

## DOCTOR OF PHILOSOPHY

'It's Just Food, Blended': Exploring Parents' Experiences of Choosing Blended Diet for Their Tube-fed Child

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***'It's Just Food, Blended':***  
**Exploring Parents' Experiences**  
**of Choosing Blended Diet for**  
**Their Tube-fed Child**

By

Sarah Durnan

April 2018



***A thesis submitted in partial fulfilment of the University's requirements  
for the Degree of Doctor of Philosophy***



## **Certificate of Ethical Approval**

Applicant:

Sarah Duman

Project Title:

Exploring the views and personal experiences of individuals in the UK who have chosen to feed their child with long term enteral feeding needs a home blended diet.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

08 August 2016

Project Reference Number:

P41654

## **Abstract**

*Aim:* This doctoral research aimed to gain an in-depth understanding of parents' experiences using a blended diet for their tube-fed child.

*Background:* Parents of tube-fed children in the UK are increasingly choosing to blend their own food at home rather than use readily available commercially prepared enteral formula. This practice is commonly referred to as 'blended diet'. There are currently no clinical guidelines on blended diet and the topic has been largely under-researched to date. Little is known about why parents choose to use blended diet and their experiences of the benefits or potential consequences. There was an urgent need for understanding to inform clinical practice.

*Methods:* An Interpretative Phenomenological Analysis (IPA) approach was used. Fifteen in-depth qualitative interviews took place with parents who were found through the peer support Facebook group, Blended Diet UK.

*Findings:* Five superordinate themes emerged through analysis of verbatim interview transcripts: 'Nothing to Lose': feeling Desperate; 'A Radical Change': Improvements in Health and Wellbeing; 'How Life Should be': A Sense of Normality; 'You Have to Muddle your way Through': Practical Challenges and 'I Have to Fight for her to be fed Food': Defending the Choice

*Conclusions:* This research identified many original ideas previously not included in other research, such as wider influences on parent's decision making, life changing improvements experienced by parents and inconsistent support from health professionals. It is the opinion of the researcher that a lack of research surrounding blended diet, especially to date, is a significant contributing factor to the absence of clear guidelines and inconsistent support. It is envisaged that this important and novel research will go some way to remedy this, but it is abundantly clear that further research is urgently needed in this area.

## **Acknowledgements**

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## **Chapter 1: Introduction**

The doctoral research reported within this thesis explores parent's experiences of blended diet using an Interpretive Phenomenological Analysis (IPA) approach. Unlike previous research on this topic which has focused largely on healthcare professional's views, this work focused exclusively on parent's perspectives. Furthermore, this research is believed to represent the first time a qualitative approach has been used in the United Kingdom (UK) to explore the experiences of using blended diet from a parental perspective. This first chapter introduces the thesis and the doctoral research project. The chapter begins with a first-person account explaining the rationale for the research project (Section 1.1). In order to locate this topic contextually, further background information is outlined in Section 1.2 including definition of the terms used throughout the thesis. The aim and objectives of the doctoral research are addressed in Section 1.3. Finally, the overall structure of the thesis is outlined in Section 1.4; this outline can be used as a guide to subsequent chapters within this thesis.

### **1.1 Rationale for the Research**

Parts of this section have been adapted for publication: Durnan (2018) 'Blended Diet, Exploring Practice in the USA' *Complete Nutrition* 18 (1) 52-53

This section provides an account of the journey which led the researcher to undertake doctoral research on the topic of blended diet. Concepts are introduced in this section here for context that are later explained and expanded on in full in Section 1.2. Whilst the thesis is set predominantly in the objective voice, here the account is self-reflective in nature and is therefore written in the first person. I am a registered dietitian working in the speciality of home enteral tube-feeding (HETF) at Nottingham University Hospitals NHS Trust (NUH). This means that I am responsible for the ongoing dietetic care of a caseload of people who are tube-fed in their own home in Nottinghamshire. Tube-fed individuals are usually prescribed a commercially prepared enteral formula to be

given through the tube. In 2013, I first encountered blended diet after moving job role from managing an adult to a paediatric caseload. The term blended diet means blending everyday foods at home to be given through the tube. At that time there were only six families in Nottinghamshire who were feeding their child in this way. The children's HETF team at NUH began to receive an increasing number of enquiries from parents who wondered if blended diet could be a suitable option for their tube-fed child. Later that year the association of UK dietitians, commonly known as the British Dietetic Association (BDA) released a public facing Policy Statement (2013) which confirmed parents who have made an informed decision to use blended diet should be supported by their dietitian. However, the document offered no guidance on how to support these families. This was a professional dilemma for me, I wanted to support the families but knew very little about blended diet. So, I began a journey to find out more; to enable me to answer the parent's questions and in turn I hoped to develop as a practitioner.

I attended the annual British Association of Parenteral and Enteral Nutrition (BAPEN) conference in November 2013 with the hope of obtaining some clarity, but it was clear that other UK dietitians were as unsure about blended diet as our own team. The key message I took home from the conference was that blended diet is more common in the USA than it is in the UK. This led me to believe it would be beneficial to meet with US dietitians who were likely to have more clinical experience supporting families to use blended diet, compared to their UK counterparts. I decided to submit an application for a 2014 Nottingham Roosevelt Memorial Travelling Scholarship ([rooseveltscholarship.org](http://rooseveltscholarship.org)). This prestigious local scholarship was founded by the mayor of Nottingham, Francis Carney in 1946 in tribute to the memory of US president Franklin Delano Roosevelt. The scholarship is offered annually to individuals living or working in Nottingham who wish to travel to the USA to investigate a work-related topic of their choice - in my case blended diet. The scholarship comprised a bursary for travel to and around the USA as well as mentorship in the successful planning and accomplishment of such a trip. After two intense rounds of interviews I discovered I had been successful and was awarded the scholarship. I travelled

to the USA on 16th September 2014 and returned to the UK just before Christmas; by the end I had travelled to fifteen states, traversed the country twice and stayed in no one place for more than ten days.

I undertook nine hospital visits as well as shadowed four community teams, two private companies and three charitable organisations, all of whom provided care for HETF patients. The American Academy of Nutrition and Dietetics' Food and Nutrition Conference and Expo (FNCE) in Atlanta, Georgia, attended by 8,000 dietitians from all over the USA provided further networking opportunities. Contrary to the ideas I had formed based on my attendance at the BAPEN conference (2013), I found that blended diet was definitely not routine practice in the USA. Most of the dietitians I spoke to during these visits said they either advised against using blended diet or, like NUH, had a relatively small percentage of patients on their caseload who were fed blended diet. However, like the UK, the US dietitians I met reported that parental interest in blended diet was steadily growing.

I also visited two multi-disciplinary feeding teams, who had a significant amount of experience supporting families to use blended diet and had both published on the topic (Dunn Klein and Evans Morris 2007; Novak et al. 2009). Professionals from both feeding teams reported observing considerable improvement in symptoms of reflux, vomiting and constipation (common side effects of tube-feeding) after the introduction of even small amounts of blended foods. Blended diet was also routinely used as a tool to encourage weaning from tube-feeding onto oral diet. The team's dietitians showed me programmes and plans which they had developed with families to ensure nutritional adequacy whilst permitting choices from individual food groups. Neither team said they saw evidence of the perceived risks that are often linked to blended diet such as feeding tube blockage, micronutrient deficiency or increased incidence of gastrointestinal infection. However, both teams carefully counselled clients on tube care, a balanced diet and good food hygiene practices. Interestingly, both teams said that they had been approached by families from the UK asking for

help and support with blended diet affirming my belief that UK families are lacking the support they desire.

In hindsight, the most valuable part of the scholarship experience was the opportunity to meet people who use blended diet daily to feed their own child. In total I met twelve US children and their families, each with their own unique reasons for choosing to blend their own food at home rather than use commercial formula. Each family I met was using blended diet in a slightly different way; some families varied the blend from day-to-day and meal-to-meal whereas other families used several set recipes. Some families fed their tube-fed child exclusively on blended foods where others used a combination of blended food and commercially prepared enteral formula. In, Portland, Oregon, I was invited by one mother to stay for a week in their family home to see first-hand how they used blended diet to feed their daughter. The girl was ten-years-old when I met her and had been gastrostomy fed for nine years. Staying with the family gave me an insight into the day-to-day use of blended diet and how it can impact on their social lives whereas in clinical practice I spend less than an hour with a family at a time.

Three months travelling through the USA taught me that blended diet is not standard practice there, but, like in the UK, more parents and families are becoming interested in blending food at home for their tube-fed child. I met individual healthcare teams who reported they had seen remarkable clinical improvement in children who transitioned to blended diet and routinely offered it as a choice to families. Those teams demonstrated that it is possible to support families to use blended diet with minimal risk. Since my return from the scholarship, at NUH we have continued to see a growing interest from parents in blended diet. There are now twenty-three families in Nottinghamshire who regularly give blended food through their child's feeding tube. It is clear that high quality research is needed to inform clinical practice in the UK and ensure families receive the best care. Just before embarking on the scholarship I was successful in obtaining a studentship to undertake Ph.D. research on the topic of blended diet at Coventry University, in part due to my scholarship experience

in the USA; particularly the valuable insight gained from meeting families. I then decided to focus my doctoral study around the experiences of parents in the UK who have chosen to blend food at home for their tube-fed child with the hope that their experiences may resonate with families and professionals and provide a mutual understanding which will help inform important decisions about a child or young person's care.

## 1.2 Background

The term tube-feeding or tube-fed used throughout this thesis refers to enteral tube-feeding. Enteral tube-feeding is the delivery of nutrition and hydration via tube into the gastrointestinal tract (Bowling 2004). It is used when a person has a functioning gastrointestinal tract, but oral feeding is either unsafe, obstructed or limited (NICE 2006). Nasogastric feeding, by inserting a fine bore tube into the stomach via the nostril is recommended only for use in the shorter term (<4weeks) (NICE 2006). In the longer term most children and young people who require enteral tube-feeding have a gastrostomy, a fistula straight through the anterior wall of the stomach placed using the percutaneous endoscopic (PEG) or radiologically inserted gastrostomy (RIG) methods (Johnson 2015). Parents, or the child's main caregiver, are usually trained by healthcare professionals to use and maintain their child's feeding tube themselves at home, this is referred to as home enteral tube-feeding (HETF) (Johnson 2015). Ongoing monitoring and support is usually provided, by dietitians at a recommended minimum frequency of three to six months (NHS QIS 2007; NICE 2006; Stewart et al. 2006).

The number of children and young people in receipt of HETF in the UK is thought to be increasing although the exact number is not known. The 2001 British Artificial Nutrition Survey (BANS) reported rapid annual growth in the numbers of children and young people in receipt of HETF between 1996 and 2001 and predicted that the numbers would continue to grow as the clinical impact of an improved nutritional state was recognised in a wider range of clinical conditions and specialities and techniques for placement improved (Elia et al. 2001). Unfortunately, there is no current indication of the overall number of

children and young people receiving HETF in the UK due to a sharp decline in the BANS response rate (Smith 2011). Locally, in Nottinghamshire there are currently 345 children and young people receiving HETF.

Enteral tube-feeding is used in the management of numerous clinical conditions however the largest group (approximately one third of the population) requiring HETF is thought to be children and young people with an oral motor impairment or swallowing dysfunction associated with a neurodisability (Elia et al. 2001; Jones et al. 2005; Smith 2011). Neurodisability is a term used to describe any condition which affects the central nervous system leading to functional limitations in movement, cognition, hearing, vision, communication, emotion, and behaviour; often in combination (Morris 2013). Neurodisability includes conditions such as cerebral palsy, Downs syndrome, neuromuscular and progressive neurological disorders as well as rare genetic conditions (Douglas and Huxham 2015). A correlation has been noted between the severity of feeding difficulties and the degree of motor impairment meaning children and young people who require HETF are also likely to have additional complex care needs (Fung et al. 2002). Other clinical conditions commonly associated with HETF in children and young people include cystic fibrosis, renal disease, cardiac conditions, gastrointestinal conditions, malignancies, metabolic conditions and HIV/AIDs (Elia 2001).

Enteral tube-feeding can be used to meet a child's full nutrition and hydration requirements when the swallow is deemed to be unsafe or it can be used to supplement oral intake when a child's swallow is considered safe, but intake is insufficient (Johnson 2015). Tube-feeding may be indicated from birth or a decision to place a gastrostomy tube may be made later in childhood after a gradual decline in oral eating ability (Sullivan 2009). The decision to place a gastrostomy feeding tube is often complex; while it may be clinically indicated parents may view the gastrostomy as a sign of advancing disability, loss of normality or their own failure to feed their child orally (Craig, Scambler and Spitz 2003). Ideally, families need all the information to make an informed decision



about gastrostomy placement, but this should be gradual, so the decision is not rushed (Mahant, Jovcevska and Cohen 2011; Martinez-Costa et al 2011).

Children and young people in the UK who require HETF are usually prescribed commercially prepared enteral formula referred to throughout this thesis as 'commercial formula'. Commercial formulas are designed specifically for the purpose of enteral tube-feeding (BDA 2013). Most commercial formula are pre-packaged in sterile, ready to hang containers which can be spiked or screwed onto enteral tubing to create a closed system which minimises microbial access and allows the formula to hang at an ambient temperature for 24-48 hours. Commercial formulas have a uniform consistency which permits them to flow easily through fine bore enteral tubing and automated feeding pumps, minimising the risk of tube occlusion (BDA 2013). A wide range of commercial formulas are available with differing energy, protein micronutrient and fibre contents designed to suit the varying needs of different age groups and clinical conditions (Campbell 2006). Commercial formula is provided free of charge to children and young people in the UK through the National Health Service (NHS). The manufacturers of commercial formula can usually deliver both the commercial formula and enteral feeding ancillaries directly to the child's home or school address (Johnson 2015).

Increasingly, parents of tube-fed children in the UK are choosing to blend their own food at home rather than use readily available commercial formula (BDA 2013). The term 'blended diet' has been used throughout this thesis to describe this practice although many different terms are also used such as 'home blended diet', 'homemade formula' 'blenderised diet', 'liquidised diet' or 'pureed diet'. Although the practice has been given a label, blended diet is not one standardised thing. US professionals working with families who use blended diet have described it as a continuum for example some families use blended diet in combination with commercial formula when other use rely solely on blended food (Dunn Klein and Evans Morris 2007). The number of children and young people fed using blended diet in the UK is unknown, in part because the numbers of children and young people in receipt of HETF in the UK in general

are unknown (Smith et al. 2011). Locally in Nottinghamshire, 7% of the children's HETF caseload are currently using blended diet. In 2013 the BDA, was forced to release a national public facing Policy Statement due to national demand from dietitians for guidance on the topic. The Policy Statement (2013) raised concerns about the safety of blended diet in comparison to commercial formula with the particular risks of feeding tube occlusion, gastric infection and nutritional deficiency. However, the Policy Statement also advised that dietitians had a duty of care to support parents who have made a fully informed choice to use blended diet (BDA 2013). To further support dietitians in clinical practice a Risk Assessment Tool and Practice Toolkit (BDA 2015) were developed. By the authors own admission, the evidence underpinning these documents, presented and critiqued in Chapter 2, is weak and an urgent need for research on the topic was identified (BDA 2015).

A recent rapid review of the evidence relating to blended diet identified that the professional and researcher opinions on the safety and efficacy are divided (Coad et al. 2017). While some feel blended diet is unsafe and substandard in comparison to commercial formula others believe there may be particular benefits such as symptom management. Additionally, some professionals have suggested that use of blended diet may have a positive impact on quality of life (Day 2017). The effect blended diet has on the everyday lives of tube-fed children and young people and their families has been listed on the National Institute for Clinical Excellence (NICE) UK database of uncertainties about effects of treatment (NICE 2014). The scarcity of high-quality research relevant to blended diet (Chapters 2 and 3) has resulted in stalemate with strong opinions expressed on both sides of the debate (Kennedy 2015; Marino and Meyer 2015). Meanwhile parental interest in blended diet continues to grow. There is a clear and urgent need for high quality research to provide understanding, progress the debate further and help resolve the current state of stalemate within clinical practice.

### **1.3 Research Aim and Objectives**

This research aimed to generate rich data and a deep understanding about individual parents' experiences of choosing blended diet to feed their long-term tube-fed child.

#### **Objectives:**

1. To explore the reasons why parents first consider an alternative to commercial formula.
2. To understand the benefits of blended diet as perceived by parents who use it to feed their tube-fed child.
3. To explore how individual parents have been supported by professional in their choice to use blended diet.
4. To identify challenges experienced by parents following their choice to use blended diet.

### **1.4 Thesis Outline**

In Chapter 1 a rationale was given explaining the need for research in this area in the UK. The researcher has a professional interest in the blended diet having worked with families using blended diet and experienced the challenges. A three-month scholarship to the USA to shadow US dietitians led to further personal interest in the topic. Background information was given, and the terms used throughout this thesis were defined. Professional and scholarship experiences have shaped the research aim and objectives which were outlined.

Chapter 2 draws together evidence collected from a narrative literature review conducted to provide context to the doctoral research. The chapter starts by looking back at the antecedents, charting the history of enteral tube-feeding

alongside the advances in medicine and health technology which have led to increased numbers of children and young people living in the community with complex care needs. The chapter moves on to examine the evidence underpinning the current arguments both for and against the use of blended diet from a range of perspectives. Possible future dilemmas resulting from a continued lack of understanding on the topic of blended diet are explored.

Chapter 3 presents the findings of a second literature with a quasi-systematic approach, the purpose of which was to identify peer-review articles where blended diet had been used over commercial formulas by families whose child was in receipt of HETF. The articles are critiqued and the findings of are examined to determine what was known about parents experience of choosing and using blended diet over commercial formulas.

Chapter 4 gives a critical account of how the research was planned and conducted. The chapter begins with the conceptual framework followed by a critical evaluation of the chosen methodology, IPA. Next, justification is given for the choices made during the research design. The data collection process is described, and a detailed account of the analytical process is provided. The latter part of the chapter looks back at the research process as a whole with reflection on ethical considerations, quality and researcher reflexivity.

Chapter 5 presents the findings of the doctoral research in a narrative account of the five superordinate themes which were revealed through IPA of fifteen in-depth qualitative interviews with parents who had chosen to give their tube-fed child blended food. Each superordinate theme has been divided into sub-themes. Extended quotations from individual interviews are used as illustration.

Chapter 6 is a discussion which situates the findings and evaluates the doctoral research. To begin, each of the four research objectives achieved are used to structure the discussion and in the light of this research, examine the previous limited literature on blended diet identified in Chapters 2 and 3 and situate the research within the wider academic literature. The discussion chapter moves on in a critique of the current research, including its strengths and limitations

Chapter 7 concludes the thesis with a summary of implications for clinical practice and recommendations for further research.

### **1.5 Chapter Summary**

The purpose of this chapter was to introduce the research. A rationale was presented followed by key background information before presentation of the aim and objectives. The thesis outline above is intended as a guide to subsequent chapters. The thesis now moves on in Chapter 2 to a narrative literature review which provides context to the doctoral research.

## **Chapter 2: Contextual Literature**

### **2.1 Introduction**

This chapter draws together evidence collected from a narrative literature review conducted to provide context to the doctoral research. Literature was found using a hand search of the reference list of key professional documents relating to blended diet and a keyword search of MEDLINE and CINAHL databases. The safety and efficacy of blended diet has been reported to be contentious (Coad et al. 2017). It was therefore important to examine the strength of the evidence underpinning the current viewpoints prior to commencing research on the topic. In order to fully understand some of the current tensions surrounding blended diet it is necessary to consider the antecedents or past history which has shaped the contemporary debate (Section 2.2). The current arguments for and against the use of blended diet are then outlined and critically evaluated. Following on, the chapter then moves to outline the current predicament for tube-fed children, their families and the healthcare professionals who support them. Finally, the chapter ends with a summary before moving on to a subsequent literature review in Chapter 3 which used a systematic approach to explore what is known specifically about parent's experiences of blended diet in peer-review literature.

### **2.2 Antecedents**

Blended diet is often viewed as a retrograde step, because liquid foods were routinely used before the development of commercial formula (BDA 2013; Kennedy 2014). In the first documentation on enteral feeding, ancient Egyptians were reported to have given wine, milk, whey and wheat broth enemas to individuals who could not eat and drink food orally (Harkness 2002). Early orogastric and nasogastric feeds in the eighteenth century were based on milk and cream, other common ingredients referenced in medical literature included eggs, beef, tea, custard, mashed potato, brandy and whisky (Dukes 1876; Hott 1894). Rudimentary commercial enteral formula only started to emerge in the 1930s and were made from ingredients such as protein hydrolysate, corn oil,

dextrimaltose, vitamins and mineral supplements, however up until the late 1960s hospitals continued to produce enteral feeds for their patients by blending everyday foods (Chernoff 2006). In the 1950s, Henry Ford Hospital in the USA published a series of papers on enteral feeding which described the blending and straining of foods such as beef steak, liver, eggs, milk, fruits and vegetables, the authors argued that foods were both better tolerated and cheaper than the available commercial formulas (Barron and Falls 1953). In the 1960s hospitals started to examine the labour cost of blending foods in-house for enteral tube-feeding, in addition some clinicians favoured commercial formula because they deemed them to have better osmolarity and be more sanitary in comparison to blended food (Harkness 2002). A thin viscosity became preferable as enteral feeding tubes became narrower over time and automated feeding pumps were more frequently used (Campbell 2006). Today there are hundreds of commercial formulas available on prescription, different formulas have been developed to suit the specific nutritional needs of different age groups and different disease states (Campbell 2006). From the 1970s until relatively recently the blending of foods for enteral feeding was considered by many to have been superseded by commercial formula (Campbell 2006). However, the blended diet outlined in this thesis is conceptually different to the hospital food blends of the past which were prepared in bulk. Instead, blended diet is being prepared at home by a parent for their own child with complex but often stable medical conditions. Parents use everyday food ingredients that could be eaten orally if the child or young person were able to swallow. In some, usually poorer, parts of the world blended foods are still routinely used because commercial formula is either unavailable or unaffordable (Johnson, Spurlock and Galloway 2013). However, the practice of preparing food blends out of necessity differs considerably from the use of blended diet described in this thesis where parents are choosing blended diet over freely available commercial formula.

The number of children and young people receiving home enteral tube-feeding (HETF) in the UK has increased over the past three decades alongside advances in medical treatment (Elia 2001; Micklewright 1996; Smith 2011). In

1980 the percutaneous endoscopic method of gastrostomy placement (PEG) was first presented, allowing a fistula through the anterior wall of the stomach to be sited under sedation rather than general anaesthetic, meaning gastrostomy tube placement was possible in more medically fragile patients (Ponsky 2011). Feeding problems and growth failure were, until this point, considered by many to be an irremediable component of many childhood conditions, particularly neurodisabilities (Evans et al. 1985; Vining et al. 1976). Neurodisability is an umbrella medical term which encompasses numerous conditions associated with impairment of the nervous system such as cerebral palsy (NHS England 2013). Many children with neurodisability have complex and continuing needs and are frequent users of the health services (NHS England 2013). Survival rates of high risk new born babies have improved but the rate of neurodisability in this group has also remained high (Hack et al. 2005). Similarly, the treatment of paediatric acquired brain injuries has improved but is associated with a likelihood of neurodisability (Douglas and Huxham 2014). Neurodisability affects the ability to move, communicate and eat orally meaning the child or young person has life-long complex needs (Sullivan 2009). The survival rates for other clinical conditions commonly associated with HETF has also improved (Elia et al. 2001; Shaw 2015). Enteral tube-feeding is partly responsible for the improved survival rate of children with complex care needs because it provides a reliable route of nutrition and hydration for children who would otherwise be unable to eat sufficiently to survive (Sullivan 2009). Children who would have died in childhood had they been born in the 1950s, 1960s are now living well into adulthood and transitioning to adult NHS services (Council for Disabled Children 2017). The number of young people aged sixteen to nineteen living with complex health conditions in the UK has been reported to have doubled in the last decade (Department of Health 2016). The group of children and young people for whom blended diet is now being considered differs considerably to the acutely unwell patients who last received blended foods in hospitals in the UK in the 1950s and 1960s.

The role of the parent in a child's healthcare has also changed significantly since the 1950s or 1960s. In the 1950s children's healthcare predominantly took



place in hospital, care centred on asepsis and rigid routines, and children were frequently separated from their parents (Darbyshire 1993). Influential studies on the effects of maternal separation for hospitalised children raised questions and prompted debate over how children were cared for and led to slow change in practice (Bowlby 1953; Robertson 1958). In 1976, the Department of Health and Social Security's Court Report on child health services, recognised that children have different needs to adults and advised nurses and parents to work in partnership. In the late 1990s the UK committee for the United Nations Children Fund (1999/2000) advocated encouraging, supporting and empowering parents to care for their sick children. The increased survival rates of children have coincided with changes in healthcare policy which promote the management of chronic conditions in the community setting. Parents are being trained to carry out life sustaining medical care, such as HETF, ventilation and suction in the family home environment. In September 2014 reforms set out in the Children and Families Act came into force (Council for Disabled Children 2016). These reforms focus on taking the views, wishes and feeling of children and their parents into consideration when making plans for children's education, health and care needs (Special Educational Needs (SEN) reforms). Parents have been empowered to make decisions about their child's health and well-being. This can often lead to tensions when healthcare professionals disagree with the choices parents make for their child for example, in the case of blended diet if parents and professionals have conflicting views.

### **2.3 A Critique of the Current Viewpoints on Blended Diet**

In a recent rapid review of the evidence, Coad et al. (2017), identified three distinct professional and researcher viewpoints on blended diet. Firstly, those who feel blended diet is unsafe and substandard in comparison to commercial formula. Secondly, those who see the benefits of blended diet in particular circumstances. Finally, those who see value in the use of blended diet but are cautious due to the lack of published research evidence. This section works through each of those viewpoints and critically evaluates the evidence which supports them.

### 2.3.1 Unsafe and Substandard

Drawing on the first point from Coad et al (2017) the safety and adequacy of blended diet in comparison to commercial formulas has been questioned. In an invited review of paediatric enteral feeding, the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPAGHAN) committee on nutrition specifically stated that the use of blended diet is not encouraged due to the risk of nutritional inadequacy and microbial contamination however, no references were provided in support of this statement (Braegger et al. 2010). In 2013, in response to an ever-increasing number of enquiries from both parents and dietitians about blended diet, the British Dietetic Association (BDA), released a public facing Policy Statement. Like ESPAGHAN the BDA stated they did not endorse the practice of blended diet due to risk of nutritional inadequacy and microbial contamination and additionally tube occlusion (BDA 2013; Braegger et al. 2010). However, the Policy Statement also advised that UK dietitians have a duty of care to support parents who have made a fully informed decision (BDA 2013). To further guide dietitians in clinical practice, the Parenteral and Enteral Nutrition Group (PENG) of the BDA developed a Risk Assessment Tool, to protect both patients and professionals from litigation (Kennedy 2014). Additionally, four UK registered dietitians with prior experience supporting parents to use blended diet worked in conjunction with PENG to develop a Practice Toolkit which included a comprehensive review of the scarce literature and recommendations for best practice based mainly on their own clinical experiences (BDA 2015).

The first potential associated risk highlighted in the BDA Policy Statement (2013) was nutritional inadequacy. The literature review conducted as part of the Practice Toolkit identified only three studies which related to the nutritional adequacy of blended diet (Mokhalalati et al. 2004; Sakphisutthiikul 2012; Sullivan et al. 2004; cited in BDA 2015). All three of these studies found variability between the nutrient content of blended food in comparison to commercial formula. Yet, as all three studies focused on food blended in bulk in hospital kitchens for an acutely unwell adult population, care should be taken in

extrapolating these findings to medically stable children who are receiving care in a community setting. The motivation for using blended food seemed to be the affordability of commercial formula. This could mean less money was invested in food ingredients, equipment and staff training too. Furthermore, the variability noted could have been due to human error including inconsistent measuring, preparation techniques or miscalculation of nutritional content by the dietitians involved in the research. Although the nutrient content of the blends varied this would not necessarily translate into a nutritional deficiency. It has been argued that tube-fed individuals do not need to consistently have exactly the same volume of nutrients everyday as this is not how people usually eat orally (O’Gorman 2012). A final criticism is the conflict of interest as two of these papers were funded by Abbott Laboratories, the world’s largest manufacturer of commercial enteral formula, who have a vested interest in promoting the use of their own products (Mokhalalati et al. 2004; Sullivan et al. 2004). The studies underpinning claims that blended diet poses an increased risk of nutritional deficiency and decline in nutritional status are limited. Conclusions cannot be drawn, based on these papers alone, as to whether blended diet does pose a risk when parents prepare a blend for their tube-fed child in their own home in the UK.

The second potential risk associated with blended diet raised by both ESPAGHAN (2010) and the BDA Policy Statement (2013) was an increased risk of gastric infection. In comparison to sterile commercial formula it was thought there were more opportunities for microbial contamination during the preparation and storage of blended foods. Five studies were identified which looked specifically at the microbial contamination of blended food in comparison to commercial formula (Borghi et al. 2013; Jalali et al. 2009; Mokhalalati et al. 2004; Sullivan 2001; White 1998). All five found an increased microbial count in the food blends in comparison to commercial formula. However, all these studies focused on food blended in bulk in hospital kitchens for an acutely unwell adult population. Hospital kitchens are very different to kitchens in the modern family home and for this reason the findings cannot be generalised to blends prepared at home by a parent for an individual child. Furthermore, none

of the studies reported if the higher microbial count actually translated into gastric infection in the patients. Advocates of blended diet have argued that stomach acids protect against microbial infection and therefore question why medically stable individuals with long-term gastrostomy tubes living in the community would need to have a sterile formula when food eaten orally is not usually sterile (O’Gorman 2012). In recent literature reviews on the topic of blended diet authors have questioned whether adherence to a sterile diet in the longer-term could have a negative effect on the gut microbiome and a subsequent effect on health (Coad et al. 2017; Martin and Gardener 2017). The studies supporting claims that blended diet poses an increased risk of gastric infection are limited and cannot be generalised to a UK parent preparing food at home for their own child.

The third potential risk suggested by the BDA position statement (2013) was feeding-tube occlusion (blockage); this was thought to be more likely as mechanically blended food is more viscous than liquid commercial formula. The Enteral Plastics Safety Group (EPSG), a group consisting of the nine leading UK enteral feeding device suppliers, released a consensus statement (2014) which specified that they do not recommend the use of blended diet through enteral feeding tubes in the UK. However, no research evidence was referenced in support of this statement. A further criticism is three of the tube manufacturers contributing to the consensus statement also manufacturer commercial formulas and have a potential conflict of interest in promoting the use of their own product. Additionally, the information booklets of one brand of gastrostomy device, a member of ESPG, conflicted with the statement and specified that blended diet could be given through the device (BDA 2013). Only one study focused on the use of blended diet in comparison to commercial formula was identified in the literature review accompanying the Practice Toolkit, this study found that the risk of tube blockage increased as the gauge of the feeding tubes decreased (Gallagher-Allred 1983 cited in BDA 2015). However, the paper is outdated as both the machinery available to blend food ingredients and enteral feeding tubes have advanced since the 1980s. Based on weak evidence US authors have suggested that  $\geq 14\text{Fr}$  gauge feeding-tubes

may be more suitable than tubes with a narrower gauge (Mortenson 2006; Johnson 2013). However, this suggestion seems arbitrary. Brown (2015) a nurse with considerable experience in the field of HETF states the difference between a 14Fr and 12Fr tube is negligible (2-3mm difference). There is no convincing research evidence to suggest blended diet causes an increased incidence of feeding tube occlusion. Additionally, tube occlusion is less problematic in low-profile balloon retained devices which can be easily changed in the community.

In summary, the evidence underpinning the viewpoint that blended diet is unsafe and substandard is weak and there are difficulties in generalising the findings to a parent who is blending food at home for their own individual child. High quality research which focuses specifically on this population is urgently needed.

### **2.3.2 Benefits in Particular Circumstances**

The second viewpoint identified by Coad et al. (2017) was that blended diet could have particular use in symptom relief or have social and emotional benefits. as an alternative to commercial formulas in particular circumstances. Gastrointestinal symptoms such as reflux, retching and vomiting are common complications of enteral tube-feeding (Johnson 2015). These symptoms are particularly common in children and young people who are tube-fed as a result of a neurodisability and symptoms can be persistent despite medication or surgical intervention known as fundoplication (Sullivan 2009). In an uncontrolled observational cohort study conducted in the US, Pentiuk et al. (2011) investigated the effects of blended diet specifically on gagging and retching symptoms which had persisted after fundoplication in thirty-three children with complex care needs. They found that 52% of the children were reported by parents to have a 76-100% improvement in symptoms, furthermore 73% had a  $\geq 50\%$  improvement in gagging and retching while none of the children's symptoms were reported to have worsened (Pentiuk et al. 2011). A recent Canadian study had similar findings; from a sample of twenty children with complex care needs, vomiting was reported to decrease from 76% to 53%

additionally gagging and retching was reported to decrease from 82% to 47% (Gallagher et al. 2018). Improvements in retching and vomiting symptoms have also been reported in individual cases presented in the literature (Johnson, Spurlock and Galloway 2013; Thiyagesh and Hill 2016). In the US, Samela, Mokha and Emerick (2017) trialled a food blend in ten children with intestinal failure and found it improved stooling patterns. However, these studies are unlikely to reflect the blended diet described in this thesis which is usually devised and made at home by parents. Samela, Mokha and Emerick (2017) used a US commercial pre-packaged food blend. The recipes for blends in both Pentiuik et al (2011) and Gallagher (2018) were devised by the research dietitian. This means the findings of these studies are not necessarily generalisable to parents who choose, prepare and blend food ingredients for themselves at home. Furthermore, using set recipes and pre-package blends may have negated some of the social or emotional benefits which have been suggested.

Some professionals have speculated that blended diet could have social and emotional benefits for tube-fed children and their families. Qualitative studies have identified that the transition from oral-feeding to gastrostomy feeding can have a detrimental effect on parent-child bonding (Brotherton, Abbott and Aggett 2007; Sleight 2005; Thorne, Radford and McCormick 1997). In an editorial piece, Dr Ward Platt, a UK consultant paediatrician, pointed out that commercial formula could be viewed as lacking the 'emotional content: the parental love and care that normally goes into feeding a child' (2017:102: i). Likewise, in opinion pieces dietitians and nurses have suggested that the parents they had supported viewed cooking and preparing blended diet for their child as evidence of their love for their child and a key part of their parental, nurturing role (Brown 2015; Kennedy 2015). However, a qualitative meta-analysis examining the impact of transition from oral to gastrostomy tube-feeding on maternal emotional state and identity (n=7 articles and n=127 participants) found heterogenous opinions (Wilken 2012). While some mothers reported missing the emotional and social aspects of feeding their child orally others viewed gastrostomy being positive in the parent-child relationship

because mealtimes were no longer a struggle (Wilken 2012). As studies looking at the transition from oral feeding to gastrostomy feeding have demonstrated, parent's opinion in relation to social and emotional aspects of feeding are diverse.

A suggestion has been made in the US that the current 'trend' in the popularity of blended diet reflects a trend in the general population toward natural, organic and unprocessed or 'whole food' (Martin and Gardener 2017). In a dietetic magazine article Mortenson (2006) suggested that parents are receiving conflicting advice; on the one hand they are advised by public health messages to eat a variety of foods but on the other asked to give their tube-fed child the same commercial formula every day. Without the use of research methods this idea seems rather speculative. However, Petersen et al. (2006) in a descriptive study of fourteen parents found that care givers considered tube-feeding to be unnatural and subsequently decided to give foods such as juice, cereal and soup through the tube. Unfortunately, the authors did not recognise this as blended diet and did not explore the giving of food through the tube in any depth.

In summary, two small scale studies have suggested that the use of blended diet, defined as food blended in the home using everyday food ingredients may have a positive effect on adverse symptoms commonly associated with tube-feeding such as retching and vomiting. However, little attention has been paid to the impact this has on family's quality of life. Studies which take blended diet out of context and attempt to manipulate and control it under quantitative research conditions may negate some of the psychosocial benefits which have been suggested by professionals working in the field of HETF such as the nurturing bond of a parent providing food for their child. The evidence underpinning the suggestion that blended diet may have positive social and emotional impact on families is weak.

### **2.3.3 Health Professional Caution due to the Lack of Research Evidence**

The contradictory stance taken by the BDA (2013) presents real challenges for practicing dietitians. On the one hand the professional body advised it does not endorse the practice but on the other stipulates that dietitians have a duty of care to support parents who have made an informed decision (BDA 2013). A recent web-based survey of UK registered dietitians found 81% had received no training on blended diet; this meant confidence in advising on blended diet in clinical practice was low (Armstrong et al. 2017). Furthermore, some dietitians are likely to be cautious due to the risk of litigation against the professional suggested in the BDA's Risk Assessment Tool (Kennedy 2014). Additionally, some dietitians may feel that supporting blended diet means they are practicing outside the limits of their knowledge and skill, thus breaking with the Health and Care Professional's Council (HCPC) standard of conduct, performance and ethics (2016). Interestingly, Armstrong et al. (2017) found fifty-seven of the seventy-seven dietitians surveyed said they would change their perception of blended diet if there were an evidence base or guidelines. Dietitians, like other NHS healthcare professionals, are encouraged to take an evidence-based approach in their practice (Igo 2010). Evidence-based practice has been defined as 'the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients' (Sackett et al. 1996:312). In the case of blended diet for children and young people receiving HETF in the UK, research evidence is scarce and expert opinion divided meaning dietitians in practice are reliant mainly upon their own clinical judgement and past experiences when faced with a parent asking for support with blended diet.

### **2.4 Current Predicament**

The opposing professional views on blended diet have reached a stalemate however as evaluated in Section 2.3 both are based on weak and limited evidence. The lack of high-quality research and conflicting expert opinion means blended diet is a challenging topic for professionals working in the field



of HETF. Meanwhile, parental interest in blended diet continues to grow. Any parent with access to the internet can find information about blended diet. Numerous parents in the UK have written online blogs about their own positive experiences of blended diet for example [brainstars.co.uk](http://brainstars.co.uk), [dietetics.co.uk](http://dietetics.co.uk) and [rettgirl.blogspot.co.uk](http://rettgirl.blogspot.co.uk). A grandmother of a tube-fed boy has set up a website with the aim of providing UK specific information to families about blended diet including suggested counter arguments to the concerns put forward in the BDA Policy Statement (2013) ([renacahill wixsite](http://renacahill.wixsite) n.d.). Additionally, UK parents are able to access websites in the US where a similar trend in preference towards blended diet has been observed (Martin and Gardiner 2017) such as [food for tubies](http://foodfortubies.com) (n.d.), [feeding tube awareness](http://feedingtubeawareness.com) (2015) and the Oley Foundation (n.d.). As well as information on the internet several recipe books have been written by tube-fed people and their carers on the topic and can be purchased online (Boseman 2015; Colors 2017; O’Gorman 2012; Stinson and Holsten 2017). The quality of the information and advice given in these resources could be questioned as they are based mainly on individual opinion and self-published.

As well as having easy access to resources, parents are able to connect with other parents using blended diet online. Several groups have been set up on social media such as Facebook (n.d.), Yahoo (n.d.), Pinterest (n.d.) and YouTube (n.d.), dedicated to blended diet, allowing parents to offer each other practical support by sharing ideas and recipes. One of several Facebook groups dedicated to blended diet (Blended Diet UK) has trebled in membership over the past three years from 800 members to 2822 members (Facebook n.d.). PINNT, a support group for people receiving HETF in the UK, has described blended diet as a subject that ‘will not go away’ (Brown 2017:10). The topic of blended diet has become ‘emotionally charged’ (Kellie 2015). Kennedy (2015:40) suggested that dietitians in these online support groups are perceived by parents to be ‘poorly trained, lacking scientific and practical knowledge’. One mother of a gastrostomy fed child has started a petition requesting the National Health Service (NHS) and BDA acknowledge home blended diet as a method of tube-feeding and offer it as a choice to all individuals who need HETF, at the time of writing the petition had 2989 signatures (Change.org 2014). However,

the quality of the information online has been questioned and it has been argued clinical practice should not be changed based on anecdotal and emotive parental reports (Marino and Meyer 2015).

It is the parents and families of tube-fed children and young people in the UK that are driving interest in blended diet, but it is health professionals who have to respond to their resounding collective voices despite the challenge outlined. Clearly, this current predicament indicates that there is an urgent need for high quality research to progress the debate further and resolve the current state of stalemate within clinical practice. The BDA points to a need for a shared understanding between professional and parents with regard to potential risks (2013:3). Equally professionals need to understand the appeal and experiences of blended diet use. Without this understanding it would be difficult to support families in clinical practice and also difficult to design high quality research to investigate the safety and efficacy.

## **2.5 Chapter Summary**

In summary, historical research and developments in enteral feeding have framed the current concerns surrounding blended diet. However, blends prepared in the family home by parents for their own tube-fed child bear little resemblance to the blends of the past which were prepared by hospital catering staff on a large scale. Enteral feeding has developed alongside other medical treatments such as the PEG procedure and improved in clinical outcomes for children (Ponsky 2011). A shift from hospital to community care in the UK means that more parents are being empowered to look after their child with complex health in the home (Department of Health 2016). Blended diet has been described as a regressive step (BDA 2013). However, this contemporary version of blended diet is being considered for a new group of children and young people, who would not have survived early infancy in the 1960s but are now living into adulthood. Moreover, it is considered in a new setting, the family home. Furthermore, parents and families in the UK have increased access to a wide range of food ingredients, kitchen equipment and information in comparison to people preparing food blends in the past or in poorer parts of the

world where commercial formula is either unavailable or unaffordable. However, the quality of information currently available online could be considered questionable. The collective evidence from this contextual chapter highlighted that the arguments both for and against using blended diet are currently weak and professional opinion on the topic is divided. There are currently no evidenced-based guidelines on blended diet and a lack of research cannot necessarily be considered evidence against. An understanding of parent's experiences of blended diet is vital to inform clinical practice and future research on the topic. Subsequently, a second literature review was conducted using a quasi-systematic approach to find out what is known about parents experience of blended diet in the peer review literature (Chapter 3).

## **Chapter 3: Literature Review with Systematic Approach**

### **3.1 Introduction**

The previous chapter explored the historical and international literature which has framed the current debate and the opposing viewpoints on the use of blended diet for home enterally tube-fed (HETF) children and young people. The review highlighted that the contemporary UK version of blended diet described in this thesis and being chosen by parents differs considerably from the food blends used in hospitals in the 1950s and 1960s and additionally from the food blends used in hospitals in less developed parts of the world out of financial necessity. Instead blended diet is being used by parents who have been empowered to care for their child with complex needs in the family home. There are currently no evidence-based guidelines on blended diet (BDA 2015). However, considerable benefits have been anecdotally suggested by professionals in the field of HETF. Whilst the context was set in the previous chapter, here a more focused literature review was needed to expand critically and inform the doctoral research. Therefore, this chapter presents the findings of a second literature review using a systematic approach, the purpose of which was to identify peer-review articles where blended diet had been used over commercial formula by families for HETF. It was envisaged this review would provide critical discussion and insight into why increasing numbers of parents in the UK are choosing blended diet (BDA 2013) and in turn inform the design of the doctoral research (Chapter 4).

### **3.2 Review Methods**

#### **3.2.1 The Search Strategy**

The overall search strategy introduced in Chapter 2 aimed to find both published and unpublished articles relating to the use of blended diet for children and young people. The search strategy included several steps. Firstly, an initial limited search of MEDLINE and CINAHL was undertaken followed by analysis of the text words contained in the title and abstract, and of the index

terms used to describe the article. A search strategy was created using a PICO method for qualitative research. This involved identification of keywords which described the person for example 'tube-fed', 'enteral', 'gastrostomy' or 'feeding tube'; the phenomena of interest for example 'blended', 'pureed' or 'liquidised' and the context for example 'community' or 'feeding clinic'. Multiple terms were identified which describe the use of enteral feeding for example 'gastrostomy' 'G-tube' or 'PEG', and authors used a variety of terms to describe blended diet for example 'blenderised diet', 'liquidised diet', 'pureed by gastrostomy tube diet'. MEDLINE MeSH headings were also used where applicable to ensure relevant papers were identified. The full search strategy and search string can be found in Appendix 1 of this thesis. The search was repeated in the CINAHL and PsychINFO databases using the same keywords. Again, database specific subject headings were used where applicable. The full search strategy and search string for CINAHL and PsychINFO databases can be found in Appendix 2. Following on, the reference lists of all papers selected for inclusion were hand searched for other relevant papers. An additional hand search was carried out on the reference list of the BDA Policy Statement (2013) and Practice Toolkit (2015). A further search of the grey literature was conducted by entering keywords into the grey literature database; Open Grey (Opengrey n.d.). Next, a search of the British library EThOS database of doctoral theses was conducted using key words (n.d.). Finally, a search of Google (n.d.) was carried out using keywords from the search strategy. No limits other than the inclusion and exclusion criteria were put onto the search results.

### **3.2.2 Inclusion and Exclusion Criteria**

Inclusion and exclusion criteria were set (Table 3:1). Articles written in the English language were considered for inclusion. All animal and in vitro studies were excluded from the review. Primary research studies, clinical case studies and professional opinion pieces which had been through formal peer review journals articles were included. Posters, abstracts, dissertations, blogs, books and professional opinion pieces which had not been subject to peer review were excluded. Literature reviews as secondary evidence were excluded from this

review. The review incorporated articles which focused on children or young people and additionally studies which focused on both adults and child but presented the findings separately. Articles which focused only on adults were excluded. Articles focused on home enteral tube-feeding (HETF) were included and articles focused on the in-patient, hospital setting where excluded. For inclusion articles needed to refer to the use of blended diet as a choice when commercial formula was readily available or affordable, whereas, articles which focused on the use of blended food due either an unavailability or unaffordability of commercial formula were excluded. Finally, any article which did not make reference to the parent's experiences was excluded.

**Table 3.1:** *The inclusion and exclusion criteria for the literature review*

Inclusion Criteria	Exclusion Criteria
Written in English	In languages other than English
Human studies	Animal and in vitro studies
Primary research studies, case studies, professional opinion pieces which had been through formal peer review	Posters, abstracts, dissertations, Blogs and non-peer review articles which have not been peer reviewed
Focus is on blended diet	Focus is not on blended diet
Studies which focus on children or young people (aged 0-25 years)	Adult studies which do not include children or young people
Focus on the community setting	Focus on the inpatient setting
Focus on blended diet as a choice when commercial formula is readily available/affordable	Blended food used due to unavailability/unaffordability of commercial formula
Reference to parent's experience	No reference to parent's experience

### 3.3. Results

#### 3.3.1 Search Results

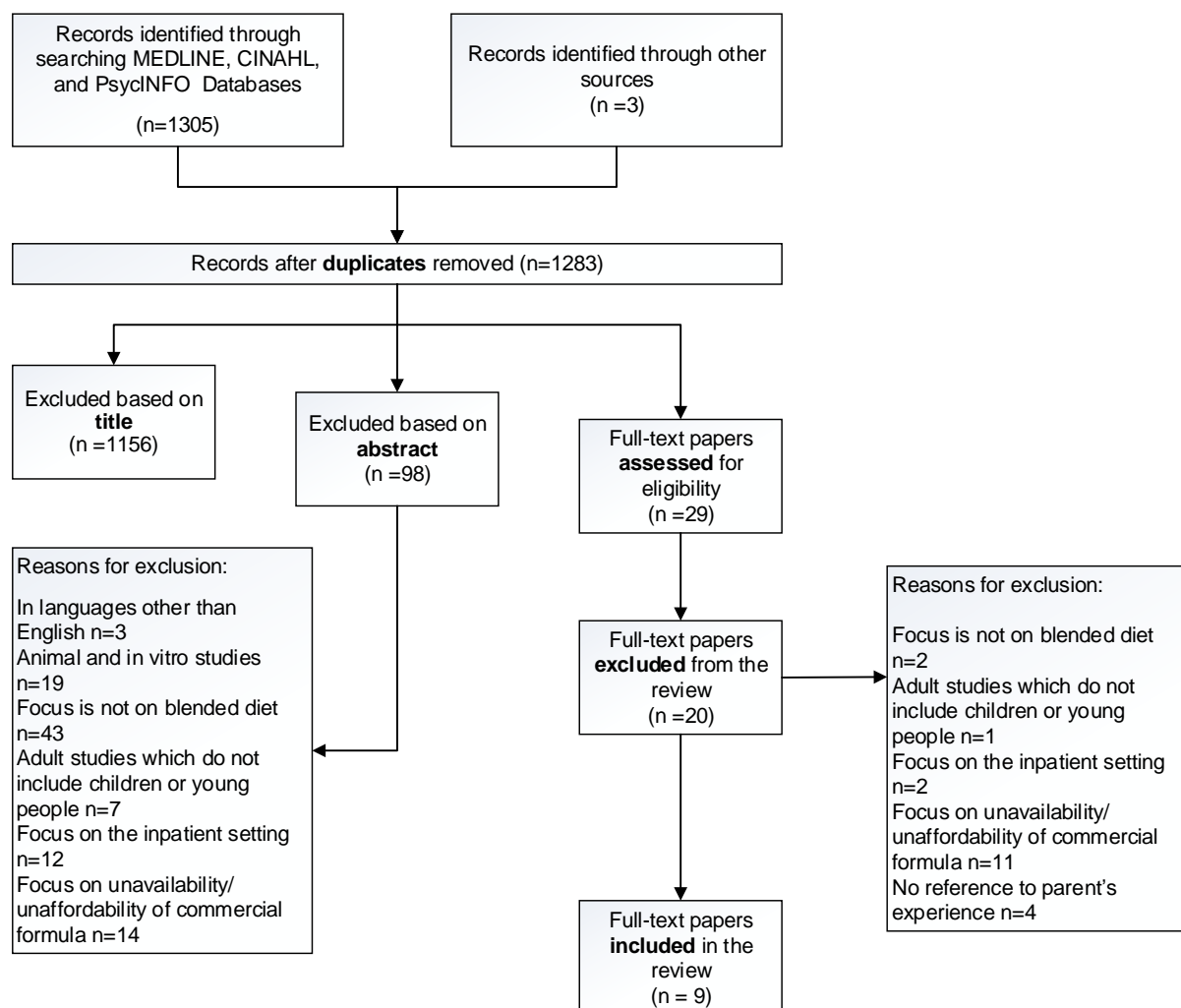
Running the search strategy in the MEDLINE database generated 1238 results. Limiting the search to humans only at this stage, reduced the number of results to 786, however this removed some of the papers known to be relevant. To eliminate the risk of missing relevant papers, the search was not restricted at this stage and animal studies were removed later by hand on review of the title or abstract. A search of the CINAHL database generated 45 results. The PsychINFO search generated 22 results.

