

Exploring Information Sharing with Families Making Decisions about Gastrostomy Feeding for Children with Neurodisabilities

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Abstract

Feeding difficulties are common in children with neurodisabilities. If children have problems safely swallowing adequate food or fluid, gastrostomy (GT) feeding via a tube through the abdominal wall may be offered to augment or replace oral feeding. Systematic reviews have indicated that the risks and benefits of the procedure in this patient group are unclear. Prior retrospective research has highlighted how for mothers, uncertainty about this procedure can result in decisional stress and conflict, leading to delays in GT placement. By contrast, high levels of maternal satisfaction with the GT tube have been identified once it has been placed. The perceptions and experiences of other stakeholders taking part in the decision-making process, most notably fathers, has not yet been explored.

This study aimed to investigate GT decision-making experiences for families with children with neurodisabilities. The first arm of the study is retrospective and uses an Interpretative Description to explore the perspectives of 26 family members and seven healthcare professionals involved in making decisions about GT placement. This is reinforced by two short interviews with children with neurodisabilities who had the decision made about them. In the second arm of the project, a longitudinal study was completed with one family, including analysis of the clinical encounters where the family actively discuss GT placement with their clinical team.

Four key themes have been identified: maternal embodiment, the pleasure and commensality of food and drink, feeding as care, and normalisation and stigma. Key differences in the views of mothers, fathers and other stakeholders emerged around these themes. This research also demonstrates how GT decision-making needs to be understood as a distributed process across time and place. Clinical encounters require delicate interactional work. They should provide the interactional space to allow stakeholders the opportunity to participate in the processes of information sharing, evaluation of risks and benefits, and decision-making around feeding method.

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Dedication

I would like to dedicate this thesis to my beloved mother, Hazel Williams, who sadly passed away during this study; her belief in its eventual completion made this journey possible.

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Chapter 1 Background to Study

1.1 Introduction

Eating and drinking is a surprisingly complex procedure. An infant's ability to feed successfully requires careful co-ordination of the suck, swallow and breathe process (Gewolb & Vice, 2006). Premature infants often have early feeding difficulties because their co-ordination of breathing and swallowing is more disorganised. Choking on food has been highlighted to be a common cause of death in children under three years of age (The American Academy of Pediatrics, 2010). Approximately 20-50% of typically-developing children are reported to experience some type of feeding problems (Benjasuwantep, Chaithirayanon, & Eiamudomkan, 2013). However, in typically-developing children, feeding difficulties are usually a temporary source of concern and significant nutritional deficiencies rarely result (Manikam & Perman, 2000).

Persistent difficulties with feeding are concerning because of their negative impact on a child's growth, development, health and societal participation. Furthermore, feeding is an indicator of neurological maturation and feeding impairment either at the suckling stage, or later on during the weaning process is strongly predictive of neurodisability (Gewolb & Vice, 2006; Reilly, Skuse, & Poblete, 1996). Early identification and intervention is therefore warranted. However, despite parents reporting feeding problems very early in an infant's life, the average age of entry into specialised care for feeding difficulty has been reported to be around two years (Benjasuwantep et al., 2013; Rommel, De Meyer, Feenstra, & Veereman-Wauters, 2003).

The focus of this thesis is how parents of children with neurodisabilities make decisions around the potential intervention of gastrostomy tube (GT) placement. In this chapter, I will present the background to the study. This includes the definitions of neurodisability and feeding difficulty, a brief overview of the GT procedure including what is known about its risks and benefits, and the reasons why this decision can sometimes be a difficult one for parents to make. At the end of this chapter an overview of the organisation of this thesis is presented, including the study aims, the research approaches taken and the organisation of the analysis and discussion.

1.2 Definitions of impairment and disability

The terms disability and impairment, although sometimes used synonymously, have specific definitions in social science literature:

“Impairment is the functional limitation within the individual caused by physical, mental or sensory impairment. Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers” (Barnes, 1991, p.2).

The movement from the traditional model of impairment as a personal misfortune to the more recent model of disability as a political and social responsibility, represented a transition regarding the ways in which people with disabilities can be positioned in society (Knight, 2013). Whereas previously social disadvantage was viewed as an unavoidable consequence of impairment, the social model offers up a challenge that society should be organised in ways that takes the needs of people with impairments into account. Debates about these two models continue (Kisler, 2014).

Neurodisability has been broadly described as “a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations” (Morris et al., 2013, p.1). Neurodisabilities include life-long conditions such as cerebral palsy (CP), autism and epilepsy. These conditions sometimes co-occur.

In order to recognise some of the differences in oral feeding which can be identified in infants and children with feeding and swallowing disorders, a summary of the normal developmental progression of feeding and swallowing in typically-developing infants now follows.

1.3 Early development of feeding and swallowing

Swallowing, otherwise known as deglutition, begins with the placement of the material to be swallowed in the mouth and continues until it enters the stomach. Eating refers to the oral phase function which includes oral preparation and transit of a bolus, whereas feeding is described as including “anticipatory reactions, food getting, the placement of food in the mouth, and bolus management, including

chewing (mastication) if necessary and the transfer of the bolus with the tongue into the pharynx” (Delaney & Arvedson, 2008, p.105). As young infants cannot feed alone, it also includes interactions between children and their caregivers.

To feed successfully the typically-developing full-term infant must coordinate the rhythmic sequences of sucking, swallowing, and breathing. The nipple fixing and suckling process are aided by the anatomy of the oral and pharyngeal structures of the infant including lips, jaw, cheeks, tongue, palate, pharynx, and larynx (Arvedson, 2008). As a typical infant develops they become increasingly efficient at this process so that they can gradually increase their intake of milk as they grow.

The healthy infant requires only breast milk or formula. Weaning refers to the developmental stage of changing from a milk only diet to the chewing of semi-solids. The National Institute for Health and Care Excellence (NICE) recommends that babies may be ready for weaning at around 6 months of age (NICE, 2014) Adjustments must be made in expectation for individual children based on personal requirements and developmental stage.

Gisel (2008) examined the gradual transition from the suckling of liquids to solid feeding in typically-developing children. Chewing time for each texture decreased with the child’s increasing age indicating that children became more efficient at chewing as they matured. By the age of three years most typically-developing children will be skilled in biting, chewing and swallowing an extensive range of food textures and consistencies (Arvedson & Delaney, 2011). To achieve this, physical developmental changes are required including improved postural stability via improved head and trunk control, the emergence of teeth and the downward and forward growth of the mandible.

Feeding and swallowing difficulty can manifest at any phase in the feeding process from getting food to the mouth, sucking, chewing, or propelling food boluses through upper digestive tract to the stomach (Arvedson, 2008). Children with neurodisabilities who initially demonstrate adequate feeding and a safe swallow, may develop more difficulty with feeding; signs and symptoms of dysfunctional swallow, such as aspiration, may appear later as these developmental changes occur.

In the following section, I define and describe some of the concepts around paediatric feeding disorders.

1.4 Defining paediatric feeding disorders and dysphagia

There has been little consensus to date amongst healthcare professions around the terms used to describe and conceptualise paediatric feeding problems (Estrem, Pados, Park, Knafl, & Thoyre, 2016). This can inhibit effective communication between members of the different healthcare disciplines and caregivers who may focus on different aspects of the feeding difficulty (Bryant-Waugh, Markham, Kreipe, & Walsh, 2010). For the purpose of this thesis, the term “paediatric feeding disorder” refers to children whose feeding is impaired because they have difficulty consuming adequate food and fluid for optimal nutrition by mouth (Manikam & Perman, 2000).

Dysphagia, or swallowing disorder, has been defined as “an impairment of emotional, cognitive sensory and/or motor acts involved with transferring a substance from the mouth to the stomach resulting in failure to maintain hydration and nutrition and posing a risk of choking and aspiration” (Tanner, 2006: p152). Dysphagia usually involves the first two phases of swallowing and is therefore often defined as oropharyngeal dysphagia (OPD) (Rugiu, 2007). Children with OPD may accept food into their mouths but fail to co-ordinate their swallow (Leopold & Kagel, 1997). Neurological damage, and sometimes associated structural anomalies, impede their oral phase ability to form a food bolus and transport it to the back of the mouth in preparation for swallowing. Disorders in the pharyngeal phase of the swallow without disruption to oro-motor function can also occur and can result in food being inhaled into the airway when the child takes a breath following the swallow (Logemann, 1983).

In addition to OPD, a range of other physical and structural abnormalities which disrupt feeding also exist. These include poor lip closure for breast and bottle feeding, muscle rigidity or weakness, malocclusion, high palate, difficulties with oro-motor control such as tongue thrusting, a tonic bite reflex, abnormalities of posture and hypersensitivity in and around the mouth (Manikam & Perman, 2000). Muscular features continue into the gastro-intestinal system and children may also present with oesophageal dysmotility, gastro-oesophageal reflux (GOR), vomiting and constipation (Andrew, Parr, & Sullivan,

2012). GOR can lead to strictures caused by stomach acid damage to the lining of the oesophagus making it more difficult for food to pass to the stomach. Intake and retention can be severely limited in children with GOR because the discomfort may lead to food avoidance. Feeding problems may also be exacerbated by associated sensory, cognitive, communicative, and behavioural disturbances.

1.5 Prevalence of feeding disorders in neurodisability

It is generally accepted that clinically significant feeding difficulties are disproportionately represented in children with neurodisabilities with up to 80% of children in this group estimated to be affected (Bahr & Johanson, 2013; Brackett, Arvedson, & Manno, 2006; Kerwin, 1999; Lefton-Greif, 2008; Manikam & Perman, 2000).

Cerebral Palsy (CP), with a prevalence of around two children for every 1000 live births (Cans, De-la-Cruz, & Mermet, 2017), is the most common neurodisability that leads to dysphagia and is currently conceptualised as follows:

“Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy and by secondary musculoskeletal problems” (Rosenbaum et al., 2007).

Although estimates vary due to different sub-type inclusion criteria, prior studies have indicated that 30-90% of children with CP have feeding difficulties (Day et al., 2007; Dahlseng et al., 2012; Fung et al., 2002; Gisel & Patrick, 1988; Parkes et al., 2008; Reilly & Morgan, 2008; Reilly et al., 1996; Sullivan et al., 2000, 2002) or show evidence of under nutrition (Schwarz, Corredor, Fisher-Medina, Cohen, & Rabinowitz, 2001).

Most research on feeding difficulty in childhood neurodisability has therefore tended to focus almost exclusively on children with cerebral palsy (CP). It is difficult to know how far research that has been almost entirely generated in a CP population can transfer to other neurodisabilities. It is also important to note that, although CP is a non-progressive disorder some of the comorbidities such as musculoskeletal difficulties

change with age and this can affect later feeding. These issues also need to be considered when relating my research findings, which include children with a variety of neurodisability conditions, to the results of previous studies.

In the following section, I will describe how feeding impairments in children with CP and other neurodisabilities can be assessed and diagnosed.

1.6 Assessment of feeding impairments

1.6.1 *A multidisciplinary approach*

Assessment of feeding difficulty can be complex and requires a wide range of skills from a multi-disciplinary team usually headed by a paediatrician, a doctor who has specialist training in the medical care of children with neurodisabilities. Speech and language therapists (SALTs) typically play a leading role in evaluating swallowing dysfunction, sometimes working in conjunction with radiologists to provide video-fluoroscopic (i.e. dynamic) and static studies of swallowing. Dieticians have the overall responsibility for assessing nutritional needs. Occupational Therapists (OTs) may work closely with the family in developing the best posture for feeding, helping manage sensory feeding difficulties, or providing modified equipment. Other important team members are gastroenterologists who may eventually have responsibility for the placement of the GT, nurses, physiotherapists and psychologists. This extensive team also needs to engage with the child's parents and other people with a significant relationship to the child.

1.6.2 *Clinical examination and tests*

Determining the need for nutritional intervention in children with neurodisabilities requires a thorough review of medical, development, psychosocial and feeding histories as well as a physical examination (Arvedson, 2013; Bell & Samson-Fang, 2013; Kuperminc & Stevenson, 2008; Marchand, Motil, & Nutrition, 2006). Observation of the child feeding should be an integral component of this. Parents are requested to feed the child as they would customarily, using the child's normal foods and utensils. Observations by the team include an assessment of gross and oral motor skills as well as parent and child behaviours and interactions. If the safety of the swallow is unknown, the dynamic procedure of video-fluoroscopy (VF) may be carried out. This helps evaluate the ability

of a child to swallow various foods and fluids and provides information about anatomical structures, and the adequacy of airway protection during swallowing. The VF is a snapshot procedure which can only confirm whether the child aspirates trialled consistencies at the time of assessment and cannot confirm that the child does not aspirate at other times. There is a risk of an inconsistent swallow or variable interpretation by clinicians (Stoeckli, Huisman, Seifert, & Martin--Harris, 2003) and therefore the VF should only be viewed as providing additional information to clinicians in a dysphagia assessment, supplementing that gained by history, examination and feeding observation.

In the above sections, I have briefly defined and outlined neurodisability and feeding impairment and described how it may be recognised and assessed. I will now move on to describe the consequences of feeding impairments in children with neurodisabilities.

1.7 Consequences of feeding impairment in neurodisability

A lack of a uniform definition of malnutrition means that its prevalence in children with neurodisabilities may be under-reported (Mehta et al., 2013). Nevertheless, malnutrition is still recognised to be a common consequence of feeding difficulties (Kuperminc et al., 2013; Kuperminc & Stevenson, 2008; Sullivan et al., 2002). Children with CP, for example, show disrupted growth against typical age and sex standards (Samson-Fang & Stevenson, 2000) which is sometimes apparent within the first six months of life (Reilly et al., 1996). Poor growth in CP can sometimes be attributed to additional factors, most notably hormonal influences (Uday, Shaw, Krone, & Kirk, 2017) but there it still a general consensus that poor nutritional status is a major contributor to growth failure (Kuperminc & Stevenson, 2008).

Poor nutrition can also have significant consequences regarding the child's neurodevelopment, and psychological and physiological function including reduced muscle power, impaired bone health, increased risk of pneumonia, increased risk of cardiac failure, decreased immunity, and altered socio-emotional development due to the decreased energy available for voluntary activities (Kuperminc & Stevenson, 2008). Nutritional deficits may exacerbate the effects of primary brain injury in very young children with neurodisabilities. Dysphagia is of particular concern because it can lead to

aspiration of food or fluid into the lungs with resultant recurrent chest infections and chronic lung disease (Sullivan et al. 2000). Further risks exist of further brain damage occurring from inadequate oxygen to the brain if a child needs to be ventilated due to chest infection or seizures (Stevenson et al. 2006). However, Cass et al. (2007) demonstrated that there is not an absolute correlation between OPD and respiratory morbidity and advised that a pragmatic approach needs to be taken when assessing the consequences of feeding difficulty.

1.8 Early interventions for feeding impairments

In recent years, our understanding of brain growth in the first two years suggests that early feeding intervention for children with poor nutrition might help improve outcomes. However, more evidence is still required to show that early intervention leads to better brain growth, improved neurodevelopment and reduced disability (Andrew et al., 2012).

If a feeding difficulty sufficient to cause concern is identified, therapeutic strategies need to be explored. The three biggest treatment considerations are airway protection, nutrition, and hydration. Modifications which may be employed to achieve these aims may include fortification or adjustments to taste, frequency, temperature, texture, or consistency of food. Postural modifications to promote the safety of the swallow such as changes in position and adaptive equipment may be recommended. Management strategies may also include therapies to treat underlying organic presentations such as reflux. The appropriate length of time for trialling these therapeutic strategies will vary depending on the age of the child and the degree to which their nutritional status is compromised. However, when multi-disciplinary assessment confirms that children have problems safely swallowing enough food or fluid to support their hydration and nutritional needs and other feeding intervention strategies have been unsuccessful, enteral feeding may need to be considered to augment or replace oral feeding. This conclusion may be reached at different times by members of the clinical team and parents and is therefore an area of care that is potentially contentious.

1.9 Enteral feeding

The definition of enteral nutrition (EN) as outlined by the European Society of Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) includes the delivery of liquid feed formulations via tube and is indicated in children with at least a partially functional gastro-intestinal tract and insufficient oral intake (Braegger et al., 2010). Although sometimes used as a sole source of nutrition for children with unsafe swallow, it can also be used to supplement oral intake in those children considered safe and able to consume some food or fluid orally. Several delivery routes for EN exist: these include nasogastric (NGT), nasoduodenal, nasojejunal, gastric (GT) and jejunal. As this study focuses on decision-making around GT placement and its risks and benefits compared to oral and NGT feeding my discussions of these procedures will be limited to NGT and GT.

NGT feeding, where a silicon tube is passed through the nose down to the stomach, is considered suited for short-term use or as a precursor to GT feeding to check whether enteral feeding is tolerable or leads to improved growth. Opinions regarding how long NGT feeding should continue differ, but it is generally considered that the use of an NGT should ideally not exceed 1-3 months (Bell & Samson-Fang, 2013; Turner, Abobo, Blatz, Hartfield, & Mager, 2016).

In the following section I will describe what is meant by GT feeding and give a brief outline of the procedure.

1.9.1 Definition and overview of GT feeding

A GT is a silicone tube through which feeds and medication can be administered. It is inserted through a surgical opening in the abdominal wall (stoma) directly into the stomach as shown in Figure 1-1 Gastrostomy Tube Placement

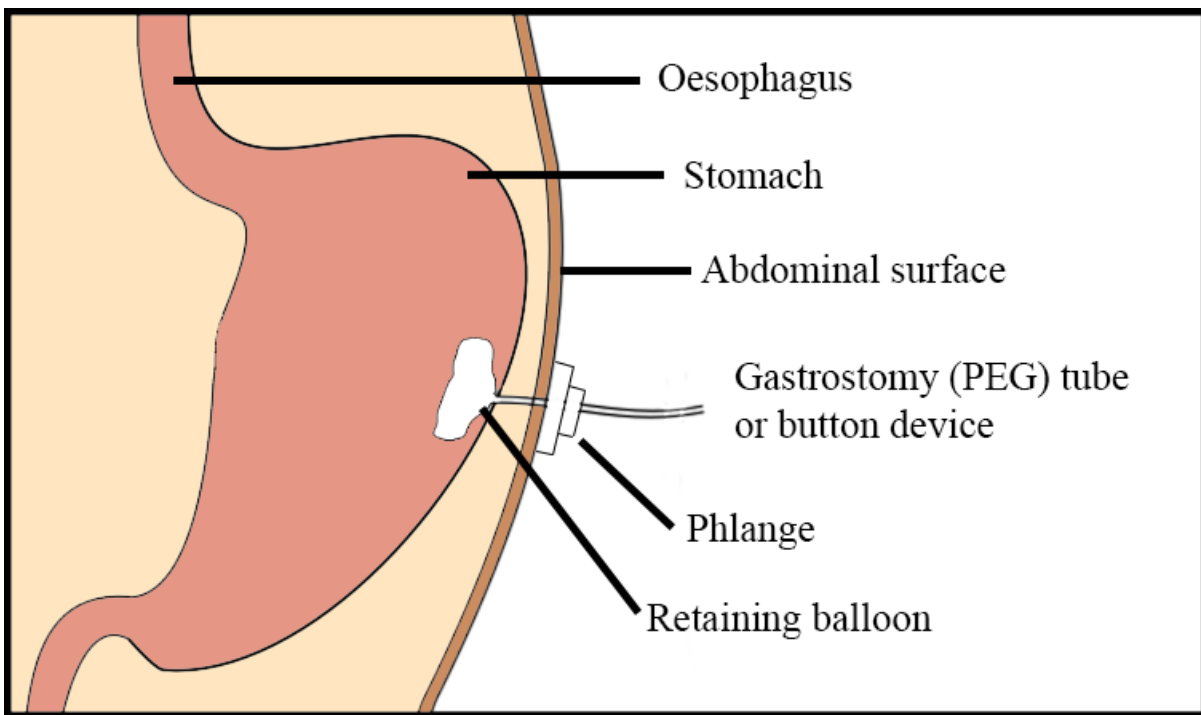


Figure 1-1 Gastrostomy Tube Placement

The procedure is carried out under general anaesthetic (GA) which carries a small degree of risk. The GT can be inserted by different surgical methods including laparoscopy and laparotomy. However, in most cases the procedure is carried out as a procedure known as percutaneous endoscopic GT (PEG) (Gauderer, Ponsky, & Izant, 1980). A PEG has better outcome measures in terms of lower level of surgical invasiveness and costs and improved patient tolerance (D. Fox et al., 2014). The PEG technique is used so commonly that the term PEG is frequently used as a synonym for the GT and the feeding process often referred to as PEG feeding.

The original PEG/GT stays in place until the surgical site has healed over a period of several weeks and is usually replaced by a more discreet and practical low-profile button, which is a one-way valve that sits flush with the skin. The first change from the surgical tube to button is also carried out endoscopically under GA. The button is held in place by a mushroom retention tip or a water filled balloon which is inflated inside the stomach. Parents and carers can be trained to replace the tube if it accidentally dislodges. Once placed, GTs are far more difficult to pull out than NGTs and this is one reason they are recommended for longer-term or permanent use. However, they can be intentionally

removed if eating and drinking skills improve and are sufficient to safely support adequate nutrition and hydration.

1.9.2 *The relative risks and benefits of Oral, NGT and GT feeding*

Although the primary goal of a GT is to improve nutrition, health and well-being, the benefits and risks of GT feeding in children with CP and other neurodisabilities are currently unclear. Studies of outcomes following GT placement have often included a range of ages and underlying conditions. Four systematic reviews (to my knowledge) examining the effects of GT placement in children with neurodisabilities using a variety of outcome measures have been conducted in recent years (Ferluga, Sathe, Krishnaswami, & Mcpheeters, 2014; Gantasala, Sullivan, & Thomas, 2013; Samson-Fang, Butler, & O'Donnell, 2003; Sleigh & Brocklehurst, 2004). These systematic reviews only included studies of children with CP, so the effects on children with other neurodisabilities are not clear. The studies included in the reviews had considerable heterogeneity in design, including different methods of recruitment, assessment outcomes and length of follow up. Nevertheless, all reviews concluded that the most notable improvement was weight gain and there was no clear evidence for overall benefits of GT feeding in terms of functional status, health, or quality of life. The evidence for the effectiveness of GT feeding, at least in CP, is therefore insufficient, although Ferluga et al. (2014) concluded that carrying out comparative studies in the form of controlled studies could be ethically challenging. However, these results do not imply that there are no benefits in opting for GT feeding. Instead they suggest that there is little reliable evidence, especially regarding risk, from which parents can draw conclusions at present. Therefore, a much stronger evidence base is required to guide families and professionals involved in making difficult decision about GT placement.

It is important to note that these reviews do not include NGT feeding and therefore give no information about the relative risks and benefits of GT or oral feeding compare with NGT feeding. Both NGT and GT have their own risks and benefits. Both can be subject to everyday care problems such as tube kinking, occlusion, disconnection or breakage although these may be partially reduced by careful management with strict adherence to care protocols. Other problems include gagging (56%), reduced appetite (45.2%),

frequent vomiting (50%), nausea (14.8%), excessive perspiration (7.5%), granulation tissue (5.2%) and skin irritation (1.9%) (Pahsini, Marinschek, Khan, Dunitz-Scheer, & Jaron Scheer, 2016). An NGT does not require a surgical operation to place it and is therefore considered less invasive. However, several hazards specific to NGT feeding remain. These include nasolabial irritation and soreness, epistaxis (nose bleeds) and pharyngeal irritation (Vermilyea & Goh, 2016). More worrying is the risk of accidentally introducing the NGT into the lungs. Although this should be a “never” event 40 cases of NGTs misplaced into the lungs were reported to the United Kingdom National Reporting and Learning System in the 12 month period from 1st April 2015 to 31st March 2016 (NHS Improvement, 2017).

Data comparing the outcomes and acceptability of prolonged NGT and GT use in children remains limited. Both NGT and GT feeds were shown in early studies to improve anthropometric outcomes in child populations with either renal disease or neurodisabilities, with no difference in complication rates (Wood et al. 1990; Naureckas & Kaufer-Christoffel 1994). Furthermore, a Cochrane review investigating the adult population found that percutaneous GT was associated with significantly less intervention failure than NGT, yet there was no statistically significant difference in complications (Gomes et al., 2015). However, it is not known whether these results are transferable to the paediatric population. Paediatric patients may be at higher risk from GT surgery because of anatomical and physiological immaturity and this may be increased if their condition has resulted in changes to local anatomy such as scoliosis (Chang & Hsieh, 2013). However, one review showed that child and parent satisfaction, as well as various objective outcomes, were significantly improved after GT in a group of 58 children of whom three quarters had had an NGT prior to the GT intervention (Avitsland et al., 2006).

GT placement is not without risk and in the following section I will go on to discuss some of the potential complications of GT placement.

1.9.2.1 Potential complications of GT placement

Estimates of the risk factors around GT placement vary depending upon the medical condition and age of the recipient, but have been demonstrated to have an overall

complication rate of 4.9-50.0% with a mortality rate of 0.5-1.2% (Fröhlich, Richter, Carbon, Barth, & Köhler, 2010). Early complications occurring within 30 days usually arise as a direct complication of the GT placement or from the associated anaesthesia. Abdominal pain can occur due to air distending the small bowel, but this usually resolves within 72 hours. However, persistent pain could be indicative of colonic injury, the risk of which may be increased by poor surgical technique (Milanichi & Allins, 2007). More minor complications such as peritoneal irritation and dislocation of the tube can also occur (Fröhlich et al., 2010).

Most late onset complications, which can affect as many as 44% of children with a GT, occur during the first two years after insertion (Segal et al., 2001). Minor skin infections can occur sometime after primary wound healing, but are usually easily treated with local antibiotic, antifungal or antiseptic therapy although systemic antibiotic therapy is sometimes required (Fröhlich et al., 2010). Granulation tissue can gradually develop and may need to be cauterised. Ulcers can derive from mechanical problems and may require tightening of the flanges or changing tube size. More serious but rare complications include small bowel obstruction, fistulae and adhesions. The most common major long-term complication in children is buried bumper syndrome, the migration of the internal flange into the gastric or abdominal wall-with a prevalence of 2.3% (Kohler, Lang, & Behrens, 2008).

In addition to the above complications, gastro-oesophageal reflux (GOR) is sometimes cited as resulting from GT feeding. However, GOR can occur both before and after the onset of enteral feeding. The results of studies to date have been mainly retrospective design and inconclusive, but overall there seems to be little significant difference between the occurrence of GOR before and after the placement of a GT. However, a GT may be an aggravation in a small minority of children especially those with neurodisabilities (Razeghi, Lang, & Behrens, 2002).

1.9.2.2 Complications after ceasing GT feeding

Some children may develop a safe swallow and GT may be removed. Intentional removal of the GT tube usually results in spontaneous closure of the stoma within a few hours.

However, failure to close may require a surgical procedure if the situation is not resolved within one month (Razeghi et al., 2002).

Concern has been expressed that recommencing oral feeding in children who have received prolonged feedings by GT may be difficult (Manikam & Perman, 2000). Non-oral feeding could theoretically mean that children may lose existing chewing and swallowing skills and have difficulty in recognising hunger and satiety. However, the first study to date to assess the development of food refusal in relation to tube feeding has demonstrated much higher rates of later food refusal in children fed by NGT rather than GT (Ricciuto, Baird, & Sant'Anna, 2015). This led the authors to conclude that NGT feeding may have been allowed to continue for too long in their sample. However, their study included children with a wide variety of diseases so this finding may not be transferable to children with neurodisability.

1.9.2.3 Feeding regimes

As well as decisions about GT placement, decisions also need to be made regarding feeding regimes. Whatever enteral feeding method is chosen, the regime must be tailored to the individual child's needs, including the contribution made by oral intake as well as family lifestyle. This is not straightforward because accurate estimation of nutritional requirements is a complex process due to the nature of disability, age, and degree of feeding difficulty for each individual child. A wide range of commercial enteral feeds designed to provide complete nutrition exist but some families prefer to give pureed family food via enteral tubes. Although concerns have been expressed regarding the nutritional adequacy and microbiological safety of home prepared feeds there has been little evidence to date to support this stance (Bell & Samson-Fang, 2013). Some have argued that home-cooked food should not be overlooked as an option for those families who might prefer it, and the use of blended feeds has recently started to gain more research attention (Coad et al., 2017; Johnson, Spurlock, & Galloway, 2013; Pentiuik, O'Flaherty, Santoro, Willging, & Kaul, 2011).

1.9.2.4 The prevalence and timing of commencement of GT feeding

Surprisingly little is known about the rates of GT placement in children with neurodisabilities. Most of what is known pertains to CP and excludes other

neurodisabilities, or conversely includes a wide range of conditions which may not be representative of children with dysphagia. The largest recent European study included 1295 children (aged six months to 11 years 8 months) with CP from six countries (Dahlseng et al., 2012). This showed that 11% of children with CP had a GT in place, with the prevalence being highest in western Sweden and lowest in Iceland. The median age of GT placement was 22 months, but this also varied across countries from 16 months in Western Sweden to 70 months in Northern England. It is not currently known whether the figure for Northern England is representative of the UK as a whole. Other studies have indicated a median age for insertion of 14.4 months in Norway (Kvelling et al., 2016), 19.7 months in Canada (Mahant, Friedman, Connolly, Goia, & MacArthur, 2009), 4.6 years in Taiwan (Wu, Wu, & Ni, 2013) and 6.2 years in Poland with NGT feeding typically been used first for 37.6 weeks (Wiernicka et al., 2012). These differences may result in part from variations in both access to treatment and equipment, cultural and parental expectations, as well as clinical views regarding which children may benefit from GT placement. However, decision-making around GT placement is extremely complex and forms the major part of this thesis. I will discuss these issues further in my literature review in Chapter 2.

The timing of GT placement may be important. Martínez-Costa et al. (2011) examined anthropometric consequences of GT placement in 26 children using Body Mass Index (BMI) as a measure. They concluded nutritional improvements for children whose GT was placed before 18 months of age was significantly better than in those where it was placed later. These findings led the authors to recommend early GT placement. However, there are significant limitations to this study. Nine children in their sample had previously received long term NG feeding. The ages of this sub-group of children is not stated but “long term” suggests that the supplemented children would have been in the older group. The authors’ interpretation fails to consider that children who have already been in long term receipt of supplementary NG feeds are unlikely to show as much nutritional benefit when the GT tube was eventually placed as those who did not. Furthermore the children received a “variety of diets” via the GT, which limits the deductions that can be safely drawn. Only BMI was used as a nutrition outcome measure despite the authors stating that accurate height could not be recorded in seven children.

BMI has been found to be an inaccurate measure of nutritional status in this patient group (Bellou, 2011). However, in support of these findings Dahlseng et al. (2012) unexpectedly found that the GT was generally introduced later in children with severe CP than in those with milder forms. They concluded that in some children the GT may have been introduced too late and recommended earlier placement.

In this background section, I have outlined some of the clinical considerations around GT placement in a child with a feeding difficulty and neurodisability. I have described how prior research has not been able to demonstrate clearly the risks and benefits in relation to oral and NGT feeding. The decision to commence tube feeding is complex for the families and carers of children with neurodisabilities. In addition to the poorly understood risk and benefits, the values and meanings of feeding and eating are more complex to families than simply providing adequate nutrition and maintaining or achieving weight gain. I will now describe how these issues have prompted the rationale for this research.

1.10 Rationale for the research

My aims for this research were two-fold. Firstly, to find out what information and support are most helpful to parents, I wished to gain a wider perspective on the contextual factors and family values influencing family's decisions around the provision of a GT tube to their child with a neurodisability.

Secondly, shared decision-making (SDM), the practice of engaging individuals in making decisions about their own or their children's care in partnership with clinicians, is more likely to result in informed choice and consent (Elwyn et al., 2010). Very little is known about how decisions made on behalf of children are negotiated between families and their health care professionals. I wished to explore how clinician/parent interactions influence SDM around GT placement for children with feeding difficulties.

The findings from this study will be used to inform clinicians and researchers how information sharing and support can be most effectively provided thus improving the decision-making experience for both clinicians and families.

1.11 Overview of this thesis

This thesis is structured into twelve chapters. In this opening chapter, I have provided the contextual information which outlines those factors which may lead to the need for parents to decide about GT placement in their child with a neurodisability and feeding impairments. Following a description of the procedure, I have explained how research to date has been able to demonstrate some of the risks and benefits of GT feeding; however, the balance of these risks and benefits is unclear meaning that the decision can be a complex one for parents to make.

In the following chapter, I outline in brief some of the models and theories that have derived from the literature around SDM in clinical practice. I then provide a review of the research regarding the decision-making process for paediatric GT placement that has been conducted to date. I outline the gaps in this research and explore the need for further study.

In Chapter 3, I describe the reasons, both philosophical and pragmatic, for selecting the two methodological approaches which I used for this study. I then go on to describe the specific research procedures including the recruitment process and the specific ethical considerations that need to be considered when working with families with young children.

Moving on to Chapters 4 to 10, I present the empirical findings of my study presented as seven distinct chapters. As this is a qualitative and pragmatic study, I have chosen not to adopt the traditional style of presentation of results followed by analysis and then discussion. Instead, each chapter is presented thematically in a narrative style in which the results, analysis and discussion are presented together and related to the existing body of literature.

In Chapter 4, I explore how previous knowledge around this topic has been drawn from research with mothers, with assumptions being made that maternal values can accurately represent shared parental values around infant feeding. I discuss whether this assumption holds true by considering whether early infant feeding holds a special “essentialist” status as an inter-embodied activity which may be experienced and valued in different ways by fathers and mothers. I discuss the implications of this in relation to

the introduction of non-oral feeding methods and the relationship parents have with their healthcare providers.

In Chapter 5, I discuss the relationship of oral feeding to pleasure, satiety, and commensality. I question whether oral feeding is always a pleasurable activity for everyone and discuss some of the ways that food pleasure may be learned behaviour. I also debate whether the introduction of GT feeding necessarily means that all feeding pleasure is lost. I conclude by discussing some issues around feeding as a commensal or social activity.

In Chapter 6, I move on to discuss the burden of care that arises from feeding a child with a neurodisability who does not have a GT in place. I draw on sociological literature around care to illustrate whether this burden is shared proportionately between parents not just in terms of physical care but also emotional and relationship work. I also discuss whether feeding care is tied to social concepts of “good” mothers.

In Chapter 7, I highlight the close relationship between feeding difficulty and the potential diagnosis of a neurodisability for a child. I go on to discuss how method of feeding may influence the ways that families cope with a disability diagnosis and the influencing concepts of normalisation and stigma. I discuss some of the ways in which parents tried to hold onto hope and what this may mean in terms of the values placed on the achievement of oral feeding as a developmental milestone.

In Chapters 8 to 10, I scrutinise “what goes on” when parents make the GT decision in partnership with their clinical team and family members. I explore how values and information around feeding are shared, how risks are presented and evaluated and how the parents’ perspectives and eventual decision can be affected by both clinical encounters and interactions with significant others.

In Chapter 11, I engage with some of the reflections made by the participants of my study regarding the quality of their decision and their satisfaction with their choice after GT feeding had been implemented.

Finally, in Chapter 12, I draw together my empirical findings and outline the impact and implications of this thesis and make recommendations for clinical practice.

Chapter 2 Literature Review

2.1 Introduction

Shared decision-making (SDM) developed as a way of engaging patients in a partnership with their clinicians to make evidence-based medical decisions that are also aligned with the patient's values, preferences, and treatment goals (Charles, Gafni, & Whelan, 1997, 1999a; Fiks et al., 2010). Most of what is understood about SDM has been derived from adult healthcare research and comparatively little research has been published in SDM in paediatrics to date (Fiks & Jimenez, 2010).

In this chapter, I will briefly consider what is meant by SDM in clinical practice and highlight the reasons why making medical decisions on behalf of children differs significantly from adult decision-making. I will then discuss whether SDM is an appropriate model for making decisions around GT placement on behalf of a child. In the remainder of this chapter I will describe the relevant literature around GT decision-making for a child with a neurodisability including an outline of my search processes.

2.2 A brief review of adult models of clinical decision-making

Very little is known about clinical decision-making in paediatrics (Fiks & Jimenez, 2010). In this section, I will briefly outline some of the concepts around decision-making that have been drawn from adult research with adults before moving on to discuss what implications this has for paediatric decision-making.

In the traditional medical model, a doctor diagnoses a patient's condition and decides to implement treatment. This model is now frequently viewed as paternalistic because the patient central to the decision (and/or their families) are excluded from the decision-making process (Charles et al., 1997; Charles, Gafni, & Whelan, 1999b; Emanuel & Emanuel, 1992). Some medical decisions suit this model because there is only one clearly preferred therapeutic option, or, as sometimes in emergency contexts, treatment must be instigated without delay (Flynn et al., 2012). However, for many decisions, especially pertaining to chronic conditions, the risks and benefits are unclear, or may vary according to the patient's own personal values. These are known as preference-sensitive

decisions because the patient's own personal preferences need to be united with medical knowledge to provide the most satisfactory medical care.

Two systematic reviews of decision-making literature with adults have demonstrated confusion about what SDM entails in terms of responsibility sharing which has made comparisons across studies difficult (Makoul & Clayman, 2006; Moumjid, Gafni, Bremond, Carrere, & Bre, 2007) but demonstrated that the most commonly cited models were those framed by Charles and colleagues (Charles et al., 1997, 1999b; Montori, Gafni, & Charles, 2006). Charles and colleagues offer three competing models to the traditional paternalistic model: the physician as agent model (where the clinician makes the decision having elicited the patient's values; the informed consent model (where the patient makes the decision after gaining the relevant information) and the SDM model (where the clinician's knowledge is united with the patient's preferences to make choices). To clarify this third concept of SDM Charles and colleagues outlined the three distinct steps which, in their view, allow SDM to be achieved. These three steps can be summarised as:

- i. A two-way information exchange of knowledge and values between health professionals and patients
- ii. The patient and health professional debate the pros and cons of the proposed treatment together
- iii. The choice of treatment is agreed upon by the health professional and the patient jointly

Although these models succeed in highlighting some of the dimensions of SDM they are limited because of their typical conceptualisation around one-off, dyadic, acute, adult healthcare decisions (Rapley, 2008). SDM models focus on ideal situations and there is a paucity of studies investigating multi-disciplinary collaborative practice meaning that such models are unable to demonstrate how the roles of multidisciplinary team and family members can integrate when making medical decisions (Reeves, Perrier, Goldman, Freeth, & Zwarenstein, 2013). I will now go on to discuss the implications of this in paediatrics where a number of stakeholders may be involved in the decision.

2.3 Shared Decision-Making in Paediatrics

Adult models fail to capture the unique challenges presented by paediatric decisions. As young children usually lack decision-making capacity, consent to medical procedures must be given instead by a person with parental responsibility who has the capacity to consent and has been appropriately informed. This is usually the child's parents but may sometimes be the child's legally appointed guardian. In addition to capacity, other issues exerting particular influence over paediatric decisions include the child's rapidly altering physical development, a longer life expectancy leading to higher stakes in the risks and benefits, and the lack of history regarding the child's known preferences. In addition to this, significant other family members such as grandparents with their own values and preferences may also potentially play a role in the decision (Lipstein et al., 2015; Lipstein, Brinkman, & Britto, 2012).

Although parents have been described as the "risk owners", clinicians may still operate as "risk managers" because parents' preferences must be considered with the clinician's view of the child's best interests (Craig & Higgs, 2012). If parents and clinicians disagree on what is clinically best for a child a dilemma arises and this can undermine the appropriateness and feasibility of SDM. The child's welfare should be the primary concern, and courts can overrule parent's decisions if they believe a particular line of treatment or even treatment withdrawal is in the child's best interests.

Research into how paediatric health-care decisions are made is scarce (Gabe, Olumide, & Bury, 2004). Two systematic reviews examining the specific support needs of parents making healthcare decisions on behalf of children have, however, demonstrated that many parents were interested in participating in SDM. Support needs included gaining information, talking to others and a sense of control when evaluating options (Jackson, Cheater, & Reid, 2008; Lipstein et al., 2012).

More recently, Wyatt et al. (2017) conducted a systematic review of the literature around paediatric SDM. They found that whilst the number of citations around paediatric SDM interventions has increased dramatically since 2010, research has remained extremely limited and only fifteen papers were identified as being suitable for their meta-analysis. The most common clinical scenarios investigated were immunisation, attention deficit

hyperactivity disorder and acute respiratory tract infection. The findings of their review showed inconsistent effects on the key outcomes which differed from study to study but did significantly increase parent knowledge and decreased decisional conflict.

Wyatt and colleagues (2017) expressed concern that 63% of the studies only included the parents and not the child. This issue was of lesser concern in my study because the children included were either very young or had some degree of intellectual disability. A minimal role for the children can therefore be assumed.

Researchers investigating SDM in adults have traditionally focused on scenarios where there is clinical equipoise and there is no clearly superior medical option (Elwyn et al., 2012). However, in contrast to this, Wyatt et al (2017) showed that the clinical scenarios in the paediatric literature focused more on attempts to steer parents towards actions where there is a clinically preferred option such as immunisation. Such research may be helpful but does little to unravel the complexity of decision processes when there is no clearly preferred clinical option.

Only one paediatric SDM model is identifiable in the literature (Whitney et al., 2006). This model, which has emerged from the field of paediatric oncology, is somewhat complex and has received only scant attention. To the best of my knowledge it has not been validated nor extended into other paediatric decision domains. However, their overarching argument, which I will revisit in this thesis, is that different decision-making paradigms (traditional, informed, and shared) may be the ethically appropriate choice in paediatrics depending on clinical context.

In summary, no commonly cited paediatric model for SDM exists. Most of what is known about paediatric decision-making is drawn from a very small number of studies or based on adult research. Given the additional complexities of paediatric decision-making this is a matter needing urgent attention. By undertaking this study, I also expand the knowledge base around paediatric decision-making. I will now provide a review of the research regarding the decision-making process for paediatric GT placement that has been conducted to date.

2.4 Narrative Literature Review

2.4.1 Aims and objectives

To review the existing literature regarding GT decision-making for children with neurodisabilities and feeding difficulties.

2.4.2 Methods

Studies reviewing decision-making around GT placement in children have sometimes included children with a variety of medical conditions. However, the nature of the illness process is a highly significant factor when making the decision about GT placement. Thorne, Radford, & McCormick (1997) found that parents faced with their child's immediate life-threatening event understood GT to be a "reasonable component of an otherwise complex and overwhelming treatment plan" (p.91). However, in contrast to this, the decision to place a GT in a child with neurodisabilities may signal to parents that health professionals have given up any expectations of recovery. In addition to this, some research has also indicated that people with neurodisabilities may have higher rates of complications after GT insertion than those with other conditions (Kastner, Criscione, & Walsh, 1994). These reasons suggest the existence of a variety of decision-making pathways. This review therefore specifically focuses on research pertinent to decision-making processes around GT placement for children with neurodisabilities rather than other potential reasons for GT placement, such as heart disease or cancer.

When I first began this literature review in 2012, preliminary searches revealed that a thorough systematic review of qualitative studies of decision-making around GT feeding in children with neurodisabilities had only just been published (Mahant, Jovcevska, & Cohen, 2011). They concluded, from their synthesis of the eleven studies which they identified, that the main decisional difficulties for parents related to "the meaning of feeding by mouth and feeding through a tube for parents and the values they place on them" (Mahant et al., 2011 p 1480). However, their review only included qualitative studies which had used in-depth interviews or focus groups. These qualitative studies focused almost exclusively on the maternal experience. Quantitative surveys or observational studies were also excluded. I therefore set out to extend their review by also including quantitative and observational studies. The protocol for this search was

designed in conjunction with a medical librarian (Appendix A: Systematic Review Protocol, p 244). In 2012, this extensive systematic search identified only five additional papers which met the criteria because most of the quantitative research and additional qualitative research papers included children with a range of medical conditions, some of them unspecified. RSS Alerts were set up with all included databases as well as Google Scholar. Further systematic searches were also carried out annually using identical search strategies to the above up until 31st of July 2017. These additional research strategies resulted in only two further papers which met the inclusion criteria. One of these was a quantitative paper from Saudi Arabia (Alsaggaf, Jan, Saadah, & Alsaggaf, 2013) and the other was a UK qualitative paper which was one of a series by the same lead author (Brotherton & Abbott, 2011).

All included studies involved some element of decision-making, although the actual purpose of the included research was primarily to examine the caregiver experience and discussions around the decision itself were extremely limited. Each individual study was reviewed and data extracted onto an extraction sheet (Appendix B: Data Extraction Sheet, p. 251) specifically designed for this purpose with the aid of ESRC guidelines on narrative synthesis (Popay et al., 2006).

2.4.3 Results

The summary statistics for the final systematic search carried out in July 2017 can be seen in Appendix C: (Search Summary Statistics, p 256). A brief summary of this review is presented in tabulated form to highlight the gaps in knowledge around decision-making around GT placement in children with neurodisabilities (Appendix D: Data Extraction Table). Almost all GT decision-making research has been retrospective in nature by examining the decision-making process after the decision had been made and the GT in-situ.

Only three of the studies have examined parent perspectives prior to GT placement. Brotherson, Oakland, Secrist-Mertz, Litchfield, & Larson (1995) interviewed three families about the decision-making process prior to insertion. However, that study was carried out in the USA and some of the factors influencing the decision (such as the cost of equipment and feeds) differ from the situation in the UK, where healthcare is free at

the point of care. The other two studies (Craig & Scambler, 2006; Craig, Scambler, & Spitz, 2003) were from the UK and formed part of one larger study and therefore included interviews with the same cohort of 22 mothers. Eighteen mothers had already made the decision to go ahead at the time of first interview and therefore the perceptions and experiences of these mothers during the decision-making process and how these may be modified was not captured. The only pre-decision study examining clinicians' perspectives involved fictional cases (Worley, Stevenson, Rosenbloom, & Sullivan, 2007).

Most of the research evidence around decision-making in GT feeding discussed below has been obtained retrospectively. In most cases, the children had been GT fed for several years and parents' accounts of the decision may have been modified with experience. Only two studies explored some parents' decision-making processes related to GT insertion immediately post-surgery. One study only included two participants at this stage of the journey (Brotherson et al., 1995). A larger Canadian study (n=50) also included ten children with cardiac disease and the speed with which the decision had to be made is unknown (Guirriere, McKeever, LLevellan-Thomas, & Berall, 2003).

Nearly all of these retrospective accounts have been gathered from mothers. Their attitudes and values may differ from fathers and other caregiving relatives as these have not yet been adequately studied. No UK study has included fathers and only 8 fathers have been included worldwide. Some research (Guirriere et al., 2003; Morrow, Quine, Loughlin, & Craig, 2008; Petersen, Kedia, Davis, Newman, & Temple, 2006; Smith, Camfield, & Camfield, 1999; Thorne, Radford, et al., 1997) has included other types of caregivers such as foster carers or staff in group homes who may hold different viewpoints or degrees of accountability. As Thorne et al (1997 p. 96) point out "the decision to introduce a GT may have entirely different meanings for the family with total daily responsibility than it has for the family that has relinquished everyday care to others".

Such a paucity of published research meant that there was little to add to the review around decision-making that was already in existence. Given that most of the included studies focused on caregiving with the decision-making process being a minor point, I repeated the literature search to include other papers that also described the caregiving

experience of families caring for children who have had a GT placed even if the decision was not explicitly discussed in the paper. This literature review resulted in an additional thirteen papers although only four of these originated in the UK, and two of these focused on different aspects of a study which had already been included (Brotherton, Abbott, Hurley, & Aggett, 2007; Brotherton, Abbott, & Aggett, 2007).

Although my narrative review specifically focuses on those papers which include a decision-making element, I also drew on the additional caregiving literature to support or refute those findings where appropriate to provide as much background knowledge as possible. A thematic approach was used to organise what is known about decision-making around GT placement in children with neurodisabilities. These are “the decisional dilemma”, “factors affecting decision-making”, “outcomes of the GT placement decision” and “parent and professional conflict”.

2.4.3.1 The decision dilemma

Retrospective studies carried out following GT placement have suggested that despite it being a reversible procedure, the decision-making process for parents was often one of decisional uncertainty, stress and conflict (Brotherson et al., 1995; Craig & Scambler, 2006; Craig et al., 2003; Guirriere et al., 2003; Morrow et al., 2008; Petersen et al., 2006; Rouse, Herrington, Assey, Baker, & Golden, 2002; Sleight, 2005; Spalding & McKeever, 1998; Thorne, Radford, et al., 1997). Parents wanted to protect their child from suffering and possibly life-threatening interventions such as anaesthetics (Guirriere et al., 2003; Morrow et al., 2008).

