	Dx/Rw	N/C	Yes	Yes	No	Yes	No	
An Anthology of Advances in Enteral Tube Feeding.	Campbell S	2006	USA	Dx/Rw	N/C	Yes	Yes	No	No	No	
The Registered Dietitian Nutritionist's Guide to Homemade Tube Feeding	Walia C et al	2016	USA	Dx/Rw	N/C	Yes	No	No	Yes	Yes	
Policy Statement Use of Liquidised Food with Enteral Feeding Tubes	British Deitetic Asscoation	2013	UK	Edn	N/C	Yes	No	Yes	No	Yes	
Nutritional quality and osmolality of home-made enteral diets, and follow-up of growth of severely disabled children receiving home enteral nutrition therapy	Santos V et al	2009	Brazil	NR	Quan	Yes	No	No	Yes	No	
Commercial enteral formulas and nutrition support teams improve the outcome of home enteral tube feeding.	Klek S et al	2011	Poland	NR	Quan	Yes	Yes	No	No	No	
Transition to a Tube Feeding Formula With Real Food Ingredients in Pediatric Patients With Intestinal Failure	Samela K et al	2016	USA	NR	Quan	Yes	Yes	No	Yes	No	
Outpatient Nutrition Management of the Neurologically Impaired Child	Mascarenhas M et al	2008	USA	Dx/Rw	N/C	Yes	No	No	Yes	No	
Bacterial contamination of hospital - prepared enteral tube feeding formulas in Isfahan, Iran	Jalali M et al	2009	Iran	NR	Quan	Yes	No	Yes	No	No	
Determination of the Fiber Content of Enteral Feedings	Fredstrom et al	1991	USA	NR	Quan	Yes	No	No	No	No	
Guidelines for Evaluating and Categorizing Enteral Feeding Formulas According to Therapeutic Equivalence	Heimberger D.C et al	1985	USA	Edn	N/C	Yes	Yes	No	No	Yes	
Bacterial Contamination of Tube-Feeding Formulas	Anderson K et al	1984	USA	NR	Quan	Yes	No	No	Yes	No	
Liquid Formulas for Oral and Tube Feeding	Shils M et al	1977	USA	NR	Quan	Yes	Yes	No	Yes	Yes	
Blended Food for Enteral Feeding via a Gastrostomy	Brown S	2014	UK	Dx/Rw	N/C	Yes	No	Yes	Yes	Yes	
Deconstructing Pediatric Blenderized Tube Feeding Getting Started and Problem Solving Common Concerns	Zettel S	2016	USA	Dx/Rw	N/C	Yes	No	No	No	Yes	
Food and nutritional safety of hospitalized patients under treatment with enteral nutrition therapy	Amaral Felisio B et al	2012	Brazil	NR	Quan	Yes	No	No	No	No	
Physicochemical and nutritional characteristics of handmade enteral diets	Machado de Sousa L et al	2014	Brazil	NR	Mixed	Yes	No	No	Yes	No	
Home Enteral Nutrition: Updates, Trends, and Challenges	Martin, K. and Gardner, G	2017	USA	Dx/Rw	N/C	Yes	Yes	Yes	Yes	Yes	
Dietitians' perceptions and experience of blenderised feeds for paediatric tube-feeding	Armstrong J et al	2017	UK	NR	Mixed	Yes	No	No	Yes	Yes	
Blended foods for tube-fed children: a safe and realistic option? A rapid review of the evidence	Coad, J. et al.	2016	UK	Dx/Rw	N/C	Yes	No	Yes	Yes	No	
ASPEN Safe Practices for Enteral Nutrition Therapy	Boullata, J et al	2017	USA	Edn	N/C	Yes	No	Yes	No	No	
Enteral Formulas in Nutrition Support Practice: Is There a Better Choice for Your Patient?	Escurro A and Hummell A	2016	USA	Dx/Rw	N/C	Yes	No	Yes	Yes	No	
ENFit Enteral Nutrition Connectors: Benefits and Challenges	Guenter P, Lyman B	2016	USA	Dx/Rw	N/C	No	No	Yes	No	No	
Use of Lihquidised Food Through Gastrostomy	Thiyagesh V, Hill H	2016	UK	NR	Qual	Yes	No	No	No	No	
Blended diets - A challenge at the coal face!	Thomas S	2016	UK	NR	Qual	No	No	No	Yes	Yes	

**Key:** NR – new research, Dx/Rw discussion, or review, Edn-educational, N/C –not categorised, Quan -Qualitative, Qual-Qualitative