#### 3.3.2 The Selection of Papers for Inclusion

Figure 3.1 illustrates the four stages of selection process for this review. In total 1305 papers were identified using the search strategy outline in Sub-section 3.2.1. Citations from the three databases were exported to the Ref Works reference management programme (Refworks Proquest n.d.). A further three papers were identified through a hand search of the BDA policy statement reference list and were added to the Ref Works reference management programme manually. Twenty-five papers were identified by more than one of the three databases; duplicates were removed leaving a total of  $n=1283$  articles. Sub-folders were created within Ref Works to track the exclusion and inclusion process (excluded by title, excluded by abstract, excluded by full text and included in the review).

In the first stage the titles of all  $n=1283$  identified papers were read by the researcher. From review of the title alone it was clear that  $n=1156$  papers were not relevant to the research question posed. The majority of these papers were not healthcare related and referred to other topics such as engineering or referred to research in animals. These papers were moved to the sub-folder named excluded by title. In the second stage, the abstracts of the remaining  $n=127$  papers were read by the researcher.  $N=98$  papers were excluded during this step as they did not meet the inclusion criteria (Table 3.1). The full text version of  $n=29$  papers were located and reviewed. After reading the full text

n=20 papers were excluded from the review because they did not meet the inclusion criteria. On closer inspection these papers either did not focus on blended diet use in HETF or did not make reference to parent's experience and were therefore not able to answer the question posed in this review. In total n=9 papers met the inclusion criteria set (Table 3.1) and were included in the review. Included papers are summarised in Table 3.2.



**Figure 3.1:** PRISMA flow diagram showing the selection process



### **3.3.3 Quality Assessment and Data Synthesis**

Each included article was re-read and critically appraised to assess quality. Primary research studies were appraised using the Critical Appraisal Skill Programme (CASP) validated checklists ([casp-uk.net](http://casp-uk.net)). Professional opinion pieces were appraised using the Joanna Briggs Institute Notari Tool, which is designed specifically for the purpose of assessing professional opinion (Joannabriggs.org 2015). A data extraction sheet was used to record the critical appraisal which included the study design, methodology, outcomes, author conclusions and limitations. Sections of each article relating to parents' experiences of blended diet were highlighted and relevant sections from the different articles were then compared to identify agreement and controversy.

### **3.3.4 Summary of Papers Included in the Review**

This sub-section summarises the nine papers included in the review. Table 3.2 presents key information about the papers included in the review; the author and year of publication, research method employed, sample size, issues identified and limitations. The papers have been arranged into five categories; uncontrolled prospective cohort studies (n=2), survey of parents of a tube-fed child (n=1), surveys of dietitians (n=2), experience of clinical experts (n=1) and individual cases presented by professionals in the field of HETF (n=3). Research methods were reported by n=5 articles, the remaining articles focused on single cases or professional opinion. Articles originated from the UK (n=3), Canada (n= 1) and USA (n=5).

**Table 3.2:** A summary of papers included in the review, sample size, key issues identified and limitations

Uncontrolled Prospective Cohort Studies				
Authors and Year	Study Details	Sample	Key Findings	Limitations
Pentiuk, O’Flaherty, Santoro, Willging and Kaul, 2011	<p>Uncontrolled prospective cohort study.</p> <p><b>Focus: Telephone survey where parents were asked to rate percentage improvement in gagging and retching symptoms 2 months after transition to a blended diet (as prescribed by the research team’s dietitian) from commercial formula.</b></p> <p><b>Anthropometric data also were collected at routine follow-up clinic appointments</b></p>	<p>Convenience sample of 33 gastrostomy fed children (mean age 34.2 months) who presented at Children’s Hospital Medical Centre, Cincinnati, Ohio, USA with persistent gagging and retching following a fundoplication procedure.</p>	<p>52% of the children were reported to have a 76-100% improvement in gagging and vomiting on blended diet. 73% had a ≥50% improvement in gagging and vomiting.</p> <p>None were reported to have worsened symptoms.</p> <p>Four children were reported to have lost weight initially although three were able to regain the lost weight following adaptation of the blend by the dietitian.</p> <p>57% were reported to have seen an increase in the child’s oral intake.</p> <p>Parents ‘anecdotally’ reported decreased incidence of constipation.</p> <p>Parent satisfaction with the blended diet was reported to have been ‘exceptionally high’ the primary reason for continuing blended diet was believed to be improved symptoms although the authors noted that some parents viewed blended diet to be more ‘natural’ than commercial formula.</p>	<p>Short period of follow-up</p> <p>Small sample size</p> <p>Uncontrolled</p> <p>The authors do not specify if the survey tool was validated.</p> <p>The authors do not specify if any families declined to take part in the research due to the additional work and cost involved.</p> <p>Risk of research bias as parents were asked to rate how much symptoms have improved.</p> <p>Although parents noted reduced incidence of constipation it was not measured as a clinical outcome in this study.</p> <p>The methods employed did not allow for detailed exploration of why parents felt so satisfied with blended diet or why it was important to them to use a more natural method of feeding.</p> <p>The blend in this study was devised by the research team’s dietitian. In other reported cases the blend is devised by the parents; so, the results may not be applicable to all types of blend diet.</p>

<p>Gallagher, Flint, Mouzaki, Carpenter, Haliburton, Bannister, Norgrove, Hoffman, Mack, Stintzi and Marcon, 2018</p>	<p>Uncontrolled Prospective cohort study.  <b>Focus: six-month feasibility study which investigated transition to a blended diet (devised by the research team's dietitian) from commercial formula.</b></p> <p><b>Questionnaires (a mixture of open-ended questions and Likert scales) were used to assess parent's perceptions of their child's GI symptoms, stool frequency and consistency, oromotor skills and overall satisfaction with blended diet.</b></p> <p><b>Anthropometric data, dietary</b></p>	<p>Convenience sample of 20 gastrostomy fed children (mean age <math>3.4 \pm 2.2</math> years) with additional complex care needs who presented between May 2014 and July 2015 in outpatient clinics at the Hospital for Sick Children, Toronto, Ontario, Canada</p>	<p>n=17 children successfully transitioned to blended diet (n=1 transitioned to oral dietary intake after 3 months, n=1 was lost to follow up and n=1 found blended diet to be too much additional work)</p> <p>Children's vomiting was reported to decrease from 76% to 53% (<math>p=0.015</math>)</p> <p>53% Gagging/retching was reported to decrease from 82% to 47% (<math>p=0.072</math>)</p> <p>No significant change in stool frequency was reported.</p> <p>Amongst those children who had a safe swallow oral intake was reported to increase 67% to 80%.</p> <p>Caregivers were reported to perceive the child to be in significantly less discomfort at 6 months and were more satisfied with tube-feeding.</p> <p>Satisfaction was reported to be high and participants unanimously indicated they would recommend blended diet to other parents</p> <p>The proportion of children with triceps skinfold above the fifth percentile was reported to increase from the beginning of the study to the end 76% vs 82% (<math>p=0.001</math>)</p> <p>Participants were found to have similar or greater micronutrient intake when compared to commercial formula</p> <p>The bacterial diversity and richness in stool samples significantly</p>	<p>Relatively short period of follow-up</p> <p>Small sample size</p> <p>The questionnaire method used did not permit the parents to explain in depth or detail why they felt so satisfied with blended diet in comparison to commercial formula.</p> <p>The blend in this study was devised by the research team's dietitian. In other reported cases the blend is devised by the parents; so, the results may not be applicable to all types of blend diet.</p>
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	intake and stool samples were also collected and analysed at enrolment, 3 months and 6 months		increased, while the relative abundance of Proteobacteria decreased.	
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Survey of Parents of a Tube-fed Child				
Authors and Year	Study Details	Sample	Key Findings	Limitations
Johnson, Spurlock, Epp, Hurt and Mundi, 2017	Cross-Sectional descriptive survey of parents of tube-fed children in the USA. <b>Focus: Electronic survey using a validated tool.</b>	A link to an electronic survey was placed on the website <a href="http://www.feedingtubeawareness.com">www.feedingtubeawareness.com</a> , a non-profit support group for the parents of tube-fed children. The group has a membership of 40,000. Respondents n=433 parents of tube-fed children (mean age 4.79±4.1 years) 50.5% of respondents used commercial formula and 49.5% used blended diet	Reasons parents chose Blended Diet: To provide whole foods 20.2% Decrease symptoms 19.7% Provide Family Meals 12.2% Increase Oral intake 10.8% Address allergies 5.3% Did not like formula 19.7% Reasons families did not use blended diet: Lack of knowledge 50.9% Time constraints 20%	Poor response rate (n=433/40,000). The survey tool been validated for use in an adult population but not in paediatrics. 12% of parents provided narrative commentary suggesting the survey design did not capture all possible answers. Further problematic questions were identified by respondents. The survey method used did not permit the parents to explain their reasoning or views in depth or detail.

Surveys of Dietitians				
Authors and Year	Study Details	Sample	Key Findings	Limitations
Armstrong, Buchanan, Duncan, Ross and Gerasimidis, 2017	Cross-Sectional descriptive survey of UK registered Dietitians. <b>Focus: Registered Dietitians perceptions and experience of blended diet (reference is made throughout to carers' perceptions).</b>	An electronic survey was sent to n=400 members of the BDA paediatric group n=83 responded (n=6 were removed prior to analysis because they were incomplete)	<p>Only n=59 respondents had previously discussed blended diet with a parent or carer. Over half of these respondents indicated that patients and carers expressed a positive view of blended diet.</p> <p>Possible issues identified: Diarrhoea, growth faltering, impractical outside the home, increased preparation and handling, infection risk, nutritional inadequacy, reflux aspiration and vomiting, tube occlusion, weight loss.</p> <p>Adverse outcomes (nutritional inadequacy, weight loss, tube occlusion and infection) were reported to be less commonly seen in clinical practice than expected.</p> <p>Possible benefits identified: carer involvement, reduced incidence of constipation, diarrhoea reflux/vomiting, more physiological, nutritional adequacy, stimulates oral intake, tailoring of the diet to meet individual needs and weight gain/growth.</p>	<p>Response rate (n=77/400)</p> <p>Only 30% of respondents had a case load which consisted of more than 50% children.</p> <p>Only n=43 respondents had any experience of working with families who use blended diet.</p> <p>The majority of respondents worked in a district general hospital setting rather than community HETF setting.</p> <p>Parent perceptions were reported via their child's dietitian. This assumed that the dietitian would be aware and understand parent's thoughts, views and opinions on the topic of blended diet.</p>
Johnson, Spurlock and Pierce 2015	Cross-Sectional descriptive survey of US paediatric registered dietitians. <b>Focus:</b>	An electronic survey was sent to n=2448 members of the Academy of Nutrition	<p>57.6% of those surveyed use and recommend blended diet to patients and their families.</p> <p>Of n=131 reporting n=92 reported this was due to parent request and n=30</p>	<p>Modest response rate 9.9%.</p> <p>The majority of respondents (70.4%) worked in a hospital rather than community HETF setting.</p>

	<p><b>attitudes and experience of dietitians regarding blended diet (reference is made throughout to carers' perceptions).</b></p>	<p>and Dietetics, n=243 responded</p>	<p>reported improvement in tube-feeding tolerance n=8 were unable to obtain commercial formula.</p> <p>Of n=136 reporting n=113 reported that families had positive experience with blended diet (n=10 neutral and n=13 negative)</p> <p>Respondents free text comments on why parents request blended diet included: 'vegetarianism', 'desire to eliminate chemicals from the child's diet' and to 'promote oral feeding'</p>	<p>13.9% of respondents had no experience of working with families who use blended diet.</p> <p>6.1% of respondents reported financial motivation rather than preference which is not applicable to the UK setting</p> <p>Survey questions were not validated or tested previously for reliability.</p> <p>Not all respondents answered all the questions suggesting problematic questions.</p> <p>Parent perceptions were reported via their child's dietitian. This assumed that the dietitian would be aware and understand parent's thoughts, views and opinions on the topic of blended diet.</p>
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Professional Opinion				
Authors and Year	Study Details	Sample	Key Findings	Limitations
Novak, Wilson, Ausderau and Cullinane, 2009	Practice Roundtable Discussion <b>Focus: Questions are posed to a multi-disciplinary team with considerable experience using blended diet in clinical practice.</b>	The experience of one US multi-disciplinary consisting n=4 healthcare professionals (Paediatricians, Dietitians, and an OTR/L Therapist).	<p>The team suggest that blended diet is better tolerated by tube-fed children in some cases than commercial formula.</p> <p>Blended diet is suggested to be effective in the prevention of constipation</p> <p>A role in normalising the feeding experience for families is suggested.</p> <p>The team suggest that some families enjoy preparing blended diet for their child</p> <p>A potential role in weaning a child from tube-feeding onto an oral diet is suggested.</p> <p>The team suggest that blended diet permits a more involved role for the parent in feeding their child than commercial formula.</p> <p>The team caution that blended diet requires more thought, preparation and time than commercial formula.</p>	<p>No research methods are employed.</p> <p>Limited evidence from other sources is cited to back up the team's suggestions.</p> <p>Parents perceptions are reported through healthcare professionals which assumes that the healthcare professionals understand parent's thoughts, views and opinions on the topic of blended diet.</p>

Individual Cases presented by Professionals in the Field				
Authors and Year	Study Details	Sample	Key Findings	Limitations
Brown, 2014	Experience piece written by a children's nurse. <b>Focus: Limited scoping exercise and development of a local policy to facilitate the use of using blended diet.</b>	The experience of one children's nurse who worked in one UK hospice facility which provided respite care for n=15 tube-fed children who follow a blended diet.	Physical benefits anecdotally reported by the parents of the children who are fed blended diet and attend the hospice for respite care: 'improvements in condition of hair and skin', improved 'mood and sleeping at night especially in the absence of overnight feeds', reduced incidence of 'reflux and need for anti-reflux medication', improved 'bowel function'.  Social and emotional benefits anecdotally reported by the parents of the children who are fed blended diet and attend the hospice for respite care 'a sense of empowerment and control in meeting a basic need of their child'	No research methods are used.  Parents perceptions were reported through the healthcare professional which assumes that the healthcare professionals understand parent's thoughts, views and opinions on the topic of blended diet.
Thomas, 2017	Experience piece written by a children's nurse. <b>Focus: Multi-agency working to facilitate blended diet use in a school setting.</b>	The experience of one children's nurse who worked with one UK school to enable n=1 child with complex care needs to receive blended diet at one mainstream school.	Reported remedy of persistent diarrhoea which in turn meant the child could attend school. The authors suggested this improved the child's quality of life, physical and developmental progress.	No research methods are used  Only one quotation from the child's mother is presented and no analysis is used.
Johnson, Spurlock and Galloway, 2013	An individual case report. <b>Focus: Reasons why one mother chose blended diet and the</b>	Clinical case report n=1 gastrostomy-fed 5-year-old boy with additional complex care needs.	Blended diet was reportedly recommended to the child's mother by a friend.  Prior to starting blended diet, the child was fed commercial formula and reportedly experienced 'vomiting',	No research methods are used.  No search strategy is included in the literature review.



	<p><b>outcomes of that experience.</b></p> <p><b>The article includes a narrative literature review and proposes a 'decision tree' to help clinicians consider which children are suitable candidates to use a blended diet.</b></p>		<p>'reflux, retching and feeding intolerance', 'poor growth trajectory' and oral 'food refusal'</p> <p>After starting the blended diet, the child was reported to have experienced 'immediate improvement in feeding tolerance'; 'maintenance of growth trajectory' and improved interest in food'</p> <p>The authors suggested that the mother in this case viewed the additional time and expense involved as an 'investment' with a view to in weaning her son completely from tube-feeding onto an oral diet.</p>	<p>The mother's views and experiences are reported through the child's dietitian rather than expressed in her own words.</p> <p>The decision tree is based on scant evidence and one clinical case and of limited use in clinical practice.</p>
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### **3.4 Themes and Discussion**

This section presents the seven emergent themes following synthesis of the nine articles identified in this literature review. Each theme was present in at least six of the nine articles identified in the literature review. Themes are introduced, agreement and controversies within and between the articles are examined followed by a short discussion of each theme within each subsection. The themes were; tube-feeding tolerance, risks, weight, oral dietary intake, additional time required, the bond between parent and child and parental desire to use natural foods.

#### **3.4.1 Tube-feeding Intolerance**

Tube-feeding intolerance was referenced in all nine of the papers included in the literature review. The term feeding intolerance is used to encompass a group of gastrointestinal symptoms which are common in tube-feeding these include; bloating, stomach cramps, nausea and vomiting, reflux, constipation and diarrhoea (NICE 2013). These symptoms can occur individually or in combination and are reported to have a negative effect on the child and their family's quality of life (Nicholson, Korman and Richardson 2000). Pentiuk et al. (2011) specifically focused on children who had undergone fundoplication surgery to prevent reflux and vomiting, however, subsequently suffered from persistent retching (unproductive efforts to vomit). Pentiuk et al. (2011) hypothesised that blended diet would affect stomach emptying and be better tolerated than commercial formulas. Of the thirty-three children who were given blended diet 52% were reported to have a 76-100% improvement in symptoms when surveyed two months after transition. Furthermore, 73% had a  $\geq 50\%$  improvement in gagging and retching and none of the children's tube-feeding symptoms were reported to have worsened (Pentiuk et al. 2011). Additionally, the children were anecdotally reported by parents to have a decreased incidence of constipation although unfortunately the authors did not measure this outcome (Pentiuk et al. 2011).

Like Pentiuik et al. (2011), Gallagher et al. (2018) found retching was reported to decrease from 82% to 47% ( $p=0.072$ ) when parents were surveyed six weeks after transition to blended diet. The children in the Gallagher et al. (2018) study had not previously undergone fundoplication surgery and vomiting was also reported by parents to decrease from 76% to 53% ( $p=0.015$ ). Unlike Pentiuik et al. (2018), Gallagher et al. (2018) found no change in stool frequency. However, the bacterial diversity of stool samples was significantly increased ( $p=0.05$ ), while the relative abundance of harmful proteobacteria was decreased which was considered to be beneficial. Gallagher et al. (2018) found parents perceived their child to be in less discomfort at six months after transition to blended diet. Both Pentiuik et al. (2011) and Gallagher et al. (2018) reported parents to be highly satisfied with the improvements they saw in their child following transition to blended diet although the impact on quality of life was not specifically discussed.

In the single case presented by Johnson, Spurlock and Galloway (2013) immediate improvement in tube-feeding tolerance was observed. The surveys of dietitians and professional opinion pieces also suggested that blended diet could be better tolerated by some tube-fed children in comparison to commercial formulas (Armstrong 2017; Johnson, Spurlock and Pierce 2015; Novak 2009). Novak et al. (2009) suggested that volume tolerance can improve on blended diet alongside a reduction in vomiting. Brown, (2014) reported some children in her care had been able to reduce anti-reflux medication after starting blended diet, however she also cautioned that some food ingredients if used in blends are likely to make reflux symptoms worse. However, Gallagher et al. (2018) noted only a small insignificant reduction in the use of such medication (88%-76%). Only Thomas, (2017) mentioned diarrhoea. She suggested that improved tube-feeding tolerance secondary to blended diet use can improve a child's quality of life. In the case presented reduced incidence of diarrhoea meant the child could attend school regularly (Thomas 2017). Conversely, in a US survey of parents of tube-fed children, Johnson et al. (2017) found only 19.7% of the parents surveyed reported tube-feeding intolerance to be the

primary reason for using blended diet. This suggests there are other factors which motivate parents to choose blended diet.

The articles identified in this literature review suggested that symptoms of retching and vomiting may reduce following transition to blended diet. The research suggests conflicting effects on stool frequency. However, differences are likely because the studies did not use the same food ingredients in blends and probably had different fibre and fluid contents in comparison to each other (Pentiuk et al. 2011; Gallagher et al. 2018). The blends were devised by a research dietitian and so the findings may not be applicable to parents who create their own blends without the support of a dietitian, as 50.7% of parents interviewed in the Johnson et al. (2017) survey reported doing. Furthermore, both studies were dependent on parents reporting improvements in symptoms using survey methods which are often open to individual interpretation. The frequency and severity of symptoms prior to transition onto blended diet were not reported by either paper (Pentiuk et al. 2011; Gallagher et al. 2018). Both papers identified that parents were highly satisfied with blended diet however the survey methods employed did not permit exploration of the impact of these symptoms on the child and family's quality of life. Other issues may motivate parents to try blended diet. No indication is given as to the impact of tube feeding intolerance on family life.

### **3.4.2 Risks**

A theme of risks was evident in all the papers included in this review. Parents in both uncontrolled cohort studies were given training to mitigate against risk of nutritional inadequacy, tube occlusion and gastrointestinal tract infection (Gallagher et al. 2018; Pentiuk et al. 2011). In both studies the diet was tailored to each individual child by the research team's dietitian using a dietary analysis programme and parents were taught how to store the blend safely and flush the tube to avoid occlusion (Gallagher et al 2018; Pentiuk et al. 2011). These risks were also a major concern for the surveyed dietitians and within the professional opinion pieces (Armstrong et al. 2017; Johnson, Spurlock and Galloway 2013; Johnson, Spurlock and Pierce 2015; Novak et al. 2009). The

main focus of the reports by Brown (2014) and Thomas (2017) was on the steps taken to minimise risk in a hospice and school settings respectively.

Interestingly, Armstrong et al. (2017) found dietitians with experience of blended diet in clinical practice were less concerned about the potential risks compared to dietitians without experience of blended diet. This would suggest that the risks are perceived rather than actual. Respondents in the US survey of parents using blended diet found only half sought help from a registered dietitian when devising recipes for blends (Johnson et al. 2017). In discussion Johnson et al. (2017) suggested that using blended diet without the support of a registered dietitian may pose a greater risk of nutritional inadequacy than use with advice from a registered dietitian.

Johnson, Spurlock and Galloway (2013) produced a decision tree based on a narrative literature review and a single case which, although a potentially helpful aid in clinical practice given the scarcity of research evidence seems rather speculative. This decision tree may have influenced other professionals in clinical practice such as, Brown (2014) and Thomas (2017) who took precautions to minimise risks when facilitating the use of blended diet outside of the home. Equally, support from professionals following this guidance may mean the risks are less likely to occur. The risks were also major concerns for dietitians surveyed by both Armstrong et al. (2017) and Johnson, Spurlock and Pierce (2015). However, Armstrong et al. (2017) identified different perceptions of the risks based on experience. None of the articles identified, including the US survey of parents, have attempted to ask parents using blended diet whether or not they have observed tube occlusion or signs or gastric infection in their day-to-day use of blended diet (Johnson et al. 2017). None of the articles included in this review comment on parent's perception or experiences of nutritional inadequacy, tube occlusion or gastric infection. The articles included in the review indicate that potential risks are major concerns for professionals however parental views have not been explored.

### 3.4.3 Weight

The effect of blended diet on weight was conflicting across eight of the included papers. Children in the Pentiuk et al. (2011) study were reported to have poor weight gain after transition to blended diet. However, the research dietitian was able to modify the blend to make it more energy dense and promote catch-up growth. Pentiuk et al. (2011) gave no indication as to whether the child was gaining lean muscle mass or excess adipose tissue. Gallagher et al. (2018) measured weight, length, triceps-skin fold (TSF) and mid-upper arm circumference and found the proportion of children with TSF above the fifth percentile was reported to increase from the beginning of the study to the end 76% vs 82% ( $p=0.001$ ) suggesting an increase in body fat rather than lean muscle mass. In the single case presented by Johnson, Spurlock and Galloway (2013) the child maintained a healthy growth trajectory over the three-year period on blended diet but had a previous history of weight loss on commercial formula. Johnson, Spurlock and Pierce (2015) found dietitians reported improved growth as a positive outcome of blended diet. US dietitians surveyed reported improved growth to be a benefit of transition to blended diet. In the survey of US parents 89.5% of respondents reported they were able to meet their child's growth goals using only blended diet (Johnson et al. 2017). The survey of UK dietitians found 45% thought weight gain was a benefit of blended diet but contradictorily weight loss was also perceived to be an issue by 45% (Armstrong et al. 2017). Likewise, Brown (2014) and Novak et al. (2009) have both warned of the potential for weight loss as a result of potential nutritional inadequacies.

Focusing solely on weight gain in children and young people with complex care needs may be unhelpful as previous studies have identified a risk of overfeeding and subsequent accumulation of adipose stores which can be detrimental rather than beneficial to health (Sullivan et al. 2005; Vernon-Roberts et al. 2010). This explains why Gallagher et al. (2018) investigated not only the impact on weight but additionally the impact of blended diet on lean muscle mass and fat mass using TSF. Additionally, there may have been other factors

which contributed to the weight gain or loss such as episodes of acute illness, activity or metabolic conditions. The research dietitian in the Pentiuk et al. (2011) study was able to adapt the blend for the three of the four children who initially lost weight, subsequently these three children regained the lost weight and the other withdrew from the study. From the literature identified in this review it is unclear whether blended diet has a positive or negative impact on weight. However, the studies identified followed children and young people over a relatively short period of time and there are likely to be other contributing factors to changes in weight.

#### **3.4.4 Improved Oral Intake**

Seven of the articles discuss a potential role for blended diet in weaning children who have a safe swallow from tube-feeding onto oral intake. Novak et al. (2009) suggested that blended diet allowed a tube-fed child the opportunity to smell, taste and belch foods allowing their gastrointestinal tract to become accustomed to the food. Stimulation of oral intake was also a benefit reported by both UK and US studies (Armstrong et al. 2017; Johnson, Spurlock and Pierce 2015). Pentiuk et al. (2011) reported that 57% the thirty-three children who took part in their study had an increase in oral intake and no child was reported to eat less on blended diet. Likewise, Gallagher et al. (2018) found the percentage of children eating any food orally increased from 67% to 82% during the study period. Furthermore, one participant transitioned to 100% oral intake three months into enrolment in the study (Gallagher et al. 2018). In the case presented by Johnson, Spurlock and Galloway (2013) the mother's main objective was weaning from tube-feeding onto an oral diet, her son had a safe swallow but refused food orally. Johnson, Spurlock and Galloway reported slow gradual progress with increasing oral intake over a three-year period. However, only 10.8% of respondents in the survey of US parents noted oral intake as their motivation for using blended diet (Johnson et al. 2017).

The authors of the cohort studies do not explain how many of the participants had a safe swallow and could eat orally. The remaining participants may have shown increased interest in food but were unable to eat due to risk of aspiration,

in this case increased interest in food might not be beneficial for the child. Novak et al. (2009) are a US multidisciplinary team whose clinical work focuses on weaning from tube-feeding; they are likely to see parents who are predominantly interested in tube weaning and therefore potentially over estimated this as a reason why parents choose blended diet. This could explain why only a relatively small percentage (10.8%) in the Johnson et al. (2017) indicated oral intake as motivation for using blended diet. However, the Johnson, Spurlock and Galloway (2015) survey had a relatively poor response rate (9.9%) and so the findings cannot be generalised. The surveys of dietitians additionally identified increased oral intake as a benefit but less so in comparison to the reduction of tube-feeding intolerance and increased parent involvement in feeding (Armstrong et al. 2017; Johnson, Spurlock and Galloway 2015). It is possible that an attempt to increase oral intake prompts parents to try blended diet.

#### **3.4.5 Increased Time and Effort**

Considerable time and effort involved in preparing blended diet was referenced in seven of the articles. A primary reason why parents surveyed in the Johnson et al. (2017) study did not use blended diet was time constraints (20%). Likewise, US dietitians surveyed by Johnson, Spurlock and Pierce (2015) identified time constraints as a barrier to using blended diet in clinical practice and additionally as a reason why parents opt not to use it over commercial formula. Novak et al. (2009) advised that blended diet takes considerably more time and commitment than using commercial formula and parents need to be motivated. Brown (2014) and Thomas (2015) make reference to considerable time invested by parent in preparing blends at home. However, the mother in the case outlined by Johnson, Spurlock and Galloway (2013) was reported to view blended diet as time invested in weaning her son from tube-feeding onto oral diet (Sub-section 3.4.4).

The additional time required is a potential concern, particularly for parents of a child who has additional complex care needs as time is likely to be more pressured. However, none of the articles indicated how much additional time



blended diet would take. In the Johnson et al. (2017), study time is a barrier reported by parents who do not use blended diet however the question of time was not posed to those parents who do use blended diet. In both uncontrolled cohort studies one parent withdrew from the study because of the additional time and work involved in preparing blends. This suggests some parents may not be able or willing to prepare blended diet for their tube-fed child. The authors unfortunately do not note whether potential participants declined to enrol in the study due to the perceived time and work involved (Pentiuk et al 2011; Gallagher et al. 2018). The articles included in this review suggested blended diet involves considerable time and effort on behalf of the parents which seems to conflict with the increasing interest in blended diet reported by the BDA (2013).

#### **3.4.5 Bond Between Parent and Child**

The bond between parent and child was referenced in six articles included in this review however professional opinion seemed to conflict with the survey of US parents. Increased parental involvement in feeding was perceived to be a key benefit in surveys of professionals and professional opinion pieces alike (Armstrong 2017; Brown 2014; Johnson, Spurlock and Pierce 2015; Novak 2009). In her discussion Brown (2014) cites a qualitative study which focused on mothers' experiences of transition from oral to gastrostomy feeding which found that it 'lacked emotional content' and mothers 'mourned the loss of nurturing if a child no longer ate' (Sleigh 2005 cited in Brown 2014). Likewise, in their discussion of a single US case Johnson, Spurlock and Galloway (2013) suggested blended diet helps parents to feel more involved in the care of their child. Conversely, in the later survey of US parents Johnson et al. (2017) found only 12.2% of respondents had wished to provide their tube-fed child with a family meal indicating a possible disconnect between the opinions of parents and professionals.

Peer-review professional opinion and single case report articles included in this review have raised important questions about the potential social and psychological benefits of blended diet (Brown 2014; Johnson, Spurlock and

Galloway 2013; Novak et al. 2009; Thomas 2017). However, this suggestion seems to conflict with the US survey of parents (Johnson et al. 2017). This study is important as it appears to be the first to ask parents directly about their experiences of blended diet rather than asking professionals how they perceive parents to feel and think. Nonetheless, questions about emotions are difficult to answer using survey methods, particularly multiple closed or multiple-choice questions and Likert scales like those used in the Johnson et al. (2017) study. It is likely that the subjectivity of this potential aspect of blended diet has been oversimplified. Social and emotional benefits were not noted in the Pentiuik et al. (2011) and Gallagher (2018) studies, it is likely that attempts to manipulate or prescribe blended diet in a trial context may negate some of the social and emotional benefits such as being able to choose and prepare food for the child. Use of qualitative research methods would permit naturalistic inquiry and depth of exploration in relation to the suggested social and emotional benefits of blended diet.

#### **3.4.6 Desire to use Natural Foods**

Parents desire to use natural foods was referenced in six of the articles included in the review. In the survey of US parents Johnson et al. 2017 found 20.2% of respondents cited a desire to use 'whole foods' as their main reason for choosing blended diet (Johnson et al. 2017). A further 19.7% of parents indicated that they did not like commercial formula although it is not clear if these were the same parents who expressed a desire to use whole foods (Johnson et al. 2017). In the survey of US dietitians, free text comments indicated that dietitians perceived parents wished to eliminate chemicals from their child's diet or follow a vegetarian or vegan diet (Johnson, Spurlock and Pierce 2015). Pentiuik et al. (2011) stated that some of the parents in their study viewed blended diet as more natural than commercial formula although this outcome was not specifically measured. A common goal set by parents in the Gallagher et al. (2018:4) the was to use of 'real food', however no explanation is provided as to what this means and why it was important to the parents.

Like the Pentiuik et al. (2006) study it has previously been noted that parents view gastrostomy feeding as unnatural (Peterson et al. 2006). Unfortunately, again the term was not defined by the authors and like Pentiuik et al. (2006) the method employed did not allow further exploration of the idea. There are potentially similarities between 'whole foods' and 'natural foods' because in the US the term can mean a food that has been minimally processed. This seems to link to a suggestion in a US literature review by Martin and Gardiner (2017) which implied the increasing popularity of blended diet was linked to a trend in the general population toward organic and unprocessed foods. Additionally, Mortenson (2006) suggested the popularity of blended diet is due to parents receiving mixed messages about including a variety of foods in the diet yet being asked to give their tube-fed child the same commercial formula every day. However, the term 'whole foods' was not defined and is open to interpretation by respondents and readers alike (Johnson et al. 2017). Based on the evidence available this idea seems rather speculative.

### **3.4 Conclusion**

This literature review using a systematic approach, identified just nine peer-review articles which focused on the use of blended diet for HETF as an alternative to commercial formulas. Furthermore, only five of the identified articles reported any research methods. The remaining four articles were a professional opinion piece and three single case reports. Most articles originated from North America (n=6), only one UK article reported research methods meaning that research is particularly lacking for the UK. This in part fuelled the reasoning and rationale for the doctoral study reported here.

Seven themes were identified from synthesis of the nine articles (each theme was evident in at least two thirds of the articles). Themes included tube-feeding tolerance, risks, weight, oral dietary intake, additional time required, the bond between parent and child and parental desire to use natural foods. However, the five studies which used survey methods to investigate perceptions of blended diet. Furthermore, attempts to prescribe blended diet and investigate it under clinical conditions may have negated some of the suggested social and

emotional benefits such as being able to choose food for a child. Survey methods are limited in scope when investigating complex and emotive ideas such as the impact on quality of life and the bond between parent and child. Furthermore, survey methods do not permit deeper investigation or allow the researcher to ask further questions. Moreover, in two of the surveys dietitians were asked to report on how they perceived parents to view blended diet meaning that the information is second hand and assumptions are made that professionals are fully aware of parental views which is unlikely. (Armstrong et al. 2017; Johnson, Spurlock and Pierce 2015). Only one study to date has attempted to ask parents directly about their experiences however this was again limited because of the methods employed (Johnson et al. 2017). The voice of the parent even though they are driving interest in blended diet is largely absent from the peer review literature.

The articles identified in this literature review have raised important questions about the potential benefits and challenges relating to the use of blended diet in comparison to commercial formula. However, these articles are limited. Most use limited survey methods in an attempt to investigate parent's perceptions of blended diet. Furthermore, two studies attempted to access parent's perceptions by asking healthcare professionals. This is limited given what is known about professionals conflicting views on the topic. Attempts to study blended diet under quantitative research conditions where the blend is adapted and manipulated may negate some of the potential social and emotional benefits that have been suggested. Robust qualitative research is needed to explore blended diet in depth prioritising the parent's perspective as the experiential experts in order to provide a greater understanding of why parent choose blended diet for their child. It would be useful to explore blended diet by asking parents with experience of using it what it means to them. The findings of this literature review have been used to inform the conceptualisation and design of the doctoral research as outlined in Chapter 4.

## **Chapter 4: Methodology**

### **4.1 Introduction**

Having set the scene from both the contextual evidence (Chapter 1) and more systematised review (Chapter 3) this chapter will now set out a critical account of how the research was conceptualised, planned and conducted. It was decided to use a conceptual framework to frame the design and an Interpretative Phenomenological Analysis (IPA) methodology was used to achieve the aim and objectives. The theoretical underpinnings of IPA are critically evaluated alongside researcher reflexivity. However, to commence this chapter the aim and objectives are included in Figure 4.1 as a reminder and the justification is summarised as to why this research focuses on the experiences of parents.

**Aim:** To generate rich data and a deep understanding about individual parent's experience of choosing blended diet to feed their long-term tube-fed child.

**Objectives:**

1. To explore the reasons why individual parents first consider an alternative to commercial formula.
2. To understand the benefits of blended diet as perceived by parents who use it to feed their tube-fed child.
3. To explore how individual parents have been supported by professional in their choice to use blended diet.
4. To identify challenges experienced by parents following their choice to use blended diet.

**Figure 4.1:** *The aim and objectives of this doctoral research (Section 1.5)*

There were four distinct reasons why the research focused on the experience of parents using home blended diet to feed their child:

1. The phenomenon is driven by the parents of tube-fed children and young people in the UK (BDA 2013). Yet, the voice of parents is missing from the existing peer-review literature on the topic (Chapter 3).
2. Parents are legally responsible for making decisions on behalf of their children. They are responsible for the delivery of day-to-day care in the home environment (Smith, Francine and Hilary 2015). Tube-feeding is commonly associated with severe complex care needs such as neurodisability which frequently affects cognition and communication making it difficult to directly explore the child's thoughts and feelings on the topic.
3. Parents who prepare and use blended diet are the experiential experts on its use; they are uniquely placed to comment on the benefits and issues.
4. Service users should be involved in the design and improvement of healthcare services (Department of Health 2008)

#### **4.1.1 The Conceptual Framework**

A conceptual rather than theoretical framework has been used in this thesis to structure the ideas which shaped how the research was designed and in turn how data were collected, analysed and presented. A concept is defined as '*a label used to describe a phenomenon*' (Meleis 1991:12). Quantitative research tends to use theory at the beginning of a project to develop a hypothesis then go on to test the relationships between variables to explain or predict phenomena (Savin-Baden and Howell Major 2013). However, theory is used differently in qualitative research as most theory development takes place following data collection or data analysis. Various metaphors have been used to illustrate the importance of the conceptual framework for example: a researcher's map (Miles, Huberman and Saldana 2014), a lens to focus the

work (Maxwell 2012) and the core or backbone of a doctoral thesis (Smyth 2004). Letherby (2003) makes a helpful analogy to food preparation which seemed in fitting with the topic of this research:

Our choice of recipe (method) and the way we prepare and cook the ingredients (methodology) affects the kind of dish (knowledge) we get. Further, different cooks using the same ingredients, because of their different views of cooking and food (epistemology), may produce quite different dishes. It is important that the 'recipe' and cooking processes do not get lost. Letherby 2003:17

One important part of the conceptual framework missing from Letherby's analogy is the paradigm or world view. Paradigms are expressed in their ontological, epistemological and methodological positions (Durham et al. 2015). Figure 4.2 illustrates the conceptual framework of this research including the paradigm, ontology, epistemology and methodology. This doctoral research took a subjectivist rather than objectivist world view. The research took a stance which assumed reality (Ontology) is socially constructed and therefore knowledge (epistemology) is qualitative, relativist and inductive. There were two reasons why qualitative methods were chosen for this doctoral research. Firstly, literature identified in Chapters 2 and 3 of this thesis suggested that there may be potential social and emotional benefits to the use of blended diet in comparison to commercial formula. Qualitative methods were deemed best suited to investigate complex concepts such as social constructs and emotions in depth. Secondly, as identified in Chapter 3 an attempt to study blended diet by prescribing the blend to the parent may negate some of the proposed social benefits such as being able to choose food for a child (Novak et al. 2009). Phenomenology was chosen because of the focus on understanding the meaning of lived experiences (other approaches which were considered but ultimately discounted are explored in Sub-section 4.2.2).

IPA was chosen to meet the objectives set (Figure 4.1) because the methodology allowed exploration of parent's thoughts, feelings and perceptions

and through interpretation understanding of the meanings parents attributed to their lived reality could be gained. Additionally, as IPA is idiographic, the methodology is respectful of the uniqueness of each participant; no one person thinks or feels exactly the same way as another person. Furthermore, a potential challenge posed was the parents themselves may not have fully understood their choices and feelings about blended diet. IPA encourages participants to reflect and try to understand themselves during the data collection process (the theoretical underpinnings of IPA are discussed in more depth in Section 4.2).

Some materials have been removed from this thesis due to Third Party Copyright. The unabridged version of the thesis can be viewed at the Lanchester Library, Coventry University.

**Figure 4.2:** *Illustration of the paradigm, ontology, epistemology and methodology of this doctoral research (adapted from Durham et al. 2015)*

This research also draws on concepts originating in feminist research. Skeggs (1994:77) claims that 'feminist research begins with the premise that the nature of reality in western society is unequal and hierarchical'. In other words, Skeggs (1994) is saying that there is a power imbalance where some individuals are represented more than others. Although feminist research has its origins in understanding why inequality exists between women and men, Letherby (2003)



more recently suggested that the aim of contemporary feminist research is to change things for the better for women and men living in the world. Feminism has focused on experience as a way of challenging traditional dominant points of view by giving underrepresented groups voice about their own personal experience (Maynard 1994). In the case of blended diet, it could be considered that healthcare professionals have the dominant point of view because their opinions are presented in medical journals and respected professional magazines. Parent's opinions which are voiced for example in online blogs and on social media are often dismissed by healthcare professionals as being anecdotal, they are viewed as unreliable sources (Marino and Meyer 2015). This potentially contrasting view of what constitutes knowledge on the topic may have led to tensions between parents and healthcare professionals. Willig (2013) suggests there is no single feminist epistemology or methodology. Reinharz (1992) points out that feminist researchers have used an array of methods and argues any research method can be used in a pro-feminist or non-feminist way. Kelly et al. (1994) suggest it is not the methods that are used but the particular ways in which the research is carried out which makes it feminist. Letherby (2003) describes feminism as an overarching ideal approach to doing research which is respectful of respondents and acknowledges the subjective involvement of the researcher. This research has taken a feminist ideology by respectfully using rigorous research methodology to give parents a voice about their personal experiences with blended diet. Letherby (2003) points out that it cannot be assumed that participants will give a true account of their experience as they are likely to have their own agenda. In this research, for example the parents' agenda could be to influence the endorsement of blended diet by the BDA or NHS (change.org 2014). It is therefore important to use methodology which recognises that it is never truly possible to access an experience but rather to gain an understanding of how the individual has made sense of an experience.

A final conceptual label which has been used to inform the design of this research is interpretive description. The term was coined by Thorne, Reimer Kirkham and MacDonald-Emes in 1997, three nurse researchers who found

traditional qualitative research methodologies required adaptation for real world utility. Interpretive Description had particular resonance since the work which inspired it focused on the meanings of long-term gastrostomy in children with severe disability (Thorne, Radford and McCormick 1997). Like IPA, Interpretive Description shares an epistemological focus on interpretation, is part of the field of 'applied' qualitative methodology and was developed in the late 1990s. Unlike IPA, Interpretive Description is not a methodology per se but a theoretical positioning which justifies the departure from the full scope of a conventional qualitative research tradition (Thorne 2016). Smith (2011) encouraged adaptation of IPA and it has been used in numerous fields of qualitative inquiry by healthcare professions from different professional backgrounds (Biggerstaff and Thompson 2008). However, IPA does have its roots in healthcare psychology, its use in this research by a dietitian was likely to alter the type and depth of analysis. IPA has been chosen as a tool which can be used to meet the aim and objectives of this research. Interpretive Description here justifies why IPA may not have been used to its full functionality and the subtle adaptations made to suit this purpose. It also demonstrates a commitment to designing, conducting and presenting research which has implications and can be applied by dietitians and other health professionals working with tube-fed children and young people.

## **4.2 Methodological Considerations**

IPA was considered to be the best approach to achieve the aim and objectives set (Figure 4.1). In the first part of this section IPA is introduced and its philosophical underpinnings explored in the context of this research. Section 4.2.2 comprises a critical evaluation of IPA.

### **4.2.1 Interpretive Phenomenological Analysis (IPA)**

IPA is a type of hermeneutic phenomenology which takes a strong idiographic approach (Smith, Flowers and Larkin 2009). Phenomenology is a qualitative approach which assumes knowledge and meaning can be generated by attempting to understand lived experience (Finlay 2011). Hermeneutic

phenomenology is a distinct branch of phenomenology which incorporates the theory of interpretation (Bäckström and Sundin 2007). An idiographic approach means analysing each case individually before conducting any cross-case analysis (Smith 2004). The approach has grown rapidly in popularity since it was first described by Jonathon Smith, a researcher in the field of psychology in 1996. Smith proposed that IPA has attracted interest because it provides 'practical and accessible guidelines' (2004:40) that are offered with a clear epistemological position. Although Smith does not claim to have invented phenomenology, hermeneutics or the idiographic approach that define IPA he has 'put the three terms together in this particular configuration' (2004:40) and suggested guidelines which help ensure research is designed and data analysed in a fashion that stays true to the approach's epistemological position. As a novice qualitative researcher these suggested guidelines and the clear epistemological position were helpful.

IPA has 'gained popularity and momentum' (Pringle et al. 2011: 20) since it was first described. Langdridge (2007) describes IPA as the most widely known qualitative approach to phenomenological psychology. Despite having roots in psychology, IPA has been used in a wide range of fields of qualitative inquiry including business, education and healthcare (Wagstaff et al. 2014). A review carried out by Smith (2011) identified 293 empirical studies which identified themselves as IPA. In health research Biggerstaff and Thompson (2008) described IPA as a rigorous qualitative methodology which can be used to understand the service users lived experience. In this case IPA methodology allowed the perspective of individual parents who had chosen blended diet to feed their child to be explored and understood.

In part, IPA draws on phenomenology, as it has been re-shaped by the philosophers Heidegger, Merleau-Ponty and Sartre (Larkin and Thompson 2012). Husserl is credited as being the founding father of phenomenology; the theory of being (1927). Husserl (1927) was interested in how a person becomes conscious of their own experience of a phenomenon. He believed that with an in-depth reflection the individual could explore thoughts and feelings thus

illuminating the experience for others too. In this research, parents' reflections on their thoughts and feelings about choosing blended diet could illuminate the experience for others too.

Husserl (1927) also believed it was possible to transcend everyday assumptions about a phenomenon by 'bracketing off' former knowledge, this is where Heidegger, Merleau-Ponty and Sartre disagree (Larkin and Thompson 2012). Heidegger (1962/1927) argued that all experience is interpreted by the individual based on their own positioning within the world, from which they cannot be separated. For this research, this means individual parent's experience of choosing blended diet is likely to have been shaped by their own past experiences.

Merleau-Ponty (1945) developed the idea that human beings are connected to the world around them with each person seeing themselves as different from everything and everyone else in the world. Merleau-Ponty's work implies that two individual human beings will never have the exact shared experience as each other because experience is shaped by a unique embodied position within the world and while empathy for another person can be experienced the experience itself cannot be captured and absorbed (Smith, Flowers and Larkin 2009). It will not be possible to truly access the experience, but it is possible rather an attempt should be made to empathise.

Sartre (1948) extended existential phenomenology by suggesting people are shaped by the world and the other people around them. This means individual parents will have tried to make sense of the experience by making comparisons to the other people around them. For example, comparing their own experiences with their peers on online support groups. Furthermore, Sartre (1948) suggested that the things people expect to see but are absent are as important as the things that are there in defining who we are and how we see the world. For example, if an individual parent expected to have a healthy child and but now has a child with complex care needs the way they expected life to be is likely to shape the way they see the world now.

Interestingly, Heidegger (1962/1927) linked phenomenology in his work to hermeneutics, the theory of interpretation. Heidegger proposed that whenever human beings try to understand they interpret based on their own circumstances, experiences and pre-conceptions. Unlike Husserl (1927), Heidegger (1962/1927) did not believe it is possible to 'bracket' off previous knowledge or context to obtain a presupposition-less understanding (1962/1927). This means as a researcher it is not possible to completely detach from past experiences; only to be aware of them.

The theory of hermeneutics which underpins IPA was further shaped by Schleiermacher (1998) who suggested that interpretation is split into two levels: grammatical and psychological. He also recommended that the interpreter should try to understand not only the text but the person who wrote it too. Scheimemacher suggested that a detailed interpretation can lead to the interpreter having a better understanding of the meaning of the text than the author. Scheimermacher's work was criticised as psychologising by Gadamer (1990/1960) who suggested the focus of interpretation should be on the content of the text itself and the effect the text has (discursive). The contrasting opinions of Schleiermacher and Gadamer suggest there were different levels of interpretation possible in this research. Smith (2007) argued that Schleiermacher's work bridged the essentialist and discursive, this means the researcher had an opportunity to make sense of the parents' words and a gain a picture of the parent as a person, to provide a holistic analysis.

Smith (2004:44) referred to this as a 'double hermeneutic' in which the analyst plays a 'central role'. Heidegger's hermeneutic philosophy would suggest that the interpretation (the findings of this thesis) will have been inevitably shaped by the analyst. In this case the analyst was a specialist home enteral tube-feeding (HETF) dietitian with experience of working with families using blended diet. Additionally, the researcher had their own personal beliefs about food and diet in general. Larkin and Thompson (2011) suggested it is not possible to seal off pre-conceptions in IPA research but it is important to aim to be open-minded and be aware of biases to minimise the impact. For this reason, a reflexive diary

was kept by the researcher throughout the research process (this is explored in detail in Section 4.8).

The third and final theoretical underpinning of IPA is the idiographic approach. This means that the focus is on the particular (individual) rather than the nomothetic (group) level (Smith, Flowers and Larkin 2009). Idiography works on two levels within IPA, firstly the sense of detail and depth in analysis of each individual case and secondly seeking to understand how an experience is understood from each personal perspective shaped by the individual's place in the world (Smith, Flowers and Larkin 2009). IPA encourages the researcher to focus on detailed analysis of the individual case first before making any comparisons between cases: this approach fits well with the overall feminist research ideology ensuring that parents were well represented within the research and the focus remained on their unique and individual experiences. The idiographic approach is a central focus of IPA. Taking an idiographic approach in this case meant focusing on individual parent's experiences first before attempting to make comparisons between individuals. Maintaining an idiographic approach influenced the choice of research method and design (Section 4.3) chosen in this research and the structure of the subsequent analysis (Section 4.5).

#### **4.2.2 Critical Evaluation of IPA**

This sub-section contains a critical evaluation of IPA, its strengths and limitations are considered, in relation to the aim and objectives of this research. IPA has its roots in psychology and the majority of IPA studies are in the field of health psychology. However, Brocki and Wearden (2006) suggested IPA is relevant to other fields of qualitative inquiry too; it is popular in health psychology because the methodology was developed by people working in the field and it is considered a suitable methodology for the exploration of the subject. There is now, a large body of IPA research which looks at illness and healthcare in a variety of different settings (Biggerstaff and Thompson 2008). Furthermore, there are several studies which have used IPA to gain an understanding of parent's decision making on behalf of their child (Daniel et al.

2005; Glasscoe and Smith 2010; Macleod, Crufurd and Booth 2002). Use of the conceptual label: interpretative description (Section 4.1.1) acknowledges that IPA in this research is being used outside the field of health psychology (Thorne 2016).

Furthermore, Smith and Osborn (2003:53) described IPA as 'especially useful when one is concerned with complexity, process or novelty'. As discussed in Chapters 1-3 the topic of blended diet could be considered to be all three. Blended diet is certainly not straight forward. Additionally, this contemporary version of blended diet, which is chosen in preference to commercial formula can be considered novel (Chapter 2). This research aimed to focus on parent's decision process to use blended diet to feed their child. These three factors would suggest IPA was a useful methodology and tool by which to explore the topic of blended diet.