Petersen et al. (2006) retrospectively examined perceptions of feeding and adherence to feeding recommendations for 26 caregivers of children who had CP and a GT. A negative response to the GT recommendation was reported by 18/26 caregivers. The authors suggested that some parents delay GT placement even after their child has had several hospitalisations for respiratory infections due to aspiration, despite showing less hesitation in agreeing to other more invasive or permanent procedures. Similarly, Spalding & McKeever(1998) found that only one mother in their study readily consented to having the GT placed. The other mothers needed to “give in” to the tube and this caused delay. Other authors also drew attention to the delay arising from uncertainty

which seems to be an international phenomenon (Alsaggaf et al., 2013; Avitsland et al., 2006; Brotherton & Abbott, 2011; Martínez-Costa, Calderón, Gómez-López, Borraz, & Pedrón-Giner, 2013; Wilson et al., 2010).

Knowledge about decision-making has therefore been drawn from a very small number of studies and the UK experience is poorly represented. In Peterson's study, for example, the majority of their participants were African Americans who may place a different cultural value on oral feeding and the applicability of this finding to a UK population is limited.

2.4.3.2 Factors influencing decision-making

2.4.3.2.1 The experience of oral feeding

In some studies, parents described extremely lengthy mealtimes producing strong emotions of frustration, anger, rejection and guilt during oral feeding (Brotherton et al., 1995; Sleigh, 2005; Spalding & McKeever, 1998). Feeding was sometimes described as a "battleground" (Thorne, Radford, et al., 1997) or "war" (Craig et al., 2003) and left little time for other family activities (Rouse et al., 2002). Some mothers stopped going out with their child to avoid unsolicited advice about feeding and for fear of being accused of neglect (Spalding and McKeever, 1998). Mothers sometimes recalled difficulties in convincing health professionals or other family members that their children had significant feeding difficulties (Spalding and McKeever, 1998).

Conversely, GT feeding was frequently viewed as a way of depriving the child of the pleasure and socialisation of the "normal" activity of oral feeding (Calderón et al., 2011; Craig & Scambler, 2006; Craig et al., 2003; Guirriere et al., 2003; S. W. Smith et al., 1999; Spalding & McKeever, 1998).

In a phenomenological study, the "lived experience" of two groups of mothers feeding a child with CP either orally or by GT was captured via interviews and expressed as prose (Sleigh, 2005). Her descriptive account demonstrates how both groups treasured oral feeding because the undivided attention is a means of providing intimate knowledge of the "normal" child with ordinary feelings and needs (p 378).

These two conflicting emotional stances are a major source of decisional dilemma which force mothers into a position of having to renegotiate their identities as successful mothers (Craig and Scrambler, 2006). In an endeavour to avoid GT feeding, mothers sometimes felt compelled to “try harder” with oral feeding (Thorne et al., 1997; Sleight, 2005). However, these findings have emerged from the experiences of mothers and may not apply to fathers.

2.4.3.2.2 The bio-medical emphasis

Health professionals often place high values on the child’s weight when making the decision to recommend a GT in a child with a neurodisability. At a multi-disciplinary professional conference held in London in 2004, healthcare professionals were asked to consider briefly presented cases and vote on important issues in GT decision-making using their clinical experience and knowledge of the relevant literature (Worley et al., 2007). If 90% of participants agreed with a statement it was considered that consensus was reached. Two of their five points of consensus were that “Under-nutrition severe enough to result in diminished subcutaneous fat with or without muscle wasting results in adverse health consequences” and “the initiation of enteral feeding in children with CP results in weight gain, reduces adverse consequences of under nutrition, improves the quality of life of children, and improves the quality of life of caregivers”. However, as discussed in Chapter 1, four systematic reviews have concluded that the risks and benefits of GT in this population are unclear (Ferluga et al., 2014; Gantasala et al., 2013; Samson-Fang et al., 2003; Sleight & Brocklehurst, 2004).

Craig et al (2003) concluded that this biomedical emphasis on health and weight gain does not adequately reflect parental concerns and that parents need more support when making their decision. Some parents felt their children were naturally thin because of their diagnosis and health professional’s expectations were too high (Morrow et al., 2008). Mothers felt under constant pressure to ensure their child was adequately nourished and felt guilty or ashamed about their child’s nutritional status (Morrow et al., 2008). Some health professionals felt that parents were reluctant to accept weight gain as important because of anxieties about the difficulty of managing a heavier child. However, this did not in fact emerge in these studies as an important issue for parents.

2.4.3.2.3 The information gap

Inadequate information about medical, emotional and routine practical aspects of GT feeding has been reported as a dominant theme leading to decisional conflict in a number of studies (Alsaggaf et al., 2013; Craig et al., 2003; Guirriere et al., 2003; Morrow et al., 2008; Thorne, Radford, et al., 1997). In one study, 25% of parents reported that they received most information only after agreeing to the GT placement procedure (Guirriere et al., 2003). Parents wanted information about the possible benefits of GT as well as its disadvantages. Parents expressed a wish to find out more, possibly through speaking to other parents.

2.4.3.2.4 Visibility of disability and stigma

Some parents reported an increased visibility of their child's disability following GT placement which they felt identified their child to others as abnormal in some way (Armstrong, Radford, & Thorne, 1997; Brotherson et al., 1995; Guirriere et al., 2003; Spalding & McKeever, 1998; Thorne, Kirkham, & MacDonald-Emes, 1997). This led one research team to suggest that some parents actually perceived the GT as a greater visible sign of disability than their child being extremely thin (Brotherson et al., 1995). When making their decision about GT placement, parents appear to oppose this form of feeding as unnatural and stigmatising. However, Craig and Scambler (2006), judged prevailing theories of stigma and coping to be more descriptive than explanatory. They argued that the visibility of an NGT could also be a source of unwanted attention, whereas a GT could be concealed and was therefore more discreet.

2.4.3.2.5 Issues around permanence and normalcy

Caregivers often viewed their disabled children as being on the spectrum of normality whilst health professionals were more likely to describe such children as "not normal" (Morrow et al., 2008). Parents may delay the decision to initiate GT feeding because it provides unwanted confirmation that their child's disability is permanent and severe (Craig et al., 2003; Spalding & McKeever, 1998). In contrast, Spalding and McKeever also found that for some mothers, the recommendation of a GT by medical professionals provided confirmation that their extraordinary difficulties in feeding their child was finally being acknowledged by others.

2.4.3.2.6 Family pressure

During the decision-making process, some parents felt pressurised by extended family members to accept or refuse any offer of GT placement. Some family members threatened to refuse to help care for the child if fed by GT (Guirriere et al., 2003).

2.4.3.3 Outcomes of GT placement

Despite caregivers being initially resistant to GT placement, quantitative surveys have consistently suggested that around 90% of caregivers are highly satisfied with the eventual outcome following GT placement and many would have accepted it earlier if they could have anticipated this outcome (Alsaggaf et al., 2013; Avitsland et al., 2006; Avitsland et al., 2013; Martínez-Costa et al., 2013; Pemberton, Frankfurter, Bailey, Jones, & Walton, 2013; S. W. Smith et al., 1999; Tawfik, Dickson, Clarke, & Thomas, 1997; Wilson et al., 2010). This positive response comes despite respondents often reporting high levels of minor complications and also attributing family problems and stress to tube feeding (Armstrong et al., 1997; Avitsland et al., 2006; Calderón et al., 2011; Michaelis, Warzak, Stanek, & Van Riper, 1992; Pahsini, Marinschek, Khan, Dunitz-Scheer, & Jaron Scheer, 2016; Pederson, Parsons, & Dewey, 2004; Pemberton et al., 2013; Smith et al., 1999; Townsley & Robinson, 1999).

It is possible that the quantitative survey questionnaires requested only cursory data on quality of life. Sullivan et al. (2004) used a validated questionnaire (SF 36 II, 1999) measuring eight health domains and found that 12 months after GT placement, carers reported a significant and measurable improvement in their own quality of life after insertion of the GT feeding tube in their child. However, this instrument includes domains not relevant to feeding such as the parent's own pain. It is arguable that using such closed structure questions to evaluate the health and social outcomes for children and parents may not always adequately capture feeding related concerns.

Nevertheless qualitative research also lends support to the finding that the majority of caregivers report satisfaction with the GT despite their previous decisional conflict (Brotherson et al., 1995; Guirriere et al., 2003; Morrow et al., 2008; Petersen et al., 2006; Spalding & McKeever, 1998). Almost immediately after the GT had been inserted, most mothers felt considerable relief because the “godsend” and “blessing” (p 239) led to

positive changes for the family (Spalding & McKeever, 1998). The majority of parents in these studies reported beneficial effects of improved nutrition and hydration, decreased health complications, and a reduced burden of care. A prospective longitudinal study investigating the quality of life of children with neurodisabilities showed no changes in the quality of life of the child pre- and post-GT. However, parents did feel that the GT tube had a positive impact on the child's general health (Mahant, Friedman, Connolly, Goia, & Macarthur, 2009).

Those research studies which included health professionals also indicate a dominant belief that the GT had a positive impact on quality of life for carer and child (Morrow et al., 2008; Rouse et al., 2002; Thorne, Kirkham, et al., 1997). However, a quarter of the mothers in Spalding and McKeever's study were disappointed from initiation of GT feeding because their child did not thrive as hoped. Furthermore, although other mothers reported initial satisfaction, this gave way to growing concerns around the perceived abnormality of the feeding method. They reported that tube feeding was time-consuming and feeding schedules continued to dominate family life. All the mothers in this study hoped to see the "mixed blessing" of the GT closed eventually (p 241).

Parents with a negative experience of GT described poor follow-up services, inadequate resources, and deterioration in the child's quality of life as measured by the child's health, happiness or socialisation (Morrow et al., 2008, p 121). Respite care for GT fed children may be limited or difficult to access (Thorne et al., 1997; Smith et al., 1999). Brotherson et al. (1995) found that more than half of families in their sample lost practical support from friends and family once tube-feeding commenced.

Qualitative research clearly indicates a more complex picture with mothers having "an almost secret ambivalence that results from loss of normality and intimacy that had been associated with oral feeding" (Sleigh, 2005 p 380). Even when satisfaction with the GT is reported, many mothers questioned the nutritional value of the formula and supplemented feeds through the GT with foods such as soup, cereal or juice (Petersen et al., 2006 p 713). Some continued to feed their child orally foods "with taste" against strict nil by mouth recommendations (Thorne et al., 1997; Peterson et al., 2006).

2.4.3.4 Parent and Professional conflict

Only two studies explored parent and professional relationships from the perspective of both parents and healthcare professionals (Thorne et al, 1997, Morrow et al, 2008). These studies both suggest that there are several important differences which influence the way in which GT is viewed by parents and professionals. To healthcare workers, GT may be viewed as a familiar and logical step in the management of feeding problems in children with neurodisabilities. However, for families, the decision to have a GT placed is a unique occurrence and may be an extremely significant and meaningful transitional event.

Thorne et al (1997) found that some healthcare professionals failed to recognise the symbolic significance of GT placement and felt confused and frustrated by seemingly irrational refusals by parents. The same study also concluded that although the decision to try GT feeding was sometimes considered to be mutual, in the clear majority of cases conflict between professional and parent opinions occurred. Usually, the healthcare team were convinced of the need for GT long before the idea was acceptable to parents, although there were occasional circumstances when it was the professionals who remained resistant to the idea. Nevertheless, neither parents nor nurses considered caregiver convenience an appropriate rationale for GT even when feeding was stressful and time consuming. It was only when serious concerns about weight gain and safety of swallow arose that discussions about the decision to insert a GT became acceptable to parents. Thorne et al (1997, p 98) concluded that “GT decision-making is highly context-dependent, replete with multiple meanings, and typically complicated by avoidable miscommunications and misunderstandings between parents and health care professionals”.

Similarly, Morrow et al (2008) found that health professionals and parents spoke expansively about the difficulties encountered when communicating with each other. Parents and professionals raised the same issues of parent-child interaction, delivery of health services, the child’s emotional well-being, the child’s physical well-being, and the child’s socialisation, but placed different emphasis on the values they placed on them.

Some mothers also stated that the tube insertion had been booked for their child before they had given consent, resulting in conflict with healthcare professionals.

In the most recently published decision-making study from the UK, Brotherton and Abbott(2011) drew attention to parent-professional conflict, in the form of lack of mutual trust, during the decision-making process around GT placement. Their sample included seventeen biological mothers and three female foster carers. Mothers were sampled from a range of ethnic backgrounds; however, the ethnicities of the included sample were not stated. Children had a variety of medical conditions although the number of children with neurodisabilities was again not specified. The findings of this study are difficult to interpret because of inadequate definitions and conceptualisations. For example, children are described as having dysphasia (a language disorder) rather than dysphagia. The authors concluded from their study that “Experiences of decision-making ranged from perceived coercion to true choice, which encompasses a truly child-centred decision” (p 587). It is difficult to see how their concepts of “perceived coercion” and “true choice” align with the more established definitions that I described in section 2.2. It is also unclear as to why “coercion” is described as being perceived whereas “true choice” is not. It is also difficult to be sure what the authors mean by “truly child-centred decision”. This statement seems to suggest that the decision is only child-centred when there is no perceived coercion of mothers, but it is possible that maternal resistance may not always be in the child’s best interests.

2.4.4 Summary and Implications for this thesis

This literature review demonstrates that mothers making decisions about GT feeding for child with a neurodisability feel inadequately informed and find this decision difficult. The very strong focus on maternal research means that the values and opinions of fathers and other family members have been largely unexplored. Despite this decisional conflict, global reports strongly suggest that most caregivers are highly satisfied with the eventual outcome once the GT has been placed.

There remains a paucity of studies addressing the GT decision and its potential outcomes. More research is needed to elicit the decision-making preferences and values of both parents to improve understanding of the steps and sequence of decision-making

and the values which enable or delay the decision. This would help determine where researchers and clinicians can intervene to provide the most effective information and support during the decision-making process.

Retrospective accounts also indicate that conflict between parents and professionals can occur during the decision-making process and that this can sometimes delay GT placement. However, no studies to date have examined the interactions between health care providers and parents as GT is being considered. Rapley (2008) proposed that it would be empirically rich to use ethnographic research to track a single patient or single decision to plot these distributed networks of encounters. One possible way to address this is to assess the deliberation process in real time by observing, recording, and analysing parent interactions with clinicians and significant others involved in the decision-making process.

In the following chapter, I will outline the theoretical foundations that I considered in order to ensure my research design should be a good fit for the research questions that arose from the literature review (Bryman, Becker, & Sempik, 2008; Langridge, 2004; Silverman, 2011; Willig, 2001). I will introduce the epistemological background to the methodologies employed in this study and then move on to describe the methods used.

Chapter 3 Methodological Approaches

3.1 Introduction

In the two previous chapters, I have summarised what is already known about decision-making around GT feeding in children with neurodisabilities. In this chapter, I firstly provide a brief overview of the epistemological and methodological frameworks that I embraced to form the justification for the alignment of my research within the qualitative paradigm, as well as the actual methodologies chosen to approach the enquiry. The second half of the chapter details the research process which I undertook including the data collection stages, analysis, ethical considerations, and reflexive actions.

3.2 Research Design

The two preceding chapters have highlighted several gaps in the knowledge around decision-making in GT feeding in children with neurodisabilities. Firstly, what is known to date around this topic, and indeed children's healthcare more generally, has focused almost entirely on the views of the child's mother, yet the resulting findings are frequently presented as representative of both parents (Coley, 2001; Davison, Charles, Khandpur, & Nelson, 2017; Khandpur, Blaine, Fisher, & Davison, 2014; Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). I therefore began with the starting point that research around GT decision-making in children with neurodisabilities had not adequately considered the viewpoints of fathers, the extended network of significant family members and friends, or members of the healthcare team. Therefore, canvassing the opinions and exploring the contributions of this network forms the first primary focus of this study.

Secondly, what is currently known from previous studies has been gathered retrospectively, sometimes many years after the event. Whenever there are challenging medical decisions to make, the risks and benefits must be weighed up, and judgements made, regarding what level of risk is acceptable (Elwyn, Edwards, Gwyn, & Grol, 1999). It is therefore difficult to reflect accurately on previous decisions because the previously unspecifiable risks and the consequences of taking those risks are now known. This

means that participants' evaluation of their decisions may have changed in the light of this new knowledge. Therefore, a second focus of this study was to track GT decision-making in real-time as the risks and benefits are being evaluated.

Thirdly, as I have described in Chapter 1, whilst concepts and frameworks around sharing decisions in adult medical encounters have been rapidly developing over recent decades, decision-making in paediatrics lags behind. The third focus of this study is therefore to explore how paediatric medical decisions are shared, how conflict in paediatric decision-making can be avoided, and how difficult decision processes can be supported by healthcare teams.

Confusion can arise around the value of research if the philosophical background of the research is not properly considered (Guba & Lincoln, 1994). I will therefore briefly explain the influence of philosophy on my research strategy. In the following section, I begin by describing the rationale for choosing qualitative research.

3.3 The qualitative research paradigm

Qualitative research is an umbrella-term that encompasses a wide range of methods of data collection, analytical approach, methodology and interpretation which provides alternatives to the traditional quantitative approach which emerged from a positivist paradigm. Qualitative research aims to improve the understanding of social phenomena in natural settings with emphasis on the meanings, experience and views of all participants (Charmaz, 2006; Corbin & Strauss, 2008; Mays & Pope, 1995). Findings can sometimes supply evidence that contradicts prevailing quantitative assumptions. Although some have argued that such explorations can lend themselves to generating theory via inductive reasoning (e.g. Bryman, Becker and Sempik, 2008) I have not set out to generate theory, but to locate myself in the centre of the GT decision-making world by being actively involved with the entire research process of recruitment, data collection and interpretation. I believe this to be crucial in producing a transparent account of the families' experiences.

As the purpose of this thesis is to improve clinical support around GT decision-making, I concur with Carter and Little (2007) in arguing that ontological discussions around the

nature of reality are outside the remit of a pragmatic piece of research. I will therefore limit my philosophical discussions to epistemology, methodology and methods.

3.4 Epistemology

Epistemology is the theory of knowledge. Three core epistemological stances can be demonstrated in the literature (Crotty, 1998).

Objectivism is the stance most usually aligned with quantitative research methods. This holds that an object remains an object regardless of whether anyone is consciously aware of it. Discovering the meaning of an object simply means that we are unveiling something that already existed.

Subjectivism is the antonym of objectivism. Embracing this philosophy takes on the belief that objects make no contribution of their own to the generation of meaning which is entirely imposed on objects by subjects. No access to the external world beyond our own observations and interpretations is therefore possible.

Thirdly, constructivism or interpretivism refers to how interactions between subjects and objects construct meaning, and can result in more than one valid interpretation. Taking this position means that the methods of natural science are not appropriate to explore the social world, because researcher and participants impact on each other.

A second epistemic debate concerns the relative merits of inductive and deductive methods of scientific enquiry. Snape & Spencer (2003) explain this as “Induction looks for patterns and associations derived from observations of the world; deduction generates propositions and hypotheses theoretically through a logically derived process” (p.23). The inductive approach is generally associated with qualitative enquiry because of the focus on “rich description and emergent concepts and theories” (Snape & Spencer 2003 p. 14).

The epistemology that underpins my study is therefore both constructivist/interpretivist and inductive and I recognise that any findings are a product of the interaction between the research participants and myself.

3.5 Methodologies

I have already described how my research is broadly qualitative in nature. The choice of which qualitative method to use should theoretically reflect the researcher's epistemological positions but in reality many named research methodologies have derived from a variety of epistemologies and they have sometimes been used erroneously (Thorne, Kirkham, & MacDonald-Emes, 1997). I believe that in the "real" world of social research within resource-stretched clinical environments, the major focus should be on addressing the research question and study aims. For this reason, I have embraced two distinct qualitative methodological approaches which I believe most closely match the aims of my study.

3.5.1 Interpretative description

For most of this study, I have used the methodological approach of interpretative description which was originally developed for a nursing context, and derives from an ethnographic, grounded theory, and phenomenological ancestry (Thorne et al., 1997; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004, Thorne, 2008). The overall aim of this methodology is to generate an interpretation which goes beyond a simple journalistic description of the themes in the data. A good interpretative description should inform clinical understanding of the phenomenon and enable clinicians to develop appropriate intervention strategies by producing an in-depth analysis whilst staying as close to the original data obtained as possible (Neergaard, Olesen, Andersen, & Sondergaard, 2009). For example, interpretive description has been successfully used to examine decision-making in childhood asthma (Archibald, Caine, Ali, Hartling, & Scott, 2015) and indeed for one of the studies on tube-feeding (Thorne et al. 1997). It is therefore a good fit for my own aims and epistemological stance.

In keeping with other strands of qualitative analysis, interpretative description is based on the belief that the best sources of expert knowledge are those people who have lived those experiences themselves (Morse, 1989). However, because clinical research is bound by timescales, ethical considerations and costs, a pragmatic view must be taken for the study design. Under clinical research restrictions a truly inductive bottom-up approach is not usually possible. To gain the appropriate approvals, the research must

build upon existing knowledge drawn from thoughtful consideration of the work of others as well as what has been observed clinically or raised by patients and their families. Interpretative description therefore presumes that some theoretical knowledge or identified clinical pattern observation already exists. However, a critical understanding of the topic, preferably drawn from a systematic review of what is already known about the subject, forms the basis of the preliminary analytical framework that helps researchers make their first decisions regarding the research design, ethical considerations and sampling methods.

3.5.1.1 Sample selection

The initial scoping and critical appraisal of the literature which had formed part of the analytical framework identified several limitations in the previous research around GT decision-making. This meant that although the positions or experience of each participant could not be known until data collection was underway, I was able to place my emphasis on recruiting participants whose voices had not previously been heard. The methods used to select my participants will be discussed more fully in the practical method section.

3.5.1.2 Data analysis

Interpretive description encourages repeated immersion in the data. This immersion does not mean simply sorting into themes but requires creating linkages, theorising and re-contextualising (Morse, 1994). This meant that I needed to intimately know and describe individual cases as well as addressing the dialectic between individual cases and common patterns (Thorne et al., 1997). Strategic periods of immersion in data collection are interspersed with periods of immersion with the data itself in order to refine and develop emerging concepts (Strauss, 1987).

3.5.2 Conversation analysis

3.5.2.1 Introduction

As described in Chapter 2, paediatric GT decision-making is a clinical area where conflict has previously been identified. These studies have attributed this conflict and delay to several important differences in how parents and healthcare professionals view GT. However, previous research approaches have been retrospective in nature and have not

focused specifically on the decision-making process as it unfolds. They have therefore only been able to make a limited contribution to our understanding of the interactional processes involved.

One of my intentions when embarking on this study was to seek to improve understanding about parent/health professional interactions by uniquely applying the methodology of conversation analysis (CA) to this context. CA is an established method of studying social action by focusing on specific sections of episodes of human interaction which would have occurred quite naturally (Sacks, Schegloff, & Jefferson, 1974). Although I did employ the technique originally on some specific interactional sequences in my data, once complete I did not feel that this additional layer of technical understanding added much that was useful to this thesis in any pragmatic or clinical sense. In fact, I found myself agreeing with some writers who argued that the obsession with the mechanism of talk and the “clacking” of turns (Moerman, 1987 preface xi) could turn off busy practitioners who might otherwise have been willing to engage with my findings. Instead, I have limited my analysis to the use of some of the broader concepts of CA which aid understanding of how encounters and speaking turns within those encounters are organised. In this section, I therefore very briefly describe the central concepts of CA as applied to my practice and justify how this has helped me gain additional insight into how interactions about a child’s feeding difficulty are organised between parents and professionals.

3.5.2.2 Method development

CA focuses on the structures of interaction by drawing on conversational sequences which are well-established in ordinary daily life, and is underpinned by a belief that talk carries out social actions (Schegloff, 1991). The methodology of CA was originally developed by Sacks (Sacks, Schegloff, & Jefferson, 1974), who was inspired by Goffman’s study of social order and face-to-face interaction (Goffman, 1990) and Garfinkel’s development of ethnomethodology (Garfinkel, 1967). I will be drawing on both of these theorists in Chapters 8 to 10.

3.5.2.3 Conversation Analysis and Medical Interactions

Knowledge derived from earlier CA studies is particularly relevant to my chapters on family interactions with health practitioners, because users of the method have been able to demonstrate how such interactions typically unfold. For example, CA has been used to depict the typical or “ideal” sequences which occur during patient’s appointments with General Practitioners (ten Have, 1991). The consultation sequence begins with an opening, followed by the patient’s complaint, the examination or test, the diagnosis, treatment or advice-giving and finally, closing. Typical encounters leave little room for patients to initiate their own sequences of action. This results in patients needing to use “free” moments to launch talk that occurs out of this sequence. For example, patients have been observed to introduce a fresh medical complaint when the doctor was writing a prescription. More recently, CA has been used to examine how healthcare professionals close encounters with people with dementia in the acute hospital setting (Allwood et al., 2017). In Chapters 8 to 10, I will draw on these findings and some of the broader CA techniques, which I will detail further in the following section, to enable a more comprehensive exploration of:

- 1) How parent and clinician participants systematically organise their interactions to resolve problems in shared understanding, and
- 2) How the conversational pattern leads, or fails to lead, to shared decision-making.

3.5.3 Conclusion to Methodologies

In the above section, I have justified the use of qualitative research for this study. Although many forms of qualitative research exist, I have suggested that the method of interpretive description (Thorne, Kirkham, et al., 1997; Thorne et al., 2004) most closely describes the steps I wish to undertake for this research whilst adhering to the ethical requirements of a paediatric clinical service. I have also argued why I believe that drawing on the broader principles of CA provides a powerful tool for the analysis of parent/health professional interactions. In the next section, I will detail the specific methods employed in this study, explaining how I undertook an interpretive description. I will also outline how some aspects of CA were implemented in this project.

3.6 Methods

3.6.1 Introduction

In this section, I will detail the specific research process adopted. This will include the development and finalisation of my research design, the ethical considerations, data collection methods and the analytical process including some reflections on my role as researcher.

3.6.2 Research Design

3.6.2.1 Aims and objectives:

The original aim of my research for which I gained a favourable ethical opinion (Appendix E) was to examine how clinician/parent interactions influence parents' decisions about GT feeding for children with neurodisabilities and feeding difficulties.

Objective one (I) of my study, as reported in Chapter 2, was to review systematically the existing literature regarding GT decision-making for children with neurodisability. The knowledge derived from this literature review informed the development of the research question and the further aims and objectives of this study.

The two further objectives of the study for which I initially gained ethical approval were:

- II. To describe the interactions between a small number of parents and professionals and understand how these may influence the GT decision-making process from the first referral for feeding difficulty.
- III. To test the generalisability of the findings from I and II across NHS trusts.

3.6.2.2 Review phase

The systematic search of the literature and recruitment drive began in tandem. As I undertook these procedures two important issues became known. Firstly, although my initial review had suggested that a reasonable amount of retrospective work had been carried out, it gradually became clear that this retrospective work was inadequate in its scope. Most of the retrospective research evidence evolved from the opinions of mothers. It was clear that the perceptions, experiences and needs of other decision stakeholders, most notably fathers, had not been captured. Secondly, recruitment for

objective two of the study in which I wished to observe and describe a number of interactions around GT decision-making was proving extremely problematic. I was attempting to recruit families very early in the GT decision-making process. For ethical reasons that I will describe in the methods section, I did not have direct access to the families in the clinical services and was reliant on families being identified by clinicians. The clinicians' workloads meant that they tended to remember the study requirements when encountering a family where the GT decision was already well underway and most of the decision-making stages had been missed. I therefore redirected much of my attention to the identified knowledge gaps around the inadequate attention paid to the viewpoints of fathers, significant others and health professionals as well as ensuring consideration of families with disparate views around the decision. I accordingly changed the third objective of my research to reflect the findings of the literature review and submitted an ethical amendment which was approved (Appendix F). My revised third objective was therefore:

- III. To retrospectively explore the viewpoints of people who have a significant relationship to a child who may have influenced a recent decision about gastrostomy feeding for a child with a neurodisability. Significant people may include parents, grandparents, siblings, carers, schoolteachers, and healthcare workers depending upon each child's unique circumstances.

3.6.2.3 Study Procedure

3.6.2.3.1 Identification and Recruitment of Participant Families

I actively sought families representing a variety of decision pathways to capture as wide a range of the experience of decision-making around GT placement in children with neurodisabilities as possible. Suitable families were recruited from the neurodisability services of two local NHS trusts. The main eligibility criteria were for each family to have a young child with a medical history indicative of feeding difficulty and a confirmed or expected diagnosis of neurodisability. Favourable ethical opinion for the study was obtained from the Grampian National Research Ethics Committee and the NHS Trust Research and Development offices for each Trust. Once approval was secured I met the

key staff members involved with the families to establish a relationship and brief them fully about the study.

Families fitting the eligibility criteria were initially informed about the study by interested paediatricians and speech and language therapists who were already involved in their care and with whom I had discussed the study. Parents and/or carers were shown a brief information leaflet during their appointment. Any family who was interested in participating was asked to complete a form requesting permission for their contact details to be passed to me by the clinicians in the provided stamped addressed envelope. I contacted parents who had returned permission slips by telephone to briefly explain the aims and rationale of the study and exactly what would be involved for participant families. I clearly explained to the family members that they did not have to take part in the study, but if they chose to do so, they could withdraw at any time without giving a reason and that this would not affect their child's care.

If the parents were still interested after these introductory discussions I sent a more detailed parent information sheet to their home address (Appendix G: Example PIS). Parents were given one week to study this information and consider their participation before I made a follow up telephone call. If, after this period of reflection, they were still willing to enter the study, I arranged to meet with the family at their preferred location which proved to be the family home in each case. During this first meeting, parents were asked to provide written consent to participate in the study including digital audio recording of the clinical encounters and interviews. Baseline information about the child's early birth and developmental history and descriptive accounts of their past and current feeding status was gathered. Parents participating in the retrospective study were asked to provide the names of those people who they felt had played the biggest part in influencing their GT decisions, and I obtained their permission for me to approach them. I also asked for parental consent for me to have access to copies of letters and reports about their child's feeding from their child's hospital notes (Appendix H: example consent). Over the life of the study, verbal checks on continued participation, and consent to attend each consultation or meeting was also sought.

3.6.2.3.2 Recruitment of participant clinicians

Health professionals providing feeding clinic services to families recruited to the study were also invited to participate in the study. The potential clinician participants were given a clinician information sheet explaining the study. They were then given at least one week to study this information and consider their participation before I made a follow-up call. If they were willing to be included, I arranged to meet with them at their workplace and written consent to participate in, and digitally record, the clinical encounters and interviews was obtained.

3.6.2.3.3 Participant details

Six families were recruited to the retrospective arm of the study and one family to the longitudinal arm. In the following section, I will very briefly introduce each child at the centre of the decision. Each child and related participants has been allocated a pseudonym. For clarity, the family network around each child have pseudonyms beginning with the same letter. For example, Elliott's parents are Elaine and Eddie. I have kept the information about each child deliberately brief because of ethical considerations as many have very rare conditions. However, all families were resident in the North of England, all children had two parents living at home, all fathers were in full-time employment and all interview participants had English as their first language.

Participants in the retrospective study included six mothers, four fathers, one paternal grandmother, two maternal grandmothers, two maternal grandfathers, two maternal best friends, one paternal aunt and one adult sibling. Unique to this research, two children aged five and sixteen could participate. The 5-year-old child had a GT at the time of his interview whereas the 16-year-old had previously had a GT that had been removed. These children provided some particularly useful insights into what it was like to have the decision made about them and what it was like to live with that decision. One father declined and another cancelled on several occasions, which I viewed as implied non-consent.

From the clinical teams, I interviewed two speech and language therapists, one dietician, one health visitor, two paediatricians, and one GP over nine interviews. One paediatrician and the dietician were interviewed twice as they were involved with two

of the children. One dietician had left her post, one gastroenterologist did not reply to the invitation and one community nurse declined.

For the longitudinal arm of the study, I observed and recorded one videofluoroscopy, two Team Around the Family (TAF) meetings, one feeding clinic and one appointment with the gastroenterologist. I also interviewed one speech and language therapist to discuss a videofluoroscopy. Details of the participant families are summarised in Table 3-1.

Name	Sex	Diagnosis	Reason for recruitment	Status at recruitment	Interview participants
Adam	M	Multiple disabilities including CP and cortical blindness	Strong maternal resistance	GT in place	Mother (Angela), Father (Anthony), Paediatrician, Dietician, SALT, HV, GP
Billy	M	Down's syndrome plus other rare genetic condition	Wanted earlier offer	Awaiting GT	Mother (Beth) Father (Brian) Maternal GM (Brenda)
Craig	M	Not known	No resistance to GT	GT in place	Mother (Claire), Father (Colin), Maternal GM (Clara), Paternal GM (Clodagh), Paternal aunt (Christine) Maternal best friend (Chloe).
David	M	CP	Paternal indecision	GT in place	Mother (Denise), Maternal GF (Dick), SALT, Paediatrician
Elliot	M	Multiple disabilities causing impaired motor function. No intellectual impairment	Strong maternal resistance	Resisting GT	Mother (Elaine), Father (Eddie), Maternal GM (Ethel), Maternal GF (Eammon), Adult sibling (Evan), child, maternal best friend (Esther), Paediatrician, Dietician
Florence	F	Extreme prematurity. Global developmental delay	Ongoing decision	Ongoing decision	SALT
Gary	M	CP	No resistance to GT	GT removed	Mother, child

Table 3-1: Participant Families

3.6.2.3.4 Carrying out interviews

All family participants chose to be interviewed at either the child's home or their own. Most interviews were carried out individually and in a private room. Both interviews which included grandfathers were carried out jointly with another person at their request. The post-GT follow-up interview with Elliot's family was a joint interview with three family members participating plus a further family member observed. The two children, Gary age 16 and Elliott aged five, were both given the opportunity to be interviewed with the parent or individually. Both opted to be interviewed individually with parental consent. To minimise disruption to clinical services, clinical team members were all interviewed at the place which was most convenient to them, which was usually their place of work.

Interview topic guides were developed to guide the interviews, prior to ethical approval. The guides were set out in a logical order beginning with the child's diagnosis of feeding difficulty through to the GT placement where this had been made. However, participants were informed from the outset that they could tell their story in their own way. The topic guide needed to be highly flexible because of my wish to take an inductive approach to the analysis and I wanted to be sure that families had the opportunity to cover topics of interest that may not have occurred to me. I was also aware that the subject under discussion was a sensitive one that could be distressing for participants. It was therefore essential to retain maximum flexibility to ensure diplomacy and sensitivity to the participants' emotional needs. The topic guides therefore acted more as aide-memoirs and had flexible open-ended structures that contained overarching questions and some additional points which could be explored if needed. Often the issues on the topic guide were explored quite spontaneously without the question needing to be asked.

The length of interviews varied. Members of the clinical team were bound by their schedules and it was important to honour this. These interviews were kept deliberately short and were no more than 20 minutes. Interviews with family members ranged from around 15 minutes to more than two hours. One mother contacted me following her

interview to request a second visit to explore additional issues that had occurred to her after a period of reflection, and this request was honoured.

To ensure accuracy, interviews were recorded with a digital recording device with the participant's written consent. Brief field notes, which included descriptions of key interview factors, were also taken. For example, in one family home, a large selection of home-made cakes was offered and this observation became relevant during the analysis when my experience was aligned with the experience of the health professionals working with the family. Field notes were taken after the interview rather than disrupting the flow of interview at the time. Each interview was followed by an informal chat and the participants given a thank you card and a £10 shopping voucher as an appreciation for their contribution to the study.

3.6.2.3.5 Carrying out clinical observations

The observations for the longitudinal study (family of Florence) were naturalistic, occurring at the location where the consultation or meeting was already happening. The TAF meetings were conducted at specialist neurodisability centres. The feeding clinic, videofluoroscopy and gastroenterology appointment were carried out in the clinics at a tertiary paediatric hospital. I kept in touch regularly with Florence's family regarding upcoming feeding-related appointment times. The day before the expected encounter the family were asked if they were happy for me to attend that appointment. As they were always agreeable, I then arranged to meet Florence and her family at the appointment venue at a designated time. Other than introducing myself and obtaining verbal consent from all those present, I did not participate in these clinical encounters but remained in the background as unobtrusively as possible and generated field notes around the consultation.

For the clinical consultations, I wanted to ensure that I conducted data collection in a manner consistent with CA principles. The process of recording the consultation was therefore guided by two aims. Firstly, I needed to collect very clear audio records of what was naturally occurring during the clinical interactions to enhance reliability of the data by ensuring that pauses, tone, and overlaps were all captured and could be replayed (Perakyla, 1997). Secondly, I wished to ensure that the recording process was

unobtrusive so that as far as possible, participants would not be affected. By employing two digital devices whenever several individuals were present I could place the digital devices outside of the meeting circle rather than in the centre.

Prior to the study it was agreed that where possible, short, post-appointment debrief interviews lasting 5-20 minutes would take place. However, due to participant preference I only succeeded in doing this on one occasion. This was an interview with a speech and language therapist following a videofluoroscopy. My field notes were reflective and highlighted any observations that struck me as most noteworthy during the consultation. This included descriptions and information about the space, people, activities, and sometimes observations of emotions expressed.

3.6.2.3.6 Informal observations

In addition to these recorded observations, I also made regular visits to the feeding clinic and spoke with other people with a shared interest in GT feeding to gain general experience of this clinical topic. This gave the opportunity to informally observe the running of the clinics, the decisions that had been made and the dilemmas families faced. At the beginning of each feeding clinic the clinicians present discussed the families attending the clinic that day. With the permission of the clinical team it was then possible for me to ask parents if I could attend their consultation as an observer. These informal observations, which were not digitally recorded, allowed me to become immersed in the topic and provided some of the background for the thinking and interpretation that I needed to accurately relay the participants' stories.

3.6.2.4 Ethical considerations

3.6.2.4.1 Data storage

Caldicott approval was sought and obtained from the Research and Development officers for the two Trusts. Data from my recording devices were uploaded to a secure password-protected server to be stored according to the Data Protection Act, 1998. I transcribed all the data myself and removed all personal identifiers from the transcripts and typed up field notes. References to specific places were also anonymised. Consent forms, correspondence and data transcriptions were stored in locked filing cabinets within an area of restricted access.

3.6.2.4.2 Dealing with sensitive issues

Previous research has identified that GT decision-making can be a sensitive issue for parents. From the outset, I acknowledged that these issues could be potentially distressing to participants. During data collection, I encountered sadness and tears on several occasions. Whenever participants showed any evidence of distress, I allowed the interview to stop to offer support to participants, and at this point I reminded them that they were free to withdraw from the study at any time. In every case, participants wished to return to the interview once they had composed themselves.

3.6.2.5 Data analysis

The research processes of recruitment, observation, interviewing, transcribing, coding and analysing the data were all conducted concomitantly throughout the study. This was partly because recruitment needed to be ongoing, but also offered the opportunity to further explore emerging themes with later participants.

The first stage of analysis involved familiarising myself with the data. To begin this process, I transcribed the data myself, using repeated listening, to provide a written representation of the recorded interaction which could then support (but not replace) my recordings (Sidnell, 2010). At the beginning of the study, my intention was to apply CA to specific sequences of interest. Although I discarded this method towards the end of the research, I had developed a very strong appreciation of the importance of additional factors present in the data such as pauses and intonation. For this reason, my transcriptions contain additional detail such as, for example, the length of hesitations in seconds portrayed as (0.2). This proved extremely useful when I came to analyse the interactional parts of the data.

3.6.2.5.1 Coding the data as a structural exercise

Once the interview had been transcribed, I further immersed myself in the data by applying one or more codes to each word, line, or sometimes larger sections of text within the data using the NVIVO qualitative data analysis package as a management tool (QSR International Pty Ltd., 2012). Although this is not strictly part of interpretive analysis approach, Thorne et al. (2004) do acknowledge coding to be an acceptable part of a very early analytical stage to help provide the initial scaffolding to begin to construct

the analysis. Once the data was coded, I gathered minor themes into major themes in the manner of Braun & Clarke (2006) until I had several overarching themes. I engaged with the data in several different ways. For example, I compared paternal themes with maternal themes or families that made a quick decision versus those that were resistant to GT. Interacting with the data in this way allowed me to think about what role and position different participants may be taking when engaging with particular themes. Using this process, I began to see that there were three main topic groups underpinning my analysis. Firstly, I could gradually recognise the underlying themes that were influencing parents and clinicians when making the decision. These themes form Chapters 4 to 7 of this analysis. The second group were the interactional strategies that were being used to share these themes, evaluate risk and eventually reach a decision which form Chapters 8 to 10 of this analysis. Thirdly, in my data there was clear evidence of post-decision re-appraisal which I report in Chapter 11.

3.6.2.5.2 Interpretative Description

After carrying out this process, I had developed sufficient knowledge and confidence in my data to follow Thorne et al., (2004) in letting go “of the life raft” (p.5). Thus, having identified my themes, I was able to put NVIVO aside and allow my data interpretation to develop intellectually. This exercise involved determining exactly what was happening in the data and then re-contextualising these understandings into written findings that others could easily read and assimilate (Morse, 1994). With the help of my supervisors, I actively sought out alternative descriptions and tried to challenge, rather than reinforce, the early constructs which I had developed via my data manipulations through NVIVO.

All participants provided me with rich insights. The views of all the participants in this study have been included at some point in my analysis. However, it is notable that some participants feature more than others in sections of this thesis. The reasons for this are twofold. Firstly, some participants were more vocal than others and simply provided more detailed discussion. Secondly, the values placed on different aspects of the decision-making process varied from family to family. Thus, for some families, the values placed around feeding itself mattered a great deal and they spoke at length about these

topics and thus feature strongly in that thematic chapter. For other families, other aspects such as the care burden featured in more detail, and they provided data reported in a different chapter. My focus throughout the analysis centres around the issues that have influenced the decision-making process. Thus, it has been the importance of an issue, particularly in relation to clinical practice, that features most strongly in the analysis rather than the number of people who raised that issue.

3.6.2.5.3 A brief summary of CA techniques

As I discussed in section 3.5.2, I had originally decided to apply CA to small extracts of my data. Engaging with CA in its strictest sense proved to be an unnecessary analytical step, which I did not feel shed additional light on the clinical applications of this study. However, established CA studies have highlighted many familiar and recognisable patterns that occur during talk. Having already familiarised myself with the CA process I have been able to draw on this expanding body of research to relate my findings to established work on what is known about typical interactional sequences. Ten Have (2007) lists these as: turn-taking organisation; sequence organisation; repair organisation and the organisation of turn-construction/design. These organisations of talk are very briefly summarised below.

3.6.2.5.3.1 *Turn taking organisation*

A person's turn at talk is made up of one or more "turn-constructive units" (TCUs) (Sacks, Schegloff, & Jefferson, 1974) which could be a word, phrase or sentence. Speakers only have an automatic right to one TCU and interactants need to actively monitor talk to recognise its completion via grammar, intonation, or completion of an action. At this point, known as a transition relevance place (TRP), a change in speaker is permitted to occur. The phenomenon of interest for my examination of SDM was how TCUs are recognised by listeners as complete in group consultations and meetings and how the next speaker is allocated.

3.6.2.5.3.2 *Sequence organisation*

The most basic sequence of natural talk is the "adjacency pair". The second speaker is normatively required to produce a second pair part (SPP) that appropriately 'fits' the

prior turn (first pair part or FPP). For example, the second pair fit for a question is normatively an answer.

3.6.2.5.3.3 Repair organisation

Disruptions to the flow of natural talk such as hesitations frequently occur and these can indicate “trouble” in the talk. Repair organisation allows such trouble to be corrected by self-initiated repair to avoid misunderstandings and conflict (Sidnell, 2010). If self-initiated repair does not occur, second speakers may be faced with a socially awkward dilemma and may be obliged to draw attention to something wrong in the prior speaker’s turn using other-initiated repair.

3.6.2.5.3.4 The Organisation of turn design

The major feature of turn-design of salience to this thesis is “preference organisation”. Often there are two alternative possible responses to a first speaker’s turn. For example, an invitation allows either acceptance or refusal. These alternative responses are not equivalent in terms of maintaining social solidarity. Acceptance is a positive action and refusing is viewed as a negative one. Responses are therefore undertaken differently. Positive responses (the “preferred” response) tend to be immediate and explicit, whereas negative responses (the “dispreferred” response) are usually softened by delay and mitigation. People normatively organise their speaking turns to encourage positive responses. Speakers producing the “wrong” response may be held accountable for an explanation. This clearly has implications for GT refusal.

3.6.2.5.3.5 Conclusion

These four major organisations work together to produce a ‘sequential’ description of interaction which reveals how social action can be understood as a dynamic process. To increase understanding of the interactions in my thesis, I have drawn on the above ideas to consider how second speakers have understood the prior turn and how misunderstandings can be perceived and resolved during GT decision-making.

3.6.2.6 Rigour and credibility

Research integrity with regard to issues of trustworthiness, credibility, applicability and consistency has been an important consideration in the writing of this thesis. My interpretive description should hopefully serve to both illustrate the decision-making

dilemmas for individual families and draw together understanding of commonalities across decision situations. Together this has resulted in an account which I hope has a high degree of research integrity. I believe this to be an important topic and I have tried to avoid errors which could result in negative consequences towards practice (Long & Johnson, 2000).

3.6.2.6.1 Trustworthiness

I have maintained trustworthiness by giving a transparent justification of the methodology and methods and a detailed procedural description of my data generation and management. I have also supplied verbatim quotations from the data to illustrate and support my interpretations.

3.6.2.6.2 Credibility

Throughout this process I have needed to work to convince my supervisors of the credibility of my findings. Sometimes my ideas, although credible to me, were not adequately supported by my data or I failed to consider different possibilities. In some cases, such critique has led me to withdraw my assertions or frame them more tentatively. On other occasions, I have been able to re-examine my data and demonstrate more clearly the reasons why I have been able to place this interpretation on the data. One way that I have developed credibility is by sharing interpretations with others (Morse, Barrett, Mayan, Olson, & Spiers, 2002) by attending a qualitative data analysis group regularly with my peers. This involved sharing our anonymised transcripts. My colleagues and I have worked together in this group to help each other interrogate our data asking such questions as “why did they use that term?” “Why do they keep repeating that point?” and “why did this person hesitate so long before answering?” It has been extremely useful and I hope that my developing understanding of the different ways that data can be interpreted is clearly represented in my analysis.

3.6.2.6.3 Applicability

A qualitative study is credible when its results, presented with adequate descriptions of context, are recognizable to people who share the experience and those who care for or treat them. Therefore Thorne et al.(2004) suggest that a good interpretive description should pass the “thoughtful clinician test” (p.8). For this reason, two of my supervisors

are also health professionals and work with children who have neurodisability conditions and feeding difficulties. On occasions, my findings have not rung true with their clinical experience and this has opened up the opportunity for further discussion regarding why this might be the case. Conversely, my findings have sometimes backed up clinical experience and opened up new ways of seeing that had not been identified before, or produced counter-evidence to earlier research. I will talk more about this as the analysis progresses.

3.6.2.6.4 Consistency

I have used triangulation by attempting to answer the research question in more than one way via interviews and longitudinal observation. I have attempted through my recruitment strategy to seek representation of diverse perspectives on the topic. By recruiting participants with specific criteria who have been under-represented in prior research, I have sought to actively seek and explore examples of decision-making which have not fitted the general pattern, as in the case of Elliot's mother's values around oral feeding which I explore in Chapter 4.

3.6.2.6.5 Reflexivity

Like Thorne et al (2004), I am resistant to ideas suggesting that qualitative research gives participants their own voice or that the data can speak for itself. Ultimately, it has been me, and to a lesser extent, those who have critiqued my work, who have deemed which parts of my data are relevant and how my categories and conceptualisations have been structured in my thesis. Thus, I have "generated" my findings from the data rather than them "emerging" from the data unaided (Morse, 1994). I concede that this understanding is partly formed from the positions I take and the values I hold and that there could be alternative ways to interpret this data.

At this point, I feel it appropriate to set out my position of researcher within this study. At its commencement, I already had the pragmatic knowledge of caring for a child with a GT and an understanding of some of the difficulties that may be encountered. During the life of the study, I was unfortunate to encounter very serious illness within several members of my own immediate family that involved many medical encounters and decisions in a wide variety of clinical settings. I (and my sisters) were also faced with

making preference sensitive medical decisions ourselves. During the writing of this thesis, I have sometimes been angry, judgemental, frustrated and sad. Yet at the same time I have been immensely grateful to the medical teams who have cared for us so well. Having these experiences has led me to fully embrace the viewpoint that any attempt to put aside prior knowledge, thoughts and experience is impossible. I have instead elected instead to follow the recommendation of Licqurish & Seibold (2011) and openly acknowledge them as part of the research process, and consider how my own lived experiences might lead to a deeper understanding of what I have learned from my participants. Because of these matters I have chosen to use the first person when reporting my findings in acknowledgement of my own integral part in the research process.