**Table 3 Summary of Aims and Findings of the Studies**

Paper Ref	Aim	Finding
1	To investigate levels of contamination in hospital prepared tube feeds	Commercial feeds from prefilled or closed systems are safest in terms of microbial contamination
2	To gain perspective of MDT members on the issues surrounding BD	Balanced account of the pros and cons of BD from a range of perspectives
3	To analyze the nutritional quality and viscosity of blenderized enteral tube feedings	Hospital prepared blenderized enteral tube feedings give unpredictable levels of micro and macronutrients and The viscosity of the feed may be unsuitable for infusion through feeding tubes
4	To compare the force required to deliver a range of feeds with new EnFit system	Homemade blended feed required most force and commercial 1kcal/ml fibre formula required the least
5	To learn more about the use of BD amongst home enteral nutrition population	Most patients used BD as part of nutritional regime
6	To analyse BD in comparison to commercially prepared formula	Batches of BD cannot be guaranteed as being consistent. Energy levels were insufficient to meet needs. Increasing calorific content risks increasing viscosity
7	To describe and evaluate all aspects of BD with a real case	Balanced report and useful decision making tree
8	To elicit experiences of paediatric dietitians with BD in clinical practices	98% were positive about use of BD and 28% wanted more information about it. Parental request is the main reason for use
9	Review of management, tube weaning and emotional support of tube fed children	Limited evidence suggests blenderized tube feedings may reduce side effects in children with a fundoplication. Randomized controlled trials are needed to evaluate the effectiveness of blenderized tube feedings in children with and without fundoplication
10	Describe a case when BD resulted in scurvy in a child with multiple diagnoses	Fussiness may be improved by BD but more serious deficiencies can occur so BD nutrition should be agreed by dietitian
11	To share basic sources of nutrients which can be used for homemade feeds and rules of preparation	Advised on equipment nutrient and hygiene issues
12	To examine the impact of the proposed new connector on a number of clinical areas including BD	ENFit design may negatively impact patients who use PEGs for venting, for delivery of medications and BD, compared to the current legacy system.
13	Study to assess the prevalence of the use of BD amongst members of the Oley Foundation	Most patients use some BD, making it essential that clinicians expand their knowledge related to BD to appropriately care for this patient population
14	Invited review to present the different methods of enteral nutrition (EN) access placement, maintenance, formula	Whole EN 'process' should be regularly monitored by MDT
15	To inform clinicians of research regarding use of specialty formulas.	EN products do not have to undergo the 4-phase process for gaining FDA approval, as required for pharmaceutical agents. Standard formulas, however, are rarely studied, except when being compared with specialty formulas.
16	To describe tube weaning programme	Hunger based weaning may be appropriate but a MDT approach including family and child are crucial
17	To gain clinical perspective on feeding with Rett syndrome	Parents wanted more information about blended diets and blenders and issues to be aware of that may arise out of their need for high calorie diets
18	To evaluate effect of BD diet on children with fundoplication	BD is an effective way of feeding these children and can lead to reduction in gagging and retching
19	To summarize history of diets, and points to consider when using a BD	Despite EN policy stating commercial feeds should be used no RCT have evaluated BD vs Commercial formula
20	To summarise advances in tube feeding formulas in USA	Describes the range of commercially available formulas and their benefits
21	To provide advice to dietitians about advantages and disadvantages of BD including patient selection and recipe planning	Current literature on BD is mainly based on expert opinion and more research is required into this area
22	To provide advice to dietitians about BD and their professional duty	Dietitians can support families who wish to sue BD but cannot recommend the use
23	To evaluate nutritional quality of BD and growth parameters	Despite inconsistent levels of macro nutrients and energy BD had no negative effect on patients' weight
24	To examine the effect of HEF on clinical outcomes	Home nutrition support is up to 75% more cost effective than hospital or nursing home
25	To determine the effects of BD on children with intestinal failure	100% transitioned to real food formula and it was well tolerated and improved stooling patterns
26	To discuss optimal nutritional management of neurologically impaired child	Improved nutritional status is linked with improved QoL and health outcomes
27	To assess levels of microbacterial contamination in hospital prepared blends	Microbial quality of majority of blenderised feeds are not within safety guidelines
28	To determine levels of fibre in different types of formula feeds	Fibre levels vary greatly and there is no ideal content, but changing from blenderised to soy polysaccharide fibre may be beneficial
29	To provide a framework to evaluate products and assist clinicians in selecting most appropriate formula	Framework provided to simplify decision making and decrease patient cost
30	To quantify and analyse bacterial contamination of formulas	Use of sterile nonmanipulated formulas in a closed administration set is recommended, along with routine, periodic bacteriologic surveillance of enteral feeding programs.
31	To analyse the nutritional content of a range of commercial formulas	More comparative studies regarding efficacy of various formulas are required
32	To describe how information was gathered and risk assessments developed to enable BD in hospice setting	Hospice was able to replicate care and support in the home thus enabling continued BD in the hospice environment
33	To describe approaches to planning a blended diet	BD can be a viable option for some but need nutritional guidance
34	To evaluate nutritional value and make proposals to improve qualitative and quantitative aspects of BD in a hospital setting	Found significant losses of nutrients during processing and preparation and daily energy intake was insufficient
35	To evaluate the quality of homemade BD analysing stability, viscosity, flow, pH, chemical and nutritional composition.	Diets were inadequate in terms of macronutrients, but adequate for physical chemical aspects. Recommend using mixed formula and BD to meet nutritional requirements and psychosocial value
36	To review current practice in HEN with regard to current and future practice and highlight gaps in research	Due to trend towards BD, clinicians need to be informed about BD
37	To explore paediatric dietitians' perceptions and experiences of BD use.	Dietitians experienced significantly fewer issues with the use of BD in clinical practice compared with their self-reported apprehensions in the survey.
38	Review evidence around BD	May be benefits to BD but concerns still remain
39	Provide recommendations for safe practice around enteral nutrition	Registered dietitians should be involved in development of the BD composition for patients
40	Evaluate different enteral formulas	Careful evaluation of formulas required in conjunction with available scientific and research studies prior to routine use in clinical practice.
41	To examine benefits and challenges for Enfit	Need open dialogue between manufacturers, clinicians and patients for success
42	Single case study to describe impact of BD	Improved tolerance and reduction in reflux and increase weight gain
43	To develop a protocol around administering BD in schools	Package of care and protocol developed

## Appendix 2: Interview Guide

### Introduction

I'd like to understand more about what BD means to you as a *Mum* – how you came to decide to use BDs

1. **Could you start of by telling me a bit about x – their personality, likes and dislikes and their needs?** I'd like to have a picture of the child we are talking about.
2. **Can you tell me about x's feeding right from the start?**
  - 2.1 Did you have a plan about how you wanted to feed?
  - 2.2 Can you tell about the sequence/stages in their feeding development
  - 2.3 How did you feel about your child having a gastrostomy?
3. **Could you tell me about how you found out about BDs and what factors led you to decide to try it?**
  - 3.1 What support do you have or seek - both practical and emotional from community – family and HCPs
  - 3.2 Can you tell me about the information you have – what form it took when it was sought or offered and the impact it had
4. **In the broadest sense of the word what impacts does using BD have?**
  - 4.1 How do you seeing it affecting the lifestyle of your family or the QoL of your family and that of your child?
  - 4.2 And can you tell me about any other health or wellbeing impacts you or others have commented on regarding your child?
  - 4.3 What affect has BD had in terms of increasing or decreasing stresses in your life?
5. **What are your views/beliefs/ feelings about BD and about formula feeds?**
  - 5.1 Relate to the necessities and concerns framework
6. **How do you feel your decision to use BD fits with your overall views of medicines and lifestyle.**
  - 6.1 Might a close friend or relative have predicted that you would have chosen BD?
    - 6.1a. How does it fit in with your
      - Beliefs about feeding
      - Medicines
      - Professionals/experts
      - Self-belief/ resilience

**Thank you for talking to me. Is there anything else that you would like to add or are there any areas you would like to go back to before we close?**