A criticism levelled at qualitative research in general, particularly if viewed from a positivist perspective where generalisability is seen as a hallmark of quality, is the focus on small sample sizes. IPA uses small sample sizes even in comparison to other qualitative approaches such as grounded theory, which recruits large numbers of participants with a view to generate theory (Barbour 2007). Several IPA studies have been carried out which focus only on one case, Smith, Flowers and Larkin (2009) argued that smaller participant numbers facilitate a deeper and more interpretive analysis. This draws on Warnock (1987) who suggested that looking closely at the individual can take the research closer to the universal, especially if the individual account resonates with aspects of shared humanity. Even in IPA studies with multiple participants focus is first, in detail, on individual experience. Malim et al. (1992) argued that generalisations from idiographic approaches are not possible especially when small sample sizes are used. Smith et al. (2009) advised IPA researchers to consider 'theoretical transferability rather than empirical generalisability'. Furthermore, Smith (2004) suggested that theory generation is not the purpose of IPA, although the understandings gained from IPA research can contribute to theory in a broader sense. The aim of this research project was not to generate

theory per se but to contribute toward improving clinical practice by providing greater understanding.

IPA methodology has been criticised by some qualitative researchers too. Chamberlain (2011) for example, questioned whether the theories of phenomenology and interpretation could be meshed together in the way Smith (1996) has suggested. This argument stems from an extensive debate over what counts as phenomenology and how phenomenological research should be carried out. Giorgi (2010) a Husserl-inspired phenomenologist, has suggested IPA has little to do with philosophical phenomenology. However, Brooks et al. (2015) highlighted that although phenomenology stems from the work of Husserl, different branches of phenomenology have developed over time, each shaped by different philosophies. Smith (2004) was clear that IPA is strongly aligned to the interpretative or hermeneutic branch of phenomenology. Brooks et al. (2015) also argued that IPA, rather than taking one particular theoretical phenomenological position draws upon a range of phenomenological thinking. Pringle et al. (2011:21) suggested the interpretation element could 'more fully uncover or bring into the light the meanings phenomenology is seeking to achieve'. IPA can be considered phenomenological because it seeks out embodied, experiential meanings and offers 'a fresh, complex, rich description of a phenomenon as it is concretely lived'. Finlay (2009:7).

Willig (2013), a discourse analyst, argued that IPA and other forms of phenomenological research suffer from both conceptual and practical limitations. She pointed out that phenomenology relies upon participants having the language tools to communicate their experience in detail and questions if this subsequently limits the number of people who are eligible to take part in IPA studies (Willig 2013). This is a limitation for this research as it means some parents may not be comfortable in sharing or describing their experiences, for example, if English is a second language. This unfortunately means some parents may have been excluded from taking part. Willig (2013) also argued that the same experience can be described by the same person in a number of different ways, the language that is chosen will paint a picture but does not



allow direct access to the experience (Willig 2013). However, as explained in sub-section 4.2.2, IPA draws on the philosophy of Merleau-Ponty (1945) and acknowledges it is never possible to truly access experience, instead attempts are made to empathise. This research did not attempt to directly access the parents experience instead efforts were made in an attempt to understand their point of view in relation to their own lived experiences.

It could also be argued that there is no guarantee that the parents would give an accurate or true account of their experiences. Participants are likely to have their own personal agenda when taking part in research (Letherby 2003). Additionally, participants' accounts of their experiences could have been shaped and influenced by the experiences of others or other similar experiences in their own lives. In this research it was important to consider that participants could have spoken to others family members or other parents in similar positions or read online blogs and accessed online support groups (Section 2.4). There will have been external influences on the parent's sense making in relation to blended diet. By using IPA this research is not interested in whether or not a parent's account of is 'true' or 'false' but rather how they have made sense, understood and attributed meaning to their own experiences (Larkin and Thompson 2011).

Equally, this research involved parents drawing upon memory of experiences that happened some several years previously. Memory has been found to change over time (Schmolck, Buffalo and Squire 2016). However, Gutgsell, Harris and Wilson (2015) suggest the clarity of memory depends on the importance attributed to the experience. Smith, Flowers and Larkin (2009) argued that IPA is particularly relevant when an experience led a participant to 'contemplate, take stock, worry and try to make sense of what is happening'. It is likely that parents will have made a conscious decision to use blended diet. Furthermore, this research was interested in understanding the present meanings parents attributed to blended diet based on their understanding of their own past experiences rather than the accuracy of their recall.

IPA starts with thematic analysis but aims to move beyond thematic analysis into interpretation (Smith, Flowers and Larkin 2009). Braun and Clarke (2006) consider thematic analysis a method in its own right and suggested that methods such as IPA are constrained by their theoretical roots. The opposing view is that the theoretical roots 'add a sense of depth and purpose' which thematic analysis used as a standalone method in its own right may lack (Pringle et al. 2011:21). This research aimed not only to present what participants said about their experiences but also to look closely at their sense and meaning making to provide a greater depth of understanding.

Chamberlain (2011:51) argues IPA may be 'considered wanting' as there is insufficient guidance on the 'depth, scope and appropriate interpretative level' that is appropriate. Moreover, Brocki and Wearden (2006) point out that IPA is limited by the researcher's own ability to reflect and analyse data. However, Smith, Flowers and Larkin (2009) stated that the guidelines are designed to encourage reflective engagement, whilst maintaining a commitment to the theories IPA is based on. Subsequently, Smith (2004) suggested that different levels of interpretation can be attained using IPA depending on the experience of the researcher (2004). Todorova (2011) suggested that IPAs popularity is due to its attempt to strike a balance between complexity and accessibility, likewise, between and prescription and flexibility. In this case IPA offered a set of guidelines which were accessible to a novice qualitative researcher; however, these guidelines were not prescriptive and could be adapted to meet the specific aim and objectives of this research.

### **4.3 The Research Design**

The purpose of this section is to demonstrate how the research was designed and conducted whilst maintaining a commitment to the conceptual framework (Section 4.1.1) and methodological approach (Section 4.2.1). Sub-section 4.3.1 begins by introducing the in-depth interview and justifies why this research tool (method) was chosen over others. The sub-section then moves on to look at the specifics of the interview design including: the form, duration, location and

recording of the interviews. Sub-section 4.3.2 explores the sampling strategies employed and the rationale behind the inclusion and exclusion criteria used.

#### **4.3.1 Choice of Research Tool (Method)**

Face to face interviews were chosen as the tool best suited to meet the aim and objectives of this research. Smith, Flowers and Larkin (2009) suggest IPA is best suited to a method which allows participants to give 'a rich detailed, first-person account of their experiences'. Most IPA studies use in-depth interviews as a tool to collect data (Brocki and Wearden 2006). Smith and Osborn (2003) describe interviews as an exemplary method because they allow the researcher and participant(s) to enter into dialogue whereby questions can be modified according to the participant(s) response. The qualitative interview has been described as a conversation with purpose in which researcher adapts questions depending on participants responses, they also allow for rapport (close connection or relationship) to be built (Savin-Baden and Howell Major 2013). Smith, Flowers and Osborn (1997) suggest rapport with the interviewer is important to put the participant(s) at ease or develop trust and suggest it is unlikely good data will be obtained without it.

Brocki and Wearden (2006) additionally identified that the vast majority of IPA studies were conducted face-to-face. This type of interview, where the participant and researcher are in the same room at the same time, made rapport easier as the researcher can respond to non-verbal as well as verbal cues (Savin-Baden and Howell Major 2013). A second advantage of the face to face interview is that the researcher can respond to the participant in real time for example to rephrase a question when a participant has misunderstood or ask a participant to expand on an interesting response (Smith, Flowers and Larkin 2009). Alexander and Clare (2004) pointed out since the participant is the experiential expert in IPA so it is important that the researcher has understood them correctly.

In a review of IPA studies Smith (2011) noted that it is possible to carry out good IPA interviews over the telephone or via email. Turner, Barlow and Ilbery

(2002) used telephone interviews due to the geographical locations of participants however they do acknowledge the limitations such as difficulty in establishing and maintaining rapport and inability to respond to non-verbal cues. Murray and Rhodes (2005) conducted their interviews via email but a limitation is the length of time between responses, this could cause a participant to be distracted or lose their train of thought. Email can also be considered less personal than face to face or telephone interviews interaction and the tone can be difficult to judge. A decision was taken not to use email due to the difficulty in responding in real time. However, potential participants were offered a choice of face to face, telephone or Skype interviews given the likelihood of them having other commitments such as caring for a child with complex needs. Interestingly all participants preferred to meet in person.

Serious consideration was given to the use of focus group interviews as a data collection method. Focus group interviews would have allowed participant to interact with each other potentially triggering interesting ideas and debate. Additionally, focus group interviews could have saved time and resources by permitting multiple voices to be heard at once. Dunne and Quale (2001) believed that their participants gave the same account in the group interview as they would in a one to one interview however, they cannot know this for sure. Flowers, Duncan and Knussen (2003), Flowers, Knussen and Duncan (2001) and Flowers Duncan and Frankis (2000a) disagreed, they conducted focus group interviews alongside one to one interviews and found there were differences in the two types of data generated. Furthermore, Tomkins and Eatough (2010:246) suggested there is a risk focus group interviews can create a 'false impression of consensus'. Palmer et al. (2010) suggested it may be more difficult to stay true to the underpinning idiographic principals using focus group interviews because the answers are shaped by the group patterns and dynamics. Smith (2004) is unconvinced that focus group data can be described as phenomenological.

In feminist research, Wilkinson (1999) suggested focus group interviews work best when speaking with pre-existing groups for example friends or family

members. Although parents may have 'met' online through support groups like the Blended diet UK Facebook page they are not a pre-existing group as such and were likely to live in a wide spread of locations across the UK. It was not fair to ask participants to travel to a focus group interview especially as they would be likely to have other commitments including the care of a child with complex care needs. Additionally, Savin-Baden and Howell Major (2013) suggested that focus group interviews work best in situations where there is likely to be consensus. As discussed in Chapter 3 of this thesis, the perspectives of parents have not been explored previously so it was not clear if their opinions, like professionals, would have been divided. It was thought that individuals may not be fully able to voice their perspective of their own personal experiences in a group setting because someone in the group may have dominated, and others may subsequently be afraid to disagree with them. A decision was instead made to use one to one interviews rather than focus group interviews.

It was decided that the interview should take place in a location that the parent had chosen; this could be their own home or a public place for example a coffee shop. The reason for this was to make participants feel comfortable and in control in the hope that they would then be more able to give a rich and detailed account of their experiences (Smith, Flowers and Larkin 2009). For practical and considerate reasons, it was also likely that participants would have the responsibility of caring for a child with complex care needs it was important that the research should not interfere with their ability to carry out that care.

Each interview was captured using a digital audio recorder, this meant that the interview it could be replayed and listened to and transcribed at a later date. Using an audio recorder allowed the researcher to focus on listening and responding to the participant instead of dividing their attention by taking notes (Sacks 1984). It could be argued that video recording would have captured the participant's facial and nonverbal expressions however these are not routinely examined in IPA studies and it could potentially put some participants off taking part (Smith, Flowers and Larkin 2009). The small digital audio recorder was

easily portable and unobtrusive. It was also possible to store the device securely in a locked filing cabinet (see Section 5.5.2). Participants could have felt self-conscious being recorded and therefore less willing to disclose sensitive information. Steps were taken to put the participant at ease by ensuring anonymity and offering participants control over the device.

Smith Flowers and Larkin (2009) suggest a time frame between 45-90 minutes to obtain data which is rich and detailed enough for IPA. An additional thirty minutes prior to starting the interview was factored into the visiting time to allow for rapport to be built, obtain written consent and to put the participant (and researcher) at ease this was subsequently the duration aimed for in this research. After the audio recorder was stopped time was taken to thank the participant, allow the participant time to ask further questions and explain the next steps in the research process. It was important to strike a balance between having an interview which was long and detailed enough and being respectful of participant's potentially busy lives.

A semi-structured interview schedule with eight main questions and a series of prompts and probes was used (See Appendix 3). The interview schedule was developed using the literature (Chapter 3) and guidelines for developing interview schedules for IPA in the text written by Smith, Flowers and Larkin (2009). Carpenter and Suto (2008) argued against the use of structure in an interview; they implied that any structure given to an interview aims to illicit a desired response which goes against the underlying principles of phenomenology. Conversely Collins (1998) argued that even the most unstructured interview has some form of structure or purpose and the labels structured and unstructured are unhelpful. As a novice qualitative interviewer, it was decided it would be useful to have some structure for the interview, to make sure the interview led to a complete picture of the parents' experiences and nothing was missed. It was envisaged that the interview schedule would act as a guide to encourage conversation. The interview schedule was informed by the existing literature (Chapters 2 to 4) as well as previous clinical experience (Chapter 1: Section 1.3). Planning the schedule meant that the interview

structure was carefully thought through; it also meant that interview technique could be practiced with the supervision team. This was helpful as it allowed practice before using the schedule with participants. As seen in Figure 4.3, questions were designed to be open and expansive allowing the participant to talk at length. Care was also taken to ensure that the main questions were not leading or judgemental; it was important not to put words in the participant's mouths but allow them to explain their experiences and understanding of blended diet in their own words. It was expected that the participant would do the majority of the talking during the interview, but a series of prompts were developed alongside the main questions to give the researcher the tools to encourage the participant to explain their understanding of their experiences.

Probes were also used to encourage the participant to expand or develop an answer in their own words. In standardised interviews (using a positivist framework) probes are not used as it is seen as important to deliver the question to each participant in exactly the same way. Probes were used in this research to encourage the parent to reflect on a previous answer or give more detail in order to understand their reasoning. Gilbert (2008) suggested that probing is a key skill in qualitative interviewing as probes encourage the participants to give a full response. Smith, Flowers and Larkin (2009) advised that probes should be neutral and encourage the participant to elaborate in their own words (Figure 4.3). The interview schedule (Appendix 3) was not designed to be a fixed or rigid tool and was used flexibly to ensure all questions were covered by the end of the interview there was also room to re-visit points or ask participants to expand further if required.

Could you describe your first experience of using blended diet?

Prompt: How did you feel when you first used blended diet?

Probe: That's interesting why?

What do you mean by? Why? How did you feel? What did you think?

**Figure 4.3:** *An example of an open non-judgemental question with associated prompts and probes (the full interview schedule can be seen in Appendix 3)*

It was decided that it would be possible to capture the parents' experiences of choosing blended diet in one interview rather than conducting multiple interviews with the same participant. In some cases, IPA has been used to interview the same participant on more than one occasion at different time points (Smith, 1999). This is more appropriate when interviewing a participant before and after a certain event for example Smith (1999) interviewed mothers before and after having a baby. This research design involved looking back at a decision parents had already made in the past rather than looking at experience before and after an event. There were also time and cost implications which would have made revisiting participants who came from a wide geographical spread impractical. It was decided that the aim and objectives of the research study could be met during one face to face interview.

#### **4.3.2 The Sampling Strategy**

This sub-section sets out how participants were approached and selected to take part in the research study. Firstly, the reasons behind the sample size used are specified. The sampling strategies used are then outlined and critiqued. Finally, Table 4.1 and the accompanying text outline the inclusion and exclusion criteria and the justification behind the choices.

A target of between ten and fifteen interviews was decided upon. Brocki and Wearden (2006) identified that IPA studies ranged in participant numbers from one single case to thirty individual interviews. In this case, there were four reasons from choosing the target number of participants:

1. Firstly, as discussed in Sub-section 5.3.1 IPA is an idiographic approach, it privileges the experience of the individual. This involved detailed analysis of each interview on an individual level rather than striving to recruit large numbers in order to make generalisations. It is difficult to meet the commitments of IPA with a sample which is too



large as this affects the depth of the analysis possible (Smith and Osborn 2003).

2. In the later stages of IPA, the analyst looks across the cases for examples of convergence and divergence (Pringle et al. 2011). To illuminate the experience of using blended diet it was thought best to present an array of between ten to fifteen individual experiences.
3. The researcher was new to qualitative research interviewing: it was thought that the quality of the interviews would improve with practice and experience (Smith, Flowers and Larkin 2009). If on moderation by the supervision team the interviews had been found to be leading, then interviews would have been discounted from the findings: it seemed prudent to strive for a larger number of participants in case of this. The interview schedule was tested out with a parent of a tube-fed child who used blended diet. On review with the supervision team the depth of data collected was deemed sufficient to be included in the analysis (Anna).
4. Practically, the number of in-depth interviews possible was limited as it would take time and money to travel to interview locations.

A purposive sampling strategy using the Blended Diet UK Facebook group was used to find parents of children with long term enteral feeding needs who had chosen blended diet. As discussed in Chapter 1, it is thought that some individuals may use blended diet at home without the knowledge of their healthcare team (Coad, Toft and Kelly 2015) and so might be cautious about revealing that they are using blended diet to their healthcare team. In IPA research, it is important that individuals are able to speak freely about their personal experience (Smith, Flowers and Larkin 2009). Cotterill (1992) and Conneeley (2002) suggest recruitment through a patient's own healthcare service can have an effect on the power dynamic. It was believed that if recruitment took place through an NHS dietetic service, for example a

participant may report what they thought their dietitian or doctor would want to hear rather than give a true account of their own experience. At the time this doctoral research was designed, the Blended Diet UK Facebook had over 1400 members (Facebook n.d.). Support groups and networks have been used in qualitative research to obtain participants from hard to reach groups and it was thought this would provide an alternative route independent from NHS services (Section 4.6). These strategies were used with the hope of finding participants who were happy to speak freely about their experience and volunteer their time to the research.

The sampling strategy aimed to find parents who had chosen to feed blended diet to their child via an enteral tube. As discussed in Chapter 2 the exact number of families using blended diet in the UK is not known (BDA 2013). Those using blended diet are potentially a hard to reach group and the numbers of individuals willing to speak openly about their experience was potentially small. For these reasons, it was decided not to limit the sample in terms of nationality, ethnic background, gender or age. Additionally, by not limiting the sample any potential issues that arose could be explored for example, were younger parents different to older parents. Table 4.1 outlines the final inclusion and exclusion criteria used in the research design. Throughout the sampling process a pragmatic approach was used as the inclusion and exclusion criteria were reviewed as expressions of interest were received.

**Table 4.1:** *Inclusion and exclusion criteria for participation in the research.*

Inclusion Criteria	Exclusion Criteria
Parent of a tube-fed child or young person between the ages of 1 to 25 years.	Other relations, carers and healthcare professionals.
Using blended diet (either alongside or in place of commercial enteral formula) to meet their child's	Parent who is considering using blended diet to feed their child but who have not yet started the practice.

nutritional needs for at least 12 months.	Parent who has used blended diet in the past to feed their child but no longer uses it.
Living in the UK	Parent who has used blended diet to feed their child for <12 months.
Good grasp of the English language	Living outside of the UK
	Need to be able to describe their experience in depth and detail

The research focused on the experience of parents using blended diet. As discussed in Chapters 2 and 3, the majority of papers published on blended diet express the opinions of healthcare professionals and the voice of the parent is missing despite the phenomenon being driven by parents. Other family members and carers were excluded as the research was interested in a healthcare choice it was important that the participant had legal parental responsibility to make that choice on behalf of their child. To capture the potentially influential input of other family members including grandparents, participants were asked about the support they had received in making the decision to use blended diet. Consideration was given to limiting the research to the experience of mothers as the majority of online blogs have been written by mothers rather than fathers. However, Brotherton and Abbott (2012) looked at choice and decision making in HETF and have focused only on mothers. In discussion the authors highlighted a need for inquiry into the father's perspective. Additionally, excluding fathers from the research would have sent out a message that father's experience was less valuable than mothers. It could also have perpetuated a gender stereotype, reinforcing ideas that feeding a child is mainly a maternal concern.

The age limit of the children and young people using blended diet was carefully considered and an upper age limit of twenty-five-years was decided upon for the cut-off age. Legally a child is considered an adult at the age of eighteen-years-old. Consideration was given to excluding parents whose child was over

the age of eighteen-years-old. This cut off was extended to twenty-five-years for three reasons. Firstly, the point at which a child transitions from child to adult NHS services is not clear cut and often varies depending on the individual service. Secondly, in cases where the child has complex or life limiting needs the transition is more complicated and the parent may make decisions in the child's best interests until they are well into adulthood. Finally, the design of the study involved the parents looking back at a decision to feed their child a blended diet which may have been made several years previously when the young person was still a child.

It was decided to recruit only those individuals who had been using blended diet for more than twelve months. It was thought that parents who had been using blended diet for at least twelve months would have sufficient experience to draw upon and it would be more likely they had experienced more interactions with healthcare professionals than individuals who had just started blended diet. Also, as discussed in Chapter 2 the use of blended diet is a contentious issue in the UK and professionals have expressed concern over the safety of its use. There was a risk that parents in the process of making a decision to use blended diet would use the research to gain access to a registered dietitian with an interest in blended diet and ask for advice, which would not be appropriate. Care was taken to manage the participant's expectations and ensure that the line between researcher and therapist did not become blurred (this is discussed further in Section 4.6 below).

The research focused on individuals living and receiving healthcare in the UK. As discussed in Chapter 2 there is evidence to suggest that interest in blended diet is growing in other countries such as America (Johnson, Spurlock and Galloway 2013; Johnson, Spurlock and Pierce 2015; Mortenson 2006; Novak 2009 Pentiuik et al. 2011) and Australia (O'Gorman 2012). This doctoral research was informed not only by the literature but also by the researcher's practical clinical experience working in the NHS. The researcher had a good understanding of UK healthcare services which in turn facilitated understanding and interpretation of parents' experiences. There were also practical reasons

why it was not possible to carry out international research for example financial and time constraints. It was envisaged that the findings of this research would generate more understanding and be more useful to NHS services if the research focused on individuals with experience of using NHS services.

The research project excluded non-English speakers which may be perceived as limitation. However, there were methodological, ethical and practical reasons for this exclusion. Epistemologically IPA requires a rich detailed account and a language barrier would have made this difficult to achieve. It was not financially viable to employ a translator and ethically by using relative or family member to translate confidentiality and anonymity could have been breached.

#### **4.4 Data Collection**

This section outlines how data was collected. The section begins by commenting on the response to the advertisement placed on the Blended Diet UK Facebook group (Sub-section 4.4.1). Anonymised information about the parents participating in this research is then provided (Sub-section 4.4.2). The section ends with a first-person reflection on the data collection process (Sub-section 4.4.3).

##### **4.4.1 Response and Eligibility**

The response to the research from parents was good. In email correspondence, the administrators of the Blended Diet UK Facebook group were keen for research to take place and promoted the research on the private group. Several members of the Blended Diet UK Facebook group further promoted the research by frequently commenting to ensure the advertisement stayed at the top of the news feed, even though they were not asked to do this. The voluntary promotion of the research on the Blended Diet UK Facebook group page and the level of response demonstrated an enthusiasm, within the blended diet community, for research to take place.

Eighteen people responded to the advertisement by email within the recruitment period. A further three participants were identified through snowball sampling

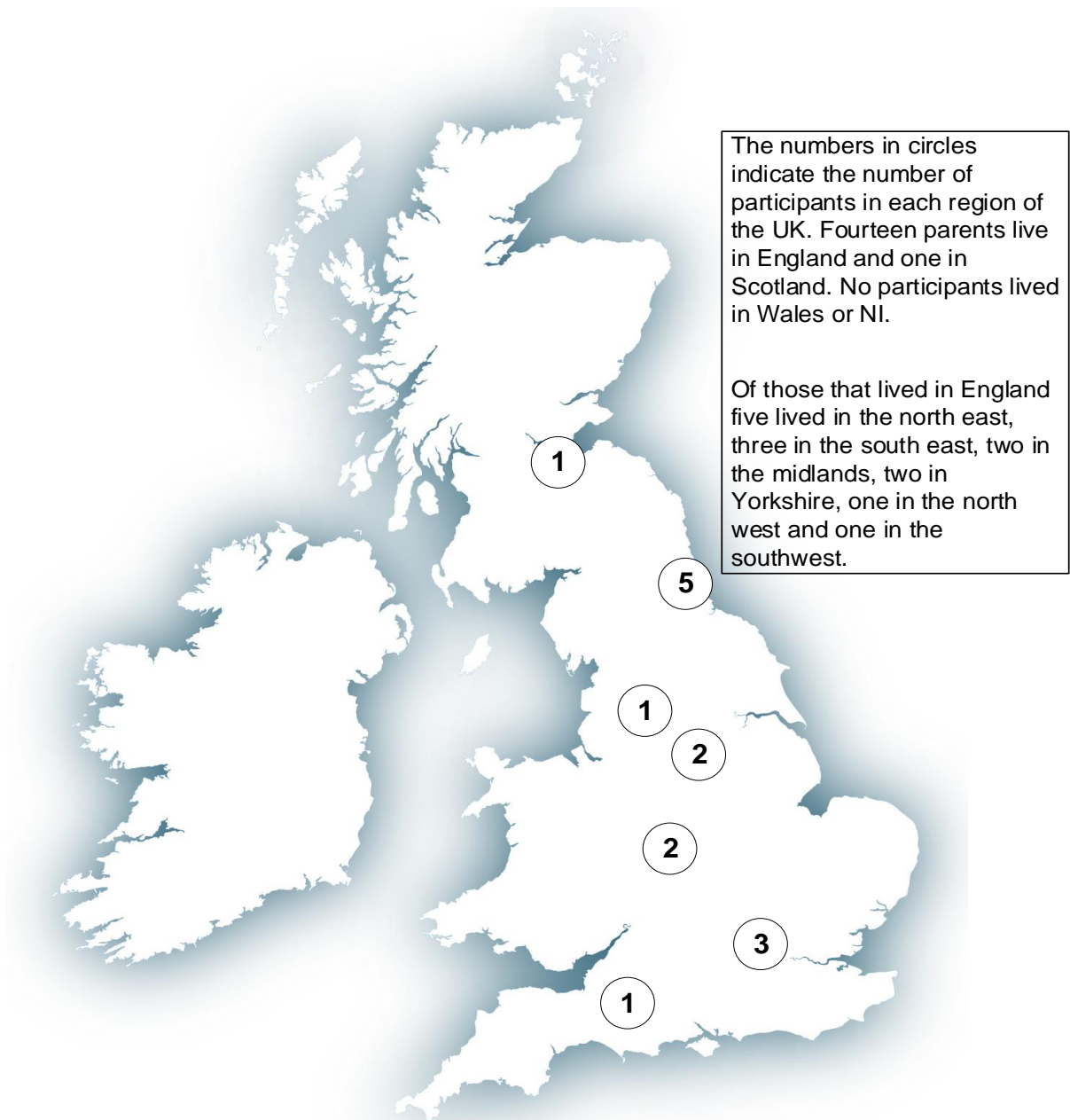
where one of the initial respondents to the advertisement, passed on information about the research to local friends. These four people had met originally on the Blended Diet UK Facebook and formed their own social group, meeting regularly in local cafés. Interestingly, the three parents identified through snowball sampling no longer used the Blended Diet UK Facebook page on a regular basis as they felt they no longer needed regular help and support from the group. A further three people responded after the recruitment period ended and were not interviewed.

Fifteen people out of a total of twenty-four respondents met the inclusion criteria for the research and emailed within the recruitment period, this was the maximum number hoped for and likely due to the promotion within the Blended Diet UK Facebook group (Table 4.1 in Sub-section 4.2.3). Five people who responded within the recruitment period were excluded: two respondents were excluded because they were healthcare professionals rather than parents, one respondent was excluded because they lived in the Republic of Ireland rather than the UK, and two respondents were excluded as they had been using blended diet for less than one year.

#### **4.4.2 Research Participants**

A total of fifteen interviews were arranged, the upper end of the target set in the research design (Sub-section 4.3.2). It seemed prudent to schedule the maximum, with the view that some participants may withdraw from the research. However, all the respondents attended their interview on the scheduled date. On several occasions parents seemed to prioritise the research over other commitments for example by taking time off work or asking grandparents to look after the children so that they could focus on the interview. One child was admitted to hospital at short notice; rather than cancelling the interview, which would have been understandable, the mother asked to meet at the hospital instead. These instances reflect how important the parents perceived the research to be and additionally how normal hospital stays were perceived to be.

Twelve of the interviews took place in the participants own home, at their request. In addition to the interview that took place in the private hospital side room two interviews took place in cafés, in public settings care was taken to stay out of ear shot of other people, to maintain confidentiality. The participants lived in a wide spread of geographical locations in the UK, Figure 4.3 demonstrates roughly which region of the UK the participants lived in.



**Figure 4.4:** Indicative geographical spread of participants

The interviews ranged in duration from forty-eight minutes to one and a half hours. The parents seemed to be comfortable being audio recorded and spoke at length about their experiences, views, feelings and beliefs about blended diet. Most of the parents required minimal prompts from the researcher. As anticipated, interviews were occasionally interrupted due to a need for the parent to deliver care to their tube-fed child or other children. Other interruptions included unscheduled visits from healthcare professionals, deliveries and family pets.

Background information about the participant and their tube-fed child was collected such as the age of their tube-fed child at the time of the interview, the age of the child when a feeding-tube was placed, the length of time the child had been fed blended diet and the proportion of blended food used in comparison to commercial formula, this is presented in Table 4.2. The researcher did not routinely collect data on participants age, ethnicity or profession although in some instances participants made reference to this in their interviews. Clinical information about the child, for example their medical diagnosis was not collected as it was thought that disclosure of a rare diagnosis may make identification of the child possible. Most parents in this research spoke about their child's additional complex care needs such as ventilation, home oxygen and frequent suctioning. Most of the children and young people could be described as having some form of neurodisability, an impairment of the brain or neuromuscular system which result in functional limitations impacting on movement, cognition, hearing, vision, communication, emotion, and behaviour; often in combination (Morris 2013).



**Table 4.2:** *Participants pseudonyms, the age of their tube-fed child at the time of the interview, the age of the child when a feeding-tube was placed, the length of time the child had been fed blended diet and the proportion of blended food used in comparison to commercial formula.*

Participants pseudonym	Age of Child (Years)	Tube-fed since (Age)	Length of Time fed on Blended Diet (Years)	Proportion of Blended Diet Used in Comparison to Commercial Formula or Oral Dietary Intake
Anna	8	20 months	4	Fed commercial formula at lunch at school
Beth	4	Birth	2.5	Only blended diet
Claire	3	Birth	2	Commercial amino acid formula as supplement overnight
Diane	20	13 years	5	Only blended diet
Emily	14	1 year	5	Only blended diet
Fiona	9	3 years	5	Only blended diet
Gemma	12	8 years	2	Eats pureed food orally in addition to blended diet
Hannah	12	2 years	9	Has commercial formula overnight as a supplement
Imogen	19	4 years	3	Only blended diet
Jane	9	20 months	5	Only blended diet
Katie	4	Birth	3.5	Only blended diet
Laura	15	7 years	9	Only blended diet
Marie	15	7 years	2	Only blended diet
Nathan	9	3 months	4	Only blended diet
Olivia	11	Birth	5.5	Has commercial amino acid formula as supplement overnight

At the time of the interviews the ages of the tube-fed children and young people ranged from three to twenty-years-old; their mean age was 10.8 years. Most of

the children were tube-fed because they had an unsafe swallow and as a result ate no food orally. Olivia's son had a safe swallow but was unable to eat due to a severe oral sensitivity which Olivia reported resulted from intubation at a young age. The age at which the child or young person started tube-feeding varied. Eight of children or young people had been tube-fed since they were less than a year old, three had a feeding tube placed when they were pre-school children (age 1-4 years) and four had a feeding tube placed later in childhood. The children and young people who had a feeding tube placed later in childhood or adolescence had eaten food orally previously. Laura and Marie reported a gradual decline in oromotor skills whereas Diane and Hannah's children had experienced a rapid loss of swallow due to a neurodegenerative disease.

The length of time the parents had been using blended diet to feed their tube-fed child ranged from two to nine years. The mean length of time parents had been using blended diet was 4.4 years. All the children had gastrostomy feeding tubes at the time of the interview, however a few parents said that they had previously initially fed blended diet through a nasogastric feeding tube. Ten parents said that they only use blended food through the gastrostomy tube to feed their child. Gemma's son ate some pureed food orally alongside the blended food given through his tube. Four parents gave their tube-fed child commercial formula alongside blended diet. Anna's daughter had commercial formula at lunchtime in school while Claire, Hannah and Olivia gave an amino acid based commercial formula overnight as a supplement.

Most of the parents were mothers, with just one father, Nathan, recruited to the research. In several cases the fathers of the tube-fed children were in the house looking after the child while the mother took part in the interview. Participants often talked about how they believed their partner, or the rest of the family felt about the experience of using blended diet in the home. Diane was a single mother and talked at length about the difficulties she had experienced because she was making the decisions and caring for her child on her own.

## 4.5 Analytical Process

Having described how data were collected in Section 4.4; Section 4.5 demonstrates how data were handled, managed and analysed. The section begins with transcription (Sub-section 4.5.1). Next, the data management strategies used are then described and critiqued (Sub-section 4.5.2). Finally, the six-step analytic process used in this research is described in detail (Sub-section 4.5.3).

### 4.5.1 Transcription

A verbatim record of the interview was required before analysis could take place (Smith, Flowers and Larkin 2009). Larkin and Thompson (2011) suggested analysis requires 'an organised, detailed, plausible and transparent account of the meaning in data'. The written record enables data to be analysed, it would be very difficult to listen for patterns in audio data and present those findings. The word verbatim means to be expressed in exactly the same words as were originally used by the participant. It was important that the transcript presented a true record of the interview so that participants were represented fairly and accurately (Smith, Flowers and Larkin (2009). Savin-Baden and Howell Major (2013) describe 'verbatim' as a slippery term because it involves an assumption being made about what counts as data. Unlike discursive approaches IPA is interested in what is said rather than how it is said and so pauses for example were noted but the exact length of the pause was not recorded (Smith, Flowers and Larkin (2009). Consideration was given to the use of a professional transcriber as this would have been less time consuming. However, Smith, Flowers and Larkin (2009) describe the process of transcription as an interpretation activity because the transcriber has to choose what is noted, for example when is a pause long enough to have meaning. Furthermore, O'Connell and Kowal (1995) suggest that any part of the interview that is not going to be analysed should not be transcribed and so decisions had to be made over which parts of the interview were relevant to the research aim and which were not, an example of this can be seen in Figure 4.3 below. Smith, Flowers and Larkin (2009) point out that interruptions can have an effect on the

rhythm of the interview, so it is important that they are recorded. Transcription was also seen as a way in which the researcher/analyst could start to become immersed in data which Smith, Flowers and Larkin (2009) suggest is an important first step as explained in Sub-section 4.5.3; this was further justification for personally transcribing the interviews.

143 P: they won't let us take [her] food into [local hospital] but  
144 [the hospice] are happy for us to take it in and heat it up because.....  
145 [interruption by youngest child, talks to child-not transcribed]  
146 P: Where was I?  
147 I: You were telling me about taking food into [the hospice]

**Figure 4.5:** Extract of verbatim transcript demonstrating how data were anonymised

For ethical reasons, it was important to protect participants' anonymity. The name of the participant, their child and other family members were changed to a fictitious name (Table 4.2). If the participant mentioned a health, education or social care profession the name was removed and replaced with the job title in brackets for example [class teacher]. Any information that could be used to identify where a participant's child lived, went to school or received care was also removed and replaced in brackets with a general description of what had been removed for example [town], [local shopping centre], [school], or [local hospital]. Regional words used by participants were removed and replaced so it would not be possible to identify a participant's location from a verbatim quotation. For example, many regional words exist for bread such as: 'bap', 'cob', 'stotty' were replaced with [bread]. Some of the children had extremely rare conditions which had resulted in their inability to eat orally. There was concern that a professional who knows the child well may be able to identify the child because of the condition therefore specific diagnoses were removed and replaced with [genetic condition] or [metabolic condition]. An example of an anonymised extract can be seen in Figure 4.5.

### **4.5.2 Data Management**

Each verbatim interview transcription was given page and line numbers so that quotations extracted in later stages of analysis could be traced back to their original place in the transcript as a whole. Transcripts were also time stamped at ten-minute intervals so the place on the audio recording could be easily found if necessary. The transcript was given wide margins on the left and right-hand sides of the pages to allow space for annotation by the researcher in the early stages of analysis (Sub-section 4.5.3). Transcripts were printed, filed and indexed in a lever arch file so the researcher could easily locate and work with data. The reflective notes which were written immediately after the interview by the researcher were also typed and filed alongside the verbatim transcripts. The file was kept in a locked filing cabinet and electronic copies and MP3 audio recording were kept on a password protected external hard drive to store data securely (Section 4.6). Managing data in this way meant there was an audit trail which could be tracked back from final report back to the original interview recording. Smith, Flowers and Larkin (2009) suggest that internal audit is a valuable tool through which validity in IPA can be checked.

### **4.5.3 Analysis of Transcripts**

Smith, Flowers and Larkin (2009) have suggested a series of steps which can be taken during analysis which help researchers to remain true to the underpinning theoretical principals of IPA (Section 4.2). Some qualitative researchers would argue against the use of set steps in qualitative data analysis (Sub-section 4.2.2). However, Smith (2011:58) argued that the steps suggested are guidelines rather than prescriptions aimed at 'breaking the analysis into a series of manageable chunks'. Smith, Flowers and Larkin (2009) suggest the steps are particularly useful for novice researchers; which is why they have been used as the basis of the analysis in this doctoral research. It is important to note that Smith, Flowers and Larkin (2009) also encourage a 'healthy flexibility' and there are times where the steps have been adapted or added to.

**Step 1: Reading and Re-reading (Immersion in Data)**

In this research the majority of this step took place during the transcription process. As discussed in Sub-section 4.5.1 each interview was transcribed verbatim by the researcher. The transcription process involved listening to the audio recording three times; before transcription, during transcription, and after transcription whilst reading the transcript to check for errors. Whilst time consuming for the researcher to individually transcribe the audio recordings and write up the reflective notes (which were audio recorded immediately after the interview) this encouraged further reflection and led to a familiarity with the interview recordings and transcripts. Pietkiewicz and Smith (2014) suggest that each reading and listening can provide new insight. It was important that these insights were recorded so during the transcription process a second Microsoft Word document was open to record initial thoughts these included the researcher's initial 'dietetic' thoughts. These insights could be considered 'free-coding' (Larkin and Thompson 2011) and helped to reveal preconceptions before moving on to systematic coding in Step 2. The transcript was read through a fourth time whilst listening to the audio recording, if there had been a month or more between the transcription and the second step to refresh the researcher's memory.

**Step 2: Initial Noting**

Step 2 involved reading a paper copy of the transcript line by line and making comments in the wide right-hand side margin of the page. This step of the analysis process was the most time consuming. Smith, Flowers and Larkin (2009) suggest the purpose of this step is to 'divide the text into meaning units and assign a comment to each'. Savin-Baden and Howell Major (2013:421) call this initial phase of qualitative data analysis 'cutting' as the original transcript is cut into smaller meaningful chunks, they suggest that the meaning unit can be a sentence, phrase or single word. Different coloured pens were used to differentiate between descriptive (blue), linguistic (green) and conceptual (red) comments. As comments were hand written care was taken to make sure they were legible. Descriptive comments stayed close to the understanding of the

participant's meanings. Linguistic comments referred to the type of language that had been used for example interpreting a metaphor. Conceptual comments were more distant from the participants' own words and demonstrated where the researcher had attempted to understand the participant by drawing on external ideas such as professional or personal experience. Smith, Flowers and Larkin (2009) describe the conceptual noting as a Gadamerian dialogue between pre-understanding and newly emerging understanding. Conceptual comments were tentative and so usually took the form of questions.

### **Step 3: Developing Emergent Themes**

In IPA studies the patterns of meaning which are found within a transcript are called 'themes' (Larkin and Thompson 2011). Working with the handwritten notes made in Step 2, the left-hand margin was used to label a theme. Smith, Flowers and Larkin (2009) advise that themes should reflect a synergistic process of description and interpretation they should also be a 'concise and pithy statement reflecting both the participants' original words and the researchers understanding of what was important in the comments on the right-hand margin. Willig (2013) suggested that the theme label should 'capture the experiential quality of what is being described' because of IPA's commitment to phenomenology.

### **Step 4: Searching for Connections Across Emergent Themes**

The emergent themes were typed in chronological order into a Microsoft Word document, which was saved as part of the audit trail. The list was then copied into a Microsoft Excel spread sheet; this was used to move themes around and look for relationships between themes. This involved 'putting like with like' and identifying themes which were in contrast to each other; Smith, Flowers and Larkin (2009), term these clusters of themes super-ordinate themes. This is not an easy task; Wagstaff et al. (2014:6) described the process of identifying superordinate themes like 'drowning in a deep bowl of spaghetti'. This stage took a considerable amount of time as some themes seemed to be able to fit under more than one superordinate theme resulting in overlaps and subsequent

reorganisation. The Microsoft Excel spreadsheet was then used to create a summary table of the super-ordinate themes, and clusters of themes which related to the research aim and objectives. Quotations from the transcript were copied and pasted into the table along with the corresponding page and line number so it could be traced back to the original transcript at a later stage.

### **Step 5- Moving to the Next Case**

IPA is an idiographic approach as discussed in Section 4.2. For this reason, it was important to treat each case individually before moving to make comparisons across cases, this meant that Steps 1-4 were repeated for each interview. Smith, Flowers and Larkin (2009) advise bracketing the ideas generated from the first case (as far as is possible) whilst analysing the second and so on. IPA is based on Heidegger's philosophy of phenomenology so does not agree with Husserl's idea that it is possible to completely 'bracket off' previous learning or insight. Smith (2007) referred to this as a hermeneutic circle where 'fore-understanding' is changed with each insight. Finlay (2009) suggests an analysis can be considered phenomenological if the analyst attempts to maintain a phenomenological, open-minded attitude. The reflexive diary was used to note and ideas or patterns that formed during analysis.

### **Step 6: Looking for Patterns Across Cases**

Finally, the superordinate themes across the cases were compared and contrasted. Close attention was paid to how a theme in one case illuminated aspects of another account and thus data were prioritised and reduced. The final result of this process was an organised master table of themes nested within superordinate themes (Table 5.1 in Chapter 5) illustrates how themes were contained within superordinate themes and to which research objective they were linked. Brief quotations used by the participants themselves were used where possible to label the super-ordinate themes to maintain analytic focus on their experience (Willig 2013).



## 4.6 Ethical Considerations

The purpose of this section is to show the detailed thought which has been given to ethical concerns and considerations. While ethical considerations have been cited in earlier sections of this Methodology Chapter, this section aims to be explicit about the commitment to ethics throughout the research process. Ethical approval for this research was granted by the Coventry University Research Ethics Committee in August 2016 (Appendix 4). Data collection took place from August 2016 to December 2016; no data were collected until full approval was granted. The Coventry University's Research Ethics, Governance and Integrity Framework was read and adhered to. As a Health and Care Professionals Council (HCPC) registrant there was also a duty to adhere to the HCPC standards of conduct, performance and ethics (HCPC 2016).

The research was clearly beneficial to children and young people in the UK in receipt of home enteral tube-feeding (HETF) and their families. Justifications for research into blended diet has been set out in the Introduction Chapter of this thesis and in earlier sections of this Methodology Chapter (see Sub-section 5.3.1). The research has the potential to improve service delivery by seeking the experience and views of service users. Knowledge gained from understanding which emerged from this research can be used to inform healthcare professionals working in the field and to inform further research on blended diet. The research also has the potential for further impact, for example providing an insight into the experiences on caring for a child with HETF and additional complex healthcare needs and wider insight into the role food plays in human lives.

The sampling strategy (Sub-section 4.3.2) allowed potential participants to express an interest in the research without disclosing their details to a third party. Participants could contact the researcher directly using the contact details which were provided on the advertisement (Appendix 5). The advertisement was posted on the Blended Diet UK Facebook page, at the time membership was n=1400. Blended Diet UK Facebook group members could also share the post with friends outside of the group who they thought might be interested in

taking part. Finding participants in this way meant that potential participants did not need to make contact via a dietitian or other healthcare professional. These strategies helped to maintain participants' anonymity and meant that participation in the study was voluntary.

Participants were fully informed about what the research would involve before they agreed to take part. Respondents to the advertisement were sent an email thanking them for their interest and double checking that they met the inclusion criteria (Table 4.1). If the respondent met the inclusion criteria, they were sent a copy of the Participant Information Sheet (PIS) (Appendix 6) and consent form (Appendix 7) via email with a read receipt to ensure they had received it. The PIS provided background to the research, the aim, the researcher's background, an explanation of how data would be collected and stored as well as details of the Coventry University complaints procedure. The research involved discussion of care provided to children or young people with complex care needs and there was a risk that a participant could disclose information which caused concern about the safety of a child or young person. If a disclosure had occurred during the research process the researcher would have escalated the concern through services local to the participant. This was also explained in the PIS. The consent form was sent so that potential participants had a clear understanding of what they would be asked to agree, and sign should they chose to take part. The email asked that potential participants should read the documents and encouraged them to ask questions.

Potential participants were given two weeks to read the documents before a follow up email (Appendix 8) was sent asking if they had any further questions and inviting them to take part. A two-week time frame was used as it was thought this would give the participant time to read, re-read and think over their potential participation in the research. A project specific mobile telephone number was provided with the copies of the PIS sheet and consent form so that potential participants could ask questions via telephone if they preferred. Participant understanding was checked again at the start of the interview. The PIS and consent form were read through verbally face to face with the

participant before the interview started. This ensured that the participant had read all the information and offered them the chance to ask further questions to make sure they were fully informed before starting the audio recorder.

Participants were made aware they had the right to withdraw from the research at any time, information that they provided would be treated in confidence, that they would be audio recorded, data would be securely kept and that any quotations used in the final thesis or future publications would be anonymised.

There was a potential risk that participants would view the research as an opportunity to seek clinical advice from a dietitian with experience of working with families who use blended diet. It was important that the line between researcher and dietitian did not become blurred. Care was taken to manage the participant's expectations to ensure that participants knew what the researcher's role was and make clear that the researcher would not be able to offer clinical advice regarding the enteral feeding of their child before, during or after the interview (this is discussed further in Section 4.8).

Participants were able to choose the location of the interview. It was envisaged that participants would choose to be interviewed in either their own home or in a public place such as a café. The purpose of this was to 1) allow participants to feel comfortable and at ease when answering the questions and 2) to be respectful of other commitments they may have such as childcare or work. If participants chose to meet in a public place, the researcher made sure a quiet corner was chosen where the conversation could not be overheard. As questions were of a potentially emotive or sensitive nature, participants were made aware that they were not obliged to disclose anything that they wished to keep private. It was also explained that the interview schedule was not fixed, and the conversation could deviate, or they would be asked to expand on answers. It was explained that occasional notes would be made to jog the researcher's memory to return to a point rather than interrupt their flow of thought. The workings of the audio recording device were explained to the participant, so they could stop the device and the interview themselves at any time.

Protection of participants' personal details and security of data obtained were of the uttermost importance. The audio recording device, completed consent forms and the paper transcripts were kept in a securely locked filing cabinet. In transit, the researcher was with the audio recorder, signed consent form or paper transcripts at all times so that it could not be lost or stolen from the car.

Personal details which were required for data collection such as the participant's home address, mobile number and email address were seen only by the researcher and not kept after data collection. Downloaded audio recordings were kept on a password protected external hard drive that only the researcher had access to. Audio recordings were destroyed once the final report was written. Steps were taken to protect participant's anonymity. There is debate as to whether confidentiality can be guaranteed in qualitative research. The concept of confidentiality relates to the idea of privacy however in qualitative research data; in the form of verbatim quotations are included in the thesis and publications meaning anonymity was offered but people close to participants may be able to recognise them from their quotations (Oliver 2010).

A pseudonym was assigned by the researcher in place of the participant's name rather than using a number or initial which could seem impersonal when presented in the final report or publications (Oliver 2004). Participants were informed of their pseudonym which meant they would be able to recognise their own quotations within this thesis or publications yet remain anonymous to the outside world (Letherby 2003). Place names were also removed as were the names of healthcare professionals and hospitals. Further details of how transcripts were anonymised can be seen in Figure 4.5, Sub-section 4.5.1.

The researcher had a responsibility not only to the participants but also to the wider research community. Care was taken to reply fully to respondents who did not meet the inclusion criteria. Individuals who had taken the time to compose an email deserved a response; not responding could have put them off volunteering to take part in other research projects in the future.

## 4.7 Quality

This section considers the steps taken to enhance the quality of the research project before moving on to the findings (Chapter 5). Yardley's (2000) four broad principles of sensitivity to context, commitment and rigour, transparency and coherence and impact and importance have been used in this thesis to evaluate the quality of the research project. Assessment of quality within qualitative research has been the focus of much deliberation within methodology literature (Seale 2000). Criteria long used to assess the quality of quantitative research such as validity, reliability and generalisability are not easily applicable to qualitative research (Savin-Baden and Major 2013). Many different markers of quality in qualitative research have been suggested and debated by scholars (Emden and Sadelowski 1998; Calderon 2009; Hammersley 1990; Lincoln and Guba 1985; Tracy 2010). Some scholars have suggested that any criteria imposed on qualitative research are potentially restrictive and unhelpful (Bochner 2000; Smith 1984). Yet, criteria are useful guides particularly to novice researchers so long as they are flexibly applied (Seale 2000). Within the field of IPA research Yardley's (2000) four principles have been recommended and are frequently used (Smith, Flowers and Larkin 2009). This section is an exploration of this research in relation to Yardley's four broad principles (2000).

### 4.7.1 Sensitivity to Context

The first broad principle suggested by Yardley (2000) was sensitivity to context. Yardley (2000) offers a number of ways in which research can be sensitive to context for example seeking out relevant literature and considering the ethical issues. Smith, Flowers and Larkin (2009) suggested the rationale for IPA as a methodology can indicate a sensitivity to context. The use of blended diet for tube-fed children and young people in the UK is known to be a contentious and emotive topic (Coad et al. 2017; Kellie 2015). IPA methodology was chosen in response to a need for sensitivity when investigating the topic of blended diet. During data collection steps were taken to put the parents participating in the research at ease, show empathy and give parents more control over the

interview. For example, by meeting participants at a location of their choosing and offering parents control of the audio recorder. The attention given to in-depth analysis of data, attempting to make sense of the parents own sense making through immersive reading and re-reading also demonstrates sensitivity to context (Smith, Flowers and Larkin 2009). Furthermore, the findings of this thesis have been written to include extensive verbatim quotations from the interviews, this gives the parents a voice within the research, one which has, to date been missing from the debate on blended diet. Additionally, the quotations allow the researchers interpretations to be checked by the reader.

#### **4.7.2 Commitment and Rigour**

Yardley's (2000) second broad principle was commitment and rigour. Commitment means engagement with the topic. The researcher's engagement with the topic of blended diet predates the doctoral research (Section 1.1). In IPA commitment overlaps with sensitivity as commitment is also demonstrated by attentiveness to the participant during the data collection process and attentiveness to subsequent in-depth analysis (Smith, Flowers and Larkin 2009). Rigour refers to the thoroughness of the research, as a novice researcher this included skill development. Masters level modules in qualitative methods and qualitative data analysis were taken. Additionally, the interview schedule was developed and practiced with Ph.D. supervisors ahead of the first interview. Care was taken in this research to ensure analysis of data was systematic and interpretive. Due to the relatively large number of participants in this IPA research it was not possible to provide quotations from every participant for every sub-theme, instead, in the findings (Chapter 5), the researcher selected quotations which captured the essence of collective accounts to illustrate the narrative. Evidence of the sub-themes presence within individual interviews is provided in Key Word Tables (Appendix 9).