3.6.3 Conclusion

This section has built on the previous methodology section to outline in more detail the exact methods that were undertaken in carrying out this study from setting up its framework to the analytical procedures that I undertook. The following chapters outline my main findings around the process of decision-making around children with neurodisabilities. These chapters form three main analytical sections. In Chapters 4 to 7, I describe the themes that influence family/clinician decisions. In Chapters 8 to 10, I focus on how this information about values is shared and the risks assessed, to activate a decision. Chapter 11 examines how families appraise their decision after a GT has been placed.

Chapter 4 Feeding as an Embodied Experience

4.1 Introduction

By the time research into decision-making around GT feeding began in the late 1990s, social science researchers were already suggesting that prevalent theories of gender and parenthood were inadequate because “they do not seek an integration of biological and sociological constructs” (Rossi, 1985, p1). Rossi argued that most sociological work in a diverse array of fields confounded “mothering” and “parenting” by using the word “parents” even when all the included participants were mothers. Thirty years later, as my literature review has shown, nearly all research around GT decision-making to date has continued to use mothering and parenting interchangeably. Given that both pregnancy and breastfeeding are inseparable from biological sex, it seems to me to be problematic to attribute similar values around oral feeding, particularly breastfeeding, to both mothers and fathers.

Lupton (2013) reviewed the theoretical literature around infant embodiment and examined the ways in which infants’ bodies are conceptualised in contemporary western societies. The concept of inter-embodiment encapsulates the notion that “apparently individuated and autonomous bodies are actually experienced at the phenomenological level as intertwined” (Lupton, 2013:39). Pregnancy and childbirth is the exemplar case of breached boundaries because it forces re-conceptualisation of the Western ideal of autonomous individuals.

In this chapter, I will argue that this inter-embodiment can also extend into the mother-child relationship after birth and into early childhood via embodied caring practices that mothers undertake with their infants such as breastfeeding. I aim to show how mothers and fathers may not necessarily share the same values and concerns around the purpose of early infant feeding. I will also demonstrate how significant others such as family members and healthcare professionals may make assumptions around parental shared values and how this may impact on the decisions made around the feeding choices made on behalf of children with a neurodisability and a feeding difficulty.

4.2 Early infant feeding as an inter-embodied experience

In a study of co-sleeping between Japanese infants and their carers, Tahhan (2008) introduces the concept of “skinship”, which refers to the interpersonal states created by the touch and intimacy facilitated by the proximity of carer and child. In western societies, regular co-sleeping is less common and sometimes discouraged but parents may still achieve skinship through other bodily practices (Ball, Hooker and Kelly, 1999). One important practice that enables skinship for mothers and infants is breastfeeding. Breastfeeding is an inter-embodied experience because it involves parts of the mother’s body (the breast and nipple) literally being co-joined to that of the infant. Breastfeeding goes beyond the cuddles or sucking on fingers that other carers might offer because in addition to skinship, breastmilk also nourishes the infant. Hence, the in-utero relationship where the maternal body grows and nourishes the infant’s body continues after birth and the boundaries of maternal self and infant are blurred. Like pregnancy, breastfeeding can also challenge the idea of autonomous personhood held up as the ideal in western societies (Hausman, 2004). Women who enjoy breastfeeding speak of feeling strongly connected to their infants. These types of descriptions of the pleasurable inter-embodied nature of breastfeeding are a recurring theme identified in breastfeeding literature (Schmied and Lupton, 2001).

In Chapter 2, I discussed how previous research around children with disabilities has shown how mothers often “treasure” the ability to orally-feed their infants (Sleigh, 2005). My work generally supports that finding, most notably in relation to breastfeeding, which was the preferred feeding method for most of the mothers in this study. In common with other breastfeeding literature, mothers portrayed breastfeeding as an experience which enabled them to develop an intimate relationship with their infant as Claire describes¹:

¹ To help orientate the reader the participant relationships and roles can be viewed in Table 3.1

You know you cradle them, you hold them you know, you stroke their heads you sing to them when they're breastfeeding or you are rocking them or [R: Yeah yeah] it's all that () that (0.2) (*Claire, mother of Craig*).

Claire's description of breast-feeding trades off social ideals of breast-feeding and is primarily an inter-embodied one. The use of the terms "cradle" "hold" "stroke" and "rock" all emphasise connectivity via touch and relate to how bonding may be mediated via the inter-embodiment achieved through breastfeeding. It is this very strong imagery that results in me, the interviewer, then offering the remark "skin to skin kind of?" A comment that Claire accepts. Angela also draws on the concepts of bonding and "time together" that may be enabled through breastfeeding:

And it was also time together as well ah ah it was that (1.0) that ooh how do I put that? I could never breast feed him and it's been interesting because it was a really (0.8) it it's never left us that that desire to breastfeed him and to not be able to do that it still makes us cry and now I was talking to another Mum who's erm son had Down's syndrome and something else that affects his vision and things (0.4) and err we met up last week and he he he's a couple of years younger than Adam and he was sort of clawing at her clothes and pulling her top down and we laughed and that but then she said to him "stop flashing me boobs" or something like that and I said "they're not yours, they're his though aren't they?" and she said "no, they never were" [R: aww] and I just sort of smiled at her and she looked and I thought "yeah" it's not, it's it's there's something about feeding your children that is the most fundamental thing that you can do and there's something (1.0) sort of (0.4) primal that you you can (sighs) that sort of ownership (*Angela, mother of Adam*)

Angela's statement that being unable to breastfeed "still makes us cry" suggests that she is mourning the loss of breastfeeding. It is perhaps important to mention here that the use of "us" in this context reflects the local dialect meaning "me" and does not necessarily mean that more than one person is involved. Angela's loss was brought into focus when she met up with another mother who also had a child with a disability suggesting that Angela saw this incident as one that triggered her feelings of sadness and that this grief remained unresolved. Angela describes breastfeeding as being "primal" and resulting in

a “sort of ownership”. Although it is unclear whether Angela positions this ownership as a mother owning the child or vice versa it is clear that Angela recognises this connection to be an inter-embodied one which forms a fundamental aspect of the mother-baby relationship.

Because the baby portrayed in this narrative appeared to be attempting to gain access to his mother’s breasts, Angela assumed that he must be breast-fed. Angela’s question to this mother “they’re not yours, they’re his, though aren’t they?” again indicates that Angela saw breastfeeding as a process which generated a specific intimacy i.e. an inter-embodiment between mother and child that was so profound it allowed him to take ownership of her “boobs”. Although it is not explicitly stated whether this mother was unable to breastfeed, Angela’s description of her own smile and the other mother’s “look” suggests that she positions this event of one of shared understanding and mutual empathy.

Feeding children who have fewer physical possibilities than others can be problematic. Although I will discuss this important issue in depth in Chapter 6. I think it is important at this point to highlight the closely interwoven relationship between embodiment, bonding and the burden of feeding. Craig & Scambler (2006) described how commencement of GT feeding due to poor feeding is often seen as an indication of “failure” forcing women to renegotiate their identities as “successful” mothers. In an endeavour to avoid GT feeding mothers have sometimes felt compelled to “try harder” with oral feeding (Sleigh, 2005; Thorne, Radford, et al., 1997). My research suggests that this feeling of failure and the desire to try harder is not just about achieving optimum nutrition for the developing infant but is closely related to maternal-infant bonding. For example, Beth:

I wanted to feed him to bond with him [R: yes, yeah] erm (0.4) but when obviously (1.0) this time (1.0) I've struggled and struggled to feed him because I feel as if that's what I should be doing as a Mum [R: yeah] and at first I thought because he wasn't taking it for us 'am I doing something wrong?' [R: Right] I did feel () a fail, not a f, yes probably () a failure (*Beth, mother of Billy*).

Beth's wanting "to feed him to bond with him" suggests that for Beth bonding without the inter-embodiment enabled by breastfeeding may be far more difficult to achieve. Her comment that she "struggled and struggled to feed him" because she felt that was what she "should be doing as a mum" has resonance with Angela's description of feeding as being primal to mothering. For Beth, like the mothers in Craig and Scambler's study, lack of feeding success means that she was not doing what the category of "Mums" should do, was doing it "wrong" and was therefore "probably a failure". It is important to note that Beth had previously successfully breastfed her two older children. Her uncertainty regarding whether she is, or is not, a failure suggests a tension between the rational knowledge that she has successfully breastfed in the past and is proven capable of doing what "Mums" do and her inner belief that this time she must be doing something wrong and has, therefore, failed. In the following extract, Gail describes a cycle of how the stress of feeding difficulty could compound the problem.

No I did try. Erm [R: yeah] I think that with the stress of e-verything around about his birth I don't ever remember getting () milk coming in [R: oh really?] yeah, because it was so stressful (*Gail, mother of Gary*).

Gail associates her physical problem of the milk not "coming in" with the emotional stress that resulted from the birth. In doing so she portrays how, for her, the psychological emotion of stress and fear is also a physical, embodied experience which impacts on the inter-embodied experience of feeding. In the following extract, Gail also relates Gary's emotional status with his inability to feed.

Some days I'd say "look if there's a physical reason that he can't eat" [R: yeah] I would have accepted it and said "Right, fair enough" [R: right] but there was no physical reason for it, it was purely psychological [R: oh, okay] (*Gail, mother of Gary*).

It is notable that whilst Gail attributes her part in the feeding impasse to stress, she seems less willing to accept psychological explanations for Gary's feeding difficulty.

Not all barriers to inter-embodiment are positioned as psychological ones. Following a very brief "skin on skin" period Claire's newborn infant Craig, was "whipped off" to the neonatal unit in a different hospital where he was placed in an incubator. Here, Claire

describes the emotional effect of the forced separation from her infant that extinguished the possibilities for inter-embodiment.

Erm () the shock of having him being whipped off to special care and then () not being able to- it was just yeah, I was dealing with I can't, I can't even describe () how many emotions I was going through post you know, postnatal depression and [R: Yeah, yeah] you get the baby blues and () I just seemed to be crying if somebody came into the room I was crying () it was just unreal (*Claire, mother of Craig*).

A modern, Perspex incubator isolates infants and creates an artificial barrier between mother and child. As sound and vision are relatively unaffected, it is likely that Claire particularly laments the loss of touch. Controlled studies investigating the effects of tactile stimulation on the development of premature and low-birth weight neonates has led to superior growth and developmental performance (Ardiel & Rankin, 2010). Such findings have led to procedural changes at many hospitals to help enable touch via the development of inter-embodiment in the form of “Kangaroo Care” (E. R. Smith, Bergelson, Constantian, Valsangkar, & Chan, 2017).

An infant’s life is woven into a complex web of human relationships, which may be even more intense where a child has greater need (Goode, 1994). This is skilfully described by Angela:

And then, and then as a mother, you have all those- I mean it might just be a pile of steaming whatever but I know what I believe about our connection [R: yeah yeah]and the things he tells us (*Angela, mother of Adam*).

Angela possibly realises that others may be cynical about this special relationship with Adam and pre-empts any potential criticism. However, for Angela, this connection with their severely disabled son is so profound that it allows for communication to occur “the things he tells us”. One way this connection might be achieved is through eye contact. None of the parents whose children had unimpaired or partial vision mentioned eye contact with their baby as part of this bonding/embodiment via breastfeeding process. Disability literature has describe how the fully “able” body seems absent and that we only pay it attention when it is impaired (Leder, 1990; Murray & Sixsmith, 1999).

Accordingly, it is Angela whose child Adam has cortical blindness who refers to the importance of eye contact when feeding.

And it's especially like Adam where (1.0) because of his vision he'll look in your direction but you never get eye contact [R: no] and it was a way of er uh er a kind of communication as well and we used to, we had a little song for when it was mealtimes and (0.6) erm just daftness that grew out of the routine of it and we we developed ways of letting him know what was coming (*Angela, mother of Adam*).

For Angela, feeding is more than just nourishment. In conjunction with sound and “daftness” oral feeding takes on a central role as a form of communication. Accordingly, although Angela accepts that Adam cannot see, and therefore cannot make eye contact it is notable that she still uses the word “look” when Adam turns his head towards them. There is a sense here of visual communication embodied in and through sound. For Angela, her singing initiated a very rewarding response from her child. In the book “A World without Words” Goode (1994) explored the value of such unique and subtle communication practices that families and carers use to communicate with children with profound disabilities including deafness and blindness. He argued that it is not possible to interpret some of these subtle behaviours using the concepts of the hearing and seeing world. In the following extract, Angela reflects on other ways in which these subtle embodied connections can be formed outside of the feeding experience:

Anthony and I think that, sometimes his expressions and his timing through his vocalisations or or he has so many different types of smile [R: yeah] you just think when Anthony comes in from work and picks him up, he looks like the cat that got the cream, you know [R: yeah] (*Angela, mother of Adam*).

Angela's description illustrates how she and Anthony drew on Adam's smiles and vocalisations as something that enabled bonding. Her description of Adam looking “like a cat that got the cream” paints evocative imagery of Anthony being rewarded by Adam's satisfaction through being touched. The story is therefore one of Adam, using vocalisations and many different types of smile, making his own active contribution to the bonding process. That Angela understands this to be an embodied relationship is summarised in the following extract:

And it -because of the way he is, anything he experiences has to come through us (*Angela, mother of Adam*).

“The way he is” is a reference to Adam’s multiple disabilities. By accepting the philosophy that the human body mediates experiences of self it follows that impaired bodies will mediate different experiences of self. Angela positions herself as having the understanding that Adam’s impaired senses mean that his body cannot access “experiences of self” in the same way as a fully able-bodied person. For this reason, Adam’s experiences must come not *from* the parents but *through* the parents. The parents must experience the world first and pass on that knowledge through inter-embodied experiences such as touch.

If bonding through inter-embodiment cannot be achieved through breastfeeding then it is necessary to find other means to do so via other “skinship” activities such as cuddling, nappy changing or bathing. In the following extract, Billy’s grandmother Brenda described what happened when Beth who was “desperate to breastfeed him” could not breastfeed:

Erm (0.4) so they, she extracted her milk (0.2) and erm (0.5) tried with a bottle but he just wouldn’t suck then they had to feed him (0.2) through the tube [R: Right] Erm (0.5) but he (0.2) got, he was happy that he was at least getting breast [R: Yes] milk [R: Yeah] Erm she would have loved to have fed him herself if not that, even the bottle er cos she had that () closeness (*Brenda, maternal grandmother of Billy*).

Brenda’s description of giving breastmilk via bottle contrasts sharply with social ideals of embodiment through breastfeeding. Rather than offer a portrait of the mother, Beth, “lovingly” nourishing her infant, she instead describes how her milk is “extracted” to give via two different mechanical devices of a bottle then tube. Brenda therefore separates out two aspects of feeding, the nutritional and the bonding. Although Brenda understood that Beth would have preferred to breastfeed for the “closeness”, Brenda herself accepts that this can be achieved entirely separately from nutrition. In the following extract, she explains this:

Brenda Erm (0.5) tsk (0.4) I still got me cuddles.[R: Yeah (laughs)] you know, I could still nurse him and cuddle him.

Researcher Yeah, yeah, so you didn't have to be actually (0.2)

Brenda putting nutrition [R: putting nutrition] Could still give him the odd bottle [R: yeah, yeah] But to me as long as they are getting the love and (0.2) [R: Yeah, yeah] you know the(0.4) medical side can sort out his feeding.[R: Yeah] Make sure he's getting that [R: yeah] It's not a perfect world

(Brenda, Grandmother of Billy)

Brenda's description of "getting me cuddles" suggests an inter-embodied experience obtained via touch but separated from the pragmatic experience of "putting nutrition" in. Adequate nutrition can be provided by medicalised means, "the medical side can sort out his feeding" but it is the family that can provide "love". However, Brenda's comment "it's not a perfect world" suggests that she sees this situation as less satisfactory than natural feeding but acknowledges that in life compromises may be required.

In my interviews, only Elliot's mother Elaine did not place high importance on oral feeding. In contrast to the other families in this study, where a healthy child had been expected, Elaine's child Elliot had not been expected to survive birth. His anticipated multiple disabilities were so severe that pregnancy termination had been offered. For Elaine, the combination of joy and anxiety aroused by Elliot's unexpected survival trumped any desire to establish any particular feeding method, as she notes, "we had other things to worry about at the time". This suggests that where an infant's life is in jeopardy, pushing for oral feeding may seem like an indulgence. For many mothers, it is only when the infant is stable that their horizons may broaden to embrace other matters and the disruption of inter-embodiment emerges as a major concern.

I have shown that for most of the biological mothers in this study, breastfeeding is seen as an inter-embodied activity that continues the biological process of intra-uterine foetal nourishment into extra-uterine infant sustenance. It is important to note that all the parents in my study were the child's biological parents and this research cannot therefore embrace the views of adoptive or fostering parents which could differ significantly. However, I would argue that for the biological mothers in this study, these ideals around inter-embodiment, may have been initially engendered by the pregnancy experience (Doucet, 2006). Mothers may mourn the loss of this inter-embodied experience. However, advocating breastfeeding is sometimes difficult for feminist arguments because of its links to the biological essentialism which underpins social expectations of women's nurturing roles thus making early infant feeding "women's work". I will go on to discuss this matter in Chapter 6. However, at this point, I will discuss whether early infant feeding as "mother's work" impacts on father's values around oral feeding.

4.3 Early infant feeding as a means to an end

My findings suggest that fathers do not view oral infant feeding in the same inter-embodied way as mothers. The lack of both a first-hand pregnancy experience and the biological apparatus of breasts means that for fathers early infant feeding only be enabled via breast substitution devices such as bottles and teats. Oral feeding may therefore be valued in more pragmatic terms, as the means of ensuring the adequate nutrition and hydration of the infant.

Er (1.0) it didn't, you know, I didn't really worry about that as long as he was getting (0.2) [R: yeah] something in. It was to, no matter. How it was happening () didn't concern me... Yeah she tried it and I said 'well, y'know fair enough it hasn't happened!' [R: Yeah] 'He's still getting your milk' [R: yeah] You know, it don't matter how he's getting it' (*Brian, father of Billy*).

Brian describes how he had no real anxiety "I didn't worry about that" regarding the method of getting milk in which was "no matter". What was important to Brian was the nutritional nature of the foodstuff "your milk" rather than the mechanical process of

feeding. In a similar way, Colin explains what this means in terms of paternal-infant bonding when feeding with an NGT:

Yes, I still, I still feel like I'm bonding with him just as [R: yeah] much as I would be if we were feeding him with a bottle. Sometimes he just sits in his- sometimes he sits in his chair sometimes I pick him up and you know so (*Colin, father of Craig*).

For Colin, using the less embodied method of NGT feeding does not impede the bonding process, "I still feel like I am bonding with him." Colin does not even seem to position physical touch as an essential part of the feeding experience, "sometimes he sits in his chair and sometimes I pick him up". Bonding with infants can therefore be positioned by these fathers as a process that may occur *in parallel to* feeding rather than as something that derives *from* feeding. Bonding is therefore far less dependent on physical proximity and does not need to be an inter-embodied experience.

Previous research around the role of fathers in the early life of healthy breastfeeding infants has raised the possibility that some fathers of infants have experienced breastfeeding to be a barrier to access to their infant resulting in strong feelings of exclusion from the mother-infant dyad (Bar-Yam & Darby, 1997; A. Brown & Davies, 2014; Gamble & Morse, 2017; Littman, VanderBrug Medendorp, & Goldfarb, 1994). One Canadian study found that first-time fathers reported feeling ineffective and jealous around breastfeeding, which they saw as limiting their own contact time with their infant (de Montigny & Lacharité, 2004). For some mothers of "healthy" infants, the desire to encourage the father's involvement can sometimes be a contributing factor in a mother's decision to introduce feeding bottles. (Earle, 2017) or to wean early (De Montigny, Girard, Lacharité, Dubeau, & Devault, 2013). In the context of children with additional needs, an Australian study of fathers of low birth weight babies were ambivalent about breastfeeding because they had difficulty in determining what their own role should be when their infant was breastfed (Sweet & Darbyshire, 2009).

It is therefore not entirely surprising that fathers of children with specific feeding needs may not feel as passionate about the maintenance of oral feeding in infants as their children's mothers may do. However, although fathers may not treasure oral feeding in

the infant in the same way as mothers, they may still view supporting mothers' efforts to feed as an important part of their role as Anthony explains:

[It] gave her some sense of normality [R: yeah] so I, I sort of went along with it but, I was siding with her because I had no real opinion either way, I, I didn't like the NG tube, and if we could have feed him orally, great (*Anthony, Father of Adam*).

Anthony, despite his own reservations about feeding was aware that "it was important for Angela" (Anthony, line 17) so "sort of went along with it". Having "no real opinion either way" does not tie in with the perception of oral feeding as something that is treasured. Instead, his preference for oral feeding emerges from a wish to support Angela and her need to feel normal.

In summary, my research indicates that fathers in this study may view oral feeding not as an inter-embodied activity but more as "a means to an end". The purpose of feeding an infant for fathers is to ensure adequate nutrition and hydration and this may be achieved in several ways. The impact of this is critical in GT because mothers and fathers may not share the same values around the importance of maintaining oral feeding, notably breast, in young infants. I will now explore what this means in terms of healthcare workers assumptions around shared parental feeding values and what this could imply for GT .

4.4 Assumptions around shared parental feeding values

Despite the different values placed around early infant feeding for mothers and fathers, my data suggests that whenever the mother's feeding preference has been stated, both health practitioners and significant other family members tend to assume that fathers share the mothers' values around the importance of infant feeding. For example, it is notable that when talking about the nutritional side in the earlier extract, Brenda draws on the opinions of the child's father "he was happy that he was at least getting breast milk" which echoes my findings that fathers are more concerned with nutritional quality than feeding mechanics. However, when discussing the second aspect of feeding, the "closeness", Brenda takes her position from the mother "she would have loved to have

fed him herself". Possibly, Brenda has at some level, an awareness of a subtle difference between the values of oral feeding for mothers and fathers, which I explore further:

- Brenda I think it would have (0.5) I think () it would have been very important for Brian, because Billy is Brian's first baby [R: Yeah, yeah and] so
- Researcher Did he ever say this to you?
- Brenda Well not to me personally no, no,
- Researcher No, but you get to the kind of sense that it was very important to him?
- Brenda Yes, I think you know (0.2) well it would just have been nice for him to just be able to (0.2) to [R: Yeah] to feed him.

(Brenda, Grandmother of Billy)

Brenda makes the judgement that oral feeding would be "very important for Brian" because this was his "first baby". However, she concedes that Brian had never told her this personally and it was therefore assumed knowledge. It should be noted that, Brian had already stated in his own interview that he was not concerned about how the milk got in. It would have still been "nice" for Brian to be able to feed Billy via a more conventional route, but Brian's actual paternal concern was not the mechanics of providing nutrition but ensuring the nutrition that best supported his child's growth and developmental progress.

Healthcare professionals sometimes make assumptions about oral feeding preferences without having had the opportunity to counsel fathers for their view, as the following conversation from an interview with a speech therapist illustrates:

Researcher When you say the family, d'you think both parents were equally () persistent with the feeding?

SALT₁ Erm I think most of my contact has been with Mum. I have, I've met dad a few times but I've had a lot more contact with Mum erm who's always been very keen. I (o.1) I think. Now, I wonder how mu, how much that was more Mum than Dad but I don't think I particularly had those thoughts (o.1) until he was ill, six months ago.

Researcher Yes, so you never heard him say that, that he wished they weren't continuing or? Could you?

Both ((talking together, unclear))

SALT₁ No but I haven't had, actually had very many erm of that, really had that sort of conversation with Dad, ever.

(SALT₁, speech therapist for Adam).

SALT₁ has no doubt that Angela was “very keen” on oral feeding. However, it is only when the life-threatening episode occurs that she begins to question whether Anthony actually shared the same values around the importance of feeding as Angela. SALT₁ did have some encounters with Anthony, albeit less frequently than with Angela, and possibly it had not occurred to SALT₁ to counsel Anthony's views because Angela's views were unequivocal and therefore difficult to challenge. DIET₁ discussed the same issue:

I think that having the opportunities to feed Adam orally was something that Angela felt quite strongly around erm and probably Anthony as well, though I didn't really have that conversation with him. But I didn't get, you know, I didn't see him as often [R: yeah] And I kinda got the impression from Angela that oral

feeding was something that she wanted to do as a Mum because of their love of food in their, in their environment as well you know she's obviously a baker, she loves food, she, she enjoys that aspect of things (*Diet1, Dietician for Adam*).

It is noticeable that the dietician also assumed that Anthony would “probably” feel the same way as Angela. Her statement “I really didn’t have that conversation with him” closely resembles SALT1’s comment that she had not “had that sort of conversation with Dad, ever.” Most clinical encounters with the family seem to have been with the mother. Both healthcare professionals report having a less familiar relationship with the father – “I’ve met Dad a few times” (SALT1) and he was in “some of the erm appointments” (DIET1). This is not unusual. For example, Hobson & Noyes (2011) explored the involvement of fathers of children with complex healthcare needs. They found that all fathers interviewed wanted to attend hospital appointments with their child but often had trouble negotiating time away from work. Therefore, when SALT1 states that she has never heard the father raise doubts about the continuation of oral feeding, she does qualify this by declaring that she had never actually had that “sort of conversation with Dad, ever”.

Nevertheless, it is clear that Anthony is present at some of the encounters so it seems apparent that eliciting the father’s concerns is potentially problematic in some other way. One possibility is that it is difficult for clinical staff to ask fathers to express their opinions in a shared environment, especially during home visits which may form the mother’s territory. Centrally, pursuing the opinions of fathers may imply that the mother’s values are being questioned and so could cause conflicts if any divergent values are highlighted. It is therefore a difficult conversation and one that health practitioners may choose not to make.

When health professionals do see fathers, they may talk about different topics to feeding. For example, GP1 stated that “I almost only ever speak to dad about medication” (GP1, line 38). Clearly the GP appreciates that Anthony is involved in Adams care, yet feeding remains within the mother’s domain whereas other aspects of care, in this case medication, include the father. However, we cannot know from this description, whether it is Anthony or the GP who initiates these discussions around medication. It is

arguable therefore that fathers themselves may resist raising the topic of feeding. This may be out of loyalty to their partners in not wishing to offer an alternate view.

Although David's father declined to participate in this study, other participants stated that he was strongly attached to oral feeding. As I have already discussed, it cannot be assumed that fathers share the same values as mothers, without canvassing them directly, so we cannot be sure that this is the case. However, even if correct, the explanations for this attachment may differ. For example, David's paediatrician, PAED2:

I think so, I mean dad's a chef () erm but als- and so that's () I suppose that's what he does isn't it? Prepare food and feed? [R: Yeah] And Mum () er and that's what mums do () you know so yeah, I think it's very important for all of them (*PAED2, paediatrician for David*).

PAED2 positions himself as believing that both parents place a strong importance on oral feeding. However, he posits two different reasons for this. The reason given for the mother's values ties in closely with the category of mothers "that's what mums do" and echoes Beth's quote above "that's what I should be doing as a mum". However, PAED2 does not position the father's values as being tied to the relationship category of "fathers" and what fathers do, but to his occupational category of "chef" and what chefs do "prepare food and feed".

4.5 Summary

My research suggests that it may be inappropriate to make assumptions about shared parental values from research that has been primarily conducted with mothers. In close accordance with prior research, my findings suggest mothers place a high value on oral feeding and particularly the pleasurable inter-embodied nature of breastfeeding

However, my research suggests that fathers and other family members do not place the same value on early infant feeding as an inter-embodied activity as mothers do. Early infant feeding is instead valued in the more pragmatic terms as the "means to an end" to ensure the adequate nutrition and hydration of the infant so that he/she may grow and develop. Bonding is achievable through cuddles and other forms of bodily contact.

These differences in values suggest that clinicians should avoid the trap of assuming that parents share identical values and goals around feeding. Although mothers may have a closer relationship with healthcare providers, where possible, efforts need to be made to pursue the opinions of fathers.

Later in this thesis (see Chapter 6, p 90), I will discuss the burden of care which evolves from feeding a disabled child. I will question whether this sense of feeding as an inter-embodied practice places the burden of responsibility for the child's nourishment on mothers. I also discuss whether this in turn does "rationalise through biological essentialism the other caregiving burdens that women get left with" (Hausman, 2004 p 277). However, it could also be hypothesised that as children are weaned and gradually leave infancy behind, parental values around oral feeding might also change. In the following chapter, I will therefore explore the emergent issues for parents around persistent feeding difficulty as the child develops.

Chapter 5 Pleasure and Commensality

5.1 Introduction

In Chapter 4, I discussed how mothers in my study often viewed early infant feeding as an inter-embodied experience that formed a key part of their mothering experience. However, fathers placed more of a focus on the adequacy of nutrition “making sure the milk gets in” than the pragmatics of how this could be achieved. I argued that these differences may impact on parents’ openness to the introduction of alternative feeding methods.

I have suggested that these differences may emerge from the focus on inter-embodiment that accompanies breastfeeding ideals. It could be hypothesised that as children are weaned and develop increased levels of independence, parental values around oral feeding might also change. In the following section, I go on to discuss how this topic of embodiment intersects with family values around the developing issues of feeding pleasure and commensality as children progress beyond infancy.

5.2 The origins of eating pleasure

In typically-developing children, early childhood is a time for rapid progress in oral feeding. During a period of approximately one year, children characteristically move on from milk feeding to eating a wide variety of family foods. The physical and physiological processes needed to achieve this are described in Chapter 1 and include brain and gastrointestinal tract development as well as considerable evolution of oral abilities such as learning to coordinate the movements of tongue mouth and pharynx to enable processes such as chewing and swallowing (Arvedson & Delaney, 2011). However, children do not only need to learn “how” to eat but also “what” to eat and “how much” to eat (Schwartz, Scholtens, Lalanne, Weenen, & Nicklaus, 2011). It has been demonstrated that children’s eating behaviour during this period of development is largely predictive of eating behaviour later in life suggesting that it is a sensitive phase of feeding development (Nicklaus & Remy, 2013). It is therefore necessary that in addition to the physical and physiological processes outlined above, children also learn which foods are good to eat and this, in turn, is dependent upon food pleasure.

The motivation to seek out and consume appropriate foods is dependent upon enjoyment mediated by neurological food reward processes (Berridge, 1996). However, young infants are fed exclusively on breastmilk or milk formulae. Although the flavour of breastmilk does adapt to reflect some aspects of the maternal diet (Mennella & Beauchamp, 1991) milk formulae remain constant. The impact of flavour exposure is therefore one important element of the development of food pleasure. However, taking a brief neurological perspective, research has demonstrated that two separate mechanisms are involved in the development of food pleasure (Castro & Berridge, 2014).

The first mechanism is the hedonic drive - the liking of food - which arises from activity in the network of "hedonic hotspots" within the brain which co-ordinate opioid activity (Castro & Berridge, 2014). The second mechanism is motivation to eat - the wanting of food - which is underpinned by the mesolimbic dopamine system (Berridge, Ho, Richard, & DiFeliceantonio, 2010). These food reward circuits interact with the homeostatic networks that underpin the mechanisms of satiety and hunger to make food more attractive when hungry. Considerable feeding pleasure is drawn from the sensory properties of food such as taste, smell and chemosensory aspects such as the heat from chilli (Cooke & Fildes, 2011). Most of these pleasures are learned, with the only known innate food pleasures being an attraction to sweet tastes and a rejection of bitter tastes. However, food pleasure does not just derive from these conscious experiences of reward but also the unconscious sensation of fulfilment experienced after the satisfaction of a need (Nicklaus, 2016). It is important to note that in older children and adults these processes are also dependent on higher-level cognitions including working and episodic memory processes which can alter expectations around food reward by incorporating external information such as experience, social context and advertising. Social context is of significance in very young children because their levels of co-dependency on others to meet their nutritional needs means they never eat alone.

Parents who have themselves learned to enjoy food may struggle to recognise that the experience of food and eating may be different for infants and younger children than it is in typically-developing older children and adults. Struggling to coordinate the movements of mouth, tongue and pharynx in order to swallow may be exhausting for children with dysphagia and can leave little energy for other activities which children

may find enjoyable or are good for other areas of development. Even where children innately enjoy the sweetness offered by some foods, the effort required may mean that they do not value feeding experiences over and above other activities such as playtime. Choking, drooling and vomiting when feeding can be humiliating, unpleasant and frightening (H. Johnson, Desai, & Reddihough, 2011). In fact, as discussed in Chapter 2, research to date around feeding difficulty consistently mentions the “battles” and “wars” that ensue as children actively resist being fed. My research is consistent with that finding, with considerable discussion by family members regarding how disabled children have actively resisted food. For example, in the following extract, maternal grandmother, Brenda, describes Billy’s response to being offered solid food.

Because he’s just that exhausted taking a bottle [R: Ah that’s terrible] (1.0) and he’s just not interested in solid foods [R: No] He won’t suffer them. (0.4). How do you give a baby solids who simply won’t open his mouth? [R: Yeah] It’s classed as abuse now if you forced his mouth open. [R: Yeah absolutely, yeah, yeah] And Billy, if Billy doesn’t want it, Billy doesn’t have it (*Brenda, maternal grandmother of Billy*).

Even though Billy is receiving expressed breastmilk by bottle, and does not need to suckle as actively as he would at the breast, feeding is still tiring for Billy “he’s just that exhausted”. The phrase “he won’t suffer them” followed by the emotive words of “force” and “abuse” do not suggest that Billy is actively engaged in an activity that he finds agreeable. Brenda reports that Billy’s response to an experience that he finds unpleasant is to refuse feeding by clamping his mouth firmly shut “if Billy doesn’t want it, Billy doesn’t have it”. In this battle of wills between carer and child, Billy wins. Other participants referred to children having evidence of oral aversion. For example, Maternal Grandmother Ethel describes Elliott’s description of food as “feeling funny”. Such a term suggests that food is an unfamiliar sensation to Elliot and he has not yet learned that food can be pleasurable in the mouth. In the following extract, 16-year-old Gary remembers how he used to feel when offered food or drink.

But () it had to be (sniffs) I, I couldn’t eat at all then I- I, I couldn’t, I couldn’t [R: no] I wouldn’t even touch a single bit () of food [R: no, ok] at the time so I, I

couldn't even drink, I couldn't even drink either [R: no] I tried to but tsk but I panicked (*Gary, 16-year-old child with CP*).

Gary does not attribute this inability to “eat at all” to his physical disabilities, nor does he equate this inability with a lack of motivation. Gary did not refuse attempts to eat or drink “I tried to” but instead relates this problem to an anxiety response “I panicked”. Gary’s suggestion that his problems were more psychological in nature tie-in very closely to his mother’s position that despite his diagnosis of CP and obvious physical constraints, Gary’s aversion to food was psychological rather than physical.

Children need to learn to like and accept novel foods. This has been related to several mechanisms, one of which is “learned safety”. It is thought that exposing infants to unfamiliar foods may generate an initial fear, neophobia, “I panicked” which is reduced when the food is ingested safely (Nicklaus, 2016). Acceptance of a new vegetable for example usually takes at least ten safe exposures (S. A. Sullivan & Birch, 1994). Conversely, any ingestion of food which is followed by negative consequences, such as choking or vomiting, is likely to increase resistance to feeding as well as inhibit the development of the pleasure pathways. The consequence of this is that when Gary later decided that he wished to be free of his GT feeds to improve his social participation he needed to learn how to enjoy food.

I I it tsk (0.5) I didn't want to do it at first but () now I (sniffs) now () now I enjoy doing it (*Gary, 16-year-old child with CP*).

Gary’s claim (about feeding) that “I didn’t want to do it at first” suggests that eating and drinking were not initially enjoyable. This ties in with research evidence showing that foods consumed by infants are not generally enjoyed on first taste (S. A. Sullivan & Birch, 1994). It is only in the “now” when Gary has learned about the pleasure of eating through repeated exposure that he can finally enjoy eating. However, despite his feeding problems Gary did go on to enjoy eating “now I enjoy doing it”.

Members of Elliott’s family who participated in this study all agreed that Elliott was presented with food and drink at every family mealtime in the same way as his siblings. Elliott was portrayed as enjoying the social side of these mealtimes. These enjoyable aspects may have contrasted with the actual ingestion of food which may have been

uncomfortable because of the presence of the NGT in the back of the throat resulting in negative associations for Elliot. This ties in with recent findings by (Ricciuto et al., 2015) who demonstrated that NGT feeding may have a more negative impact on later oral feeding than GT feeding does.

In addition to this, family commensal eating is never likely to be a neutral experience because it can be fraught with emotional signals or verbal instructions that attempt to modify the child's eating behaviour which can also have negative connotations (Wilk, 2010). In the following extract, Eddie, Elliot's father, describes these mealtime occasions:

Eddie: Well like I say, he could pretend to eat it at a mealtime, yeah, he will probably do that but he won't eat anything

Researcher: So just like you might with playdoh and plastic food and everything he doesn't know the difference?

Eddie: No

Researcher: Yes () so, there's not much pleasure in it?

Eddie: No

Researcher: really for him?

Eddie: Not that I can see

Researcher: There. He doesn't recognise it as a (o.2) a pleasurable thing ?

Eddie

No, I just wonder () if his taste-buds (o.2) have been starved of taste so that they no longer work will they one day (?be sore). If I love the taste of something I think I'll have some more of that stuff, if I don't, I don't.

(Eddie, Father of Elliot)

In Eddie's view, Elliott's participation in these mealtimes forms part of his play. Elliott mimics his siblings by pretending to eat his food. Thus, little pleasure is apparently derived from the actual oral intake of food or drink. Given Eddie's own enjoyment of food it is hard for him to make sense of Elliot's lack of pleasure and he questions whether Elliot's taste buds have ceased to function. It is notable that Eddie's own motivation to eat "more of that stuff" is embedded in his own learning of taste and flavour "If I love the taste of something" rather than hunger. However, Elliot's grandfather Eammon observed that "there's always going to be a certain amount of satisfaction in having a full stomach [R: yeah] no matter how it got there" (line 958-961). This comment ties in with notions of satiety and the post absorptive properties of foods. The motivational aspects of eating are controlled by the hypothalamus and associated dopamine release and these are highly related to the energy density of foods (Zheng et al., 2009). It is interesting to note how Eammon, like Eddie, also tries to make sense of Elliot's experiences of taste through reflecting on his own embodied, sensory, experiences of eating which have led to their own learning of feeding pleasure.

In the following extract Angela also draws on her own embodied, sensory experiences of eating but combines this with the process of inter-embodiment with her slightly older infant, to transform a "horrible" day into a "glorious" one:

It was a horrible day, it was freezing cold it was pouring down really windy and I was stuck in the caravan on me own with him screamin'. ... so I just wrapped him up in that (peapod carrier) and we went for a walk up the hills, and then the rain and it was the same thing I found him tipping his head back and feeling the rain on his face and stuff like that so what started out as an horrendous, disastrous day with me counting the seconds for Anthony coming home actually turned out

to be glorious and we came back in, erm and I made hot chocolate and I bought doughnuts anyway the night before (0.2) and I er sat giving him hot chocolate off a teaspoon and the jam out of the middle of a doughnut and it was the loveliest thing that we had had this really blustery cold walk and then we came back to hot chocolate and doughnuts so (0.4) we, me ten year old niece says “I’m a feeder” (1.0) (*Angela, mother of Adam*)

Angela’s description of the day is evocative in the way she conjures up several embodied experiences mediated through the senses. It was “freezing cold” and the child was “screamin”. By being closely intertwined and therefore inter-bodied with his mother via the peapod carrier, Adam and his mother could enjoy the shared experience of a walk in which they could together relish the sensations of the blustery wind and raindrops. The day then finished with a highly pleasurable taste experience in the form of hot chocolate and doughnuts. Angela’s treasuring of the sensory pleasures of oral feeding is neatly summed up by her niece’s portrayal of her as “a feeder”.

In Angela’s description, feeding pleasure is related to little tastes “hot chocolate off a teaspoon” and “jam from a doughnut” rather than eating large quantities of food. There is evidence that feeding pleasure from filling the stomach, whether from oral eating or artificially administered feeds, may diminish when satiety approaches, as Gary describes:

- | | |
|-------------|---|
| Researcher: | Do you like the feel of having a full tummy? |
| Gary: | Yeah that (2.0) ah yeah () I get that feeling (0.2) all the () e-every time I eat something I’ve I’ve I get that feeling every time I eat something |
| Researcher: | Do you? Even if it’s quite small? |
| Gary: | Yeah |
| Researcher: | Yeah |

Gary: Even, even e (sniffs) even if it's quite small and

Researcher: So you, so you feel fill up very fast

Gary: Yeah

Researcher: Yeah. Can you remember how it felt () when you use to have the () erm GT feed? Did you get that feeling of a full tummy then?

Gary: Pss oh tsk Yeah I did erm tsk I I used to turn my feed off when I () when I when I wasn't supposed to if was full

Researcher: Right (laughs)] yeah (1.0)

(Gary, aged 16)

The way Gary seizes control of his own feeding apparatus is discussed further in Chapter 6 "Feeding as Care". What is important to acknowledge here, is that Gary understands a full stomach feeling, which he finds to be a pleasant one, represents satiety. However, for Gary, the pleasurable feeling of satiety may be reached very early on during feeding because motivation and satiety have links to energy requirements which can be lower in children with CP (Walker, Bell, Boyd, & Davies, 2012). When approaching satiety his motivation is likely to cease and taste and other aspects of enjoyment also drop. For Gary, once satiety is reached, further intake beyond this either does not produce further reward or begins to become unpleasant. When previously tube-fed, Gary turned his feed off himself when he started to feel full, even though he acknowledges that this was not something he was supposed to do.

Colin describes how he also detects non-oral feeding pleasure in his own son Craig:

You can see now how he's got a little machine now (0.3) erm (0.3) which when when Claire switches it on obviously it () when it boots up it makes beeping

noises and he sits in his () he sits in his chair [R: yeah] and he he knows what's happening he looks at it and he starts getting excited because it's like obviously [R: Like Pavlov's dogs] Aye because he knows it's like his feed time and just [R: Yeah, yeah] we would obviously, we would probably do it with somebody who puts a nice () plate of food in front of you () he gets himself excited because the machine starts beeping because he knows it's erm time for his feed (*Colin, father of Craig*).

Colin's description suggests one of behavioural learning, which I position as "like Pavlov's dogs" an observation which Colin accepts. The beeping of the machine is the "bell" which provides an auditory cue forewarning the arrival of the feed. This aural cue is accompanied by touch, "he sits in his chair" and visual cues, "he looks at it". These are important signals for Craig who "knows what's happening" and thus recognises these events as feeding time.

Some aspects of the pleasure and commensality of food and drink are under higher cognitive control and can be facilitated or inhibited by memory processes. Both working memory and episodic memory are thought to be important determinants of human responses to the food cues which are strong motivators for eating and drinking (Higgs, 2016). Working memory - the cognitive system that temporarily holds information that is currently being processed - influences how much attention may be paid to environmental food cues because mental images of an object held in the working memory can cause attention to be drawn to similar stimuli (Soto, Heinke, Humphreys, & Blanco, 2005). Episodic memory - the remembering of events - may have an influence because it creates expectations of how food will taste based on the accumulation of past experiences.

In the above section, I have demonstrated how family members, and even the children themselves, recognise that feeding pleasure can be multifactorial. Feeding pleasure can be obtained in many ways and the loss or reduction of oral feeding does not mean that all feeding pleasure must necessarily be lost. This has relevance for the decision-making process around GT feeding because many reports have suggested that imaginary constructions around the loss of feeding pleasure can be a strong factor in GT resistance. (Craig & Scambler, 2006; Craig et al., 2003; Guirriere et al., 2003; S. W. Smith et al., 1999;

Spalding & McKeever, 1998). In the section which follows I will describe how families construct values around the commensality of food and drink and what this means in terms of GT decision-making.

5.3 Commensality in the family context

Doucet (2006) argued that as children grow, fathers begin to enjoy a greater level of embodied interactions such as rough-and-tumble play or outside excursions with their children. This allows fathers to develop a closer relationship with their infants that contributes to their sense of emotional and embodied intimacy. My research tends to support that view, suggesting that as children develop and grow beyond the infant phase, and become less inter-embodied with their mothers, fathers and other supporting relatives hope to become increasingly involved with the child. It is possible that whereas mothers see bonding as *supporting* later development, some fathers may see bonding as something that is *derived* through the child's development and concerns about the child's feeding abilities become paramount. For example, Colin:

My biggest concern is that obviously, obviously as babies (0.5) grow up you you used you get used to eating don't you? [R: Yeah, yeah] and my concern is that obviously a few years, in a few years' time () you know the lads, the lads like he's 6 months old now and he's probably never really had anything () substantial through his mouth [R: Yes, yeah] So the older he gets (0.2) you know it's as if like well if things do (), if things do () at some point sort themselves out or if something's able to be done the y'know like is he going to be out there he's gonna obviously have to learn how to (0.5) how to eat, drink, swallow that sort of thing [R: Yeah] You know and obviously it's probably quite easy when they're, when they're new-borns because it's all they have to do [R: Yeah] Whereas the older he gets (0.2) It's probably going to be a little bit, a little bit strange for him (*Colin, father of Craig*).

The biggest anxiety for Colin is how Craig's feeding may evolve in the "in a few years' time". In raising this question, Colin suggests that a typically-developing young infant would be able to feed instinctively "because it's all they have to do." The longer this non-oral phase continues, the more difficult or "strange" it would be for Craig to learn to "eat, drink and swallow". Other fathers view non-oral feeding as a temporary phase "to just

get us by” (*Brian, father of Billy, line 346*). Thus, Brian positions the tube as a way of ensuring he gets everything while “we develop ... the other skills that he needs”. It is interesting to note at this point that these descriptions of the skills that must be learned focus on the development of oro-motor skills and do not highlight any enjoyment of food, which as I have discussed above must also be learned.

Family members, especially fathers, expressed concern about the child’s future social self and issues around commensality. Some writers have argued that the routine and ritual elements of family mealtimes are strongly related to children’s well-being and the creation of family identity (Fiese, Foley, & Spagnola, 2006). Others have questioned the normative power of the “happy meal” which they posit as an “ideological substrate” emerging from, and underpinned by, political, family and individual powers which together serve to maintain gender and cultural inequalities and displace social responsibility from state to individuals (Wilk, 2010, p 428). The families in this study identified closely with the first social construction with talk often centring around the importance of family mealtimes.

Food memories and their associations with routine and ritual may be constructed and reconstructed amongst families in such a way that likes and dislikes may filter down throughout the generations and become part of family habit. In the following extract, Colin draws on episodic memories to describe the importance of food and drink in the forming of group cohesion amongst the male members of his family:

It’s certain things like obviously it’s probably something that I obviously I grew up with me () erm with me Dad and () me uncles and things like that you know from a small age like sorta going out and () [R: Yeah] sitting with them drinking cokes and then obviously it escalates when I get older and things like that and I just think ‘oh, I wonder what it would be like for him ?’ If, when he reaches that () stage of his life aye we did it we’ve done it done it for a long time so now obviously he’s probably just the next () the next stage when he gets old enough to do it he’ll come along so it just seems weird () and I just imagine meself sitting there and we are all having drinks and () (sighs) and pumping him with a syringe full of Coke or something like that you know (laughs) (*Colin, father of Craig*).

Colin's account provides a clear description of an episodic memory around the bonding of his male relatives "me dad and me uncles" in the (hearable as) traditionally masculine environment of the pub. Part of this bonding process involves the activity of initially drinking cokes which then "escalates" (presumably to alcohol) as he got older. This situation starts young "from a small age" and has been "done for long time now". Thus, it has become an embedded part of family ritual both across the generations and the individual's development span. Colin raises his concern that without the ability to consume fluids orally, this traditional family ritual would seem "weird".

Colin's episodic memory of such male bonding events focuses on the types of drinks consumed. However, it is important to recognise that everyone constructs episodic memories of an event differently and others may focus on other aspects of such events such as playing pool or darts. However, for Colin, this "weirdness" of not been able to drink Coke positions the child outside the group. This is neatly summarised by his description in which we (the group) are all (actively) having drinks whereas the child (the external other) is pumped (passively) with a syringe full of Coke. By drawing on episodic memory such as this, Colin positions himself as being concerned that Craig's ability to bond with the male group may be compromised in the future through his poor feeding ability. This ties in with other findings around disability in children leading to some to conclude that disability in childhood "contributes to the disintegration of expected narratives about both children and their futures"(McLaughlin & Coleman-Fountain, 2014, p.1).

However, at this point, it is important to return to the differences between early infant feeding and the feeding of an older child. In the following extract, Colin explains why these commensal differences matter less with young infants:

Aye, if it's a baby I don't think it's really (0.5) obviously I think, you know cos he's not going to remember anyway (*Colin, father of Craig*).

Colin's use of the phrase "if it's a baby" segregates the category "baby" from older children and adults. Colin's rationale for the lesser importance of oral feeding in infants is that "he's not going to remember anyway". Thus, Colin relates the importance of episodic memory in the development of bonding.