## Appendix 3: Codes and definitions from NVivo for thematic analysis of interviews and blogs

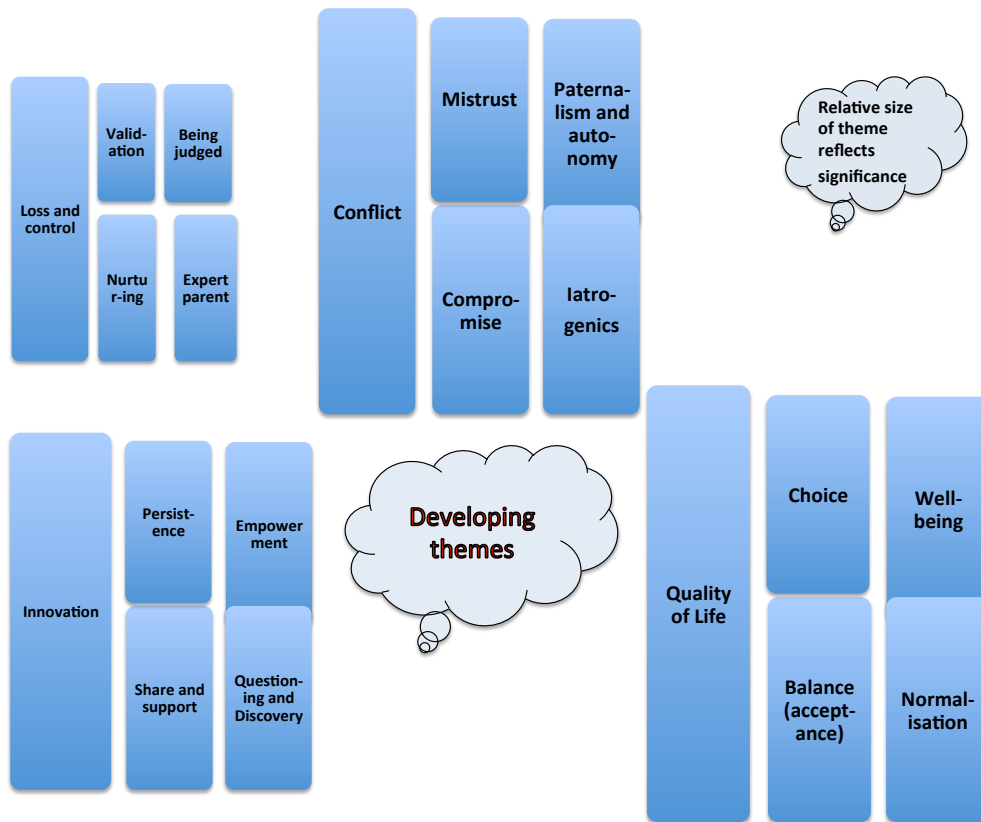
### Interview codes

Code	Subcode	Description
<b>Child's well being</b>		Physical, emotional, psychological attributes about the child
	Physical	Symptoms described by parent attributed to formula
	Psychological	includes emotional and psychological aspects of child's well being
	Developmental	Includes physical and mental development/difficulties
	Diagnosis or condition	General information about the child's medical condition that is general and not necessarily linked to BTF
<b>Choice</b>		Example of a child or parent or being able to or wanting to be able to make or express choice
<b>Compromise</b>		May include compromise with others or in practice
<b>Communication</b>		Includes communicative intent ability and means of communication. Also communication in relation to mealtimes/feeding
<b>Conflict</b>		Situations that describe wither inner conflict, conflicting views or conflicting information/advice ?? may include resistance
	Conflict of interest	The role of the formula manufacturers
	Conflict with Dietitian	Disagreement with dietitian and parent/carer or other
<b>Emotion</b>		Emotional impact on parent/carer
	Fear and uncertainty	more on the part of others involved in the care and feeding of the child - something akin to their self efficacy but with more complexity of insurance, training and liability
	Helplessness	Mixture of uncertainty and disempowerment and despair sometimes tinged with anger
	Secrecy	Not telling others about actions
	Struggle	Parents trying to achieve something for or with their child
<b>Family</b>		Impact on family as a whole or individual family members
<b>Financial</b>		Relates to cost for families or health services or others
<b>Information and discovery</b>		Gathering or imparting information and resources about BD in general. Practical solutions
<b>Medicalisation</b>		Descriptions and issues relating to medical or surgical aspects
	Therapeutic relationship	Interactions with medical professionals
	Tube weaning	Issues relating to tube weaning
<b>Normalisation</b>		Pertaining to a desire to normalise or a description of how something is viewed as being normal. ??Need to consider what families consider to be normal
<b>Nurturing</b>		The need to nurture of care for your child around feeding and nutrition
<b>Nutrition</b>		Specific detail about an aspect of nutrition
	Mealtimes	Relating to the social aspects of feeding eating and drinking
	Mechanics of BD	Includes issues such as blenders, tubing etc.
	Allergies	Allergies or food intolerance
	Oral	Oral trials or impact of BD on oral intake
	Foods	Description of foods used or eaten without nutritional analysis or comment
	Unnatural	Reference to additives and chemicals and sense of being processed/manufactured
<b>Parental belief</b>		Statements defining belief/view or opinion
<b>Questioning</b>		Lack of answers
<b>Schools etc</b>		Other non home/family locations and people impacted upon
<b>Self Efficacy</b>		Evidence of parent carer finding things /figuring things out or doing things for themselves
<b>Support</b>		Received from others - directly or inadvertently or without really being aware of it
<b>Trial and error</b>		When nobody is sure what to do or what will work. Lack of clear plan
	Figuring it our for myself	Akin to trial and error but with more of a feel of process and gradual learning

## Blog codes

Code	Description
Appointments	Outpatient or inpatient - at hospital clinic etc.
Bloggng -soapbox	Sharing experiences and offering / encouraging communication with or from others
Chores	Maybe related to BD or having SN child
Conflict mismatch	When parents and practitioners don't see eye to eye -likely to have an element of aggression /tension
Equipment - cost	Related to BD and tube feeding may have a financial aspect too
Family Life	Normal everyday activities incl holidays seeing grandparents etc. Life as part of a family
In charge or control	Parents taking the initiative or showing others
Irony humour sarcasm	All the above and consider in analysis the purpose or impact of it
Medicalisation	Descriptions and issues relating to medical or surgical aspects that may or may not be related to BD
Nurturing	The need/drive of a parent to care for and protect their child
Oral	Anything about oral intake and SLT
Parental feelings and beliefs	Expressions of emotion
Real food	Description of choosing buying prep or cooking or feeding
Religion	Any reference to religion or spiritual faith
Sleep	Any reference to a sleep issue- parent or child
Support	Getting support or providing support including information
The establishment	Includes conflict and just describing how things are in the real world for families using BD
Vomit	Any reference to vomit
Well being	About the child themself as a person - may cover illness too and give an impression of the child's personality

## Appendix 4: Thematic map

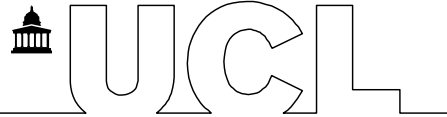




## Appendix 5: Information Sheet

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RESEARCH DEPARTMENT OF LANGUAGE AND COGNITION  
UNIVERSITY COLLEGE LONDON  
Chandler House, 2 Wakefield Street, London WC1N 1PF



Date: April 2017

Information Sheet For: Parents/carers

### **Factors affecting the decision of parents to select blended tube feeding for their gastrostomy fed child?**

This study has been approved by the Research Ethics Committee of the UCL Division of Psychology and Language Sciences (Language and Cognition Research Department)  
Project ID LCRD.2016.05

#### **Principle investigator:**

Name Steven Bloch

Email address [s.bloch@ucl.ac.uk](mailto:s.bloch@ucl.ac.uk)

Phone number 07531 265456

#### **Research Student:**

Anne Breaks

[anne.breaks.14@ucl.ac.uk](mailto:anne.breaks.14@ucl.ac.uk)

0780 8723798

#### **Information about the research**

We would like to invite you to take part in a research project. Before you decide you need to understand:

- Why we are doing the research
- What you have to do if you decide to take part.