#### **4.7.3 Transparency and Coherence**

The third broad principle is transparency and coherence (Yardley 2000). Transparency refers to how clearly the research process is described (Smith,

Flowers and Larkin 2009). Each decision regarding the research design has been documented and justified within this Methodology Chapter with a view to providing transparency. The full Interview Schedule used in the interviews has been provided in Appendix 3. Coherence describes the 'fit' between the research question and conceptual framework used (Yardley 2000). Moreover, a narrative approach has been used within the findings (Chapter 5) of this thesis with the aim of providing a cohesive account of the research findings. IPA is however interpretive and so cautious language has been used within the findings chapter to reflect the interpretative nature of the research. Reflexivity has been used within this thesis to acknowledge the impact of the researcher's subjectivity had upon the research this has included the researcher's interest in the topic of blended diet and the journey which has led to the undertaking of the doctoral research (Section 1.4). Furthermore, the role of the researcher in the data collection was explored in Sub-section 4.4.2 and the role in the analysis is detailed in Sub-section 4.5.3.

#### **4.7.4 Impact and Importance**

The final principle put forward by Yardley (2000) is impact and importance, which means producing research which is interesting or useful. As identified in the literature review chapters of this thesis there is scarce literature on blended diet use. Most of the literature is either historic or originates from a country where commercial formula is either unavailable or unaffordable and the results of such studies cannot be generalised to the UK where commercial formula is available free of charge through the NHS. Yet the demand from parents for support in relation to blended diet is increasing. There is an urgent need for clinical guidelines on blended diet. In addition, recommendations for future research efforts have been made throughout the discussion and conclusion chapters to present the implications for clinical practice so this research has meaningful impact.

#### 4.8 Personal and Methodological Reflexivity

This section, unlike the majority of the thesis, is written in the first person because it contains a reflexive account of the doctoral research. Subjectivity is inevitably present throughout research processes and is often considered as something to be minimised or controlled. However, in qualitative research subjectivity is a necessary means to understand complex phenomenon, where there are likely to be multiple subjective views (Letherby 2003). Reflexivity is the engagement in a self-aware, meta-analysis of how the researcher has influenced this research project (Finlay 2002). As discussed in Sub-section 4.2.1 IPA has a double hermeneutic because in the role of the researcher it's important to make sense of the participant trying to make sense of their own experience. A third hermeneutic layer has been suggested as the reader of the reported research attempts make sense of the research and the journey taken (Smith, Flowers and Larkin 2009). To facilitate the third hermeneutic layer, it is necessary to be transparent about the impact the researcher has had on the research. This transparency can also be considered as an indication of quality in qualitative research (Yardley 2000) (Sub-section 4.7.3).

As first introduced in Section 1.4, my interest in the topic of blended diet stemmed from professional experience as a dietitian specialising in children's home enteral tube feeding (HETF). I was unsure how to support families using blended diet on my clinical caseload. Furthermore, as a team of HETF dietitians we received an increasing number of queries from parents about blended diet. My colleagues' opinions on the topic were divided and the lack of research and clinical guidance was both problematic and frustrating. Blended diet was thought to be more common in the USA than the UK, so I believed there would be benefit in meeting US professionals with more clinical experience (BDA 2013). Before embarking on this research journey, I was lucky enough to be awarded a scholarship to travel to and around the USA to learn about blended diet use there (Durnan 2018). However, I discovered like the UK blended diet in the US is far from commonplace. Nonetheless, I was able to meet numerous professionals who successfully used blended diet in their clinical practice. In



hindsight, the most valuable part of the scholarship experience was the opportunity to meet twelve parents who prepared and used blended diet daily to feed their child. Both my clinical and scholarship experiences led me to believe that an understanding of blended diet could only be attained by asking the experiential experts, the parents who have chosen it for their own child.

Traditionally dietitians have taken a quantitative approach to research with the randomised controlled trial being viewed as the gold standard in improving outcomes for patients (Fade 2003). However, more recently dietitians have been encouraged to consider 'the art of dietetics'; how our clients interpret the advice they are given and how this impacts on their understanding (Lawrence 2015: 30). My former undergraduate degree (biomedical science) and postgraduate academic studies focused on quantitative methods, yet these did not seem to be suitable tools by which to explore the complexities of blended diet particularly, as potential psychological and social benefits had been suggested (BDA 2013; Day 2017). Furthermore, difficulty in measuring the nutritional content of blended diet had been a concern of mine when I first encountered the topic. Since quantitative research methods are concerned with the measurable they seemed to be of limited use. Additionally, I reasoned that the unmeasurable nature of blended diet may have been at least part of the appeal for the parents I had met and attempting to control and manipulate the blends they used may negate some of the benefits perceived by parents.

The way in which the participant views the researcher can affect the type of data that is collected. For example, participants may have spoken about different aspects of their experience if I were another parent for example. I was honest with participants about the reasons for my interest in blended diet. My professional background was disclosed in the PIS (Appendix 6) and verbally at the start of each interview; I felt it was important to be open and honest about my interest in the topic.

Ballinger and Payne highlighted that participants can view the researcher as a professional with authority and influence (2000). Participants may think the answers given will in some way affect the care they receive. This could be

particularly problematic where professionals are interviewing their own patients. However, I attempted to distance myself from my professional role for the purpose of the interview. I found participants for the research through their peer support networks on social media rather than through NHS dietetics services. I avoided more formal professional styles of email and dressed in smart casual attire avoiding the smart professional clothes I would have usually worn on a domiciliary visit in my clinical role. I did not want participants to view me as a professional or authority figure who could in some way affect their child's care. As described in Sub-section 4.3.1 to further redress any power imbalance I had taken care to give participants control over the interview process by asking participants to choose the location of the interview and offering them control of the audio recorder.

Distancing myself from my clinical role had a dual purpose. In my own mind I wanted to separate the roles of researcher and dietitian. Dilemmas of conducting qualitative research in the role of researcher/practitioner are well documented (Finlay 2009; Thorne 2016). I knew my dietetic experience would be both a benefit and a hinderance during the data collection process. My dietetic experience was beneficial, it meant I had a good knowledge of HETF and I could use the skills I routinely use in dietetic consultations such as building rapport and attentive listening. As expected, because the research mainly took place in the participants own home occasional interruptions occurred and because I am used to working in this setting I felt able to deal with these. However, my role within the interviews was as a researcher not a clinical dietitian. Almost automatically dietetic type questions would form in my head in response to participants accounts. Rather than asking these questions I took care to focus carefully on the participants words, use open questions and allow the interview to lead where the participant wished rather than a taking the more familiar form of a dietetic consultation. By doing this I hoped to maintain a phenomenological attitude. Although it was impossible to 'bracket out' pre-understandings, I was acutely aware of them (Smith Flowers and Larkin 2009). Practicing the interview schedule with supervisors helped initially, and subsequently this became easier as more interviews were conducted.

Most of the interviews took place in the participants own home usually at the kitchen table over a cup of tea. The pace and flow of the interviews was comfortable, and in some cases, participants answered my questions before I had asked them. In the main, participants seemed to be very open about their experiences and information was forthcoming with minimal encouragement. As I became more experienced, I developed the confidence to probe further and encouraged participants to expand on their ideas. This potentially means that interviews which took place in December 2016 for example Nathan's and Olivia's contained richer data than early interviews in the August (Anna and Beth). Additionally, in early interviews when parents spoke of other people's experience, I attempted to steer them back to talking about their own experience. However, I came to understand that the participants were attempting to understand their own experience by comparing and contrasting it with the experience of other parents. This turned out to be rich data during analysis.

I had been concerned that participants may view the interviews as an opportunity to ask clinical questions as this has been noted by other qualitative researchers investigating their own area of professional speciality (Conneeley 2002; Finlay 2002; Richards and Emslie 2000). Interestingly, none of the participants in the research asked dietetic questions of me. This is probably because care was taken to manage participants expectations. In both the PIS (Appendix 6) and through any further correspondence care was taken to be clear about my role as a researcher within the research. Additionally, the decision to include only parents who had been using blended diet for a year or more meant participants had already negotiated their own way through the early stages of choosing and getting started with blended diet (Sub-sections 5.2 and 5.5). The participants in this study were already certain of their choice. Furthermore, there was a strong sense that the participants had already fought, and in the main won, acceptance from professionals (Section 5.6). Taking part in this research seemed to be about improving the experience for other parents in the future rather than helping themselves. This led to an interesting power

dynamic because I was no longer the expert, the participants were, and they knew it.

The 'insider' or 'outsider' status of the researcher is thought to influence the type of data collected, for example the answers parents gave could have differed considerably if I had for example been myself the parent of a tube-fed child (Dwyer and Buckle 2009; Naples 1996). I had been concerned that my professional background as a dietitian may have prevented participants from being honest about their experience of other NHS healthcare professionals however this did not seem to be the case. Parents spoke at length and in great depth about the support they had received, both good and bad. As detailed in Section 5.4 some of the parents had very negative past experiences with members of my profession. During some of the interviews I found this difficult to hear, and I felt the need to apologise on behalf of my profession. Interestingly, when listening back to the interviews one could assume that the participant did not know I was a dietitian even though this information had been disclosed. For example, Emily explained she had started a nutrition degree to 'stick two fingers up at the dietitians'. Furthermore, Olivia believed that 'sometimes they get their knickers in a twist' about blended diet. The language in both examples and within other recordings demonstrated that participants viewed me as separate to 'other' dietitians otherwise they could have said 'you dietitians'. Although I was not myself the parent of a tube-fed child, an insider, I was somewhere between, as I clearly did have a genuine interest in the topic and was taking considerable time to attempt to understand their point of view as parents (Dwyer and Buckle 2009). It is likely I was viewed as an ally to the cause because I was taking the time to listen (Finlay 2002). Interviews can be a cathartic experience for research participants because they are being listened to (Richards and Emslie 2000). In this research the cathartic effect was evident as several participants took the time after the interview to either email or text me to thank me for my time.

After data collection the first stage of data management, the allocation of pseudonyms was problematic. I had planned to allow participants to choose

their own pseudonyms. Letherby (2003) suggested this as another way to address the potential power imbalance between researcher and participant and additionally enable the participant to recognise their own quotations within the report whilst retaining their anonymity. However, some participants had asked me to pick their pseudonym for them. Furthermore, it became clear to me that participants were choosing the names of close friends or relatives. I was concerned this would mean that their personal accounts would be recognisable to others such as their child's health professionals. A decision was made instead to allocate a pseudonym myself, in alphabetical order based on the sequence of the interviews.

I decided to transcribe each interview myself. Although this was time-consuming this had considerable benefits during the analysis stage. Having listened slowly to the recordings and typed the participants words I felt immersed in the data (Section 4.5.3). At this stage, further attempts were made to acknowledge my dietetic preconceptions by recording initial thoughts in a reflexive diary (Larkin and Thompson 2011). At first the task of analysing the twenty-two hours' worth of verbatim transcripts seemed overwhelming and it took several months to transcribe the interviews. The analysis took even longer, and I was aware the depth of interpretation possible would be affected by the relatively large sample size for IPA. The analysis phase was difficult, the hardest part seemed to be moving from analysing individual accounts in their own right Steps 1-5 to looking for emergent themes across all the cases (Sub-section 4.5.3). It felt as though I was throwing away interesting data from individual parents because it did not link to other parent's accounts or fit with the aim and objectives of this research. However, it would have been impossible to include everything. Supervision at this stage was vital and I found the advice of my supervisors to be extremely helpful. During this stage my supervisors and I had discussions about the depth of interpretation needed. The depth of interpretation in IPA research seems to vary considerably. The hermeneutic circle seemed potentially endless, and this has been noted by other novice IPA researchers (Wagstaff et al. 2014) (Section 4.2.1). Aligning this work with the concepts of interpretive description helped to keep me focused; IPA methodology was being

used for a purpose, my initial interest in blended diet was grounded clinical practice, therefore the findings needed to illuminate the experience and have implications for clinical practice (Thorne 2016).

Finally, I was aware I was ultimately accountable for selecting and rejecting themes. In writing up participants quotations to form a narrative (Chapter 5); I had interpretative control. I attempted to be even handed, to represent each participant evenly and examine examples of conflicting views and controversies. However, in some cases more quotations have been used from some participants than others. This is because they have summarised well the views that I felt others were also expressing. I felt a responsibility to the participants who gave up their time to contribute to the research and I hope I have represented them and their personal experiences well within this thesis.

#### **4.9 Chapter Summary**

The overall purpose of this research was to explore parents' experiences of choosing and using blended diet for their child and the meanings they attributed to those experiences. This chapter has focused on the research process itself. The aim of the chapter was to provide a detailed account of how the research was conceptualised, designed and realised and a rationale for each of the choices was given. The chapter also reflected back over the research process examining the ethical, quality and reflexive considerations throughout the research process. The thesis now moves on to present the findings of the research in Chapter 5.

## **Chapter 5 Findings**

### **5.1 Introduction**

Having now set the thesis in the literature (Chapters 2 and 3) and the methodology (Chapter 4) this chapter will present the findings in form of the five superordinate themes which emerged through using IPA with the fifteen in-depth qualitative interviews with parents who had chosen to give their tube-fed child blended food. Each superordinate theme has been divided into three to six sub-themes. A master table of themes can be seen in Table 5.1. As discussed in Chapter 4 of this thesis a decision was made that superordinate themes should be present in all individual cases whereas sub-themes were present in at least two thirds of individual cases, this is evidenced in Appendix 9 (Smith, Flowers and Larkin 2009). Consequently, the findings chapter will be a narrative account of the five superordinate themes and their sub-themes with quotations from the individual interviews used as illustration.

Throughout this chapter, extended quotations from the interviews are set out from the main body of the text, and the participants' pseudonyms are referenced. Short quotations from participants, indicated with single quotation marks, have been used to further discuss convergence and divergence within an individual interview or between cases. The quotations have been edited to improve readability, for example hesitations such as 'erm', 'you know' and 'kind of like' have been removed. Square brackets have been used where either information has been removed to protect anonymity or further explanation has been added by the researcher. Capitalisation has been used to indicate where emphasis was placed on a word. It is important to note that the superordinate themes and sub-themes do not represent all aspects of each individual participants' experiences of using blended diet but stemmed from the aim and objectives of this research study (Section 1.5). It is acknowledged that the themes are a result of a subjective interpretation of data by the researcher, a children's home enteral tube-feeding (HETF) dietitian; another person may have analysed and interpreted the data differently. The findings of this doctoral

research, the first to prioritise the parents' perspectives, provides unique insight into the experiences of blended diet and caring for a tube-fed child.



**Table 5.1:** Master table showing how sub-themes revealed through IPA are nested within overarching super-ordinate themes. Short quotations from interviews have been used to title each superordinate and subtheme. The right-hand column indicates which of the research objectives each superordinate theme relates to.

Section	Superordinate Themes	Sub-section	Subtheme	Research Objective
5.2	'Nothing to Lose': Feeling Desperate	5.2.1	'I Was at My Wits End': An Unbearable Situation	1
		5.2.2	'One More Option': Finding an Alternative	
		5.2.3	'I Took the Decision to Go Rogue': Choosing to Take a Risk	
5.3	'A Radical Change': Improvements in Health and Wellbeing	5.3.1	'Food Stays Down': Remedy of Reflux, Retching and Vomiting	2
		5.3.2	'A Proper Poo': Improved Bowel Habit	
		5.3.3	'A Better Weight': Healthy Growth	
		5.3.4	'I Think she is More Immune to Things: Perceived Immunity	
		5.3.5	'Looks Better': Visible Improvements	
		5.3.6	'He's a lot Happier Nowadays': Signs of Improved Wellbeing	
5.4	'How life Should be': A Sense of Normality	5.4.1	'She is Part of Things Now': Inclusion	2
		5.4.2	'I Can be His Mum Rather Than His Nurse': A Feeling of De-medicalisation	
		5.4.3	'They Deserve Real Food': A Human Right	
		5.4.4	'A Vast Array of Ingredients': Opening up Food Choice	
5.5	'You Have to Muddle Your Way Through': Practical Challenges	5.5.1	'When you start out it's Hard': Learning how to do Blended Diet'	3, 4
		5.5.2	'A bit of a Chore': Additional Time and Effort	
		5.5.3	'It's a BIG Investment': Extra Money	
5.6	I Have to Fight for her to be fed Food': Defending the Choice	5.6.1	'It Depends Who You Get': Inconsistent Support	3, 4
		5.6.2	'At the End of the Day it's Your Child': Control	
		5.6.3	'As Soon as I Leave the House I'm in a Grey Area': Blended Diet Outside the Home	
		5.6.4	'We've All Supported Each Other' Helping Other Parents and Campaigning for Change	

## **5.2 'Nothing to Lose': Feeling Desperate**

This section explores the vivid feelings of desperation described by the parents when their child appeared to be in pain or suffering when fed commercial formula. The superordinate theme relates to research objective one which sought to explore why parents consider an alternative to commercial formula (Section 1.5). The superordinate theme has been divided into three sub-themes. Section 5.2.1 explores the unbearable situation the parents believed themselves to be in when using commercial formula only. Section 5.2.2 details the second sub-theme, the finding and consideration of blended diet as an alternative. The third and final sub-theme within this section examines parents' moral reasoning; why they chose to take a potential risk and start to use blended diet (Section 5.2.3).

### **5.2.1 'I Was at My Wits End'- An Unbearable Situation**

There was a sense that all the parents had, at some point, found themselves in an unbearable situation where their child did not seem to tolerate commercial formula and treatment options offered to them by healthcare professionals seemed ineffective. This sub-section presents the deep dissatisfaction parents had with commercial formula. In the main this dissatisfaction was due to observed signs in their child of pain or suffering which in turn caused the parents themselves distress and anxiety. Numerous adverse symptoms were reported by the parents, in most cases parents perceived that several adverse symptoms were experienced by the child in combination. This sub-section also explores the severity of symptoms and the restrictive effect they had on the child or young person and their families.

Adverse symptoms of reflux, retching and vomiting were most commonly reported in the interviews and were a major concern for twelve of the parents in this research. On reflection all the parents believed these adverse symptoms were linked to commercial formula use. The frequency and severity of these symptoms meant parents feared for their child's safety as Nathan's quotation demonstrates:

We were coming to that place, the option of last resort. We had tried everything and she's not getting better. Now what I have to consider as a parent is; not just the nutrition of my daughter which is obviously hugely important, but the health and safety of her because whilst she was on these [commercial] formulas she would vomit, and she would aspirate on that vomit, so we had lots of admissions to hospital because of chest infections. This became desperate this wasn't some kind of tree hugging exercise, I want to go down the natural route, no! I needed to stop my daughter from vomiting two to three times a day for her health and safety that's it there's no new age hippy thing here going on. **Nathan**

His daughter's recurrent vomiting, aspiration (inhalation of vomit) and subsequent chest infections left Nathan feeling desperate and that he would try anything to improve the situation. Later in the interview he said that his daughter was prescribed 'heaps upon heaps of medications' but these did not seem to help reduce the vomiting. As a parent he had made his own assessment of the risks to his daughter. His priority was to stop her from being sick, aspirating into her lungs and developing potentially life-threatening pneumonia. Like Nathan, other parents described 'horrific' and 'constant cycles' of vomiting. Stopping the vomiting was a more pressing, short-term goal than good nutrition. Nathan's emphasis that this was not 'a tree hugging exercise' or a desire 'to go down the natural route' suggested he felt his motivation for considering blended diet had been misjudged by professionals in the past. Nathan gave a strong impression that blended diet was not a matter of personal preference; his decision was 'desperate', he felt he could not continue to watch his child's health decline.

Anti-reflux surgery, fundoplication, had been offered to six of the parents as a treatment option for their child's adverse symptoms. A reluctance to subject their child to risky surgery was expressed by three parents interviewed who declined surgery. Fiona and Emily found the fundoplication surgery did stop their child's vomiting, but the retching continued:

They [the doctors] said retching is quite often a side effect of the surgery and they couldn't offer any interventions that would help other than a sedative, it was a sedative that they use pre-op ...so we tried this sedative medication and it was horrendous I just thought this is no quality of life for [her] I don't want to be feeding my child something that is going to make her poorly but then resolve it by giving her a sedative it didn't seem right it was a really hard time I can remember feeling really frustrated and really sad. **Fiona**

Fiona did not think the medical treatment offered to manage her daughter's retching was an acceptable option in the longer term. Her daughter's doctors were unable to offer any other treatment options. As a parent, Fiona considered all aspects of her daughter's life not just symptom management and being sedated meant she was unable to interact and live her life.

In an attempt to minimise reflux, retching or vomiting symptoms most parents were instructed to administer commercial formula at a slow rate over a long period of time via an automated feeding pump which the parents found restrictive:

She didn't tolerate any movement while on it [commercial formula]. I used to have to turn it [the feeding pump] off about twenty minutes before I started to move her, even to change her nappy. Then it wasn't continuous, and we were losing hours but couldn't up the volume, so it was a catch twenty-two type of thing. I couldn't move her or get her in the car, I couldn't take her to play groups it was just so tiring. She couldn't join in things because she was constantly attached to the pump all the time. I just wanted to be able to move my child without her vomiting everywhere and she was losing weight we were getting her weighed every week it was just so stressful. **Claire**

By describing the experience as a catch twenty-two Claire painted an image of an impossible situation where she was trying to give her daughter a prescribed volume of feed when there are not enough hours in the day to do so at a rate she can tolerate. Feeding appeared to have been on Claire's mind whenever she moved her daughter, even something as routine as a nappy change became problematic. Claire described the feeding pump as 'tying', her daughter was tied to the pump and subsequently they were both tied to the house unable to go out and socialise. Like Claire, another ten parents said their child could only tolerate commercial formula at a slow hourly rate through an automated feeding pump, which limited movement and had a negative impact on family life. For example, Gemma's son was attached to the feeding pump for seventeen hours, his entire waking day. Anna said her daughter was always 'plugged in', while feeding she had to position her daughter in a special chair, which limited other activities such as play. Similarly, Jane found it difficult to embrace her daughter or provide comfort when she was on a continuous feed:

She would want to be picked up, so it was 'oh just let me make sure I've got the bag, I've got to put it on me and I've got to make sure I don't get the wires caught because otherwise the pump will alarm. **Jane**

Hannah, Imogen and Laura did not say that their child had suffered with reflux, retching or vomiting when fed exclusively using commercial formula. However, these three parents also gave the impression that they found themselves in an unbearable situation. Like the other twelve parents they believed their child was very unwell or was in severe pain and felt that the treatment offered to them by healthcare professionals was ineffective or had unacceptable side effects. For Hannah, her main concern was her son's unmanageable constipation:

As time went by his condition combined with just having this milk substitute whatever you want to call it, medical feed, it caused problems with him going to the toilet. He just could not go without huge interventions he could go for maybe a few

weeks which is not healthy, it used to be so upsetting seeing him that upset and in that much pain. **Hannah**

Although the symptom is different, Hannah mirrored the idea that she could not watch her child suffer pain. Hannah also described how the medical interventions she was asked to carry out to manage her son's constipation: out caused her son further distress:

I'd have to use those awful glycerine suppositories and they were horrendous he would cry because of the sensation. I did massage too, I'd have to move his legs about because he is immobile. Eventually he would do a massive hard poo and he would bleed and be very, very sore. It was just so wrong.

**Hannah**

Hannah had to cope with the physical consequences of this treatment but also had to deal emotionally with being the person to cause her son pain. Like Hannah, eight of the parents interviewed said their child experienced chronic constipation when fed on commercial formula alone however in most this was coupled with the reflux, retching and vomiting symptoms. Conversely, loose and unformed stools were a concern for Olivia, Nathan and Katie. Emily found her daughter had episodes of both constipation and diarrhoea:

She had bouts where she would get diarrhoea and we'd have to go down to half strength milk [commercial formula], I think for about six months we never got her fully back to full strength milk. She was in and out of hospital with upset tummies. She also struggled with constipation a lot, we used to use [brand of laxative] but on the [brand of laxative] she was either constipated or she had diarrhoea, you couldn't get anywhere in between. **Emily**

In the quotation above, Emily describes a constant struggle to find the right balance both with the calorie content of the formula and with the dosage of

laxatives. Emily was unable to consistently give her daughter the prescribed dose of commercial formula because of her tolerance issues subsequently Emily was 'worried' about her daughter's weight. Like Emily, weight loss had been a considerable concern for ten parents:

She was really, really thin, painfully thin and sleeping all the time she was really blue she wasn't a good colour at all and she was catching every infection going and that's when I spoke to the consultant [about blended diet] and she said you've got nothing to lose here because you are not winning on what we are doing. **Diane**

Diane emphasised the extent of the weight loss in the quotation, her daughter had not just lost weight, she was 'painfully thin'. Diane linked the weight loss to her daughter's lethargy, pallor and poor immunity. A similar picture emerged from other parents who described their child as 'grey', 'washed out', 'sickly', 'fed-up' and 'flat'. When Diane discussed the idea of blended diet with her daughter's consultant, she was told that she had 'nothing to lose' giving the impression that her daughter's prognosis was very poor at that stage (Sub-section 5.2.2). Like Nathan and others, she feared for her child's life.

Conversely, Jane and Imogen said their child gained too much weight, too quickly when fed on commercial formula:

One of the many problems we had with the [brand of commercial formula] was she gained weight very, very quickly on it. She was puffy, bloaty, pasty and therefore we had to really cut back what she was having which then meant it wasn't nutritionally complete any more. She gained I think, half a kilo in a week at about age three, she went from just below the 25<sup>th</sup> centile to just above the 50<sup>th</sup> centile within a week. But her height was below the 9<sup>th</sup> it's not actually healthy for a child who is in a wheelchair the whole time to have such discrepancy between height and weight. So, she [the dietitian] cut it [the

commercial formula] back which then meant it wasn't nutritionally complete anymore, so she was then on supplements as well, it was just getting a bit stupid really. **Jane**

Jane gave the impression that her daughter's weight gain was excessive and rapid, and she too looked visibly unwell. Jane believed her to be too heavy for her height but cutting the total volume of commercial formula and thus the micronutrient content did not make sense to her. Jane questioned whether there was a better way of providing her daughter with all the protein and micronutrients she required in meals that were less energy dense than the commercial formula. Imogen described the pattern of her son's weight gain 'he was like a toad he had these skinny arms and legs and this massive torso and face'. Like Jane, Imogen believed her son's pattern of weight gain on commercial formula to be unhealthy. Imogen also thought that the commercial formula contained the wrong fats for her son's metabolic condition:

The main issue was [his] condition is a metabolic condition he can't metabolise long chain fatty acids. Most people break down long chain fatty acids into short chain fatty acids but what happens with children with [his] condition is they accumulate very long chain fatty acids and that is essentially slowly poisoning them, over time their body is accumulating these very long chain fatty acids. It's really no good for their system so given that is the issue with his condition, to me it seems crazy to give a complete feed with long chain fatty acids in it. There are no medium chain fatty acid complete feeds, so the choice was to have all the wrong fats for him. **Imogen**

The commercial formula offered to Imogen contained long-chain-triglycerides which she had been told he could not metabolise. By feeding him the commercial formula she felt she was causing him long term harm by 'slowly poisoning' him. Imogen demonstrated a good level of medical knowledge about her son's complex condition; later in the interview she explained she had spent



considerable time researching the rare condition. Like Imogen, Laura did not think that commercial formula was a viable option for her son in the longer term:

He was always very hungry, I just knew he was never going to survive on milk [commercial formula] I could just see us hitting that point and previously in my job when I worked as a hospital pharmacist in paediatrics I'd seen so many very scrawny CP [Cerebral Palsy] kids who used to come in for scoliosis surgery and I was determined that he wasn't going to be one of them.

### **Laura**

Laura believed that her son's hunger could not be satisfied with commercial formula alone. She drew upon her past professional experience of tube-fed children when considering her own sons health. With hindsight she felt the 'very scrawny' children she saw professionally had been underfed and she did not want her own son to feel or look hungry.

Marie's experience was slightly different in comparison to the other fourteen parents interviewed. While others had tried blended diet after struggling with commercial formula first, for months or years, Marie decided she would give her son blended food through his feeding tube before the gastrostomy was placed:

We were being asked to put in a PEG for years and we'd always refused because it meant [commercial] formula and he was eating quite well, we fed him [orally] alright it was just the system couldn't feed him as well as I could, eventually we decided alright he can't eat enough, he can still eat but he can't eat enough we said to the consultant then that we'd like to put his blended food down the tube, I was expecting a lot of no no noing but he sat up and got really excited about it. **Marie**

Marie's son's oromotor skills (strength and coordination of lips, cheeks, tongue and jaw which are needed for speech and oral eating) had gradually declined over a long period of time. Marie had initially resisted having a gastrostomy

feeding tube because it meant her son could not have food. This prompted Marie to search for an alternative to commercial formula. Marie's use of the word 'system' is interesting here. Later in the interview Marie explained what she meant by the word system: 'school and respite and hospitals' and gave justification for her frustration 'I could do things that the system wouldn't allow'. In other words, she was able to take risks when professionals could or would not, such as continuing oral feeding or later giving blended food through the gastrostomy tube. Marie had expected resistance from the consultant about blended diet but found he was open to the idea. One explanation for this could be that the consultant perceived blended diet through a gastrostomy tube to present less risk than continued oral intake with an unsafe swallow reflex. Marie explained that her son was given commercial formula later during a hospital admission:

He was in hospital and they [the hospital staff] tried it [commercial formula] through the pump, they introduced it very slowly and he was happy as Larry and I thought oh great he could have this then, alright. We get home and of course the doses are increasing; as days go on he gets antsy and unhappy and constipated and oh horrible. **Marie**

Marie's experience is the reverse of the other parents interviewed because she tried blended diet before commercial formula. However, like the other parents Marie felt commercial formula caused her son considerable distress.

To summarise this sub-theme, all the parents believed that their child's adverse symptoms were associated with commercial formula use. None of the parents interviewed thought their child could be fed commercial formula in the longer term. For most parents, the symptoms were felt to be severe and persistent and impacted on all aspects of family life. In many cases the parents believed the symptoms to be life threatening. Parents felt conventional treatment options offered by health care professionals were ineffective. There was a sense that they had exhausted all other available or acceptable options. A deep dissatisfaction with commercial formula and stress when conventional symptom

management options such a medication and surgery did not work led the parents to seek out, or return to, an alternative (see Sub-section 5.2.2).

### 5.2.2 'One More Option': Finding an Alternative

This sub-section explores how the parents first encountered blended diet as an alternative to commercial formula. The parents described a diversity in which they first encountered the idea of blended diet as demonstrated in Table 5.2.

**Table 5.2:** *Demonstrates how parents first encountered the concept of administering blended food through their child's feeding tube.*

<b>Parent</b>	<b>Source</b>
<b>Anna</b>	Community dietitian
<b>Beth</b>	Intuition
<b>Claire</b>	Another parent online
<b>Diane</b>	Another parent on the same hospital ward
<b>Emily</b>	Another parent at school
<b>Fiona</b>	Online search
<b>Gemma</b>	Another parent at school
<b>Hannah</b>	Intuition
<b>Imogen</b>	Another parent online
<b>Jane</b>	Another parent online
<b>Katie</b>	Intuition
<b>Laura</b>	Family in the USA
<b>Marie</b>	Friend in Australia
<b>Nathan</b>	Another parent online
<b>Olivia</b>	Another parent online

In the main the parents were told about blended diet by another parent of a tube-fed child. A third of the parents interviewed were told about blended diet by a personal acquaintance. Emily for example, met another parent using blended diet at her daughter's school:

A friend knew another mum who was doing it [blended diet]. They'd probably been doing it for about a year before. She [a friend] knew that both of the children were at the same school although there is quite a big age difference between them and she said, the other little boy has absolutely thrived, and he's not had to have the fundoplication done because he's moved on to blended food. **Emily**

The internet was another common way in which parents discovered blended diet. Fiona conducted a search on Google and found the US study by Pentiuik et al. (2011) which focused on the effects of blended diet on persistent retching symptoms post fundoplication surgery. After reading the paper she thought blended diet may help her daughter's symptoms. A third of the parents first encountered the concept of blended diet by chance while using the social media platform Facebook:

I saw it on Facebook, one of the [name of medical condition] mums, obviously it goes hand in hand with [name of medical condition], they struggle with feeding. Her child was tube-fed as well, she was asking some questions about blended diet and I was like 'oh what's a blended diet I've never heard of it?' I asked her, and she was like 'oh join this group', so I joined the blended diet group on Facebook and got all the information off there and then got THE book that complete tube-feeding book.

**Claire**

Claire used a peer-support group related to her daughter's medical condition. A chance mention of blended diet sparked her interest and prompted further research. Claire's emphasis in describing the O'Gorman (2012) book, written by a tube-fed Australian man suggested she viewed it as a reliable and key text. Like Claire other parents referenced this book within their interviews, another parent referred to it as the 'tube-feeding bible'. There was a strong sense that all the parents interviewed highly valued the experience of other parents who had been in similar situations to themselves:

It was so refreshing, reassuring and comforting to find a group of people, like minded, like me who are in a similar situation for whatever reason the child couldn't tolerate formula and who needed an alternative choice and just sharing people's experiences and anxieties. If it wasn't for the group, I don't think I'd be here where I am today. **Fiona**

The Blended Diet UK Facebook group was viewed as a community or support network where parents could share experiences. In Fiona's case members of the Blended Diet UK Facebook group had supported her through a difficult period of her life when she felt professionals had been unable or unwilling to help. Connecting with other parents and hearing about their positive experiences influenced the parent's decision making and moral reasoning over blended diet:

There was a staggering amount of success stories! Now, I'm quite a cynical guy, my job is analytical, so I do analyse things and I'm reading these messages and I'm thinking they can't ALL be good news stories and they just kept on coming back to me yes, yes, yes it works! **Nathan**

Despite his initial cynicism Nathan was persuaded by the volume of 'success stories' relating to blended diet which were readily available online. His emphasis on 'all' indicated that he did not hear any negative reports from parents online about blended diet.

Anna's experience contrasted with the majority of accounts. Anna was the only parent who had been offered a choice to use blended diet by a healthcare professional:

Our dietitian basically said because we'd worked our way through all of the milks that our next option was a jejunostomy tube, but she said I've got one more option if you're willing to try it which was the blended diet. So, at this point we didn't want to

go through another operation. So, we thought well let's try the blended diet and then if that doesn't work we'll go to the jejunostomy tube, we'll have the operation. She recommended a book and signposted us to a few different Facebook groups. I think she had a couple of children [on her caseload] that were on it already. So, she gave me some sheets about what I should be putting in and got us started. **Anna**

Like other parents, Anna sought out the experiences of other parents when deciding if blended diet was a viable option for her daughter and family. Unlike the other parents Anna had been 'signposted' to sources of information which the dietitian presumably had deemed reliable.

Beth, Hannah and Katie's experiences also contrasted with the majority of accounts. For all three the decision to give blended food through their child's feeding tube had been intuitive:

I didn't know that there was a thing called the blended diet, I just tried some fruit juice because I thought, well its liquid, liquid goes down his tube and its apples which are good if you want to go to the toilet, so I just tried it and he was fine. **Hannah**

Hannah considered what she would personally do if she had constipation and applied that reasoning to her son. Like Hannah, Katie also independently decided to give her daughter blended food:

I started meeting up with our old NCT [National Childbirth Trust] group who all had beautifully, perfectly normal developing children and obviously they are all six or seven months of age and they were all talking about the big topic, weaning. Initially I found that really hard because I knew I would not be weaning my child because she is tube-fed and obviously she was so sick all the time anyway, so we didn't even think about food. However, after a few meet-ups with them and them constantly

talking about the purees and what their children love and don't love I thought hang on a second at the bottom of her heart [she] is a normal child why should I not give her food? Only there's this tube so the only thing that we need to change is the consistency. **Katie**

After talking to friends whose children ate food orally; Katie started to question why her daughter should be treated differently. The above quotation reflected a lost sense of normality which is further explored in Section 5.4. For Beth, Hannah and Katie, it seemed common sense to give blended food to their tube-fed child. All three became aware of blended diet as a concept or movement even when they subsequently encountered opposition from health professionals (Section 5.6) and subsequently looked online for advice.

In summary, there were a diverse set of ways in which the parents interviewed first encountered the idea of blended diet. However, all parents had sought the advice of their peers when considering if blended diet was a viable option for their child and family in the longer term. All parents interviewed considered positive experiences of other parents against their own apprehensions and those of healthcare professionals. Ultimately, the parents in this study chose to take the risk, to try, or continue to use, blended diet.

### **5.2.3 'I Took the Decision to Go Rogue': Choosing to Take a Risk**

Parents decision to take a risk and try blended diet is explored within this Sub-section. An awareness of the risks perceived to be associated with blended diet (tube blockage, microbial contamination and nutritional inadequacy) was demonstrated in all parent interviews. However, taking into account their circumstances (Section 5.2.1), the parents considered blended diet to be a risk worth taking. It was evident that parents told their child's healthcare professionals about their choice to use blended diet at different stages in their consideration and use of blended diet, for example nine discussed after first encountering the idea whereas others kept it secret until later. Each parent had

been advised at some point by at least one of their child's healthcare professionals not to use blended diet, but all eventually chose to use it:

I had been thinking about it for some time, after talking to people you start to think well why can't I do it? These other people are doing it and they are fine, they are not blocking tubes. You start to rationalise it more and think well actually what's the worst that can happen in the grand scheme of things I'm only giving him food, I'm not poisoning him. What didn't help was my background with work [children's nurse], it was drummed in that it's this way or no way. I think it took me a period of time to get my head around that, we can look at other things for him, we've got to look at what's best for him. **Gemma**

Gemma had been considering trying blended diet for a while. It was not a straight forward decision, complicated by her professional concerns about blended diet. After speaking with other parents who used blended diet, she was not convinced that they had experienced the perceived risks. Gemma's case is particularly interesting because of her professional background as a children's nurse. Gemma had professional as well as personal knowledge of tube-feeding, the internal conflict she described illustrated a different way of thinking about tube-feeding between professionals and parents.

A third of the parents had pre-empted opposition from healthcare professionals based on their peers' experiences. These five parents chose to try blended diet first themselves before discussing it with health professionals:

I had heard from other people that dietitians were not happy [about blended diet] I knew people weren't going to be happy, that generally didn't put me off. I did it for three weeks and then I sent an email to all of the professionals involved with [him] they all got it at the same time it basically said here's what I've done. **Olivia**



Olivia did not wait to ask for permission from her child's healthcare team, she did not feel she needed it. Olivia, explained she did not think this was necessary based on her past professional experience as a children's rights worker she also described herself as a 'decisive person' (Section 5.6.2). Once Olivia had tried blended diet and seen improvement (Section 5.3), she told her sons health professionals which made it more difficult for professionals to raise objections.

Like Olivia, six other parents had kept their use of blended diet from the child's healthcare professionals:

I had to just do it in secret which I didn't really want to do. I started doing it in secret and then people would ask what are you feeding her? And I'd lie, oh I'm feeding her formula. I made sure when people came around there was just formula out because I thought people were going to be checking, the health visitor, the community nurses, I felt like they were watching us.

**Claire**

Claire decided to try blended diet even though the healthcare professionals involved in her daughter's care initially advised against it. Instead of being put off by the healthcare professionals' concerns, she decided to try blended diet alone at home. Claire would have preferred to be open about her use of blended diet, but she felt she was in a difficult position where the people visiting her home to care for her child were '*checking*' and '*watching*' her. Instead of being a source of support Claire felt the professionals visiting her at home would consider she was not acting in the best interests of her child.

Even when parents had the support of some of the healthcare team, they had still felt unable to be open about blended diet with other professionals. For example, even though Diane had the support of her daughter's paediatric consultant, who had told her that she '*had nothing to lose*' by trying blended diet, she still felt she had to conceal it from the dietitian who worked with her daughter:

You feel like you are doing something that you really shouldn't be doing. You have to be secretive about it and not let on to certain professionals what you are doing. That's how I felt at the start of it. I really didn't get any support at the start apart from our paediatrician who didn't really advise much she just told me to feed her what I liked. **Diane**

Parents felt that a focus on the potential risks by professionals overshadowed their first experience of blended diet, creating an air of anxiety:

I'll never forget the nerves, it comes down to that constant harassing: you'll block the tube, there will be an infection, you'll make him ill and even though I knew in my heart it was the right thing I was really nervous but I'm afraid if I think something is right for my kid I don't wait for permission to do it. **Marie**

Marie believed she was making a decision that was in her son's best interest. She had considered the potential risk and benefits and researched the topic. Her son's doctor had been receptive to the idea and yet other professionals continued to focus on the potential risks. Marie spoke of how she 'knew in her heart' that blended diet was the 'right thing' to do. This has been interpreted as meaning emotions were intertwined in parent's decision-making process. This sentiment has similarities to other accounts where parents reflected that they 'went with my gut' or 'instinctively' decided to try blended diet.

Witnessing a radical improvement in their child's health and wellbeing after transition to blended diet reinforced the feeling that they had made the right choice:

All those years she was on medicalised [commercial] formula and when she came off the medicalised formula her bowels movements and everything else normalised. Now, I know its anecdotal evidence but its powerful evidence, it can't be a

coincidence, the formula gave her all sorts of problems from going in, to staying in to coming out. **Nathan**

This extract helps to summarise this superordinate theme. After deciding to 'go rogue' and cautiously try blended diet against professional advice Nathan observed radical improvements in his daughter's health and wellbeing. While Nathan acknowledged that his own personal account of the experience may be viewed by some as 'anecdotal evidence', to Nathan this was 'powerful evidence', sufficient to convince him he had made the right decision for his daughter and motivation to continue to use blended diet in the longer term.

### **5.3 'A Radical Change': Improvements in Health and Wellbeing**

This second superordinate theme to emerge encompassed the radical improvement parents recalled witnessing in their child's health and wellbeing following transition to blended diet. The superordinate theme relates to the research objective which sought to understand the benefits of blended diet as perceived by parents. The superordinate theme has been subdivided into six sub-themes relating to different health and wellbeing improvements; Remedy of Reflux, Retching and Vomiting (Sub-section 5.3.1), Improved Bowel Habit (Sub-section 5.3.2), Better Weight (Sub-section 5.3.3), Perceived Immunity (Sub-section 5.3.4), Visible Improvements (Sub-section 5.3.5) and Signs of Improved Wellbeing (Sub-section 5.3.6).

#### **5.3.1 'Food Stays Down': Remedy of Reflux, Retching and Vomiting**

This sub-section explores the reported remedy of reflux, retching and vomiting symptoms reported by eleven parents. As identified in Section 5.2 reflux, retching and vomiting symptoms had been major concerns for twelve of the parents prior to transition to blended diet. Nearly all the parents remembered an almost immediate cessation of symptoms:

She used to aspirate into her lungs which was why she was in hospital all the time she had severe reflux, everything went in her lungs she was constantly having pneumonia she was

always having suction and she had this blended diet and she was clear and we were just sitting there like staring at her because we couldn't believe the difference it had made straight away. **Beth**

There are similarities in the early part of this quotation to Nathan's quotation in Sub-section 5.2.1. Like Nathan, Beth's daughter had experienced recurrent episodes of aspiration (regurgitated stomach contents are inhaled) pneumonia. Beth was surprised by the immediate improvement in her daughter's symptoms. Like Beth, ten other parents interviewed described witnessing cessation of reflux, retching or vomiting symptoms., Nathan explained, again in alignment with Beth, how he felt apprehensive at first and considered other possible reasons for the change in his daughter:

None of us actually spoke it because you don't want to tempt problems but, in our heads, we were thinking she hasn't thrown up, she's keeping food down. It has been seven days since she last threw up, the last day that she threw up was on the last day that she had [commercial] formula. **Nathan**

Nathan describes a sense of disbelief and this is also evident in Beth's views. Even though he had listened to the success stories of other parents he was still sceptical about blended diet. Gemma observed similar improvements in her son and ventured that the reason for the improvement was related to the viscosity of blended diet in comparison to liquid commercial formula:

It's sort of a custard consistency. They are a little bit thicker, it makes sense that it will sit in his tummy better, stay down and be less likely to cause any reflux. **Gemma**

For three parents, the child's transition to blended diet coincided with a decision to omit dairy produce; choosing instead to use dairy alternatives. For example, Imogen explained 'I don't end up putting a lot of dairy or eggs into his blend because I just find that the vegan diet just keeps better'.

Reflux symptoms were so improved after transition to blended diet that parents found they were able to wean their child from anti-reflux medication:

She's on this concoction of medications so if there's anything we can do to reduce that medication we'll do everything in our powers. She doesn't have any medication now for reflux. I think the medications that have been stopped for her like Omeprazole they've also got side effects if they're taken for a long time that can affect your gut and the rest of your systems, so I feel as though, the real food has replaced the need for these medications. Its gentler on her body she's not needing those chemicals because the food is doing the job it should be doing; that's what our bodies are designed for really. **Fiona**

Fiona felt good about reducing the 'concoction' of medications given to her daughter. Other parents mirrored this sentiment in their accounts they felt they were giving their child a 'toxic mix' or 'heaps upon heaps' of medications. The potential side effects of these medications had worried parents. Emily also found she was able to omit anti-reflux medication. The experience left her questioning what would have happened had she tried her daughter on blended diet at an earlier stage:

Once I'd started, I actually felt that I'd been let down by the professionals; not telling us about it [blended diet]. If we'd had blended food from the start she probably wouldn't have been on meds for years and years and years that she doesn't need to be on. She possibly wouldn't have needed the fundoplication [surgery]. I just think what might she have been like? Because before she was in and out of hospital there wasn't a month that she didn't have an emergency admission, from [age] three to about ten when we started the blended food, I just think if she'd been on proper food at that point would she have been in hospital all that many times and could I have kept a job down instead of packing in work to care for her? **Emily**

Emily felt 'let down' by professionals who she felt could have offered her the choice to try blended diet sooner. For seven years she watched her daughter experience pain and distress, which resolved swiftly following transition to blended diet. Emily doubted if her daughter would have needed fundoplication surgery and medications, both of which carry risks and side effects. In addition, Emily's career and finances had been limited as she had to stay at home to care for her sick child, she felt both their lives have been significantly impacted by the lack of opportunity to use blended diet.

Interestingly, Anna, Katie and Nathan reported that symptoms of reflux, retching or vomiting returned when their child was fed commercial formula at a later point after being symptom free on blended diet. Katie's daughter, for example, was given commercial formula following a hospital admission:

Our daughter is really good at proving mummy right, I said [to the nurse] well she will have severe diarrhoea and she will probably vomit as well and she did so within hours of having the [commercial] formula going in; then the nurse said you know your daughter well. **Katie**

The return of the symptoms on re-introduction of commercial formula has further strengthened Katie's belief that commercial formula was the cause of her daughter's reflux, retching and vomiting. Katie had tried to explain this to the nurse caring for her daughter and was not believed until the nurse witnessed the vomiting herself.

Volume tolerance was reported to have improved following transition to blended diet. Parents found their child could manage larger volumes of blended diet and it could be given at a quicker rate in comparison to commercial formula. Instead of using an automated feeding pump, bolus feeding (larger volumes over shorter periods) was possible:

She can tolerate more, quicker. So, like yesterday I gave her 200mls in half an hour if I'd given her 200mls of the milk

[commercial formula] I'd have to give that over an hour, an hour and a half, and she'd maybe not finish it. If she's feeding, she tends to have to sit in a chair in case, she does wriggle. We've had it where she has been sat on us and she's wriggled, and the tubes popped out and err [pulls face, gestures feed going everywhere with hands]. You have to feed her in her chair so there is more time now to be doing family things, we can go out more and do stuff, we are not restricted to whenever we are not hooked up to feeds. **Anna**

As referenced in Section 5.2.1, Anna like other parents interviewed, found giving commercial formula continuously using an automated feeding pump was tiring because her daughter needed to sit in a certain position while being tube-fed. Improved volume tolerance which Anna linked to the transition to blended diet subsequently meant they were free from the feeding pump and were able to do family things, as less time was taken up by feeding.

In summary, eleven of the twelve parents whose child had previously suffered from severe and unmanageable reflux, retching or vomiting symptom reported that introduction of blended diet through their child's feeding led to a near immediate remedy of these symptoms. All eleven parents believed the timing could not be coincidental particularly when symptoms returned when commercial formula was used again later. Two potential reasons for this improvement were noted by parents interviewed: firstly, the viscosity of blended diet in comparison to commercial formula and secondly the omission of dairy from the child's diet. The parents were pleased because they had been able to reduce the anti-reflux medications prescribed to their child. Additionally, the parents treasured the freedom afforded by their child's improved volume tolerance. For most of the children, improvements in reflux, retching and vomiting symptoms were reported to coincide with improvements in bowel habit.

### 5.3.2 'A Proper Poo': Improved Bowel Habit

In eleven cases the parents reported considerable improvement in bowel habit which coincided with the introduction of blended diet. This sub-section explores the impact those improvements had on the children and their family. Irregular bowel habit had been a previous concern for twelve of the parents when their child was fed commercial formula. The parents made a clear connection between the child's bowel habit and the child's general health and happiness (Sub-section 5.3.5). As introduced in Section 5.2.1 Hannah's main reason for trying blended diet was her son's severe chronic constipation and his distress following medical interventions such as suppositories and regular abdominal massage:

Soon after we'd started it [blended diet] he went to the toilet on his own and it's so crazy, but we were actually celebrating the fact that our child has gone to the toilet. I was ringing his dad and I was like [he] has been to the toilet on his own he didn't need any help he didn't need a suppository, I didn't need to massage him or anything he just went to the toilet on his own and it was fine. **Hannah**

Hannah felt the need to justify 'celebrating' something as basic as her child opening his bowels but this meant her son was no longer in distress and additionally Hannah did not have the emotional stress of being the one causing her son pain and discomfort as suppositories and massage were no longer needed, this was a great relief. Constipation was reported to improve in all cases except by Jane:

It's not solved her constipation she has had an ACE [antegrade continent enema procedure], so she's had bowel surgery but at least I know that I am doing all that I can, she has a mega high fibre diet. **Jane**



Jane's daughter still required an ACE procedure, where a tube is placed into the bowel to be used for regular enema and bowel wash outs. Jane still appreciated being able to give her daughter a high fibre diet to help her open her bowels.

In cases where bowel motions had been described as loose and frequent on commercial formula parents also reported improvements:

I remember within a week what a difference, he wasn't vomiting, he was having boluses he did a poo for the first time in his life, a proper poo [laughs] so very, very quickly there was a difference. **Olivia**

Olivia first gave blended diet to her son when he was five years old. Prior to this, her son had been fed exclusively on commercial formula since birth. Olivia indicated that on commercial formula he had not had a 'proper poo' in the first five years of his life. To Olivia the timing of the introduction and the almost immediate cessation of symptoms cannot be coincidence, she was convinced the improvement is due to blended diet.