Family members may need to accept that the future with their child may be very different to both their own experiences of childhood and may diverge in many ways from the future that they may have originally imagined for their child. I will discuss concepts around hope in relation to the child's development, diagnosis and prognosis in Chapter 7. However, at this point in this thesis, it is worth mentioning that families do hold on very strongly to hopes around future feeding, as Anthony explains:

I don't think that Adam's oro-motor skills are going to improve so much that he is going to start wolfing down cottage pie or anything but if there's a real possibility that [R: yeah yeah I mean] then it would be unfair in my mind not to say that there is a possibility (*Anthony, father of Adam*).

Anthony's use of the term "oro-motor skills" indicates that Anthony has a growing familiarity with medical, technical, language born out of caring for a disabled child. Anthony's experience of orally feeding Adam terminated with the near death of his child through aspiration, thus making him wary of both unnecessary risks and unrealistic expectations. Anthony's hopes for Adam centre around a yet to be determined middle ground which lies somewhere between the opposites of being totally tube fed and the unlikely future of "wolfing down cottage pie". Anthony's use of the term "it would be unfair in my mind" suggests that he does not want his own risk aversion to impact on Adam's opportunities to learn to eat orally.

Not everyone shared the same concern around future feeding. For example, Elliott's brother Evan, discusses the issue of Elliot not orally feeding:

Er-erm well I don't know what everyone else would be like but I () wouldn't, I wouldn't have a huge problem with that. I mean I think it would be () better for Elliott if he could eat [R: yeah] erm () maybe just better for him really when he gets older. ... he takes most things in his stride so () I don't worry about him too much but erm (o.2) I think it would () be better for him but if he couldn't then () he would deal with that (*Evan, Elliott's adult brother*).

Evan describes himself as "not having a huge problem" if Elliott does not go on to achieve oral feeding. His choice of adjective "huge" suggests that Evan does not see the situation as perfect but it isn't the worst it could be. Evan's concern centres around Elliott's well-

being which is tied to the child having the skills to cope. Evan therefore draws on Elliott's personal characteristics as a resilient person, one who "takes things in his stride" to emphasise the fact that Elliott would be able to cope no matter how he was fed. For Evan, Elliott could still achieve a good quality of life with or without oral feeding and it was not a "huge problem".

One of the two children who participated in this study, 16-year-old Gary, made the decision himself to end GT feeding and work towards an oral diet. Gary could have tastes of food orally in addition to gaining the bulk of his calories via his GT tube. Gary's choice to have his GT removed was unlikely to be tied to issues around the pleasure of eating. It is more probable that factors around his belonging to his peer group which are partially underpinned by the shared experience of food and drink. For example, in the following extract, Gary describes his ambition to eat at McDonald's:

Yeah, I would, I would love to do that! [R: yeah] I'm () I 'm (I'm) nearly there with it, I'm I'm nearly there [R: right] I can see myself an' well mam can see it as well, I'm nearly there (*Gary, aged 16*).

Gary's assertion that he "would love to do that" and "I'm nearly there with it" suggest that the outing of "going to McDonald's" is something that Gary views as a personal goal. The achievement of this goal is becoming more within reach and is so close that Gary and his mother can now visualise it "I can see myself". Gary later explains how he has no interest in going to a "posh" restaurant, which suggests that Gary's desire is not linked to the experience of luxury, but of taking part in a normal teenage activity that is likely to be popular with his peers. Thus, by achieving the goal of eating orally in McDonald's, Gary moves a step closer to normality.

5.4 Summary and implications

In this chapter, I have discussed how many eating skills are learned behaviours both in terms of developing the complex motor and oro-motor skills needed for physical feeding ability but also in terms of developing food pleasure via exposure to a variety of foods. One belief around oral feeding is that it is a pleasurable activity for everyone. This has important implications for parents making a decision about feeding because they may feel that the GT option may deprive their child of the pleasure of eating.

However, my research shows that the situation is more nuanced than this. Most parents have learned to enjoy food and may not always recognise that children with dysphagia may not value feeding experiences in quite the same way. Parents' own appreciation of food may be strongly tied to their own enjoyment of flavours, sensory experiences of eating, and the commensal aspects of the shared meal. Where eating and drinking is exhausting, the disadvantages may outweigh the pleasures of feeding for some children with feeding difficulty. This may be one reason why research around feeding difficulty consistently mentions the "battles" and "wars" that ensue as children resist being fed. This research is unique because it includes the viewpoint of a child with dysphagia who could eloquently describe his early feelings of panic around food and relate his story of how he had to learn to enjoy food.

Commensal eating and drinking may be highly tied to the parents' memories of their own experiences. As a young child moves beyond infancy, the development of the child's future social self and his position within the family become of increasing concern, and in this study, this was particularly raised by fathers. Families may need time to accept that their child's future may differ from their own experiences and they may need help in reimagining their child's future as one in which eating and drinking takes on a lesser role in social activities.

In the following chapter, I will move on to describe the burden of feeding that arises from feeding a child with a neurodisability either orally or by NGT.

Chapter 6 Feeding as Care

6.1 Introduction

In this chapter, I will discuss how the issues around feeding values -which I discussed in Chapters 4 and 5- impact on the additional care needed for a child with a neurodisability and feeding impairment.

Before embracing this topic, it is important to define what I mean by “care”. Caring work has been historically conceptualised in early sociological research as work that is carried out in the domestic environment, usually by women, who are not generally compensated in any financial way for their work. Such work, although freely given, is not necessarily voluntary but embedded in female duties and obligations (Graham, 1991). Fisher & Tronto (1990) emphasised that care is a complex activity because it is both a disposition and an activity which includes four concepts of care:

- “caring about” – recognising unmet needs
- “taking care of” - taking responsibility to meet needs
- “caregiving” - carrying out the actions necessary, and
- “care receiving” - responding to the care given.

I will be drawing on these four concepts of care to demonstrate that care is a complex activity that goes beyond physical care throughout this chapter.

In typically-developing children, the requirement for physical care changes over time as children mature and become able to meet their own needs. However, a recent systematic review of patterns of time-use for children with complex needs has shown the time taken to meet the needs of child with a neurodisability is both much greater and more prolonged than it is with a typically-developing child (McCann, Bull, & Winzenberg, 2012). Ensuring adequate nutrition and hydration is one such aspect of caring for many children with neurodisabilities. In addition to the standard care tasks that most parents undertake, parents of children with neurodisabilities may have to perform a wide range of clinical procedures which are usually viewed as belonging to the remit of nursing or other clinical services (Kirk, Glendinning, & Callery, 2005; McCann et al., 2012; Ward, Glass, & Ford, 2014). Some of these include tasks, such as NGT insertion, that may cause

the child distress (Spiers, Parker, Gridley, & Atkin, 2011; Tong, Lowe, Sainsbury, & Craig, 2010).

As I have already shown, my research suggests that the values placed around early infant feeding by mothers can be qualitatively different to the values placed by fathers and I have posited that this may be related to issues around inter-embodiment. In this section, I will show that when a GT is not present, mothers are seemingly obliged, perhaps as an outcome of this sense of embodiment, to take on a large proportion of the “caring for” and “taking care of” aspects of feeding. However, other aspects of care around feeding, particularly the emotional burdens “caring about” are felt by everybody involved. Uniquely my research also includes the point of view of two children, the “care-receivers”. In this chapter, I will focus on two types of feeding care which affect these families. These are maintaining oral feeding and managing NGT feeding. In Chapter 7, I will go on to discuss how the burden of care around feeding and its management changes once a GT has been placed. I will begin by discussing the levels of care required to feed a child with a feeding difficulty orally.

6.2 The daily grind of oral feeding

Earlier research with mothers has suggested a degree of cognitive dissonance around feeding. On the one hand, as I discussed in Chapter 4, early infant feeding is often represented as a close and intimate experience of inter-embodiment between mother and child (Sleigh, 2005). Yet mothers have simultaneously described oral feeding of disabled children using terms of conflict such as “a battleground” (Thorne, Radford, et al., 1997) or “war” (Craig et al., 2003). These two conflicting emotional stances have been suggested to be a major source of decisional dilemma around GT which force mothers into a position of having to renegotiate their identities as successful mothers (Craig & Scambler, 2006). My research broadly supports these findings. For example, in the following extract, Angela describes one aspect of her feeding experience:

We were just sort of erm persisting with oral feeding so before every NG feed I would try with the bottle first and see if he would take anything and erm 'cos he just screamed all the time and people will always say ‘I know, I had one like that.’
[R: humph] I don't think they realised that when he was awake he was screaming.

I wouldn't, I couldn't be sat like this now, he would be screaming and the only upside of that was that he used to wear himself out screaming, so he slept a lot as well (*Angela, mother of Adam*).

For Angela, Adam screaming “all the time” when “persisting with oral feeding” suggests that the feeding encounter was a daily test of endurance. The interjections that Angela describes “I know, I had one like that” presumably come from well-meaning acquaintances with the worthy intention of empathy. However, Angela positions those comments not as a reciprocity of perspectives but as evidence that these “people” are failing to recognise the intensity of her experience, “I don’t think they realised”. In making this statement, Angela is drawing on experiential knowledge. Parents sometimes claim that their knowledge derives from the highly intensive experience of “caring for” a disabled child. As such, it differs qualitatively from a more objective scientific “caring about” that professionals may claim to have because it can only develop through very close contact with the child (Callery, 1997; Goode, 1994; Kirk et al., 2005). For Angela, all, not just some, of Adam’s waking moments were disrupted by screaming, “I couldn’t be sat like this now” and the only respite from this is when he exhausts himself to sleep. Chloe witnessed the effects of stress around feeding on her best friend Claire:

She's () really tired [R: yeah] it's very tiring thing [feeding] but, if you've got a baby it's a tiring thing as well [R: it is (laughs)] so to be honest with you I think () it is tiring but with the additional sort of stress () around Craig's problems () erm that hasn't helped (*Chloe, best friend of Craig's Mum, Claire*)

Chloe’s comment ties in with Angela’s message. All babies may be tiring, but the stress arising from having a baby with a neurodisability and a feeding difficulty was over and above what might be normally expected, creating “an additional sort of stress”. My findings support other research that illustrates the higher demands on the families of children with neurodisabilities. For example, in a study of 33 families with children with disabilities or other special needs, Whiting (2013) found that the unrelenting care required to care for their child left parents at risk of both physical and emotional exhaustion.

Any decision to persist with oral feeding impacts on fathers as well as mothers. The children national service framework (NSF) England (2004) identified that fathers play an integral role in the family when a child is disabled (Sloper & Statham, 2004). However, there remains very little research around fathers despite them providing a significant amount of care for a disabled child (Hobson & Noyes, 2011). Fathers often remain the main financial provider which restricts the time for them to give physical care and they may find that taking on an active role to be particularly challenging and stressful (Hobson & Noyes, 2011). In my study, Angela and Anthony both work and share childcare tasks and I therefore draw largely on their data, which is particularly rich, to illustrate the impact of the additional feeding care needs on this family. On Angela's working days, Anthony takes on the responsibility for "taking care of" childcare. In the following extract, Anthony describes his experience of feeding Adam:

But it was, it was say at home, it was hard work I always found and realising (0.2) how quickly he deteriorated, I think that was like well, I'd ah for a long time I'd err (0.6) really I really didn't enjoy feeding him, I found I was really anxious and [R: yeah, yeah] and it was taking about an hour (*Anthony, father of Adam*)

Anthony refers not only to the physical "hard work" of feeding but also to the emotional work of managing his anxiety around risk coupled with the drain on his time. Hesitations occur in Anthony's account prior to his disclosure that he didn't really enjoy feeding Adam, and suggest a potential difficulty in revealing that information. The use of "for a long time" indicates that this situation of challenging emotional work is not a new problem and this stress has been an enduring one.

For some families, the additional feeding workload begins at birth but for others it can creep in gradually either when children are weak following illness, or conversely, as children became stronger and more determined to fight feeding. Some children, such as Adam, also receive medication for comorbidities such as epilepsy which can further impede feeding by making children drowsy, as Anthony explains:

It wasn't just getting food into him but getting everything into him had become such an issue but he had an unsafe swallow and he was also barely awake as well so (*Anthony, father of Adam*).

It is only in hindsight, when the struggle with oral feeding is abruptly terminated following a life-threatening incident of aspiration, that Anthony is fully able to recognise how demanding the burden of feeding has become. By using the term “such an issue” Anthony implies that the feeding problem is a major emotional drain on the family. In Chapter 9, I will discuss how Anthony discloses that it was not until after this critical incident occurs that he fully comprehended what professionals really meant when they used the term “unsafe swallow”. Nevertheless, even without appreciating fully the graveness of this risk, Anthony still struggles to contain his anxiety. This additional emotional work “caring about” can impact negatively on relationships, as Angela describes:

And we were constantly rowing because erm (o.2) I would get wound up about getting the food into him if he wasn't feeding particularly well at that time
(*Angela, mother of Adam*)

Angela attributes this constant rowing to the emotional burden “I would get wound up” that arose as a direct consequence of her efforts to ensure that Adam gets adequate nourishment “getting the food into him”.

Problems with relationships, sometimes leading to family breakdown, are well documented in the literature (Ward et al., 2014). However, a recent meta-analysis on marital adjustment in parents of children with disabilities has found a much smaller effect on parents' partnerships than has been previously assumed, as parents begin to find ways to develop the resilience to cope with the significant emotional, social, physical and financial pressures required to raise a disabled child (Risdal & Singer, 2004). In the following extract for example, Angela explains how the couple attempt to diffuse this feeding related tension by creating family time away from their usual environment:

Because our life was so tense and frazzled and we were rowing so much the rare family time that we had were walks through to spring flower meadows or er a weekend up at the caravan or something like that (*Angela, mother of Adam*).

Angela's use of the term “our life” suggests that being tense and frazzled is a deeply shared experience. This is potentially one way to develop parental resilience. Angela's detail that “rowing” can be reduced by creating “rare” family time in the openness of the

spring flower meadows or by being in the caravan suggests that the feeding stress is in some way related to the additional responsibilities of home. This ties in closely with Anthony's comment above "say at home I always found". At home, the time that is needed to fulfil Adam's nutritional needs competes with the other time demands generated by domestic tasks. By eliminating the rival activities, stress and disharmony reduces to more manageable proportions. Similarly, in the following extract, Angela describes how another non-feeding activity was managed to reduce stress:

I'd spent most of Monday in tears trying to feed him and and he took all his medication orally and he takes, altogether he takes five different medications erm (o.6) and err (o.6) I'd gone to the GP myself on Monday morning (o.6) erm and she had signed us off work for a month because of stress (*Angela, mother of Adam*).

Whereas Anthony positions himself as viewing feeding as "the issue", Angela's way of dealing with competing tasks is to centralise her life around the need to orally feed. Rather than opting for a method with the potential to reduce the burden of oral feeding (for example, by opting for GT) she instead reduces the stress on the family by eliminating the rival burden of paid work.

Reducing other sources of tension is one way to manage the burden of oral feeding, but not all sources of additional pressure can be eradicated and families develop techniques to deal with stress. In the following extract, Angela describes one of her coping mechanisms:

Every time I felt meself getting a bit worried and anxious or what, if I just like CBT just keep swimmin, just keep swimmin' and that's what we was gonna do! (*Angela, mother of Adam*).

Angela's use of the phrase "every time" indicates that this anxiety emerges with some regularity. Cognitive behavioural therapy (CBT) is a talking therapy that helps people manage their difficulties by changing the way they think or behave in response to stressors. Angela's chant to herself when stressed "just keep swimmin" creates a soothing mantra which she equates to being "just like CBT". Being able to "keep swimmin" is also a practical strategy to resist drowning, thus Angela's statement also serves as a metaphor

for trying to keep their heads above water in order to survive. Although it is unclear whether Angela's use of "we" refers to the mother and child dyad or the couple's relationship, it is apparent that Angela positions this survival as something that can only be attained via joint effort "that's what we was gonna do!"

Mothers who are struggling to cope may resist seeking help in case their maternal practice may be judged inadequate. Angela narrates how the couple's friend, Peter, unable to cope with the stress of parenthood simply abandons the family home leaving his wife to cope alone:

There was one night Peter couldn't take it any more so he just walked out the house and left Jane with Rhianna and she didn't know where he was for two days [R: really?] and erm he was tiny and they came to see us and they were absolutely and completely honest about how those made them feel [R: yeah] and erm and what that did to them and erm me sister's mother in law she said err "our Gregory, Gregory I could've, I could've thrown him through the window!"
(*Angela, mother of Adam*).

Angela links the story of Peter with the anguish of another desperate parent, this time a mother who posits the desperate act of throwing a child through the window as an inviting prospect. In relating these two scenarios of other parents reaching the end of their tethers, Angela can normalise the ambivalence felt by many parents towards their demanding offspring. Angela's respect for their honesty motivates her into making a candid admission of her own:

No! I di, I remember standin in that room 'cos we used to try and get him to sleep on his own and standin in that room and bouncin' him in the middle of the night and wondering what would happen if I just let go! (*Angela, mother of Adam*)

Angela's narrative shares the same imaginary quality as Gregory's mum's story "I wondered what would happen if I just let go". In her discussions around feeding and inter-embodiment, Lupton (2013) argued that feeding can encroach upon the carer's self-autonomy and freedom resulting in a desire to be liberated. Angela's portrayal of it being "the middle of the night" demonstrates the bleakness and loneliness of her situation and her wish to be liberated. This is not just night time, which could include late evening,

but the middle of the night when most people would hope to be asleep. Angela is left bouncing her screaming baby and there is seemingly no way to make him stop other than by harming him. Lack of sleep as a major stressor has been identified in many studies of families caring for a child with additional needs (Kirk, 1998; McCann, Bull, & Winzenberg, 2014). However, the picture painted by Angela of night-time care is not just one of exhaustion but also one of isolation, inadequacy, and fear. The generous revelations of others normalise the situation for Angela, and reduces her sense of isolation thus allowing her to speak freely about her feelings. Some new parents may not be lucky enough to encounter other carers with the same degree of frankness. This could leave parents of disabled children afraid to divulge fully their concerns about the challenges and frustrations they face around feeding:

Although the physical workload of oral feeding is recognised by others, the degree of stress that mothers may be under may not always be fully appreciated by professionals.

It was a thing that she spent hours and hours doing with him (o.2) well she would feed him for hours. ... She, she liked feeding him! She liked him eating like a normal, like a normal [R: Yeah] child, she, she definitely liked the fact that he quite liked eating and stuff. But I think it was getting tricky and trickier (*GP1, GP for Adam*)

The GP realises that the feeding is a laborious and time-consuming task which is becoming increasingly difficult. The mother's determination to stick with oral feeding, is interpreted by the GP as something that she enjoys doing. She positions this enjoyment as emerging from the mother's desire for the child to be "like a normal child". As discussed earlier, Angela's partner Anthony did not enjoy participating in oral feeding and recognises that Angela's desire to orally feed emerges from her desire to gain "a sense of normality". Being rewarded with a sense of normality is not the same thing as enjoyment. It does not mean that it is not extremely stressful for mothers, as Beth describes:

I've struggled and struggled to feed him because I feel as if that's what I should be doing as a Mum (*Beth, mother of Billy*)

Beth positions the struggle as necessary because that is what she should be “doing as a mum”. Trying to create a pseudo-situation of normality where normalcy does not exist can place a strain on families. It is important that health professionals and others recognise when this pursuit of normality may not be realistic and is causing great strain. Family and friends can sometimes sense the frustration felt by mothers when professionals do not appear to fully appreciate the full spectrum of difficulties these mothers encounter. As Brenda explains:

(0.5) Erm (1.0) once or twice Beth (0.2) did get a bit upset (0.2) erm (0.2) when the dietician, with the dietician (0.5) you know who used to insist that Billy should be doing this now, and Billy (0.2) should be doing that now [R: Right] eating and you know Beth felt that she wasn't taking into consideration Billy's other (0.5) problems. [R: Right yeah, it didn't] It use to frustrate Beth (*Brenda, Grandmother of Billy*).

Brenda's description that Beth would get “a bit upset” with the dietician highlights the additional burden of the complex interactional work that may sometimes be required by mothers to elucidate the degree of feeding difficulty to professionals and that they are not failing to be “good” mothers. This dietician is positioned as recognising that Billy was delayed in reaching developmental milestones “Billy should be doing this now”. However, Brenda's use of the term “used to insist” suggests that Brenda positions the dietician as implying that it is Beth's efforts to feed Billy that are inadequate and it is this that results in his poor progress.

Feeding difficulty, inadequate nourishment and poor progress can create a vicious circle within which it is difficult to determine cause and effect. The presence of childhood neurodisability within the family means that private parenting is extended into a public activity conducted under the scrutiny of healthcare professionals and other observers. I will talk further about this in Chapter 7 on disability, normalisation, and stigma. At this point, I will highlight the paradox that despite this scrutiny, previous research has reported mothers recalling difficulties in convincing health professionals or other family members that their children did have significant feeding difficulties (Spalding & McKeever, 1998).

Brian also expressed concern regarding that Billy's problems were not being properly identified:

Up until (0.5) erm obviously he had this put in () when he hadn't put on any weight () [R: right, yeah] at all. He hadn't lost anything so no-one was concerned () [R: yeah] that he wasn't actually that he hadn't put anything on [R: Yeah] Erm (1.0) but it was actually only () when Beth mentioned that his nappies were currently dry [R: Right] That they got concerned (0.5) [R: Yeah] So I think in that case [R: yeah] You wonder if in () August they would say well he hasn't put on any weight for three months () but maybe longer erm (0.5) they'd have said "let's try something else" whether and would he have been like this ? So would he be sitting up now and? (*Brian, father of Billy*).

When talking about infant feeding, Brian emphasised that he had little involvement with Billy's oral feeding. Brian may not have engaged fully with the physical task of feeding, but it is nevertheless apparent that Brian carries a burden of anxiety "caring about" around the outcomes of feeding. Brian surmises that the professionals' concern is only aroused either by weight loss or indicators of dehydration such as dry nappies. Brian's anxiety does not centre around the static weight per se but the impact that inadequate nutrition might have on his child's developmental progress. Brian positions himself as wondering whether earlier intervention should have been considered and whether this may have resulted in faster progression for Billy, "would he be sitting up now?"

However, there is evidence in my data that health professionals frequently had a good understanding of the physical demands created by feeding a child with a feeding difficulty:

The family had always been very keen to erm tsk continue with oral feeding to an extent that I think a lot of families wouldn't have managed () to maintain (*SALTi: speech therapist for Adam*).

It is notable that this burden of work is posited as a direct outcome of the parents' own choice "the family had always been very keen" rather than any ideals around social expectations of good mothering. SALTi's use of the term "family" is interesting because it presents the parents as a single unit sharing the same ideals about how their child

should be fed. However, as I earlier discussed in Chapter 3, fathers do not necessarily share these same values around oral feeding as their partners.

PAED₁ describes her understanding of the relentlessness of the feeding task” as being “the daily grind of trying to safely get enough calories into him”. It is interesting to note that from the paediatrician’s perspective “the daily grind” of feeding Adam is not restricted only to the adequacy of calorific intake but about “safely” achieving this. The absolute safety of oral feeding can be difficult to guarantee in children with neurodisabilities. The paediatrician is most probably concerned with Adam’s risk of aspirating feeds because of an unsafe swallow. However, this does not necessarily make sense to parents in quite the same way as part of the feeding burden because they may be unfamiliar with this term (see Chapter 11). However, anxiety around the safety of feeding is an additional burden for health professionals to manage and this ties in with concept of care as responsibility “taking care of” (Fisher & Tronto, 1990). PAED₁ further expands on this burden of responsibility:

The fact that he had a history of vomiting, erm, you know, it was, how are we going to feed him? How are we going to get the feed into him? You know, if we, if we didn't have a GT then obviously we were limited because we couldn't feed him overnight because of the risks of aspiration (*PAED₁, Adam's community paediatrician*)

The paediatrician’s frequent use of the word “we” indicates that this is a concern that she shares with others and this could potentially be either family members or other health professionals. As her unease is linked directly to the parental choice of declining GT, it is more likely that she is referring to the other members of the multidisciplinary team that also share this responsibility.

In the above section, I have expanded some of the issues around the burden of care required to orally feed a child with a neurodisability, by relating my work to the sociological constructs of care as detailed by (Fisher & Tronto, 1990). As I discussed in Chapter 1, when oral feeding is insufficient or unsafe, parents may be offered the option of an NGT. In the following section, I go on to discuss the impact on care burden that arises from NGT feeding and how this additional burden is shared.

6.3 NGT feeding as mother's work

As I described in Chapter 1, NGT feeding is a form of enteral tube-feeding via the nose which can be temporarily used to meet the nutritional needs of a child with a feeding difficulty. All children in my study were fed by NGT at some point during their lifetime, sometimes for extensive periods of time because of waiting list times or parental resistance to GT feeding. However, eventual and profound dissatisfaction with the NGT was a key trigger in this study for the move towards GT placement. How the key decision makers evaluate the benefits and risks of NGT versus GT feeding will be discussed further in Chapter 10. At this point, I focus specifically on the additional care that arises when a child with a disability has an NGT in-situ and how this workload is shared.

Parents of children with complex long-term health conditions or disabilities often take on the additional responsibility for the technical aspects of healthcare which can include the care of NGTs (Kirk et al., 2005; Tong et al., 2010). One feature of the care required for a child with a NGT is the need to reinsert them at regular intervals, often because they have been deliberately or accidentally pulled out by the child. The task of replacing the NGT is viewed very strongly by participants in my study as an unpleasant and stressful task.

Because his Mam had to keep inserting it back in and () [R: yeah] y'know that's distress, quite distressing for () for her as well as him so (*Colin, father of Craig*).

I mean obviously Claire was () shown how to put the tube back in but it's still [R: yeah] quite distressing for her to have to do that (*Chloe, best friend of Craig's mother*)

It is interesting to note that when Colin starts to describe the procedure as being distressing for Claire he stops mid-word and modulates this to “quite” distressing, resulting in the use of the exact same term as that employed by Claire’s best friend Chloe. It is possible that this is a topic that has been talked about within their circle with the same terms used. Colin also notes the distress suffered by Craig “as well as him”. Thus, Claire’s anguish may not necessarily emerge from any squeamish aversion she is experiencing with regard to this task but is a sorrow arising from her baby’s distress. One finding of a qualitative interview study exploring the experience of being the parent

of a technology-dependent child suggested that performing a clinical procedure on their own children was the most distressing part of caregiving for parents because it could involve deliberately inflicting pain (Kirk et al., 2005). Other researchers have also noted that many parents find the responsibility of carrying out tasks which are distressing for the child, including inserting NG tubes, to be emotionally difficult (Tong et al., 2010). Noting that Colin's narrative is one of an observer, rather than a participant, I ask him to outline his own contribution to this procedure:

Researcher: Did you ever try putting the NGT down yourself?

Colin: errrrmmm

Researcher: Or was it something you?

Colin: Actually I didn't, no

Researcher: No? Well I was just interested that you only said Claire

Colin: I do, I've got some aarrhgh ,I, I, I I I've a lot of admiration for her because it was just something I, dunno, for me. I just, it was something that I just (0.2)

Researcher: you just couldn't do it?

Colin: I couldn't face doing, no, no.

(Colin, father of Craig)

The frequent hesitations in Colin's account suggests that he does not feel comfortable in having to account for the fact that he has not taken on the physical share of a task which he already admits his wife finds distressing. He gives his reason for this as:

I'm just a big wuss actually (laughs) *(Colin, father of Craig)*.

In Chapter 5, I discussed how Colin draws on very traditional male context (the pub) when describing his personal values around feeding. It is possible that his version of masculinity may be a traditional one. Choosing the humorous slang term “wuss” accompanied by laughter, suggests an attempt to ward off any potential threats to this version of masculinity by turning it into a joke. “Wuss” is situated as un-masculine and may be used to describe someone who is not a “real” man. His earlier statement that he has a lot of admiration for Claire confirms that his non-participation is not because he sees the task as in some way beneath him but because he sees Claire’s strengths as being aligned differently to his own and that Claire is more suited to this intimate and “dirty” work. However, other authors have found that some parents do choose to decline distressing tasks (Spiers et al., 2011). It is therefore important to relate once again to the work of Fisher & Tronto (1990) and draw a distinction between the practical “caregiving” and emotional “caring about” work that is embedded in the task. Although Colin (and other family members) do not take on the physical task of tube insertion, this does not mean that they do not engage emotionally with the task. Colin’s inability to “face” the task does not suggest selfishness but is indicative of a person who is profoundly engaged with the emotional work of the task. It is possible that in downplaying “distressing” to “quite distressing” Colin attempts to avoid portraying himself as a selfish person, unsupportive to the one person, Claire, who is prepared to carry out this role.

During the longitudinal arm of this study, it was ascertained that Florence’s oral feeding may be both inconsistent and potentially unsafe. The decision needed to be made as to whether continuing supplementary NGT feeding was right approach or whether a GT should be considered. Although it was the mother, Fiona, who replaced the NGT it was the father, Frank, who was resistant to the idea of GT feeding. The health visitor explored this drawback of the NGT needing to be regularly replaced:

HV2:

So how often does it need to be replaced because I know you were saying that it, she gets very distressed doesn’t she?
[Fiona: yeah] when it does need to be

Fiona: Well I mean she's fine afterwards but she knows now as soon as you come near her with a tape and a new tube she knows what's happening and she she doesn't like it does she?

Frank: ((very quietly)) no ()

(TAF1: lines 229-235)

Up until this point in the meeting there had been no major comments from Frank, and indeed there is little evidence of his opinion being actively sought up until this point². When brought in to the conversation to support the fact that Florence did not like having the NGT replaced, he gives the preferred response of “no” which is demanded by Fiona’s question format “she doesn’t like it does she?” However, Frank gives his answer very quietly. This could indicate that Frank is uncomfortable with acknowledging that his resistance to GT feeding might result in his daughter having to endure something unpleasant.

Similarly, Claire’s mother, Cilla, also portrays herself as a person who finds the position of observer to be emotionally draining, “When you go for it, he's fighting you couldn't do it” (*Cilla, mother of Claire, line 207*). Cilla’s use of “you” is the colloquial use of “one” in everyday speech. By using “you” rather than “Claire” Cilla opens up the idea that others are, in some capacity, involved in this task. As it is accepted that Claire is the only person actively engaged in the caregiving aspects of the task, this must refer instead to other care aspects of the task such as the emotional work of “caring about”. In the following extract, Claire describes her own engagement with the replacing of the NGT:

It's it's quite a (0.5) traumatic (0.2) erm thing to do with your child I think () having to insert a tube (*Claire, mother of Craig*).

²An issue that I will discuss further in Chapter 8

Claire's use of the word "traumatic" upgrades Colin's description of "quite distressing" to something far more harrowing. Choosing the preposition "with", rather than "to" your child is interesting. This suggests that Claire positions herself and Craig as mutual participants in the trauma of the event. A trauma that others avoid: "I was the only one who could put the tubes down 'cos Colin's refused to learn" (*Claire, mother of Craig*).

Claire's choice of the word "refused" rather than "unable" suggests that Colin is encouraged to take on this responsibility himself but declines to do so. This results in the feeding burden of pressure on Claire who was left as "the only one" able to replace the NGTs. Thus, Claire does not only carry the dual burdens of physical (caregiving) and emotional (caring about) aspects of the task but the responsibility for (taking care of) the task as well (Fisher & Tronto, 1990). This is not a minor responsibility because the importance of correct insertion of an NGT should not be underestimated. A study of neonatal patients used radiographs to document sub optimal placement of NGTs in nearly 50% of infants. Although not all such misplacements are critical, occasionally they may be misdirected to the lungs. Such incidents can result in potential for harm to the child due to aspiration (Quandt, Schraner, Bucher, & Mieth, 2009). It is often challenging for highly trained and experience healthcare providers to discern tube misplacement yet this burden of responsibility is placed on families in the home setting. Whether taking this on as a caregiving task is a lesser burden than taking on the responsibility to book health professionals to come and do it could be an interesting matter for future research around the distribution of responsibilities when children with neurodisabilities are cared for in the home.

It is important to note that those fathers who do not replace NGTs, or get involved in feeding at all, may still be fully engaged with all other aspects of childcare. Non-participation in replacement of NGTs is therefore something that is difficult to explain. Elliott for example, also had a respiratory stent to aid his breathing at night due to sleep apnoea. This stent was inserted by his father, Eddie, and was a similarly distressing and "dirty" task to perform. Yet, even so, Eddie did not carry out the task of inserting NGTs because it was "horrendous"- a concept I try to explore further in a joint interview:

Eddie: I couldn't do it, I couldn't do it

Researcher: I'm just interested to know why

Eddie: because the stent

Researcher: If the stent is worse, why not the NGT?

Eddie: Because I () I had issues with it!

Everyone: ((General laughter))

Eddie: It was like it was like that at-at the hospital

Elaine: He was like "I can't"

(Elaine and Eddie, parents of Elliot)

"Having issues with it" and it being "horrendous" do not really explain Eddie's reluctance to participate in this task. Even if Eddie shared Colin's version of masculinity, he is already proven to be proficient in similar tasks. Hobson and Noyes (2011) found that fathers in their study were often prepared to take on many aspects of childcare including intimate care. It is therefore hard to explain why Eddie is prepared take on other potentially unpleasant tasks, such as the stent, but are unwilling or unable to pass NGTs³. This question led me to explore this further in discussions with a senior nurse involved in training of families with children with NGTs. She confirmed, that in her experience, it is highly unusual for fathers to be involved in passing NGTs. One potential reason for this is that there is something specific about the feeding of young infants, a job that in essentialist terms, mothers are biologically equipped to do and are therefore responsible for. This essentialism makes fathers more reluctant to be involved because

³ Interestingly the data also shows that Elliott's mother, Elaine, was willing to place the NGT but not the stent.

“taking care of” feeding is not their biological responsibility. Alternatively, it could be argued that this situation emerges because it is the main carer that takes on the task of feeding and this is more typically the mother. Only one father in this study (Gary’s father) was prepared to pass the NGT and he was indeed the main carer. However, we should note that in Gary’s case, his mother also took on the role of inserting NGTs even though she was not the primary carer. Denise, was the only mother in my study not prepared to take on the burden of inserting the NGT herself. When she does not do so, the responsibility for the role is not taken on by the father but reverts to a clinical role.

And he used to pull that out all the time so I had to get the nurses to come back in and put it back i...n, and [R: yeah] it was just so stressful, to have it through the nose [R: right] ... no, I couldn't even be there, well I was there, trying to hold his hand, but I couldn't look [R: oh right yeah] er, but I just don't like that [R: no ok] thing, yeah...I didn't have the courage to do that (laughs) (*Denise, mother of David*).

David’s grandfather, Dick, is closely involved in supporting Denise with her child care and, like other grandparents in this sample, plays a significant part in providing respite for the current feeding method of GT feeding. This raises the suggestion that when a mother declines the role of inserting the NGT herself, it is unlikely to be taken on by another family member, even when they are prepared to help with all other aspects of childcare-including GT feeding.

Although Denise did not insert the NGT herself, her extract still illustrates the amplified burden when caring for a child with an NGT in-situ. Firstly, there is the additional administrative task “taking care of” making appointments with the nurses to replace the NGT which may need to be done urgently should it be pulled out accidentally. This may involve a trip out to the clinic or the inconvenience of waiting in for unspecified amounts of time for the nurse to arrive. Secondly, it again highlights the emotional work “caring about” which is involved in observing and assisting with the replacement of the NGT. Denise refers to “how she couldn’t even be there” and “trying to hold his hand but I couldn’t look” which suggests she found the scenario too difficult to remain present as an observer to maintain the physical contact with her child. Denise does not even refer to the NGT by name but calls it “that thing”, something so repellent that it is

unmentionable. Although Denise confesses to not having enough courage to replace the NGT she softens her statement with a laugh. Thus, like Colin's use of "wuss", she preemptively acts to prevent conflict by staving off the possibility of accusations of weakness from others.

6.4 Summary and conclusion

The additional burden of care that arises from feeding a child with a neurodisability and feeding impairment has been frequently discussed in other GT decision-making literature in terms of it being a physical "caregiving" task, most notably the laborious time taken to feed orally. However, by separating out the different aspects of feeding tasks it is easier to recognise that the "caregiving" and "taking care of" aspects of both oral and NGT feeding may fall disproportionately to the mother (Fisher & Tronto, 1990). However, my research would also suggest that the emotional burden embedded in feeding tasks "the caring about" is more equally shared.

Inserting an NGT was generally accepted to be a distressing and unpleasant task to carry out and emotionally draining to observe. For the families in my study, there was a notable reluctance for fathers to take on this task even though they may participate in other potentially distasteful aspects of childcare or use other medical technologies. Why fathers may be so reluctant to take on this particular aspect of care is a matter that deserves further research. This would enable the provision of appropriate training to support fathers in taking on this aspect of care. However, as I will also demonstrate in Chapter 11, replacing an NGT with a GT can be liberating in terms of the potential for respite provision.

The high workload around feeding which mothers carried was noted by others. However, despite the previous work by Craig & Scambler (2006), inadequate attention may still be paid to the social pressures underpinning social constructs of good mothers. This may result in mothers persisting with inadequate support around caregiving aspects of feeding tasks. In the following chapter, I will move on to describe how feeding problems and the method of feeding can influence the ways that families come to terms with a disability diagnosis and how feeding difficulty impacts on notions of normalisation and stigma.

Chapter 7 Disability, Normalisation, and Stigma

7.1 Introduction

As discussed in Chapter 1, poor oral feeding can be an unfavourable developmental indicator for a child's later development. The close intertwining of the issues around the recognition, diagnosis, and acceptance of both feeding impairment and neurodisability can have implications for a parent's ability to engage with a feeding method which has long-term implications. In this chapter, I will discuss some of the issues that arise as parents attempt to come to terms with their child's diagnosis.

7.2 Coming to terms with diagnosis

A significant disruption of parent's global interpretation of life's events occurs when a child is diagnosed with a severe disability (McLaughlin, 2006; Trute, Benzies, Worthington, Reddon, & Moore, 2010). Following such a challenge, personal identity must be reconstructed in order to integrate this disruptive experience into a new life story (Ryan & Runswick - Cole, 2008).

Mothers usually play a central role in the lives of children with disabilities and studies attest to both joy and sorrow (Kearney & Griffin, 2001; Landsman, 2003; McKeever & Miller, 2004). My study, which also incorporates fathers and other family members has illustrated how family adaptation to the disability diagnosis, and the associated acceptance of feeding impairment, is highly variable across families and takes different lengths of time.

Clinical signs of a child's disability can present at several points along a child's developmental trajectory including before birth, immediately after birth or later in infancy. For some of the families participating in my study, concerns about the potential of severe disability were first raised during pregnancy. For example, initially Elliot was anticipated to have genetic conditions estimated to be incompatible with life. When some degree of disability was expected, as in the case of Elliott, feeding problems seemed to be more acceptable as part of that disability. As Elaine outlines:

That was the top and bottom of it () that was, that was what we had to deal with first whether he survived or not (...) and then after that it was just "champion, he's here, it doesn't matter" (*Elaine, mother of Elliott*).

Elaine illustrates how the importance of survival was the family's over-riding concern. This had little to do with feeding which could be artificially maintained.

For other families, where the possibility of less critical abnormalities had been identified, ongoing investigations both before and after birth were continuing sources of stress. As I discussed in Chapter 1, child disability research has focused strongly on mothers and is culturally laden with notions of what makes "good" versus "bad" mothers. One thing "good" mothers should do is to carefully monitor their infants and identify anything unusual by comparing their developmental characteristics to known norms. Beth's case illustrates how this process begins before birth. During pregnancy, a small cerebellum was initially suspected and Beth as a "good mother" dutifully attended five separate scans all of which failed to confirm anything atypical. Nevertheless, this combination of factors alerted Beth to a greater possibility that her child may have a neurodisability and, as in the case of Elliot, this had implications for the management of Billy's feeding difficulty after his birth.

However, for most families, neither disability nor feeding problems had been predicted and coming to terms with feeding difficulty both impacted on, and was influenced by, the parallel need to reach acceptance around disability. In the following chapter, I will go on to discuss some of the ways the information about disability diagnosis is shared. At this point I will discuss the acceptance of disability in relation to coming to terms with the associated feeding difficulty.

In the following extract, PAED₁ describes how she views the process of families coming to terms with a disability diagnosis and how her view may differ from other members of the multidisciplinary team:

It's the key I think to coming to terms with diagnoses and coming to terms with level of disabilities of your child () I think families should do that at their own pace () whereas I think some of the allied health professionals get very frustrated if they feel the families are over-estimating their child's abilities [R: yeah] and

they get very irritated that they don't understand how () disabled the-their child is an' whereas I think it's partly my job to say wh-it doesn't matter, co-th-they will come to that decision and come to that knowledge when they, when they can (*PAED1, paediatrician for Adam*).

This slow process of parents gradually assimilating information may run the risk of parents “overestimating their child’s abilities” causing friction within the multidisciplinary team, “they get very irritated”. Slow as the process may be, PAED1 positions herself as believing that the speed of acceptance does not matter and families will reach that understanding when they are ready to do so. Landsman (2005) suggests that mothers need to negotiate their way through the different models of disability. Firstly, they must negotiate the medical model with its focus on impairment remediation before they can embrace the social model with its messages of acceptance and valuing of difference. I described in Chapter 5 the importance of feeding in relation to commensality. Health professionals may therefore need to consider both medical and social models of disability and impairment when sharing their assessments with families.

One of the reasons why parents may resist a diagnosis of feeding problems is because of the wish to hold onto hope, as Claire explains:

Well I knew he had a feeding problem [R: yeah] and I was always hopeful that he was gonna take from the bottle [R: () yeah] but perhaps they were less () hopeful than I was (o.2) or () not hopeful at all, and [R: yeah] obviously knew I was in denial () and I don't know if they perhaps it was () pity, or if it was () critical, d'you know what I mean? (*Claire, mother of Craig*).

Claire understands that Craig has a feeding problem but tried to maintain optimism that this difficulty would resolve. At this point in time, Craig’s diagnosis is unknown and therefore his prognosis around feeding uncertain. It would not seem unreasonable that any parent in this situation would wish to hold onto hope. However, Claire proposes that staff are less optimistic, a position that could suggest that Claire is in “denial”. McKeever and Miller (2004) argue that by ignoring the socio-political context of disability a risk of interpreting maternal feelings and behaviours in pathological ways can exist.

In the following extract, Angela, who during our interview openly defines herself as being “hugely blinkered” to “always see the rosy side” also describes how it took time to begin to accept the full level of Adam’s disability:

Yeah, I think in that in that situation a little bit of a knowledge is a dangerous thing and because of me job, because of me work in early years and (o.2) erm (o.4) it I ah (o.4) in that idea of of development and all children developing at their own rate (o.2) I just kept thinking well he might not get all the way there but he might get a little bit of the way there and and I’m kind of a, well I’m definitely a glass half full person anyway (o.6) so (laughs) I was always gonna believe the better side of whatever I was told [R: yeah yeah] so it was probably it took me a bit longer probably to get to the realisation (laughs) (*Angela, mother of Adam*).

Angela is experienced in working with children and understands the wide range of typical child development. Although Angela acknowledges Adam will never reach the potential that he may have done if his development had been typical “all the way there” it takes time for her to accept the full extent of his impairments. Her own knowledge, “a dangerous thing”, coupled with this hope means that when a range of possibilities are presented to Angela she chooses to focus on the more positive outcomes.

Parents may also accept impairments at a different pace to their partners as PAED₁ explains:

Anthony’s always much blunter about his developmental problems, about Adam’s developmental problems than Angela is (...) well cru.- almost cruel well not always realistic almost cruel sometimes [R: aww] and I always think it’s because it’s his. maybe that’s his way of coping by saying that he doesn’t do anything does he? (*PAED₁, paediatrician for Adam*).

PAED₁ does not condemn Anthony for being “almost cruel sometimes” but positions this as being Anthony’s “way of coping”. For Anthony, it is perhaps easier to accept that Adam’s progress is minimal “he doesn’t do anything does he?” than to hold onto forlorn hopes for the future. Mothers of children with intellectual disability tend to experience increased levels of stress and depression compared to mothers of typically-developing children (Singer, 2006). Chronic sorrow can re-emerge at particular developmental

stages for parent and child particularly when development deviates from social norms (Bruce, Schultz, & Smyrnios, 1996; Bruce, Schultz, Smyrnios, & Schultz, 1994). However, the well-being of fathers appears to be less affected by the child's diagnosis than that of mothers (Gerstein, Crnic, Blacher, & Baker, 2009; Pelchat, Lefebvre, & Levert, 2007; Saloviita, Italinna, & Leinonen, 2003). One explanation for this is that fathers are more likely to remain in paid work while mothers are left with the day-to-day tasks at home (Carpenter and Towers, 2008). Whatever the reason, this forms another explanation regarding why fathers can sometimes be less distraught at the loss of oral feeding in young infants.

In the above section, I have discussed how families try to maintain elements around hope as they begin to come to terms with diagnosis. Trying to maintain oral feeding is one way to hold onto hope and forms one explanation as to why parents may resist moves towards non-oral feeding. In the following section, I will discuss how the interpretation and magnification of small improvements help to underpin that hope.

7.3 Dealing with a disrupted narrative

So far, I have discussed how acceptance of a diagnosis of neurodisability can be a complex and difficult process. Accepting that a child may need long-term feeding support represents one part of this process which parents and families may struggle to deal with. In the following two sub-sections I discuss this in relation to expectation and achievement.

7.3.1 *Magnifying little steps*

When a child has profound disabilities, modest achievements which are usually taken for granted, can take on much greater levels of importance. For example, Claire describes the values she placed on Craig's "normal traits":

And he's trying to play with his toes and things like that which is what [R: yeah] babies do so, erm, so yeah you can see quite a lot of (0.2) (...) normal traits coming - no, typical traits, I hate the word normal as well but you get [R: yeah] cause everyone kept saying to me, in special care (...) if he was a normal baby, an I keep, an I was like thinking well he is a normal baby he's just got [R: yeah] problems (Claire, mother of Craig).

As Claire describes Craig's current development, she repairs her use of the word "normal" to "typical". Claire expresses her dislike of the word "normal" with its accompanying insinuation that the converse may be true for her child. For Claire, Craig's development may not be typical, but to Claire he is still to all extents and purposes a normal baby, albeit one who carries additional problems that impact on his development. Brown (2013) sought a retrospective view of the lived experience of the recurrent grief of mothers of young adults with intellectual disability through various transition points. She concluded that "mothers highlight their sense of self as 'mother' within a dissonance of personal desires and what is achievable" (p: 120). Thus, both grief and joy may be experienced when children with disabilities meet milestones, even if on a very different trajectory to typically-developing children (DeMarle and Le Roux, 2001). This means that minor gains in function can be highly treasured as five-year-old Elliot explains:

Elliot	There was another operation afterwards when I was a baby () and my thumb was at this side ()
Researcher	Oh right
Elliot:	and down () I couldn't do a thumb's up!
Researcher	Yes () that's right because when I was talking to your mum before () she said that () tha-that you wanted to be able to do a thumb's up () and now you can () show me!
Elliot	((Demonstrates thumb's up))
Researcher	Yay! Yay! You can do it with both sides
Elliot	Well not really with this hand because it's a bit pshh

Researcher Well but still (0.2), that's much better than when I saw it before

Elliot Yeah, but this one is a real thumb's up!

(Elliot, aged 5)

Elliot's improved function is still not normal function because the new thumb is still "a bit pshh" and does not compare favourably with the other hand which is a "real thumb's up". Nevertheless, this minor improvement is very important to Elliot. A thumb's up is a form of communication and his ability to use this gesture increases his ability to participate in society even though his progress remains delayed with respect to other areas.

Most prominent Western child developmental models are built upon or associated with stage theories of development (Fischer, 1980). Under such models, children are believed to pass through a pre-ordered sequence of stages directly correlated with age-related increases in information processing capacity and efficiency. Oral feeding may therefore not just be constructed as a chronologically unfolding developmental stage but as an essential building block on the pathway to independence. In Craig & Scambler's (2006) study a common reason mothers gave for wanting to continue to feed their child orally was the preservation of this key developmental building block. This derived from a belief that the same types of motor skills used in feeding (for example, mouth, tongue and lip coordination) would also be needed for language as well as a return to eventual oral feeding resulting in an emphasis on promoting oral activity.

As discussed in earlier chapters, society gives mothers the responsibility "the taking care of" ensuring the required input for their child to progress to the next stage. Lack of success at drawing level with other children may be attributed by outsiders to problematic mothering where mothers have "failed" to put in the right kind of parental inputs or therapy. However, a paradox also occurs because in individualistic cultures, "good" mothers must also ensure that excessive regulation does not damage their child's autonomy. Craig and Scambler (2006) therefore argued that women who disregard medical advice to replace oral feeding with GT feeding are not inherently being

neglectful or ignorant but are drawing on an individualistic child-centred ideology to craft the best developmental environment for their child.

In this section, I have discussed how parents may try to hold onto hope when coming to terms with their child's diagnosis and one way of doing this is by emphasising little successes which can include the maintenance of oral feeding. As I will demonstrate in the following section, family concerns arose that a diagnosis of neurodisability could result in outsiders setting targets for their child which were more modest than those that parents and another significant others hoped were possible.