Please read this information carefully and talk to your family and friends about the research.

Part 1 of this information sheet tells you the aims of the research and what will happen to you if you take part. Part 2 gives you more details about the research project.

Please feel free to ask questions by contacting Anne Breaks (contact details below) if:

- You do not understand something
- You need more information
- You have any concerns

***Take time to think, talk about it with your family and friends before you decide if you do want to take part in this research***

## **PART 1**

### **Why the research is being carried out?**

- To understand more about why increasing numbers of families are opting to use blended tube feeds.
- To understand how best to identify and support families who chose this form of feeding
- The results will be used to help design a larger study to discover how widespread views are, and to help practitioners provide better support for families.

### **Why me?**

We want to speak to parent/carers of children and young people up to the age of 25 years to ask them about their decision to use blended diets and their overall experience.

### **Do I have to say 'yes'?**

No. It is entirely your choice. If you don't want to take part then you do not need to do anything more and you will not be contacted about this study again.

If you do decide to take part, you will be asked to sign a consent form so that we have a record of your decision. You can stop taking part at any time without telling us why.

### **What will I have to do?**

If you give consent you will be contacted to arrange a meeting with the researcher. This will usually be either in your own home or in a location of your choice or via Skype. The interview with the researcher will be audio- recorded to enable your responses to be studied. The meeting is likely to take between 45 minutes and 2 hours.

### **What are the possible benefits of taking part?**

Your involvement will help our understanding why families use blended tube feeding and in turn to improve the support provided.

**Are there any disadvantages to taking part?**

As part of the research process the recording of your interview may be heard by another registered speech and language therapist. This is to ensure that statements or comments you have made are analysed consistently.

**What happens when the research project ends?**

When the project ends we will write a report. A summary of this report will be made available to you. Your interview recording will be deleted at the end of the study unless you give written permission for us to keep it.

**What if there is a problem?**

Should any complaints about the research process arise, we promise to deal with them quickly and effectively. The process of making a complaint is explained in Part 2 of this information sheet.

**Will my taking part in this study be kept confidential?**

Yes. All information about you will be treated as confidential. I will tell you how in Part 2 of this information sheet.

***Still interested in taking part? Please continue and read Part 2***

**PART 2**

**What will happen if I want to stop taking part?**

If you tell us you don't want to take part after giving consent then we will not include you in the study. If you do not want your interview used in the research after it has been carried out then we will delete it straight away.

**How to make a complaint**

Contact the Project Leader, Steven Bloch whose contact details are at the end of this information sheet. Steven will address the issue. All communication will be treated in strict confidence.

**Will my taking part in this study be kept confidential?**

Yes. All information about you will be treated as confidential. We will follow the rules of the Data Protection Act 1998. Your interview recording will be stored on a password-protected computer, and you can decide how long we can keep it. We will use a false name or a number to protect your identity; no one will know who you are from the transcripts. We may also use some of the transcripts in writing papers and presentations for academics

and health professionals. Again, no one will be able to identify you from this work.

**What will happen to the results of the research project?**

All of the interviews will be transcribed. This means that everything that you say will be written down. We will then look at the interview transcripts in detail and identify common themes that occur. In the second phase of the study, these themes will form the basis of a questionnaire that will be distributed to parent/carers of children and young people who are fed via a gastrostomy. The results of the questionnaire will be used to develop better support packages for families.

We will ensure that the results are publicised through the blended tube feeding websites, forums and support groups, as well as in articles for publication in academic journals.

**Who is organising and funding the project?**

The Language and Cognition Research Department in the Division of Psychology and Language Science at UCL is organising the project.

**Who has checked that this project is okay?**

All research is looked at by an independent group of people, called a Research Ethics Committee. They protect your safety, rights, wellbeing and dignity. This study has been reviewed and approved by the Research Ethics Committee of the UCL Division of Psychology and Language Sciences (Language and Cognition Research Department)  
Project ID: LCRD.2016.05

**Where to get more information**

For specific information about the project, phone or email Anne Breaks (contact details below).

If you are unhappy with the project phone or write to the Project Leader, Steven Bloch (contact details below).

For general information about research, download the document 'Knowing how: A guide to getting involved in research' from <http://www.invo.org.uk/wp-content/uploads/2012/01/knowinghow2001.pdf>

**Contact details**

Researcher: Anne Breaks [anne.breaks.14@ucl.ac.uk](mailto:anne.breaks.14@ucl.ac.uk)  
Project Leader: Steven Bloch [s.bloch@ucl.ac.uk](mailto:s.bloch@ucl.ac.uk)

***Thank you for reading this information.  
If you would like to take part please sign the attached consent form and post it back in the envelope provided or email it to [anne.breaks.14@ucl.ac.uk](mailto:anne.breaks.14@ucl.ac.uk)***

## Appendix 6: Patient consent form

Research Department of Language and Cognition  
Division of Psychology and Language Sciences  
Faculty of Brain Sciences  
Chandler House  
2 Wakefield Street London WC1N1PF



### INFORMED CONSENT FORM FOR PARTICIPANT IN RESEARCH STUDIES

**Title of Project: Factors that affect the decision of parents to select blended tube feeding for their gastrostomy fed child**

This study has been approved by the Research Ethics Committee of the UCL Division of Psychology and Language Sciences (Language and Cognition Research Department)  
Project ID Number: LCRD.2016.5

Name of Researcher: Anne Breaks

Thank you for your interest in taking part in this research. Before you agree to take part the person organising the research must explain the project to you. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to take part. You will be given a copy of this Consent Form to keep and refer to at any time.

1. I confirm that I have read and understand the participant information sheet and/or the project as been explained to me.
2. I have had the opportunity to ask questions and discuss the study.
3. I am happy with answers to my questions
4. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason.
5. I understand that my information will be anonymised and treated as strictly confidential and handled in accordance with in accordance with the Data Protection Act 1998
6. I agree to take part in the above named project

If you agree with the above statements please print and sign your name below:

.....  
Name (printed):

.....  
Signature:

.....  
Date:

Please return this form to:  
Anne Breaks, University College London, Chandler House, 2 Wakefield Street, London WC1N 1PF or  
email to: [Anne.breaks.14@ucl.ac.uk](mailto:Anne.breaks.14@ucl.ac.uk)

## Appendix 7: Tube feeding questionnaire

# TUBE FEEDING SURVEY

Thank you for completing this survey which is part of a research project into the use of blended diets with children and young people (up to the age of 26 years) who have a gastrostomy.