Similarly, to anti-reflux medications, parents found they were able to wean their child from the medications they had previously used in an attempt to regulate bowel habit:

She used to be on bowel medication, and it was either not enough or too much and she wasn't really... you couldn't say she was bowel continent, she had accidents regularly or she'd be constipated. Within probably months she came off the [brand of laxative] and was totally continent and the only time she's had accidents has been when she's been poorly when she's had a tummy bug. Which is a massive improvement it means you can go out places and you're not planning your life around where you can find a changing table. **Emily**

Emily's daughter was nine-years-old when she started blended diet; she had been tube-fed since she was one-year old and been bowel incontinent prior to

starting blended diet. Emily believed that blended diet helped her daughter to become 'bowel continent' because motions were formed. This subsequently reduced the need for personal care and meant a sense of freedom because leaving the home was easier. The opportunity to adjust the fibre intake of the child was believed by the parents to be the reason for the observed effect on bowel habit:

I can adjust it, if she's getting maybe a little bit constipated, the next blend I could go easier on the fibre, I've got control but when it was medicalised [commercial] formula it's here it is the same feed that you had for nearly five years now, here we go again. **Nathan**

In the quotation above Nathan explained that he was able to adjust the fibre content of his daughters blends daily based on her bowel habit, where he was unable to do this when she was using commercial formula. Later in his interview Nathan theorised that the human body has evolved to process food rather than a liquid diet:

The human body has evolved over millions of years to ingest natural fibres soluble, insoluble the things that we can digest easily to things that we can't. The gut is designed to have a bit of a rough and tumble with natural foods, here we are on a liquid diet for the rest of your life it can't be right. **Nathan**

Previously Nathan gave his daughter 'medicalised' [commercial] formula on the advice of health professionals. Since observing improvement in his daughter's bowel habit with 'natural foods' using blended diet he had questioned this. Nathan used his understanding of evolution to rationalise his experiences.

In summary, the majority of parents reported that their child's bowel habits improved after the introduction of blended diet. Improvements were noted both in cases where the child had previously suffered with constipation and in cases where the child had loose and frequent stooling. Parents found medication they

had used previously to control bowel habit could be decreased. Parents described a sense of freedom as continence was a reduced problem. The parents attributed the improvement in bowel habit to use and manipulation of natural fibres in blends. Reduced nutrient losses, for example reduced incidence of vomiting and diarrhoea were credited with a healthier pattern of growth in most cases.

### 5.3.3 'A Better Weight': Healthy Growth

This sub-section explores weight and growth which had previously been a concern for thirteen of the parents interviewed (Section 5.2.1). For parents whose child had been vomiting weight was, prior to blended diet, a major cause of concern. Parents 'dreading' getting their child weighed every week. A healthier pattern of growth and 'better weight' was described on blended diet. This improved pattern of weight gain was sustained:

It's been amazing how much she has gained weight, its lovely. We've not had to worry so much about her weight, getting those extra kilos on. We were lucky if we could get a kilo on in a year since being on the blended diet we've gained so much. **Anna**

At four-years-old Anna's daughter struggled to gain as little as a kilogram of body weight but, since moving onto blended diet, weight gain is no longer a concern. As Anna indicated earlier in the interview, her daughter was very underweight and needed to gain more weight to 'catch up'. Conversely, Jane, who had found that her daughter gained too much weight too quickly on commercial formula, found that she had a slower and healthier pattern of growth on blended diet; 'she is growing just like any other nine-year-old she wears age 9-10 clothes'.

Parents suggested that they were able to monitor their child's weight and manipulate the volume of blended diet given to them in accordance to maintain a healthy body weight:

If they are losing weight well, they obviously need a bit more or they are getting a bit fat, so we need to give a bit less. There's no medical reason for [him] not to eat, he physically can't put things in his mouth because of his gag reflex, his oral sensitivity, there's not metabolic issues or anything like that and I just think about his [gastrostomy] button [low profile device] as an alternative way of getting it in. **Olivia**

Olivia reasoned that she would adapt the amount of food her son ate if he ate orally. She was giving the same foods she would have given him just via an alternate route. Other parents also viewed the gastrostomy as a 'second mouth' or 'just another way in' for food. As well as manipulating the volume given, the parents described how they were able to adjust the energy-density:

I've added in oils, I added in things that were a bit more calorific like the odd biscuit to help boost the weight back up. For the first time in her life it then shot up, so we put her on... not a diet but we pulled back on the fatty stuff and snacks. **Anna**

Later in the interview Anna explained that she had enrolled in the weight watchers weigh loss programme, and as a result she felt she had a good knowledge of the calorie content of foods. She used this knowledge to adjust the energy density of her daughter's blends. Like Anna, several other parents joked that they had 'overdone it at first' and 'cut back' on high calorie foods used in the child's blends.

Only one parent, Imogen, reported that weight loss had been a significant problem for her son following the introduction of the blended diet. However, she believed this was due to his rare condition which meant he could not metabolise long-chain-fatty acids:

One of the biggest issues we've had with [him] is weight loss and that's because he's not having all the wrong fats anymore his old feed was very high in fat and that's wrong for [him], so

he suffers with weight loss here and there because it's a lot harder to get the calories in but that's specific to my son, to this condition. **Imogen**

Imogen believed that her son's episodes of unplanned weight loss were due to his need for a low-fat diet rather than blended diet in general. With a low-fat diet Imogen found it difficult to make energy dense blends, to promote weight gain.

To summarise this sub-theme, the majority of parents interviewed believed their child had a healthier pattern of weight gain and growth on blended diet in comparison to their growth on commercial formula. This was the case whether the initial concern had been weight loss or excess weight gain. The parents reasoned that weight gain improved because they had control over the blend and could adapt the volume and energy density. Imogen's son continued to struggle with weight gain on blended diet however this was suggested to be attributable this to his low-fat diet rather than blended diet. Healthy growth was reported to coincide with improvements in overall health and perceived immunity to common illness.

#### **5.3.4 'I Think she is More Immune to Things': Perceived Immunity**

Parents perceived their child to be 'more immune' and generally healthier on blended diet in fourteen cases. This sub-theme explores the reasons behind this perception, such as their better resistance to common illness:

She gets less colds and flus, her body resistance to those has improved a lot. She was very vulnerable before if somebody looked at her with a cold, she would catch it. You could argue that she is getting older, but you could also argue that it is linked. **Nathan**

Nathan believed his daughter was susceptible to colds when fed commercial formula whereas she seems less susceptible since being fed blended diet. He acknowledged that her immune function could have improved with age but believed ultimately that her improved health was linked to use of blended diet.

Like Nathan, Imogen also found her son to be less susceptible to common illnesses:

I often wonder if he'd have been on his [blended] diet would he have even had pneumonia? He hasn't had it since or would he have been in [hospital] for so long because I know he used to have colds for a month, he used to really suffer with colds. He doesn't get colds anymore he hasn't had a cold in absolutely ages. **Imogen**

Imogen made a link between the timing of the introduction of blended diet to her son and his resilience to illness. This led her to question the impact blended diet could have had if used at an earlier stage. Like Imogen, nine other parents said that their child had needed less hospitalisation since they had started blended diet:

He spent most of his life in hospital, He's not had a single overnight emergency admission since we started giving him [blended] food and he almost lived in hospital. He is well, and he is absorbing the nutrients from the food, your body is made for food we are not made to have a liquid diet and I know even in his uniqueness his body still always needed food. **Olivia**

The contrast between the health of Olivia's son before after the introduction of blended diet appears to be striking. Improvement in general health reinforced the belief that blended diet was better for her son in comparison to commercial formula. Olivia reasoned that this was because he was able to tolerate blended diet and thus able to utilise the nutrients within it. There was also a sense that the commercial formula was not real food, this is discussed further in Sub-section 5.4.3). As well as reduced hospital admissions other evidence of improved health was indicated by the parents interviewed:

He is now almost sixteen and he has never had a chest infection and he has got a school attendance rate of way over

ninety-five-percent, so I think you know the proof is there he is fit, he is healthy. **Laura**

As the quotation demonstrates Laura viewed a good attendance throughout his school career as evidence of good health and wellbeing. It was important to her that her son should be well enough to have a good attendance at school.

In summary, the majority of parents referenced considerable improvements in their child's general health. The parents believed these improvements in health were related to blended diet. The parents felt this was evidenced by reduced hospital admissions and improved school attendance. In addition to general health improvements the parents also believed their child looked visibly better than they had previously on commercial formula.

### 5.3.5 'Looks Better': Visible Improvements

Visible improvements were noted in nearly all the parent's accounts, this sub-section examines why parents believed their child 'looks better' on blended diet. Previously, on commercial formula, parents had described their child being 'grey' and 'washed out' or having 'sunken eyes'. Interestingly, only one parent, Marie did not make any references to visible improvements. However, she had not used commercial formula to feed her son in the longer term (Sub-section 5.2.1). In thirteen cases parents made references to an improvement in their child's complexion:

Her skin was a lot better within about a week, not that she had bad skin, but it looked brighter and a lot of people commented on that even ones who didn't know that we'd changed her food they were like 'ooh she's got more colour in her'. **Beth**

Beth was keen to point out her daughter's 'brighter' appearance was not just something that she had observed, but others, even people who did not know about the change in diet, noted the improvement. Reference was also made to other visible signs of health such as the condition of their child's hair or strength of their fingernails:

There were slower changes, an improvement in her complexion, her hair just started to grow there was a shine about her hair and her fingernails started to grow. It's difficult to put down isn't it but she just looked better she had dark circles under her eyes and they disappeared, not straight away but they disappeared. Now you could argue they would have disappeared anyway if she was on [brand of commercial formula] well I'd say for the first five years they were there then they disappeared at the same time that we went to blended diet you could say it's a coincidence, but I like to think it was related.

### **Nathan**

Again, Nathan offered counter arguments which suggested he has, in the past, been told these signs are coincidental, but he firmly believes they are linked. Like Nathan, other parents talked about their child now having 'tons of' hair and it being in 'better condition' with a 'shine' after starting their child on blended diet. Like Beth's quotation other parents strengthened their observations, which could be viewed as being highly subjective, with reference to other people noticing improvement too:

Everyone comments about her looking so healthily and growing so well and a lot of people who don't know her who see her don't initially think something is wrong with her because she doesn't look sick. **Katie**

Despite her daughter having serious complex care needs, Katie believed her daughter no longer looked unwell. This contributed to the sense of normality experienced by parents (Section 5.4).

To summarise this sub-theme, the majority of parents observed visible improvements in their child, such as their complexion and growth of hair and fingernails. The parents supported this claim by suggesting other people had observed these improvements too. In addition to looking better, parents



described how their child seemed happier following their transition to blended diet.

### 5.3.6 'He's a lot Happier Nowadays': Signs of Improved Wellbeing

This sub-section covers the main signs which led parents to believe their child appeared happier since using blended diet compared to commercial formula. As described in Sub-section 5.2.1, parents reported their children had a wide range of adverse symptoms such as reflux, vomiting, constipation and diarrhoea prior to starting blended diet. However, all the parents believed their child to be in pain or distress, they linked the pain and distress to the use of commercial formula. Due to their respective conditions, most of the children would have been unable to vocalise their distress but parents noted signs of improvement:

She was more relaxed, when she was on the formula, she was always kind of wincing as if there was some kind of a gut ache, an intestinal ache. She always had these facial gestures and arching her back a lot which I know now is probably a sign of GORD [Gastro oesophageal reflux disorder]. **Nathan**

Reduction of facial gestures and back arching were interpreted by Nathan to be signs of reduced incidence of pain. Parents subsequently asserted that a reduction in pain would mean that their child was happier:

Nobody likes being sick it makes you grumpy it is obvious to see that it [blended diet] is what she prefers we noticed a radical change in her [she went] from being this really sickly child to being happy, she had much more energy. **Claire**

To Claire it made sense that a child who is no longer being physically sick or having severe constipation is likely to be a happier child. For children who could not verbalise how they were feeling, the parents, like Claire, often tried to put themselves in their child's position and imagine how they would feel were they experiencing that symptom.

As introduced in Sub-section 5.2.1 alleviation of hunger symptoms was Laura's main motivation for trying blended diet:

He always tolerated them [commercial formula] fine, they just didn't leave him satisfied he was just coming home in the afternoon screaming. I think the first time [after trying blended diet], it was a case of wow this has gone down well, and he was quickly satisfied. I just felt for a child who had ate normal food for virtually seven years of his life to then revert back to milk was of the opposite of what you do with a baby when you wean them from milk onto solids. They need more satisfaction from solids. **Laura**

The screaming was interpreted by Laura to be a sign of hunger in her son. Laura's reference to weaning and having to 'revert' suggested she viewed commercial formula as a backwards step. Commercial formula was frequently referred to as 'milk' or 'feed' or 'formula' by parents in all the interviews. The quotation above demonstrates that these words have connotations for parents, describing commercial enteral formula in this way may seem infantilizing to the parents of older children or young people. Laura did not think that a liquid diet would satisfy her son; this idea was reinforced as her son stopped screaming when blended diet was introduced. Nathan also believed his daughter was more satisfied with blended diet than commercial formula, he thought this too, had a knock-on effect on her sleep:

One thing we noticed was a sense of satiety, satisfaction. What I mean, on her last meal of an evening she would fall asleep shortly after a feed and I remember thinking this is so strange. It just got me thinking well don't we often feel sleepy after a big meal at night. So, I'm convinced that there was an element of satiety that you get from eating something bulky, alright it's been liquidised but it's still bulky food, food that requires effort to extract. **Nathan**

Nathan considered how he would feel after a big meal and believed his daughter would feel the same. He wondered if the blended diet required more digestion than the commercial formula which would then in turn feel more satisfying in comparison to the commercial formula.

Improved energy levels following blended diet introduction were described by seven of the parents. This meant that they could interact and be more engaged in the world around them:

I'm kind of comparing [her] to how she was on [commercial] formula, but she seems to have a bit more energy, she seems to be more responsive, she just seems to have that bit more sparkle in her eye. **Fiona**

This quotation has been interpreted as meaning Fiona believed her daughter was happier and more interested in interacting with the people around her. By describing her as having a 'sparkle in her eye' Fiona painted an image of an improvement which is hard to pin-point; something that someone who did not know her daughter well would find difficult to see. Other parents, like Beth, described noticing more obvious signs of improved wellbeing and alertness:

She became louder, she seemed to be awake more and she had more concentration. I can only imagine that the formula made her feel lethargic and that she didn't have much energy; she definitely had more energy on food. She was just generally more alert she started reaching for things, so we think she didn't feel well before and that now she feels better. **Beth**

Again, the use of the word 'food' is interesting, it seemed the parents did not consider commercial formula to be food; and this is explored in depth in Section 5.4.3. The gastrostomy tube was placed in later life in four cases, these children had eaten orally up until that point. Diane's daughter for example was thirteen-years-old when she lost the ability to swallow food safely due to a

neurodegenerative condition. Diane believed that being able to have the same food as other people again meant her daughter was happier:

I would say within three to four months I had a totally different child, she was much more alert she was much happier. She quite accepted that she could have a little taste on her lips and the rest went down the tube, she'd sit back at the table with people again we could start going out again. **Diane**

The quotations above both summarises this superordinate theme and links to the next section (Section 5.4). After transition to blended diet Diane felt that she 'had a totally different child' and she reported that blended diet had a positive, life changing effect on their lives. Diane's daughter's improved health and improved mood also meant they were able to socialise with other people over food as they had previously, before the gastrostomy tube was placed.

#### **5.4 'How Life Should be': A Sense of Normality**

The third superordinate theme relates to the sense of normality which the parents interviewed had found with blended diet in comparison to their experience of commercial formula. The superordinate theme relates to the research objective of this research, which sought to understand the benefits of blended diet as perceived by parents. All the parents interviewed felt blended diet had in some way made the experience of feeding their child more normal, more like feeding a child orally. While none of the parents said that a desire to normalise feeding was the reason they initially chose to start blended diet, it seemed for most, that this sense of normality had become a powerful motivation to continue with the practice. The superordinate theme has been divided into separate but related sub-themes. The first, in Sub-section 5.4.1 examines how twelve parents felt their tube-fed child was more included in family life. Sub-section 5.4.2, explores how blended diet has de-medicalised tube-feeding for parents. As previously highlighted in this chapter parents did not view commercial formula as food, Sub-section 5.4.3 explores why. A theme of choice

was evident in all the interviews, not only the overall choice to use blended diet, but small everyday food choices too (Sub-section 5.4.4).

#### 5.4.1 'She is Part of Things Now': Inclusion

This sub-theme explores the social inclusion which fourteen parents felt blended diet afforded in comparison the commercial formula. While a desire to include their child in the social aspects of food and eating did not seem to be parent's main motivation when deciding to try blended diet, on reflection, they believed their tube-fed child had been excluded from these aspects of life when fed exclusively using commercial formula. This is illustrated by Katie:

Everyone's life is very much about food: you invite your friends what do you do? You give them some food and drink, you're hospitable. You meet a friend for a chat where do you go? Usually a café. There's always food involved, food is part of our life, of our existence. I feel if I didn't give [her] normal food she would miss out on this. You share a lot of things in life through food and I think if any person is tube-fed and only getting [commercial] formula then they don't take part in that life. She partakes now! For me on a psychological level that is extremely important. **Katie**

Katie specified in the quotation that it was important for her as a parent, that her child should not miss out on experiences and interactions involving food. It was not clear whether she thought her daughter perceived that she was missing out or was different to her peers. Katie pointed out that food is part of human daily life and meals and food often brings people together in social situations. By not having food Katie felt her daughter was excluded from a whole aspect of human life. In other parts of her interview Katie had explained that she is a person who 'likes to cook' for family and friends or meet friends for food. Katie's own enjoyment of food and cooking made it more difficult to accept that her daughter could not eat and was therefore excluded. Other parents, such as Emily, shared this sentiment: 'It was quite sad considering how much I enjoy food'. Emily

identified as someone who enjoyed food but felt sad she could not share her enjoyment of food with her daughter.

The positive effect of inclusion was described by twelve of the parents interviewed. For Nathan the possibility of sharing a family meal with his daughter is invaluable:

That kind of binds you to the family you can go home thinking there's four people in this house one person is severely disabled and fed by a tube but guess what we are all sat round the table and having the same dinner, great that's just... you can't put a price on that. **Nathan**

Although his main motivation to start blended diet was his daughters severe and recurrent reflux and vomiting symptoms (Section 5.2.1) the possibility to include her in family mealtimes was an additional, unexpected benefit. After starting blended diet, he felt like his daughter is sharing a meal with the rest of the family despite her being tube-fed.

For some families, it was reported that the child shared the same food as the rest of the family at every mealtime:

[He] has exactly what we have, he doesn't have anything different, whatever we have on that night for dinner [he] has blended so he's just eating what we are eating, I feel like he's not being left out, he's doing what everybody else is doing. It makes it a more of a social thing. That was a massive hang up for us when they [Paediatrician and Dietitian] said about getting a gastrostomy tube. I was really worried about the social aspect being taken away from [him], of eating with the rest of the family, where I find this way, with blended diet he's got that, we didn't have it with [commercial] formula, but he has got that with blenderised diet. **Gemma**

Gemma, like Marie (Section 5.2.3) had delayed her son having a gastrostomy tube because of a fear that he would lose the 'social aspect' of eating. Again, social inclusion was not Gemma's main motivation for starting blended diet, she wanted to stop her son's 'horrendous vomiting'. However, blended diet offered a way in which her tube-fed son could be included without this consequence. Like Gemma, on reflection, other parents questioned why their tube-fed child needed to have completely commercial formula solely because of the feeding tube. As introduced in Sub-section 5.3.6 Diane noticed a marked change in her thirteen-year-old daughter's mood and behaviour when she first stopped eating orally:

Originally, when she stopped eating normally and she had to go onto a PEG and just have [brand of commercial formula] it was awful! I didn't feel I could eat in front of her, I felt so guilty, we stopped going out to meet friends socially for meals because she couldn't eat, and she would turn her head away from us she wouldn't give anybody eye contact or she would deliberately stare at you and start making her mouth move as if she was eating. It used to really upset me, I think I found that harder than when she stopped walking which was her other big milestone, when she started to be wheelchair bound. Eating was worse because that was her one joy in life, she loved her food and loved eating, we did eat out a lot we were quite sociable around food and all that was taken away from her. Socially it [blended diet] is much easier for [her] we can all join in together, we go to three or four different restaurants and I take her blender with me. **Diane**

Diane described how her daughter used to enjoy food and going out to eat with friends. Diane found her daughter's loss of food more difficult to accept than her loss of mobility. Since starting blended diet, she feels her daughter exhibits less signs that she misses food and Diane subsequently feels less guilt. It is interesting that Diane was able to blend food outside of the home, when they

are eating out. Claire, Laura, Katie and Olivia also described experiences where they had given their child blended food in a restaurant or on holiday.

Unlike Gemma, seven parents did not always give their tube-fed child the same foods, blended, as the rest of the family or ate their meals at the same time:

Very often particularly on school days she doesn't actually eat with us she wants to lie on her bed as soon as she gets home, so I'll do her feed in her bedroom while [younger sister] is eating hers in here so it's not, oh wonderful family togetherness, but it's still actually here comes your dinner, you are having food. **Jane**

Being able to feed the child the same food as other people appeared to be particularly important for the parents during special occasions, such as birthdays and Christmas. For example, Jane made certain her daughter was able to have her blended diet on the table at her birthday party:

We had one lovely birthday party where I think we probably had four or five tubies [tube-fed children] who are on blended so on the table with all the party food were syringes of hummus and vegetable sandwiches and syringes of cakes all in 20ml syringes for people to just help themselves. That was just really nice, it was look it's her birthday, so her food is going on the table. We don't always do that it's a bit of a big deal. **Jane**

For Jane, food was an important part of her daughter's birthday celebration and she felt it was worth extra effort on that occasion to make sure her (blended) food was presented in pride of place on the table. Like Jane, the 'togetherness' of a shared meals and individual foods on special occasions seemed particularly central to twelve other parents accounts:

I especially like Christmases and birthdays where we blend cake and things and have a bit more fun with the blend and it's just nice to know that she's having the fun festive food and the



treats that you're all having its quite nice like she not missing out anymore. **Anna**

In a similar way, Anna added treats to her daughter's blends which meant her daughter could 'join in'. Other parents spoke at length about being able to include their child by giving small food-based treats such as a chocolate Easter bunny, advent calendar chocolate and pancakes.

The use of blended diet allowed family members and friends to be involved in providing food for the tube-fed child. For example, Anna and Jane's younger daughters brought home sweets or cakes made at nursery for their older sisters to have in their blends. Additionally, Claire and Fiona both talked about how friends and family brought over home grown vegetables:

My friend has an allotment, they'll say what can I grow for [her] I want to grow something that she can have. Or my mum might bring something from her green-house for her. They feel like they are contributing something, that's just dead nice because obviously they don't do much normal grandparent stuff, they haven't had much chance so it's quite nice that they feel like they are included. **Claire**

Claire reported that growing food which could be added to her granddaughter's blends made her mother feel that she is 'contributing something'. It seemed that an extended family member may be excluded from their perceived usual role because of the child's complex care needs. In this case, blended diet offered an opportunity for grandma to be included. Conversations with family and friends about food were also possible because of blended diet use:

My four-year-old will say what's [she] having for her tea tonight mum? Instead of saying oh yeah, she's having [brand of commercial formula], I can say oh she's having sweet potatoes and carrots and lentils, and she'll go yum. So, although [she]

can't communicate [her sister] seems to take more of an interest now. **Fiona**

In this case the younger sibling is likely to understand the taste and texture of sweet potatoes, carrots and lentils, because she had eaten it before herself and therefore she had an understanding of what her sister had to eat too, it would have been a shared experience.

In six cases parents said they were able to actively engage their tube-fed child in activities involving food such as baking and cooking:

If I'm pureeing up something that we've had he knows he is having what we've had too. We do talk about what he has had, I think it's important for him to know different textures, flavours and aromas. You can tell when he has had too much garlic because he stinks like the rest of us [laughs] **Laura**

Laura talked to her son while she prepared his blends. Laura could include her tube-fed son in the cooking process by talking to him about the food he had blended. Laura pointed out that although her son did not swallow food, he was still able to experience the texture, flavour and aroma. The comment about the garlic has been interpreted, because of the laugh, as something that they as a family joked about, an in-joke, part of the experience of sharing a meal. Sharing the same food and including the child in activities involving food seemed particularly important to the parents whose children had an awareness and interest in food. On the other hand, some parents interviewed said their child had 'no interest in food'. Unlike the other parents Marie and Olivia did not see a benefit to giving their sons food-based treats on special occasions because their children have no interest in food:

I would love to be able to just feed him whatever we are eating, but he has a long list of allergies, we have to be very careful what he gets. I tend to cook for him separately. I have done things like made sure he had Christmas dinner on Christmas

day but he's not caring, it's going in his tube anyway, so what's the point and I think that's because he doesn't have an interest in food, me doing that is about me making sure that he is included whether he is interested or not **Olivia**

Olivia no longer saw the point in including her son in special meals because he had no interest in food due to his oral sensitivity. Despite her son's lack of interest in food she would still 'love' to be able to give him the same food as the rest of the family but was not able to due to his allergies. Olivia's thinking on inclusion in family meals and special occasions had changed in time, she believed that had been for her benefit rather than her sons. Reference to inclusion was missing from Imogen's interview however she did say that she personally 'got a kick' out of preparing food for her son. Like Olivia's son's 'long list' of allergies, the different fat profile Imogen's son needs probably meant he could not have the same food as the rest of the family and would not have been able to if he ate his food orally. Marie explained that she did not worry about her son missing out on treats:

My son is cognitively impaired. He has no concept of birthdays, Christmas, Easter, or of treats. This makes my life easier because I don't have to worry about him thinking he's missing out on anything if he doesn't have a piece of cake, a bar of chocolate or [name of fast food restaurant]. His meals are really delicious and I believe make him feel great, as any good meal can make you feel. So, with all that in mind I don't give [him] treats, empty calories are as empty to him as they are to anybody and since he has a limited calorie intake, I think it's important to make them count. Calories and weight gain are just half of the goal, good nutrition is the other half. **Marie**

Unlike some of the other children her son had 'no concept' of special occasions or treats. Marie believed cake, chocolate and fast food are 'empty calories' this has been interpreted to mean she viewed these treats as being energy dense without vitamin and minerals; instead she chose to give her son 'good nutrition'.

When Marie said they are 'really delicious' this indicated she would have been happy to eat them herself, if she also chose not to eat treats and her son is included as he had the same healthy food as his mother. Marie implied she would have been more worried if her son did have a concept of birthdays and Christmas. However, he did not and for Marie it seemed blended diet was about optimising the quality of her son's nutritional intake.

To summarise this sub-theme, inclusion, be it of the child, the parent's or others, was evident from fourteen of the parent's accounts. However, there was diversity in how the parents included their child. Family meals were important to some but less important to others, most felt blended diet permitted inclusion on special occasions. Blended diet use encouraged the inclusion of family members who could be involved in providing food for the tube-fed child. Allergies and special diets made it more difficult for parents to share the same foods as their family. In addition to inclusion, blended diet also felt less medical to parents in comparison to commercial formula.

#### **5.4.2 'I Can Be His Mum Rather Than His Nurse': A Feeling of De-medicalisation**

This sub-theme explores why blending everyday food themselves, at home seemed in comparison to the 'medicalised' formula, to be more part of their normal parenting role. This is illustrated well by Fiona:

When she was born, we knew that something was wrong and then a few years after that we got a diagnosis everything seemed to be very medical. As she got older her needs seemed to get more complex, we seemed to get more equipment in the house everything seemed more sterile and hospital like and when this idea, the blended diet came of real food it somehow changed things and made things... actually this is more how like life should be, it brought some normality to a household that's been so entrenched with medical stuff.

**Fiona**

Use of the words 'sterile' and 'hospital like' have been interpreted as meaning that medical equipment and clinical tasks were taking over her home and family life. The word 'more' implied a progression, the complexity of her daughter's health needs became greater with time. The word 'entrenched' indicated this clinical way of life was firmly established, which made sense as her daughter had been tube-fed for a long period of time. The word 'entrenched' could also indicate that Fiona felt her home life was being gradually invaded by 'medical stuff'. Clinical procedures, that would not normally be associated with a person's home, were part of her everyday life. When Fiona referred to 'how life should be' she was possibly thinking about life before her child was born, or how she imagined family life would be before she found out her child had complex care needs. Like Fiona, thirteen other parents described the experience of blending food for their child to be less 'clinical' or 'medicalised', compared to feeding using commercial enteral formula. This de-medicalisation seemed to be important because of the number of other clinical procedures the parents had to perform for their child on a daily basis:

I'm actually feeding my child that is nice when there is so much medical stuff going on with her. She is catheterised, she has bowel wash outs, she has meds four times a day, there is so much. It's normal for us now but it's so really completely alien let's be honest. **Jane**

Jane described the other complex clinical procedures her daughter needed in addition to tube-feeding. These procedures became normal to her as she did them every day and did so for several years. However, Jane felt it should not be normal to do so many clinical interventions at home. Jane found blended diet less 'alien' because it involved preparing everyday foods that other people would normally eat orally:

Formula is not food to me, this is like medicine because that is how it's being treated when you are in a hospital everything gets measured out in millilitres and in calories and you have to give that amount at that set time, at that speed normally via a

feeding pump. So, feeding formula to me that classic tube-feeding as it was done in hospital it's a medicalised version of sustaining someone but it's not giving someone nourishing food. **Katie**

As referenced earlier in Sub-section 5.4.2, Katie, like other parents did not view commercial formula as food. Additionally, the way in which commercial formula was prescribed in set regimens seemed very clinical and unnatural to her. The words 'sustaining' and 'nourishing' have been interpreted as Katie believing in a difference between existing and living. Additionally, earlier in her interview Katie had described her 'excitement' when she first brought her tube-fed child food from a shop rather than the pharmacy, as a parent would do for a child who ate food orally.

The language that all the parents used to talk about blended food for example 'breakfast', 'lunch', 'dinner' and 'snacks' contrasted with how they spoke about commercial formula, which was referred to as 'feed', 'bolus' or 'feeding regimen'. Jane expanded on why this might have been:

She's having her lunch, or she is having her dinner the same as everybody else does, it seems to be its dinner rather than feed there is a psychological thing whereas actually when its plugging her in to a pump its feed its more clinical and its more it turns what should be something completely natural into something that is completely unnatural. **Jane**

For Jane the normality of blended diet is not necessarily having the same food with the rest of the family (Sub-section 5.4.1). Instead, her daughter had something that the rest of the family would eat, something recognisable to them as food, in a similar meal pattern.

In summary, the parents interviewed thought of themselves as having dual roles in their child's medically complex lives. Home life had become overshadowed by medical equipment and clinical procedures. While administration of

commercial formula was viewed as yet another clinical procedure or part of a nursing role, blended diet fit more comfortably with expectations of a parenting role. The way in which commercial formula is prescribed and delivered contributed to the way parents viewed it. Furthermore, as referenced in earlier sections the parents interviewed in this research did not view commercial formula as 'real food'.

#### **5.4.3 'They Deserve Real Food': A Human Right**

This sub-section deals with theme which emerged from all of the interviews. The parents interviewed gave the impression that they did not think of commercial formula as 'food'. Words such as 'chemical', 'false' or 'synthetic' were used throughout the interviews to describe commercial formula whereas blended diet which was referred to as 'real', 'normal', 'healthy', 'natural' and 'fresh'. The parents seemed to believe some of the physical improvements they had seen in their child such as perceived immunity (Section 5.3.4) were due to the 'fresh' and 'nutritious' quality of the food they gave their child:

I have to say he has been a pretty healthy child all through his fifteen years of life and I think that is down to the fact that he's always had proper fresh food and he has always had the energy to fight off infections and cope with whatever life throws at him. **Laura**

Hannah spoke of how she had never felt comfortable feeding their child commercial formula:

When you look on the back of those packets of [brand of commercial formula] there are so many chemicals. I know it's got lots of vitamins and minerals in it but as far as I can see a lot of the calories come from some form of sugar. It's disgusting, have you ever spilt it? It's like glue how can that possibly be any good for you? Yuck, I think I've tasted it once just because I like to think ok what am I putting into my child

and oh it was disgusting it was like syrup or extra thick condensed milk it was just horrid. **Hannah**

Hannah likened commercial formula to foods that are high in sugar and processed food which she believed to be bad for human health. Other parents likened the commercial formula to UHT milk, dieting milkshakes and cream liquor, all foods which would not usually be fed to a child. Hannah did not recognise the chemical names she saw on the commercial formula packaging as food. She also did not personally like the taste and texture of the commercial formula and questioned whether she should be giving her child something she would not choose to eat herself, Katie expanded on this idea:

I wouldn't want to drink that; the smell is horrific and sometimes I licked my fingers because I had a drip of it on my fingers and I thought oh god that's just so sweet and horrible! I wouldn't want to eat that myself, I wouldn't drink that, and it makes you then think gosh but I'm giving that to my child everyday all the time, that can't be good. **Katie**

Like Hannah, Katie would not choose to drink commercial formula herself as it tasted 'sweet and horrible'. Even though her daughter would not be able to taste the formula as it goes directly into her stomach via the gastrostomy tube other elements mattered to Katie such as the 'horrific' smell and the sweetness. It is possible that children may encounter the taste the commercial formula when vomiting. Later in the interview Katie said that:

Every human being even a child should have a choice of what they put into their digestive system and whether it is through their mouth or through a tube doesn't matter. **Katie**

For children, particularly younger children it is usual for parents to choose what the child eats. Her use of the word 'should' here suggested Katie believed that tube-fed children are denied a choice and treated differently to people who eat food orally. Anna and Emily echoed this idea saying that their child 'deserved



real food' or that their 'human rights' were being ignored when they were not allowed to feed their child in the way they wished.

Nathan shared the view that blended diet was more 'natural' and therefore perceived as healthier than commercial formula had developed after starting blended diet, his thinking had changed with time based on his experiences:

If you think eating healthy, natural foods is good enough for seven billion people on this planet why wouldn't it be good enough for my daughter? At the time, I didn't know that, I was like everybody else, this [commercial formula] is prescribed, this must be good, so we gave it to [her]. I think we'll look back in history in twenty-years-time thinking wasn't it barbaric that kids born in the seventies, eighties and nineties were given this drivel. **Nathan**

The use of the word 'barbaric' has been interpreted to mean he now thought it cruel to give tube-fed children and young people commercial formula; which he believed had the potential to make them very unwell. The word barbaric could also be interpreted to mean primitive or unevolved, perhaps demonstrating a hope that understanding of enteral feeding will improve in the next twenty years. To Nathan, commercial formula is 'drivel' something he would not now consider feeding to his daughter. Like Nathan, five other parents said they would no longer consider giving their child any type of commercial formula. Conversely, Claire, Hannah and Olivia continued to use commercial formula as an overnight supplement. By contrast, both Imogen and Marie reasoned they would have preferred to be able to use some commercial formula as this would have been 'easier' particularly when the child was being fed outside of the home (see Sub-section 5.3.6). Both stressed they were not 'anti-formula' but did not feel it suited the needs of their child.

In summary, all the parents viewed commercial formula to be very different to 'real food'. However, there was a continuum of attitudes towards commercial formula, some would not consider giving their child commercial formula under

any circumstance whereas others saw a role for commercial formula within their tube-fed child's diet alongside blended diet. A further drawback of commercial formula was the uniformity whereas blended diet provided parents with a wide array of choice.

#### 5.4.4 'A Vast Array of Ingredients': Opening up Food Choice

This sub-theme explores the food choices parents described in association with blended diet. In fourteen cases parents spoke about the variety and choice available when using blended diet. The variety of aromas was important to Laura as introduced in Sub-section 5.4.1, whereas the visual appearance was important to Olivia:

I like the fact that his food doesn't always look the same do you know if you get formula it's the same all the time whereas some days its pink, some days its orange, some days its green.

#### **Olivia**

For Olivia the variety in the visual appearance of the blend was valued. Commercial formula on the other hand is always the same 'beige' colour every day which Jane described as 'monotonous'. Nathan enjoyed being able to choose from a wide variety of food ingredients for his daughter:

When it was medicalised [commercial] formula, it was here is the same feed that you have had [every day] for five years, here we go again. You've got a cold, it's the same feed, you've got constipation, it's the same feed. Now that I've been doing it [blended diet] for four years I've got a vast array of ingredients I can use. I can say ah well these are in season now, pumpkins for example, yeah let's put some of that in, why not? **Nathan**

Prior to starting blended diet Nathan's daughters had the same commercial formula every day for five years. Blended diet allowed Nathan to be creative and give his daughter seasonal foods or adapt her blend if she was unwell, something he would have done for his other children or himself. Like Nathan,

nine other parents, said that blended diet gave them the opportunity to give home remedies to common minor illnesses. For example, 'chicken soup' or 'lemon and honey'. Imogen expanded on this idea:

It's nice to have extra options, I don't particularly feel... I'm not one of these people that will go for alternative medications or anything like that, he has a lot of medication that keeps him alive and I would never even consider taking him off them, but he had a lot of medications and its nice not to put something chemical in him every now and then **Imogen**

Imogen did not identify herself as a person that used alternative medicines but felt it was better to manage minor episodes of illness herself at home rather than always turning to prescribed medication. Other parents spoke of how they had managed their child's clinical condition by making choices about the food ingredients they used in their child's blends. For example, Anna spoke of how she had been able to treat her daughter's iron deficiency using advice from her dietitian about foods high in iron such as dried apricots, lentils and beans. Similarly, Claire was able to manage her daughter's renal condition by adapting her daughter's potassium intake following dietary advice from a specialist renal dietitian.

In six cases parents spoke about how their tube-fed child was able to make their own choices about the foods that went into their blend. As illustrated in Beth's quotation:

In the last six months or so she has shown a huge interest in it [blended food]. If I'm doing breakfasts blends, I'll have the four cereals out and I'll ask her which one do you want to go in this blend and she'll pick. She has to switch the blender on too that's her job. **Beth**

Beth gave her four-year-old daughter small choices over what she had in her blend. Beth believed that her daughter enjoyed having a choice and being

involved in the preparation of blends. The amount of choice was increased comparatively for Emily's fourteen-year-old daughter:

She loves pizza 'you go pick me up a pizza' [said alongside Makaton sign] and every time we go to the [shopping] centre she wants pizza, pizza, pizza on her talking computer. There's nothing wrong with having the odd bit of processed food but I'm in control of what she's eating overall, she has no idea of what a healthy meal is because she hasn't learned about food really.

### **Emily**

Like Beth, Emily allows her daughter to make occasional choices about food but as her parent, retains overall control of her diet. More control perhaps than a parent of a fourteen-year-old who does not have complex needs would have. Diane's twenty-year-old daughter who ate orally until the age of thirteen is given full choices about what she eats:

If we have a Chinese take away, we'll ask her if she wants some, what she would like, and she gets some pureed down her tube, which might horrify some people but why shouldn't she. **Diane**

Diane pre-empts that people may be shocked that she gives takeaway through her daughter's tube, but her daughter is an adult and able to make some choices for herself. By contrast, Marie and Olivia, explained their tube-fed sons have no interest in choosing their own foods:

[He] is kind of different from other kids, he's eleven now and he has absolutely no interest in food what so ever, none. He doesn't get hungry and I think that's because he was fed continuously for five years. If you don't feed [him] he won't come and tell you he's hungry, he won't say you forgot to give me my dinner, he doesn't have that interest in food. **Olivia**

Olivia still felt that one day, although 'he will always need support', he would 'become responsible for his own nutrition' and interested in making choices for himself.

Claire joked that her tube-fed daughter was a lot easier to feed than other children in the family who ate orally, the tube-fed child was never 'picky', because, unlike other children in the family they did not have a choice over what went into the blend through their feeding tube:

Me and my friends on blends always joke that a positive thing of tube-feeding is they [the child] don't have a choice over what they eat. We don't get picky children going 'ooh I don't like Brussels sprouts', or 'I don't like this, that and the other' we've got the perfect child they will eat whatever we will give. They don't get junk food and we don't shove pizzas in for them.

**Claire**

Claire was implying that children who eat orally may prefer to eat fast food rather than healthy foods. Interestingly, Claire's tube-fed daughter did not taste the food and therefore did not object, this idea was shared by Emily and Imogen. Additionally, five other parents said that they regularly gave their tube-fed child foods that their other children, who eat orally would not usually eat, for example, kale, manuka honey and coconut oil:

I'm buying food that probably I wouldn't have bought for the other kids but for her it makes sense. I can pack a nutritious punch in a small thing. That's why I do my daughters shopping separately, that's why she's got her own cabinet at home because there is stuff that we use for her that we generally didn't buy ourselves so look at stuff like hemp oil, avocado oil, soya milk, almond milk all that kind of stuff. **Nathan**

Nathan explained that he gave his daughter foods which 'pack a nutritional punch' which has been interpreted as food he believed to have high nutritive

value in a small volume, even though he would not choose those food for the rest of the family. Conversely, other parents like Anna and Gemma would not choose to give their tube-fed child any foods that the rest of the family would not usually eat. However, Gemma and Anna did choose to blend ingredients slightly differently to each other:

I watched YouTube videos, families show you how they do their blends and they'd blend for the day, I couldn't get my head around the fact that they would put ham and strawberries and cucumber and frozen peas and peach all in the same blend. I still can't get my head around that. It has to be a sweet or a savoury blend to me. I think you wouldn't choose to eat that on a plate. **Gemma**

Gemma chose to blend sweet and savoury dishes separately for her son, whereas Anna was happy to blend sweet and savoury together:

I tend to blend everything together so sweet and savoury. I wouldn't want to eat it like just like that, but your tummy mixes your pudding with your main course naturally anyway. All we are doing is mixing it ready for her. **Anna**

In summary, most parents liked that their blends varied in appearance and aroma from day to day. Parents valued being able to give different ingredients and adapt the blends. Blended diet afforded the parents a wide variety of food choices for their child. In some cases, the child or young person was able to make their own decisions about the food ingredients that went into their blend. The parents had made different choices in comparison to each other, for example the ingredients chosen or how the prepared blend. This potentially explains why the parents felt they had to work their own way through the practical challenges, working out what best suited their child and family.

## 5.5 'You Have to Muddle your way Through': Practical Challenges

All the parents interviewed had experienced practical challenges, and through a process of 'trial and error' found ways to overcome barriers to blended diet. This superordinate theme relates to the research objective which sought to explore the challenges experienced by individual parents when choosing blended food. The superordinate theme has been divided into three separate sub-themes. Firstly, the fourteen parents who could remember starting blended diet all described a tough time (Sub-section 5.5.1). Secondly, the parents interviewed said that planning and preparing a blended diet for their tube-fed child required more time and effort than commercial formula (Sub-section 5.5.2). Finally, the parents' discussion about the financial cost of blending diet in comparison to using commercial formula will be explored (Sub-section 5.5.3).

### 5.5.1 'When you Start out it's Hard': Learning how to do Blended Diet

Commencing blended diet with the children was a vivid memory for fourteen of the parents. All fourteen parents described a mixture of apprehension and excitement. The first few months, when they were learning how to blend were a challenging time:

Starting off not knowing what to do, I just had a breakdown one weekend over it all. I knew that I really did not want her back on formula because of how poorly it [commercial formula] had made her, it [blended diet] had got to work. **Beth**

Beth felt she had no other option than to try blended diet but found the practicalities of '*starting off*' challenging, despite having the support of her daughter's dietitian. The quotation above indicated pressure to get blended diet right because it felt like her last hope. As introduced in Sub-section 5.2.3, eleven of the parents decided to try blended diet initially without the support of a healthcare professional. This seemed to have made getting started even more challenging:

I did feel as though I was doing it on my own because we weren't involving the professionals. You kind of find a way through, you have to muddle your way through. **Fiona**

Fiona felt as though she had to 'muddle' her way through to find what foods to blend and which suited her daughter without the advice and support of healthcare professionals. Parents reported putting time and effort into researching recipes and getting the consistency of the blend right. The parents described reading academic papers, books, blogs and talking to other parents who had chosen to feed their child blended diet on forums such as the Blended diet UK Facebook group (peer support is explored further in Sub-section 5.6.4). Anna, who was very committed to using blended diet from the outset who had been told about blended diet by her daughter's experienced dietitian found it tricky to get started. However, there was a sense from all the parents that with time things became easier as Oliva's quotation illustrates:

My head was full of numbers and calculations and when I made it the whole kitchen was a mess it was like the Swedish chef had been at work it was everywhere and that was a challenge and I think it's important for people to know it doesn't stay like that you get your routine, you get your rhythm. **Olivia**

Olivia initially measured out the ingredients, kept to recipes and calculated the nutritional content of her sons blends. Six other parents explained how they used to keep complex spread-sheets documenting the exact quantities they used and the amounts of micronutrients that would provide. In her metaphor comparing her former self to the Muppets Swedish chef, Olivia painted a picture of a kitchen in chaos. Anna and Imogen spoke of similar things; they found it difficult initially to obtain a smooth consistency using a regular hand-held blender which led to there being 'mess everywhere'. Imogen explained how she used to try to make sure the food did not even touch the kitchen work surfaces to avoid any risk of contamination. There was a sense that with time the parents relaxed as they got into a 'routine'. Jane could not remember starting blended



diet, her daughter had been fed using blended diet for five years and she found it had become 'a complete habit'.

To summarise this sub-theme, parents undoubtedly felt extra workload was worth the benefits that blended diet provided. All the parents who remembered starting blended diet found it to be a challenging time. It was stressful because parents had to work out individual recipes for their child and achieve the correct consistency often using basic kitchen blenders. The situation was compounded by a lack of support from professionals (Section 5.6.1) and by a pressure to 'get it right'. However, with time and practice blending became easier part of their daily routine. Nevertheless, blended diet sometimes felt like a chore.

### 5.5.2 'A Bit of a Chore': Additional Time and Effort

This sub-theme explores the time and effort involved in preparing blended diet. Commercial formula required very little time or effort from the parents as Hannah described:

From a practical point of view, it [blended diet] is actually more awkward because with the milk [commercial formula] you get it delivered and you just stick the tube in, hook it up and it's gone. With the food you've got to buy it, you've got to prepare it, you've got to make it, you've got to keep it fresh and refrigerate it, use it before it's gone past it, and of course there is more stuff to clean up too. **Hannah**

In comparison to commercial formula, blended diet required more from the parents. The organisation and effort needed seemed to be a potential downside of blended diet compared to the ease and convenience of commercial formula. Nathan for example found it took an 'entire day' to batch prepare a week's worth of blends for his daughter. However, using a meal by meal approach Katie stated that blending foods for their daughter took only a little more time and work than shopping, preparing and cooking for the rest of the family. Although blended diet is more work compared to commercial formula, it is not as much more work compared to preparing and cooking food for a child who eats their

food orally. This idea was echoed by Diane who used to prepare and cook food for her daughter when she ate orally and so she questioned why she would not be not be prepared to do so after the feeding-tube placement.

Organisation and planning were referenced in twelve of the parent's accounts particularly when travelling away from the home; for example, when going on holiday. Laura explained how she always felt she had to 'be on top of things' and have blends in storage ready prepared. Seven parents found the additional planning and organisation more difficult when they were busy:

Sometimes when you are tired you think I wish she was on [commercial] formula, it's easy but not very often because of the benefits. I much prefer her on blended food there is no way I'd ever let her go back on formula not even if she went into hospital and they insisted, even then I wouldn't. **Emily**

There was a sense that at times preparing blended diet felt like a chore; something which had to be done just like another household task. For Emily the thought that commercial formula would be easier occasionally crosses her mind, especially when she is tired, but then she remembers the benefits (Sections 5.3 and 5.4) and would not entertain the idea of reintroducing formula. In some cases, parents said they would like the option to have a pre-prepared blend they could take away with them when travelling away from home:

What would be really nice, in my utopian world, is for an adult sized equivalent pouch [of blended food] that could be taken for convenience out and about not for every day just for the odd days where you can shove it in in the bag; otherwise your life sometimes is a bit time restricted and you live by set times it would just to give the freedom to stay out a bit longer...anyway I can dream. **Laura**

Although she would rather blend foods herself there are occasions when Laura would like the option of a convenience food to enable to family more flexibility.

Like Laura, Imogen found there were certain times when she would prefer not to blend but usually found it rewarding to make her son's blends herself:

You get a kick out of it. I hate doing it sometimes, especially when I think he's got two meals left and I look in the freezer and there is nothing, that is a horrible feeling. Even sometimes when I don't want to do it and I'm really quite grumpy about having to do it I end up enjoying it. It's really weird, there is something about it. It feels really good. **Imogen**

Similarly, six other parents found preparing blended diet to be 'fulfilling' or 'satisfying' and usually 'enjoyed' spending additional time preparing it. Marie described cooking and preparing blended diet for her son as 'quite therapeutic'. This sub-theme relates to the parents' perceptions of the parenting role (Section 5.4.2).

By contrast, two parents explained that they found feeding their child blended diet to be more convenient than commercial formula. For Jane blended diet was easier because her daughter was no longer reliant on the automated feeding pump. Katie on the other hand found it more convenient to be able to buy her daughter's food from a regular grocery shop:

If you have blended diet... we've had it a few times you are out and about, you are running late, but we have some water and the tube and a syringe. I just go to a shop, I just buy her a smoothie, or a yoghurt and we draw this up and she has a little snack to sustain her for another hour or two until she gets proper meal. **Katie**

Previously, Katie's daughter's commercial formula would have been delivered directly to their home on prescription. Katie would have to remember to take enough commercial formula with her on outings as it would not be possible to obtain it elsewhere.

In summary, while all the parents agreed more work and time was needed for blended diet in comparison to commercial formula, the amount of additional work described varied. Most found it took little extra work in comparison to preparing and cooking for a child who ate orally. In part this seemed to be dependent on the approach the parent took to blending, for example preparing blend in batches or using a meal by meal approach. While blended diet sometimes felt like a chore parents believed it was a worthwhile task. There were times when all the parents found blended diet required more organisation and planning than usual. Parents had found ways to overcome these challenges for example, by investing in a better blender.