7.3.2 Making No Excuses

In the following extract, Elliott's brother, Evan, discusses the importance of feeding in regard to Elliott's overall development:

I think (0.5) it's generally agreed to be important to Elliott's () development (R: yeah) because he th-() I mean we always treat Elliot () obviously there is are limitations around what he can do (0.2) but () we always try and treat Elliott just as you know (R: yeah) He- he doesn't need to be () kind of coddled () all the time, Elliot generally will just do stuff (R: yeah) by himself. It's hard to tell Elliott that he can't do something (laughs) (*Evan, brother of Elliott*).

Evan's use of the term "generally agreed" suggests that the relationship between Elliot's feeding and his overall development is something that has been discussed within the family. Whilst Evan draws upon models of disability as personal impairment, "there are limitations around what he can do" and accepts that Elliott's multiple disabilities must place some restrictions on what he is able to achieve, he draws on the social model of disability by arguing that the family, and indeed Elliott himself, do not want to see laxer limits for Elliott than they would for non-disabled children; they don't want to see him "coddled".

In the following extract, Elliott's Grandmother Ethel expands on this theme in relation to Elaine's desire that Elliot should attend mainstream school:

She wants him to be challenged [R: yeah, yeah] at school (...) she says I don't want them- anybody making excuses for him [R: no] because he's disabled [R: yeah ()

yeah] she won't have him labelled that way (*Ethel, maternal grandmother of Elliott*).

Due to the prenatal diagnosis of Elliott's disabilities, Elaine was forewarned that Elliot was unlikely to survive and at best would have profound disabilities. Nevertheless, Elaine is described by Ethel in a way that suggests that she is firmly committed to Elliott living a life in which his full potential is not limited by the lowered expectations of other people. Elaine is also portrayed as not wishing to see Elliott being overly-accommodated out of misplaced sympathy by making excuses. Ethel's self-repair from "them" to "anybody" is illuminating because it suggests that Ethel is expanding the category of those involved with Elliott to beyond the educational system.

Health practitioners also shared concern about the need to maintain a sufficiently challenging environment for disabled children as SALT₂ explains in relation to David:

He is very self-aware, and he is very into, you know "I like to be like everybody else I like to strive, I like to be" he likes to be challenged cognitively at, you know, an appropriate level (...) and he is qu-, he is quite able, really, in terms of cognitive functioning compared to his physical function, so [R:yeah] he needs that challenge (*SALT₂, speech and language therapist for David*).

By dividing David's abilities into two separate and distinct groups of cognitive and physical function, SALT₂ is drawing on dualistic ideas where the mind exists as a separate entity from the body. As such, SALT₂ emphasises how David is physically disabled but cognitively able. It is interesting to note how SALT₂ describes David as "very self-aware." SALT₂'s concern is that David's obvious physical impairments may impact on the way people orientate to his cognitive abilities too. David needs to be recognised by others as having sufficient ability to embrace more difficult tasks; he needs the provision of the "appropriate" input and environment.

In the following section, I will go on to build on these issues in relation to the stigma arising around disability and the effects that this may have on parental decisions about GT placement.

7.4 Stigma as a process of spoiled identity

7.4.1 Definitions of stigma

Stigma has been defined by Goffman (1963) as the process by which the reaction of others spoils normal identity. If the stigma is visibly apparent, people can quickly have their social identity discredited which then renders them stigmatised (Goffman, 1990, p 13). Stigma does not only impact on the affected individual but also on their associates such as family members. The terms “courtesy stigma” (Goffman, 1963: p 41) or “associative stigma” (S. Mehta & Farina, 1988) have been coined to describe the situation whereby stigma extends to significant others by association (Ali, Hassiotis, Strydom, & King, 2012).

7.4.2 Keeping up appearances

Research to date has shown that mothers of children with NGTs frequently talked about the stigmatising effects of NGTs because their visibility attracted unwanted public attention (Craig & Scambler, 2006). The NGT therefore performs as a “stigma symbol” (Goffman, 1990) which alerts onlookers to the fact that the child has some kind of health or development issue.

The stigma attached to NGT feeding was a topic that was discussed extensively by the families participating in my own study. However, there was considerable disparity in viewpoint. In this section, I explore this discrepancy and extend previous findings by offering suggestions as to why the NGT may be seen as more stigmatising to some families than it is to others. This has implications for clinical practice because the level of stigma attached to NGT feeding is an important influence on the family’s decision to opt for a GT.

7.4.3 The stigma of NGT feeding

I begin with Anthony’s recollections of his son Adam when his NGT was in-situ:

It was yeah, that’s why it wasn’t very cosmetic (points to photos of child on wall with NGT) [R: oh yeah]that’s when he had just come home or was it when he

was still in SCBU⁴? erm so, its'a very visible it it, he looks disabled, if you look closely now most people just think he's a rather large baby when you see him going around but when he's got a tube hanging out his nose most, well you might as well have a flag on there [R: yeah] and a wheelchair []: yeah]so, I know it really shouldn't matter in the grand scheme of things but it's one less thing to have people staring and people do stare still , they used to stare before at his nose with the NGT in (*Anthony, father of Adam*).

Goffman argued that individuals possessing invisible stigmas can choose to either “pass” or “reveal” their stigmatising identities. Without the NGT, Adam fits in with the normal parameters of societal expectation and Anthony can choose to pass him as “a rather large baby”. However, when a tube is present, “hanging outside of the nose”, it acts as a flag, “a stigma marker”, to alert spectators that something is amiss with this child. Anthony argues that as Adam is profoundly disabled the NGT could be viewed merely as unattractive and not particularly important in comparison to his other impairments. However according to Anthony, being rid of the NGT means there is one less thing for people to stare at. This suggests that stigma markers could have a cumulative effect.

In the following extract, Eddie uses the actual term “stigma” to describe the unwanted effect of the NGT:

I think (1.0) it's ah- (0.2) it's the stigma it's (0.2) having (0.6) it in open view and just [R: yeah]it tells people there is something wrong with your child [R: right]not that there is something wrong with your child but obviously () your child's not eating (?inaudible) [R: yeah yeah]and it's () it's like going around with someone tapping on your forehead (0.2) Get rid of that and for Elliott getting rid of that ()you cannot tell [R: yeah, yeah] and if he's sitting () on a chair or a bike or summat, they don't realise his, how his disabilities are [R: yeah] because () he's intelligent enough () h-he talks fine erm I guess his hands are something you can see but when you see that tube i- in () you automatically think () there's

⁴ Special Care Baby Unit

something wrong with him [R: yeah, okay] so if you get rid of that then you've got to look a lot closer (*Eddie father of Elliott*).

According to Goffman, a discrepancy can occur between a person's carefully managed "virtual identity" where their disability is hidden and their "actual identity" (Goffman, 1990, p.125). Those with a hidden disability may still be "discreditable" if any negative information about their person should emerge during a social interaction. Once identified, the discreditable become discredited and must then manage the tension in social interactions which is caused by their stigmatising condition. Whereas Elliot's mobility issues can be disguised by Elliott sitting on a chair or bike and are hence merely "discreditable", the NGT means that Elliot is discredited because it is always in "open view". Eddie's tactile description that it's like someone "tapping on your forehead" has great resonance with Anthony's visual description of "you might as well have a flag on there" because both suggest something that is impossible to disregard. Although Eddie explains that Elliot's malformed hands are also visible, he appears to downgrade this as a source of stigma. The fact that Eddie relates the two quite separate issues of the finger deformities and Elliott's more typical intelligence and language skills suggests that malformed hands by themselves merely represent a physical disablement and "he's not the freaky kid who's got something stuck up his nose" (line 429). However, adding in the NGT causes people to "automatically think" that there is something more seriously wrong.

7.4.3.1 *The special status of the human face*

Elliot's mother Elaine had also previously discussed the issue of visibility with her best friend Esther, a mother who had previously fed her own children by NGT for a metabolic condition rather than neurological reasons.

Well that was Esther's argument with us all the time y'know "Elaine they will see his NGT first" and I'm like "no (,) they will see the wheelchair, the walking frame or the trike first [R: yeah (laughs)] before the NG" (*Elaine, mother of Elliott*).

Esther, accustomed as she was to NGT feeding, nevertheless raises the same point as Eddie, "they" (presumably outsiders of this family group) will "see his NGT first". Elaine employs the same reasoning as her own mother in suggesting that surely the much larger

mobility equipment is far more visible than an NGT. Clearly, Esther is raising a different angle to degree of conspicuousness here. Her use of the word “first” could suggest the NGT represents the most concerning of Elliott’s difficulties. One possibility is that Esther could be drawing on the innate perceptual bias towards faces, which possibly evolved to promote good caregiving behaviour (Lorenz, 1971). Human beings seem to be hardwired with a face recognition module as even very young infants seem to prefer real faces to scrambled faces (Fantz, 1961); (Barrera & Maurer, 1981), moving faces to still ones (Tronick, Als, Adamson, Wise, & Brazelton, 1978); and can discriminate their own mother’s face (or at least the external contours) from that of a stranger within hours of birth (Pascalis, de Schonen, Morton, Deruelle, & Fabre-Grenet, 1995; Walton, Bower, & Bower, 1992).

This very specific importance of the face is commented on by Brian “I don’t like this on his face” (line 190). Brian was enthusiastic about supporting Billy’s oral intake through an NGT because he “knows that he needs it.” Billy’s face is already an atypical baby’s face because of his Down’s syndrome features and eye conditions. Billy’s NGT could therefore be viewed as comparatively minor, but nevertheless its presence “on his face” is a negative factor for Brian “because it doesn’t look great”.

In the following extract, Elaine describes an interaction with the school photographer:

Elaine: Elliot is not bothered by it I mean () he's just had his, he's just had his nursery photos taken and the () the photographer had left a note with his key worker saying “did I want the NG taken out?” because they could photo shop it and I was like “well no” (laughs)

Researcher: Because it's part of him?

Elaine: It is Elliot

Researcher: It's part of him (laughs) yeah, I can see that

Elaine:

There's one family photo and it's at me mum's and erm Elizabeth (o.2) she was, she was six months old at the time, had ripped his tube out on the way down [R: ahum] she got a hold of him in the car seat () and pulled his tube out on the way down to the photographers and he hasn't got it on and we're like "doesn't he look weird?" [R: Yeah, yeah] and it's because it's part of him.

(Elaine. Mother of Elliot)

The photographer is suggesting that he uses computer software to manipulate the photograph to produce the temporary illusion that Elliot's face is free of tubing. It is important to mention that in the case of Elliott the NGT was inserted immediately after birth. My interjection with the question "it's part of him" emerged from my understanding that Elaine's expectations of seeing the tube meant that the NGT had come to represent an integral part of Elliot's appearance. However, Elaine's initial description goes beyond this, it's not just "part of" Elliot" but it is Elliot.

Craig & Scambler (2006) discuss how, from some mothers' points of view, children could seemingly lose some aspect of identity when a NGT was inserted, the child would then regain their identity when the NGT was removed. This led to the authors postulating that switching to the less immediately transformable GT could affect the child's identity in a more permanent kind of way. My research suggests the possibility that the opposite could also be true. In this case, the NGT had been normalised into such an integral part of Elliott that he is described as "looked weird" without it. Thus, removal of Elliot's NGT does not reinstate his natural identity but modifies it to something new, something "weird". However, it is important to note that, although Elaine preferred the NGT to be in-situ on the photograph, she does not mention consulting with anyone else around this decision, which appears to have been a spontaneous one "well, no". It could therefore be that other members of the family circle held different viewpoints. For example, Elaine's friend Esther:

We've never really seen his little face, only a couple of times when he's had his tube out and we've taken a quick photo erm and it will just () I don't know it will it's like I say it's that (0.5) normalisation isn't it? That he's just gonna be this little boy who people aren't saying "what's that?" because kids do it and [R: yeah] and Elaine always explains to them what it is erm but it's just, I just think that it'll just be nice not to have that (*Esther, best friend of Elliott's mother Elaine*).

Whereas Elaine sees the tube as an integral part of Elliot, Esther's reference to the way that they have only seen his "little face" a couple of times when "he's had his tube out" suggests that the tube blocks out Elliot's facial features. The NGT is, in reality, a small transparent tube which only covers a tiny portion of the face. Her use of the word "normalisation" suggests that she is talking about a transformation occurring when the NGT is removed so that Elliot's real "little face" is revealed. However, simply removing the NGT does not make Elliott's feeding difficulties or other disabilities go away. Therefore, Esther is not talking about normalisation per se but other people's perception of normality. Without the tube, everything looks normal and there is nothing for other people to comment on "what's that?" Whereas Elaine seems quite happy to "explain to people what it is", Esther appears to favour the ability to pass unnoticed.

Although the importance of faces could be one explanation for the stigma attached to NGT feeding, Evan raises the intriguing possibility that an NGT may identify a person as being "actively ill".

7.4.3.2 Actively ill versus disability

In the following extract, Evan also refers to faces:

But I'd say (0.2) I think () it made (), it did make him look more sick and i-it made people think that he was like () like actively () ill (Elaine: yeah) rather than like () obviously he's got () sort of like physical disabilities but Elliott day-to-day is fine (R: yeah)but people () like tret (dialect treated)(...) always tret him like he was like sickly (R: yes) because there's a bit of medical apparatus coming out of his face (*Evan, brother of Elliott*).

Evan suggests that the visibility of the NGT also has the capacity to change the appearance of a disabled-but-well child into one who appears "actively ill". Whilst Elliott

has noticeable physical disabilities, this does not make him unwell, indeed “day to day is fine”. However, the visible presence of this “medical apparatus” transforms Elliott from a healthy child to one that looks “actively ill” as Evan further explains in a group family interview:

Yeah, I think when he had the NG in he he sorta always just looked like a patient on day release rather (group laughter) rather than (R:yeah yeah) yeah he looked like he'd just nipped out of the hospital when he's () he's still got half of the equipment (*Evan, brother of Elliott*).

The NGT and its associated apparatus are out of place because they do not belong in a typical home environment but are designated hospital equipment. The presence of the NGT transforms a disabled but healthy child into one too poorly to live at home who thus resembles “a patient on day release”. The term “nipped out” suggests an extremely short period of time. Thus, Elliott appears so sick that only a short release from hospital is possible and he could be suspected to have a progressive or deteriorating condition like “kids with cancer” (Eddie) rather than a child who is living with a permanent disability. This resonates with Craig & Scambler's (2006) study who also found that NGTs were associated with “looking the part” of sick children such as those with cancer. This notion that NGT feeding belongs in hospitals was also alluded to by SALT₃.

She might be in a buggy and stuff like that ...a bit delayed but looks like an engaging friendly little child, that can be a barrier to have the thing stuck on your face that looks like () you should be in hospital (*SALT₃, speech therapist for Florence*).

SALT₃'s description is strikingly similar to Evan's. Unlike Elliot, Florence is not discredited by physical impairments, because she is just “a bit delayed”. To all extents and purposes, Florence appears to be an “engaging, friendly little child”. However, the NGT discredits Florence. She becomes actively ill, a child “that should be in hospital” rather than a healthy child who can be cared for in the home. Transforming a child from one who looks actively ill to one that passes because she looks healthy could therefore be achieved by removing the NGT.

7.4.3.3 *Dealing with courtesy stigma*

Concepts around the importance of “passing” as normal could be a contentious issue for families as this extract of conversation with Elliott’s grandparents, Eammon and Ethel demonstrates:

Researcher Do you think it's important to the family
tha-then that he is fed by mouth?

Ethel ((sighs))

Eammon I think he's going to have to at some stage
(2.0) to be accepted as normal or as near
normal as we can get him

Researcher you mean by society kind of at-large?

Eammon yes

Researcher but yeah okay () so the family (o .2) would
accept him how he is?

Ethel but you see I disagree there you see

Researcher Aghhh!! oh that's good (laughs)

Ethel (laughs) (o.5) he doesn't have to do
anything!

(Eammon and Ethel, Maternal Grandparents of Elliot)

Eammon positions the ability to eat and drink an essential component not of normality per se but as an essential component of being passed as normal by outsiders. His additional comment “as near normal as we can get him” most likely refers to the fact that Elliott has multiple disabilities which clearly denote him as in some way different, and as such he can only ever pass as “near normal” (Goffman, 1963). In doing so, Eammon is drawing on the medical model of disability as personal impairment. However, Ethel,

in contrast, draws the social model of disability “he doesn’t have to do anything”. For Ethel, it is not Elliott’s job to work towards society’s acceptance of him, as she further explains:

But as Eammon says to be accepted as being normal () he’s he’s not normal! [R: no] His body is never going to be normal () and that is far more (o.2) visually (o.2) erm the fact that he runs around in a walker (o.2) rather than () [R: Okay] running around on his own that is far more (o.2) to the fore than a, than a bit of tube sticking out of his nose (*Ethel, maternal grandmother of Elliott*).

In contrast to Eddie, Ethel positions herself as viewing “a bit of tube sticking out of his nose” as a lesser marker of difference because it is only a “bit of a tube” than Elliott’s obvious need for mobility support. However, Ethel had worked as a nurse for many years and it is possible that she has become more acclimatised than others to seeing people with pumps and tubing attached than Eammon has, making it less of a remarkable occurrence for her. What is notable, is that Elliot can simultaneously be both discredited (for example by his wheelchair) and yet merely discreditable (with regard to feeding) and stigma can therefore be context dependent.

Other participants agreed that visibility of disability should not necessarily be viewed as problematic:

Well it did (o.3) yes () but () that didn't bother me [R: no] (o.1) but for Claire and Colin (o.8) it did [R: yeah] you know cos (o.7) they were the Mummy and Daddy and they didn't want people (o.6) y'know (o.5) coming up and (o.5) glaring and asking questions, and I says [R: yeah] but this is a natural thing, Claire (o.5) people () do come up and they are concerned [R: yeah] you know? (*Clodagh, paternal grandmother of Craig*).

Clodagh explains how the visibility of the NGT “didn’t bother me” but was aware that it was distressing for Craig’s parents, Claire and Colin. On the face of it, it could be that Clodagh is made of sterner stuff than the parents but alternatively there could be less courtesy stigma attached when the affected child is another branch away in terms of the family tree. However, Clodagh’s comments that people are coming up and asking questions suggest that there are not just issues of privacy and confidentiality here but

also additional demands on parents' time and resources. In efforts to play a supportive role to Colin and Claire, Clodagh posits the argument that this curiosity is a "natural thing" which emerges from people's concern about the child; in effect they are being caring. However, this does not tie in with her poignant description of these people as "glaring". This suggests that whereas Clodagh is putting forward the idea that people's interest may stem from natural concern she actually orientates to this concern as stigmatising and it is most likely unwelcome.

Being "looked at" or being in a position where "everyone was staring" (Denise) was a commonly recurring theme in my data which has appeared in a number of the above quotes as well as many others. For example:

Erm it's more discreet you are not going to have people (1.0) sort of staring at him because he has a tubing through his nose or [R: yeah] So to me it can only be (1.0).[R: That's great] better, Yeah (*Brenda, maternal grandmother of Billy*).

Brenda refers to "people" (presumably the general public) as "sort of staring at him". Billy has very distinctive facial features arising from his disability. Brenda nonetheless positions the NGT as being the trigger for this staring. The use of "sort of" suggests that Brenda is trying to soften "staring" to something less hostile. In this context, by "better" Brenda is unlikely to be referring to an improvement in nutrition, convenience or the child's ability to feed orally, but specifically to the reduction in staring which might hopefully arise from GT placement. In the following section I move on to discuss the effects of GT placement on constructs of stigma.

7.4.4 *The effects of GT placement on stigma.*

In the following extract, Craig's paternal aunt discusses the extra discretion that a GT could potentially provide:

No [R: (0.2) yeah] no because it's hidden away and there's nothing (1.0) y-you can't really, unless you () know that he's got that in [R: yeah] you can't see that there's anything [R: no] major wrong with him [R: yeah] you know you can you can tell that there's something () up with him but you don't know it's anything to do with the feeding [R: right, ok] cause it's not there (*Christine, paternal aunt of Craig*).

In Christine's account, the GT is "hidden away" meaning others cannot see that there is "something major" wrong with him. In Goffman's terms, he remains discreditable but is not discredited. What is interesting here is that Christine does not refute that there is something "up with him". Even without a NGT, Craig's disabilities remain noticeable. However, without the NGT there is nothing to indicate that there is anything "major". One reason for this is suggested by her comment "you don't know it's anything to do with the feeding". This suggests that it is specifically the inability to feed that is viewed as more stigmatising or, as I discussed in section 7.4.3, that stigmatic symbols could be cumulative.

Even when a GT has been placed, stigma around feeding can still exist as Brian explains:

I was in KFC yesterday with his little rucksack (R: Laughs) a lot of looks he was getting when putting his feed in (*Brian, father of Billy*).

"The little rucksack" referred to by Brian, is a specially designed backpack that is used to carry the electronic pump. It is particularly useful in the case of an older child who can carry their feed on their back thus allowing them to move freely. My laugh refers to the fact that "the little rucksack" is very familiar to me because I had cared for a child with a GT before and was viewing this description with nostalgia. These rucksacks look like typical children's backpacks with only the tubing being visible. When a GT is in place, this tubing can be run around from the backpack to the GT port underneath the child's clothing. This level of discretion cannot be achieved with a NGT which must still attach to the face. Although Brian specifically connects "the little rucksack" to the "lot of looks he was getting" the standard appearance of the backpack means that it is more likely that these looks are due to the presence of the tubing. The looks are unlikely to be due to Billy's unusual facial features alone because Brian specifically associates these looks occurring when "putting his feed in". A "lot of looks" suggests something subtler than prolonged staring and people may be merely glancing and then looking away. This may arise from nothing more than a mild curiosity and no menace is intended. However even subtle glances are still something that parents find difficult to accept. For example, Beth stated that "it's where it is and people do look (R: yeah) which is horrible but they do." (line 212).

7.4.5 Summary

In this chapter, I have discussed how oral feeding can be positioned by parents as an important developmental step which underpins other aspects of development. Absence of oral feeding can therefore be viewed as a poor prognostic marker. As parents hold onto hope they may try to preserve oral feeding where possible.

Enteral feeding methods may be positioned by some parents and other family members as stigmatising. Craig and Scambler (2006) had posited that stigma may have been one reason why the mothers in their study resisted GT placement. However, they found that this was unlikely to be explanatory feature. I have proffered that one potential reason for this is because when a GT is in-situ parents have the choice whether to “pass” or “reveal” the stigma marker whereas the visibility of the NGT only permits the option to “pass” when it is temporarily removed.

Other highly visible markers of physical disability such as walkers were viewed as inciting less negative attention from others than the NGT. My data suggests at least two potential reasons for this. One is that the NGT is more stigmatising than other visible aids because it is taped to the face and humans pay particular attention to faces. Secondly, there is some suggestion in my data that an NGT can render the child as being “actively ill” rather than disabled. This can draw additional attention to the child in community settings because they are outside of hospital and thus out of context. These points have implications for clinical practice because the level of stigma attached to NGT feeding is an important influence on the family’s decision to opt for a GT.

In the following three chapters on sharing information, assessing risk and making the decision, I will illustrate how families and healthcare workers assimilate the main influencing themes that I have discussed in Chapters 4 to 7 into their decision and what circumstances unite to form the tipping point where the status quo is breached and a GT decision is made.

Chapter 8 Sharing Information about Feeding

8.1 Introduction

In the preceding chapters, I have discussed key factors that may influence family decisions about GT placement. In this chapter, and the two that follow, I will explore how information around feeding is shared between families and their clinical team, how the risks and benefits of the different feeding methods are evaluated, and the combinations of circumstances that then unite to prompt a GT decision. Research studies have established how, in addition to complex social and other factors, a parent's perspective can be affected by professional encounters (Landsman, 2003). I will therefore include a specific focus on interactions with others and how these influence the ways the eventual decision is distributed between the child, their parents, their healthcare team and friends and family in order to reach a decision about GT placement. In this chapter, I also set out to explore and help explain some of the tensions that are created during meetings with the child's parents.

8.2 A brief reminder of shared decision-making

In Chapter 2, I briefly described how Shared Decision-Making (SDM) is increasingly advocated as the ideal model for adult medical treatment decision-making (Charles et al., 1999a; Gabe et al., 2004; Montori et al., 2006). SDM, to briefly recap, is a decision-making partnership in which the clinician's knowledge is united with the patient's preferences to make choices about medical or surgical treatment options.

Relatively little interest has been shown in SDM in paediatrics to date (Fiks et al., 2010; Fiks & Jimenez, 2010; Moore & Kirk, 2010). Paediatric SDM is still an emerging area and although some papers have attempted to address the specific needs of parents making decisions with their children (Gabe et al., 2004) no models for making decisions on behalf of children currently exist. I have therefore needed to draw on the knowledge gathered from the adult studies to help describe how the encounters between the families in this study and their professional teams unfolded. Additionally, Rapley (2008, p. 430) further argued that decision-making is "distributed across time, courses of actions, people, situations and technologies". I have therefore also attempted to draw on Rapley's distributed model by examining further what happens when decisions cannot

be made by the central person but must be made by significant others such as parents or carers.

8.3 Revisiting Goffman

Before beginning this chapter it may be valuable to briefly consider two of Goffman's ideas (Goffman 1990). Firstly, Goffman maintained that the term "speaker" can have various meanings and devised the concept of "production format" to illustrate different speaking circumstances. In Goffman's terms, speakers can be the animator (the person, or increasingly the technology who gives sound to the utterance), the author (the person who composes the words which are spoken) or the principal (the group or individual whose viewpoint is being represented in the speech). The animator, author and principal are often the same person but can also exist as separate entities. During this discussion, I will relate my work to Goffman's ideas regarding production formats when discussing interactions in my data because it is important to consider that individual speakers may not necessarily be representing themselves as the "principal" but could be speaking on behalf of the organisations or categories that they represent.

Secondly, Goffman's concept of a "participation framework" refers to the variety of roles played by different people when interacting as a group. Goffman argued that when a person makes a spoken contribution to a group encounter, each person in the assembly holds a specific participation status. For example, one person may speak directly to another in the group making these two people the key participants in that interaction. However, other people in the group are also part of that interaction even if they are not themselves addressed directly. This contrasts with people outside of the group who may hear what is being said just as clearly as those within the group but only hold the role of eavesdroppers and do not have the same rights to participate as actual group members. In my case, as researcher, my status was non-participatory. Despite my physical presence within the group circle, my role was merely to record the progress of the meeting rather than to make spoken contributions to it.

8.4 Eliciting concerns

The primary way for a patient or their carers to get their concerns onto the consultation agenda is by medical practitioners actively soliciting "the patient's complaint" (ten Have, 1991) or "the presenting concerns" (Robinson, 2006) early on in the medical encounter.

The initial sequences of the consultations that I observed were in line with these typical findings. For example, during Florence's attendance at the feeding tertiary centre, PAED₃ initiated a typical opening sequence to elucidate the parent's concerns. PAED₃ initiated this sequence in a very open-ended and fluid way "probably the best thing for me is to just hear it in your own words exactly about her feeding how things are and how she is doing" (PAED₃, lines 26-27). This question was aimed directly at the parents and thus, presented the opportunity for either of the parents to discuss any issues of concern. However, at this consultation it was Florence's mother, Fiona who presented the concerns about Florence's feeding and thus acted in Goffman's terms as "the animator". In contrast to this, at the first Team Around the Family (TAF) meeting the acting chairperson (health visitor) handed over to the dietician rather than the parents.

Erm, well I'm a bit out of my depth of -if we start out with the feeding issues (laughter) so I shall hand it over to to you who know much more about these things (*HV2: health visitor for Florence lines, 22-24*).

Supporting infant feeding is part of a health visitor's role (National Institute for Health and Clinical Excellence, 2014). HV₂ had met with Fiona the day before and was certainly up to speed with the feeding issues and unlikely to be "out of her depth". However, in a TAF meeting, designated experts for a variety of clinical specialisms are present. By downplaying her own knowledge HV₂ was acting to acknowledge the dietician's expertise "you who know much more about these things". For HV₂ to have set the feeding scene herself could have run the risk of transgressing professional boundaries and undermining the expert status of the dietician. However, as main carers, the real day-to-day experts around Florence's feeding needs are the parents. Although HV₂ allocated the duty of updating Florence's feeding position to the dietician, it is notable that the dietician worked jointly with the mother to produce an account of Florence's current feeding status. Thus, even when practitioners do not set up the interaction in such a way as to elicit the presenting concerns of the patient (or in this case the patient's representative) this does not mean that opportunities to contribute are necessarily lost.

Well, you see () Florence's () been NGT fed at the moment so () it's mainly s-a supplementary [Fiona: yeah it is] feeds [Fiona: yeah] and it's mainly [Florence: shouts] fluids as well, 'cos she's eating quite well solids [Fiona: ahum] so is that

() about right sort of, y'know? [Fiona: yeah] (*DIET2: Dietician for Florence lines 26-36*).

As the dietician described Florence's feeding, Fiona interjected at frequent intervals to lend support to the narrative. Despite being presented as the person who "knows much more about these things" the dietician actively sought out agreement from the mother "So is that about () right sort of, you know?" In doing so, she positions herself, in Goffman's terms as the "animator" the person giving voice to what is known about Florence's feeding whilst acknowledging Fiona as being the "principal" the person having ownership of that knowledge. This ties in with the encounter in the feeding clinic, that I have illustrated above and indicates that it is the mother who takes on the role of principal, regardless of whether or not she is also the animator.

There are several potential reasons why it is Florence's mother, Fiona, rather than father Frank who adopts this position of principal. Firstly, to draw on Goffman's theory around participation frameworks, the dietician may have identified Fiona as the other main participant in this interaction by using gaze or body language, thus giving Fiona a higher participation status than Frank. This is an important point because, as I have identified in my thematic work, inadequate attention may be paid to the opinions of fathers, who are sometimes automatically assumed to hold the same knowledge and opinions even though this has never been actively canvassed. However, it is also feasible that Frank was also selected to participate by gaze or body language but also viewed his wife as a reliable principal and saw no need to intervene. Alternatively, he may not have agreed with the points raised but either resisted the bringing in of conflict at this early stage in the discussions, or could not find an appropriate interactional space in which to do so and I will discuss more about this further on.

In the following extract, the dietician continued again as animator but once again acknowledged Fiona to be the principal owner of this information.

I think you said Fiona that she struggled certainly with her, just her overall food intake [Fiona: she did] y'know, you felt [Fiona: yeah] you know, that the tube needs to go back down again (*DIET2, dietician for Florence, lines 40-44*).

The dietician's comment "I think you said Fiona" is one way that the dietician can show that she had been listening closely to what Fiona had to say. It also means that she was

not suggesting that she had access to Fiona's internal thought processes but was acting as the animator of the story as told by the author and principal, Fiona. As a competent adult, and a qualified nurse, Fiona is likely to be perfectly capable of articulating Florence's story herself. However, handing over the narrative to another person is one way of bringing in the support of an expert witness. The dietician as the nutritional expert is probably the person with the most potential to raise the credibility of Fiona's narrative in a situation where an array of different viewpoints may be held.

A little later in the meeting, Fiona attempts to include Frank:

Fiona: Over Christmas she had the episodes of being sick again but I think it's [DIET₂: Right] as soon as she's got a cold [DIET₂: ahum] you know a slight cold and it bungs her up a bit which means her feeds end up coming back up [DIET₂: yeah] So we had a bad couple of weeks didn't we?

SALT₁: Cos she's, did you say she was vomiting some of the tube feeds as well?

Frank Yeah

Fiona: Yeah

SALT₁: It wasn't just an oral feed

Fiona: Yeah

(TATF:1 lines 66-77)

Fiona's account was one of a fluctuating feeding situation. By using the present continuant tense "as soon as she's got a cold" even a "slight cold" which "bungs her up a bit" Fiona offers the idea that this is not merely a single past event but an ongoing situation likely to re-occur again even under the most trivial of circumstances. By saying "didn't we?" Fiona, the animator, was offering Frank the opportunity to share the story and thus be a joint principal. However, it is SALT₁, rather than Frank who interceded to ask "did you say she was vomiting some of the tube feeds as well?" SALT₁'s use of "Did you say..." could suggest that this is a conversation that Fiona and SALT₁ have already

had. In asking this question, SALT₁ supports Fiona by creating an interactional opportunity for Fiona to further explicate the problem as one where the alternative to oral feeding, i.e. NGT feeding, fails to provide an effective solution to the problem. Alternatively, SALT₁ could also be encouraging Frank to join in and Frank's "yeah" could be orientating to SALT₁'s question as being directed at him. Without video evidence to illustrate gaze direction, the significance of Frank's "yeah" uncertain. However, it nevertheless serves to illustrate one of the problems in group meetings as different stakeholders jostle for interactional space to voice their own concerns.

8.5 Negotiating agreement when feeding fluctuates

One problem which emerges when assessing feeding impairment is that feeding ability may fluctuate according to circumstances; for example, how tired the child may be when observed. During one of the TAF meetings during the longitudinal arm of the study, discussion arose around whether Florence's frequent chest infections were due to issues arising from her premature birth or whether they were an indication of aspiration. I will go on to address this issue as a critical decision factor further in Chapter 10. During this meeting, SALT₁ suggested that one potential method of establishing whether Florence's frequent chest infections were related to aspiration would be via the trialling of a non-oral-feeding phase. However, she did not promote this idea as a particularly welcome one because of an encounter with Florence the week before:

She is just so desperate to eat and drink. I mean when I was there last week she was constantly asking for her cup wasn't she? [Fiona: mmm] and she's doing so well, I mean she really is with eating and drinking (*SALT₁: Speech Therapist for Florence, lines 148-151, TAF₁*).

Fiona's response of "mmm" is a non-committal token of receipt indicating that she hears what SALT₁ is saying but this does not necessarily imply complete agreement. The health visitor orients to this paradox of why such concern is being raised about Florence when apparently, according to SALT₁'s account, she is doing "so well". She therefore seeks further clarification:

HV₂: Is it that she just can't get the volume?
[Fiona: yeah] down her that she needs and

Fiona: and just, she just goes through phases. Sometimes you will have a really good day and she'll drink a lot and eat a lot and then the next day she will just refuse. Like () this morning, we've been holding back on her morning feeds and giving her breakfast instead() in the hope that she'll, she's eating her () porridge really well so her milk is in that but the drinking this morning she was just like y'know (laughs) I don't want it and then you tried yesterday

PORT₁: I tried yesterday yeah [Fiona: yeah] and she just absolutely refused

SALT₁: Whereas last week she was just [Fiona: ahuh] she'd have drank half a bottle and she was loving it

Fiona: She's just not () reliable every day

(TAF₁, lines 152-166)

Fiona confirms that there is a problem with volume, but expands this by also stating that it is not just about volume but about “phases”. In doing so, she avoids any direct contradiction of SALT₁'s assessment which could demonstrate disagreement, but instead implies that SALT₁ may have seen Florence on one of the “good” days. Fiona draws in the portage worker at this point to add support to her account that not all days were this successful. PORT₁'s response that “she just absolutely refused” is unequivocal. This suggests that although Florence seems to enjoy drinking some of the time “she was loving it” at other times Florence does not merely decline a drink but rejects it with all the vigour a two-year-old can muster. However, this does not mean that SALT₁'s account was inaccurate at the particular time and in the specific context that she witnessed Florence drinking. She therefore reiterated her story that “last week...she'd have drank half a bottle”. Fiona does not dispute this snapshot version of an event but stresses that this is not an accurate representation of everyday life, because Florence is “just not reliable everyday”. Given what is known about pleasure and satiety discussed in Chapter

5, one possibility is that Florence's pleasure may be strongly linked to her sense of satiety. When not hungry or thirsty Florence's pleasure in eating and drinking diminishes.

In the above section, I have discussed some of the ways in which narratives around feeding can be shared between mothers and health professionals. I have demonstrated that mothers may be identified by health professionals as the key narrator around feeding issues which may be at the expense of fathers. In the following section, I will discuss the ways that information around diagnostic news is shared.

8.6 Sharing information about diagnostic news

Following a physical examination of Florence, PAED₃ initiates the following sequence:

PAED₃: When she was in under the care of PAED-NEURO₁
she had quite a lot of investigations didn't she?

Fiona: Yeah, she did yeah

PAED₃: and erm obviously her development's a little bit
delayed erm () which is probably more to do with her
prematurity but at the moment has she got, has
anyone got any other thoughts at the moment?

Fiona: No, not at the moment I have just asked PAED₁ her
paediatrician to repeat her urine [PAED₃: umm] Just
because (0.2) erm () at the time there was (inaudible)
acid in her urine but they couldn't pin point what
they were [PAED₃: right] but they put it down to her
just starting on the erm on the (inaudible) [PAED₃:
Yeah] Fiona: But now she's not really having milk any
more [PAED₃: right] so erm

PAED₃: I'm just kind of thinking it through

Fiona: Yeah, she's going repeat them again

PAED₃: If it's alright with you I will just have a little look
 through the investigations [Fiona: yeah] that's fine!
(0.2) OK

(Feeding clinic: Lines 444-467)

PAED₃ needs to carefully negotiate her delivery of the news that Florence's progress is below norms. To do so, PAED₃ first sets out to discover what the parents already know about Florence's development. Her question "When she was in under the care of PAED-NEURO₁ she had quite a lot of investigations didn't she?" offers up the opportunity for Fiona and Frank to mention any results that they already know about. Fiona gives the preferred response to "didn't she?" of "Yeah, she did, yeah". In typical encounters, the preferred response to the question is sufficient and does not demand further elucidation. However, SDM relies on a bilateral exchange of information which would include sharing what is known about clinical results. The fact that neither Fiona nor Frank take this opportunity to do so suggests that by leaving space in the encounter they are engaging in an interactional strategy that may lead PAED₃ to list which tests were carried out.

However, this non-committal response puts PAED₃ in a situation of being no closer to finding out exactly what the parents know. This may be the reason for PAED₃'s hesitation of "erm" before giving a softened "a little bit delayed" summary of the clinical findings to date. Neither Fiona nor Frank give any receipt token to this comment so it remains unknown to PAED₃ as to whether this knowledge comes as unwelcome news, or is something that is already known to them. PAED₃ appears to orientate to their lack of response as possibly being the former because she goes on to downplay the situation further by offering up a potential reason for this bad news "erm () which is probably more to do with her prematurity". Relating Florence's problems to her prematurity in this way leaves the diagnosis, prognosis, and treatment options open to future discussion as Florence catches up chronologically and the parents have time to absorb this news.

Despite playing down this potential for delay, PAED₃ nevertheless gently lays the foundations for further bad news by hinting that there could be something else going on besides prematurity "has anyone got any other thoughts at the moment?" What is

notable here is that whereas PAED₃ may be acting in Goffman's terms, as the "animator" of the potential bad news which may yet come, she could be speaking on behalf of other members of the team such as the neuro-paediatrician who may have raised concerns in another forum and is thus the author. Fiona responds "no, not at the moment" before going on to relay her own concern about an abnormality found in Florence's urine. This abnormality in the urine may not relate to PAED₃'s concerns, but her comments "I'm just kind of thinking it through" and "If it's alright with you, I will just have a little look through the investigations" suggest that she is open to considering a number of issues regarding Florence's development. Although nothing much more is said about the topic of Florence's general progress at this point "that's fine, okay" PAED₃ has simultaneously prepared the foundations for the future bad news that Florence's development may be in some way atypical. Following this preparation work for potential bad news, PAED₃ moves on to talk about the more positive aspects of Florence's development:

Erm so it sounds like since the referral things have moved on [Frank: moved on, yeah) and the tube's out (Fiona: yeah) so that's really positive, isn't it? (1.0) erm and I think the other positive thing is that obviously, the constipation is a little bit better (PAED₃, FC).

Although PAED₃ suggests that the removal of the NGT is a really positive step, her question "isn't it?" does not receive a response from either parent despite the formation of the question requiring the preferred response of "yes". The most likely reason for this is that the parents were agreeing with the statement as it was being uttered and see her question as merely rhetorical. However, it is also possible that the parents are assimilating the bad news which they have just received. After a one second pause, awkward in interactional terms, PAED₃ comes up with a second piece of good news, the ongoing issue of constipation is becoming less of a concern. However positive these two statements are, at this point in time Florence's developmental progress remains below norms and does not exclude the possibility that Florence has a neurodisability.

Although Fiona has not orientated to the potential bad news during this interaction she does refer to how the paediatrician was "fishing for something" at the next multidisciplinary meeting. This demonstrates that PAED₃'s delicate interactional work was successful in preparing the ground for a later diagnosis of neurodisability.

The above section details how bad news around disability can be shared with parents. Investigations for children with neurodisabilities can be ongoing for a considerable period of time. Clinicians need to find a balance between delivering accurate news sensitively whilst keeping parents up to date with news. It is important to note that this interaction is one in a sequence (Rapley, 2008). Although information may be successfully shared at one meeting, this knowledge needs to transfer to the next interactional space. In the following section I will discuss some of the ways that this can be achieved.

8.7 Taking concerns around feeding across interactional spaces

In the following extract, Florence's mother Fiona shares information regarding Florence's current feeding status with the gastroenterologist at a clinical consultation set up around the previous TAF meeting to discuss the possibility of GT placement. Other interactants were not present:

Fiona	In the night she might need a top-up erm (0.2) she has most of her fluids through the NG (0.2) but she is having an oral diet now.
GASTRO ₃ :	(3.0) (looking at notes) Dr PAED ₁ () would like her to have a PEG (Fiona: ahumm) GT. Is that right?

(Appointment with GASTRO₃: Lines 1-5)

Fiona described how the NGT is employed as a supplement to oral feeding. As Florence is "having an oral diet now" with the NGT being used to top up "most of her fluids", the medical complaint is not that the child cannot eat, but that she does not take in sufficient liquid. How, or by whom, the status of 'in-need-of-fluid-top-up' has been determined is not raised by the mother. Likewise, whether the problem is a physical one because Florence cannot physically drink sufficient daily amounts, or behavioural because she refuses sufficient amounts is not stated. However, GASTRO₃ does not explore these potentially relevant issues with the mother possibly because this has been discussed before.

This consultation is one in a series of consultations which has included multi-disciplinary meetings, a video-fluoroscopy and a feeding clinic appointment. It is therefore reasonable, given limited time and resources that GASTRO₃ might choose to move on to the point of the referral rather than unpack the case history. Therefore, after a pause to look at the notes, GASTRO₃ links the consultations across time and space by stating that “PAED₁ would like her to have a PEG”. One notable interactional point here is that GASTRO₃ is acting, in Goffman’s terms, as the “Animator” for PAED₁ who is the “Author” of the request (Goffman, 1981). However, this request for a GT was formulated some weeks before. Given the change of interactional space, Fiona’s use of the word “now” implies a change in status. Florence’s feeding ability may have progressed significantly since the referral had been made but GASTRO₃ does not pursue this. However, Fiona has the next turn as speaker. If she was reviewing her opinion regarding the necessity of the GT, she would have had the opportunity to say so, instead she adds extra information in support of the referral:

- | | |
|---------------------|--|
| Fiona | Yeah, we’ve kind of been (0.2) because we thought when she first got the NGT in and then we re-introduced or-oral diet we thought the NG would only be temporary but (0.2) erm () we’ve kind of like really moved down the line now and she’s still got her NG |
| Gastro ₃ | she’s still got it in? |
| Fiona: | Yeah |

(Appointment with GASTRO₃: Lines 6-9)

Fiona uses the word “we” five times in the above sentence. Although the members of “we” are not stated, this does clarify that what is known about Florence’s feeding progress is drawn from shared experiences and does not represent the isolated viewpoint of PAED₁. In the same extract, Fiona repeats the fact that oral diet has been re-introduced, adding that this has happened since the establishment of the NGT, but again GASTRO₃ does not orientate to this improvement. This may be because Fiona’s

comments “we’ve moved down the line now” and “she’s still got her NG” are interpreted by GASTRO₃ as being problematic.

One major disadvantage of NGT feeding versus GT feeding is that the NGT can be pulled out relatively easily. GASTRO₃ therefore explores whether this issue forms part of the “patient complaint” by asking ‘Does she pull the tube out often?’ Fiona’s response is as follows:

Erm. When we-it first went back in () she did. Erm () but also () we’ve had an episode of a chest infection about two weeks ago and in an entire day she had seven NGTs. Because whenever she’s snotty or got a cold everything comes up and the tube comes out. So that was quite () stressful (*Fiona: Appointment with GASTRO₃: Lines 12-15*).

Fiona situates her response to “Pulling the tube out often” in the past “when it first went back in”. Such an answer could suggest that the problem is no longer an issue. However, interactionally, Fiona uses the same strategy in using the present continuant tense that I discussed earlier in this chapter to illustrate how one “entire day” still represents an on-going feeding situation that was likely to re-occur again “whenever she’s snotty or got a cold”.

The above section serves to illustrate how interactants can seize opportunities to carry information across time, persons, and interactional spaces even when the opportunities to do so are limited. In the following section, I will explore some examples of the more troublesome problems that can occur in the sharing of information.

8.8 When information fails to be shared successfully

8.8.1 As a cause of frustration

In the following section, I will discuss some of the aspects regarding how insufficient sharing of information between family and professionals at an early stage in the decision-making process can potentially lead to relationship breakdown causing unnecessary delay in GT placement. In the following extract Billy’s father Brian describes his frustration over the sharing of information:

Brian: It was June (0.5) I've got records from June last year [R: Right] up until (0.5) erm obviously he had this put in () when he hadn't put on any weight () [R: right, yeah] at all. He hadn't lost anything so no-one was concerned ()

Researcher: Yeah, that he wasn't actually

Brian: That he hadn't put anything on [R: Yeah] Erm (1.0) but it was actually only () when Beth mentioned that his nappies were currently dry [R: Right] that they got concerned (0.5)

(Brian, father of Billy)

Brian positions the professionals as being prepared to accept Billy's steady weight "he hadn't lost anything so no-one was concerned". Brian's reference to keeping records from "June last year" suggest that this matter was of concern to him before it became a matter of professional unease. One reason for this may be because information was not being satisfactorily exchanged between professionals and the parents. His wife Beth for example describes her difficult relationship with dieticians:

When the dieticians are saying 'well do this, and do that' and I'm- as (1.0) a (1.0) practitioner with child, children meself and you're being told [R: (incomprehensible) laughs] It's like 'don't insult me intelligence!' *(Beth, mother of Billy)*.

In the above quote, Beth is describing an encounter where she has raised concerns about Billy's poor feeding. Rather than accepting this information by taking Beth's word for it, Beth is given further feeding advice "do this and do that". Beth draws on discourses of prior wisdom to illustrate her frustration with this. Beth is herself a practitioner (nursery nurse) and Billy is her third child. To have her concerns pushed aside and replaced by well-meaning but unsolicited advice, is positioned by Beth as patronising "don't insult me intelligence". In the following extract, Beth describes another information sharing interaction between herself and the medical team:

I was determined to fight on () but then () when we went in she says something and I says 'well he's not eating he's' and they didn't realise how bad it was [R: right] because (0.4) I said 'yes we'll give him a, he'll take a 6 ounce bottle' but then when we says 'well but it takes 3 and a half hours' () they went 'that's not normal' (*Beth, mother of Billy*).

As illustrated in examples from both my own work and previous work by other authors, (Craig, 2013) Beth draws on “military” metaphors to illustrate the burden of feeding that she was facing “I was determined to fight on”. The use of “I” suggests that this was a battle that Beth may have felt that she was fighting alone. Beth’s description of this health encounter does suggest that Beth did not share this information spontaneously but waited until the interactional space arose. Possibly she was asked directly but her use of the word “well” suggests that she seized her chance to repair a statement made by somebody else, “she says something and I says ‘well he's not eating’” Although Beth does not report the next part of the interaction, it would appear that this information was received by the hearers as news “they didn’t realise how bad it was”. Once Beth had explained the details of the feeding problem, i.e. that Billy could take a bottle but it took a very long time, the clinicians exchanged their own piece of information “that’s not normal”. This interaction is therefore recognisably part of an information exchange sequence in SDM models but is notably one in which the mother may have had to draw upon her own interactional skills bring new or relevant information into the discussion in order for a decision to be made.

8.8.2 As a cause of conflict

In the following extract, Anthony describes an incident that arose during a TAF meeting held in the family home. During this meeting, one member of the team, the dietician, felt that re-inserting an NGT should be considered:

We developed well such a fascist relationship with the err dietician.[R: right, yeah] She was very keen t' reinsert an NG tube at one point [R:. oh yeah, and you didn't want that?] I didn't want her to, but she sort of was leaning back and mouthing to the paediatrician in THIS room [R: Oh, really?] about well, 'we will have a chat about this later' and I thought it was very unprofessional and a bit rude (*Anthony, father of Adam 103-113*).