Your answers will be anonymous, but if you would like to be kept informed about the research please give your contact details at the end of the form. There are no right or wrong answers; it is your opinions that we are seeking.

UCL Language and Cognition research department granted ethical approval for the research (ID LCRD.2016.05) and it is registered with the UCL data protection officer. If you have any queries, or would prefer a paper version of the survey please contact [anne.breaks.14@ucl.ac.uk](mailto:anne.breaks.14@ucl.ac.uk).

Once completed, paper responses can either be scanned and returned to [anne.breaks.14@ucl.ac.uk](mailto:anne.breaks.14@ucl.ac.uk) or sent to Anne Breaks c/o Research Department of Language and Cognition Chandler House 2 Wakefield Street London WC1N 1PF

### SECTION 1: Your views about feeding

The following statements have been made by parents whose child or young person has a gastrostomy. Please indicate the extent to which you agree or disagree with the statements.

1) I feel involved in my child's feeding.

<input type="radio"/>	Strongly disagree
<input type="radio"/>	Disagree
<input type="radio"/>	Neutral
<input type="radio"/>	Agree
<input type="radio"/>	Strongly agree

2) A more flexible approach to feeding my child would suit me better.

<input type="radio"/>	Strongly disagree
<input type="radio"/>	Disagree
<input type="radio"/>	Neutral
<input type="radio"/>	Agree
<input type="radio"/>	Strongly agree

3) Formula feeds are the best way to be sure my child has the calories and nutrients he/she needs.

<input type="radio"/>	Strongly disagree
<input type="radio"/>	Disagree
<input type="radio"/>	Neutral
<input type="radio"/>	Agree
<input type="radio"/>	Strongly agree

4) The food my child is given improves his/her quality of life.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

5) Feeding my child is stressful.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

6) I feel that my child receives the help and support with feeding that I want for him/her.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree



7) My child is usually well.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

8) I know what is best for my child with regard to feeding.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

## **SECTION 2: Your views about formula feeds**

We would like to ask you about your views about formula feeds prescribed for your child.

Please indicate the extent to which you agree or disagree with each statement even if you do not use formula feeds

1) My child's health at present depends on their formula feed

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

2) Having to use formula feeds worries me

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

3) My child's life would be impossible without formula feed

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

4) Without formula feed my child would be very ill

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

5) I sometimes worry about the long term effects of formula feed

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

6) My child's formula feed is mystery to me

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

7) My child's health in the future will depend on formula feed

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

8) My child's formula feed disrupts their life

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

9) My child's health at present depends on their formula feed

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

10) My child's formula feed protects them from becoming worse

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

### **SECTION 3: Your views about medicines in general**

Again there are no right or wrong answers. We are interested in your personal views.

Please indicate the extent to which you agree or disagree with each statement.

1) Doctors use too many medicines

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

2) People who take medicines should stop their treatment for a while every now and again

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

3) Most medicines are addictive.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

4) Natural remedies are safer than medicines

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

5) Medicines do more harm than good

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

6) All medicines are poisons

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

7) Doctors place too much trust on medicines

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree

8) If doctors had more time with patients they would prescribe fewer medicines.

- Strongly disagree
- Disagree
- Neutral
- Agree
- Strongly agree



#### SECTION 4: About You

This section is not specifically about feeding. Please indicate the extent to which you agree with each statement.

1) I can always manage to solve difficult problems if I try hard enough

- Not at all true
- Hardly true
- Moderately true
- Exactly true

2) If someone opposes me, I can find the means and ways to get what I want.

- Not at all true
- Hardly true
- Moderately true
- Exactly true

3) It is easy for me to stick to my aims and accomplish my goals.

- Not at all true
- Hardly true
- Moderately true
- Exactly true

4) I am confident that I could deal efficiently with unexpected events.

- Not at all true
- Hardly true
- Moderately true
- Exactly true

5) Thanks to my resourcefulness, I know how to handle unforeseen situations.

- Not at all true
- Hardly true
- Moderately true
- Exactly true

6) I can solve most problems if I invest the necessary effort.

- Not at all true
- Hardly true
- Moderately true
- Exactly true

7) I can remain calm when facing difficulties because I can rely on my coping abilities.

- Not at all true
- Hardly true
- Moderately true
- Exactly true

8) When I am confronted with a problem, I can usually find several solutions.

- Not at all true
- Hardly true
- Moderately true
- Exactly true

9) If I am in trouble, I can usually think of a solution.

- Not at all true
- Hardly true
- Moderately true
- Exactly true

10) I can usually handle whatever comes my way.

- Not at all true
- Hardly true
- Moderately true
- Exactly true

### SECTION 5: The Bristol Stool Chart

Parents sometimes report issues with their child's bowel movements. The Bristol stool Chart provides descriptions of human stools (poo). We know that there will be some variations. Overall please indicate which type best describes your child's stools. Please use the space below to describe any other issues or concerns you have about your child's stools.

- Type 1
- Type 2
- Type 3
- Type 4
- Type 5
- Type 6
- Type 7

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces, <b>Entirely liquid</b>

**SECTION 6: Health, Quality of Life and gastrostomy**

Over the past month, how would you rate your child's health?

<input type="radio"/>	Excellent
<input type="radio"/>	Very good
<input type="radio"/>	Good
<input type="radio"/>	Fair
<input type="radio"/>	Poor

How would you rate your child's 'quality of life', their general well being in terms of health comfort and happiness?

<input type="radio"/>	Excellent
<input type="radio"/>	Very good
<input type="radio"/>	Good
<input type="radio"/>	Fair
<input type="radio"/>	Poor

Date of birth of your child with gastrostomy:

Diagnosis: (please give diagnosis or describe your child's problems)

Date when your child had their gastrostomy (*if you can't remember the exact date, please just give month and year*):

What was the reason for your child having a gastrostomy? \*

- Failure to thrive
- Unsafe swallow
- Gastro oesophageal reflux
- Inadequate oral intake
- Other (please specify below)

Does your child ever have any food orally?

- Yes
- No

Do you use the gastrostomy to give your child their medicines?

- Yes
- No
- Sometimes
- Does not require any medicines

Does your child ever eat any food orally?

- Yes
- No

Do you or have you in the past fed your child with anything other than formula feeds via their gastrostomy?

- Yes
- No (*if no please skip to section 8*)

**SECTION 7: Blended diets**

Approximately how long have you been giving your child a blended diet (ie food other than formula feeds via their gastrostomy)?

- Less than 6 months
- Between 6 months and 1 year
- More than 1 year but less than 5 years
- More than 5 years

What were your reasons for using a blended diet?  
(please tick all that apply)

- Did not tolerate formula
- Parental preference
- Vomiting
- Reflux
- Bowel movements
- Other – please specify

Please tell us more about any other reasons you decided to use a blended diet.