### 5.5.3 'It's a BIG investment': Extra Money

In addition to time and work twelve parents pointed out that blended diet cost them more financially in comparison to commercial formula. This sub-theme explores the expenses of blended diet and why parents were willing to invest in the feeding practice:

The [commercial] formula is provided free of charge I worked out roughly in my head it costs about £35-40 a week in shopping but the benefits in her far out strip the cost or the effort so I will do it I'd rather spend that time and that money ten times over than go back to anything else. **Nathan**

Children and young people with complex care needs in the UK are entitled to free prescriptions through the NHS. If the parent chooses to use blended diet, then they have to buy the food ingredients themselves for the child. However, Nathan believed the benefits (see Sections 5.3.2-5.3.3) outweigh the financial cost and effort involved. He stated he would pay 'ten times' more if necessary rather than returning to a time when his daughter was seriously unwell which indicates the value he placed on her wellbeing. Other parents, such as Olivia said that they actually preferred paying for their child's food:

I'm responsible for feeding him it's not the state that's feeding him [he] was five and a half coming on six years old and I had

never paid any money to feed him, the NHS gave me everything in order to feed my child and that is not normal, not normal at all...Somebody needs find out how much money we are actually saving the NHS because we are saving them a fortune. **Olivia**

Olivia felt it was part of her responsibility as a parent (see also Section 5.4.2), to provide food for her son. Like Olivia, Katie described feeling 'excited' and 'proud' the first time she went out to buy their child food from a supermarket, rather than collecting commercial formula from a pharmacy or having it delivered to the home. Buying and preparing food for a child is an everyday task which is taken for granted by parents of children who eat food orally but seemed to have been something the parents interviewed in this study had missed. In the quotation, Olivia believed by choosing blended diet she is saving the NHS money which can be used elsewhere.

The parents described expensive one-off financial costs they had incurred because of choosing to use blended diet in addition to the food ingredients themselves:

We invested in a high-powered blender we brought a [brand of blender] which was quite a lot of money [RRP £599] but we kind of thought we've got to do this we've got to give it a fair crack of the whip, we've got to do it properly. **Fiona**

Like Fiona, most parents had purchased a high-powered food blender after speaking to other parents who had been blending for a longer time. Fiona thought that she should invest in good equipment in order to give blended diet a fair trial. Those parents who had tried blended diet first using a hand-held blender, such as Imogen, reflected said that buying a high-powered blender had made their life much easier:

'It was just chaos, there was mess everywhere, it was dribbling all over the place, it was too thick, and I was adding water and

water it was over spilling. It was just the most awful, awful experience and it was so thick [laughs]. I had to sieve it, but I couldn't sieve it through, so I had all this mess everywhere and ended up with at most half] of what I had originally [laughs]. I decided I never, ever wanted to blend again; but of course, I did and that was my experience until we got a high-powered blender, that changed everything. **Imogen**

The quotation has similarities to Olivia's in Section 5.5.1 but rather than time and practice for Imogen it was the equipment which made blending easier. It is interesting that she continued to blend despite it being an awful experience and this again suggest a self-imposed pressure to do what she believed to be best for her son. Imogen laughed throughout this account. At the time it was a stressful experience but now she has relaxed, found an easier way to blend and looked back at her first experiences with humour. Imogen felt the cost of the blender was a worthwhile investment. Interestingly, Anna managed to obtain a high-powered blender through a children's charity and fundraising with the support of her daughter's dietitian.

A second smaller, slightly cheaper blender was used by seven of the parents. They referenced using it to take on holiday or as a spare.

I've also brought the [brand of blender] which is smaller and easier to travel and as good as a [high powered blender] to be honest. I keep in my car so that I've always got it. **Diane**

Like Diane, several parents had brought additional equipment to overcome practical challenges such as travelling or feeding outside the home. Designated freezers for storing batch made blends were also reference by four parents. Dehydrators which remove the water content from the blend making a powder, were referenced by six of the parents:

We did dehydrated blends, they wouldn't allow a real food blend in because of the storing and the heating of it and I said I

totally understand but with the dehydrated you've just got to give me boiled water nothing else, it's the same as mixing a powdered formula. **Beth**

Drawing on this quotation, Beth would have preferred to give her daughter freshly made liquid blends but there are certain circumstances outside of the home (Section 5.6.3) where the safe storage and reheating of blended food prepared at home has not been feasible. The dehydrator is used by Beth as a measure to circumnavigate practical problems or opposition as she only requires boiling water to reconstitute the powdered blend.

In summary, although blended diet cost the parents more money in comparison to commercial formula it was a cost they were willing to pay in lieu of the positive life changing impact they felt blended diet had for their child and family. Further, some expressed that as parents they, not the NHS were responsible for the cost of feeding their child. Expensive equipment was viewed as an investment often bought to simplify processes or overcome the logistics of giving blended diet outside of the home or in response to opposition to blended diet which the parents encountered.

## **5.6 'I Have to Fight for her to be fed Food': Defending the Choice**

The final superordinate theme relates to the resistance the parent had encountered following their decision to use blended diet from either the health, care or education professionals involved in their child's care. This theme relates to the research objective exploring the challenges parents faced in choosing blended diet and to the objective exploring how parents felt they had been supported in their choice. The theme has been divided into four separate sub-themes. Section 5.6.1 explores the inconsistent support individual parents had experienced from healthcare professionals, inconsistencies were also evident across cases. Section 5.6.2 explores how parents felt that their ability to make choices for their child was questioned and their decision making as a parent undermined. All the parents interviewed had experienced difficulties when they attempted to feed their child blended food outside of the home. However, where

the individual parents encountered difficulty varied for some it was at school for others at respite care. In some instances, individual parents reported conflicting experiences within the same setting (Section 5.6.3). Section 5.6.4 explores the peer support parents have relied upon and the ways in which they are pressing for future change.

### 5.6.1 'It Depends Who You Get': Inconsistent Support

The support given to parents from healthcare professionals following their decision to use blended diet was vastly inconsistent as explored in this sub-theme. The support parents received seemed to depend on the views and experiences of the individual healthcare professional. Numerous professions were referenced as being involved in the care of the child or young person. Across the cases there seemed to be no pattern and no one health professional group was reported by the parents to be more or less supportive of blended diet than another.

Examples of good support were provided by twelve of the parents, for example Laura described the support she received from her son's community nurse:

We have a home support team and my nurse comes out to the house and does all the staff training I train them up how to administer [his] meals and she comes and watches them and signs them off. **Laura**

Laura's son's community nurse provided practical support by helping Laura to train home carers to give blended diet. Like Laura other parents described how professionals had supported them with the practical challenges of blended diet (Section 5.5) additionally, in facilitating the use of blended diet either by carers or outside of the home (Sub-section 5.6.3).

All the parents in this research recounted experiences when they had faced opposition to their choice from healthcare professionals. Numerous healthcare professionals were referenced in the interviews as being involved in the child's



care and having an opinion on blended diet. Parents had to repeatedly justify their choice to use blended diet to different healthcare professionals and attempt to muster support. Imagery of conflict was used to describe individual experiences for example 'argument', 'fight' or 'battle'. There was a sense that some professionals had been the biggest barrier to choosing blended diet encountered by the parents.

The most negative experience was the withdrawal of professional care for the child. Katie's dietitian for example refused to work with her if she continued to use blended diet to feed her daughter:

They [the dietitian] said I can't support you I'm not allowed to talk about blended diet with you, if you don't want the [commercial] formula feed then there is nothing I can do for you and then we agreed to disagree and off we went, and I was just never sent an appointment again. **Katie**

Katie felt she was given an ultimatum, go back to commercial formula or lose support from the dietitian. Katie chose to continue with blended diet and received no further follow up dietetic care for her daughter for several years. Like Katie, Hannah and Emily had similar experiences finding that there was a 'categorical no' from their child's dietitian. In these cases, the parents attempted to educate themselves about nutrition, Emily was determined and believed she could take steps to provide her daughter with good nutrition without the help of a dietitian: 'I've actually started doing a nutrition degree because I wanted to stick two fingers up at the dietitians'

In a further nine cases, parents perceived healthcare professionals to be initially 'shocked' or even 'horrified' at the mention of blended diet and others were disapproving:

She [the dietitian] just tutted and walked out of the room, she didn't approve at all and said that she wouldn't back me. I used

to be frightened to tell people, I used to get a lot of tutting at it, what on earth was I doing. **Diane**

Diane felt that she was being judged by some healthcare professionals despite having discussed blended diet openly with her daughter's paediatrician and having their approval. Interestingly, when Diane's daughter transitioned to adult services, she found the dietitian within the adult service was more supportive of her choice. Likewise, even though it had been Anna's dietitian who initially suggested blended diet to her, she still felt she had to convince her daughters paediatrician who was not 'quite on board'. Similarly, Laura had the support of her son's dietitian, gastroenterologist and community nurse but the school nurse was opposed to the idea:

The school nurse was completely against it because she said we would burst his stomach by forcing food in that way, by plunging food in. I said don't you realise it's the largest muscle in the body I would have to be putting phenomenal pressure into it, when I told the gastroenterologist he just laughed. **Laura**

It seemed that the support offered was dependent on the professionals' personal views, opinions and past experience rather than a unified stance towards blended diet. Five parents said they had experienced different attitudes between members of the same profession for example Diane had been using blended diet to feed her daughter for five years, during that time her daughter had transitioned to adult services she had found her new dietitian and nurse to be 'more interested' and 'quite keen'. Some parents had found that individual professionals' attitude and opinion of blended diet had changed over time:

Even the most sceptical of her care givers; sceptical in terms of look this is medicalised formula, this is nutritionally balanced this is made by medical firms and thoroughly tested how can you possibly compete with that, would now say do not even consider putting her back on it [commercial formula]. You don't have to take my word for it you can talk to dozens of

professionals including healthcare and education professionals who'll testify that they've seen a huge change. **Nathan**

Nathan believed that the professionals working with his daughter are as convinced as he is about the positive improvements in his daughter. Other parents expressed this too, for example Gemma explained that her son's consultant was 'coming around to the idea' despite previously being reluctant. Furthermore, five parents said that at least one of their child's healthcare professionals actively encouraged other parents to use blended diet after observing the improvement in the health and wellbeing of their child:

Our community nurse is fantastic, and she gets it and she sees the difference because she knew [him] when he was really, really unwell and she sees where he is now, so she shouldn't recommend it she still does it. **Olivia**

Parents sometimes felt professional support of their decision to use blended diet was reluctant or half-hearted:

She [the dietitian] is just very nervous about talking with me about [him] and I think, I know she is really worried about what the BDA will think if she supports me actively, we are just sort of cruising at the minute there is not much support there. **Marie**

From this quotation, Marie sensed that her son's dietitian is reluctant to talk to her about blended diet because the BDA does not recommend the practice. Other parents, too, made reference to the BDA's policy statement. Nathan, for example, believed his daughter's dietitian could not openly support him because she had to 'tow the party line'. Marie went on later in her interview to expand on the type of support she would like from her son's dietitian:

It would be nice to have a true support

*Researcher:* What do you mean by true support?

I mean...I don't really know because I've never actually had it... My friend's son, he goes to the same school, he's severely autistic with really challenging behaviour, she's been to see a dietitian and she got a food programme worked out and the kid's behaviour has turned around he is just a new boy [talks about friend's son omitted]. I remember her telling me how great her dietitian was. She's been given really good nutritional advice about foods to try and why and they've gone through all the benefits of this food versus that whereas I have to go online, and I have to read something and decide whether that is right or wrong. All this stuff, is coconut a superfood? Or chai seeds? Avocados? I would like to have someone who can cut through all of that for me and give me some advice about food without being frightened and that's it my poor dietitian, bless her, is just so worried that something is going to happen, and she will be blamed that she is not giving me any advice really so I've had to go and make guesses myself, educated guesses **Marie**

Marie compared her experience of dietitians to her friend's experience. Marie's son's dietitian will not discuss food with her because she knows Marie plans to put the food through her son's gastrostomy tube. Marie believed her son's dietitian to be risk averse and concerned she will be 'blamed'. This leaves Marie to educate herself on nutrition using the internet, she had to sift through information on the internet, making judgements on what is and is not reliable information. Like Marie most parents made reference to educating themselves on food using the internet. By contrast, four parents have found their child's dietitian to be very supportive despite a lack of previous experience and knowledge relating to blended diet:

My dietitian came to see me about it and she's been amazing she just went 'this is the information from the Dietetics Association to say that you can't do it' she threw it on the floor

‘this is the information from the manufacturers of the button to say that you can’t do it’ she threw it on the floor and she went ‘so how are we going to start then’ but she didn’t know anything about it so it was a case of just run with it. **Beth**

Beth’s dietitian did not know where to start with blended diet, but Beth felt that her dietitian had been amazing, and still had the sense that her daughter’s dietitian was there to help and support her even though she had little clinical experience of blended diet herself. Although there was a sense of trial and error, the dietitian was respectful of Beth’s decision and provided emotional and practical support. Beth appreciated the dietitian’s honesty about her inexperience. Even though Beth had a supportive dietitian her child’s consultant had said ‘no straight away’ to blended diet. By contrast Claire for example experienced the opposite in comparison to Beth, her daughter’s consultant was ‘on board’ but her daughter’s dietitian was ‘horrified’.

Parents felt that professionals involved in the child’s care had misunderstood their motivation for choosing blended diet for their tube-fed child in fourteen cases. Parents believed they were judged by professionals, Fiona described a ‘stigma’ likewise Laura believed she was viewed as a ‘quack’:

I’ve tried to level with them as an equal, as a healthcare professional as well. I’m a sensible Mum, I’m not some quack but I think sometimes I’m viewed as this spear heading, single woman campaign, a lentil feeding, sandal wearing type crusader which I’m not I just want to feed him normal food.

**Laura**

The quotation echoes Fiona’s sense that she had been perceived to be a ‘mad hippy’ or Nathan’s impression that professionals believed his choice to use blended diet to be a ‘tree hugging exercise’ (Section 5.2.1), or a ‘desire to go down the natural route’. Laura believed she was misunderstood, that the professional involved in her son’s care thought she was ‘some quack’ and did not acknowledge her health professional background (a pharmacist). Laura felt

she was viewed as 'single woman campaign' or 'crusader' but said she was not trying to push an alternative therapy, she just wanted to use every-day food to feed her child rather than commercial formula. Laura found it difficult 'to level' with healthcare professionals; to get them to understand her point of view and her reasoning.

In summary, the support parents received from healthcare professionals was vastly inconsistent. There was no pattern to the support described by the parents either across cases or within individual accounts. The range of support described by parents was from very good to reluctant to non-existent. Where support was non-existent parents attempted to educate themselves on nutrition and sought help from other parents (Section 5.6.4). Finally, parents felt that they had been misjudged by some health professionals and their ability to make the best decision for their child had been questioned.

### **5.6.2 'At the End of the Day it's Your Child': Control**

This sub-theme relates to control. There seemed to be an ongoing struggle between parents and the services which surrounded the family. All the parents interviewed felt blended diet gave them more control over what their child was fed, as illustrated in Claire's quotation:

It's natural to feed your child and when they are formula fed that's quite a big mum thing taken away. If you've got quite a lot of other medical things, then you feel like you're not in control. I think with this [blended diet] you are one hundred percent in control, she grows, and she gets all her vitamins and minerals because I provide her with the food and I make sure what goes in is good stuff. **Claire**

Claire explained that she felt 'one hundred percent in control' because she decides what her daughter eats not medical professionals. This sub-theme relates also to Sub-theme 5.4.2, the feeling of de-medicalisation. Claire felt blended diet returned a part of her parenting role to her. On reflection when her child's gastrostomy tube was placed Claire felt that part of her role as a mother

had been denied. As introduced in Sub-section 5.4.2 blended diet was 'empowering' to parents. However, Marie felt healthcare professionals mistakenly assumed this was the motivation for choosing blended diet over commercial formula:

I think what they thought I wanted to keep feeding him food because it made me feel better whereas in fact like I say if he could have had the formula and I could have avoided all those arguments I would have done it, but they thought I was just trying to cling on to feeding him. **Marie**

In this extract, Marie was clear that she would have given her son commercial formula had he been able to tolerate it without adverse effect. She hinted at a conflict or misunderstanding between herself and healthcare professionals that caused 'arguments'. She felt that healthcare professions perceived her to be using blended diet for her own benefit rather than in the best interests of her son.

There was also a sense that the parents had been previously overruled by the advice of healthcare professionals:

I feel massively empowered, from having a child who's come into the world and has all these additional needs you are kind of at the mercy of the professionals and your world is intertwined with lots of advice, what you should be doing and so having this choice over food what you can give is massively empowering that's really good and I think that effects the relationship that you have with the child I think it gives you much more confidence, I think that I have gained some confidence back.

**Fiona**

Fiona described having a choice over what to feed her daughter as 'massively empowering'. She felt as though she had taken back control from the healthcare professionals. Her use of the words 'at the mercy of' had a suggestion of a

power struggle with healthcare professionals, one which she felt was her right to decide for her child. She was not expecting to have a child with complex care needs and those needs had become progressively complex. She reported that her 'world is intertwined' which could be taken to mean mixed up with or inescapable. Blended diet gave her control as over time she had become more and more confident that she was best able to make decisions about her own daughter's care. Marie, like Emily echoed this sentiment suggesting that she knew her child 'much better' than the healthcare professionals:

I knew this [blended diet] was what I had to do for my sake and his sake. The thing people [professionals] forget when they say, oh don't do it because of this or that, well they are not the one up in the middle of the night with a kid crying because they've got a severe tummy ache because of what you've put in their stomach. That is hard to deal; so, if I can put good stuff [blended diet] in and not have an unhappy kid that's what I am going to do. **Marie**

Marie felt that she made the decision to use blended diet in her child best interests, she could no longer watch him 'crying' suffering with 'severe tummy ache'. The professionals are not there 'in the middle of the night' has been interpreted as Marie thinking that the professionals did not see the extent of the child's suffering because they are not there all the time. Marie did not think professionals are best placed to make decisions on behalf of her son, she is the one looking after him day-to-day.

Olivia was suspicious of professional's motives towards their resistance to blended diet:

I just think sometimes they get their knickers in a twist, my gut feeling if you want my opinion in terms of dietitians I don't think it's about safety, I don't think it's about blocking tubes, I think it's about control they do not have control of the calories they



don't have control in terms of the volume and I think they struggle with that. **Olivia**

Olivia did not have a very positive opinion of the dietetic profession. She believed that dietitians were resistant to blended diet mainly because dietitians preferred to know the exact quantities given to a child, and blended diet made this difficult. Later in her interview Olivia described herself as 'a decisive person' which suggested she believed it took a certain assertive personality type to opt to try blended diet. Like Olivia, other parents said they had needed to be 'brave' or needed 'nerve' to go against professional advice. Olivia elaborated on this idea later in her interview:

There are people who maybe aren't as confident. When you've got consultants and parents there is a power imbalance, if you get a consultant telling you not to do something not everyone will want to fight that. **Olivia**

Olivia was not afraid of conflict and felt she was best placed to make key decisions about her son's health rather than medical professionals. Like Olivia, nine parents gave the impression that they were not someone who was not going to take no for an answer:

My dietitian is fine with it [blended diet] but I think she knows better than to cross me. I don't mean that in a negative way. I just said to her that I was doing it and I said it's working it's fine we haven't blocked any of the tubes, he's never had any stomach infections, he's not got sickness or diarrhoea basically just went in there and said we are doing it. **Laura**

There was a sense that parents had been apprehensive at first but with time became resolved that they were doing the best thing for their child:

I felt like a naughty school child and I shouldn't have really. I wouldn't now, it doesn't worry me telling anybody now about

our experience with blended diet but at the time I felt like I was really doing something that I shouldn't be. **Gemma**

Gemma felt like a she was going to be told off by a person in authority. She felt differently after using blended diet for two years: her own positive experience strengthened her resolve, she felt that she knows what is best for her own child's health and happiness. Fiona offered an explanation as to why a power imbalance existed:

There's this uneasiness about blended diet there's this attached anxiety and fear that if parents don't do what the professional say then they'll be thought of in a bad light or that the safeguarding team will be in touch. I think you've got to be quite brave when you're doing blended diet, I think you've got to have a bit about you. **Fiona**

Fiona suggested there is an unspoken threat that a decision to go against professional advice may affect the quality of future care or lead to escalation to the safeguarding team, a concern raised that she is causing her child harm because of the risks which have been linked to blended diet use. Interestingly, the potential risks associated with blended diet (tube occlusion, gastric infection and nutritional inadequacy) were mentioned infrequently in the interviews and mainly in reference to experience of conflict with professionals. Only Gemma said she had experienced a blocked tube on one occasion, caused by a strawberry seed, and had taken measures to stop this from happening again such as using a high-powered blender, sieving blends that contained seeded fruit (Section 5.5.3). After using blended diet for at least a year the parents interviewed were unconvinced that blended diet posed a real risk to their child:

The risks are always mentioned but I don't think there's actually any evidence, it's all anticipatory risks or potential risks, but I don't think there's actually been any evidence. **Fiona**

While researching blended diet, Fiona herself she had found no 'evidence' that the risks are anything but 'anticipatory' on the part of healthcare professionals. Marie was resolute that she had made to best choice for her child and yet found she had to repeatedly justify her choice:

It's really tiring, it's like beating your head against a brick wall trying to explain that a formula is making your kid ill. Why should he have the formula just because he's got a PEG. All the issues like risk of infection, tube blocking and how do you know he is getting the nutrition? I remember arguing with the dietitians yelling almost, saying how do you know that you eat nutritionally well, how do you know that you are getting enough calories? In the end they saw that he was putting on weight, he wasn't going to pass away, there was no infection the PEG didn't block. **Marie**

Even though Marie had not seen evidence of tube occlusion, weight loss, or gastric infection in her son following transition to blended diet, her son's dietitian continued to focus on these perceived risks which Marie found frustrating. The analogy of 'beating your head against a brick wall' has similarities to Laura who found 'it difficult to level' with professionals (section 5.6.1). Neither of these parents felt able to make professionals understand their point of view. Yet, the parents believed that blended diet was a choice worth fighting for as Katie explained 'I feel that I am letting my child down that gives me the fighting power to keep going'.

To summarise this sub-theme, blended diet enabled parents to take back an element of control in a life which was dominated by healthcare professionals. However, a perceived power imbalance between themselves and healthcare professions existed. Conflict occurred when there was a difference of opinions about blended diet. Many parents felt a focus on perceived risk frequently overshadowed their child's care. The majority of parents had to defend their decision repeatedly to different professionals yet their steadfast resolve that they were doing the right thing for their child motivated them to continue.

Further conflict was encountered when parents requested to give blended diet outside of the family home.

### **5.6.3 'As Soon as I Leave the House I'm in a Grey Area': Blended Diet Outside the home**

This sub-theme explores parent's experiences of giving blended diet outside of the home and the inconsistencies which emerged within accounts and across individual cases. All the parents described facing some level of difficulty using blended diet outside of the home:

If I do it [blended diet] at home just for myself it's all fine but as soon as I leave the house I'm in a grey area because officially I'm not allowed to feed my child food that's how I would put it and that goes to the extreme when my child is in hospital I have to fight for her to be fed food. I feel my liberty as a parent is taken away by dietitians and doctors in a hospital who don't know any better, who just obviously have to follow protocol.

#### **Katie**

Katie felt she was in a 'grey area' because there are no official guidelines or protocols relating to blended diet. Katie felt she did not have control over what her daughter was fed in hospital. Interestingly, although this research focused on blended diet within the community setting most parents spoke at length about using blended diet in a hospital setting.

Like Katie all the parents interviewed described having difficulty feeding their child blended diet outside of the family home either in school, hospital, or respite care. Some schools, respite facilities and hospitals were able to facilitate the use of blended diet whereas others were not.

In five cases parents described having contrasting experiences on different wards within the same hospital:

It depends on the ward, sometimes they'll blend stuff for us or I'll take my blend in and give her but sometimes they are like we

are not giving her anything...it seems to depend on what the sister is like who runs the ward if she's ok with it and how much involvement the dietitians got because sometimes we'll go in and we'll never see one and then other times they are wanting to know exactly what we are doing. **Claire**

Claire believed that the attitude of staff working on a hospital ward toward blended diet depended on the individual ward sister and the involvement of the dietitian. Some wards had offered to blend food for the family whereas others would not give her any blended food. Imogen found that her local hospital was happy to give blended diet but the larger more specialist centre was reluctant.

Marie's son was able to have blended diet prepared in house by the school catering staff. A further seven parents reported their child's school or nursery were happy to give blended diet sent in from home during the school day. For some parents, like Gemma this had been achieved this with relative ease:

They [the child's school] have always been really proactive with it [blended diet]. There were already two children there who did it [blended diet] so I think that helped, because they had experience. **Gemma**

In contrast, five parents found that their child's school or nursery initially refused to give blended food through the feeding tube at school. For some, like Nathan this had a significant impact on the family:

My wife was considering keeping her away from school but that's not practical. So, my wife cut down her hours specifically to go to school at lunch time and as long as she prepared it and she gave it rather than anybody at the school then that would be acceptable...that went on for several months until our dietitian and the school got together and we drafted a pretty detailed feed regime, a guide for storage and administration of the feed because we blend it at home and freeze it and also a

risk assessment on what could go wrong so there were three big documents. **Nathan**

Nathan's wife chose to reduce her hours at work to go into school and give her daughter blended diet rather than letting her daughter return to commercial formula. In turn, this had had a significant impact on her career as well as the family's finances. Like Nathan, five parents found they were able to introduce blended diet in school after working to prepare individualised care plans and risk assessments. Others had less difficulty for example, Diane was pleasantly surprised when her daughter's new college was 'fine' with giving blended food when it had previously not been possible at her daughter's school. At the time of the interview three parents were involved in ongoing discussions with their child's school. Beth and Katie were anticipating problems when their child moved from nursery to primary school.

In four cases the difficulty had been with a hospice or respite carers' employers rather than the school or hospital:

The carers can't be trained on giving blended food because the BDA and the Royal College of Nursing don't support it so they can't be trained they aren't insured to tube feed her it puts a huge pressure on me to having to do all the tube-feeding even though I've got respite care I am meant to do all of the tube-feeding so it means that I shouldn't really be leaving her for any more than a few hours because I need to get back to doing the next meal. **Emily**

Emily had found that the respite carers who are supposed to support her to look after her daughter cannot be trained to prepare or give blended diet. Emily felt this put her under 'huge pressure' as she was the only one who was able to feed her daughter therefore negating the value of respite care. Other parents such as Hannah had been unable to train carers to give blended diet. On the contrary six parents had found their child's respite care providers to be very supportive of their choice:

The hospice that we are associated with they are very pro-blended diet they even have a blender there and for most children that go there who have a blended diet it is totally normal you can request the food that your child might like to eat, or you would like your child to eat and they will cook it for you and it gets blended and no questions asked its totally normal which is very nice. **Katie**

Katie believed that her daughter's hospice is 'very pro-blended diet' because they had invested in their own blender and cooked and prepared the blends themselves in-house.

In summary, in most instances the children's schools, respite care or hospital wards facilitated the use of blended diet. Parents in this research perceived the school, respite facility or hospital ward stance on blended diet to be dependent on the individual views or opinions of the staff. In some cases, parents had worked hard toward getting blended diet accepted in settings outside of the home, this had usually taken time to achieve. In other cases, schools, respite facilities and hospital wards were not able to give blended diet and so parents either had to use commercial formula or be excluded from the service. In some cases where blended diet could not be given parents had considered keeping the child out of school, turned down respite care or discharged their child home early from a hospital stay. In these instances, parents turned to their peers for support.

#### **5.6.4 'We've All Supported Each Other': Helping Other Parents and Campaigning for change**

All the parents in this research spoke at length about the support they had received from their peers, other parents of tube-fed children. As introduced in Section 5.2.2 all of the parents in this research had sought out the experience of other parents when they were considering blended diet. This final sub-theme explores how parents have in turn helped others themselves and why they feel change is needed:

I have no qualms that the people that you interview will say that its either changed their lives or changed their child's life or made a massive difference. I think that more people should know about it, more people should be given the opportunity to at least give it a go if they want to; not to feel guilty not to feel that they are doing something wrong. They should be supported in it. **Gemma**

As explored in Section 5.3 and Section 5.4 Gemma, like the other parents believed using blended diet had changed her family's life. She had no 'qualms' or doubts that other parents will have had similar experiences to hers. At times using blended diet had been difficult for her because of the focus on risk which overshadowed her choice and meant there was difficulty in gathering adequate support from the professionals involved in her son's care (Section 5.6). Gemma has fought for her choice to be accepted but hopes the experience for other parent in the future, will be easier. She indicated more people should know about blended diet, this has similarities to Emily who said she felt 'let down' by professionals who did not offer her the choice sooner (Sub-section 5.3.1). Likewise, Gemma believed that more support should be offered at the start, when parents first trial blended diet rather than being made to feel 'guilty' or as though she was 'doing something wrong'. Gemma, a children's nurse herself, saw a vital role for healthcare professionals in supporting parents with blended diet.

When parents interviewed in this research were denied support or received limited or inadequate support from healthcare professionals they turned to their peers for support, usually online. The parents who took part in this research were found though the Blended Diet UK Facebook (Sub-section 4.3.2). For some parent's connections made online had formed into real life supportive friendships:

Through Facebook I realised there were quite a few mums in the area, I hadn't met them, but they had the same hospital, the same consultants they had been doing it [blended diet] a bit



longer. They were a lot of help, stick to your guns, don't let them tell you what you can and cannot do with your daughter.

### **Claire**

Claire found support from other parents in the local area who had more experience of blended diet than her. This meant she was able to use their experience to her advantage, additionally they encouraged her to 'stick to your guns' in the arguments she encountered with professionals. There was a clear sense that the blended diet group was a community, and that more experienced parents will help those who are just starting out.

Most of the parents interviewed in this research specified that a desire to help others in a similar situation to themselves was the main reason they had taken part:

I wanted to put the information out there; good and bad. I couldn't call my information unbiased per se, I probably am biased because I am doing blended diet. However, I wanted to put a very honest account out there. It's not always easy but its right for him. **Imogen**

Imogen acknowledged that she is likely to have a 'biased' opinion of blended diet because she had chosen to use it to feed her tube-fed child and had positive experiences, but by taking part in the research she hoped to give an 'honest' account of both the 'good and bad' aspects of the experience. Katie hoped to increase awareness about blended diet amongst healthcare professionals:

I hope that this research will help create more awareness amongst people, especially amongst the medical world in terms of doctors, nurses, dietitians to just be a little bit more open minded about these options and choices that people should have in life. **Katie**

Katie felt that blended diet should be a choice offered to parents of all tube-fed children and that professionals involved in enteral feeding should be more aware and 'open-minded' about the topic. Five parents had been asked by professionals to help develop resources or talk to other parents who were considering blended diet. Anna and other families local to her using blended diet had been asked by their dietitian to help develop resources for other parents:

We did a lot of work with her [the dietitian] and with some other families. We produced a leaflet to give to parents who are starting out; it is quite a nice leaflet. **Anna**

In four cases, parents had acted as an advocate for other parents who faced opposition about using blended diet from professionals:

On more than one occasion I've had people say to me: we are happy with you doing it because we know you are sensible but some folk on the case load oh, their hygiene's not great, you have to go out there and you have to give people the opportunity and if they are struggling then you need to help them you can't just say there is a blanket ban on it because some people might not do it OK, that's not good practice. **Olivia**

Olivia felt that the professionals working with her and her son had accepted her personal choice to feed her son blended diet. However, Olivia felt the professionals did not believe that everyone is as 'sensible' as her. Olivia viewed this situation to be discriminative as professionals were making a judgement of parents. Instead she believed that professionals should give everyone the 'opportunity' and help them to use blended diet safely.

In summary, the parents interviewed in this research had helped other parents to start blended diet following their own positive experience. While most identified that blended diet is 'not for everyone' they did believe that it should be

offered as a choice rather than being something parents had discover for themselves and then fight to do.

### **5.7 Chapter Summary**

This section summarises the findings chapter before moving onto a discussion in Chapter 6. This research found most parents interviewed were driven to search for an alternative to commercial formula because they felt their child was suffering when fed on commercial formula alone. Additionally, most parents interviewed felt they had exhausted all other options offered to them by healthcare professionals. Blended diet had been encountered in a variety of ways; most through a peer. Some parents decided to try blended diet based on intuition and became aware of blended diet as a concept later. Interestingly, in one case (Anna) blended diet had been offered to as a choice by the dietitian. Most parents interviewed in this research had decided to try blended diet based on their own assessment of the risks involved balanced against the anticipated benefits; in most cases without the permission or support of healthcare professionals.

Following transition to blended diet the parents interviewed reported a positive transformative change in their child's health and wellbeing involving, remedy of symptoms commonly referred to in the literature as 'tube-feeding intolerance' including; reflux, retching, vomiting, diarrhoea and constipation. Additionally, the parents interviewed reported their child's weight was improved, the child seemed less prone to common illnesses, looked far better and appeared much happier. Furthermore, on reflection the parents felt blended diet provided a sense of normality to their family lives. Parents were able to include their child in events and activities which centred around food. Additionally, they were able to make daily choices around the food included in their child's blend and personalise it. Blended diet was perceived by the parents interviewed on the whole to be less medicalised in comparison to commercial formula. Over time most of the parents interviewed in this research had come to view food as a right that their tube-fed child had previously been denied.

Initially commencing blended diet was described to be challenging particularly for those parents who did not have the support of their child's healthcare team. Blended diet took considerably more work in comparison to commercial formula. However, parents felt this extra work was worthwhile considering the improvements they had experienced, and they quickly gained confidence. Attempting to use blended diet outside of the home was particularly challenging leading to some parents declining services such as respite care. The support parents received from healthcare professionals in relation to their choice was vastly inconsistent both across and within cases. When support from professionals was lacking, the parent had turned to other parents for support. In return they had also offered support to other parents. Having presented all the findings here, Chapter 6 moves onto a full critical discussion.

## **Chapter 6: Discussion**

### **6.1 Introduction**

This discussion chapter critically situates and evaluates the doctoral research in relation to previous work, the contribution of this research, and future work in this area. Parents who have chosen blended diet are a vocal and motivated group on social media (BDA 2013). Yet, the voice of the parent has been largely absent from the current debate in the literature, particularly in the UK (Chapter 3). This thesis provides a unique insight into the experiences of individual parents who have chosen to use blended diet to feed their child in the UK and an understanding of why the topic has become so emotionally charged (Kellie 2015). IPA methodology permitted an in-depth exploration and interpretation of parents' understandings of their experiences and through reflection demonstrated how their thoughts and opinions on the topic have developed over time (Smith, Flowers and Larkin 2009). It is envisaged this work will illuminate the experience for other parents who are considering blended diet for their child and give insight into the experience from the perspective of the parents for professionals working in the field of home enteral tube-feeding (HETF). The research findings will also be used to inform future research into the complex topic of blended diet. The current research additionally contributes to wider academic knowledge in areas including; the experiences of caring for a child or young person with complex health needs, parents' decision making, perceptions of support and conflict in healthcare and the role of food in human psychology and social life.

The four broad research objectives (Section 1.3; Figure 4.1) are used to structure this discussion chapter and it is believed these objectives have been met. In the context of this research, the limited existing body of evidence on blended diet (identified in Chapters 2 and 3 of this thesis) is critically examined. The explorative nature of this research meant that themes emerged during the analysis process which were not anticipated during the research design therefore, to frame previously unanticipated ideas, this chapter also discusses

literature which has not previously been introduced in this thesis. The chapter begins by examining the reasons why parents choose blended diet (Section 6.2). The second objective related to parent's perceptions of the benefits which can be described as life changing (Section 6.3). The challenges identified are discussed in combination with the support parents had received and the type of support they should expect to receive in the future (Section 6.4). The chapter moves on in Section 6.5 with a critique of the current research, including its strengths and limitations.

## **6.2 Choosing Blended Diet**

The findings of this thesis study demonstrated the primary motivation for the use of blended diet was the health and wellbeing of the child or young person. Parents made the decision to adopt blended diet in the wider context of their own assessment of risks posed to their child by the adverse symptoms they associated with commercial formula use this has not previously been considered in the existing literature relating to blended diet.

Moreover, the research highlighted that the adoption of blended diet for parents was often not a choice, rather a 'last resort'. The research showed that parents were in a difficult situation; their child was suffering, and they felt powerless to relieve it. The severe and unrelenting symptoms described by parents in this research impacted on every aspect of their family life; even being able to embrace or comfort their child (Sub-section 5.2.1). Although other research has acknowledged parents can perceive their child to be in a great deal of distress due to adverse symptoms (Pentiuk et al. 2011) or recognised that the symptoms could impact on quality of life (Nicholson, Korman and Richardson 2000), this thesis study has illuminated what the experience of caring for a child with severe tube-feeding complications is really like. The term 'tube-feeding intolerance' used frequently in healthcare, plays down the debilitating nature of the symptoms identified in this research (NICE 2013). Intolerance, in the context of food and feeding, has usual connotations of minor allergies or discomfort experienced when encountering specific foods or groups of foods such as wheat or dairy. The term tube-feeding intolerance in this context is not

comparable to the parent's perceptions of threat to life. This research also highlighted that parents perceived their child's body to be 'rejecting' the commercial formula consequently, as Olivia phrased it, her son was 'clinically starving'. Olivia, like others, had been told nothing further could be done and that her son's prognosis was poor. The severe symptoms described in this research have previously been suggested as prognosticators for children with complex care needs (Siden et al. 2009). This research thus illuminates the issue that, from the parent's perspective, there is a danger of healthcare professionals attributing such symptoms as signs of the terminal phase of a life-limiting illness when something as simple as blended food could offer a remedy (Section 6.3).

This research also shows that parents perceive treatment options which are routinely offered in clinical practice to be unacceptable. In particular, continuous feeding and fixed positioning during feeding meant the child and parent were 'tied' to the feeding pump and consequently homebound. Additionally, feeding impacted on other aspects of the child's care such as repositioning to be able to perform personal care; this was illustrated emotively by Claire in Sub-section 5.2.1. NICE guidance on reflux management in children (2015) does suggest these strategies should be tried but acknowledged the evidence underpinning continuous feeding is weak and based on only one limited comparative study (Sutphen and Dillard 1988 cited in NICE 2015). Furthermore, this study focused on infants rather than older children with tube-feeding, meaning the findings are unlikely to be generalisable. No studies were identified by NICE (2015) which had focused on the effectiveness of altered position on reflux symptoms in older children with neurodisability. Strategies of continuous feeding and altered positioning should be reconsidered as first line treatment for tube-fed children and young people experiencing reflux, particularly in the longer term, given the restrictive effect on the child and family identified in this research.

Anti-reflux medication had been previously offered by healthcare professionals to parents for the management of the child's severe reflux, retching and vomiting symptoms. This research identified that the number and high dosage

of medications are a major concern for parents particularly in instances when the medications are perceived to be ineffective. Anti-reflux medications such as proton-pump inhibitors, H<sup>2</sup> antagonists and prokinetics are frequently prescribed to children and young people who are tube-fed because of a neurodisability and experience reflux symptoms. However, a recent Cochrane review identified no robust randomised control trials which looked at their effectiveness in this group (Tighe et al. 2014). Fundoplication (anti-reflux) surgery had been offered to parents in this research as a treatment option before the adoption of blended diet. This research identified parents are reluctant to put their child through this high-risk surgery and wish to explore other the options first such as blended diet. This decision-making process is likely to have been an extremely difficult one, with parents having to weigh emotional reactions to observing and experiencing the effects of illness with the imagery synonymous with the pain and gravity of surgery. The risk to the child is also not the only risk being considered; the parent is also taking an emotional risk as if there are complications or adverse outcomes of any surgical or medical intervention, then they will have to live with the emotional consequences such as feelings of guilt. Parental concerns are well-founded as fundoplication surgery regardless of technique is associated with major intra and post operation complications (Cameron, Cochran and McGill 1997; Di Lorenzo and Orenstein 2002). Furthermore, fundoplication has been associated with morbidity rate of 50%, mortality rates up to 50% and re-operation rates of 20% (Martinez et al. 1992). Additionally, children with neurodisability, have more than twice the complication rate, three times the morbidity rate and are four times as likely to require a second operation because of failure of the first procedure or because the fundoplication loosens over time (Martinez et al. 1992). The risks posed by pharmacological and surgical treatment are not included in the BDA's current Risk Assessment Tool (Kennedy 2014). This research demonstrates that such risks have a strong influence on parents decision-making process and were ultimately a major factor in the decision to try blended diet.

Collectively, the study findings also brought home the disconnect between parents and healthcare professionals. The parents considered the wellbeing of



their child and family as a whole, rather than a specific focus on single aspects of their child's care. The parents, where some healthcare professionals seemed unwilling, weighed perceived threats or significant impacts to their child's life against the potential risks of blended diet (nutritional inadequacy, feeding tube occlusion and microbial infection) which seemed, in comparison, small. As highlighted in this research parents can experience this kind of misdirected focus when interacting with specialists in healthcare such as HETF dietitians who express specific concerns over feeding tube patency, or paediatricians focusing on medical solutions. This could be attributable, at least in part, to a lack of relevant information and clinical guidance on the topic of blended diet. The disconnect identified in this research between parents and healthcare professionals clearly highlights an urgent need for further research on blended diet. Additionally, a wider implication has been identified. There is a requirement for a greater appreciation from healthcare professionals for the viewpoint of parents whose child has complex care needs as they are often expert in their child's care. Although this understanding surfaced through exploration of experiences of families using blended diet, it is likely to be applicable in varying degrees to any child with complex needs and their family.

In addition to reflux, retching and vomiting, other motivations for the adoption of blended diet were identified in this research. These reasons included a specific metabolic condition, debilitating constipation and a perception of persistent hunger in a child who had previously eaten solid food before tube placement. However, like the other twelve parents they also felt that commercial formula did not meet their child's long-term needs. As these reasons were specific to the individual circumstances of the families, they have not been considered in depth in this research but are significant as they illustrate the diversity of challenges faced by the families of children and young people with complex care needs and show that the reflux, retching and vomiting symptoms that are prominent in the existing literature are not the only driver for adoption of blended diet.

This research shows that, after extended periods of use, parents do not believe blended diet to pose a significant risk to their child's health. The parents had

between two and nine years' experience of using blended diet, and only one parent described a single incidence of tube blockage caused by blended food. The experiences of the parents shape their opinion of the risks such as tube occlusion, nutritional inadequacy, and gastric infection. This is illustrated by Fiona who referred to the risks as 'anticipatory' (Sub-section 5.6.2). At the point a decision is made to adopt blended diet, the parents do not have this personal experience, but do have access to the 'success stories' shared by other parents either in person or online. This allows them to characterise these risks as small in comparison with other treatment options. Arguably, the study findings conflicts with previous literature which suggested blended diet is unsafe in comparison to commercial formula (BDA 2013). However, previous literature had relied upon historic studies and studies which have focused on use of blended diet driven by financial necessity rather than parents who have made a choice to blend for their child (Chapter 2). This is one of the important, novel aspects of the study reported here. However, this research finding is supported by the findings of two recent survey studies of UK dietitians. Armstrong et al. (2017) found UK dietitians with experience of blended diet were less likely to be concerned about risk in comparison to those with no experience of blended diet, thus, reinforcing the idea that the risks are perceptions as opposed to concerns based on their experience. Likewise, in a second survey of forty-five dietitians, blended diet was not reported to result in significant complications (Cantwell and Ellahi 2017). If the issue occurred, it did not cause harm to the child. It was not a research objective to prove whether or not blended diet is safe, however, this research, alongside other work, casts doubt as to whether the risks which have been speculatively proposed do actually occur in practice. High quality research is urgently needed to establish if the risks of tube occlusion, nutritional inadequacy and gastric infection in relation to blended diet are rhetoric or reality, especially given their influence on parents and healthcare professionals decision making.

It is clear from this research that choosing blended diet amid the current controversies on the topic takes strength of conviction. This research demonstrates that parents had to defend their choice to use blended diet to

multiple professionals and on multiple occasions. Imagery of conflict was used to describe interactions with professionals who, frustratingly to parents, often seem unable or unwilling to understand the parents point of view. Interestingly and unexpectedly five parents who took part in this research alluded to being healthcare professionals themselves and a sixth was a children's rights worker. It is possible that the parents professional background meant they were more confident in fighting for their choice as vividly described by Laura in Section 5.6.1. It was also clear that parents had taken considerable time and effort in educating themselves about their child's complex condition and about blended diet. During the interview participants would reference academic papers and published texts on the topic. The parents had become the experts in their child's care. The conflict with healthcare professionals had been problematic at multiple times and settings throughout parent's experience using blended diet. In addition to the struggle faced at the time of making the decision to try blended diet, the challenges endure. This is explored further in Section 6.4.

Furthermore, this research shows parents feel their motivation for choosing blended diet is often misjudged or even prejudged and frequently have to defend their position. Often the people who the parents feel judged by are health professionals or care providers, who have a negative opinion of blended diet through limited knowledge of the previously discussed perceived risks. This can serve to amplify parents' feelings of judgement as they can feel as though false assumptions of their motivations, such as the desire to use organic foods or follow social beliefs such as veganism, could be characterised by individuals as trivial in comparison the consequences of the perceived risks, or even be a safeguarding concern. For example, Fiona stressed that she was not a 'mad hippy' and Nathan was clear that his initial motivation for trying blended diet was not a 'tree hugging exercise' instead, as discussed, blended diet stemmed from a desire to prevent his daughters severe vomiting and aspiration pneumonia. The preconception of professionals could stem from a literature review in the US which suggested increased interest in blended diet mirrors a trend in the general population toward organic and non-processed foods (Martin and Gardiner 2017). These assumptions are based only on a narrative literature

review and professional opinion and seem rather speculative, all the more so in the context of this research. Additionally, a limited recent survey suggested a desire to use 'whole foods' as a reason for parental motivation to try blended diet (Johnson et al. 2017). However, this term is clearly open to interpretation by respondents. This research is supported by O'Gorman (2012), a tube-fed man and advocate of blended diet, who suggested that healthcare professionals may stereotype individuals who chose blended diet as being 'difficult' or 'a bit militant about health foods'. It could be argued the finding in this research could have been influenced by the parents reading the O'Gorman (2012) text, however the parents were able to give their own specific examples of when they had felt misjudged. This research demonstrates a need for professionals to listen to and empathise with parents without prejudgement to gain a full understanding of their motivations behind the decision to consider or use blended diet. This challenge is further explored in Section 6.4.

To be able to make an informed choice on the adoption of blended diet, a parent must first be aware of its existence. This research showed that most parents first encountered blended diet either online or through an acquaintance at their child's school. In this way, using these research findings, as blended diet grows in popularity, parents of tube-fed children are increasingly likely to encounter other parents who are using blended diet either in person or through support groups online. This finding is supported by Nicholl et al. (2017) who found, using questionnaires and focus groups, that parents frequently and habitually use the internet and social media to gather information about their child's condition and sought peer support to aid decisions about the child's care. Blended diet is a good example of this with parents frequently using the internet to inform their decision making, receive and provide support.

Interestingly, the research also demonstrated that parents can intuitively decide to give their child blended foods. To some parents, the use of food through the tube seemed like a sensible or natural thing to do as they reasoned 'it's just food'. In particular, use of food or drink that is less viscous than commercial formula such as fruit juices or thinner soups may not even occur to parents as

something not to do, particularly in cases where no healthcare professional explicitly has told them not to do so. For example, Hannah stated that she did not know blended diet was a 'thing' until she was told much later by her child's dietitian not to do it. Two other studies support this finding. Firstly, in 1997, before many people had access to the internet and well before the invention of Facebook, Thorne, Radford and McCormick (1997) noted that many of the parents, in their interpretivist inquiry, chose to put blended food through their child's feeding tube. Secondly, Peterson et al. (2006) found that fourteen of the twenty-six carers in their descriptive study routinely gave foods such as juice, cereal or soup through their child's feeding tube, although this was not described as blended diet by the authors and was not explored further. This research suggests that that parents often try blended diet without informing their child's healthcare team, and if professionals do not discuss blended diet with parents and assume an unawareness, then there is a potential that they will miss an opportunity for intervention if its use could be considered as particularly high risk for example in the case of children who are younger than six months old, jejunal fed or immunocompromised (BDA 2013). The reasons why parents do not disclose the use of blended diet are discussed further in relation to support in Section 6.4.

In summary, this study has a unique contribution to make to the evidence in that it demonstrated that parents carefully considered the risks and made the decision to try blended diet within the context of wider concerns for their child's health and wellbeing, in combination with fears surrounding the safety and efficacy of pharmacological and surgical treatment and impact on family life. It is clear that parents who use blended diet consider the risks to be negligible against a backdrop of ineffective or unacceptable alternatives. The discovery of blended diet gave parents hope in an otherwise desperate situation. Parents reason that blended diet is simply food blended, rather than a medical treatment. Parents were encouraged by the positive experiences of and support from other parents, and often first trialled blended diet without the permission, knowledge or support of healthcare professionals. Previous research has prioritised the viewpoints of healthcare professionals and prior to this research,

parents of tube fed children who have chosen blended diet, despite being the experiential experts, have been largely voiceless within academic research. The research shows that parents are willing to take a risk in distressing circumstances. For the parents in this research the hope provided by blended diet was fulfilled and all experienced positive life changing benefits.

### **6.3 Life Changing Benefits**

This research has found that there are immense benefits attributed to the use of blended diet. The power of this discovery lies in the life changing nature of the improvements experienced by HETF children, their parents and wider families.

This section frames the discussion of the benefits described by the parents using two sub-sections; the health and wellbeing (Sub-section 6.3.1) and the social and emotional (Sub-section 6.3.2) benefits. There is an inherent and significant overlap between these, which is explored. This research suggests that that the life changing health and wellbeing improvements reported by parents in this research, although discussed individually, are interlinked. For example, a child who is no longer vomiting several times a day is able to digest and absorb the nutrients in their food, they subsequently gain weight and their complexion seems to brighten. Reduced vomiting also means reduced risk of pulmonary aspiration and life-threatening pneumonia, resulting in less emergency admissions to hospital. The child feels better in themselves and the pain linked to vomiting, reflux and constipation is resolved, they are happier. The reduced pain and satiety result in better sleep and subsequently the child is more alert and able to interact with others around them. School attendance improves as a result of better health and the child is able to engage in school activities. The wellbeing of the family is improved by the reduction in anxiety and the family focuses less on managing tube-feeding complications, and more on social or family activities.

#### **6.3.1 Health and Wellbeing Benefits of Blended Diet**

The introduction of blended diet can lead to a marked improvement in the previously debilitating symptoms of reflux, retching and vomiting or their life-

threatening complications as demonstrated by this research. Parents explained that symptoms ceased almost immediately after starting blended diet either from the first-time blended food was given through the tube or within a few days. Notably, this research suggests that this swift and almost 'unbelievable' improvement provides rapid vindication of the parents' decision to adopt blended diet and a relief that the risk taken was rewarded. This study found that parents attribute the dramatic improvement in gastric symptoms, in the main, to the increased viscosity or 'custard like' consistency of blended diet. They assert that the slightly thicker blend 'sits' better in comparison to the 'swilling' of the more liquid commercial formula. The significance placed by the parents on the viscosity of the feed is consistent with the work of Pentiuk et al. (2011), who noted that parents typically reported an immediate decrease in symptoms and who also linked this to viscosity. Additionally, a Japanese study, focused specifically on the thickening of commercial formula for tube-feeding in older children, found both the frequency and duration of reflux, retching and vomiting episodes were significantly decreased in comparison to un-thickened commercial formula (Miyazawa et al 2008). It seems likely the increased viscosity of blended diet in comparison to liquid commercial formula contributes to the immediate effect parents in this research reported.