Anthony's description of the dietician "leaning back and mouthing to the paediatrician in this room" is unpleasant imagery and it is not surprising that it is one that he positions as very problematic. Although the dietician's whispered comment "we will have to talk about this later" could be viewed as temporal, Anthony clearly understands it to mean "we will talk about this without the parents" rather than at a different time. For Anthony, this attempt to exclude the parents or any other potential objectors from further discussions is described, as leading to the development of a "fascist relationship". The deeply negative connotations associated with this term indicates that Anthony, orientates to the relationship as challenging and unlikely to be conducive to adequate sharing of information. For Anthony, the dietician's behaviour is unacceptable on two counts. Not only is it "unprofessional", because it does away with any concept of openness and engagement with parents; but it is also "a bit rude" because social niceties dictate that it is discourteous to whisper and deliberately exclude group members from full participation. Later on, in the interview, Anthony revisits the same incident:

Well I can't help but go back to that thing that she did where she wanted to reinsert the NG tube and (o.6) and she just wasn't listening to us and she, to the extent that she was paying lip service to our wishes [R: yeah] But then I could visibly see her literally going behind our back to the paediatrician about how they will talk about it later so why, why [R: yes, that is interesting] that isn't a very open discussion to have with them (*Anthony, Father of Adam, lines 158-165*).

Anthony's comment that "he can't help going back to" this incident suggests that this is a pivotal episode in his narrative. "Paying lip service" suggests that Anthony remembers the dietician seeming to listen and show support for their hopes to continue oral feeding but in an insincere manner. The dietician clearly holds a different perspective to Anthony but is positioned by him as resisting this promoting her viewpoint in an open debate. Anthony's use of the word "literally" indicates he is not just using "behind our backs" as a metaphor but that she was visibly doing so. In the following extract Angela recounts the same story:

I really liked it because he had everybody in the room at the same time and hearing the same thing erm and it just made it made it much easier and when it got to the point where the dietician was insistin' that he have his NG tube down

again it was really useful to have everybody gathered like that because erm erm PAED₁ and HV₁ (0.4) supported us and straight away the speech therapist said “I’ll just, I’ll make regular visits and I’ll see what I can do” (*Angela, Mother of Adam, lines 57-62*).

For Angela, the key benefit of the TAF meeting was the fact that it was an open forum in which everyone’s views are heard at the same time and in the same space. The dietician is portrayed as a lone dissenter who is insistent in her belief that an NGT is the way forward. Angela is grateful that the rest of the team are there to support her in her wish to persist with oral feeding both emotionally (the paediatrician and the health visitor) and in offering practical strategies (the speech and language therapist). The dietician’s mouthing to the paediatrician broke the rules of this open forum, as Angela relates:

Well it was quite literally behind our back at one point in this, in this room somebody wasn't happy with what was being said and rather than say it directly to us (0.4) she let, she tried to lean back out of our, because Anthony was here as well out of our eyeshot and mouthed to the paediatrician and the speech therapist “we’ll discuss this later and come to a decision” [R: right, yeah] and erm I think, well I didn't see her, Anthony saw her and challenged her straight away and and and and put it to rest but (1.0) I, I I’ve often I often think about that particular moment because I marvel at single parents (1.0) because I would have bowed to what she said. I would have done what she said (*Angela, mother of Adam lines: 79-87*).

Although Angela does not explicitly name the dietician, this is clearly the same event. Her use of the term “literally behind our back” and her repeat of the term “this room” strongly echoes Anthony’s use of these phrases. Possibly this is an event that has been discussed on many occasions. Her use of the unusual term “eyeshot” rather than “earshot” together with the “mouthing” evokes an image of secrecy. The dietician is positioned as attempting to be neither seen nor heard. Angela’s phrase “rather than say it to us” shows how Angela centres this problem on the lack of inclusion and engagement with parents and the impact of this on as the paediatrician clearly acknowledges:

I think that they felt that Diet₁ the dietician dangled a nasogastric tube at them as a threat from when he was very little really which I think probably eroded their relationship from the start, really (*PAED1: lines 177-179*).

The paediatrician's use of the word "threat" ties in with the "fascist" nature of the parents' relationship with the dietician as portrayed by Frank. The symbolic image of an NGT being "dangled" from when "he was very little" offers a graphic depiction of coercion tactics. It is important to note that the paediatrician is not stating her own view here but is attempting to portray how the parents may have felt and how this may have led to relationship breakdown. Similarly, the health visitor who was also present described her view of the same event:

HV ₁	I think t they were sort of concerned that they might be sort of pushed into something [R: Right, o.k] particularly by the dietician [R: yeah] I think they felt that they may be pushed towards that aarhm
Researcher:	And did you feel that the dietician was pushing them?
HV ₁	No! Not at all
Researcher	But they felt it?
HV ₁	That's how they perceived it

(HV₁, Health Visitor for Adam, lines: 43-52)

HV₁'s account does not tie in with the negative portrayal of the dietician as threatening or "fascist". For the health visitor, the issue is one of perception of other people's actions. The health visitor portrays the parents as sensitive to the possibility that they may be directed to follow a particular path against their wishes rather than the dietician being overly forceful.

Despite the relationship breakdown, the dietician also agreed to be interviewed. In the following extract, she relates her concerns about Adam.

And you can't look backwards, I think y'know you've got to work with what you've got but yes, probably, I mean I don't think Adam was a safe feeder from day one [R: yeah, yeah] erm but I think (o.4) everybody, because of Angela in

particular her views about oral feeding, supported her through that [R: yes, OK] erm and I think I was probably the one that was less (1.0)[R: right] happy with the feeding long-term y'know the the tu, the fact that everybody was sayin' 'oh yeah well we'll push the oral, we'll push with oral' and I'm, I was like 'um, OK,' but I was never 100% happy (*DIET₁, dietician for Adam, lines 51-63*).

For DIET₁, her primary role and responsibility “taking care of” (Fisher & Tronto, 1990) was to ensure that Adam got optimum nutrition in the safest manner possible. As I have shown my earlier chapters, Angela’s priority as a good mother and caregiver was aligned differently to that of the dietician and that her main concern was to give Adam the most normal experience possible. The incident that occurred at the meeting, supports the supposition that the other attendees at the meeting worked in unison to support the mother in her wish to orally feed. This left the dietician beating a lone path in her efforts to fulfil her own primary role. In the above extract, she describes how she was hesitant in accepting this decision “um, ok” and that she was not comfortable with this. This left the dietician in a tricky position. In a TAF meeting where the mother is present, how can she report her anxiety that Adam was not “a safe feeder” without causing the parents alarm? Her choice of trying to take the discussions into another space and time backfired leading to later breakdown in the professional-parent relationship.

8.8.3 Professional Capability versus Bedside Manner

In the following extract Anthony attempted to portray the dietician in a “fair” light:

Yeah to to be fair, she, she pfffuff (0.6) she might be a good dietician(0.2) but our experience of other (0.2) professionals (1.0) in comparing them, pigeon-holing them, they are obviously pigeon-holed in their own little specialities [R: yeah, yeah] and compared to other professionals I didn't find her great, plus there was this kind of personality clash that was going on [R: yeah] and even if it was just a personality clash then she, it wasn't going to be productive [R: no] even if she was good so it was like two sides of, oh, I don't know, do you still call it bedside manner now? [R: erm laughs] I am not sure that the capability and the bedside manner, she erm, she just didn't seem to have a bedside manner (0.2) ooh, she just rubbed me up the wrong way! (laughs) (*Anthony, Father of Adam, lines: 118-132*).

Anthony divides the dietician's professional identity into two distinct traits of "capability" and "bedside manner". By doing so, he can concede that the dietician might be a capable practitioner yet still maintain his conviction that she is not "great". A good bedside manner is one that reassures patients and carers and is dependent on openness. For the dietician, this creates a tension because she has legitimate concerns about the child's health but the openness required to fulfil the obligations of good bedside manner is likely to cause alarm and fail to reassure the parents.

In this extract, Anthony described the professional members of the group as "pigeon holed into their own little specialities". The use of "pigeon holes" implies a number of small, quite separate boxes. By adding the prefix "their own little" Anthony appears to position these constructs as fixed and inescapable and therefore impeding successful communications. Although, Anthony acknowledges that it just could just be a personality clash and that "she rubbed him up the wrong way":

Well it could be just me, it could be that I don't like her style but [R: yeah] but I do know of another mother who's since texted me, emailed me the other day saying she had had a massive argument with her too [*Anthony, Father of Adam, lines 152-155*]

In saying it "could just be me" Anthony is trying to do fairness and project himself as not being overly critical of another person's professional abilities. Yet, he supports his own account by relating another parent's experience to add credence to his story that relationships with this dietician can be problematic. In addition to concepts of personality clashes, Anthony also situated this dietician as a prototype for her entire profession:

Well to be fair what sealed the deal about getting rid of her was that our experience of other dieticians (0,2) sort of since he was in PICU actually so prior, or just before having the PEG, and having the PEG we met other dieticians and they weren't so (1.4) sorry, I'm trying to be polite here, but I don't know why I'm being polite [R: they suited your style?] they, they err, ooh she painted a bad picture of them for us [R: oh yeah] previously, so all the ones we met in the tertiary hospital, granted they were like more on-site, they were based in the hospital but they just seemed to have a better, a better way of dealing with parents and patients (*Anthony, Father of Adam, lines 139-149*).

Anthony's narrative of realisation, that dieticians are not all the same, is used to support the decision to part company with this dietician. "Getting rid of" is a harsh phrase indicating a poor relationship which can no longer be salvaged. Although he makes efforts to talk about her in a civil manner he struggles to come up with a respectful word that captures her manner of working. Worth contrasting here, is another incident where the healthcare worker concerned could just as easily be viewed as being both unprofessional and rude:

Anthony	But PAED ₁ took our side she, we get on so well with
Researcher:	yes, she's nice, isn't she? very down to earth
Anthony:	she, she has told me to f' off once or twice
Researcher	yeah, she's what? have I just got that down on tape? ((joint laughter))
Anthony:	Oh yes, she would laugh about it too, I was being cheeky at the time so ((more joint laughter))
Researcher	That will be a good quote for this report!
Anthony:	It's quite a good thing to say, that we feel comfortable enough that she can just tell me to 'do one'

[Anthony, father of Adam, lines 171-180]

Although unprofessionalism and rudeness were unacceptable in the dietician, in this incident Anthony conversely cites the same attributes as an indication of a comfortable and warm relationship. The most notable difference between the two interactions is whether the dialogue is open or closed. To Anthony an open relationship is indicative of a supportive professional with a "good bedside manner". If disagreements occur, he has a forum in which he can speak his mind and feel that there is trust and therapeutic alliance.

Sometimes there may be virtuous reasons why information isn't shared. One possibility is that the kept information is merely speculative and if it is controversial or distressing may be withheld until the knowledge is built on more concrete foundations. In the following interaction Claire describes such a scenario:

Well (0.2) there probably was discussions going on () out of my earshot [R: yes, yeah] so I constantly felt like () I was being talked about when I wasn't there. And Craig was being talked about when I wasn't there. Obviously I know he was () quite a strange case, so in medical terms he's probably () you know () exciting [R: (laughs) gosh] and then, but (0.2) I think, what I felt () a lot of the times, even though the - a lot of the staff are fantastic (0.2) is I always felt () that (0.5) they were always talking () about me and the little 'un () when I wasn't there, and that when I was there (1.5) they were putting on s- a show [R: (0.5) right] not (), erm, a lot a lot of them were very genuine with us, although I think they knew things that they couldn't tell us (*Claire, mother of Craig*).

Claire describes herself as believing that some health professionals were discussing Craig's case when she was "out of earshot" or "wasn't there". Claire's phrases "a lot of the staff are fantastic" and "a lot of them were very genuine with us" suggest an unspoken implication that other members of staff may not have been quite as fantastic or genuine. Goffman (1990) draws on theatrical imagery to describe human interaction. For Goffman, there is a front-of-house region where the "actors" perform in front of their audiences and the backstage where people may no longer need to perform. Claire's suggestion that some members of staff were "putting on a show" ties in closely with this metaphor. Whenever Claire was present staff put on a good front. However backstage, professionals dropped this good front and became interested in an "exciting case". Claire's description of being left in the dark regarding her child's diagnosis is one of exclusion yet she acknowledges that circumstances dictated that sometimes there were things "they couldn't tell us".

Previous research around GT decision-making has drawn attention to conflict that can occur during interactions around feeding (Mahant et al., 2011). In the above section, I have described some of the conflicts that can occur. Avoiding conflict in emotionally powerful situations can be difficult. In the following section I describe some of the ways

in which interactants have worked together to settle misunderstandings and prevent conflict.

8.8.4 Repairing misunderstandings without conflict

When a variety of representatives from different professions are present at a meeting it is inevitable that the levels of knowledge and experience will vary. It is also likely that the values placed on different aspects of care will be positioned differently by different participants. Many professions, particularly those involved in primary care, such as health visitors and GPs, may only come across GT feeding on a very occasional basis and will not have the experience that other clinical specialisms have. In the following extract, HV2 unintentionally gives out misleading information.

HV2: Ahuh (3.0) Because once it's in, it's in, isn't it? It's not removable

Fiona: (high pitched voice) it's not removable?

Dietz: Yeah, I mean you know it is a reversible procedure

HV2: Yeah, yeah, yes

Fiona: Yes

HV2: What I meant was from a positive point of view that there isn't that weekly change and all that

Fiona: Yep, no

(TAF1, lines 350-356)

In the above interaction, the health visitor makes the erroneous comment that once the GT is in-situ "it's not removable". Fiona reacts by raising her pitch to question the health visitor's statement. There are several potential reasons for the high-pitched response. This higher pitch could potentially indicate that this information has come as news to Fiona. Secondly, it could also indicate incredulity because Fiona has some familiarity with GT and already knows that they can be removed, or thirdly, it could indicate that Fiona finds this information distressing because her preference for a GT could

apparently be based on the false belief that the GT procedure is reversible. At this point, conflict could arise. However, DIET₂ immediately orientates to Fiona's change of pitch as being problematic and initiates an immediate repair by intervening to emphasise that the GT placement *is* a reversible procedure. HV₂ in turn orientates to this repair and her repeated "yeah, yeah, yes" indicates an emphatic agreement. Possibly she realises that she has mis-presented clinical misinformation and needs to save face and defend her professional front. Her next comment therefore acts to mitigate her original error "What I meant was from a positive point of view that there isn't that weekly change and all that". Thus, the misunderstanding is resolved without conflict.

8.9 Summary and Implications:

In this chapter, I have explored some of the issues around how information around feeding is shared between families and their clinical team. I have also discussed some of the ways that a parent's perspective can be affected by professional encounters which will then map on to the parents pre-existing values to influence GT decision-making.

There are three major concerns that this chapter raises. Firstly, as I have already discussed, this is the first piece of research to explicitly address father's views around GT feeding. As I have shown, these can differ significantly from the mother's attitudes. Mothers may have more opportunity to attend clinical meetings. My research would suggest that during larger meetings which fathers may also be present, it may still be the mother that gets the opportunity to be the principal supplier of information. Members of the professional team may draw on their own expertise to support the mother's version of events which may not be challenged and there may be little interactional space offered to fathers.

Secondly, insufficient attention may be paid to the distributed nature of the decision over time. For example, clinicians reading referral letters may act as if the letter was written in real time rather than many weeks before and it may sometimes be necessary to engage more with changes to ensure that the clinical picture is up-to-date.

Thirdly, these findings support other research indicating that conflict can occur during negotiations around GT feeding. My research suggests that parents welcome open discussion and may be resentful of any attempts made to exclude them by taking discussions into other interactional spaces where they are not themselves present. Given

this parental desire for openness, more research is needed to see how individual clinicians with significant concerns can have their voices heard without unduly alarming patients or carers or triggering conflict.

In the following chapter, I will develop this theme of information sharing further by talking about how evidence around risk is shared and how the different decision stakeholders interpret these risks.

Chapter 9 Evaluating Risk

9.1 Introduction

Children with neurodisabilities often have several medical issues that need support and may already be users of other assistive technologies such as special seating or mobility aids. Despite these assistive technologies being often highly valued by families they may still resist GT feeding. In Chapters 4 to 7, I discussed some of the issues which may potentially contribute towards resistance to GT feeding. I described how values around feeding may differ strongly between mothers, fathers and other significant stakeholders and explored some of the reasons why mothers in particular, sometimes struggle when it comes to GT acceptance. It is important to note that both families that resist and families that embrace GT do share many of these values around feeding. Simply identifying the factors that influence attitudes towards GT placement is clearly insufficient to explain what combination of circumstances finally activate clinicians and parents into making the decision to go ahead with GT. In Chapter 8, I described how information about the child's feeding is shared between family members and clinicians. Despite varying degrees of resistance, all the families in my study eventually reached the decision to opt for GT feeding. In this chapter and the next, I will discuss some of the combinations of circumstances that trigger the eventual decision to place a GT. This chapter focuses on how families evaluate the risk between going ahead with GT placement versus NGT or oral feeding.

Trevena et al. (2006) argue that “informing health decision choices with the best available evidence from scientific research is desirable and, where available, outcomes should be provided that have been quantified through research” (p:2). However, as I described in my opening chapters, GT decision-making may be made more difficult because the paucity of clinical trials means that the risks and benefits of GT feeding are not quantifiable for each individual child. Clinical tests such as chest x-rays can sometimes be inconclusive, with different healthcare professions attaching different levels of importance to these tests. Parents may also struggle to match the clinical interpretations of these tests with their everyday experience of feeding their child which may be better or worse than the tests might suggest. Even the “gold standard” test of video-fluoroscopy which is usually viewed as the best “objective” evidence in the clinical

management of children with feeding difficulties still only provides a snapshot of the child's swallowing ability at a moment in time and is sometimes open to subjective interpretation by clinicians. This lack of precise data around the risks and benefits of the different feeding methods for children with neurodisabilities means that making the decision is always based on uncertainty and therefore risk.

9.2 Sharing information about the risks attached to oral feeding

In Chapter 8, I discussed how DIET₂ and Fiona constructed a joint narrative around Florence's feeding. Following this discussion, the dietician provided a summary which indicated that for DIET₂, whose focus is on nutrition, the discussion around Florence's feeding status was complete. However, Florence's poor chest health, which could feasibly be related to unsafe oral feeding, had not been discussed at that time. At this point in the discussion, assessment of Florence's feeding status split into two distinct areas of "nutritional adequacy" and "safety of swallow". The area of assessing safety of swallow falls outside the recognised boundaries of a dietician's expert role and her rights to hold the interactional position of principal are terminated. Assessment of swallow typically belongs within the remit of the speech and language therapist. SALT₁ is now the principal and overlaps to take over the talk to raise the problem of Florence's "bad chest":

SALT₁: I think just that we we're still in this cycle [coughing] of bad chest. Is the bad chest caused by () trying to increase her oral intake? Particularly, her fluid intake or is it just that she's got a bad chest because she was born () sillily early (laughs) [Fiona: umm] erm and I don't think there is, there isn't any direct chest () follow-up is there at [Fiona: no] and I don't know whether that's something that's worth () pursuing because we just seem, we just seem to be in this, she's doing really well when you see her and when you watch her and you know () Fiona and Frank are really committed to t'know developing her oral eating but then we have these, we still have these periods of chest [Fiona: yeah] [Frank: Ahum] poor chest health (*SALT₁: TAF₁: lines 88-96*).

SALT₁ presented two different potential causes for Florence's bad chest; severe prematurity because she was born "Sillily early" or as a direct consequence of the attempts being made to "try to increase her fluid intake" because she has an unsafe swallow. Both explanations run the risk of causing offence. The term "sillily early" is a

potentially inappropriate turn of phrase that may be viewed by some as unkind. Secondly, blaming the chest infections on efforts to increase Florence’s oral intake could result in both the parents and dietician feeling at fault if their efforts to improve Florence’s fluid intake results in negative consequences. SALT₁ therefore acts to limit any potential damage caused by her colloquialisms by moderating the statements with laughter so that her light-hearted intention is clear. Furthermore, praising the parent’s efforts “Fiona and Frank are really committed to developing her oral eating” creates the implication that these cycles of bad chest health, as acknowledged by Fiona and Frank, occur despite the parents’ efforts and not because of them.

Fiona offers the information that she has kept an accurate record of Florence’s chest infections, which she states to be five since the placement of the NGT a few months earlier. Fiona’s careful keeping of the diary, reflects the responsible behaviour of a “good mother”, and indicates that she understands this to be something that needed monitoring. The health visitor seeks clarification on this:

HV₂: So are you saying that it is less likely to be an issue with the gastro () stomy?

SALT₁: Well no, it’s more whether (o.5) we’re still assuming that she’s, I think when she had the video fluoroscopy six months ago she was pretty good apart from on thin liquids wasn’t she?

Fiona Yeah

Frank: Yeah

(TAF₁ lines 115-118)

It is interesting to note that SALT₁’s comment “we’re still assuming that she’s” stopped short of labelling the problem. Possibly she was aware that she was acting as animator and that the principals “we” may not necessarily have been “assuming” the same thing. SALT₁ implicitly conveyed the possibility that aspiration may have been occurring on thin liquids in the past and until proved otherwise, this is still an assumption that ought

to be made. She does this in a positive way by emphasising what Florence can do rather than what she cannot “she was pretty good apart from on thin liquids”.

And she’s going back for video fluoroscopy in February erm so I’ve got a few questions just to ask them about you know () how will () make that decision about the ca- the cause of you know how much umm her [Florence: babbles] chest might be caused by erm aspiration or whether it is just a separate () bad chest issue (*SALT1: TAF1 lines 101-105*).

SALT₁ emphasises that this problem is already receiving attention and Florence is to return for VF in February. SALT₁ has “a few questions to ask them” about the causes of these bad chests. SALT₁ is therefore now positioning herself not as the principal but as the animator for the decision-making network which extends outside of the immediate group. As such, it is the team and not SALT₁ alone who will evaluate collaboratively whether swallowing is likely to be safe and whether it is “just a separate () bad chest issue”. In the following excerpt, she describes how the thin liquid issue is managed:

So have been thickening her liquids giving her thickened juices ever since but she still has, having these periods so () whether () there is still some underlying [Florence: babbles] aspiration or whether it’s just that she’s got a rubbish chest.

(*SALT1: TAF1 lines 119-122*)

With this contextual information now in place, SALT₁ again conveys the risk that aspiration could still be occurring whilst acknowledging that Florence may just have a “rubbish chest”. This term has echoes of the SALT’s earlier statement that Florence was born “sillily early” and is again potentially hearable as a rather blunt turn of phrase. She orients to this and softens her statement with the addition of the phrase “because some babies born so early do, don’t they?” In doing so, SALT₁ averts potential offence by diverting the label from Florence in particular, to premature babies in general. The registrar supports this mollification strategy by expanding this “particular to the general” strategy in the following extract.

She was on oxygen for quite a while wasn’t she? [Fiona: yeah] and she was on home oxygen? [Fiona: Yeah} So it’s not uncommon () for children to have chest infections (*REG1: TAF1 lines 126-130*).

The registrar draws on Florence's history of being on oxygen as an associated or even contributing factor, to Florence's chest infections. Rather than attributing the chest infection problem directly to the individual, Florence, she attributes it to a more generalised category of children-on-oxygen, a category of which Florence is a member. At this point of the meeting the two competing theories of aspiration or prematurity, remain in play as the potential causes of Florence's chest infections.

9.3 Sharing information about the risks of GT surgery

Expert knowledge of the surgical procedure is likely to include as a minimum, the reasons why the procedure is to be carried out, an overview of how the procedure is to be carried out and its risks and benefits. At Florence's consultation with the gastroenterologist, GASTRO₃ checked whether the mother had seen a GT before and ascertained that she was in fact a nurse with a certain degree of prior knowledge. He then went on to describe the procedure.

Right well the way we do a PEG (o.2) as you know a PEG is a tube coming out of the stomach [Fiona: ahum] the way we do it is we endoscope the child and that's putting the tube into the stomach where we look, we knock her out and we put a needle into the stomach () and erm we, it's like a biopsy people are going to, we're going to put a thread into the stomach pull it out, tighten the tube and pull the tube out. We leave it there usually for about 3 months and then we change it for a button. That's possibly because () parents find that more convenient. [Fiona: ahum] (*GASTRO₃, appointment with the gastroenterologist, lines 36-49*).

As he needed to describe the operation, GASTRO₃ held the right to speak. His description included the salient points that there is an anaesthetic involved "we knock her out" with the surgery comprising the threading of the tube via "a needle into the stomach". However, he does not check understanding and there is a risk that some aspect of what is going to happen has not been fully understood. Fiona's only verbal contribution to this interaction was by demonstrating that she was listening to what is being said by uttering receipt tokens in the form of "ahum". Although GASTRO₃'s description of the procedure could have been more coherent, Fiona does not give any indication that she has not understood the procedure and it may be that GASTRO₃ orientated to these tokens as indications that Fiona understood what is being said. However, in encounters with other surgeons that have been observed by the researcher

but not audio-recorded, props have been employed to offer another layer to understanding and engagement. These props have included a doll and the GT kit itself together with different types of PEG and button devices. Parents have been able to see how the device will be inserted, what size it is, how it will be used and how tubes differ from buttons. In other interviews in this study, parents have talked about how they have found the use of these props to be helpful. As such, the use of props would have supported a more intelligible explanation of the surgical procedure. Although this surgeon did not engage with such materials it is important to note that he did ask the mother if she had seen gastrostomies before and it is possible that such props may form part of his more typical practice.

To gain informed consent, surgeons need to explain risks and benefits to patients or their representatives. In this consultation, this was presented as follows:

There are risks with PEGS () umm the main risk is erm () probably the risk of infection () and leakage there's particularly an an issue around erm the time that they are put in. It's a blind procedure you know and y-y-you're blowing up the stomach, and looking for you know, where we put our fingers in but you can damage the colon particularly and make a hole and sometimes () although we get indications () there may be a problem because erm () children tend to (inaudible) but these normally get better. [Fiona: ahum] Sometimes we find we need to take the PEG out [Fiona: ahum] It's a rare complication but it can happen. Sometimes children will vomit a bit more once you've put a PEG in [Fiona: ahum] But that's not always the case () umm () and certainly it's much more convenient than having a naso-gastric tube [Fiona: ahum] (*GASTRO₃: consultation with gastroenterologist (lines: 50-63)*).

GASTRO₃ described potential negative outcomes that could result from the GT operation. These include infection, leakage, a hole in the colon, the need to take the PEG out and vomiting. These potential consequences are unpleasant and possibly even life-threatening. Furthermore, terms such as “blowing up” and “blind procedure” are poignant terms. Although he played down the risk of a hole as a “rare complication” this was not quantified. Although the long-term risks and benefits of the GT procedure on children with neurodisabilities are currently unclear, immediate post-operative risks such as infection and bowel damage are quantifiable, at least regarding population risk,

and it could be helpful if some of the basic statistics on the most significant dangers which I discussed in Chapter 1 were presented to families in absolute terms. For example, it could be explained that the most common major complication in children is buried bumper syndrome, which affects approximately 1 in 50 children (Kohler et al., 2008).

Against the list of negatives only one benefit of the procedure is presented, this being that “it’s much more convenient”. Presenting risks in different formats, depending on whether they focus on losses or gains, can alter people's decisions due to a cognitive bias known as framing effect (Tversky & Kahneman, 1981). Hence framed in these terms, the decision becomes one of taking on potentially deadly risks to make the caregiver’s life easier. Earlier research as described in my literature review, has demonstrated that caregiver convenience is not viewed by either healthcare workers or parents as a valid reason for GT placement.

However, it is worth contrasting GASTRO3’s assessment of risks and benefits with that presented at the TAF meeting discussed above. Here DIET2 outlines the risks and benefits of the GT procedure.

But I suppose the advantage of it is that it’s not invasive y’know invasive on her face and you know and sort of it’s erm a lot easier to manage in terms of you, you know, not having to pass it every week and () erm it will help with sort of you know sort of with the sensitising side of things as well so () I suppose (0.2) explaining the advantages that way but obviously it’s a, it’s a procedure, it’s a surgical procedure at the end of the day so () as parents that’s going to be a big () sort of decision that you needs to make (2.0) (DIET2, TAF1 286-291).

It is noteworthy that whilst the dietician lists several negatives to the NGT only one negative of the GT is mentioned, that of it “obviously” being a “surgical procedure”. “Procedure” means process or technique and can be equally applied to positive occurrences such as following a recipe, and is not inherently a negative thing. It is the risks attached to the procedure such as infection, pain, or haemorrhage that are negative. However, none of these risks are explicitly mentioned by anyone. This raises the possibility that framing of risk may be presented differently according to the point reached on the decision pathway or alternatively, that the unpacking of risks and benefits of the procedure is duty specific. Thus, exploring the surgical risks attached to

a GT operation is delegated to the surgeon but it is within the remit of other team members to consider the more holistic aspects.

9.4 Raising further concerns about risk

In the non-medical world, people do not generally raise new topics randomly but introduce them when the moment is right and their topic can fit in naturally with the prior utterance of the previous speaker (Schegloff & Sacks, 1973). Thus, in the context of medical encounters, patients or carers may also wait until the moment is right before introducing the new topic. The structure of the interaction itself means there is no guarantee that the right moment will arise naturally and they may need to carry out significant interactional work to ensure any additional topics can be raised. Failure to create the right moment has promoted the classic “by the way” syndrome (Byrne & Long, 1976). In the following extract Fiona, employs this strategy at the feeding clinic to return the discourse to an earlier topic of concern:

The only other thing that I just wanted to ask you is if Florence ended up here with another chest infection and she was poorly. If she didn't ever have an NGT would it be immediately "ah, I'd better put it back down" what do you do? Do I just [Florence: ahh] watch and you know wait like you would as if she didn't ever have it? (*Fiona, mother of Florence, FC, lines 625–629*).

Fiona's use of the phrase “the only other thing” echoes the “by the way” syndrome identified by Byrne and Long and is the verbal strategy that Fiona used to return to her major concern around managing fluid intake when Florence is unwell. In the following sequences (not shown) PAED₃ reassures her that it is not uncommon, even in typically-developing children, for feeding support to be needed when they are unwell. Occasional and intermittent need for feeding support is not necessarily a justification for either a permanent NGT or GT, especially where one parent is resisting. Fiona as a “good mother” persists in making it clear that she is not entirely comfortable with this position:

Oh I dunno, I'm thinking about it because yesterday morning she ()she she didn't sleep very well and erm when she woke up she was really floppy and I was starting to think "oh is she coming down with something? Is she poorly? and she slept, she just slept until half eleven in the morning and then she was back to sleep at

3 o'clock and I was starting to think "oh should I ring the community nurses or?"
(*Fiona, mother of Florence, FC, lines 648-652*).

Fiona remains concerned about what she would do in the case of Florence being ill. Most of the evidence Fiona has shared so far has referred to the past. Fiona, therefore brings the narrative right up to the current times, "yesterday". Florence is described as not sleeping well, waking up floppy and then napping for a large part of the day. This alerts Fiona to the possibility that Florence could be poorly, reigniting Fiona's anxiety about what should happen if Florence cannot drink sufficient amounts. It is interesting to note that throughout the consultation, including both the information-sharing, observations of feeding, and Florence's physical examination, this is the first time that Fiona mentions an illness that occurred only yesterday. One potential reason for this, highly typical of such encounters, is that no interactional space is created by the physician where families can raise additional concerns. However, this consultation is exemplary and Fiona has been given ample space to mention yesterday's illness. For example, in line 27 the PAED₃ asks the parents to explain in their own words how things are going, and in line 59, PAED₃ asks whether Florence coughs. Fiona replies that Florence coughs if "she's coming down with something" but again does not take the opportunity to mention that this had happened only yesterday. Possibly Fiona has only just remembered, but it is also possible that a minor illness that Fiona had previously considered to be of little consequence now becomes a greater source of anxiety for Fiona as the possibility of GT becomes increasingly unlikely.

In the above section, I have shown how a parent can draw on their interactional resources to raise further concerns about risk. In the following section, I will describe how parents need to balance theoretical risks in the reality of their everyday lives.

9.5 Playing the odds

One compelling reason to go ahead with GT placement is a serious risk to the child's respiratory health. However, the risks of aspiration need to be weighed up against the risks that arise from GT surgery. In this section, I will discuss how a severe aspirational event for one family altered their perceptions of risk and forced a GT decision. I will discuss whether this scenario could have been avoided, and the implications of this for

conveying risk around aspiration to other families making decisions about GT feeding for their neurodisabled child.

In the previous thematic chapters, I explored some of the reasons underpinning Adam's family's decision to try to balance these risks and maintain oral feeding "against the odds". Up until the point where the GT decision was made, Adam's parents had managed to ensure that Adam was adequately nourished and hydrated and their decision could thus be viewed as preference sensitive. Pivotal to this family's preference to continue with oral feeding, despite the very high burden of physical and emotional care involved, were the very high values placed on oral feeding by Adam's mother, Angela, who was described by her niece as "a feeder". The following extract from Adam's father, Anthony, illustrates how the decision about Adam's feeding became critical after he developed pneumonia following aspiration of his feed:

It was kind of done as if it was a done deal, I think, as soon as it was mentioned in PICU that the why we were doing it was because of the fact that he aspirated (1.0) the amount of well (sighs) the time we had just being there I feel that well that's fair enough, it's just not worth the risk and err it wasn't a huge shock with everything else, he was still being ventilated and what not, so getting a piercing in your stomach didn't seem like [R: no] like anything to worry about compared to recovering from collapsed lungs and what not (*Anthony, father of Adam*).

Once aspiration occurred, Anthony's understanding was that the GT tube placement was no longer a preference sensitive decision that could be made by the parents but was now "a done deal". The term "done deal" suggests that no further negotiation was possible. This suggests that in an emergency, decision-making may show a tendency to follow the traditional medical (paternalistic) model in which medical staff make the decision. Emergency situations have been traditionally considered to be the least conducive to shared decision-making (Flynn et al., 2012). Despite earlier parental resistance, once the clinician's decision had been made, parental agreement was straightforward "that's fair enough". Getting a "piercing in your stomach" caused a much lower level of anxiety "anything to worry about" compared to the high risk that oral feeding was now known to pose. In the following extract, Adam's mother describes her version of the same critical event.

The first time they extubated him they said we'll give him a few days recovery and then we'll take him to respiratory and do his er not respiratory, general surgery and do his GT, but then of course we had another week and a half in there instead (laughs) but err so, because of the circumstances there was no decision to make. [R: yeah, yeah, yeah] I don't, I don't know when we asked PAED₁ for a NG on the Monday night but in my head the NG was temporary [R: yeah] and we just needed to get a move and a bump and then we'll be back to feeding him orally (o.4) erm because I just didn't see what they saw (o.4) [R: yeah] and having been through that with him now, I know exactly (*Angela mother of Adam*).

The decision was first made to insert an NGT into Adam when he first developed his respiratory symptoms. This was “Monday” the night before he was admitted to PICU and before his pneumonia was identified. Even though aspiration was now a distinct possibility, Angela still positions herself as believing that the NGT would somehow stimulate Adam “get a move and a bump” into feeding orally again. Adam’s rapid deterioration and admission to intensive care resulted in Angela understanding the situation in a different way. Similarly, to Anthony’s “done deal”, for Angela the confirmation of aspiration meant that there was now “no decision to make”⁵ Angela admits that prior to the aspiration “she didn’t see what they saw”. Although there is more than one interpretation of this statement, the most likely possibility is that she is referring to the fact that healthcare staff had a different understanding of the serious consequences of aspiration than Angela did. It is only now, when Angela has witnessed aspiration for herself, that she can integrate expert knowledge into her own experience (Popay & Williams, 2006) and truly understands what it was that the healthcare professionals were worried about “what they saw”.

When making difficult or fear-provoking medical decisions, patients or carers may strive for more certainty than can be specified by healthcare workers. Even in situations where

⁵”. Having no decision to make, or having no choice, is a recurring theme amongst the families in this study which I will discuss in Chapter 10.

risks can be quantified, healthcare professionals must also rely on narrative and visual methods to communicate risk (Harris, Noble, & Lowers, 2017).

At this point, I will demonstrate how differences in family/professional understanding may be exacerbated by different understandings of the terminology used. Sometimes words that have one colloquial sense in the wider world may have another, sometimes more sinister meaning, in the narrower medical world “the clinical context” as Angela describes:

It was after Christmas and I said to Anthony “you know it's just occurred to us that when they were talking about putting him on a ventilator, they meant life support didn't they?” [R: yeah] and Anthony said “yeah” and he said and I said “isn't it funny the terminology (0.4) how differently it makes you feel about things?” and he said “yeah, talking about a bit of ventilation, let's just open the window” (*Angela, mother of Adam*).

Introducing this extract with “after Christmas” indicates a coming narrative. Angela's story is created after she has had time to reflect on and assimilate earlier experiences. After this time, Angela has integrated expert knowledge into her own experience and suddenly realises “it's just occurred to us” that the medical word “ventilator” was more ominous than she had realised at the time. Ventilation did not just mean ensuring Adam had adequate fresh air by opening a window but meant keeping him alive by artificial means “life support”.

There are important implications here for making decisions in partnership. In a study of lay versus medical technology, Young, Norman, & Humphreys (2008) demonstrated that a switch in terminology from lay to medical terms can result in a disease being perceived as more serious, more likely to be a disease, and more likely to be a rare condition. Healthcare professionals may assume that terms familiar to themselves in the medical context are being understood by families in the way intended. Getting the balance right requires delicate interactional work because what parents understand will change as they begin to assimilate aspects of the medical lexicon. Anthony explains here how his understanding of language changed with experience:

We knew his swallowing wasn't (0.4) well, great, we knew his oral motor wasn't great, I'm trying, I'm trying not to to mix up what I know now and what [R: yeah,

yeah I er yeah] so say like the things that “unsafe swallow” that's not a term we used to use (o.2) a lot until say after (*Anthony, father of Adam*).

Anthony explains how the use of “unsafe swallow” was not a term they used until after the event. The specific vocabulary of the medical world which may often be unfamiliar to patients and their families during early clinical encounters can become gradually assimilated over time. Nettleton (1991), for example, argued that (dental) patients “interpret their own experiences and construct themselves” through “the vocabulary of the experts” (p: 101). Once Adam had aspirated, the situation changed from hypothetical risk to one of certainty. With the negative outcomes of the initial decision now known, Adam’s parents position themselves (with hindsight) as having possibly taking a gamble on Adam’s well-being:

I think looking back that we had played the odds for a long time and, and we didn't really know how unsafe his swallow was and he did used to choke a bit when he was feeding but he did always used to clear it himself and that was another thing he had that although he had an unsafe swallow, we now know, he also had, he has also got a very good cough so when it did go down the wrong way , he used to be always able to clear it [R: oh right yeah] .but it was that period when he was sedated so... (*Anthony, father of Adam*).

According to Anthony’s account, the lack of awareness of the risk to Adam’s well-being of persisting with oral feeding left them effectively taking a gamble on Adam safely managing his oral feeds. Aspiration can be silent without visible signs of respiratory distress such as coughing or choking which I propose may be a conceptual barrier for families in understanding aspiration. However, choking when feeding is a visible indicator of aspiration and Anthony’s use of the terms “when it did go down the wrong way” and “he did use to choke a bit” demonstrates his awareness that this was happening. However, the use of the words “really know” act as a moderator and suggests that although Anthony does accept that Adam had an unsafe swallow and exhibited signs of this, what Anthony had not fully embraced as part of this knowledge were the life-threatening consequences of that unsafe swallow for Adam’s chest health. This was something that Anthony only understood after the event “we now know”. This is hardly surprising; in everyday life, people often talk about choking on a piece of meat in a restaurant, or food “going down the wrong way” as something that is unpleasant and

frightening but rarely life-threatening. It could therefore be that Anthony and Angela did not fully appreciate the risks that an unsafe swallow meant. Adam's "very good cough" was taken as evidence that Adam could clear, or appear to clear, any foodstuffs that he had inhaled. However, changes to Adam's medication resulted in greater sleepiness "he was sedated so" and he was unable to cough adequately to clear his airways.

One member of staff, DIET₁, was extremely worried about Adam's risk of aspiration but by raising her concern earlier in Adam's life parental/professional conflict arose which I discussed in Chapter 8. Research shows that how patients and practitioners make sense of risk may depend on how it has been framed (Linell et al., 2002). Following the insertion of the GT, Anthony came to acknowledge that in high risk cases such as this that staff do have to "muscle in a bit" and accepted the very fine line that health professionals need to negotiate as they need to be simultaneously sensitive to the "parents' wishes and what's best for Adam" (*Anthony, line 274*).

Although delaying the decision to place a GT until there was no longer any choice may have possibly led to Adam aspirating, this does not mean that the family necessarily regret their choice, as Angela explains:

I don't regret insisting on feeding him because like I always, I always would have wondered if we had of made the right decision [R: yeah, yeah so you know] yeah I mean it's horrible for Adam that that had to happen and I wish we could have stopped that sooner although in a weird way that experience has given us (o.6) more and er going through that experience it's it's highlighted that actually how precious the time is that we have with him which made the decision for GT even easier because if all of that time was gonna be spent stressin' about feeding him [R: yeah yeah] it wasn't worth it (*Angela, mother of Adam*).

If the decision to go ahead with the GT had been made by the parents when the aspirational risk was merely hypothetical, they would have been in the position of never knowing that he would have gone on to aspirate. In a parallel world, an alternative narrative could have developed in which Adam did not aspirate but instead developed excellent oral feeding skills. Angela's argument centres around the possibility for decisional regret. Although Angela acknowledges that the experience of aspiration was "horrible" for Adam, it has oddly "in a weird way" protected the parents from decisional

regret in two important ways. Firstly, the parents now know with certainty that oral feeding was risky for Adam and they can be confident that the GT is the correct thing to do, as now “there is no decision to make”. Secondly, a near death experience such as this one, has brought to the fore the possibility that Adam’s disabilities could mean that his lifespan is limited and each moment should be prized without “stressing about feeding him”. Angela’s comment “it wasn’t worth it” is most likely to mean that the benefit, the “worth,” of orally feeding Adam was insufficient when balanced against the risks that had been taken.

The making of medical decisions does not emerge from one-off healthcare encounters but are distributed over time and place (Rapley, 2008). Adam’s emergency PICU admission meant that the community paediatrician, PAED₁, was not involved with the eventual decision to place a GT. During the interview, PAED₁ reflected on what had happened.

You know I think it made them, oh and me probably, it made all three of us think “Oh gosh this isn’t a sort of lifestyle choice we’re making here, the three of us. This actually (o.6) is about his his chest health”, and it wasn’t about him gaining weight because he had always always gained sufficient weight so it’s not, that discu, it wasn’t about him thriving, it wasn’t that discussion, it was about his respiratory health (*PAED₁, Paediatrician for Adam*).

PAED₁’s use of the term “lifestyle choice” ties in closely with notions of preference-sensitive decision-making. By focusing on the gaining of “sufficient weight” as the progress marker for “thriving” which supported this choice, it is possible that the risks to his chest health were paid inadequate attention. In PAED₁’s description, the critical event in Adam’s life lead the parents to the understanding that oral feeding was not being achieved in a safe manner and that other therapeutic options needed to be revisited. Although PAED₁ initially suggests that it was the parents that came to this understanding, she self-repaired this statement to include herself “and me probably, it made all three of us think”. In doing so PAED₁ positions the decision not just as a preference-sensitive decision for the parents but as one of SDM. PAED₁’s key suggestion is that issues around safety and health should perhaps trump the “softer” issues of lifestyle choice. However, this is possibly a harsh self-appraisal by PAED₁, as by doing so it is possible to ignore quality of life issues. Additionally, PAED₁ used the benefits of

hindsight, knowing that Adam did develop pneumonia to reframe the decision made before that outcome could be known.

Other members of the clinical team were less certain that reframing what was only known after the event was possible as SALT₁ explains:

Erm I think (0.5) the absolute decision as to whether his () serious illness in the autumn of last year was caused, was directly caused by feeding is not an absolute () yes or no , but I think (0.5) it's quite a high chance that it was [R: Right, okay] caused or precipitated by aspiration , so I suppose if he'd had a GT and had, not had anything orally then that might not have happened, but I don't know that we had that full information (*SALT₁, speech therapist for Adam*).

By drawing on the vagaries of luck, “a high chance”, SALT₁ re-evaluates the risks to Adam of maintaining oral feeding as one of probabilities rather than inevitabilities. SALT₁ accepts that there was a high probability that the aspiration could have been linked to oral feeding, and therefore might have been preventable by inserting the GT sooner. However, she does not fully accept that what they know now matches what they knew at the time of the decision; she is unsure as to whether they had that “full information”.

One factor noted by several participants was that Adam's ability to manage oral feeding may have deteriorated as he became increasingly sedated due to increases in his epilepsy medication. Therefore, two trajectories of feeding ability and degree of alertness crossed “at some point his chest health was compromised by oral feeding” (DIET₁ line 133). Whereas DIET₁ suggests that this should perhaps have been the point where the discussion around alternative feeding could have occurred, she acknowledges that such assertions can only be made with hindsight “looking back”. Even if the risk of oral feeding had been fully recognised at the time, when making the GT decision these risks would still have needed to be balanced against the unknown risks of the operation and associated anaesthetic. Following the GT operation, Adam did in fact suffer a gastrointestinal bleed, sufficiently serious to warrant readmission to PICU. Like the aspiration itself, this could have led to a poor outcome for Adam, a matter discussed later between Adam's mother Angela and PAED₁:

So that clearly has been difficult and the fact that he was readmitted with a GI bleed immediately [R: yeah] So you know Angela and I said, ‘God, imagine if he'd

died from that'. [R: Yeah] and you imagine, imagine what she, I, Anthony would have felt like you know, a decision that wasn't absolutely easy, even though I put it to make it sound like it was a (0.2) done deal. It still was a decision. What if he had died [R: Yeah] from that decision? (*PAED1, Paediatrician for Adam*).

The above extract demonstrates that in terms of distributed decision-making across time and place the timeline does not only occur before and during the decision but also forms part of a post-decision shared reflective process.

In the above section, I have shown how parents deal with the consequences of risk before, during and after an adverse event and how this must be weighed up in relation to the risks of undergoing GT surgery. In the following section, I will describe one way that that helped some parents to construct the surgery as having a lesser risk by combining operations.

9.6 Reducing risk

Elliott's family were initially recruited to the study because they were perceived to be resistant to GT. However, during data collection, there was a shift from resistance to reluctant acceptance. This gave me an opportunity to interview members of the family prior to the GT operation and also allowed me to conduct post-GT retrospective interviews with the family members together, as well as include an independent interview with Elliott. These interviews revealed the dilemma that can occur when opposing viewpoints are held amongst different stakeholders offering the opportunity to explore how these views played out in family interaction. As discussed in the preceding chapters, Elliott's mother Elaine was strongly opposed to GT feeding. Unlike Adam, Elliott did not orally feed but had been fed from birth via an NGT. Although an NGT is not normally recommended for long-term use, Elaine was unwilling to consent to the GT and NGT feeding continued. Elaine saw no reason to change feeding method because, in accordance to her personal values, the disadvantages of NGT feeding weighed less than the perceived disadvantages of having a GT inserted. The turning point for Elaine came at the point where the benefits of the NGT began to be outweighed by its disadvantages as she explains:

I don't really want him to have it () erm () but we're at the point now where he's going to have to have it () his nose is just breaking down all the time [R: Aww is

it? Yeah] ... it's falling back all the time because it's getting shorter the bit outside of his body is shorter [R: right I see] so the NG is starting to bug him (*Elaine, mother of Elliott*).

According to Elaine's account, it was the situation itself that had changed rather than her own values around feeding method "I don't really want him to have it". Elaine had previously felt secure that her decision was the right one because the NGT was not causing harm to Elliott. A critical moment had been reached where the NGT was causing Elliott to have considerable discomfort. Such a situation could no longer be commensurate with social ideals of good mothering. Elaine, as a "good mother" changes her decision. To do so, Elaine must disregard her own opinion around the risks of GT feeding and embrace a child-centred approach which takes Elliott's feelings into account.

Another important factor also tipped the balance in the GT's favour. Elaine had stated that her main reason for resisting the GT was that she did not want Elliott to undergo an unnecessary operation. However, surgery was scheduled for Elliott to have an orthopaedic operation which was likely to be critical to his future function and quality of life and thus deemed more essential. The opportunity therefore arose for Elliott to have a GT placed at the same thus negating the need to face the risks of an additional anaesthetic. In the following extract, Elaine explains the impact of this additional consideration on her decision:

Researcher:	Okay so so, so if he wasn't having now another operation
Elaine:	No, no he wouldn't have it
Researcher:	You wouldn't have made the decision still, no
Elaine:	No
Researcher:	It's just that you've now got a window of opportunity to have it done?

Elaine: Well that's our deadline that's what I said to Eddie, that's well, Eddie has already made up his mind (small laugh) that's my deadline.