What types of food do you give your child?

(please tick all that apply)

- Blended up family meals
- Food that I have prepared especially for my child
- Baby foods
- Other foods (please describe)

Please tell us more about the foods you give your child.

How often do you give your child formula feeds?

- Never
- Once a day
- More than once a day

Please feel free to use the space below to make any comments on your experience of using blended diets.



**SECTION 8: Further information**

Please complete the following details

Please choose one option that best describes your ethnic group or background.

- WHITE English/Welsh/Scottish/Northern Irish/ British
- WHITE Irish
- WHITE Gypsy or Irish Traveller
- Any other white background
- MIXED/MULTIPLE ETHNIC GROUPS White and black Caribbean
- MIXED/MULTIPLE ETHNIC GROUPS White and black African
- MIXED/MULTIPLE ETHNIC GROUPS White and black Asian
- Any other mixed/multiple ethnic group
- ASIAN/ASIAN BRITISH Indian
- ASIAN/ASIAN BRITISH Pakistani
- ASIAN/ASIAN BRITISH Bangladeshi
- Any other Asian background
- BLACK AFRICAN/CARIBBEAN/BLACK BRITISH African
- BLACK AFRICAN/CARIBBEAN/BLACK BRITISH Caribbean
- OTHER ETHNIC GROUP Arab
- Any other ethnic group

Gender

- Female
- Male

Please select your age group

- 16-25 years
- 26-35 years
- 36-45 years
- 46 + years

What is your household income?

- Less than £25k
- £26-35k
- £36-50k
- £51-75k
- £76k +

What is your level of education?

- Up to GCSE/O level equivalent
- A level or equivalent
- Degree
- Post graduate
- Other (please specify)








**Thank you very much for taking the time to complete this questionnaire.**

Please write your contact details below if you would like to be kept informed about the research project.

### Appendix 8: List of contacts with whom questionnaire was shared

Organisation/Individual	Date Sent	Comment
Challengers	11.2.18	Laura via LinkedIn
3 x blogs on comments	11.2.18	
Chase Shooting Star	11.2.18	Toni +ive asked for more details
Lucy VW	11.2.18	
Choice forum	13.2.18	Posted link on forum
Global dev. delay UK	13.2.18	Posted link on forum
Cerebral Palsy UK	13.2.18	Posted link on forum
Reverse Rett	13.2.18	
Rett Uk	13.2.18	via family liaison officer
Brain Injury Trust Tadworth	13.2.18	
All Surrey Special School Heads	13.3.18	
Tube feeding awareness group	15.2.18	online
own LinkedIn page	18.2.18	
St Martin's Hospice York	18.2.18	Via Tim H
RCSLT research champions network	19.2.18	
Family voice Surrey	19.2.18	Via Benedicte
Down Syndrome Society	22.2.18	
Special Needs Jungle	22.2.18	
Headteachers at 3x Hounslow special schools	5.3.18	
9 x parent support groups	5.3.18	Via Twitter
3 x independent special schools/colleges	5.3.18	


## Appendix 9: Bristol stool chart

<b>Bristol Stool Chart</b>		
Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. <b>Entirely Liquid</b>


## Appendix 10: Feeding statements raw score distribution

N, (%)	Feeding 1		Feeding 2		Feeding 3		Feeding 4		Feeding 5		Feeding 6		Feeding 7		Feeding 8	
	BD user	Non-user	BD user	Non-user	BD user	Non-user	BD user	Non-user	BD user	Non-user	BD user	Non-user	BD user	Non-user	BD user	Non-user
Strongly disagree	8 (5.7)	1(1.5)	6 (4.3)	1(1.5)	78 (55.7)	3(4.4)	5 (3.6)	0 (0)	30 (21.4)	9 (13.2)	25 (17.9)	0 (0)	5(3.6)	3 (4.4)	1(0.7)	0 (0)
Disagree	4 (2.9)	4(5.9)	6 (4.3)	12 (17.7)	32 (22.9)	5(7.4)	5 (3.6)	3(4.4)	39 (27.9)	18 (26.5)	28 (20)	8 (11.8)	24(17.1)	12 (17.7)	0 (0)	2(2.9)
Neutral	3 (2.1)	3(4.4)	33 (23.6)	24(35.3)	19 (13.6)	15 (22.1)	9(6.4)	12 (17.7)	16 (11.43)	17 (25)	21 (15)	19 (27.9)	24(17.1)	13 (19.1)	8(5.7)	17 (25)
Agree	22 (15.7)	24 (35.3)	37 (26.4)	22 (32.4)	7 (5)	23 (33.8)	25 (17.9)	24(35.3)	46 (32.9)	15 (22.1)	42 (30)	33 (48.5)	50(35.7)	35(51.5)	49(35)	36(52.9)
Strongly agree	103 (73.6)	36 (52.9)	58 (41.4)	9(13.2)	4 (2.9)	22(32.4)	96 (68.6)	29 (42.7)	9 (6.4)	9 (13.2)	24(17.1)	8 (11.8)	37 (26.4)	5(7.4)	82 (58.6)	13 (19.1)


## Appendix 11: Risk Assessment



**PENG**  
PEDIATRIC ENTERAL NUTRITION GROUP



**NNG**  
NATIONAL NUTRITION GROUP



**PINNT**  
PEDIATRIC INTENSIVE NUTRITION NETWORK

### Risk Assessment Template for Enteral Tube Administration of Liquidised Diet

Potential Risk	What could go wrong?	Causes / Hazard	Consequences	Current controls	Risk ranking	Recommendations	Risk Ranking
					C L R		C L R
1	Nutritional deficiency and decline in nutritional status.	Non adherence to enteral feeding care plan. Administering Liquidised diet. Potential increased feed volume.	Risk of malnutrition and worsening of nutritional status. GI disturbance including vomiting, feed volume intolerance.	Recognised best practice in the UK – following full dietetic assessment recommend the administration of only products defined as Foods for Special Medical Purposes are used as enteral feeds.	C L R	Provide dietary analysis of a menu plan provided by the patient/carer. Consider the use of web based apps (question validity) which may be used to independently analyse nutritional adequacy. Discuss the patient's fluid requirements and consider the use of nutrient dense fluids to be used to dilute the feed to the required viscosity. Consider total fluid volume of bolus and required flushes. Assess the requirement for a broad spectrum vitamin and mineral supplement. Discuss the option to combine modes of feeding rather than liquidised food being used as a sole source of nutrition. Recommend detailed food and symptom diary is recorded by the patient/carer. Recommend increased frequency of monitoring of anthropometry and nutritional status.	C L R

Potential Risk	What could go wrong?	Causes / Hazard	Consequences	Current controls	Risk ranking			Recommendations			Risk Ranking		
					C	L	R	C	L	R	C	L	R
2	Patency of the enteral feeding device.	Use of enteral feeding device outside of (and not in line with) the manufacturer's guidance for use. Blockage of device. Reduced life span of tube. Temperature control guidance of liquidised feed. Below 8°C and above 63°C.	Enteral feeding device blockage. May require A&E visit, hospital admission to unblock or replace the device. Manufacturers' product licence voided, thus eliminating the purchasers rights to refund if faulty.	Refer to EPSG statement. Recognised UK practice to use medical device in line with manufacturer's guidance.				Consider carer/ patient whether they have been trained to replace device to prevent hospital admission. Consider the lumen size at each connection junction. Review and monitor the frequency of device change. Consider cost impact of additional gastrostomy tubes which may be required. Escalate and document in dietetic and medical records that your patient has chosen to use a medical device which is outside the scope of the manufacturer's information for use guidance. Temperature control guidance is unrealistic with this practice.					