An alternative explanation for the improvement identified in this research could be an undiagnosed cow's milk protein allergy. None of the parent's suggested this link, but the researcher noted that the commencement of blended diet coincided with a decision to omit cow's milk from the diet. Three of the parents in this research had made a decision to use non-dairy milk alternatives in their child's blends, although the reasons for this were not described. Cow's milk protein allergy is relatively common in children affecting 4.9% <3s (Walsh et.al. 2016). It manifests as symptoms of reflux, retching and vomiting (NICE 2015). It is possible that the symptoms of an undiagnosed cow's milk protein allergy were attributed as symptoms of tube-feeding intolerance or the child's underlying medical condition.

Symptoms of reflux, retching and vomiting have been reported to improve naturally with age (Esposito et al. 2006). It could be argued that the child may have grown out of the adverse reactions. It is unlikely to have been the case for the children and young people discussed in this research due to their varying ages and the rapid nature of their improvement on commencement of blended diet.

The purpose of this research was not to measure or prove the efficacy of blended diet. However, this research suggests that positive improvement or even complete cessation of symptoms can be observed in a matter of days after introduction of blended diet as the sole source of sustenance or in combination with commercial formula. In clinical practice this would mean it would be possible to ascertain if blended diet would be beneficial for a child using a short trial period with minimum risk. Equally, it could be possible to achieve the desired outcome by using blended diet in combination with commercial formula, as several parents included in this research did, thus lessening professional's concerns regarding the nutritional adequacy. Given the radical improvements in symptoms and the subsequent positive impact on the child's and family's quality of life it is suggested that further research is needed to ascertain why blended diet has this effect and in how many cases.

A reduction in reflux symptoms means that it should also be possible to reduce the amount of anti-reflux medication prescribed. Many of the parents described how their child no longer took any medication for reflux. This was important for the parents in this research because, as previously discussed, their use had been cited as a major concern for parents. This research finding also has cost implications for the NHS in terms of medicines usage. Likewise, a recent Canadian feasibility study found a small but significant reduction in anti-reflux medications was possible following transition to blended diet (Gallagher 2018). It could be argued that the parents in this research are more likely to have had positive experiences of blended diet because they have continued to use it. Any parent who had tried blended diet and been unsuccessful would have not met



the inclusion criteria for this research and as such a representation of their experiences will be missing (Table 4.1).

Furthermore, this study highlighted that parents believe blended diet has a positive effect on bowel habits. Parents described considerable improvements in constipation and/or diarrhoea which had been problematic before the introduction of blended diet. In many instances, where the child had been tube fed since birth, the transition to blended diet was followed by the child's first ever 'proper poo'; an event that was, in some cases, a cause for celebration. This celebration is interesting as it indicates, not only happiness at an improvement in unpleasant symptoms for their child, but also a sense of normalisation; a theme that is evident frequently throughout the benefits reported. Normalisation is further explored in Section 6.3.2. It was clear that irregular bowel habits had been a major cause for concern for parents who reported being pleased at the ability to further reduce medications previously used to regulate the child's bowel habit. Parents attributed the improvement in bowel habit to be due to the fibre content of the blends.

Although it may seem contradictory that parents reported improvement in both constipation and diarrhoea symptoms, fibre and its fermentable products (short-chain-fatty acids) have been found to have potential beneficial effects on intestinal physiology and a role in the prevention of both diarrhoea and constipation (Aggett et al. 2003; Kien 2008). Interestingly, a double-blind randomised crossover trial found the amount of fibre contained in paediatric commercial formula did not meet UK Dietary Reference Values (DRV), which suggested that children should have proportionally less than adult recommendations (Department of Health 1991; Evans et al. 2009). Since the work by Evans et al. (2009) was published, the Scientific Advisory Committee on Nutrition (SACN) produced specific guidance on fibre intakes for children and young people which are higher than previous DRVs (SACN 2015). Additionally, in an attempt to manage the severe reflux, retching and vomiting symptoms many of the children and young people had been given low-molecular fibre-free commercial formula with the aim of treating their reflux and

vomiting symptoms; this is currently recommended by ESPGHAN (Bragger 2010). This means transition to a blended diet signified a considerable increase in dietary fibre for a child whose previous commercial formula diet was either low in fibre or even free from fibre. This is likely to explain the positive effect on bowel habit and frequency reported by the parents in this research.

It could be argued that those using blended diet may be as likely to have a low fibre intake as anybody else. Many of the parents in this research reported that they gave the same foods to their tube-fed child as to the rest of the family. These family meals may be low in fibre like many of the meals consumed by the general UK population who have been found to have an inadequate fibre intake (National Diet and Nutrition Survey, 2013-2014). In the non-tube fed population, a common barrier to increasing fibre intake is often the child's dislike of the taste or texture of foods that are high in fibre. The parents in this research pointed out that, as a tube-fed child cannot taste the food, they are therefore less likely to reject it. It is also suggested that the parents in this research are more likely to be cognisant of the importance of fibre intake than the general UK population, owing to having experienced their child's bowel habit challenges.

This research shows that improvements in bowel habit have a positive impact on wellbeing and family life. Parents often perceived their child to be in a great deal of pain and distress due to severe constipation despite using large quantities of laxative medications, often challenging to find the right balance of symptom alleviation without causing diarrhoea. This pain and distress was alleviated following transition to blended diet. For those whose child has previously suffered with diarrhoea, alleviation of this symptom meant, not only a relief of distress for their child, but also the ability to leave home without the anxiety of needing to find suitable changing facilities, again linking to the concept of normality. This finding bears similarity to the report by Thomas (2017) a children's nurse, where the introduction of blended diet was reported to reduce the incidence of diarrhoea and meant one child could attend school. However, this research goes further and demonstrates the impact of these

symptoms on a child and their family as well as how beneficial a reduction in them can be on all aspects of their lives.

One other interesting, clear finding of this thesis study is that the introduction of blended diet can lead to either weight gain or loss. The majority of parents reported an improvement in the pattern of weight gain following transition to blended diet. In most instances' parents thought weight gain had been poor on commercial formula, but following its adoption, the child was able to quickly gain weight on blended diet; some joked that the weight gain had been such that they had to put the child on a 'diet'. This could be attributed to the reduction in feed loss and severe, energy expending reflux, retching and vomiting symptoms which resolved with blended diet use. Conversely, both Imogen and Jane reported that their child had previously gained 'too much weight, too quickly' when fed exclusively using commercial formula and their child's weight gain had been healthier since starting blended diet. It is possible that these two children were being overfed on commercial formula. Children and young people with very low energy expenditure as a result of immobility and low muscle tone are at risk of overfeeding if fed to DRVs which are based on the average mobile population (Sullivan et al. 2009; Vernon-Roberts et al. 2010).

It may seem contradictory that use of blended diet may lead to either weight gain or a reduction in weight gain. Nevertheless, there are likely to be two distinct reasons behind this. Firstly, the energy expenditure of children and young people with complex health needs is recognised to be diverse; the complexities of their clinical condition factors such as low resting energy expenditure, epileptic seizures, respiratory difficulties, involuntary movements will have an effect (Lambert and Meng Han 2009).

Secondly, it was clear that the parents used different food ingredients in comparison to each other, which is perhaps unsurprising given the diversity of food use within the general population which can be influenced through a multitude of factors such as experiences, allergies and religious beliefs to name a few. In the context of weight management, Jane for example was able to give food low in energy but high in other nutrients such as protein thus slowing her

daughter's weight gain. Anna on the other hand gave energy rich foods such as full fat dairy products and biscuits to boost her daughter's weight gain. This has similarities to the way in which the research dietitian in the Pentiuk et al. (2011) study was able to fortify the blend to promote weight gain when one of the participants lost weight. More strikingly this has similarities to the way the rest of the non-tube fed population regulate weight. As well as variation in food ingredients, parents spoke at length about how they often adapted the blends to meet their child's individual and changing needs. In addition to the health and wellbeing benefits, the parents described social and emotional benefits linked to being able to offer their child choice. This is further explored in Sub-section 6.3.2.

A further critical discussion point was that this research showed that parents perceived their child to be generally healthier on blended diet in comparison to how they had been on commercial formula. Parents asserted that this manifested as increased resilience to common illnesses such as coughs and colds. Additionally, parents remarked that if the child did become ill they seemed to recover more quickly than in the past. Subsequently, an improvement in school attendance and importantly a reduction in hospitalization was often referenced. For parents whose child had suffered vomiting and diarrhoea symptoms this could possibly be attributed to improved nutritional intake as the child was able to better digest the food. However, the parents whose child had not previously suffered from vomiting and diarrhoea symptoms also reported this benefit. This research finding conflicts with the suggestion that blended diet could lead to increased incidence of infection which has been suggested in professional opinion on the topic (BDA 2013; BDA 2015; Johnson, Spurlock and Pierce 2015; Novak et al. 2009). It was clear that the parents interviewed believed that the improvement in health was also linked to the quality and freshness of the foods they provided for their child. One potential explanation is the inclusion, via blended diet, of phytonutrients such as antioxidants and bioflavonoids which are thought to play an important role in long-term immune functioning but cannot be added to commercial formula due to legislation and instability (Lambert and Meng Han 2009). This is the first

research that has identified a perception of improved general health attributable to blended diet. This is thought to be due, at least in part, to the fact that previous research has looked at the transition to blended diet over a shorter term whereas the parents in this research were looking back at their experiences in the longer term, often over many years.

A general improvement in appearance was often described and it was clear parents felt their child looked visibly better or 'brighter' on blended diet in comparison to commercial formula, where descriptions of pallor or dull hair were linked to the child looking unwell. This is a particularly important aspect for parents who could see a visual reminder of how ill their child is every time they look at them. Equally, and by comparison on blended diet, the child's complexion was described as 'brighter'. In the longer-term parents also noted that their child's hair seemed to grow more and become shiny. For parents this belief was validated when other people such as professionals, teachers, carers or friends remarked on how well their child looked. The child's improved visible appearance also links to a sense of normality as Katie surmises even though her daughter has complex needs she no longer looks 'sick'. This finding is supported by Brown (2014), a children's nurse working in a UK hospice, who, in a report stated, that families under her care had noted improvements in the condition of the child's hair and skin following transition to blended diet. It is likely that studies looking at blended diet use have not identified this benefit because it is very subjective and difficult to measure or capture using survey methods, particularly by those with infrequent contact with the patients.

Another original finding of this research is that parents perceive their child to be happier on blended diet in comparison to commercial formula. Children were described as being more 'alert', as having 'more energy' and perhaps, more subtly, a 'sparkle'. Parents asserted that, because their child was no longer experiencing severe symptoms, often including pain, they were happier. Parents evidenced this by reporting a reduction in physical indicators such as wincing, arching of the back and screaming. A key parental motivation is

suggested to be happiness of a child, and the importance of this feeling should not be underestimated.

The improved health, appearance and mood identified in this research could be attributed to the improvement in the child's previous debilitating symptoms. If a child was vomiting repeatedly, they would be losing micronutrients before they could digest them, leading to deficiencies. This is particularly likely in instances where the child was losing weight which is a sign of malnutrition (Elia 2001). Malnutrition can leave an individual feeling lethargic and low in mood and has been found to cause reduced immune functioning (Elia 2001). Dry and flaky skin could indicate a deficiency of essential fatty acids, B vitamins or vitamin A, while thin sparse hair can be a sign of protein, energy, zinc or copper deficiency; a deficiency of either iron, zinc or copper can cause the finger nails to be thin and break easily (Shaw and McCarthy 2015). This research demonstrated that the commercial formula given to children cannot always be considered 'nutritionally complete' as succinctly explained by Jane (Sub-section 5.2.1); her daughter was gaining too much weight too quickly, so the volume of prescribed commercial formula was reduced by her dietitian. As a result, the formula was no longer nutritionally complete, and an additional multi-vitamin and minerals supplement was prescribed, which Jane found hard to comprehend. It is possible that some of the children in this research were previously malnourished because they were unable to tolerate and therefore digest commercial formula. This is especially likely in those children who had been described as losing weight, as wasting is an indicator of malnutrition (Shaw and MacCarthy 2014). Interestingly, parents whose child had not suffered from vomiting also reported the health, appearance and mood benefits. Overall, drawing on the collective findings, the researcher suggests that the benefits of blended diet in comparison to commercial formula are not solely attributable to reduction in vomiting but also to nutritional elements such as improved utilisation of micronutrients or prescription of incomplete volumes of commercial formula due to low energy expenditure. This requires further investigation as there are likely wider implications for the general HETF population.

One interesting finding was that this study highlighted that parents perceive their child to be more satisfied on blended diet in comparison to commercial formula meaning they worried less about whether their child was hungry, a common concern with the thinner commercial formula. Laura characterised her son's frequent screaming to be an indicator of continuous hunger and unsatisfaction on commercial formula, leading her to believe 'he was never going to survive' on commercial formula alone'. It could be argued that Laura was misinterpreting her sons screaming as hunger when there was another, separate cause. However, as identified in the Oxford feeding study, as the child's main care giver, parents are likely to know their child well and are likely to pick up on non-verbal cues and signals when a stranger to the child would not (Sullivan 2009). Additionally, studies which have focused on the effect of viscosity on human appetite responses have identified that liquid foods elicit weaker appetitive and dietary responses when compared to more viscose foods (Mattes and Rothacker 2001; Tieken et al. 2007). This research is the first to suggest satiety as a benefit of blended diet. It is likely this benefit has been overlooked in previous work because the signs are recognised by parents in their child and is perhaps overlooked or dismissed as being due to another cause by professionals who know the child less well.

One other discussion point is the specific experience of one parent. Jane initially chose to start blended diet with the hope of improving her daughters' symptoms of reflux, vomiting and constipation. Jane found that blended diet did not resolve her daughter's severe symptoms and her daughter subsequently had a fundoplication and antegrade colonic enema surgery (ACE), a procedure that is designed to help the emptying of the bowel. Interestingly, Jane continued with blended diet despite it not having the impact she had initially hoped for. Jane believed there were other benefits to blended diet in comparison to formula including improvements to weight, mood, general health and appearance that meant blended diet was of enough value to continue. Furthermore, the social and emotional benefits further explored in Sub-Section 6.3.2 were also an important factor for Jane.

To conclude this section, the majority of parents in this research had noted immediate and often life changing improvements in their child's health following transition from commercial formula to blended diet. These initial positive changes in their child encouraged the parents in this research to continue with blended diet. As time passed many parents noted additional, improvements several of which are proposed for the first time by this thesis study. In addition to considerable improvements in the health and wellbeing of their child, the parents in this research also reported feeling a sense of normality when using blended diet in comparison to commercial formula alone. This will be discussed further in Sub-section 6.3.2.

### **6.3.2 Social and Emotional Benefits of Blended Diet**

As discussed in Section 6.2, physical adverse symptoms (Sub-section 6.3.1) were the main driver for most of the parents in this research to adopt blended diet. Significantly, all of the parents in this research, on reflection, highly valued the social and emotional benefits discussed in this section. The sense of normality which they believed blended diet provided in comparison to the exclusive use of commercial formula is a common element running throughout most points of discussion covered in this chapter.

Most parents in this research believed they had been denying their child something quintessentially human; food. It was clear from this research that parents viewed commercial formula to be 'medicalised', 'fake or 'synthetic'. Blended diet is seen by parents as being 'real' food. In addition to feelings of guilt or sadness that their child cannot share in the enjoyment often derived from the eating of food, parents found it difficult to feed commercial formula to their child when they would not be prepared to eat it themselves. As an illustration, Hannah explained how she had tried the commercial formula herself and described it as 'sticky' and overly sweet. The fact that her son was unable to taste or feel the texture of the formula was of little consolation to her.

Food is defined as being something that people and animals eat, or plants absorb, to keep them alive (Oxford English Dictionary 2017). However what



people consider to be a food is far more complex. For example, in some parts of the world people commonly eat insects, however few people in western cultures would consider insects to be food, the concept of 'food' and 'non-food' is intertwined in socially constructed ideas and culture (Fischer 1988). This research suggests that, rather than a desire to use unprocessed food, parents value being able to give 'real' food interpreted as the type of food they themselves would be willing to eat which often included some unprocessed food. This research did not find that the desire to use organic or unprocessed food was a significant factor in the decision-making process for the adoption of blended diet and is in contradiction to the suggestions by Martin and Gardiner (2017).

As demonstrated by this research the way in which commercial formula is prescribed and obtained serves to compound parent's feelings that it is a medical treatment rather than a real source of food. Commercial formula is prescribed, and a regimen is written up. Parents are advised by dietitians on the doses and set times to give a feed. People rarely eat like this; the timing and quantities of meals are usually flexible. In a professional commentary on HETF one specialist palliative nurse suggests that time should be taken to fit the feeding plan around the family's life or provide the flexibility of adjusting the timings of their tube-feeding themselves allowing for some control over their lives (Day 2017). This research supports the idea that the families of HETF children and young people would value this type of flexibility and again highlights the power of normal.

Whilst professionals were not interviewed this research highlighted that the way in which professionals speak about commercial formula influences how parents view it. Rather than a 'dose' or a 'bolus', blended diet was thought of as 'breakfast' or 'dinner' which was important psychologically. Using the same terminology as people who eat orally had a normalising effect on the experience. Additionally, it was clear that parents whose child had a gastrostomy placed in later childhood considered it to be a retrograde step for a child who been weaned onto solids and eaten food for most of their lives to

revert to 'milk', 'feed' or 'formula' which have clear connotations for parents with infant feeding. In a book written by HETF professionals working in the US, Dunn Klein and Evans Morris (2004) suggested that care should be taken by professionals over the language used when talking to parents so that tube-feeding is viewed as a mealtime too; this research supports this suggestion. Irrespective of blended diet, this research has reinforced the view that giving greater consideration to the terminology used in HETF could help de-medicalise the experience for families and have a positive effect on the experiences of tube-feeding.

Similarly, this research shows the use of blended diet has a positive effect on the parent/child relationship and subsequently on the wellbeing of the child, parent and family. Happiness was discussed as a benefit in Section 6.3.1 in the context of the child. It is suggested that this benefit is not limited solely to the child. Parents viewed feeding using commercial formula as another clinical task whereas blended diet fitted more with the expected parenting role. As powerfully described by Olivia for example blended diet provided an opportunity to be her son's mum rather than his nurse. This is particularly important given the number of other clinical tasks parents of children and young people with complex health needs are asked to perform for their child on a daily basis. It was clear that the clinical interventions parents had to perform for their child felt at times like an invasion upon family life and the home began to resemble a hospital (section 5.4.2). There are similarities between this research and the finding and studies looking at other aspects of complex care in the home. Kirk, Glendinning and Callery (2005) used grounded theory to explore the experience of being the parent of a child with complex health needs and found parents viewed themselves as having dual roles, parent and nurse. In some cases, parents resented the way in which their nursing role seemed to overshadow the parenting role (Kirk, Glendinning and Callery 2005). Focusing specifically on the transition from oral to tube-feeding Craig and Scrambler (2003: 1116) interviewed twenty-two mothers and found that it conflicted with their expectations of 'good mothering'.

Additionally, the improved parent/child relationship could also be credited, in part to an improvement in volume tolerance afforded by blended diet. This benefit was introduced in Section 6.2 and is related to one of the factors discussed as the reasons for choosing to commence blended diet. The social themes relating to restriction are evident in the experiences described in this research and it is therefore suggested that blended diet allows for more freedom and subsequently more physical and social contact between a parent and their child, which in turn strengthens their relationship. For example, Jane expressed challenges in something as simple as giving her daughter a hug. Parents in this research, whose child had previously tolerated only a small volume of commercial formula over a long period of continuous pump feeding, noted that their child was able to tolerate larger volumes of blended diet, leading to a shorter duration of feed. Moving tube-fed children and young people from continuous feeding to bolus feeding is likely to be beneficial to both their health and wellbeing. This research has demonstrated that use of blended diet has a positive effect on the emotional and social wellbeing of the parent and child and suggests that, should blended diet be offered as a supported choice to parents of tube-fed children, significant benefits could be more widely experienced.

Furthermore, this research demonstrated the numerous ways in which use of blended diet allowed parents to personalise their child's diet. Commercial formula is uniform; it is the same colour, consistency and volume every day, for every meal. While professionals view this uniformity as a positive (BDA 2013), parents believe it is monotonous. The diversity of blended diet is highly valued by parents; blends vary in appearance, taste, smell and texture. It was clear that parents made individual choices in comparison to one another, in the food ingredients they chose and also the way in which they blended. Making a choice to use blended diet means there are countless more little choices that can be made every day. Parents can pick from 'a vast array of food ingredients using seasonal foods or adapting the blend if the child is under the weather. As Claire succinctly expressed, this was 'massively empowering'. Furthermore, in many cases parents were able to offer their child choices, often taken for granted in non-tube fed children, such as choosing their own breakfast cereal.

The general (oral eating) population have an enormous amount of choice with regard to food and numerous factors influence food choice such as personal preference, cultural or religious beliefs, cost or cooking skills to name a few (Cox and Anderson 2004). While medical science has focused mainly on the nutritive value of food, sociologists and psychologists have demonstrated that food is a key part of human culture and identity (Wilk 2010). Blended diet allows a level of personalisation that is prevented by the use of commercial formula, a benefit that this research demonstrates is valued highly by the parents.

In addition to being able to make choices about food, this research acknowledges blended diet as requiring greater effort by the parent than commercial formula. This is suggested to be a potential benefit as well as a potential challenge. Many of the parents attributed feelings of satisfaction to activities such as being able to shop, cook and prepare blends for their child when they had time to do so. Other articles have identified that blended diet seems to pose both an increased cost and effort alongside a higher level of satisfaction (Armstrong 2017; Gallagher 2018; Johnson et al. 2017; Johnson, Spurlock and Pierce, 2015; Novak 2009). However, it could be argued that especially in the case where parents feed their child the same meals as the rest of the family, but blended, that the difference in time, effort and cost of using blended diet is not as substantial as previous studies propose. In relation to cost, many parents may see this as part of their parental role in providing for their child and also adds to the feeling of normality and many believe that it is not the role of the NHS to provide the basics such as food for their child, with several indicating the benefits observed are well worth the costs involved.

Furthermore, the findings of this study, interestingly highlighted that blended diet use can alleviate feelings of exclusion by allowing a tube-fed child or young person and their family the opportunity to share the same foods and experiences. This was another novel finding which in turn would seem to relate to an overarching theme of normality where it is important for parents to feel that they are able to treat their tube-fed child similarly to siblings. For some of the parents blended diet meant the child or young person could have exactly

the same meals as the rest of the family but blended and given through the tube, enabling a shared experience. In addition to providing a sense of normality, this also had practical benefits such as convenience and only a marginal increase in workload over preparing a meal for the family. On reflection, parents felt their child had been missing out when they were fed commercial formula alone. As Nathan exemplified (section 5.4.1) sharing a meal together is viewed as part of a family bond. Research over the last three decades in the fields of sociology and social anthropology has found that people value family meals times highly and view them as key to family cohesion and sociality (Murcott 2012). DeVault (1991) suggested ideas of 'home' and 'family' are constructed from day to day activities like eating together which establishes and maintains a 'family culture'. Thorne, Radford and McCormick (1997) interviewed parents of long-term tube-fed children and found families felt they had lost a part of normal family life when their child had a feeding tube placed. The findings of this research are aligned with an opinion piece by Novak et al. (2009) who noted that the sharing of foods could be a major benefit of blended diet. However, this research identified the frequency at which families choose to share mealtimes varies, depending on personal preference, family situation and schedules, which is reflective of patterns in the general UK population where it has been suggested the family meal and its normative status are often an ideal rather than a reality (Wilk 2010). As such, though the ability to share mealtimes is a considerable benefit, this research suggests that it unlikely to be a key motivating factor.

This research highlights the significance that parents place on being able to share special meals or foods with their families, and crucially in the case of blended diet, including their tube-fed child. Food plays a central role in every single human celebration (Fox 2003) and the parents in this research described the negative emotional impact of their child being excluded from the opportunity to share in food related experiences when solely using commercial formula. This research shows that feelings of exclusion can also be extended to families, for example, Diane expresses guilt that they could no longer go out for meals or eat in front of her daughter. This led to a sense of isolation intensified because

they had previously been very social. This finding is in alignment with that of a descriptive study of parents whose child had transitioned from oral feeding to long-term gastrostomy feeding where Peterson et al. (2006: 716) noted that a child's inability to eat food by mouth led them to feel 'left out' and 'isolated'. As early as the 1980s, concerns about the potential for tube-fed children and young people to suffer unintentional social deprivation because they are unable to take part in aspects of life involving food have been raised (Crane 1987). This research found that blended diet can go some way to relieving this potential exclusion, although acknowledges that blended food given via a tube is not equivalent to food eaten orally. Blended diet presents a way in which tube-fed individuals can be reincluded in these aspects of life.

Interestingly, and uniquely, this research indicates that the parent may experience significant emotional benefits from being able to create a sense of inclusion for their child and their families. It is suggested that the level of importance placed on this benefit by parents can be affected by other factors such as the child's level of awareness or interest in food. Where this is low, the value attributed to these benefits could be reduced.

This research shows, that in addition to benefits to the parent and child, the use of blended diet permits other family members and friends to be included in providing food for a tube-fed child. Examples of this included, a cake baked at school by a sibling, vegetables grown on a grandmother's allotment and the gift of a chocolate advent calendar. Parents described how being able to speak about food meant the child was included more. Parents spoke to their child about the food they were preparing. Equally, being able to talk to other people about the food the child was having meant people took more of an interest. Fiona, for example, described how her younger daughter showed greater interest in her sister now she could be involved and had a shared experience relating to food.

In summary, this is believed to be the first UK doctoral research to directly ask parents about their experiences of blended diet in comparison to commercial formula, and as such has allowed the exploration of previously unconsidered

aspects of the impact of tube feeding in a social and emotional context. It uniquely considers the potential benefits of blended diet over commercial formula as opposed to the previously explored negatives of transition from oral to tube feeding. Additionally, the findings of this research suggest that parents view the commercial formula as medicine rather than food. Greater consideration needs to be given in clinical practice to de-medicalising home enteral tube-feeding (HETF).

#### **6.4 Challenges and Support in use of Blended Diet**

Early parts of this chapter have considered the factors relating to choice and the benefits identified by this research. This chapter now moves on to examine some of the key challenges faced by parents using blended diet. The discussion of these challenges also considers potential improvements to the experiences of parents using blended diet and the impacts these may have on future practice.

The biggest challenge identified in this research was the lack of support provided by healthcare professionals to parents using blended diet. Unfortunately, most parents described negative experiences when interacting with healthcare professionals on the subject of blended diet. As described in Section 6.2, the choice to use blended diet is often made under desperate circumstances. It is suggested that this is a time where a parent should be offered significant support to help deal with difficult, complex and often emotional decisions surrounding a child's care and wellbeing. The reality experienced by many of the parents in this research paints a starkly contrasting picture to this. At its worst, some parents experienced active resistance to their enquiries about blended diet being dismissed as not acting in the best interests of their child or taking reckless risk with their health. This led to feelings of belittlement or dismissal as suggested by phrases such as 'naughty school child'. This combination of an already stressful time with being made to feel guilt or fear by the opinions expressed by healthcare professionals, who often had little or no previous experience with blended diet, frequently led to creating an atmosphere of emotional turmoil for parents and families.

At some point, for each parent, a critical point was reached where the decision to commence blended diet was made. This often coincided with the parent reaching out for support from other parents, either personally or more frequently online, sharing detailed accounts of their negative experience in the process. Several parents in this research recount hearing about the bad experiences of others during their initial information gathering and first stages of consideration of blended diet use. These parents described an influence on their decision to share their thought processes with their healthcare professionals. After reaching the decision point to commence blended diet, they did so without informing healthcare professionals or requesting support. In several cases, parents did later inform healthcare professionals of the use of blended diet, but usually after an extended trial and establishment of some benefits. It is suggested that there may be a potential impact to parents wishing to, at least initially, conceal their use of blended diet. As discussed in Section 6.1, blended diet may be unsuitable for some with specific medical conditions, and it is therefore suggested, although this was not evident in any of the experiences described in this research, that there is the potential to miss an opportunity for intervention and prevention of harm. Several US professionals working in HETF have suggested blended diet is less risky when support is provided by a dietitian (Bobo 2016; Duperett, Trautlein and Dunn Klein 2004; Johnson et al. 2017; Mortenson 2006; Novak 2009). Bobo (2016) pointed to a case in the US where a child presented with micronutrient deficiencies after the family trialled blended diet alone. Those deficiencies were easily corrected following basic advice on healthy eating from a dietitian (Bobo 2016). This research demonstrates how the lack of guidance on the topic of blended diet impacts on families and highlights an urgent need for greater understanding from healthcare professional about the concerns of parents.

Inconsistent support offered to parents was identified in this research, ranging from abandonment and judgement to a supportive partnership, with parents largely attributing this to the individual healthcare professional's attitudes and experience. The experience of one parent is of particular interest as Beth describes being offered exceptional support by her dietitian who, despite being



inexperienced in blended diet, provided an excellent level of care and support. The dietitian made a particular effort to research the topic and learn in partnership with her. Beth describes this experience in an extremely positive light and believed it supported her family to achieve positive life changing outcomes. This support is also a reciprocal arrangement with Beth describing how she has supported her dietitian with production of resources for use with other families considering blended diet in her area of practice. The stark contrast between the experiences of some of the parents poses questions about how different the experiences could have been if a consistent level of support was available. Overall, one compounding finding was that a significant amount of emotional stress and anguish could be avoided if other parents had been offered the same level of support as Beth. In addition, where good support was received from a healthcare professional, on occasion the parent was asked to conceal, the use of blended diet from other healthcare professionals for fear of disapproval. This highlights a lack of interdisciplinary working between some healthcare professionals, putting the parent in a difficult position and potentially adding to the feelings of stress and anxiety.

The important question of when the topic of blended diet should be discussed is also a key topic of this research. It was clear that some of the parents felt let down by professionals who had not offered blended diet as an option to them at an earlier stage. In the majority of cases the parent had discovered blended diet themselves after watching their child suffer for months or years with adverse symptoms. Interestingly, one parent Anna had been offered blended diet as a choice by her daughter's dietitian while considering the option of anti-reflux surgery. The BDA (2013) have suggested that parents should be provided with all the information they need to make a fully informed choice about blended diet. However, no guidance is given as to when that information should be provided. This research identified that parents often do not ask professionals before trying blended diet. It is suggested therefore that conversations about blended diet should take place earlier rather than later ideally when a feeding-tube is first placed, or first considered. Previous studies have identified that gastrostomy tube placement is often delayed due to parents' perception that they are giving

up their 'last vestiges of normalcy' (Thorne et al. 1997: 95; Craig et al. 2003). This research suggests that blended diet could be especially valuable in cases where parents are reluctant to have a gastrostomy tube placed in a child who has previously eaten orally, even when it is clinically necessary. Blended diet could offer hope at a time where parents are having to come to terms with a sense of loss for normal activities such as meal times as although it does mean that a child is not eating orally, they do not have to give up on food. This could mean potentially life sustaining treatment is not delayed due to the parents social and emotional fears.

Dietitians, in particular, were perceived by parents in this research to be nervous about blended diet. Parents found themselves in a confusing situation where their child's dietitian refused to speak with them about food. This did not match parent's expectation of the dietitian's role in their child's care. This is an example of an ongoing challenge faced by parents, and not just one that exists at the point of commencing blended diet. Parents sensed that dietitians, fixated on risk, were concerned that they would be accountable if they advised on food that was subsequently going to be blended and given through the tube; the parents found themselves in an incomprehensible position where dietitians refused to talk to them about food. As a consequence, parents felt they had lost a source of reliable information and advice surrounding the nutritional support of their child. Parents describe having to spend a lot of time and effort navigating and sifting through a lot of information from varying sources, trying to make judgement calls on their reliability and suitability for their child, an activity where they would have valued support from their dietitian. For example, Marie, said she would like her son's dietitian to be able to discuss the values of particular foods and 'cut through' misleading health claims of foods which are presented in the mass media. The findings of one survey study support this idea.

Armstrong et al. (2017) suggest that dietitians are reluctant to support families who chose blended diet because they have received no formal training on blended diet use. However, this research suggests that blended diet is just food, blended. Dietitians are extensively trained about food and nutrition in health and

disease and should be able to advise parents on healthy foods and age appropriate meals for their child.

In addition to the nervousness of dietitians, opinions on and fears surrounding blended diet from other care givers added pressure and stress to the lives of the parents using it. From this research, another inconsistency has been identified. A vital source of support for parents of children with complex needs is school and respite care and as blended diet has no published guidelines, parents experience variety of levels of support from these organisations. Some parents receive good support and their wishes to use blended diet are respected and the school or respite facility take steps to allow the use of blended diet such as creating local guidelines, preparing and giving blended feeds. Regrettably, in other cases, parents were forced into choosing between their child's welfare and their own. Where blended diet is not supported by these vital sources of support for families, additional stress and pressure is described. It is also another source of conflict for parents, who often described having to 'battle' for the ability to give blends to their children in school and respite setting. In some cases, these battles were successful, but in the most difficult cases, parents had to make the decision to withdraw from schooling or miss out on the personal support that the respite care should have given them. Some schools or respite care settings would support blended diet on the proviso that the parent came in to feed the child. This had consequences of negating some of the benefits of the support provided, and in some cases even led to financial implications as the parent left employment in order to be able to provide this care.

Hospitalisation was also a major concern for parents. As with other care settings, the support of blended diet use varied between hospitals and even in some cases between wards within a hospital. In some instances, this led to parents delaying admissions or discharging their child against medical advice so that they could feed the child in the way they felt they needed to. As previously discussed, the parents are often very active via forums and social media, and although this is described as being a vital source of support, on

occasion it may also have negative effects. For example, for parents who receive little or no support from healthcare professionals or other care settings, it is likely to be exasperating to see others share positive experiences.

Starting blended diet was described as a particularly difficult experience for parents in this research. For parents whose child has been tube fed since birth starting blended diet is more difficult than the experiences of a child who has previously eaten orally. Parents in this research whose child had been tube-fed since birth explained they gradually introduced pureed foods one at a time similar to the way in which babies are usually weaned orally. Parents whose child had eaten orally previously were able to give the child the same foods the parent already knew they could tolerate, which could suggest that parents of children who have been tube fed since birth may benefit from additional support at this time while tolerated foods are identified.

This research shows that parents use different approaches to blended diet in comparison to each other. Some of the parents used a family meal approach plating up a portion of a family meal for the child and blending it fresh meal by meal. Alternatively, some parents used only a select few recipes because of their child's allergies. Others, particularly when time pressured, chose to bulk prepare blends for the child for the week. This would suggest that parents need different support depending on the approach they have taken to blended diet. A parent who is portioning up family meals for their child would likely need general age appropriate healthy eating advice ensuring that they are giving a broad range of foods from each of the food groups. For a parent who is reliant on a limited number of set recipes due to allergies for example, nutritional analysis by a dietitian is likely to be helpful, just as it would for a child eating orally.

It is acknowledged that blended diet is not appropriate for all, and this research does not suggest it as a wholesale replacement of commercial formula which undoubtedly has a prominent place in effective tube feeding. Blended diet may not be a suitable option for many families due to factors such as the increased cost (relating to both equipment and ingredients) time and effort in relation to commercial formula. Some of the costs can be significant, particularly where

parents chose high powered blenders in an attempt to diversify the foods that can be included in blends, or dehydrators for ease or ambient storage of home blended food.

Although this research describes experiences of intolerance to commercial formula, the vast majority of exclusively tube fed individuals tolerate it well and maintain a healthy weight without any problems. However, the social and emotional benefits of blended diet described in Section 6.3.2, and in particular those relating to inclusion on special occasions, could be equally applicable to the population that currently use commercial formula as their sole source of sustenance, if there was support or information available to help them try it. For example, an individual who is exclusively tube fed could be offered the opportunity to share in experiences such as Christmas dinner with their family, an event that they may never have been able to join in with before. It is suggested that, although this research has focussed on experiences of parents and their children, that these benefits are not restricted to this population. It is true that in early life, there is generally more focus put on things like birthday parties and milestones, meaning that parents and families of tube fed children may place more importance on this than an adult population; however, adults may still value an opportunity to participate on special occasions.

### **6.5 Synthesis with the Themes of the Quasi-Systematic Review**

This research sheds light on the complexities of parents' perceptions on the topic of blended diet, due to the rich data obtained using interpretive phenomenological analysis. In the quasi-systematic review which informed this doctoral research, only nine articles were identified which related to the use of blended diet for home enteral feeding. Yet, only five of these articles reported any research methods and these five articles relied predominantly upon limited survey methods. In Chapter 3 of this thesis seven key themes were identified from synthesis of the nine included articles. These themes were: tube-feeding tolerance, risks, weight, oral dietary intake, the additional time required, the bond between parent and child and a parental desire to use natural foods.

All of the articles identified within Chapter 3 made reference to a potential role for blended diet in the management of adverse symptoms associated with tube-feeding such as reflux, vomiting and diarrhoea. However, the parents in this research described the transition to blended diet as a positive transformation in their child and a subsequent improvement in the whole family's quality of life. Adverse symptoms did not simply reduce in frequency and severity; for the majority of parents in this research, adverse symptoms resolved completely and in hindsight the parents also felt their child was far healthier and happier in general in comparison to how they had been on commercial formula. It is possible an improvement in general health and wellbeing was captured within this research as the parents in this research were reflecting back upon their experiences of blended diet over several years whereas previous work has only looked at blended diet in the short term. Additionally, the improvements described by parents were subjective and could have been missed using simplistic survey methods. This research demonstrates that adverse symptoms associated with tube-feeding are likely to be powerful motivation for parents to try and persist with blended diet.

A theme of risk was evident in all of the nine articles identified in Chapter 3 and seemed to be a major concern for health professionals. This research demonstrated that parent view the risk differently to health professionals. Parents considered risks such as feeding tube-blockage, nutritional inadequacy and gastrointestinal infection against the wider risks posed to their child such as those associated with anti-reflux surgery or aspiration. By comparison the risks of blended diet suggested to parents by professionals seemed relatively low and manageable. Additionally, parents in this research believed these risks to be anticipatory rather threat to their child and reasoned that blended diet is just food. A continued focus upon risk by professionals is frustrating to parents as this limits the support they receive, limits access to services such as respite and overshadows the experience of choosing blended diet.

Opinion on the effect of blended diet on weight has conflicted within the existing literature on the topic (Chapter 3). This research suggests that use of blended diet can lead to either weight gain or weight loss depending on the energy

density and volume of the food ingredients used in the blend. Given that blended diet opens a plethora of smaller food choices for parents there is likely to be more variation between individual's blends where commercial formula is uniform and consistent. Instead of being a limitation of blended diet the variety it permits is viewed positively by parents. With extensive training on food and nutrition in health and illness, dietitians would be best suited to advise parents on a healthy balanced diet tailored to their child's individual health needs such as allergies to achieve a healthy growth trajectory.

Seven of the articles identified in Chapter 3 suggested that use of blended diet may play a role in weaning from long-term tube feeding onto an oral dietary intake. Interestingly, improved oral intake was not identified within this research. However, some parents described their child showing an increased interest in food preparation. It is possible that the sampling strategy employed within this research excluded parents whose child had been weaned onto oral diet within one year of transition to blended diet.

Previous articles on blended diet in home enteral feeding have considered the additional time required to prepare blended diet in comparison to commercial formula as being negative. This research identified that parents consider the time and work in contrast to preparing food for a child who eats orally rather than the time taken to administer commercial formula. Whilst parents in this research sometimes considered preparation of blended diet to be a chore this was within the context of other pressures on time, this pressure fluctuated depending on other factors in the parent's lives. Many of the parents within this research said they enjoyed preparing food for their tube-fed child when they felt they had more time or with increased experience.

This research demonstrated that preparation of blended food for a tube-fed child can feel less medical to parents in comparison to administration of commercial formula. This could explain why previous articles have highlighted a high level of satisfaction with blended diet and professional opinion has indicated an increased bond between parent and child. The social and emotional impact of long-term home enteral feeding has to date been under

researched, this doctoral research demonstrates the impact long term home enteral feeding can have on children and young people and their wider family. However, for the parents in this research de-medicalisation of feeding was a positive they noted on reflection rather than the incentive for initially commencing blended diet.

Six of the articles identified in Chapter 3 of this thesis pointed to parental desire to use 'natural foods'. Authors made comparisons to a trend in the general population toward 'whole' and organic foods. Parents in this research valued being able to give their child something that they recognised as food rather than medicine, something they would be willing to eat themselves. Interestingly however, parents felt that professionals had misjudged their motivation and viewed them as 'mad hippies' when use of 'real' food was a positive they noted on reflection rather than their motivation to start blended diet.

In summary, this research has highlighted a rich diversity of opinion and perception amongst parents within common themes. There are similarities to some of the themes identified within the quasi-systematic review (Chapter 3). However, it is evident that previous research in contrast to this work has tended to over simplify the complexities of the topic due to the mainly quantitative survey methods research chosen. The rigorous qualitative methodology chosen within this doctoral research is considered to be one of the key strengths of this work.

## **6.6 Strengths and Limitations of this Research**

This section critically evaluates this thesis study examining both the strengths (Sub-section 6.5.1) and limitations (Sub-section 6.5.2)

### **6.6.1 Strengths**

This research provides a valuable understanding about parents' experiences of blended diet. This knowledge which has been, to date, missing from the research literature on the topic (Armstrong 2017; BDA 2015; BDA 2015; Coad et al. 2017).



The feminist lens used to inform this doctoral research is considered to be a major strength. The research can be considered emancipatory as it has challenged dominant professional opinion on the topic by giving parent's voice about their own personal experiences of blended diet. Furthermore, the feminist lens has provided an overarching approach to the research design and conduct which has been respectful to participants and their commitments as parents caring for children and young people with complex health needs.

There were concerns over whether it was feasible to recruit sufficient participants given the contentions surrounding blended diet and the time demand on parents caring for children with complex health needs. The response to the research advertisement on the Blended Diet UK exceeded expectations. This indicates the community of parents using blended diet are highly interested in engaging in research on the topic.

Blended diet use in the UK has been under researched for this reason an exploratory approach was needed, one which allowed participants the time and space to describe the experience and the impact it had on their child and family. Although every parent using blended diet will have slightly different views and ways of using blended diet. It is envisaged the findings of this research will illuminate the experience of for others. The findings can be used to both inform clinical practice (Sub-section 7.1.1) and future research (Sub-section 7.1.2). On this point recently, the National Institute for Health Research (NIHR) released a Health Technology Assessment call for bids to investigate the risks, benefits and resource implications of blended diet use compared to commercial formula, this research can be used to inform that work.

A major strength of the current research was the rigorous methodology used. The in-depth qualitative interview method enabled the gathering of rich detailed accounts from participants which provided the type of data needed to meet the aim and objectives of this research (Section 1.5). The ethics and quality of data collection were carefully considered throughout the research process (Sections 4.6 and 4.7).

IPA permitted exploration of both individual and across case experiences meaning participants subjectivity was respected while also allowing cross case analysis. The methodology also allowed participants to explore their own understanding of their experiences within the interview. It could be argued that there was a relatively large sample size for an IPA approach. This could be considered both a strength and a limitation (Sub-section 6.7.2). The relatively large sample size for IPA is a strength because of the array experiences included. Participants who took part in this research lived in and received care from a wide spread of geographical locations. Furthermore, in many instances the parents thought or felt differently about their experiences. The fact that diversity existed within the sample is considered to be a strength as it reflects the subjectivity expected in IPA and a subjectivist world view.

The inclusion of one father in the research is considered to be a strength. Previous qualitative studies looking at the care of children and young people with HETF have focused solely on the experience of mothers which could perpetuate a gender stereotype that mothers are responsible for the care of children with complex health needs.

The researcher's position as a dietitian working in HETF did not seem to overtly limit how freely participants spoke about their experiences with other healthcare professions. The impact the researcher had on the research has been examined in depth in Section 4.8. This thesis study involved the research stepping outside of the dietetic role and into the role of the researcher trying to understand the parents' perspective in relation to blended diet.

### **6.6.2 Limitations**

This research was qualitative and exploratory. It could be argued that the experiences of a relatively small number of participants found through purposeful sampling is not generalisable to the entire HETF population. However, as discussed in depth in Section 4.7 criteria long used to assess the quality of quantitative research such as validity, reliability and generalisability are not easily applicable to qualitative research (Savin-Baden and Major 2013).

This research aimed to seek out and understand the lived experience of a specific group. However, the findings are likely to have resonance with other parents considering blended diet for their own child and professionals working in clinical practice with individuals who are in receipt of HETF.

As noted, the research included a relatively large sample size for IPA. This has limited the depth of analysis that was possible in the timeframe available. However, the aim and objectives of this research were to provide insight for clinical practice and understanding which can inform clinical practice. This aim and objective are considered to be met. The sample of participants in this research could be viewed as biased toward blended diet considering they all believed they successfully used it to feed their own child. However, this was important in attempting to understand why blended diet has become an emotive topic and why increasing number of parents in the UK are expressing an interest in trying it (BDA 2013; Kellie 2015). Further research is needed to establish the safety and efficacy of blended diet as used by parents in the UK. Additionally, it would be interesting to seek out parents who have tried blended diet and decided it is not a suitable choice for their child.

This research did not purposefully look for variation in professional background, level of education, cultural background and economic status among participants. The homogeneity of the participants was their experience of using blended diet. Interestingly, several participants did make reference to their professional background, level of education, cultural background and ability to afford equipment and food ingredients. These factors may affect parents' interest and ability to use blended diet and should be taken into account in future research on the topic.

The sampling strategy used (Sub-section 4.3.2) meant that participants were likely to know each other either through social media or even in person. This means they may have influenced each other's thinking and understanding on the topic. Furthermore, several participants alluded to reading texts such as Complete Tube Feeding (O'Gorman 2012) and Homemade Blended Formula Handbook (Dunn Klein and Evans Morris 2007). These texts have been

critiqued in Chapter 2 of this thesis. It is likely these texts will have influenced participants thinking on the topic of blended diet. However, this is an interesting finding in itself as these books are influencing the UK blended diet community, UK professionals can use them to understand parents who have chosen blended diet.

There were a disproportionate number of mothers (n=14) in comparison to fathers (n=1) in this research. Interestingly, on several occasions the father of the child was present in the home providing care for the child/children while the interview took place. Future research into blended diet should aim for greater representation of fathers as their experience is no less valuable than mothers.

This research focused on participants with parental responsibility for a tube-fed child. This was important given the contentious nature of blended diet as parents had chosen on behalf of their child to take a risk. This meant that foster carers for example where parental responsibility remains with the local authority were excluded from taking part. This does not make their experience any less valid and attempts should be made to include such parents and carers in future research on blended diet.

IPA is reliant on participants ability to communicate successfully the rich texture of their experience. The participants in this research provided in-depth accounts of their experience. However, this may mean that people who feel less confident talking at length about their experience were excluded from the research (Willig 2001). Furthermore, because of the researcher's experience working with this group of children and young people and the known prevalence of impaired cognitive function and communication difficulties among this group, a decision was made to ask the parent about the experience rather than the child or young person. It became clear that some of the children and young people that were being discussed in the interviews, such as Diane's daughter, could have expressed their own opinion on blended diet. Future research should attempt to include children and young people in research about themselves. Arts based methods and communication aids may be useful.

A decision was made to limit the research to parents who had been using blended diet for at least one year. Participants in this research had been using blended diet to feed their child for at least one year. While this meant participants had a wealth of experience to draw from, it also had implications for the questions relating to first experiences of blended diet (Appendix 3).

Participants were reliant on memories from up to nine years ago. However, only one parent, Jane, said they had difficulty remembering the experience. Others like Imogen said they remembered it 'clearly' potentially due to the life changing impact parents believed transition to blended diet had on their child and family's lives.

The length of time parents had been using blended diet also meant that their experience pre-dated key documents on blended diet such as the BDA position statement (2013), risk assessment tool (2014) and Practice Toolkit (2015).

However, this also gave interesting insight into how participant perceived professional attitudes to have changed over time. Future research should focus on parents making the decision to use blended diet in the present.

This research focused on the experiences of parents because they have been unrepresented in the debate on blended diet to date despite being the experiential experts (Chapters 2 and 3). Parents accounts included experience of conflict. It is important to note that this research only has access to one side of the story and the professionals referenced in these accounts did not have the opportunity to present their side of the story. Future research into conflict within healthcare should strive to assess both sides.

The researcher was a novice in qualitative research and IPA methodology. However, steps were taken to improve knowledge and skills such as masters level training, extensive reading and tutorials with supervisors. The use of a reflexive diary also helped refine the interview technique and encouraged development as a researcher. The reflexive diary was also used to address the subjectivity of the researcher within the research with the view of being transparent (Section 4.8).

Finally, one potential benefit of blended diet identified in the literature review with systematic approach (Chapter 3) the improvement of oral intake, was not found in this research. It is possible that the exclusion of parents who had been using blended diet for less than one year contributed to this. Interestingly Olivia, a participant in this research, in her interview made reference to other children and young people who had started eating orally within a few months of transition to blended diet and were subsequently orally fed. Such parents would have been excluded from this research because they were no longer using blended diet. Future research should aim to capture the experience of parent who have been able to wean their child from tube feeding using blended diet. Observational research which follows families through from their decision to try blended diet could address this.

## **Chapter 7: Conclusion**

### **7.1 Introduction**

This chapter concludes the thesis by summarising the key implications for clinical practice (Section 7.2) and further research (Section 7.3). The thesis ends with a final conclusion.

### **7.2 Implications for Clinical Practice**

#### **7.2.1 General Home Enteral Tube-Feeding**

- Consideration should be given to how home enteral tube-feeding (HETF) plans are devised. Use of bolus feeding at usual mealtimes may feel less medical to families. Allowing parents flexibly to alter the timing of tube-feeding would permit more freedom to leave the home or do activities.
- Thought should be given to the language used when discussing tube-feeding with parents and when writing plans for home use. Terminology such as feeding 'regimen', 'dose' and 'feed', 'may increase feelings that nourishing the child has become medicalised or that the child or young person is regressing because they are back on 'formula' or 'milk'.
- HETF services within the NHS have been developed on the premise that tube-fed individuals are fed commercial formula. In most UK regions commercial formula companies provide home delivery to patients as part of their contract with the NHS. These deliveries comprise not only the commercial formula but also the ancillaries required to feed such as enteral syringes, replacement gastrostomy devices or extension sets and loan of automated feeding pumps. In some regions commercial formula companies also fund nutrition nurses and dietitians working within the NHS HETF service. Subsequently, the increasing popularity of blended diet is likely to have economic implications for both the logistics of enteral feeding and staffing of HETF services within the NHS.