(Elaine, mother of Elliot)

Elaine is clear that without this opportunity to combine operations to reduce anaesthetic risk she would still resist GT placement despite the ongoing problems of the NGT. Elaine's repeated use of the word "no" demonstrates that she remains unequivocal about her position around GT. However, the deadline of the orthopaedic operation date now reframes this resistance. Her initial remark that it's "our deadline" is self-repaired to "my deadline" demonstrating her knowledge that Eddie did not share the same agenda. Some of the reasons for the differences in opinion between Eddie and Elaine tie in closely with the themes I have discussed around stigma and the values of feeding to mothers and fathers. However, the significance of the surgical operation itself also differed between the mother and father as Eddie describes:

I-I -I cannot see it as a big () massive (o.2) operation sort of thing and how () how (o.2) how it's a massive step for him but you know I'm just thinking instead of going up his nose it's going to be his stomach [R: yeah] I'm not (o.2) maybe I've () been blind to the facts that it is () a huge () step () or () I don't know, I don't think it is a huge step. Elaine- Elaine does but I don't (*Eddie, father of Elliott*).

Eddie appears to attach a lower level of risk to the operation than Elaine does, it is not "a big massive operation". Given that Elliott is not feeding orally, Eddie sees the transition from NGT feeding to GT feeding as the next logical stage. However, it may not be that simple. Surgical practice is organised by an oppositional discourse, "between surgery as a healing process and surgery as a (necessarily) injurious procedure" (Fox, 1993, p37). Eddie therefore acknowledges that he could be downplaying the significance of these injurious elements "been blind to the facts". Viewing GT placement as a low-tech, low risk procedure, a simple case of placing a tube into the tummy, serves to dismiss maternal concerns, which may derive from genuine fears about the additional risks that children with neurodisabilities may face. Eddie therefore acts to prevent the giving of an impression that he finds Elaine's assessment of risk unreasonable by accepting that he and Elaine hold different views around the significance of surgery.

I have already described how Elaine only agreed to go ahead with GT placement because it could be scheduled together with an additional pending operation. However, opportunity alone is not enough to trigger a decision as Ethel reports:

And I, I think if he hadn't started having problems with his nose (o.5) [R: yeah]
he still wouldn't get a () PEG in (*Ethel, maternal grandmother of Elliott*).

Whilst Elaine posits the opportunity for dual surgery as the pivotal factor, Ethel still positions the problems with the NGT feeding as the trigger. Thus, combining GT placement with an existing operation may be a convenient way to reduce cumulative risk but can only do so because the position has already become intolerable. Hence the dual operation may be viewed not as a trigger but as an implementation enabler because it reduces risk.

During the TAF₁ meeting for Florence, considerable debate arose over whether the referral for discussion around Florence's GT placement should be via the neurodisability feeding clinic at the tertiary hospital, directly to the gastroenterologist attached to the feeding clinic (GASTRO₁) or directly to the gastroenterologist (GASTRO₄) already involved in Florence's care but not attached to the feeding clinic. Florence's mother, Fiona, strongly favoured the latter because, at a previous consultation, GASTRO₄ had promised that if GT placement was agreed, she would be willing to examine Florence's bowels while she was under the same anaesthetic to investigate issues around constipation. Fiona's preferred referral pathway was therefore agreed by team members before the consultant, PAED₁, arrived at the meeting. Once she had been brought up to speed, PAED₁ suggested that referral to feeding clinic was a speedier process and would therefore be the more appropriate route. However, although Fiona and PAED₁ agreed that GT placement would be in Florence's best interest, they still did not hold shared values around the referral process. Fiona's values were not tied to speed but on the opportunity to combine procedures.

Fiona: The only thing we were saying was that erm
[Florence: babbling] GASTRO₄ said she would have a
look at her bowels if she had an anaesthetic so could
she still do the

- PAED₁: We could do that as well though yeah
- Fiona: In the feeding clinic?
- PAED₁: Yeah. We could erm make sure that we say in the referral letter please would they liase with GASTRO₄.
[Florence: yeah] In what way will they look at her bowels?
- Fiona: Her constipation. She's had problems since coming home

(TAF₁, lines 526-536)

Fiona's introductory statement "the only thing we were saying" is an interactional strategy used to revisit a matter that she had thought to be resolved. PAED₁ orientates to Fiona's question "in the feeding clinic?" as perhaps representing incredulity that the bowel examination could be organised by the feeding clinic and acts to reassure Fiona by stating how this this could be achieved "make sure that we say in the referral letter". Her question "what way will she look at her bowels?" does seem to suggest that PAED₁ harbours some doubt about the usefulness of such an investigation. Whether PAED₁ agrees or not with Fiona about the value of the referral, she does not dismiss Fiona's concerns and goes on to explore the bowel problem in depth. The disadvantage of the feeding clinic compromise is that another clinician and another stage has been introduced into the referral process. However, conflict has successfully been avoided and Fiona keeps hold of her position as "risk owner" (Craig & Higgs, 2012).

In the above section, I have discussed how one risk-reduction strategy is to combine operations. I have also discussed how this might be arranged and negotiated between families and the clinicians. In the following section, I will demonstrate how the risks around "breaking the status quo" of an established but unsatisfactory feeding method, can be positioned differently by parents and healthcare professionals.

9.7 Status Quo Bias

One potential cause of decision inertia has been hypothesised to be "Status Quo Bias," defined as "the tendency to maintain a previous decision either by actively choosing the

default or by doing nothing” (Samuelson & Zeckhauser, 1988). A behavioural bias toward accepting the status quo option in decision-making is well established (Nicolle, Fleming, Bach, Driver, & Dolan, 2011). For example, Suri, Sheppes, Schwartz, & Gross (2013) used a range of psychological experiments, involving electric shocks, to demonstrate (at least in the laboratory context) that there is a tendency for people to choose the default option even when this is clearly inferior. Bias towards sticking with the status quo has been shown to underlie many real-world decisions such as the likelihood of organ donation (Rippon, 2012). A trial evaluating hypothetical results from research studies has shown that clinicians appear far less willing to adopt new beneficial therapies than abandon old harmful ones (Aberegg et al., 2006). This is very important with respect risk management because, where a healthcare provider positions a particular option as the default, patients are more likely to make that particular choice (Halpern, Ubel, & Asch, 2007).

In the following extract, from a group interview with the family after Elliott had had his GT inserted, his brother, Evan, explains why it is much easier to stay with the status quo:

See you’ve got like all that () spurious information [Elaine: yeah] pulling you away and () you don’t wanna take the risk of the surgery as well () so it’s easier just to do nothing. Your option is surgery or just not do anything, so it’s easy enough just to sit back and go “well we’ll just leave the NGT in for now” () but then obviously once you get it done you don’t have any of the drawbacks and it is better () then (*Evan, brother of Elliott*).

By "spurious information" Evan is referring to the anecdotal bad news stories that Elaine received from other parents which competed with the clinical recommendations that were being made. Evan explains how this additional information tipped the balance in favour of the status quo because “you don’t wanna take the risk of the surgery as well () so it’s easier just to do nothing”. By “easier”, Evan is not referring to the physical burden of care but the ease of dealing with risk. Breaking the status quo and actively opting for surgery is difficult whereas it is “easy enough just to sit back” and maintain the status quo. Evan’s use of the words “for now” is a reminder that maintaining the status quo is always temporary and has the potential to be revised at a future date.

In the following example, Evan also describes how his position around GT placement changed as his knowledge status changed:

You see I don't remember a huge amount of what the benefits and drawbacks would be for Elliott. Erm (1.0) initially I thought it was kind of the (1.0) like the permanent () acceptance that he couldn't eat. You know [R: oh yeah, yeah] because it's a surgical intervention [R: yeah] Erm because he is going to have something that is actually () surgically attached to him. I – it felt to me kind of like it was they were just given up on Elliott eating now. But then as it was explained to me more I think (0.5) it should (0.5) well I may be way off, but it seems like it should kind of help him () get into eating more (*Evan, brother of Elliott*).

As Evan gained further information from alternative sources “explained to me more” he revised his opinion to a more optimistic one. Rather than reducing Elliott's oral intake the GT might encourage him to eat more. Although Evan does not stipulate the source of this further information it does tie in closely with his father's frequently repeated assertion that Elliott might be more interested in feeding if he did not have the NGT going down the back of his throat. Alternatively, Evan might mean that it was not his knowledge about the procedure that changed, but with Elliott's deteriorating skin condition, the balance of risks and benefits had begun to shift.

The above section acts as a reminder that opting to do nothing is still a choice. I have briefly touched on why sticking with the default option may be easier than actively making a new choice even if that has the potential for favourable outcomes. In the following section, I will address the situation where families position themselves as having “no choice”.

9.8 Having no choice

Weighing up risk was more straightforward for some families. For example, for Gary's family, feeding was an arduous and difficult task and his parents did not find the recommendation of GT tube placement to be a difficult one to embrace:

As soon as it [GT] was suggested we knew [R: right] because he was so poorly (*Gail, mother of Gary*).

being made up of little steps. It also chimes with other research suggesting that parents may view each new intervention as another indicator of the child's degree of disability (McLaughlin, 2006). Gary had taken small steps forward and the GT tube symbolised a reverse to that trend. For Gail, the decision was both easy and quick because there was "no choice" yet it was simultaneously challenging.

9.9 Summary and Implications

In this chapter, I have discussed some of the ways families and clinicians evaluate and share the risks and benefits of the methods of feeding available for the child with a neurodisability.

Evaluating the significance of symptoms in terms of cause and effect can be complex. because it can be hard to determine cause from effect. Parents' understanding of risk may differ from professional understanding of risk and careful interactional work is required to ensure adequate conveyance of the seriousness of the situation without causing undue alarm.

I have demonstrated how the process of evaluating risk is a multidisciplinary effort with participants from different disciplines focusing on different aspects of risk. Families need to draw together different risks and benefits presented on various occasions along the decision trajectory by a diverse range of people.

I have postulated that Status Quo Bias may be one further reason why families, especially mothers, may wish to stick with their current feeding method, no matter how imperfect. It may only be when the position of "no choice" is reached that mothers feel able to embrace the decision to place the GT, a position that fathers sometimes reached much earlier.

Some of the risk of GT placement is tied to the operation, most notably the family anaesthetic itself. One way to reduce risk would be to combine a GT with another operation where that is multi-morbidity and the opportunity for this arises. This can create a decision turning point.

I will now move on to demonstrate how families assimilate their understanding of risk into their values around feeding to reach a decision in conjunction with their clinicians.

10.1 Introduction

In Chapters 4 to 7 of this thesis, I discussed some of the key values family members have that may influence decisions about GT placement. In Chapter 8, I explored how information around these values and knowledge about feeding is shared between families and their clinical team. In Chapter 9, I described how the risks and benefits of the different feeding methods are evaluated. In this Chapter, I discuss whether these three core elements of values, sharing information, evaluating risks can successfully unite to form a shared decision around GT placement in cases where the choice is sensitive to individual preference. I again specifically focus on interactions with others, and how these influence the ways the eventual decision is distributed across time and place between parents, their healthcare team and friends and family to reach a decision about GT placement.

10.2 GT placement as a medical decision versus parental informed choice

Although it may seem an obvious statement to make, it is still worth mentioning that for parents to choose GT feeding for their child it must first be made available on the possible menu of options. Brian, for example, described how for him, the most compelling reason for going ahead with the GT for their son Billy was the fact that “they offered it”.

Yeah that’s it, I was er you know (o.5) when (o.5) they finally kinda said ‘we are getting this in’ we were at the point of saying (o.5) what do we need to do to get this sorted out? (*Brian, father of Billy*).

It is interesting to note that some parents, even when very knowledgeable, do not make proactive requests but wait to see what is offered. Brian’s use of the term “finally said” indicates that he views the GT offer as being overdue. It was only after a period of time had elapsed and the GT had not been offered that the parents began to consider a more pro-active approach “we were at the point of saying”. The GT decision for Billy, as reported by Brian, appears to be positioned towards the patriarchal end of the decision-making spectrum “we are getting this in”. Similarly, Craig’s father, Colin, suggested that they too, would take up an offer of GT “if we had the choice”. This suggests that Colin,

like Brian, views the GT as something that needs to be presented by members of the clinical team rather than something that they would be able to request.

Some parents waited for the decision to be made by someone else and then gave their consent to the procedure. Here Brian and Billy's Grandmother Brenda explain why they thought this would be appropriate.

We put our trust in erm these people to make the () the right decision [R: yeah, yeah] erm as to what's best for him you know so if they said this is what we need to do () then that's what we need to do. [R: Yeah, yeah] (*Brian, father of Billy*).

But to me (o.2) tsk if he needs it, he needs it (o.2) and the professionals wouldn't (o.2) suggest it if it wasn't (o.2) [R: Yeah] if it wasn't needed (*Brenda, maternal grandmother of Billy*).

According to Brian and Brenda's accounts, the parents' role is not to make the decision but to place their trust in "the professionals" to make the decision. Brian has full confidence that the healthcare team will do "what's best for him". It is therefore easy to accept their recommendation "that's what we need to do". By accepting medical team decisions, the parents are liberated from making difficult choices. However, this may be more simplistic than it first appears. Although Billy's mother, Beth, concurs with Brian that the GT decision-making itself was quick and easy, Beth frames the decision-making journey as a "two-step process". As Billy had not been identified as being at risk of aspiration, his problems revolved around weight gain and the time taken to feed. The first decision for Beth was whether to supplement oral feeding with NGT feeding. Once NGT feeding was in-situ and Billy began to thrive, the second part of the decision, to make tube-feeding easier, was much more straightforward.

As I discussed earlier in Chapter 5, neither Brian, nor Beth, liked the NGT so switching to a GT was the easier of the two decisions to make. However, a decision was still required to implement the first stage of NGT feeding. Furthermore, whereas Brian viewed the decision as accepting a recommendation from a trusted source, Beth still saw the decision as one the parents made as she describes below:

When Gastro2 mentioned it she said "I know it's not what everybody wants but" [R: yeah] that it's up, it was up to us she wasn't () forcing us to have it, it she says "it's your decision" [R: Yeah] (*Beth, mother of Billy*).

In Beth's narrative, GASTRO₂ is portrayed as presenting the GT choice as a preference sensitive decision "I know it's not what everybody wants". Beth's follow-up comment "it's was up to us" strongly suggests a preference sensitive choice is on offer. Nevertheless, Beth still does not describe any degree of SDM. The Gastroenterologist offered the opportunity of a GT, but her comment (as reported by Beth) of "it's your decision" firmly places the decision-making onto the shoulders of the parents and it becomes a decision of informed choice.

Offering an informed choice can have the effect of fuelling parental resistance. Todd & Jones (2003) have reported that mothers of adolescents with disability may commonly feel "under surveillance" and put up stubborn fights on behalf of the children as a means of establishing themselves as good mothers. In the following extract, Elliott's mother Elaine describes her own degree of stubbornness regarding GT feeding.

Er erm no they tend to () they are just like "PEG in?" And I'm like "no" (*Elaine, mother of Elliott*).

The way interactions develop during consultations can be very subtle. It is highly unlikely that health professionals would say "PEG in?" Even if they did frame the question in this way, such a request would demand the preferred response of "yes". Elaine's dis-preferred response of "no" would normally require softening by mitigation (Schegloff, 1991). Elaine's description is probably not an accurate portrayal of events but is instead the essential skeleton of her recollection of the conversation with all the sensitivities of interaction stripped away. The essence of the interaction is that the health professionals offered the peg (the GT) as an option and Elaine declines.

Elaine describes how this situation is made more difficult because others view GT placement as a shared decision whereas she does not:

And the doctors and things and the nurses and everybody that we see () it's like they've grown up with Elliot and they are all part of Elliot's life and they all (o.2) [R: yeah] Ahha-hahh some of them do feel like they've got a piece of Elliot [R: yeah] do know what I mean? They (o.2) they they feel like it's all right for them to make that decision for him (*Elaine, mother of Elliott*).

Elaine's reference to "things" most likely refers to allied healthcare professionals. Her phrase "that they've grown up with Elliot" is thought-provoking. Elaine may be implying

that Elliott's complex disabilities mean that managing his care has been a complex learning curve for everybody. Elliot's need for input from many different departments has made him a child that professionals are likely to talk about, remember, and importantly, gain knowledge about. This high degree of involvement means that they are "all part of Elliott's life". Growing up with Elliot in this way is likely to lead to a degree of attachment that goes beyond what is typically expected in non-chronic healthcare encounters. Because of this bond, Elaine posits that some of them feel that Elliott does not just belong to his parents but also belongs to them and as such they have a greater entitlement to be part of the decision-making process than might normally be the case. This situation could result in Elaine becoming more protective around her parental rights and may account for her unmitigated "no" to suggestions made by others which corresponds to the findings by Todd and Jones discussed above. It is notable that she uses the words "for him" which emphasises one of the main dilemmas underpinning this thesis of who holds the strongest rights when making a decision on behalf of a minor.

Whilst some families may welcome the responsibility of informed choice it is not always the case. Quill & Cassell (1995) argue that patients should not be abandoned when making unclear medical decisions but should be supported by a knowledgeable partner in the shape of their clinician who should not "shy away" (p:1). In the following extract Brian explains his position when clinicians seem to shy away from the decision:

I mean that that's annoying (o.4) with us sometimes because there's a lot of people that just won't make a () a decision [R: Oh right] and they are very scared to and () and some of the GPs, we've had it even when we've taken him up to [the secondary hospital] and the emergency () emergency care consultants and staff like that are very (o.8) scared of of making a mistake (*Brian, father of Billy*).

In the above extract, Brian is drawing on a discourse of defensive medicine. He positions some clinicians as being too scared to make decisions for which they may be held accountable, so are thus implicated as keeping to a presumably safer default position by maintaining the status quo. However, as I have demonstrated in Chapter 1, the risks and benefits of GT feeding are unclear and clinicians may therefore have inadequate evidence on which to guide their decision. Three important issues are at stake for Brian here. Firstly, Brian does not frame the more passive option of maintaining the status quo as a decision in itself, but as the evasion of the more active responsibility to *do* something

“there’s a lot of people who just won’t make a decision”. Secondly, there is a presumption that maintaining the status quo reduces the liability “of making a mistake” possibly because Brian sees this as the option least likely to stimulate criticism if poor outcomes occur. However, doing nothing is also inconsistent with concepts around duty of care because accusations of sub-optimal care are possible. Thirdly his use of “they” suggests a division of “us” and “them” and suggests that he does not view the parents as an integral part of this decision-making team.

In the above sections, I have described how the decision-making process must begin with GT placement being made available to parents as part of the information giving because parents cannot opt for something that has not been offered. I have also described how preferences around being involved in decision-making about GT placement for a child embraces the shared decision-making continuum and clinicians need to explore the degree to which families would like to be involved in the decision with respect to all aspects of enteral feeding.

10.3 Making the decision a shared one.

During the first TAF meeting for Florence, DIET₂ drew on ideals of informed choice by suggesting the GT decision was “up to you as parents”. However, as I discussed above, informed choice is not for everyone. The following extract illustrates how Fiona attempts to draw other stakeholders into the decision at this meeting.

Fiona: We have thought about it haven’t we?

Frank: We have, aye

Fiona: And we thought we would (o.2) take on your opinions really if you thought that that was gonna be best for her

DIET₂: Yeah

(TAFi: lines 305-309)

Fiona’s statement that “we thought we would (o.2) take on your opinions really” actively seeks out the viewpoints of others. Although, Frank admits that they have thought about

it “aye” he does not state what his views might be. Picking up on this silence, HV₂ orientates to potential trouble in the talk and enquires whether it is the permanency of the procedure that concerns Frank.

Yeah well sorta I think it’s just the fact that she’s going to have an operation on her I think [HV₂: yeah] you know she is still quite little to start with () I think the tube seems to be doing its purpose at the minute but yeah it’s not ideal and () [HV₂: umm] so well again like Fiona said [Fiona: yeah] we are having to listen to what are your thoughts, you know (*Frank, father of Florence MD₁, lines 334-341*).

Frank’s statement reflects some of the themes that I have discussed within the thematic analysis of the retrospective arm of this thesis. Frank draws on socially constructed images of Florence as a vulnerable infant “quite little to start with” and expresses a preference to stick with the status quo “the tube seems to be doing its purpose” despite his admission that the situation “is not ideal”. However, Frank’s comment “we are having to listen to what are your thoughts, you know” suggests, given the use of his utterance “having”, that he may not be fully complicit in the idea of taking on the views of others when debating these issues and does not suggest any desire for SDM.

In the previous chapters, I have discussed how healthcare practitioners may erroneously believe that the person attending consultations (the animator) who is usually the mother may be, or appear to be, acting to represent the viewpoint of both parents (equal principals). It is therefore interesting to note that when given this opportunity, Frank does not appear to position himself as an additional animator but more as a recipient of unsolicited advice.

In the following example, I describe shared decision-making around GT placement in practice. This encounter occurred during a feeding clinic consultation in a tertiary hospital following a referral to discuss Florence’s feeding issues. The parents were already aware that discussing GT placement was likely to form part of the agenda. During the feeding clinic, the paediatrician leading the consultation, PAED₃, broached the subject of GT placement with the parents in the following way:

Erm I know you’ve done a lot of talking to PAED₁ about longer term feeding [Fiona: ahum] support and () err I think the key things really are as you’ve identified the weight gain [Fiona: yeah] erm the fluid intake () and making sure

that she's not getting side-effects from not having enough fluid for adequate hydration erm [Florence: ahhh] so (1.0) erm () in some ways things are really improving [Fiona: yeah] erm (1.0) but obviously, she's probably got a little way to go towards a normal eating (laughs) eating habits. Erm I know PAED₁ discussed sort of long-term tube- [Fiona: yeah] y'know naso-gastric feeding for the long term [Fiona: yeah] erm and the potential more permanent options including GT. What were your feelings about that? What were you erm, what are your thoughts? (*PAED₃, FC, Lines 479-494*).

PAED₃ verbally acknowledges the contributions made by the parents to what is known about Florence's feeding issues, "you've done a lot of talking to PAED₁". Florence's feeding ability lags behind perceived feeding norms. This has the potential to be bad news to the parents who may, or may not be aware of this. PAED₃ therefore focuses on the positive "things are really improving" before proceeding to describe how this progress still falls short of normal eating habits and softens this statement with a laugh. To exchange further information, she explores two elements of the family's position around GT feeding, "your thoughts" and "your feelings". This is a very sensitive example of exploring parents' values because PAED₃ separates out two interrelated aspects of factors that may influence the parents' decision-making: rational choice "your thoughts" and emotional response "your feelings".

This distinction between rational thoughts and emotional feelings ties in with my findings in the thematic part of this analysis which illustrates this paradox, as highlighted for example by Beth's comment "when I've got me rational head on". Exploring the parent's views in this open-ended way successfully provided Fiona with the interactional space to introduce two further concerns.

If the only explanation now for her not progressing or going backwards is the right calories and the right () milk and everything (clatter) I don't want her then to put all that energy back into just growing with everything else having a standstill () and in this last () few weeks she's managed and that [PAED₃: yeah] but sometimes but not like she normally would if she hadn't have had her NGT out if you (inaudible) [PAED₃: umm (inaudible)] I guess you've got to () have that cut-off point sometimes but it is a bit of erm, but it was a bit of erm (inaudible) you know if she had a bad day with it and needed oral support like she needs to have extra water (*Fiona, mother of Florence, FC lines 506-507*).

Fiona highlighted the nutritional requirement for maintenance of adequate physical growth and raises the notion that any stalling in Florence's progress "a standstill" or even regression "going backwards" could be a consequence of inadequate nourishment "the right calories". Fiona's second concern is that on a bad day, perhaps when Florence is unwell, it may not be possible without "oral support" to meet her nutritional needs, specifically about extra fluids. Fiona acknowledges that there must be a "cut-off point" when oral support via NGT is no longer seen as essential, but nevertheless it clearly remains a concern to her. PAED₃ responds to these concerns as follows:

Uumm I think, I mean (3.0) in () I, I guess the crucial decision is what she does really now from now on isn't it? [Fiona: yeah] Because y'know since you were there in February she has made you know, significant progress () and I think if her weight continues to () to gain and she's, you know continues to not have difficulties with constipation I'm relatively comfortable with kind of [Fiona: yeah] watching and waiting really (*PAED₃, FC, lines 521-525*).

PAED₃ shares her own focus around everyday progress "if her weight continues to gain" and if she continues to "not have difficulties with constipation", PAED₃ does not dismiss Fiona's cautionary approach. PAED₃ is only "relatively comfortable" with the situation and expresses a willingness to adopt a "watching and waiting" policy.

In this consultation, PAED₃, also opens up dialogue about other ways to support nutrition that do not involve NGT or GT feeding. To do so, she asks DIET₃ whether she can suggest ways to introduce more calories. By engaging the dietician in the conversation PAED₃ takes a team approach in SDM and identifies the dietician as the expert in this area.

DIET₃: There are. I mean you are just using Pediasure but there's a Pediasure Plus which is one and a half times the amount of calories in there. There's powders and things that we can give you to add to her her jars and things like that to give her extra calories and extra (inaudible)

Frank: DIET₂ said there's some new stuff that's coming out, yoghurt and stuff, you know

DIET₃: Ah yeah, Fortini

Frank: Which sounded like a lot more calories

DIET₃: Yeah

Frank: So that then that would obviously be more beneficial for her if you can get her those

(FC, lines 528-535).

It has been notable that it has usually been Fiona who has acted as animator when discussing feeding issues. It is therefore interesting to note that when the dietician begins to talk about the potential ways of increasing calories which may help avoid NGT and GT placement, it is Frank who engages with this discussion. Frank makes suggestions of his own “yoghurt and stuff” which he postulates contain “a lot more calories”. He then goes beyond mere suggestion, by taking on an active role in suggesting that these would “obviously be more beneficial” for Florence. He then continues by formulating a request for these items “if you can get her those”. Fiona does not participate in this conversation. It is only when DIET₃ begins to talk about ensuring adequate fluid intake that Fiona intervenes with “Yeah”. On many occasions, Fiona has stated that her main anxiety around Florence's welfare is maintaining adequate hydration when she is unwell. The topic of boosting calorie provision does not support the progression to GT feeding. Promoting Florence's weight gain could have the downside of reducing the possibility of GT being offered, thus leaving Fiona's main concern about hydration unresolved. PAED₃ then acts to remind the group that Florence's calorific requirements should remain a concern.

She is doing lots of learning and developing () erm factors that would () erm sway me as a clinician and perhaps for you as parents to think about (inaudible) might be ongoing difficulties just how is she y'know erm managing to get enough calories in? And to get enough fluid in? If she was () if you find it's becoming a

bit of a battle as well does that make sense? Because it can be quite stressful, can't it? (PAED₃, FC, lines 545-549).

Rather than making the GT decision herself, or placing the decision in the parents' hands, PAED₃ shares the type of factors that might "sway her as clinician" in order that Fiona and Frank can consider the same factors but "perhaps" with regard to their own personal values "you as parents". Faced with parents who have dissenting views (albeit without animosity) PAED₃'s solution is a wait-and-see approach. Continuing as they are, whilst Florence is thriving, is a reasonable approach which ties in with the father's hopes. However, there is also the suggestion embedded in PAED₃'s talk that if feeding becomes a "battle" or "quite stressful" it may be appropriate to reconsider the situation. Adopting this position pays respect to Frank's views whilst simultaneously protecting Fiona from undue stress.

With the possibility of GT placement remaining open, but not an immediate requirement, PAED₃ continues to explore the parents' values around GT. Firstly, she asks about their experiences of GT. This line of questioning reveals that both parents are familiar with GTs although "dad is not as comfortable" (Fiona, line 572). Then PAED₃ shares further information by giving a brief overview of how the procedure is to be carried out, including its purpose as well as its risks and benefits. She also goes on to describe how other families have responded to GT feeding with reference to the problems that can occur in the early months and how these can be dealt with. Most notably, PAED₃ points out that although GT feeding can be unsettling for parents at first, most parents go on to adjust to the new experience and find it helpful. This information aligns very closely to what is known about family reactions to GT feeding to date. Despite giving this positive overview of the long-term acceptance of GT feeding, PAED₃ does not belittle parental concerns and sums up that although a GT can be helpful "it's not a (0.2) minimal undertaking" (line 603) and that it may not necessarily be for them.

Towards the end of the feeding clinic with Florence, PAED₃ sums up as follows:

- PAED₃: I think at the moment () I think () I'm comfortable with you knowing a little bit about GT and let's just see what she does with her weight and her fluids
- Fiona: Yeah
- PAED₃: Yeah, Yeah
- Frank: Yeah, yeah I'm more than happy with that, me, yeah
- PAED₃: OK

(FC, lines 618–619)

PAED₃ has demonstrated elements of SDM in practice. Following an exchange of information, she outlined the various treatment options “to watch and wait” or to opt for a GT. She debated the pros and cons with them before leaving them the space to debate the matter further.

This provision of space is important in terms of distributed decision-making because it allows the parents to assimilate the information that has been given as well as discussing the issues within the wider family circle. However, the position is a fragile one. PAED₃'s use of the term “at the moment” implies that this situation may only prove temporary. Her own “comfortable” state is reliant on Florence's success at maintaining her weight gain and taking in adequate fluids. Frank's comments “I'm more than happy with that” indicates that Frank is pleased with this watch and wait outcome. Fiona's “yeah” may mean that she too agrees with this suggestion but could also only represent a token that she understands the situation.

10.4 Taking decisions across interactional spaces

10.4.1 *Across time*

The provision of time for parents to make sense of the information and implications is useful for parents. Denise talks about the sensitivity shown by her paediatrician when he provides thinking space when her husband Damien was not yet ready to take on board the concept of GT feeding on top of a cerebral palsy (CP) diagnosis.

I think, you know, I think he knew we were still dealing what, what was happening, you know what happened to him, during birth and, erm with his having cerebral palsy diagnosed and, so I think, putting that [feed tube] on us as well I think you know that's why he didn't [R: right ok] you know, push, push it for, you know, push and say, you know (*Denise, mother of David*).

Although Denise does not talk about problems that occur during the birth during the rest of the interview, her statement “you know what happened to him during birth” suggests that David’s birth had not been straightforward. Although she links this with his eventual diagnosis of CP, it is not appropriate to speculate here regarding whether the CP is an antecedent or consequence of a difficult birth. However, Denise acknowledges that PAED₂ understood that this situation was difficult for the parents “I think he knew” and was sensitive enough to not “push” any feeding decisions onto the family at this stage.

If GT decision-making is distributed over time it is likely that the desire to go ahead with the surgery may ebb and flow as discussions progress. Decision makers may concur at a point in time that GT is the right thing to do, but this may change as days go by as other people’s opinions are voiced or new knowledge comes in. This means that medical personnel have the potential to exert additional powers over the parental verdict by speeding up the referral if they believe the parent’s decision is the right one or by slowing it down if they believe that the correct choice has not been made. As I have demonstrated, a lot of interactional work goes on when making a shared decision. Clinicians need to succeed at working in partnership with parents while simultaneously supporting the child’s best interests. PAED₂ described his anxiety that once GT placement has been agreed, there is a risk that the referral system and/or waiting lists could result in a change of heart even if there has been no improvement in the child’s situation.

I would like the decision held, I wouldn’t want four months to give them the opportunity of changing their minds! (both laugh) (*PAED₂, paediatrician for David*).

In the above extract, PAED₂ expressed his concern that the GT decision remains vulnerable to change. Therefore, any decision to choose or not choose GT is always a temporary one. Only when the GT is in-situ, can the decision truly have been made.

10.4.2 *Across the family network*

In the above sections, I have discussed how families work together with their clinical team towards reaching decision about GT placement. In this section, and unique to this research, I will go on to discuss whether and how members of the extended family network may contribute to this medical decision and whether this may have relevance to other medical decisions made on behalf of a child.

To obtain these data from the extended family network, the mothers that volunteered for this study were asked to name whom they thought to be the most significant others amongst the family and friends on decision-making. Taking as an example, Craig's family network as illustrated in Figure 10-1, It is immediately clear that in Craig's case, the members of the network cited by Claire as having the most influence (except for Craig's father) are all female relatives and friends. Quite possibly it may have been different situation had I asked Colin and not Claire, and this is something that might be worth examining in future research. For, the purpose of this research, I was fortunate enough that Claire, as well as all the other mothers kindly enabled me to interview each member cited as part of the influencing family circle.

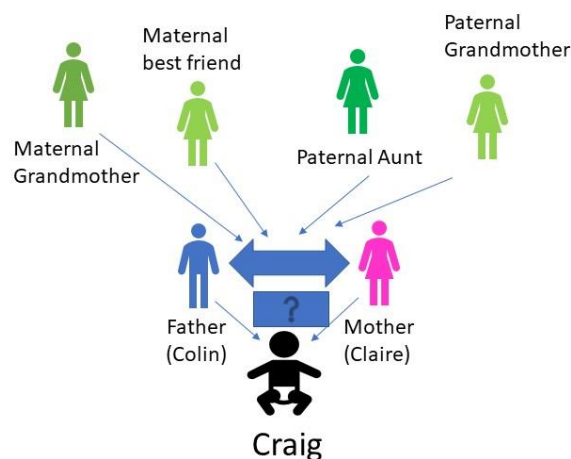


Figure 10-1: Significant others influencing the decision in Craig's family

In the following extract, Claire's best friend, Chloe, describes some of the family influences.

Erm she's very close to her Mam and erm her mother-in-law and her father-in-law and her dad so, erm I mean her husband was the first () point and obviously that that was I think quite a lotta () discussion with those two () and then I think probably outside influences would have been the () you know her mother and father and [R: yeah] father-in-law and mother-in-law, erm and then () she did discuss it with me, but it was more of an information () rather than () I mean, I think () she probably did say what do you think, and and I have offered my () opinion [R: yeah, yeah] but decision-wise it solely has obviously come down to Claire and Colin really (*Chloe, Best friend of Claire*).

Chloe describes the decision-making network in terms of a hierarchy. Work with young people making healthcare decisions around arthritis have also indicated a hierarchical structure in which mothers strongly represent the first step on the hierarchy (Hart et al., 2015). At the pinnacle of this hierarchy are Craig's parents with Claire's husband, Colin representing "the first point" in this pyramid. Both sets of grandparents are then ranked equally as outside influences. It is interesting to firstly note that the grandparents are initially not placed into their categories of marital couples (Granny A and Grandad A followed by Granny B and Grandad B) but into the categories of grandmothers (Granny A and Granny B) and then grandfathers (Grandad A and Grandad B). This suggests that Chloe may position the female influence of grandmothers as higher in the hierarchy than grandfathers. Secondly, given that all four grandparents are intimately involved with Craig's care and hold closely related genetic positions in this family network, it is somewhat surprising to hear them referred to as "outside" influences. It is likely that Chloe is drawing on notions of the social and legal responsibility here which leaves non-parents with few decisional rights regardless of their emotional or familial connection to their grandchild. In support of this theory it is worth noting how Claire herself summarises the contribution of other family members "they just said () you've got to do what's right for Craig as hard as it is".⁶ Chloe positions herself, as a non-blood relative, lower still in the hierarchy despite her close relationship to Claire and does not mention aunts and uncles at all.

⁶The dropping out of use of the second person plural "ye" in British English means that "you've got to do" could equally refer to Claire and Colin as a couple or Claire alone

Nevertheless, it is notable that she states that “she offered her opinion” thus illustrating the processes of discussion and information sharing that served to underpin the parent’s decision. One possibility is that when parents seek opinion and information from other family members they may not be actively looking for help with the decision, or even searching for alternative viewpoints, but are attempting to share the load by seeking emotional support and verification of their choice as Claire describes:

Erm (1.0) so it's it err so I think I kind of then reaffirmed that we made the right decision with [R: yeah] the support group that we've got (*Claire, Mother of Craig*).

Claire’s use of “reaffirmed” suggests that Claire and Colin already believed that they were making the right decision. The parents firstly affirmed their decision with each other “we” and this then becomes reaffirmed by other family members “the support group” resulting in an increased confidence in the choice made. It is notable, that in accordance with Chloe’s description, Clodagh unites herself with the maternal grandmother, Clara, rather than her husband when describing their input.

Yes, yes she did, uhuh (R: yes ok) () but I think Claire and Colin (0.5) had come to that decision themselves (0.4) and I think all Clara and I did was sort of push it along [R: yeah] and say yes ah this is great. You know this is what we think (*Clodagh, paternal Grandmother of Craig*).

Claire’s mother Clara agreed that as grandmothers, she and the paternal grandmother Clodagh assisted the decision by supporting the choice in order to “push it along” and not by giving alternative viewpoints. This echoes the statement by PAED₂ above who “didn’t want to give them the opportunity of changing their minds”. This suggests that an important role for some grandparents may not be in helping make the decision but by helping to support the implementation of parental choices by providing practical and emotional support. Thus, parents may affirm the decision with each other and possibly in conjunction with the clinical team, then, as part of a distributed decision-making process, the hierarchy is expanded and grandparents sanction or reaffirm the decision. Craig’s paternal grandmother Clodagh’s view of the decision-making process concords with Clara’s:

Researcher:

Do you feel that you influenced their decision?

Clodagh	No
Researcher:	No? (0.5) not at all?
Clodagh:	Not at all
Researcher:	Not maybe even it just being by supporting their decision maybe?
Clodagh	Support their decision yes but I wouldn't, I don't influence them whatsoever I listen
Researcher:	Yeah
Clodagh:	to what they have to say
Researcher:	yeah
Clodagh	and when they've decided on what they're going to do () I'd go and agree with them
Researcher	Right
Clodagh	Because it's not my decision to make.

(Clodagh, paternal grandmother of Craig)

Despite attending medical consultations with Craig and his parents and offering listening and support, Clodagh does not view this participation as having an impact “I don't influence them whatsoever”. Clodagh positions herself as presenting neutral views “and when they've decided on what they're going to do () I'd go and agree with them”. Whereas Clodagh may claim that she does not influence the decision “no, not at all” Claire has already described how support from others could reduce the feelings of isolation around the decision and increase the confidence that the decision they are making is the correct one. It is also possible that Clodagh has not formed opinions of her own around the subject. However, given the fact that Clodagh has attended many of the medical consultations it is much more likely that she has reached her own

Well she talked to u- talked to her about it and we we we said look if it's gonna erm you know keep on going [R: yeah] and we said that maybe later on (0.2) he might (0.2) go back to eating, which he has (*Dick, grandfather of David*).

Unlike Craig's grandparents who acted to support the parents' decision, Dick and Denise's mother Doris actively presented their viewpoint "we said look if it's gonna erm you know keep on going". Dick relays their position as one in which they believed that the prolonged need for feeding support warranted a longer-term solution for David. Dick acts to allay any possibility of Denise interpreting the phrase long-term as permanency, by adding the proviso that "maybe later on (0.2) he might (0.2) go back to eating". Dick's final comment "which he has" illustrates that Dick sees the positive outcome of this decision as evidence that their advice, and the decision based on that advice, had proven to be sound. However, it is difficult to assess the rightness and wrongness of a decision once the decision outcomes are known and I will discuss this further in Chapter 11.

In the case of Elliott, Elaine's strong and persistent "no" to any suggestion of GT feeding acted to close exchanges with significant others who might otherwise have been involved in the decision-making process as Eddie explains:

Erm (1.2) I've () kinda () been put through everything. Elaine will make the decision on whatever he does and I'll kind of go along with it [R: right okay] she- she obviously (1.0) takes the lead on everything for Elliott [R: right] and I kind of get (0.2) not pushed aside but I kinda think 'go with the flow ()' she knows more about kids (laughs) than I do (*Eddie, Father of Elliott*).

Eddie's description that he has "kinda () been put through everything" does not suggest that Eddie views the decision-making process in a positive way. According to Eddie's account, it is Elaine who "makes a decision on whatever he does". Eddie is left with little choice but having to go along with it, something he positions as a natural state of affairs "she obviously takes the lead". Such a comment may have its roots in social discourse around "mother knows best" as indicated by his follow up remark "she knows more about kids (laughs) than I do". It could be that Eddie is trying to be tactful around the potentially delicate issue of seeming to go against his own wife in an interview. It is notable that he refuses a description of being "pushed aside" but instead offers himself

up as being an easy-going person, happy to adopt a position of passive acceptance “he goes with the flow”.

One concern that has arisen from this work, as presented in my earlier chapters, is that father’s viewpoints around the importance of oral feeding may differ significantly from the mother’s. However, the mother’s viewpoint appears to take precedence. One reason for this is the greater attendance at consultations by mothers who are frequently the main carer. Often, it is the mother’s viewpoint that is presented to healthcare professionals who may consider that position to be representative of both parents, especially if it is as unequivocally presented as it was by Elaine. There may be little opportunity for fathers to proffer their own views and it is important that healthcare professionals try and ensure that they make efforts to canvas father’s views whenever it is realistic to do so. The following extract illustrates how Eddie’s viewpoint around the GT differed significantly from Elaine’s:

So I would probably just discuss it with Elaine but she has said “well we will go for it now” [R: yeah] I think, I think I did say () like “enough is enough” it’s-it’s got to be, he can’t be expected to have that [NG] tube [R: oh right so] for the rest of his life” (*Eddie, father of Elliott*).

Eddie’s description is one where the decision he wanted as Elliot’s father has now been reached. However, the decision is still not described as a joint decision but is ascribed to Elaine’s change of heart “well we’ll go for it now”. Only then, does Eddie feel able to make a stand “enough is enough”. Eddie’s statement implies that now Elaine has reached the decision he wanted, it should stand “it’s got to be”. This again echoes some of the comments I have already reported in this chapter illustrating the desire by others that once the decision has been reached it should be implemented.

I cannot really put much emphasis on it because (o.2) we, I mean Elaine was kind of insisting (o.2) then () it was never gonna be a case of doing what () ourselves felt we and that kind of thing it was just a (), it was her decision that she didn’t want it because it was an operation and that was the end of it (...) No matter what you said, you could have come with a bag () full of money sort of thing d’know [R: yeah] “if I give you this will you do it” sort of thing but it was never, it was never, gonna be my decision until (1.0) erm it came to like obviously well it’s gone on far too long now and he needs it (*Eddie father of Elliott*).

Eddie talks about the pressure he was under as Elaine's partner. His suggestion that "Elaine was kind of insisting" implies a position where Elaine was never going to stand down. In this context, the word "ourselves" most likely refers to Eddie and other dissenting relatives. Elaine's reason for resisting GT "it was an operation" was firm and once her decision was made there was nothing that could be done to change it. Both discussion "that was the end of it" and bribery "a bag full of money" were futile. Despite Eddie arguing that it was "never gonna be my decision", legally he has equal rights in the decision-making process.

Elaine's unshakeable position was commented on by other close members of the family. For example, Elliot's brother Evan commented "You can't influence Elaine's decisions!" And similarly, Elaine's mother Ethel commented that "There is very little, i- if she's (0.5) decided something particularly about () the children [R: yeah] then it is her decision." However, whilst Elaine spearheaded the decision-making process this did not mean that family members did not hold opinions of their own. Elliott's brother, Evan explains here how he firstly constructed the decision as a preference sensitive one which was appropriate for Elaine to make.

I know I kinda left the decision () itself to Elaine but I've always maintained that I think that () either way is marginal [R: yeah, yeah] Erm so I thought it was more a question of (0.2) personal choice () at the start [R: right Ok] but then again I say that as someone who has got absolutely no idea [R: (laughs)] of (inaudible) I don't know what the pros and cons are of each (*Evan, brother of Elliott*).

Evan, as Elliott's adult brother has no legal rights to make medical decisions about Elliott. However, it is interesting to note that having excluded himself, Evan leaves the decision to Elaine alone rather than to both of his parents. Evan neatly summarises how this decision is a preference sensitive one "either way is marginal" and "a question of personal choice". However, it is important to note that he describes how he held this opinion "at the start". This suggests that whilst Evan initially accepted the decision to be preference sensitive and to belong only to Elaine he later starts to re-evaluate this. Evan works full time and had not attended any recent appointments with his brother and was not party to all the information given by the medical team. Evan positions himself as believing it is necessary to understand "the pros and cons of each" to participate fully in the decision-making. Without this direct knowledge, he plays down his reservations

about the correctness of the decision by making the admission that he is “someone who has got absolutely no idea”. In making this statement Evan supports Elaine’s right to make the decision, not because she is Elliott’s mother but because she has been party to a greater amount of information than Evan has.

10.5 Summary

In this Chapter, I have described how interactions between parents and others influence the ways a decision around GT placement is distributed across time and place between parents, their healthcare team and friends and family. I have described how the process must begin with GT placement being made available to parents as an option because parents cannot opt for something that has not been offered and may not always proactively request GT. Although the offer of a GT can be upsetting for some mothers, clinicians do need to ensure that both parents are aware that GT is an option and this may be a case of choosing when the time is right.

This research supports other findings suggesting a variety of preferences for involvement in SDM. I have demonstrated how negotiating both the preference for involvement and the GT decision itself can require subtle interactional work to maintain a successful working partnership.

Although making a decision around GT placement has often been portrayed as a single decision to “peg or not to peg” (Pennington, 2002) the decision may include more than one step with the decision being made to enterally feed first followed by insertion of a GT if this is successful. This has potential implications for research because sometimes the GT decision for parents may have been reported as straightforward but has excluded more complex decision-making processes made around enterally feeding via NGT.

Additionally, this is the first piece of research to explicitly address father’s participation in SDM around GT feeding. I conclude that some fathers would like to have a greater stake in the decision and the interactional space for them to lend their own voice to the decision may be missing in some encounters. Even where the interactional space exists, there is potentially some evidence to suggest that father’s views may not carry the same weight as mother’s in the decision-making process. Father’s opinion should be sought as part of information sharing whenever it is practical to do so.

This research lends strong support to concepts of decision-making as distributed across time and place (Rapley, 2008). When shared decision-making is the preferred option, this provision of space is important in terms of distributed decision-making because it allows the parents to assimilate the information that has been given as well as discussing the issues within the wider family circle. Key family roles included attending clinics to help retain information, debating risks and benefits, offering emotional support or reaffirming the decision. Family and friends do not seem to position their roles as one in which they directly participate or influence the decision anyway, however these may be strong decisional influences for parents which are missing from current GT decision-making literature.

In Chapter 11, I will conclude my analysis by engaging with some of the reflections made by the participants of my study regarding the quality of their decision after GT feeding had been implemented.

11.1 Introduction

In Chapter 6, on “Feeding as Care,” I began by defining the meaning of “care” and drawing on Fisher & Tronto (1990) to argue that feeding care is multifaceted and embedded in female duties and obligations. As discussed in my literature review, previous research has agreed that mothers have usually been highly satisfied with the outcome of GT placement (Brotherson et al., 1995; Guirriere et al., 2003; Morrow et al., 2008; Petersen et al., 2006; Spalding & McKeever, 1998). In this Chapter, I will go on to discuss how the burden of care around feeding and its management changed for the families in this study once a GT has been placed. I will then discuss how this affects post-hoc appraisal of the GT decision and impacts on parental relationships with themselves and others. Unique to this research I am also able to offer some short insights into the child’s point of view.

11.2 Rebirth and change

The following interview comments were made post-GT from Angela and Elaine, both mothers who had taken a strong stance against GT placement for several years:

Awwwww, it has it has taken; we are like (laughs) we are like born again (*Angela, mother of Adam*).

Yeah () it’s made a huge difference () it completely changed everything (*Elaine, mother of Elliott*).

Being “born again” is a biblical term typically accepted to mean a spiritual rebirth. In the same way that oral feeding is often described in military terms of conflict in battles, the terms used in my research for GT feeding have biblical overtones that tie in with previous research. For example, in Spalding and McKeever’s study (1998) most mothers felt considerable relief after the GT because the “godsend” and “blessing” (p 239) led to positive changes for the family. However, although mothers in their study reported initial satisfaction, this eventually gave way to growing concerns around feeding schedules which continued to dominate family life. For Elaine and Angela, the GT was a relatively new practice which provided a sharp contrast with the challenging nature of

their recent feeding experiences. This sense of a new beginning may not necessarily have been maintained in the long term.

The actual level of stress resulting from feeding difficulty was not always appreciated until after the GT had been placed:

Yes, I mean Mum has said that to me () as well, that she feels that it's taken away that whole stress of the nutrition side of of food, but I think, probably she didn't realise how stressful feeding was until () erm the acute illness when they had to really stop and [R: Yeah] and he was being fed and I suppose control's really been taken away from them at that point and then coming back and realising that it had been very all-consuming (*SALT1: speech therapist for Adam*).

SALT₁ described a situation in which oral feeding had become so dangerous that the parents had no choice, "control was taken away from them", and the daily stress of trying to maintain oral feeding was terminated. In SALT₁'s view, only now are the family in a position where they can actually pause and reflect on the "all-consuming" nature of trying to ensure adequate nutrition for their child. Angela offers a similar account:

It's it's highlighted that actually how precious the time is that we have with him which made the decision for GT even easier because if all of that time was gonna be spent stressin' (*Angela, mother of Adam*).