Potential Risk	What could go wrong?	Causes / Hazard	Consequences	Current controls	Risk ranking			Recommendations			Risk Ranking			
					C	L	R	C	L	R	C	L	R	
3	Food borne infection.	Bacterial load of the liquidised feed. Potential contamination from the utensils used in preparation and the re-usable enteral feeding ancillary equipment.	Wide ranging depending on the clinical condition of the patient, consider degree of immunocompromise, gut integrity, history of gut infections altering flora, and stoma site integrity.	Provision of a ready to feed UHT/sterile formulae. Equipment designed for re-use within manufacturer's guidance.				Adherence to national food safety guidance. Consider a risk assessment of the food preparation area. Consider using food safety guidance recommended for weaning. Adherence to temperature control guidance of liquidised feed administered to meet infection control guidance. Discuss food safety guidance if the administration of defrosted food is considered. Consider increased supply of extensions sets and single use enteral feeding syringes to reduce the risk of contamination.						



Potential Risk	What could go wrong?	Causes / Hazard	Consequences	Current controls	Risk ranking			Recommendations			Risk Ranking			
					C	L	R	C	L	R	C	L	R	
4	Legal action of the health professional. HPC ( Health and Care Professions Council)/ RCN (Royal College of Nurses),	Litigation of the health professional.	Formal complaint to HCP supporting the patient.	Record card and care plan documentation				Consider the patients care package and impact on this mode of feeding may have on their professional practice. Escalate the risk assessment outcome to the care staff that may be required to administer this mode of feeding during day-care services or respite care. Completed detailed risk assessment to demonstrate potential risks were highlighted at the onset and the patient or carer with capacity made a fully informed choice to continue with the practice. Consider an MDT or GP led best interests meeting to ensure responsibility is defined. Documentation to demonstrate that the outcome of the risk assessment followed trust guidance and was escalated as per the policy. Ensure an 'agreement of care' document is signed and in place. Improve research evidence.						

Potential Risk	What could go wrong?	Causes / Hazard	Consequences	Current controls	Risk ranking			Recommendations			Risk Ranking									
					C	L	R	C	L	R	C	L	R							
5	Cost Implication	Unplanned financial impact.	Increased cost of dietetic resource due to the risk assessment process, full nutritional analysis and recommended increased anthropometry monitoring. Increased cost to patient/ family to follow this regimen. Potential increased costs to the local health-care economy due to the management of any nutritional, infectious, enteral feeding tube complications Service impact to GP/ Nurse / A & E equipment budget, caused by increased provision of enteral feeding devices and equipment.																	



Potential Risk	What could go wrong?	Causes / Hazard	Consequences	Current controls	Risk ranking C L R	Recommendations	Risk Ranking C L R
6	Infectious complications – Potentially Life Threatening.	Food borne/ enteral feeding tube borne or stoma site infection.	Localised gut/ stoma site infection. Peritonitis which may require surgical intervention. Depending on severity may require ITU admission	Monitoring of food hygiene practices. Monitoring of enteral feeding tube integrity and stoma site	C L R	Highlight the importance of good hygiene practice. Ensure patient/ carer has been trained and demonstrated competency to clean and manage enteral feeding tube and stoma site in line with local policy. Refer to NNING Good Practice Consensus Guideline on Exit Site Management for gastrostomy Tubes in Adults and Children. Ensure adequate flushing to maintain patency of the enteral feeding tube as per local policy. Educate patient on how to identify signs and symptoms of infection and agreed course of action in line with local policy and NNING guidance.	C L R

## **Appendix 12: Extract of B19 challenging a dietitian**

One dietitian in particular, who worked with a gastroenterologist that we were considering switching to, gave us her reasons for not doing it, which included: 1) a risk of infection as homemade "formula" is not sterile; 2) a possible lack of micronutrients that commercial formulas provide; 3) the risk that the tube could become clogged from larger food particles; and 4) the fact that a BD is a lot of work for a caregiver. She instead told us flat out that our daughter should be on a toddler formula such as Pediasure or Peptamen. The first two ingredients of Pediasure are water and sugar. I questioned this. The dietitian hesitated and told me that it is nutritionally complete and that is what they recommend. She didn't sound like she even believed herself.

## Appendix 13: Blog Post: listing ingredients of Formula Feed

It's no secret that I am a fan of healthy, homemade foods. We don't particularly care for processed foods. We also try to avoid ingredients that do not come with health attributes. When you have a child that is tube fed or needs a supplement to help encourage adequate growth, the medical world is quick to recommend Pediasure or a similar "formula". Let's look at the ingredients of Pediasure:

(from the Pediasure website)

Water, Corn Maltodextrin, Sugar, Blend of Vegetable Oils (Canola, Corn), Milk Protein Concentrate, Soy Protein Isolate, Nonfat Milk. Less than 0.5% of: Natural & Artificial Flavor, Cellulose Gel, Potassium Chloride, Magnesium Phosphate, Calcium Phosphate, Potassium Citrate, Tuna Oil, Calcium Carbonate, Potassium Phosphate, Choline Chloride, Ascorbic Acid, Monoglycerides, Soy Lecithin, Cellulose Gum, Salt, Carrageenan, Potassium Hydroxide, Inositol, Taurine, Stevia Leaf Extract, Ferrous Sulfate, Monk Fruit Extract, dl-Alpha-Tocopheryl Acetate, L-Carnitine, Zinc Sulfate, Calcium Pantothenate, Niacinamide, Manganese Sulfate, Thiamine Hydrochloride, Pyridoxine Hydrochloride, Riboflavin, Lutein, Copper Sulfate, Vitamin A Palmitate, Folic Acid, Chromium Chloride, Biotin, Potassium Iodide, Sodium Selenate, Sodium Molybdate, Phylloquinone, Vitamin D3, and Vitamin B12.

Contains milk and soy ingredients.

CONTAINS MILK INGREDIENTS, CONTAINS SOY INGREDIENTS, GLUTEN-FREE, HALAL, KOSHER DAIRY, SUITABLE FOR LACTOSE INTOLERANCE, NOT FOR GALACTOSEMIA

Water: no issue with that.