### 7.2.2 The Decision to try Blended Diet

- Parents of tube-fed children and young people are increasingly likely to encounter blended diet through their acquaintances or online. Parents of tube-fed children and young people may also intuitively decide to give blended foods through their child's feeding tube. Additionally, some parents may make a decision to try blended diet without discussing it first with a healthcare professional; because of this blended diet should be discussed with parents when the feeding tube is placed, or before. This is of particular importance when use of blended diet would be considered to be higher risk. For example, when the child is younger than six-month-old, jejunal fed or immunocompromised (BDA 2013). Parents should be given explicit justification as to why it would not be a suitable option for their child.
- Parents initial interest in blended diet may stem from a deep sense of desperation with their current situation. Professionals should listen to parents concerns and respond with understanding and compassion. Ideally a multi-disciplinary approach should be taken. Any shared decision about a trial of blended diet should take a holistic child and family-centred approach considering the wider context in which the decision is being made. For example, is the child experiencing recurrent aspiration pneumonia or are the family considering anti-reflux surgery. Adverse symptoms may impact on every aspect of the child and family's lives. It is possible that blended diet is more effective in reducing adverse symptoms such as reflux, retching, and vomiting than existing strategies such as altered positioning and continuous feeding which are also based on weak evidence. It may be possible to ascertain if blended diet would be remedy symptoms in an individual using a short trial period. This is likely to be safer than the family attempting blended diet unsupported.
- Consideration should be given to offering parents of exclusively tube-fed children and young people the choice to include small amount of blended diet even in instances where commercial formula is well tolerated.



Blended diet can help alleviate feelings of isolation and exclusion which are experienced by children and young people who are exclusively tube-fed. This is likely to be of particular use on social occasions which centre on food. Additionally, blended diet permits the personalisation of dietary intake and a vast array of choice in comparison to commercial formula. This may also be applicable to tube-fed adults.

- Offering blended diet as a choice to parents may additionally be beneficial in instances where parents and professionals disagree over whether a gastrostomy tube should be placed or not. Parents may see this as a compromise as they are still able to give their child food even though it is given through an alternate route. This could mean life sustaining treatment is not delayed.

### **7.2.3 Supporting Parents who have Chosen Blended Diet**

- Good communication with other healthcare professionals is needed to avoid parents receiving conflicting advice and mixed messages.
- Continued focus on perceived 'risks' is not helpful to parents.
- Current best practice guidance for the monitoring of HETF individuals have assumed the long-term use of commercial formula. This research suggests that individuals who use blended diet either in place of or alongside commercial formula are likely to have different support and monitoring needs in comparison to parents using only commercial formula.
- Parents are likely to need more support when they first start blended diet and less support as they gain experience and confidence. Age appropriate starter recipes, hints and tips may be useful and could be collected by dietitians from parents with more experience of blended diet.
- Peer-support, for example from groups on social media, such as Blended Diet UK, may be highly valuable for parents starting their child on

blended diet. However, parents should be supported in deciphering potentially conflicting or confusing advice about food by their child's dietitian.

- A third of participants in this research noted that they continued to use commercial formula alongside blended diet. In this instance the percentage of blended diet could be calculated in the same way as it would be if the child were taking some of their diet orally.
- Parents may need different types of support depending on the approach they are taking to blended diet. For example, a parent who blends family meals will require advice on providing age appropriate portions and a balance of the different food groups. On the other hand, a parent who is restricted to a hand full of recipes due to their child's allergies would benefit from dietary analysis of each individual recipe by a dietitian to ensure no micronutrients are missed.
- Consideration should be given to the use of batch blending or use of home dehydrators. For example, if a parent is preparing blends for a week do they include food ingredients which would be representative of a balanced diet over a seven-day period.
- Parents are likely to require advice from dietitians on adapting the energy density of food ingredients used in blends to either promote or slow weight gain.
- Parents are likely to require advice from dietitians on adapting the fibre and fluid content of food ingredients used in blends depending on the child's bowel habit.
- Condition specific dietary treatment should be given by a dietitian as though the child was eating the food ingredients used in the blends orally. An example drawn from this research would be foods that contained MCT rather than LCT fats for a young person with a metabolic condition.

- The findings of this research and survey studies in the UK suggest that some UK dietitians are supporting families to use blended diet. No child should be discharged from dietetic care because of their parent's decision to use blended diet.
- Multi-agency working is needed to facilitate the use of blended diet in schools and hospice facilities to avoid children and young people being excluded from education or vital respite care.
- Local hospital guidelines for the use of blended diet are required in hospitals to avoid inconsistencies between wards in the same hospital.

### **7.3 Implications for Further Research**

- Research is needed to examine whether or not the perceived risks associated with blended diet are occurring in reality or are mythical in nature.
- Future research should attempt to seek the views of the child or young person themselves. This may be possible through purposive sampling and use of communication aids.
- Future research into the safety and efficacy of blended diet should also consider the implications of batch preparing blends and using home dehydrators.
- Research is vital to establish whether or not blended diet is an effective way of improving symptoms associated with tube-feeding.
- Greater understanding of the physiological effects of blended diet in comparison to liquid commercial formula is needed. In particular the effects of the increased viscosity on stomach emptying and hunger.
- Longitudinal research is needed which looks at the effects of exclusive feeding using commercial formula. In particular the effect of omitting

phytonutrients usually present in a balanced diet and the effect on the gut microbiome.

- Future research into blended diet should include outcomes which are indicative of the child's generally health and wellbeing including their attendance and performance at school and number of hospital admission.
- Efforts should be made in future research to capture subjective outcomes such as parent's perception of the child's appearance and happiness.
- Any future health economic analysis should consider the cost of any reduction in medication and avoidance of anti-reflux surgery. Additionally, cost comparisons should be made to the cost of feeding a child orally in comparison to commercial formula as well as the potential benefit of the transference of cost from the NHS to parents.

#### 7.4 Final Conclusion

The primary aim of this research was to gain an in depth understanding of individual parents' experiences of choosing blended diet to feed their child so that it may illuminate the experience for others. In relation to this broad aim, more specific objectives were explored; the reasons parents look for an alternative to commercial formula, the benefits attributed to blended diet by parents, the experience of support from healthcare professionals from the parent's perspective, identification of challenges faced. Five superordinate themes emerged through the use of Interpretive Phenomenological Analysis; 'Nothing to Lose': Feeling Desperate; 'A Radical Change': Improvements in Health and Wellbeing; 'How Life Should be': A Sense of Normality; 'You Have to Muddle your way Through': Practical Challenges and 'I Have to Fight for her to be fed Food': Defending the Choice.

The findings of this research were found to both conflict with and support those of previous work, as well as identifying many original ideas previously not included in other research, such as the life changing improvements experienced by the parents in this research. The area of blended diet is significantly under researched, especially to date, in the representation of the experiences from the perspective of a parent. It is the opinion of the researcher that this lack of research is a significant contributing factor to the absence of clear guidelines and material available for healthcare professionals to help support families who choose to use blended diet, and to the predominantly negative experiences of the interactions described between parents and healthcare professionals surrounding its use. It is envisaged that this research will go some way to remedy this, but it is abundantly clear that further research is needed in this area. Whilst important and novel, this is just the beginning of the journey.

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**Glossary***Antegrade Colonic Enema*

For treatment of severe constipation.

Antegrade Colonic Enema (ACE) involves an operation under general anaesthetic which creates a fistula (opening) into the large bowel at a point called the caecum. This allows direct entry into the large bowel for fluid which flushes faeces out through the rectum (bowel washout).

*Amino Acid Formula*

Also known as elemental formula. These are made from amino acids, the building blocks of protein. The body does not have to break down large proteins into amino acids and therefore amino acid formula are thought to be easier to digest.

*Commercial Formula*

The term has been used throughout this thesis to describe commercially prepared enteral formula. Most commercial formula are pre-packaged in sterile, ready to hang containers which can be spiked or screwed onto enteral tubing to create a closed system which minimises microbial access and allows the formula to hang at an ambient temperature for 24-48 hours. Commercial formulas have a uniform consistency which permits them to flow easily through fine bore enteral tubing and automated feeding pumps, minimising the risk of tube occlusion. A wide

range of commercial formulas are available with differing energy, protein micronutrient and fibre contents designed to suit the varying needs of different age groups and clinical conditions. Commercial formulas are provided free of charge to children and young people in the UK through the National Health Service (NHS).

*Enteral Tube-feeding*

The delivery of nutrition and hydration via tube into the gastrointestinal tract. It is used when a person has a functioning gastrointestinal tract, but oral feeding is either unsafe, obstructed or limited.

*Fundoplication*

Surgical treatment of gastro-oesophageal reflux. The top of the stomach is used to strengthen the sphincter making it less likely for stomach contents to reflux up into the oesophagus.

*Gastrostomy*

In the longer term most children and young people who require enteral tube-feeding have a gastrostomy, a fistula straight through the anterior wall of the stomach placed either using the percutaneous endoscopic (PEG) or radiologically inserted gastrostomy (RIG) methods although occasionally by open surgery.

*Gastrostomy Button*

Low-profile device held in place with a water filled balloon (~5ml) the water can be withdrawn meaning the device can be easily changed.

<i>Gastrostomy Tube</i>	a flexible polyurethane tube held in place by a disk inside the stomach usually placed first and then changed after a year to 18ths to a gastrostomy button.
<i>Jejunostomy</i>	A fistula (opening) straight into the jejunum, used when the stomach is damaged or non-functioning
<i>Nasogastric Tube</i>	A fine bore tube into the stomach via the nostril is recommended only for use in the shorter term (<4weeks).
<i>Naso-jejunal Tube</i>	A longer fine bore tube into the jejunum via the nostril recommended only for use in the shorter term (<4weeks).
<i>Neurodisability</i>	A medical term used to describe any condition which affects the central nervous system leading to functional limitations in movement, cognition, hearing, vision, communication, emotion, and behaviour; often in combination. Neurodisability includes conditions such as cerebral palsy, Downs syndrome, neuromuscular and progressive neurological disorders as well as rare genetic conditions

## Appendices

## Appendix 1: Search Criteria using PICO for Medline

	<b>P</b>	<b>I</b>	<b>Co</b>
<b>MeSH</b>	Nutrition Therapy <b>OR</b> Intubation, gastrointestinal <b>OR</b> Enteral Nutrition <b>OR</b> Feeding tube, gastric <b>OR</b> Enteral feeding		Dieteics <b>OR</b> Hospice <b>OR</b> Food service, hospital
<b>Keyword</b>	"Enteral Feed*" <b>OR</b> Gastrostom* <b>OR</b> 'Jejunostom*' <b>OR</b> PEG <b>OR</b> "G-Tube" <b>OR</b> "Enterally Fed" <b>OR</b> Nasogastric <b>OR</b> Nasojejunal <b>OR</b>	Blend* <b>OR</b> Liquid* <b>OR</b> Pureed <b>OR</b> "Home made" <b>OR</b> "Home brew" <b>OR</b> "Home cooked" <b>OR</b> "Home prepared" <b>OR</b> "Real Food" <b>OR</b>	"Home Enteral Feeding" <b>OR</b> "Home Enteral Nutrition" <b>OR</b> Community <b>OR</b> "Own Home" <b>OR</b> Hospital <b>OR</b> Hospitals <b>OR</b> "Long Term" <b>OR</b>

	PEJ OR RIG OR "Enteral Nutrition" OR "tube feeding*" OR "Enteral Diet*" OR "Enteral Tube"	"hospital prepared" OR "Whole food"	Respite OR School OR Clinic OR "feeding team*" OR Hospice* OR "home care" OR Dieti*ian*
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(((((((((((((((((((nutrition therapy[MeSH Terms]) OR intubations, gastrointestinal[MeSH Terms]) OR enteral nutrition[MeSH Terms]) OR enteral feeding[MeSH Terms]) OR feeding tube, gastric[MeSH Terms]) OR "enteral feed") OR gastrostom\*) OR jejunostom\*) OR PEG) OR PEJ) OR RIG) OR "PEG-J") OR "enteral nutrition") OR "enteral diet\*") OR "G-tube") OR "tube feeding\*") OR "enterally fed") OR "enteral tube" OR nasogastric) OR nasojejunal)) AND (((((((((((blend\*) OR liquid\*) OR pureed) OR "home made") OR "home brew") OR "home cooked") OR "home prepared") OR "real food") OR "whole food") OR "hospital prepared")))) AND (((((((((((((((dietetics[MeSH Terms]) OR hospice[MeSH Terms]) OR food service, hospital[MeSH Terms]) OR "home enteral feeding") OR "home enteral nutrition") OR community) OR "own home") OR hospital OR hospitals) OR "long term") OR respite) OR school) OR clinic) OR "feeding team") OR hospice) OR "home care") OR dietitian\* OR dietician\*))

**Appendix 2: Search Criteria using PICO for CINAL and PsychINFO**

	<b>P</b>	<b>I</b>	<b>Co</b>
<b>Subject Headings</b>	Enteral Nutrition <b>OR</b> Gastrostomy <b>OR</b> Intubation Gastrointestinal		<b>Dietetic*</b> <b>OR</b> <b>Hospice*</b> <b>OR</b> <b>Food service</b> <b>OR</b> <b>Hospital</b>
<b>Keyword</b>	“Enteral Feed*” <b>OR</b> Gastrostom* <b>OR</b> ‘Jejunostom*’ <b>OR</b> PEG <b>OR</b> “G-Tube” <b>OR</b> “Enterally Fed” <b>OR</b> Nasogastric <b>OR</b> Nasojejunal <b>OR</b> PEJ <b>OR</b> RIG <b>OR</b>	Blend* <b>OR</b> Liquid* <b>OR</b> Pureed <b>OR</b> “Home made” <b>OR</b> “Home brew” <b>OR</b> “Home cooked” <b>OR</b> “Home prepared” <b>OR</b> “Real Food” <b>OR</b> “hospital prepared” <b>OR</b>	“Home Enteral Feeding” <b>OR</b> “Home Enteral Nutrition” <b>OR</b> Community <b>OR</b> “Own Home” <b>OR</b> Hospital <b>OR</b> Hospitals <b>OR</b> “Long Term” <b>OR</b> Respite <b>OR</b> School <b>OR</b>



	"Enteral Nutrition" <b>OR</b> "tube feeding*"	"Whole food"	Clinic <b>OR</b> "feeding team*"
	<b>OR</b> "Enteral Diet*"		<b>OR</b> Hospice*
	<b>OR</b> "Enteral Tube"		<b>OR</b> "home care" <b>OR</b> Dieti*ian*

**SU enteral nutrition OR SU gastrostomy OR SU feeding tube OR SU intubation, gastrointestinal OR ( "enteral feed") OR gastrostom\*) OR jejunostom\*) OR PEG) OR PEJ) OR RIG) OR "PEG-J") OR "enteral nutrition") OR "enteral diet\*") OR "G-tube") OR "tube feeding\*") OR "enterally fed") OR "enteral tube" OR nasogastric) OR nasojejunal)) ) AND blend\* OR liquid\*) OR pureed) OR "home made") OR "home brew") OR "home cooked") OR "home prepared") OR "real food") OR "whole food") OR "hospital prepared") AND SU dietetics OR SU hospice OR SU food service OR SU hospital OR ( OR "home enteral feeding") OR "home enteral nutrition") OR community) OR "own home") OR hospital OR hospitals) OR "long term") OR respite) OR school) OR clinic) OR "feeding team") OR hospice) OR "home care") OR dietitian\* OR dietician\***

## Appendix 3: Interview Schedule

Blended Diet Project



### Interview Schedule

The interview schedule is designed to obtain rich deep data from the participants. The interview will take the format of a conversation where the participant is able to share their experience of using blended diet. Questions will be open ended to encourage narrative. The questions below will act as prompts to ensure that the conversation stays on topic and answers the research aims and objectives.

#### **Before the interview date**

The researcher will talk to the participant over the phone to answer any questions they may have about the research and arrange a suitable date, time and location for the interview to take place. This is also an opportunity to develop rapport with the participant.

#### **On arrival at the interview**

After establishing rapport the researcher will outline what will happen during the interview and answer any questions the participant may have. The participant will be reminded that the interview can be stopped at any point. The participant will be reminded of the purpose of the audio recorder. Permission to use the audio recorder will be sought from the participant. The researcher will ensure the written consent is signed before starting the interview. Minimal demographic data will be collected this will include the participant's age as well as the age of their child.

#### **After starting the audio recorder**

The researcher will re-cap on the purpose of the interview and confirm that consent has been obtained.

03/08/2016

Sarah Durnan

(Version 3)

Blended Diet Project



The following questions will be used as a guide in the interview:

*How was your child fed before you started blended diet?*

*How did you discover blended diet?*

*Could you tell me about how you decided to try blended diet?*

*Could you describe your first experience of using blended diet?*

*For you what are the best things about feeding your child a blended diet?*

*For you what are the most challenging aspects of feeding your child using blended diet?*

*Did you have any support from other family members or healthcare professionals when deciding to use blended diet?*

*Can you describe how blended diet affects the relationship between you and your child?*

Prompts and probes will be used to encourage the participant to expand on their experience for example:

*'That's really interesting could you tell me more about that?'*

The researcher will use active listening skills to encourage the participant to explain and describe their experience. For example the use of minimal encouragers such as nodding the head or reflection and repetition of the participant's last phrase.

Blended Diet Project



The schedule is flexible, allowing the researcher to ask additional open-ended questions and clarify the participant's responses.

**A final question will be asked:**

*'Is there anything else you would like to tell me about your experience of using blended diet?'*

The participant will be thanked for their participation and the audio recorder turned off

**Before leaving:**

The researcher will remind the participant what happens next as per the information sheet. The participant will have the opportunity to ask questions. The researcher will leave their contact details with the participant in case they think of questions after the researcher leaves.

## Appendix 4: Certificate of Ethical Approval



### Certificate of Ethical Approval

Applicant:

Sarah Durnan

Project Title:

Exploring the views and personal experiences of individuals in the UK who have chosen to feed their child with long term enteral feeding needs a home blended diet.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

08 August 2016

Project Reference Number:

P41654

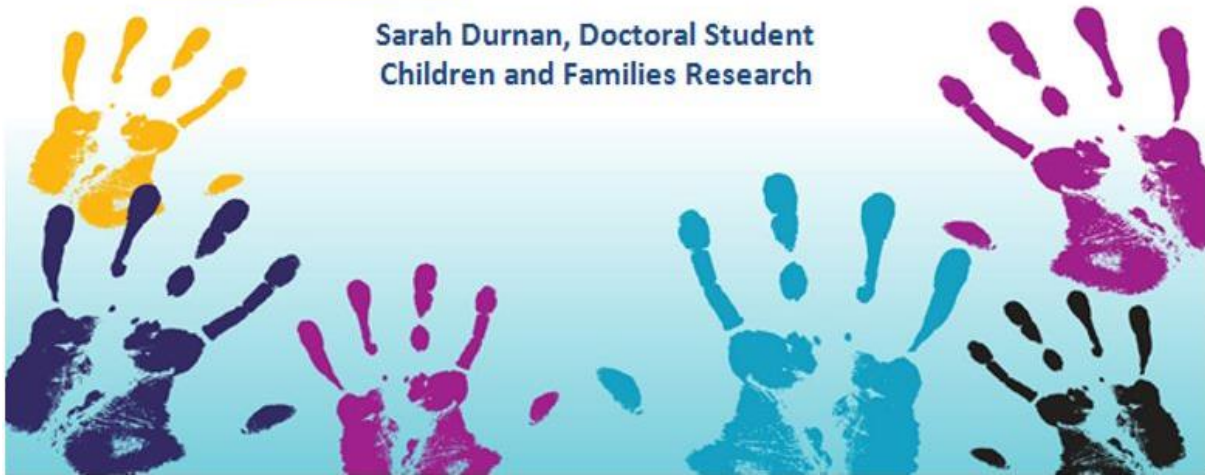
## Appendix 5: Advertisement Placed on the Blended Diet UK Facebook Page



### Blended Diet Research in the UK

Have you been using blended diet to feed your child at home for a year or more? Would you be willing to speak about your experience and give your views? If you are interested in participating in this research project please email [durnans@uni.coventry.ac.uk](mailto:durnans@uni.coventry.ac.uk) to ask questions or request an information pack.

**Sarah Durnan, Doctoral Student  
Children and Families Research**



## Appendix 6: Participant Information Sheet



### Participant Information Sheet Blended Diet Research Project

#### **Introduction**

As you probably already know interest in blended diet in the UK is growing but its use in the UK has been under researched. The existence of the Blended Diet UK Facebook group indicates that many families in the UK are already using blended diet either in place of or alongside commercial enteral formula to feed their child. This research project aims to start scientific research into blended diet in the UK by exploring the personal experiences of individuals who have chosen to feed their child a blended diet and have already been doing so for at least one year.]

#### **Who am I and what is my background?**

My name is Sarah Durnan; I am an experienced children's home enteral feeding dietitian with an interest in the use of blended diet as a method of enteral feeding for children and young people with long term enteral feeding needs. In 2014 I travelled to America for three months to find out more about the use of blended diet in the USA. I am now carrying out a PhD research project with the Children and Families Research (CFR) team at Coventry University. As part of my research I would like to interview individuals who have chosen to feed their child with long term enteral feeding needs a home blended diet. Other members of the research team are Professor Jane Coad, Dr Alex Toft and Dr Helen Flaherty. I will be collecting data in the UK starting in summer 2016.

#### **Some Frequently Asked Questions**

##### **Do I have to take part?**

Taking part in this study is completely voluntary. You do not need to give any reason if you decide not to take part after reading this information sheet. If you do agree to participate and then change your mind later you can withdraw from the study at any point up until the final report is written.

##### **What if I have more questions?**

If you have questions about the study which are not answered on this information sheet or would like to discuss the study over the telephone then please contact me using the details below, I will be happy to answer your questions and discuss the research with you.

##### **Where will I be interviewed?**

I can come to your home at a time and date chosen to suit you. Alternatively, if you prefer, I can arrange to see you at another place of your choosing. If you do not like the idea of a face-to-face interview then I can either interview you over the telephone or using Skype.

07/07/2016

**How long will it take?**

You will be invited to take part in an interview where we will explore your views and experience of using home blended diet to feed your child. The interview will take approximately 60-90 minutes of your time. I appreciate that caring for a child or young person with complex health needs is demanding. I understand that the needs of your family come first and I will be very flexible in arranging the interview to fit in with you and family's needs.

**What will happen at the interview?**

Before the interview begins I will explain the research process to make sure you understand everything about the study. I will then ask you to sign a consent form. The interview will take the form of an informal conversation. I will be interested to hear about your own experience of using blended diet and what you think the benefits and difficulties are. The interview will be audio recorded so that I do not need to take notes and can instead focus on listening to you.

**What will happen after the interview?**

After the interview I will listen to the audio recording and type it up into a written record. I will then analyse the written record. To keep your identity anonymous, I will choose a false name to use. The findings will form part of my PhD thesis and will also be shared through academic papers and conference presentations. The audio recording and typed up written records will be destroyed once the final report is written. You will be sent a copy of the final written report.

**Will other people be able to read or hear what I said at the interview?**

All personal information will be stored securely and treated as confidential. Only Professor Jane Coad, Dr Alex Toft, Dr Helen Flaherty and I will see or listen to the data. Quotations will be used in the final report, but care will be taken to ensure that they are anonymised by using false names.

**What if I have other questions?**

Please do not hesitate to contact me using the details below, I will be happy to discuss this research project further with you.

**If I am happy to take part what do I do now?**

Email me at [durnans@uni.coventry.ac.uk](mailto:durnans@uni.coventry.ac.uk) and say you are happy to be part of the research. If you meet the inclusion criteria we can either arrange a time, date and location convenient to you for an interview.

**What are the possible disadvantages and risks of taking part?**

This is a low risk study of individual's own personal experiences. It is not likely that taking part in this study will have significant disadvantages or risks. Your child's dietitian will not be made aware of your participation in this study and your name will be anonymised in the final report.

07/07/2016



**Will you be able to offer clinical advice about blended diet?**

Unfortunately I will not be able to offer any clinical advice before, during or after the interview. My role in this study is to listen and learn from your personal experiences of using blended diet to feed your child. If a significant problem or health need is brought to my attention during the study I may seek your consent to refer you to an appropriate professional or service.

**How do I make a complaint?**

If you have any questions or queries I will be happy to discuss them with you personally however should you wish to complain formally about any part of the study please contact Professor Ian Marshall, Deputy Vice-Chancellor, Coventry University, Priory Street, CV1 5FB [i.marshall@coventry.ac.uk](mailto:i.marshall@coventry.ac.uk) the complaint would then be followed up via the Coventry University complaints procedure.

**Details of Chief Investigator for this Study**

Sarah Durnan RD, BSc (Hons), PG Cert Advanced Dietetic Practice, Doctoral Research Student, Children and Families Research Team (CFR), Centre for Technology Enabled Health Research (CTEHR), Faculty of Health and Life Sciences (HLS), Coventry University, 4<sup>th</sup> Floor, Richard Crossman Building, Priory Street, Coventry, CV1 5FB.  
Mobile: 07752807540  
Email: [dumans@uni.coventry.ac.uk](mailto:dumans@uni.coventry.ac.uk)

### Appendix 7: Consent Form

Blended Diet Project



#### Informed Consent Form

Please initial

1. I confirm that I have read and understood the participant information sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason.

3. I understand that all the information I provide will be treated in confidence

4. I understand that I also have the right to change my mind about participating in the study for a short period after the interview has concluded (14 days).

5. I agree to be audio recorded as part of the research project

6. I understand that anonymised quotes from the interview may be used in the researcher's PhD thesis or in academic papers reporting on the research.

7. I agree to take part in the research project

Name of participant: .....

Signature of participant: .....

Date: .....

Name of Researcher:.....

Signature of researcher: .....

Date: .....

**Appendix 8: Example Emails to Potential Participants**

Hello [Name],

Thank you very much for your email expressing an interest in helping with my research. I'm looking for parents who have been using blended diet for a year or more to feed their child. I would be very interested to meet with you and learn about your experience!

I have attached an information sheet which will give you an introduction to the research. It also explains my own background and interest in blended diet and attempts to answer some questions about how I will be collecting information.

Please let me know if you have any further questions or would like to arrange an interview date. I'm planning interviews throughout August to December.

Best Wishes

**Sarah Durnan**  
**Doctoral Research Student**  
**Children and Families Research**  
**Centre for Technology Enabled Health Research**  
Faculty of Health & Life Sciences  
Richard Crossman Building (4th Floor)  
Coventry University  
Priory Street  
Coventry  
CV1 5FB

Hello [Name],

Sorry to bother you, I was just wondering if you have had a chance to look at the information sheet I sent and if you have any questions about the research project? I you are you still interested in taking part in the research would you like to arrange an interview date?

Best wishes

**Sarah Durnan**  
**Doctoral Research Student**  
**Children and Families Research**  
**Centre for Technology Enabled Health Research**  
Faculty of Health & Life Sciences  
Richard Crossman Building (4th Floor)  
Coventry University  
Priory Street  
Coventry  
CV1 5FB

**Appendix 9: Key Words****5.2 Superordinate Theme- 'Nothing to Lose': Feeling Desperate**

5.2.1	'I Was at My Wits End': An Unbearable Situation	Line Number (Page)
Anna	we didn't want to go through another operation	71 (3)
Beth	we didn't know what to do	35 (2)
Claire	I just felt like I'd hit a brick wall with her	108 (4)
Diane	you've got nothing to lose here because you are not winning on what we are doing	130 (5)
Emily	we never got her fully back to full strength milk. She was in and out of hospital with upset tummies	9 (1)
Fiona	I can remember feeling really frustrated and really sad	73 (3)
Gemma	I was at my wits end	60 (3)
Hannah	it used to be so upsetting seeing him that upset and in that much pain	466 (16)
Imogen	it seems crazy to give a complete feed with long chain fatty acids in it	456 (16)
Jane	it was just getting a bit stupid really	33 (2)
Katie	she had frequent bouts of chest infections and severe pneumonia she nearly died several times	27 (1)
Laura	I just knew he was never going to survive on milk [commercial formula]	111 (4)
Marie	[after trying commercial formula] I'm not putting myself through it and I certainly don't want to put him through all that	99 (4)
Nathan	we had tried everything and she's not getting better	135 (5)
Olivia	[I] thought well I've got nothing to lose	19 (1)

5.2.2	'One More Option': Finding an Alternative	Line Number (Page)
Anna	she [the dietitian] said I've got one more option if you're willing to try it	69 (3)
Beth	we went to see a medium who told us that we could give food through the tube	35 (6)
Claire	I saw it on Facebook, one of the [name of medical condition] mums	67 (3)

Diane	I met another child on the ward whose Mum was doing blended diet	49 (2)
Emily	I felt sad that was the only option... A friend knew another Mum who was doing it [blended diet].	242 (9)
Fiona	I came across this journal article which had been written in America [Pentiuk et al]	76 (3)
Gemma	there was a pupil who goes to his class that did it	47 (2)
Hannah	I didn't know that there was a thing called the blended diet, I just tried some fruit juice	246 (9)
Imogen	a friend of mine who has a little boy with the same condition she started a blended diet	94 (4)
Jane	there were two people on an online forum who had said something about feeding their kids blended	52 (2)
Katie	I just by myself just instinctively brought the classic little glass jar [baby food] and I mixed it in with her milk [formula]	66 (3)
Laura	I knew of people in the states who were pureeing up food	121 (5)
Marie	I have a friend in Australia who was looking at it [blended diet]	24 (1)
Nathan	I used to have a lot of contacts through the condition that my daughter has	121 (5)
Olivia	I knew her [parent using blended diet] through [Facebook group]	41 (2)

5.2.3	'I Took the Decision to Go Rogue': Choosing to Take a Risk	Line Number (Page)
Anna	[Suggested by the dietitian]	
Beth	they [health professionals] wouldn't let me do it, so then I went to [child law centre]	54 (2)
Claire	I had to just do it in secret which I didn't really want to do	415 (14)
Diane	you have to be secretive about it and not let on to certain professionals what you are doing	590 (20)
Emily	I hadn't told anybody I'd heard that people had been kind of in trouble	269 (10)
Fiona	I felt as though me and my husband were doing it very much alone because we hadn't involved the dietitian	115 (4)
Gemma	I lied initially	180 (7)
Hannah	I was doing something wrong I was doing something I wasn't allowed to do	137 (5)
Imogen	at that point I hadn't even told anyone I was doing it	184 (7)
Jane	if her consultant hadn't said it was OK I would have been much more wary	92 (4)
Katie	I didn't share it with the dietitian or doctor or anything I just felt I need to try to do this	121 (5)

Laura	I did on my own I didn't talk to anybody I just did it	107 (4)
Marie	I knew in my heart it was the right thing	
Nathan	I took the decision to go rogue	154 (6)
Olivia	I basically said here's what I've done here's the difference I've seen in three weeks	166 (6)

### 5.3 Superordinate Theme- 'A Radical Change': Improvements in Health and Wellbeing

5.3.1	'Food Stays Down': Remedy of Reflux, Retching and Vomiting	Line Number (Page)
Anna	the main thing that we saw that she wasn't retching anymore	173 (8)
Beth	we couldn't believe the difference it had made straight away	253 (9)
Claire	a radical change in her from being this really sickly child	331 (12)
Diane	she doesn't aspirate anymore; the food stays down	322 (11)
Emily	she has stopped retching altogether	193 (7)
Fiona	[she] was tolerating foods without any retching	274 (10)
Gemma	he's not vomited in a while that's just magnificent	236 (8)
Hannah	[did not have reflux, retching or vomiting on commercial formula]	
Imogen	[did not have reflux, retching or vomiting on commercial formula]	
Jane	'It didn't solve her reflux	293 (10)
Katie	she has no reflux at all, nothing	298 (11)
Laura	[did not have reflux, retching or vomiting on commercial formula]	
Marie	[on commercial formula] there is a lot of discomfort; reflux, constipation	101 (4)
Nathan	the last day that she threw up was on the last day that she had formula	226 (8)
Olivia	within a week what a difference... he wasn't vomiting he was having boluses	95 (4)

5.3.2	'A Proper Poo': Improvement of Bowel Habit	Line Number (Page)

Anna	you can control her bowel movements a bit more with foods, the milk would clog her up	268 (11)
Beth	[on commercial formula] she started having problems with her bowels	28 (1)
Claire	[not mentioned]	
Diane	[on commercial formula] she had constant diarrhoea she just wasn't coping at all	18 (1)
Emily	within probably months she came off the [brand of laxative] and was totally continent	134 (5)
Fiona	her bowels were working without the extra medication	338 (12)
Gemma	[not mentioned]	
Hannah	soon after we'd started it [blended diet] he went to the toilet on his own	881 (30)
Imogen	[on commercial formula] he used to suffer with quite horrible constipation	39 (2)
Jane	It's not solved her constipation she has had an ACE [antegrade continent enema procedure]	296 (10)
Katie	[on commercial formula] severe diarrhoea	474 (16)
Laura	[not mentioned]	
Marie	[on commercial formula] there is a lot of discomfort; reflux, constipation	101 (4)
Nathan	she had a bowel movement and for the first time in her life it	199 (7)
Olivia	he did a poo for the first time in his life a proper poo [laughs]	97 (4)

5.3.3	'A Better Weight': Healthy Growth	Line Number (Page)
Anna	it's been amazing how much she has gained weight, its lovely	286 (12)
Beth	she quickly gained weight	496 (17)
Claire	we saw her weight on the scales starting to stabilise and eventually starting to creep up little by little	568 (18)
Diane	she is still very thin, but I mean she's a better weight than she has ever been	412 (14)
Emily	she started to put on weight, to thrive	30 (1)
Fiona	we literally went from losing 2-3kgs within the space of a month to putting on	265 (9)
Gemma	I know he is growing because I can see his trousers are getting tight	299 (2)
Hannah	[not mentioned]	
Imogen	one of the biggest issues we've had with [him] is weight loss	288 (10)

Jane	she is growing just like any other nine-year-old she wears age 9-10 clothes	299 (11)
Katie	everyone comments about her looking so healthily and growing so well	292 (10)
Laura	he is fit he is well he is gaining weight he is gaining height	516 (18)
Marie	the weight was gaining he was growing everything was going well	165 (6)
Nathan	[not mentioned]	
Olivia	[on commercial formula] he was clinically starving	30 (1)

5.3.4	'I Think she is more Immune to Things': Perceived Immunity	Line Number (Page)
Anna	we've not really seen him [consultant] since she started [blended diet] to be fair because she's been so well	665 (27)
Beth	she hasn't had any hospital stays for the two and a half years that she's been on blended diet	388 (14)
Claire	less bugs, less hospital admissions and better recovery	340 (11)
Diane	[on commercial formula] she was catching every infection going	127 (5)
Emily	less infections less emergency admissions	127 (5)
Fiona	I think she's more immune to things	300 (11)
Gemma	we've seen like I say so much improvement in his health	420 (15)
Hannah	[not mentioned]	
Imogen	he doesn't get colds anymore	681 (23)
Jane	she's got a cough and a cold at the moment but it's actually not like her	304 (11)
Katie	she is hardly ever sick	291 (10)
Laura	he's always had proper food and he has always had the energy to fight off infections	186 (7)
Marie	he gets over them [colds] better because he is fed what he is fed	669 (23)
Nathan	she gets less colds and flus	673 (23)
Olivia	he's not had a single overnight emergency admission since we started giving him food	784 (27)



5.3.5	'Looks Better': Visible Improvements	Line Number (Page)
Anna	her skin is a lot better	267 (11)
Beth	her skin was a lot better within about a week	328 (11)
Claire	looking healthier not the sunken tired eyes from being sick all the time and she always looked a bit pasty	333 (11)
Diane	[on commercial formula] she was really blue she just wasn't a good colour at all	127 (5)
Emily	she's got a better colour, better hair, better skin	183 (4)
Fiona	her hair is in much better condition her skin is in much better condition	296 (10)
Gemma	[on commercial formula] he just looked grey and washed out	70 (3)
Hannah	his hair is better his skin is better you can just notice physically the differences in him	811 (28)
Imogen	his skin definitely looked better immediately his skin and his hair	259 (9)
Jane	but just her kind of her skin tone and the look of her	298 (10)
Katie	she doesn't look sick	292 (10)
Laura	she [the consultant] couldn't deny that he was looking fit and healthy on it	186 (7)
Marie	[not mentioned]	
Nathan	an improvement in her complexion, her hair just started to grow there was a shine about her hair	211 (8)
Olivia	there's a difference in you know his pallor	310 (11)

5.3.6	'He's a lot Happier Nowadays': Signs of Improved Wellbeing	Line Number (Page)
Anna	[she] is a lot happier a lot more alert people have said	266 (11)
Beth	she seemed to be awake more and she had more concentration	329 (12)
Claire	we noticed a radical change in her [she went] from being this really sickly child to being happy	333 (11)
Diane	I had a totally different child she was much more alert she was much happier	72 (3)
Emily	I've just assumed she is happier because she is healthier	313 (11)
Fiona	she just seems to have that bit more sparkle in her eye	308 (11)
Gemma	[not mentioned]	

Hannah	he's a lot happier nowadays	819 (28)
Imogen	[not mentioned]	
Jane	[not mentioned]	
Katie	she seemed quite happy about it	67 (23)
Laura	I've got a very healthy happy fifteen-year-old	668 (23)
Marie	the best thing is that he's happy	428 (15)
Nathan	one thing we noticed was a sense of satiety, satisfaction	452 (16)
Olivia	[not mentioned]	

#### 5.4 Superordinate Theme- 'How life Should be': A Sense of Normality

5.4.1	'She is part of things now': Inclusion	Line Number (Page)
Anna	she sits more at the table with us now and it feels like she is kind of eating with us	185 (8)
Beth	if she goes to a party I blend up the birthday cake with a bit of soya for her to have as a treat	356 (13)
Claire	she's a bit more included in the family	279 (9)
Diane	she'd sit back at the table with people again we could start going out again	72 (3)
Emily	she's more involved in family functions	112 (4)
Fiona	we try to include [her] in family meals as well so we sit around the table	360 (13)
Gemma	[he] has exactly what we have, he doesn't have anything different	231 (8)
Hannah	it just makes it inclusive and it just feels nice and normal and family orientated	515 (18)
Imogen	[not mentioned]	
Jane	she is part of things now because she is actually having lunch rather than being on a feed	352 (12)
Katie	she partakes now! For me on a psychological level that is extremely important	289 (10)
Laura	he knows he is having what we've had too	352 (12)
Marie	I don't have to worry about him thinking he's missing out on anything	519 (18)
Nathan	we are all sat round the table and having the same dinner, great that's just... you can't put a price on that	493 (17)
Olivia	me doing that is about me making sure that he is included whether he is interested or not	735 (26)

5.4.2	'I Can Be His Mum Rather Than His Nurse': A Feeling of De-medicalisation	Line Number (Page)
Anna	on the NHS milk she was literally plugged in for like 5 hours	243 (10)
Beth	[Remembering words of neonatal nurse] She will never feel like your child until everybody else has stepped back	122 (5)
Claire	when they are formula fed your like oh no that's quite a big Mam thing taken away	488 (16)
Diane	I've tried for about the last year to de-medicalise it [feeding]	226 (8)
Emily	[not mentioned]	
Fiona	it took kind of a clinical aspect out of our lives	126 (4)
Gemma	it just makes it less medicalised	323 (5)
Hannah	less clinical so it doesn't feel like another clinical intervention that you are doing with (CHILD)	515 (18)
Imogen	it feels good to be able to do one thing for him that is positive	250 (9)
Jane	plugging her into a pump its feed its more clinical	383 (13)
Katie	it's a medicalised version of sustaining someone but it's not giving someone nourishing food	105 (4)
Laura	it has become so medicalised	397 (14)
Marie	we've minimised the drugs that he has to have	432 (15)
Nathan	[refers to] medicalised formula [throughout the interview]	Throughout
Olivia	I can be his Mum rather than his nurse simple as that	539 (19)

5.4.3	'They Deserve Real Food': A Human Right	Line Number (Page)
Anna	they deserve real food not chemically formulated stuff	971 (39)
Beth	it's not normal for people to have formula it's like people who do the weight loss shakes	316 (11)
Claire	[not mentioned]	
Diane	she always ate normal food [previously] and it's just the food that she had eaten all her life	426 (15)
Emily	I could just picture it just swilling around in her stomach just making her retch all the time I just eww I couldn't live on just milk	495 (17)

Fiona	[referred to blended diet as] real food [throughout the interview]	287 (10)
Gemma	you wouldn't eat that [commercial formula] on your plate	531 (18)
Hannah	it's disgusting, have you ever spilt it? It's like glue how can that possibly be any good for you? Yuck	701 (24)
Imogen	I'm not giving him 100mls of something false	255 (9)
Jane	it turns what should be something completely natural into something that is completely unnatural	383 (13)
Katie	I wouldn't want to eat that myself I wouldn't drink that	179 (6)
Laura	a bit of the opposite from what you do from a baby when you wean them from milk	38 (2)
Marie	I don't understand why people don't think there is a benefit to having food as opposed to synthetic food	704 (24)
Nathan	healthy natural foods is good enough for 7 billion people on the planet why wouldn't it be good enough for my daughter	604 (21)
Olivia	your body is made for food we are not made to have a liquid diet	733 (25)

5.4.4	'A Vast Array of Ingredients': Opening up Food Choices	Line Number (Page)
Anna	just being able to feed them a variety of things	178 (8)
Beth	I'll have the four cereals out and I'll ask her which one do you want to go in this blend	378 (13)
Claire	it's huge, being able to cook for her or take her shopping and choose what's going in her food	507 (17)
Diane	we'll ask her what she'll have what she would like and she gets some down pureed and down her tube.	262 (9)
Emily	every time we go to the [shopping centre] she wants pizza and pizza pizza pizza on her talking computer	588 (20)
Fiona	having this choice over the food you can give is massively empowering	352 (12)
Gemma	[not mentioned]	
Hannah	I know that he is having healthy food he is having fresh food	460 (16)
Imogen	it's nice to have extra options	756 (26)
Jane	I can control what she is having I know what is going into it it's not all processed	234 (7)
Katie	these options and choices that people should have in life	616 (21)
Laura	would they be able to puree up their mushroom risotto from the children's menu they said no problem	308 (11)
Marie	you get to use your imagination, get a bit of variety in there	550 (19)

Nathan	I've got a vast array of ingredients I can use	407 (14)
Olivia	I like the fact that he's food doesn't always look the same	500 (17)

### 5.5 Superordinate Theme- 'You Have to Muddle your way Through': Practical Challenges

5.5.1	'When you Start out it's Hard': Learning how to do Blended Diet	Line Number (Page)
Anna	it's taken a while to get the right consistency	624 (26)
Beth	starting off not knowing what to do I just had a breakdown one weekend over it all	536 (19)
Claire	once I'd built up a few foods I bravely decided to turn the formula off for a bit	153 (6)
Diane	I was terrified the first time I did it	134 (5)
Emily	I was quite panicked about ensuring that they were nutritionally complete	258 (9)
Fiona	initially when you start it you need to invest time and you need to be patient	151 (6)
Gemma	it was quite stressful I think especially that first time	198 (7)
Hannah	when you start out its hard, it's scary obviously	838 (29)
Imogen	I was very very very very ultra-nervous about it when I first started	140 (5)
Jane	[couldn't remember starting]	
Katie	it's just trial and error really	208 (7)
Laura	we did a bit of experimenting	47 (1)
Marie	I was never nervous about the concept until I had to do it	250 (9)
Nathan	if you've got your wits about you and the access to the internet and an excel spreadsheet you can do it	341 (12)
Olivia	it's a bit of a phaff when you start	490 (17)

5.5.2	'A bit of a Chore': Additional Time and Effort	Line Number (Page)
Anna	it was hard work I won't lie you	142 (6)
Beth	it becomes a bit of a chore sometimes	402 (14)
Claire	it was messy and would take a long time'... 'it's quite nice being able to cook for her'	250 (9)
Diane	it is harder work than obviously sticking a bottle of feed in	197 (7)

Emily	sometimes when you are tired you think I just wish she was on [commercial] formula	460 (16)
Fiona	it's almost become like a normal household task	385 (13)
Gemma	we would work out how many mls how many calories per ml	167 (6)
Hannah	you've got to buy, it you've got to prepare it, you've got to make	483 (17)
Imogen	you know it is going to be work	637 (22)
Jane	maybe an extra five minutes and if you are cooking for every other child in your family	236 (8)
Katie	some mothers find it too much work	578 (20)
Laura	sometimes it's not convenient if you are time restricted	583 (20)
Marie	the work involved yeah which isn't overwhelming but there is definitely work involved	319 (11)
Nathan	it's about 5 or 6 hours of my time cooking and blending and its time you've got to find	508 (18)
Olivia	blended diet is not for everybody do you know it is quite hard work	595 (21)

5.5.3	'It's a BIG investment': Extra Money	Line Number (Page)
Anna	we'd fundraised enough through a charity to buy a [high powered blender]	122 (6)
Beth	It cost quite a bit in shopping	562 (19)
Claire	it's like a BIG investment to do	245 (9)
Diane	I've also brought the [brand of blender] which is smaller and easier to travel	236 (8)
Emily	[not mentioned]	460 (16)
Fiona	we invested in a high-powered blender, so we brought a [brand of blender] which was quite a lot of money [RRP £599]	151 (6)
Gemma	[not mentioned]	
Hannah	of course, the milk we get sent free every month but with the food it's about buying good quality	827 (28)
Imogen	we got a high-powered blender, that changed everything	428 (15)
Jane	I brought a [brand of high-powered blender] it's of a phaff so it's worth it	788 (27)
Katie	Psychologically as a mother I find it great to buy and cook food for my child	279 (10)
Laura	it would save me time not to have brought and cooked tea tonight I could just set all the family down to a bottle of milk, but it doesn't work like that does it?	583 (20)
Marie	you no longer get free formula you have to buy all the food	312 (11)

Nathan	I'd rather spend that time and that money ten times over than go back	515 (18)
Olivia	[he] was five and a half coming on six years old and I had never paid any money to feed him	330 (13)

### 5.6 Superordinate Theme- 'I Have to Fight for her to be fed Food': Defending the Choice

5.6.1	'It Depends Who You Get': Inconsistent Support	Line Number (Page)
Anna	when we first mentioned it to [consultant] she was like o.k, I don't know if she was quite on board	661 (27)
Beth	my dietitian came to see me about it and she's been amazing	50 (2)
Claire	it depends who you get, it depends if they've come across it before	779 (27)
Diane	she [the dietitian] just tutted and walked out of the room didn't approve at all and said that she wouldn't back me	60 (3)
Emily	she [dietitian] had said I can't give you any advice on it I can't support you	335 (12)
Fiona	the first time I mentioned blended diet she was really quite shocked, really taken back	178 (7)
Gemma	his [consultant] was really really against the idea	126 (5)
Hannah	they were like [makes gasping sound] oh my no you can't do that	166 (6)
Imogen	I asked our metabolic specialist and she immediately said no	91 (4)
Jane	her paediatrician who wasn't entirely convinced nor was the dietitian	91 (4)
Katie	they [the dietitian] said I can't support you I'm not allowed to talk about blended diet with you	540 (19)
Laura	I've tried to level with them [health professionals] as an equal	87 (3)
Marie	[the dietitian] is just very nervous about talking with me	113 (4)
Nathan	I've approached the healthcare professionals and I've been told no so for a long time	154 (6)
Olivia	our community nurse is fantastic	440 (16)

5.6.2	'At the End of the Day it's Your Child': Control	Line Number (Page)
Anna	it's my choice what I feed my child	481 (20)
Beth	arguing against the professionals to get them to allow you to do it	417 (15)
Claire	when anybody came to my house, I couldn't do what I wanted	390 (13)
Diane	I had the ongoing battle	500 (17)

Emily	having to fight to do blended diet	630 (22)
Fiona	I suppose it gave a sense of control left in a life that had been kind of dictated to by the medical world	628 (22)
Gemma	I'm totally in control over what we give him	266 (10)
Hannah	the other battle we always had ...	125 (5)
Imogen	listen and don't fight them [healthcare professionals]	611 (21)
Jane	I was prepared to argue	138 (5)
Katie	it was like a warzone	465 (16)
Laura	at the end of the day it's your child I've never asked anybody's permission	607 (21)
Marie	it's really tiring, it's like beating your head against a brick wall	140 (5)
Nathan	the argument was...	653 (2)
Olivia	I have to right to feed my child whichever way I choose	605 (21)

5.6.3	'As Soon as I Leave the House I'm in a Grey Area': Blended Diet Outside the Home	Line Number (Page)
Anna	her rights are being ignored at school	479 ((20)
Beth	school is going to be the next argument	165 (6)
Claire	It depends on the ward, sometimes they'll blend stuff for us	376 (13)
Diane	I go into the hospital now, you know we've moved to the adult ward we are just going through transition and they are completely happy that we do it	143 (5)
Emily	the carers can't be trained on giving blended food because the BDA and the Royal College of Nursing don't support it	367 (13)
Fiona	we don't want her on formula, but the hospitals don't often advocate it	433 (15)
Gemma	initially it [blended diet] caused a bit of a problem it was like oh no we [respite care] can't give it	432 (15)
Hannah	the hospital are obviously anti-blended diet	433 (15)
Imogen	they will not accept blended diets over there [children's hospital] I don't think that's fair	657 (22)
Jane	at one point she was going to a hospice where she would stay over, and I had to feed her	542 (19)
Katie	as soon as I leave the house I'm in a grey area because officially I'm not allowed to	367 (13)
Laura	the secondary head teacher noticed a member of staff giving him a yogurt pouch down his tube and went absolutely mad about it and banned it	71 (3)



Marie	at school there is certainly no problem now no one can understand what the problem was in the first place	167 (6)
Nathan	my wife cut down her hours specifically to go to school at lunch time	271 (10)
Olivia	I've had to seek legal advice [to give blended food in hospital]	162 (6)

5.6.4	'We've All Supported Each Other': Helping Other Parent and Campaigning for Change	Line Number (Page)
Anna	I want it [blended diet] to be accepted ... some people haven't even managed to get it into their hospices	961 (39)
Beth	there is another child that is on blended diet who I trained his Mum to do it	183 (7)
Claire	I'm going to help them, all the other people, not to have the difficulties we had	843 (29)
Diane	we've all supported each other	614 (21)
Emily	I tell everybody that I see tube-feeding have you heard about blended food	741 (25)
Fiona	I want to make things easier for future people who decide to do blended diet	598 (21)
Gemma	more people should be given the opportunity to at least give it a go	558 (19)
Hannah	it would make such a massive difference to so many people	863 (30)
Imogen	I wanted to put the information out there good and bad	637 (22)
Jane	I've become the blended diet woman [asked to talk to others about blended diet]	281 (10)
Katie	I've just given them some ideas some pointers of how to start and how to overcome certain obstacles	559 (19)
Laura	I'm really passionate about getting this into NHS practices	664 (23)
Marie	it's all the mummies supporting ourselves	594 (20)
Nathan	if they [other parents] want to take any advice then I'll give it	309 (11)
Olivia	when you are in a meeting if this doctor knows us feel free to mention that you know us	649 (22)