Corn Maltodextrin: (from <http://www.grainprocessing.com>) MALTRIN® is the registered trademark for maltodextrins and corn syrup solids produced by Grain Processing Corporation (GPC). The production process of MALTRIN® maltodextrins and corn syrup solids begins with corn starch slurry from the wet milling operation. The starch in water slurry is hydrolyzed with food grade acids and/or enzymes. The hydrolysis is controlled to achieve the desired end point. The resulting syrup is then

refined by filtering and carbon treatment prior to spray drying. The spray-dried powder is packaged or agglomerated and packaged.

Sugar: I'm guessing we all know what that is.

Blend of vegetable oils (canola, corn): vegetable oils are not a healthy product. Both canola and corn are likely GMO. Wellness Mama does a good job of explaining why vegetable oils are not healthy.

Milk Protein Concentrate (MPC): (according to Wiki) To make milk protein concentrate, whole milk is first separated into cream and skim milk. The skim milk is then fractionated using ultrafiltration to make a skim concentrate that is lactose-reduced.[2] This process separates milk components according to their molecular size. Milk then passes through a membrane that allows some of the lactose, minerals, and water to cross through. The casein and whey proteins, however, will not pass through the membrane due to their larger molecular size. The proteins, lactose, and minerals that do not go through the membrane are then spray dried.[3] Spray drying and evaporation further concentrate the remaining materials to form a powder.[2] Depending on the purpose of the final product, different heat treatments can be used to process ultrafiltered or blended varieties of MPC. An MPC product processed with low heat will maintain higher nutritional value.[3]

Dairy is protected from imported products by tariffs, MPC does not have those protections and as such is often IMPORTED. MPC's are largely unregulated. These are big concerns in addition to the health concerns around the processing of the milk into MPC.

Soy Protein Isolate (SPI): Even for those that think soy has a place in the diet, most are in agreement that SPI is bad news and should be avoided. The soybeans are chemically processed to create the isolate and therefore stripped of all the other nutritional benefits of the original bean. Aluminum and hexane are used in the chemical extraction process and is likely to leave behind at least some of this "toxic bath". Over 90% of the soybeans in the US is GMO- so the SPI is likely GMO.

Nonfat milk: What is the benefit of removing the healthy fat from milk and replacing it with vegetable oils? This is a mentality that I will never understand. I'll let The Healthy Home Economist give you the fat on skim milk.

I'm not going to break down each of the fillers and vitamins listed– let's just say– chemically produced vitamins are not ideal for your body. The tuna oil has hexane concerns and artificial flavors- well, the name says it all.

Now, we have an idea as to why Pediasure is less than ideal as a source of nutrition for your child. What do you use instead?

For a tube dependent child (or adult): a home blended diet is an excellent choice! The gtube is just another route to the stomach. Nourish and Liquid Hope by Functional Formularies are the best “formula” options out there- they are real, organic, whole food in liquid form. Real Food Blends is a pre-blended and packaged liquid food (but it's not organic).

For a child that is tube dependent or just needs a little extra insurance, you can make your own healthy nutritional insurance drinks (aka healthy, homemade Pediasure).

The purpose of the nutrition drink is to increase nutrient density over milk (or milk substitutes). Elizabeth is volume sensitive and we are working on oral eating skills so that we can tube wean– this means we need to pack the most nutrition into a smaller package to make it easier for her to meet her daily needs.

#### LIZZIE'S HEALTHY HOMEMADE NUTRITION DRINK

8 oz raw goat milk

1Tbs coconut cream (with no fillers)

1/2 small banana (about 3" of banana)

1/2 Tbs ground chia seeds

1/2 Tbs nut or seed butter of choice

\*\*\*optional flavoring add ins for oral drinkers:\*\*\*

Anything goes here really!

Berries

1-2 tsp cocoa powder (use peanut as your nut butter for a peanut butter cup treat!)

1/2 tsp vanilla with or without cinnamon

SweetLeaf stevia drops of choice



## **Appendix 14: Life on and off BD**

Changing from formula to blended food may not sound all that momentous, but once you know how much it changed our lives for the better, you might understand why it is so significant to me.

**Life On Formula:** We were spending at least 6-8 hours a day pretty much force feeding my daughter. She had severe oral aversion, and was projectile vomiting 3-6 times everyday. She had very low volume tolerance, delayed gastric emptying, loose stools, reflux, and chronic gastritis (inflammation of the lining of the stomach). Her gastritis was uncontrolled even though she was on the maximum dosage of several medications. The inflammation was so severe, it caused 4 mild GI bleeds in the summer of 2009. My daughter existed solely on a diet of a few isolated highly allergenic proteins, corn syrup solids, safflower oil, and what amounts to a multivitamin, also known as canned commercial formula. My life had dissolved into a never ending and vicious cycle of pumping all the breast milk my body would produce, adding formula, force feeding my daughter, cleaning up vomit, then starting the cycle all over again. We weren't sleeping much because in order to get enough calories in her, she had to be fed late into the night. My daughter's weight was on track, but we were killing ourselves to do it. We weren't supported by her doctors. I repeatedly said I thought the formula was causing her vomiting. They disagreed. The only solution they suggested was to do a Nissen surgery and place a feeding tube. When we refused to do the surgery, they tried to coerce us into it, by saying they wouldn't write anymore prescriptions for her if I continued to refuse. (I fired them from the case instead.) After two and a half years of struggling to feed our daughter, we were exhausted and miserable. Not to mention, it was horrible watching our daughter suffer like that day in and day out.

**Life Off Formula:** My daughter no longer has low volume tolerance, loose stools, reflux, vomiting, gastritis, or GI bleeds. Now that she is not being fed formula, which was literally making her sick, her oral aversion is gone. Instead of pushing away her bottle, she asks for her bottle and is eager to eat. She can easily and

independently feed herself. She is able to happily and comfortably meet her calorie and nutritional needs. An elimination diet proved she was intolerant to, among other things, dairy, corn, and sulfates, all of which are found in almost all commercial formulas. She takes a full blended diet in a bottle with a modified nipple. I cut the nipple hole bigger to accommodate the thickness of the blends. Instead of artificial garbage, she gets a wonderfully healthy diet full of fruits, vegetables, nuts, lean meats, and good fats. She eats better than any other child I know. Blended diet has made her healthier and much happier. She may always need a blended diet due to her brain bleed, and other medical issues, but she doesn't have to be trapped on formula ever again. Blended diet freed us from our feeding disorder hell.

**Appendix 15: Blogs containing reference contain visuals or reference to religion/faith**

Category	Number of blogs
Photos within Blog	26
No photos within Blog	4
Faith or religion within Blog	14
No faith or religion within Blog	16