Angela's statement "how precious the time is that we have with him" is a reference to the uncertainty about Adam's potential lifespan and how the feeding burden therefore presented a disproportional use of time that could be otherwise spent improving quality of life not just for Adam but for the whole family.

Gary's GT feeds were instigated at the age of 18 months and had continued until Gary was 15 years old. This meant that, for Gail, this honeymoon period had long since passed. At the time of interview, Gary had been living GT-free for approximately 1 year after many years of GT feeding. Gail was asked to reflect on whether the GT had improved their quality of life.

Gail (1.0) It definitely improved the quality of () Gary's life

Researcher: Right, and yourself and your husband?

Gail: I don't know if it did.

(Gail, mother of Gary)

Gail briefly hesitated after the question has been posed. I had asked one question but the answer had two competing answers. In Gary's case, his quality of life had "definitely improved" but for the parents this outcome was far less certain. In addition, the passage of time may also have affected Gail's evaluation in two main ways. Firstly, as the GT had been placed some years before, it is possible that in a similar way to Spalding and McKeever's findings, and in contrast to Angela and Elaine's narrative, some of the initial relief that accompanied the liberation from oral or NGT feeding may have been forgotten thus muting Gail's response. Secondly, this family had now also benefited from experiencing the additional contrast of a new post-GT life which may have impacted on her reconstruction of events.

In the following extract of interview Gail explains how she reappraised her view of GT after the event:

It just was, again you just thought that it's just another () abnormal, you know [R: yeah] I took, I looked at it as a step back [R: right] and really it was a step forward because once the peg was in, he thrived! *(Gail, mother of Gary)*.

In accordance with other research around neurodisability (L. Pennington & Noble, 2010), Gail's statement highlights the point that the recommendation of a GT could be viewed by parents as an additional disability "it's just another abnormal" rather than a symptom of existing disabilities and therefore "a step back". It is only with the benefit of hindsight, that Gail is able to see that GT was something that allowed enablement and was therefore "a step forward" because the abandonment of the feeding struggle and the additional nourishment allowed him to thrive.

One of the main reasons why GT was well-received by many families was due to the reduction in emotional stress particularly around calorific intake.

And Angela does say now that it's a lot less stressful now that she doesn't have to think each day how she is going to get enough calories into him today (*PAED1: Paediatrician for Adam*).

I don't know, because I think it's it's (o.2) made a difference (o.2) to them and taken away the sort of (o.2) the sort of the stress and the worry (*HV1: Health Visitor for Adam*).

PAED1's use of the word "today" accentuated that this stress was one that began anew with the dawning of "each day" and was not indicative of a stress load that was gradually improving over time. It is interesting to note that PAED1 referred to the stress on Angela alone whereas the health visitor talked in terms of the stress on them as a couple. Angela's husband, Anthony, participates in sharing Adam's care, but as already discussed, confessed to passing the burden back to Angela when the stress became too much. It is possible that PAED1 is aware of this and therefore sees the ultimate responsibility "taking care of" (Fisher & Tronto, 1990) of getting enough calories in to be part of the mother's role. Alternatively, it could be that the paediatrician generally sees Adam in the clinical environment of the hospital with just his mother, whereas the health visitor visits the family home where Angela and Anthony are perhaps more likely to present as a couple sharing the feeding burden.

11.3 Having the "other" conversation

Elliot's family had been purposefully selected for this study because of Elaine's strong stance in resisting GT. However, during the study, the decision not to have a GT placed changed. This meant that I was fortunate enough to be able to visit family members individually before the decision was made, and then secondly as a group following GT placement. It was interesting to note retrospectively how family members used the new knowledge gathered by their experience of living with GT to reappraise their initial decision in the light of new knowledge. Before the surgery the risks are unknown, and as I have described, this is a strong factor leading to decisional reluctance. Once the decision has been made, if things go wrong during surgery, or the outcomes are not positive there is no going back. The outcomes of the eventual GT placement were extremely good in Elliott's case. However, this successful outcome does not provide irrefutable evidence that breaking the status quo was the wisest option as Evan explains:

You could you could easily be having the other conversation where you're like
"oh I wish I had never done it it's infected all the time it's a right nightmare"
(*Evan, brother of Elliott*).

Evan points out how this highly successful outcome for Elliott could lead to bias in the evaluation of their decision. Negative outcomes such as infection could have occurred and this may have resulted in decisional regret "I wish I had never done it" leading to the family making this more negative appraisal "the other conversation".

From a study design point of view, it was interesting to note that retrospectively family members may use the new knowledge gathered by their experience of living with GT to reconstruct their memories of those factors that led to the decision in a way that made their original arguments seem more reasonable. For example, as I have discussed in Chapter 6, one strongly cited negative aspect of NG feeding was the risk of the NGT being dislodged or pulled out. This extract illustrates how the pro and anti-GT family members construct their memories around such events:

Eddie:	But even the nose tube you can get that pulled out we had that pulled out a number of times, it got pulled out at nursery
Evan	Yes, I remember that time
Elaine	Once, it happened once
Evan:	I remember it coming out
Elaine	Yeah, because some other child had pulled it out his nose

(Post GT group interview with Elliot's family)

In Eddie's reconstruction of events, the NGT was pulled out several times. By reconstructing his memories of the NGT as being a negative entity, Eddie is able to contrast the "then" of the troublesome NGT with the "now" of the less problematic GT tube. Evan and Elaine do not dispute that the NGT was pulled out but are united in constructing this as one single occasion "I remember that time" and "once, it happened

once". Elaine and Evan's constructions were therefore of a secure NGT that was pulled out on a single occasion by a factor outside of their control "some other child". Moving on to GT feeding had therefore been less justifiable.

11.4 A different workload

As discussed in Chapter 2, placement of GT has undoubtedly reduced certain aspects of the burden of feeding care particularly in relation to the time taken to orally feed. Although NGT feeding can also theoretically reduce time demands, I outlined in Chapter 6 how NGT placement was generally viewed by families to be a distressing procedure with which mothers, children and observers struggled to cope with both their own and their child's emotional reactions. Mothers indicated some resentment at the way in which their role as mother was subsumed by their role as the only person willing to insert the NGT. In prior research, one reason why parents found certain procedures such as passing NGTs particularly distressing was because of the need to restrain their child (Spiers & Beresford, 2017). As the GT does not need regular replacement and attaching feeds to the abdominal port is very straight forward, restraint is not required. No reference was made by these participants regarding distress caused by the GT beyond the time when the child had recovered from the soreness of the initial operation. The GT allows parents to revert to a role of comforter once again instead of being the agent of an unpleasant procedure. GT feeding was therefore generally warmly welcomed in this and other research.

However, in contrast to these positive aspects it is important to note that children with the GT in-situ could now be viewed as being technology-dependent. Previous research has noted that caring for a technology-dependent child can be socially isolating for parents as well as being associated with sleep deprivation and negative emotional responses such as anger and depression (Townesley & Robinson, 1999). For the parents in this study, the decrease in the burden of feeding that resulted from the introduction of GT feeding needed to be balanced against the other issues that can arise. The downsides as reported by my sample divided into three main themes of physical restriction, dependence on medical technology and dealing with clean and dirty spaces.

11.4.1.1 Physical restriction

This is the first research study around GT feeding in children with neurodisability to have included the viewpoints of the recipient children. Two children (Gary aged 16, and Elliott aged 5) were included from my sample of families - other children did not have sufficient verbal skills to participate. Gary and Elliott had fresh insights to offer which indicate that GT feeding brings additional burdens that the child themselves must bear. Gary did not view the impact of the GT feeds on his own well-being in the same positive light as his mother and described how severe boredom would set in during feeds:

Pss oh tsk Yeah I did erm tsk I I used to turn my feed off when I () when I when I wasn't supposed to if I was full (laughs) [R: right (laughs)] I used to tur ah , I used to turn it off so () because I (sniff sniff sniff) I couldn't go out (gulps) I couldn't go out and play I had t' I sat, I sat there for hours and [R: Right, okay] yeah, so 3 hours I had to sit there for [R: oh that's very long] and nothing [R: yeah] I had nothing. All I had to do was watch TV and and all I, all I had to do was stay in the 'ouse and that and I I couldn't go out and play at all [R: right, so very boring then] I was on my feed for three hours 'n' I used to take it off and then () Mum used to come in and tell us off because [R: laughs] like because I hadn't had enough to eat [R: Yeah] I hadn't (o.2) had I, hadn't had enough to eat and (o.5) but I'm glad I've got it out now [R: yeah] I'm glad it's out (*Gary, aged 16*).

The above statement, punctuated with sniffs and gulps required a great deal of effort by Gary. Nevertheless, he succeeded in producing an impassioned description of the reality of living on a day to day basis with prolonged GT feeds. For Gary, being a “care-receiver” (Fisher & Tronto, 1990) via GT feeding was a trial of patience involving sitting still for hours with little to do but watch television. This also restricted Gary's participation in normal activities such as being able to go out and play outside. Given that Gary has two brothers and many friends it is likely that this was not just a physical impediment for Gary but also diminished his social opportunities.

The frustration that Gary felt comes across clearly in his account. Gary's way of dealing with this was to seize back control over his feeding by turning off the pump. What is also remarkable here, as an additional element of physical control, is that Gary only did this if he felt “full,” yet he describes his mother as telling him off because “he hadn't had enough to eat”. The question of who decides when a child has had enough to eat is an

interesting one. The amount of feed that is to be given is prescribed by the dietician and would have had to be measured out accordingly by Gary's carer. In medical terms, Gary would only have been considered to have had "enough to eat" when the prescribed dose of food had been artificially administered. However, a body of research is emerging that indicates that many GT-fed children with neurodisability receive more calories than they require, and that obesity is a risk which may further diminish quality of life for the whole family (Kuperminc et al., 2013; Kuperminc & Stevenson, 2008; P. Sullivan, 2013). It is therefore possible that the medicalisation of feeding in this way conflicted with Gary's natural ability to control his own appetite. In seizing control of food intake by turning off the pump, Gary regained control of both his lifestyle and his appetite.

In the following extract, Gary continued describing his relief when GT feeding ceased:

I'm glad it's out (...) cos I, I I can do a lot more now (R: yeah) I, I can go out and play I can (0.2) do whatever (R: yeah) do whatever I do, so! (*Gary, 16 year old child*).

Gary seems slightly at a loss to describe the gains he has made since losing the GT tube and I would argue that it is the very ordinariness of his gains in participation that are so striking. Gary describes everyday activities which other children might take for granted; he can "go out" he can "play" and can do "a lot more now". For Gary, it is normalisation that brings relief that the tube is out allowing him to do "whatever".

11.4.1.2 Dependence on medical technology

The Office of Technology Assessment (OTA) in the USA broadly defined the technology-dependent child as "one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability" (1987, p3). I believe that in most cases, GT feeding for children with a neurodisability meet these criteria. The little research that has been done in the UK investigating parents' experience of caring for a technology-dependent child has highlighted the social impact on the family, most notably the interruption of family life by the medicalisation of the home routine (Kirk, 1998; Kirk et al., 2005). One study evaluating models of care (in this case for children needing care for a variety of reasons) focused on parents' psychological experience of caring for their ill child at home (Spiers et al., 2011). Although children needed homecare for many reasons, including palliative

care, in line with my study care tasks did include NGT and GT care as well as administering complex regimens of medicine. Although their findings showed an overall preference for having this care at home there were both positive and negative responses to the level of responsibility and it did not suit all families.

One particular issue with technology-dependent children is the need to be vigilant overnight leaving parents subject to exhaustion with low coping scores (Kirk, 1998). Although GT feeds can be given as boluses with a syringe, to reduce discomfort and reflux they are usually administered slowly via an electrical pump device. Gary described how dependence on a feeding pump impacted negatively on his Dad's quality of life (in this case his father was the main carer) by interrupting his sleep pattern:

Yeah (Grunts) (2.0) a a tsk well it mostly depended on me Dad as well like he had to wake up at 6 o'clock every morning to start my feed [R: right, God, that's horrible] he would wake up to switch it on then it would go off [R: right] so that I could have it in time for, in time for school (*Gary, aged 16*).

Gary's description was one where the normal routine of family life was disrupted to accommodate the requirements of the medicalised regimen. It is the medical equipment itself and the organisation of the school timetable rather than the child that demanded this early morning attention. Gary was asleep at 6am and being fed was not an immediate requirement for him.

This dependence on medical equipment could also make the home feel like a hospital as Gail described:

But it was still another thing that you're adding on, it was another () piece of machinery [R: yeah, yeah] you know, because he re-he was on () obviously he had the oxygen () and we would check his () saturation levels. We did suction, we had a suction machine [R: right] and now this feeding machine as well [R: yeah] so I don't know that it made our life easier (*Gail, Mother of Gary*).

Gail's description of the GT feeding equipment as "another piece of machinery" depicts a lifestyle already dominated by medical equipment. Although feeding was more straightforward, the family paid the cost for this in terms of an increasingly technical lifestyle which did not feel to them to be any easier than the other methods of feeding. For some families in the study, the GT feed is the only technical device required. For

other families, such as Gary's, the "adding on" of GT feeding further compounded a lifestyle that was already dependent on medical technology.

Gail: Our front room was, you know (both laugh)

Researcher: I can picture this

Gail: I've got a picture somewhere actually of our front room with just machinery and this little () tot in the middle of it all (laughs)[R: aww (laughs)]: but oh, oh gosh so yes I mean obviously he he, you know, he was, because his stomach had been tightened up as well and the PEG and he wasn't vomiting so in that respect [R: Yeah]: but then he tended to bring up, he still vomited because he had problems with his chest [R: right okay] () so I did see it as another piece of machinery (o.2) something else to

(Gail, Mother of Gary)

Gail's portrayal of her front room is one dominated by machinery surrounding a vomiting, chesty toddler. The room, more akin to a hospital ward, has been "transformed" by the technology (Kirk et al., 2005) and is no longer a place where relaxation is possible. Although the participants in this study did not talk in terms of the physical intrusion of this space by medical personnel which has been highlighted in other studies, there remained a sense of being judged by others within their own home. My findings support other research indicating some parents felt inadequately prepared to perform technology procedures (Kirk, 1998):

I think though I wasn't too sure on how to work the pump [R: right yeah] erm I was shown I think the day after he had the operation, and it still didn't sink in
(Denise, mother of David).

The operation itself is naturally a very stressful time for parents. Denise implies that she lacks confidence in the pump because the stressful situation in which she was taught

something that can necessarily be taught in one go, but can only derive through supported experience over time.

11.4.1.3 Dealing with clean and dirty spaces.

In the previous section Denise explained how “milk's not really a nice thing to [R: no] smell, or clean up”. This is an interesting concept because except for those that avoid milk for ethical reasons, for example, it is generally seen as a pleasant food. Seemingly, Denise views milk as a substance that is transformed by entering the body. For example, here Denise describes the distress she encounters when the GT button is accidentally pulled out:

Erm and once we got it settled down, I think, it might be three or four months after that they changed it to the button. And then we had it one day, he was in the hospital one day getting the button, and then the next day, it came out at nursery. So it was just milk coming out of everywhere, and then oh it was awful, so I got, I changed it back to the PEG and it just got, everybody got a fright, I got a fright I went up to nursery and there was three of them around David and there was milk coming out cause he'd just been on his feed and, there was a hole in his tummy and it was just, ah it was awful, and they were trying to put it back in, so that they didn't have to go down- we didn't have to go down the tertiary hospital but we couldn't get it back in and it closed up and ah it was awful (*Denise, mother of David*).

The pulling out of the GT button is an unusual event. As this event happened the day after the button was placed it is possible that there was a flaw in the fitting of the button. However, this single negative experience is sufficiently frightening to ensure that Denise does not risk any possibility of a repeat. Denise's statement that “everybody got a fright, I got a fright” shows that this is an anxious time for everyone not just Denise. Whilst society permits clean foodstuffs to enter the body, it is far less acceptable for foods to resurface. Vomit for example could be indicative of disease and is therefore a dirty substance (Douglas, 1966). The milk may be freshly ingested, but pouring back out immediately from the stoma is an unwelcome sight, “it was awful”. This chimes with other work around body leakage. In her work around hospice admission Lawton (1998), demonstrates that it is social intolerance to “ad-hoc” leakage from an “unbounded” body that is a major trigger for hospice admission for symptoms. Although it is perfectly

possible to replace David's tube with another button device, Denise opts to go back to the familiar peg tube which cannot be pulled out to avoid repetition of these events.

Children who depend on GT tube-feedings are also at significantly increased risk of poor oral health, particularly a build-up of tartar and subsequent gingivitis (Jawadi, Casamassimo, Griffen, Enrile, & Marcone, 2004). A concern around oral hygiene arose during an interview with a speech and language therapist which has not, to the best of my knowledge, been raised before as a GT decision-making topic, nor was it mentioned by anyone during the longitudinal arm of this study. This is not surprising because medical and dental services are usually kept quite separate and dentists are not included in the TAFs or consultations in feeding clinics. Although oral care is not strictly speaking an additional burden that arises from GT feeding, as SALT₂ pointed out, it is a burden that some families, if oral feeding does not continue, might consider to be dispensable. SALT₂ therefore argued the case that oral care should be maintained both to maintain hygiene of the mucosa and to keep the child familiar with tooth-brushing to prevent sensory defensiveness. In the following extract, she describes a scenario that occurred when oral health was not adequately maintained:

I remember seeing a child, there had been (0.2) an older, a a sort of teenager, boy [R: yeah yeah] who was fully GT fed, and was very little, had a few sips of things and food swipes by mouth but nothing much more than that and he came to me with, completely nil by mouth (0.2) and (0.5) I was concerned because I saw something dislodged in his mouth and it was an actual a big piece of plaque [R: eugh (laughs) god] and he was, and fortunate- he was lying down, and he was in a lying down position, and I thought () if that had actually got dislodged and stuck, he could have seriously choked on that (*SALT₂, Speech Therapist for David*).

I react to this narrative with distaste “eugh (laugh) God” but SALT₂'s point is not about unpleasantness. Given that children with poor swallowing are at risk of aspiration, indeed this may be the most compelling reason for a child to have a GT in the first place, it is ironic that poor oral hygiene emerging from this decision could lead to the very scenario that the GT is there to prevent. It is clearly important that the burden of oral care remains as a task, irrespective of feeding method, and this information should therefore form a key part of family education.

In the above section, I have shown that although GT feeding is very positively received as a technology that reduces the burden of caregiving tasks on families, notably mothers in this study and in research worldwide, it is not entirely burden free. In the following section, I will talk about the effect of GT placement on relationships.

11.5 The Make and Break of Relationships

11.5.1 *Maintaining solidarity with partners*

In the previous chapters, I have described how both the burden of oral and NGT feeding can have negative impacts on relationships. Even though GT feeding significantly reduces caregiver burden, some pressure on relationships remain. In the following extract, Claire reflects on a new source of stress that arises from the GT and how this impacts on her relationships with others:

We're having to unkink it and it's erm, doing the push and turn () that's quite stressful, cause I'm the only one who'll do that [R: right] and I ask people to sit with us while I do it and I can tell they're stressed just watching us do it [R: oh] erm but nobody else will learn to do it which is fine cause it's not their child (Claire, mother of Craig).

In a strikingly similar way to the insertion of NGTs becoming absorbed into the maternal role, the caregiver burden of “doing the push and turn” a technique used to ensure patency of the stoma, also defaults to the mother Claire. However, observers still participate in the emotional “caring about” work of the task, “they’re stressed just watching us do it”. Despite her feelings of stress, Claire positions herself as fully accepting that other “people” do not bear responsibility for the physical aspects of this task because “it’s not their child”. However, this justification does not apply to Craig’s father Colin:

Claire: but not even me husband will learn how to do the push and turn [R: yeah] erm (0.2) he can't cope with it [R: no] he can't cope with having to do that

Researcher: and d- d'you d'you accept that he can't cope, or d'you think he's copping out?

Claire: ah I think he's coping out, erm

(Claire, mother of Craig)

Claire's comment "not even me husband" suggests that although there is no expectation that others should participate, Craig's father ought to. Although Claire initially implies that Colin is not willing to learn, after a pause she then moderates this to a more empathetic "can't cope". However, by accepting my term "copping out" Claire acknowledges the possibility that Colin could once more be avoiding a feeding-related task. Maintaining solidarity under such circumstances could create a further burden of additional relationship work. Claire avoids this additional stress by shifting focus onto the other issues that also need the couple's attention:

I could let it cause friction but there's so many other things that we need to get sorted [R: yeah] I just [R: just accept it] yes *(Claire, mother of Craig)*.

In contrast to Claire, other families talked about the reduction in relationship stress which occurred as a result of GT placement:

And (o.4) the biggest thing is that we don't have that stress, I can't remember the last time Anthony and I had an argument *(Angela, mother of Adam)*.

Angela directly linked the stress of oral feeding to marital tension. Removing this stress was of major importance "the biggest thing" because it enabled the formation or restoration of a more harmonious relationship between the couple. Whereas the stress of oral feeding was talked about in terms of the need to survive one day at a time, the newly relaxed circumstances are talked about in more constant terms "I can't remember the last time".

In the above section, I have discussed some of the issues that can impact on relationships following GT placement. I will now expand this discussion by talking about the effects of GT placement on relationships with the clinical team.

11.5.2 *Maintaining solidarity with the clinical team.*

Research around caring for technology-dependent children at home has raised difficulties regarding the fragmentation of services and the competency of support staff

(Kirk, 1998; Kirk et al., 2005). Professional relationships can suffer because of these concerns as PAED₁ explains:

It's not been without its difficulties and that's why they've fallen out with the dietician, I think, because trying to get the dietician to understand that he didn't need as many calories as she was prescribing for him ... It's its cruel actually, so we might have to accept that he can't that we can't deliver his micronutrients (*PAED₁, Paediatrician for Adam*).

PAED₁ describes the family as “trying to get the dietician to understand” thus attributing the family “falling out” with the dietician to a specific communication failure around Adam’s calorific requirements. I have talked extensively about sharing information around feeding in the chapters leading up to the GT decision. It is therefore of interest to find that these interactional difficulties can continue after GT placement. From the parents’ position, the dietician is seemingly not prepared to reduce the number of calories prescribed resulting in Adam becoming overweight. However, the dietician’s position is one where, as the responsible professional, she needs to “take care of” Adam by providing a balanced diet which ensures that Adam receives all the essential nutrients required for optimum growth and development. The paediatricians comment “it’s cruel actually” most likely refers to the possibility that Adam’s development could be further damaged by inadequate micronutrient intake because proprietary feeds are balanced for children with more typical levels of energy expenditure (Kuperminc et al., 2013; Kuperminc & Stevenson, 2008). By saying “we might have to accept” suggests that to keep Adam’s weight down to manageable levels, compromise by the team may be needed regarding the supply of other micronutrients.

Caring for a child with a neurodisability can be very demanding. Solving feeding concerns may mean that for the clinicians the burden of feeding may simply shift to other matters as SALT₂ describes:

And I think the focus has gone from very much telling me all about all the grief about the feeding to, ‘hey we can do this with his communication’ and now becoming very demanding about his communication, which is quite right [R: yeah] because he has got quite a lot of communication needs but being able to refocus on other areas of his development maybe [R: yeah, yeah] because we’re not as anxious and as (0.2) you know t- times being taken up with all the feeding

side of things, and I'm not having to spend an awful lot more time s- talking about the feeding (*SALT2, speech therapist for David*).

SALT2 suggests that once the GT is in-situ, and the feeding catered for, the parental focus shifts to being “very demanding about his communication”. This shift in focus is something that SALT2 postulates to be a good thing to have emerged from the reduced feeding burden.

In the above section, conflicts around the care of a child with a neurodisability and feeding impairment can remain after a GT has been placed. The following section will address the major finding in this research around the provision of respite care following GT placement.

11.6 Obtaining Respite

As I discussed in Chapter 6, the intensity of caring for children with additional needs such as feeding difficulties can be unrelenting. This can result in parents having very little time to themselves and inadequate rest can leave them subject to physical and emotional exhaustion (Whiting, 2013). Respite, particularly for mothers, could be virtually impossible to obtain, especially if the child was fed by NGT.

For the families in this study, sharing the burden of feeding and obtaining respite were far easier to achieve with the GT in place. This contrasts with previous findings which have shown that respite care for GT fed children may be limited or difficult to access (S. W. Smith et al., 1999; Thorne, Radford, et al., 1997). Brotherson et al. (1995) found that more than half of families in their sample lost practical support from friends and family once GT feeding commenced.

I suggest that one potential reason my study differs so significantly from previous work may be because the previous studies took place in the 1990s prior to the numerous technical advances which have made the use of highly sophisticated technology in the home far more commonplace. It is likely that in contemporary times, most people are familiar with digitalised devices that boot up and bleep and this has considerably reduced the fear around the unknown. In addition, my research raises the possibility that the willingness of friends and family to provide respite may be hampered by the presence of tubes that suspend from the child's body in the same way as NGT feeding.

In some of the early studies the original peg tube may still have been in place because changing to the more discreet button device was not yet common practice.

It was uncomfortable for him I'd imagine and I was always on edge especially when I was looking after him I'd just 'cos I was always worried about () catching it [Eddie: catching it aye] getting it caught on something or (coughs) him pulling it out (*Evan, brother of Elliott*).

Evan describes an uncomfortable level of anxiety when babysitting. The fear derives from the risk that the dangly tube is at risk of being caught and/or pulled out. Similarly, Claire also described how “the grandparents and people” were worried about dealing with the tubing and her solution to this was to request that the PEG tubing is changed to a button. However, this does not mean it was a straightforward decision for Claire because there is now a second surgical judgement to make with the same associated anaesthetic and infection risks that complicated the original decision.

Once a button is in place, established GT feeding allows the burden of care to be more easily shared by those willing to participate. In stark contrast to NGT feeding, all of the partners participated in giving feeds via GT as well as a great number of friends and grandparents. Here, Angela explains how this improved their lives:

Erm and so Anthony and I aren't as stressed with each other and our evenings it was sometimes ten or eleven o'clock before we could settle down and I have a set routine now and other people can feed him [R: yeah] erm me sisters are askin' to learn how to use the pump so that they can do it and Anthony's mum having being a nurse is quite au fait with it and obviously when he goes to school there's not that anxiety about teachin' people how to do it (o.2) because they know how to do it and and when we go out it's so portable and we just pack up his little bag and off we go and we sit and have a coffee whilst he's hooked up and the er and far from detracting from his quality of life it has enhanced his quality of life, if not just because we're less stressed (*Angela, mother of Adam*).

Angela's use of the term “set routine” implies that prior to the GT, attempts to orally feed were variable and this dominated the day's structure. Having a set routine allows the couple the precious downtime which was missing from their relationship before. However, the set routine was not the only benefit. With the GT in place, additional

respite by a network of family members could be provided and there were improved possibilities for Adam to participate in society by attending school for example.

Previous research has generally compared oral feeding directly with GT feeding. However, no family in this study, and possibly some of the other studies as well, moved directly from oral feeding to GT feeding without an extended period of NGT feeding first. As discussed in Chapter 6, NGT re-insertion most often fell to the mother leaving families unable to provide respite:

I think I was at the time because erm 'cos he was pulling it out [R3: Yeah] and it was harder () for other people to look after them (yeah) and it was quite stressful I think and quite pressurised for other people [R3: Right] to look after him (*Claire, mother of Craig*).

As GT tubes are far less likely to be pulled out than NGTs, it is now easier for Claire to be absent as her NGT expertise is no longer vital. Claire's best friend Chloe highlighted this difference:

Erm in the beginning I was very () nervous about doing it R: yeah, yeah] and it () just because you don't you wanna make sure you're not doing anything wrong (), cause they used to do syringes when he had the tube () down [R: yes] into his stomach and that was probably, I felt more () uncomfortable doing that () than I do I felt more comfortable doing the automatic feed through the PEG. er because I know it's secured in [R: yes] and I, and I know that it's going straight into his stomach [R: yeah] and it's not having to go down through his erm () his nose [R: yeah] and in to his stomach that way, so I do feel more comfortable, doing it with the PEG (*Chloe, best friend of Craig's mother*).

Chloe's narrative describes her anxiety when she first starts helping with GT feeding. The anxiety does not seem to be due to the GT feeding per se but is an extension of her previous discomfort when attempting to assist with NGT feeding. The nose is an organ typically used for breathing and not for eating. The fear that any dislodgement of the tube could mean food going into the lungs instead of the stomach is reasonable. The GT gives peace of mind that food is being delivered "into the stomach." The choice of the word "comfortable" implies a state of calm around GT feeding that is simply not attainable when NGT feeding.

The provision of respite is not just about giving the mother a break from the burden of feeding, but was also essential for protection of the family's finances as Claire points out:

It's going to be easier for everybody cos obviously I've got a job and you know we're not in the fortunate position where I can take it or leave it, I have to work to pay the mortgage and bills and I think that acceptance then helped me accept it (*Claire, mother of Craig*).

Having a GT in place does not just relieve the personal burden on the family which Claire describes above, but also on the wider society. With the GT in place, Claire can take up her position in the workforce. This is an important factor to consider when balancing out the cost of GT insertion on state finances.

In the above section, I have discussed the impact GT feeding respite; I will now move on to consider more about how the decision can be appraised from the child's point of view.

11.7 Having a decision made about me without me

During her interview, Gail remarked that the GT was another thing "being done to him", a point which emphasised Gary's passive position in this decision. Creating conditions where a child is forced to eat either orally or by placing a NGT could be viewed by some as interfering with the child's autonomy by removing their right to refuse. This goes against the discourse of sensitive parenting. Conversely, denying the child the opportunity to receive adequate food and hydration also conflicts with concepts of sensitive parenting, as well as wider concepts of human rights. Parents are therefore left in the position where either choice may be seen to be insensitive and parents could be subjected to criticism. It is hardly surprising, therefore, that as I discussed in Chapter 10, parents may frame their responses in terms of there being little alternative by using phrases such as "something had to be done" or "no choice" as these disclaimers act to pre-emptively ward off any accusations that a poor option had been taken.

Gary was too young to partake in the decision to place a GT in infancy so was asked whether he agreed with the initial decision to have it placed:

(2.0) No no not really but () it had to be (sniffs) I, I couldn't eat at all then I< I, I couldn't, I couldn't [R: no] I wouldn't even touch a single bit () of food [R: no, ok] at the time so I, I couldn't even drink, I couldn't even drink either (*Gary, aged 16*).

On the face of it, Gary regretted the fact that he had had a GT and did not agree with his parents' decision to have it placed. However, Gary's comment that "it had to be" draws on the same resigned narrative as Gail's "no choice". Rather than apportion decision blame to the decision makers (his parents) Gary attributes some of the culpability to his infant self. Although Gary begins to say that he couldn't touch food he repairs this to "I wouldn't even touch a single bit of food" suggesting an element of psychological refusal rather than physical inability per se. However, Gary cannot remember these events and his narrative therefore draws on explanations given by his parents, Gail had previously suggested that some of Gary's feeding issues could have been tied to psychological causes. However, Gary's follow up comment that he "couldn't even drink" suggests that Gary may consider that his difficulties around eating and drinking were not within his control.

Although Gary was too young to participate in the decision to commence GT feeding during infancy he was part of the decision-making to have it removed at 14 years of age:

I was finding the right chance to get it out but it was finding the right time to say 'right () mam I want me (o.2) I want me tube out' [R: right] ... Yes it was it was my decision at, I just (gulps) I just I, I lay here one Tsk one night and I said 'right Mam that's it, take my tube out, take me peg out' and that was it (o.5) (*Gary, aged 16*).

Gary appears to have found the subject of GT removal a difficult subject to broach "I was finding the right chance" and seemed to have been planning this for some time. Gary's request to his mother "right mam that's it take my tube out" suggests that Gary either took the lead, or views himself as having taken the lead in this decision. His concluding comment "that was it" could refer to an immediate agreement around GT tube removal being made, but could also refer to the ease with which Gary was able to express his concern after a long period of waiting for the right moment to express his hopes. To explore Gary's position further, as part of this interview, Gary was offered the chance to consider what advice he would give to others in the same situation:

Researcher: if somebody else was erm making the decision to have it, would you encourage them though? Say if they were like you?

Gary: No!

Researcher: Wouldn't you?

Gary: No!

Researcher: Even if they were (o.2), say if er somebody had a baby and they were very sick like you?

Gary: Ah, then I would.

(Gary, aged 16)

Gary's initial unmitigated response of "no" suggests a clear refusal on his part to support a pro-GT choice. It is only when I explore this further by comparing the imaginary sick baby to the infant Gary "like you" that he concedes that he would agree to a GT given the same situation. Although Gary earlier indicated regret at his parent's choice to give him a GT tube, he nevertheless concedes that in some cases it is the only acceptable solution because no choice exists.

Although Elliott was also too young to be part of the decision-making process at the time, I was also able to interview him post-GT. At interview, he described his own recollection of the NGT:

Researcher: How did it feel?

Elliott: Hard

Researcher: It felt hard?

Elliott: The tape around it.

Researcher: The tape around it? Did it stick t'ya face' did it?

Elliott: Yeah

Researcher: Did it hurt?

Elliott: Yeah.

(Elliott aged 5)

Elliott was only five years old at the time of this interview and nearly two years had passed since the GT tube was placed. By this time, he was eating well orally and looking forward to the GT being removed. Elliott recalled the tape that secured the NGT as being

“hard”. As a GT tube is held in with an inflatable balloon and not by adhesive tape, it seems probable that Elliott retains an accurate memory of the NGT and has not simply transferred what he knows about GTs to his nose. As he remembers after two years, it could be that the NGT had become problematic for Elliott and that a critical decision-making point had been reached even though Elliott was too young to voice that at that time.

11.8 Summary

In this chapter, I have discussed some of the factors involved in appraising the decision around GT placement once it is in-situ. Given the burden of care involved in feeding a disabled child with a feeding difficulty, whether orally or by NGT, which I described in Chapter 6, it is not surprising to find that my research also generally supports the very high degree of GT-related satisfaction reported in other studies.

The GT decreased feeding stress in many ways. Not only were there substantial time savings but there was less anxiety about calorific intake and medication administration. A great deal of pleasure was taken in the fact that the children now thrived. Freedom from these concerns allowed parents to build routine into their daily activities where previously none had been possible and focus on spending quality time such as on the couple’s relationships and other aspects of the child’s development such as communication skills.

However, my research also suggests that this highly positive response is more complex and nuanced than prior work has previously suggested. Whereas GT feeding undoubtedly relieves some of the burdens of care associated with oral or NGT feeding, these benefits of GT feeding did not come without costs. These included the home becoming medicalised, with the imposition of new, potentially abnormal, routines and equipment.

GT feeding also placed considerable restrictions on the child’s physical movements and opportunities for societal participation as well as interfering with the child’s natural appetite control resulting in the risk of children becoming overweight.

Parents lacked confidence at the initiation of GT feeding and may need more clinical support until the child’s routine and food prescriptions becomes tailored to his

nutritional needs and levels of physical activity. Hygiene issues around stoma and dental care were also reported.

Despite these problems the placement of the GT opened up much greater opportunities for task sharing and maternal respite allowing mothers to be “born again”. These findings conflict with earlier research, where GT provision had a seemingly negative effect on the likelihood of obtaining respite. I have postulated that this may reflect a strong social and cultural shift in familiarity with smart technology. Potential respite workers talked about the reduced levels of anxiety that they felt around GT feeding compared to NGT feeding.

Although the parents appreciated the GT once it was in-situ, in contrast to other research there was no suggestion that parents wished they had done it earlier. The two children in the study demonstrated clearly that they held their own views about the decisions made on their behalf. This is an area of research which needs further investigation.

In the concluding chapter which now follows, I discuss my research findings and highlight the contribution my thesis has made to the knowledge of decision-making around GT placement for children with neurodisabilities. I discuss the implications of my findings in relation to clinical practice and further research. I also consider the limitations of my study and suggest further directions for research.

12.1 Thesis overview

In the opening chapters of this thesis, I described how dysphagia and other disorders of feeding are disproportionately represented in children with neurodisabilities most notably cerebral palsy (Bahr & Johanson, 2013; Brackett et al., 2006; Delaney & Arvedson, 2008; Kerwin, 1999; Lefton-Greif, 2008; Manikam & Perman, 2000; Reilly et al., 1996). I discussed how feeding difficulty can have serious implications for a child's health in terms of health, growth and development and societal participation (Kuperminc & Stevenson, 2008). I then explained that children who are unable to maintain an adequate nutritional and hydration status in a safe manner may be offered a GT to replace or augment oral or NGT feeding.

I outlined the critical problem of how prior research examining the risks and benefits of GT feeding has been inconclusive. Although some studies have reported improvements in weight and perceived health (Craig et al., 2006; P. Sullivan et al., 2005), four systematic reviews around GT feeding versus oral feeding in children with CP have not succeeded in confirming additional clinical benefits of GT, such as growth and reduced aspirational risk (Ferluga et al., 2014; Gantasala et al., 2013; Samson-Fang et al., 2003; Sleigh & Brocklehurst, 2004). Even less is known about children with neurodisabilities other than CP. This does not mean that benefits around GT feeding do not exist, but rather that studies may have been unable to measure all relevant outcomes. Knowledge has also been hindered by difficulties in conducting clinical trials due to ethical issues around the continuation of oral feeding in children who are already known to be underweight or have an unsafe swallow. Guidelines around GT placement are thus underdeveloped and this is one reason for a significant discrepancy in the use and timing of placement of GTs globally (Alsaggaf et al., 2013; Avitsland et al., 2006; Dahlseng et al., 2012a; Kvello et al., 2016; Wiernicka et al., 2012; Wu et al., 2013).

The impetus for this research emerged from a systematic review around what is known regarding decision-making around GT placement in children with neurodisabilities. This review revealed two important factors about previous research. Firstly, virtually all prior work around the topic of decision-making in GT placement has focused on the mother's experiences. The opinions of fathers and other significant members of the

family circle, including the child, have either been neglected entirely or implicitly presumed to be the same as mothers. The resulting findings have then been merged in the literature and incorrectly labelled as a parental rather than maternal perspective. One major aim of my research has been to address that gap.

Secondly, I noted that all prior research around GT decision-making in children with neurological disabilities had been retrospective in nature. Some of this research had been carried out many years after the event and a real-time study had never been conducted. Therefore, a second aim of my research was to extend previous work by examining the complexities of the decision-making process as it unfolds.

The outcomes of the prior research with mothers has indicated that some find the idea of GT insertion to be distressing and can be resistant to its placement (Mcgrath, Splaingard, Alba, Kaufman, & Glicklick, 1992; Sleigh & Brocklehurst, 2004). Paradoxically, despite this resistance, mothers in prior studies have generally indicated high levels of satisfaction with the GT in terms of reduced stress and workload once it is in place (Åvitsland et al., 2012; Brotherson et al., 1995; Guirriere et al., 2003; Martínez-Costa et al., 2011; Morrow et al., 2008; Petersen et al., 2006; Spalding & McKeever, 1998; P. Sullivan et al., 2004, 2005; Tawfik et al., 1997).

Literature has also drawn attention to the symbolic meanings that oral feeding has for mothers (Avitsland et al., 2012; Brotherson et al., 1995; Guirriere et al., 2003; Martínez-Costa et al., 2011; Morrow et al., 2008; Petersen et al., 2006; Sleigh, 2005; Spalding & McKeever, 1998; P. Sullivan et al., 2004, 2005; Tawfik et al., 1997). In particular, it has been argued that the offer of a GT with its implication of oral feeding failure can challenge maternal identity as “good “mothers (Craig & Scambler, 2006). Mothers might therefore wish to invest strongly in oral feeding with its perceived associated benefits of normality, pleasure and participation (Craig et al., 2003). However, as I have shown, the symbolic meanings for fathers have been under-researched.

With this thesis, I wished to increase understanding of the decisional dilemma that many parents face when choosing whether or not to go ahead with GT placement in their child with a neurodisability. In doing so I hoped to inform clinical practice in a positive way for both clinicians and the families they serve.

The aims of this study suggested that two methodological approaches would be appropriate. Firstly, interpretive description was chosen because it allowed engagement with some of the ethical and practical problems that arise when researching clinical populations. Secondly, I drew from the broader aspects of conversation analysis (CA) to provide a descriptive framework to explain what was going on in interactional terms during clinical consultations and other encounters.

My findings, which I presented narratively in Chapters 4 to 11, provide additional explanation and understanding around some of the difficulties families face when first making and then appraising a decision about GT placement for their child. In Chapters 4 to 7, I described some of the factors that underpin decisions made around feeding and highlighted how these may differ for the various stakeholders involved in the decision. The main themes I identified in my research were embodiment and inter-embodiment, feeding pleasure and commensality, feeding as care, and normalisation and stigma. In Chapters 8 to 10, I described how information is shared between families and their clinical team, how the risks and benefits are evaluated and how the decision is eventually reached and shared. In Chapter 11, I discussed how the stakeholders appraised their decision after the event in the light of new knowledge.

12.2 Contribution of this thesis to knowledge

Child disability research has focused strongly on the practice of mothers, leading Bailey to observe that “the vast majority of ‘family’ research might better be characterised as ‘maternal’ research” (Bailey, 2007: 292). Khandpur et al. (2014) drew attention to the dearth of research regarding the role of fathers in feeding children as well as their values around child nutrition. My study was the first study to include a much wider range of family views around GT placement than mothers alone. This research therefore not only addresses my original intention of increasing the knowledge around decision-making for GT placement in children with neurodisabilities, but also begins to address the more general research gap regarding the roles and values of fathers with respect to child nutrition. Secondly, this was the first study to include the perspective of the children with neurodisabilities who have had a GT placed. Thirdly, this was the first study to actively examine GT decision-making as it was actively being discussed thus throwing light on critical aspects of the decision-making process as it unfolds.

My findings were consistent with prior research in supporting the concept that making the decision about GT placement can be an extremely difficult process for mothers. Researchers have highlighted how mothers may mourn the loss of breastfeeding and view themselves as “failures” at motherhood (Craig et al., 2003; Sleigh, 2005). By also including fathers I have been able to also demonstrate that there can be significant differences in the values placed by mothers and fathers on oral feeding which may greatly impact on the decision-making process. Writers around this subject, who are sometimes from strongly social constructionist backgrounds, have tended to shy away from highlighting any apparent gender differences. However, the argument that I draw from my findings is that unlike many other aspects of life which have become gendered through social practices, it is far more difficult to sever the close links between early infant feeding and biological imperatives. My research strongly supports writers who have begun to question the appropriateness of drawing on a body of work that has been conducted almost entirely with mothers in order to make more general assumptions about parenting (Rossi, 2015).

In Chapter 4, I have demonstrated how mothers have typically positioned early infant feeding as an intimate bonding practice which has possibly been formed as a natural sequel to the inter-embodied experience of pregnancy. In tackling the key neglected area of fathers’ values around feeding, I have raised the possibility that early infant feeding may be experienced and valued by fathers in different, more pragmatic ways. These differences in values may affect parents’ willingness to persist with oral feeding in difficult circumstances and their openness to the introduction of alternative feeding methods. Health practitioners may not be aware that fathers’ and mothers’ attitudes to feeding their young infant may differ and there is a tendency to view the parents as a single unit sharing identical values and goals. Healthcare professionals sometimes make assumptions that fathers share oral feeding preferences with mothers without ever having taken the opportunity to counsel fathers for their view. One potential reason for this is that mothers may have a closer relationship with healthcare providers, in part, as they may see them more often. Alternatively, pursuing the opinions of fathers may not result in easy conversations because any questioning of the mothers’ values has the potential to lead to conflict.

In contrast to early infant feeding, where I suggest that researchers may need to re-establish more biological reasoning as a central tenet to understand early infant feeding, my research, as reported in Chapter 5 has also highlighted how the enjoyment of flavours, sensory experiences around eating and sociability that most adults and older children experience are not necessarily biologically driven but are highly socialised processes. My research has highlighted that food pleasure can be experienced in many ways. Parents who have learned to enjoy eating and drinking experiences may not always recognise that children with dysphagia may not value feeding experiences in quite the same way.

Young infants, especially those with a feeding difficulty, cannot feed themselves and mealtimes for young infants must therefore always be commensal in nature. In Chapter 5, I also discussed how parents' own prior experiences of eating and drinking with others means that commensal eating is not a neutral event. Many media images and artistic depictions of commensal eating are centred around feast-days and occasions such as birthdays and Christmas and thus portrayed as joyful events. Some of these events will be closely tied to parents' own experiences and their memories of forging family identity. It is therefore hardly surprising that family members expressed concern about the child's future social self and issues around commensality in the creation of family identity.

Prior research has demonstrated how the burden of care for children with neurodisabilities is both greater and lengthier than it is for typically-developing children. In Chapter 6, I expanded this knowledge, by drawing on the four concepts of care as outlined by Fisher & Tronto (1990) to demonstrate the burdens that arise from the additional emotional and relationship work required in caring for a child with a feeding difficulty. I have also argued that the biological nature of pregnancy and breastfeeding may progress to a situation of gender essentialism where mothers are left, or may feel that they are left, with the burden of the actual responsibility- "the taking care of"- for ensuring that the child is safely and adequately fed. This issue is particularly highlighted by my findings that some of the tasks around NG feeding, most notably its insertion, may fall disproportionately to the mother even though both parents can sometimes find NGT insertion distressing.

In Chapter 7, I described how oral feeding may be viewed as an important developmental milestone which underpins other aspects of development. Poor oral feeding is an unfavourable developmental indicator which can lead to a prolonged period of investigation and assessment. Obtaining a diagnosis is a key event in the lives of disabled children and their families (Kisler, 2014). Parents need to adjust to the changes in the expectations that they previously held for their child and this can take time. Moving away from oral feeding may be seen as unfavourable news and this can hinder discussions about GT feeding.

Non-oral feeding methods may be positioned by some parents and other family members as something that can discredit their child and render both their child and themselves stigmatised. Craig (2004) found that words such as “normal” or “unnatural” were used by her maternal participants’ constructions of feeding technologies, the GT being constructed as a “foreign object” which went against nature. Given the paradox that “natural” feeding has itself failed and that other equally artificial supportive technologies were sometimes welcomed, the difficulty in accepting alternative feeding technologies warranted further explanation. One of the most interesting findings about my research is that other highly visible markers of disability such as mobility aids could be viewed by some as far less stigmatising than tube-feeding. This suggests that expectations of negative appraisal by others could be tied more to the abnormality of feeding method than the actual disability itself. I have posited that anything that potentially causes facial disfigurement, even temporarily may be more stigmatising because of the special status of the face to human beings. When comparing GT and NGT feeding, a GT can therefore represent an opportunity to reduce stigma because its hidden features gives parents the choice whether to “pass” or “reveal” the stigma of non-oral feeding. Secondly, there is some suggestion in my data that an NGT may differ from a GT because it can render a child as being “actively ill” rather than disabled. This can draw greater attention to the child in community settings because they are exterior to the hospital and thus outside of the expected context.

Following my discussion of the factors influencing family decisions about GT placement, I then went on to discuss in Chapters 8 to 10 how information around feeding and other values is shared between families and their clinical team. My findings support other research around the topic of SDM in clinical contexts by demonstrating a variety of

preferences for involvement in decision-making and I will discuss how this could be approached in section 12.3 below. I also discussed how risks are assessed in accordance with these values and how the eventual decision is distributed across time and place between parents, their healthcare team and friends and family.

Having ascertained that fathers' views around GT feeding can differ significantly from mothers, it is disconcerting to note that my research suggests that there may not always be adequate interactional space for fathers to offer their own views. There are several reasons for this. Firstly, fathers may often be obliged to take up the position of being the family's main breadwinner. Unless their workplace is very flexible they may not have the same opportunity to attend clinical meetings and consultations as mothers may have. However, my research also suggests that even in consultations where the father is present the mother may be identified by healthcare professionals as the principal supplier of information. Members of the professional team who may have developed close relationships with mothers may then draw on their own expertise to support the mother's narratives. This can make it difficult for fathers to challenge or disagree with the mother's values. Health professionals may then assume that both parents are of the same mind regarding the importance of oral feeding and their desire for GT placement for their child.

This research lends strong support to models of decision-making which contest decision-making as one-off dyadic encounters and suggests that decisions are distributed across time and place (Rapley, 2008). In addition to this my research suggests that GT decision-making may include more than one step with the decision being made to enterally feed first followed by a second decision regarding the insertion of a GT if enteral feeding proves beneficial. This has implications for researchers who are evaluating prior decision-making research because sometimes the GT decision for parents may have been reported as quick and straightforward, but this may disregard earlier decision-making processes around enterally feeding via NGT.

I have described in detail how evaluating the risks and benefits of GT feeding for each individual child is not an exact science. I have argued that parents may sometimes struggle with balancing two, sometimes contradictory, processes of rational thought and the emotional responses towards their situation. In addition to this, many parents will

wish to present themselves as responsible parents who have given due consideration to treatments that they may actually feel ambivalent or negative about.

Parents and professionals' understanding of these risks and how the decision may affect the child's quality of life may vary because parents and professionals may not share the same knowledge. Their understanding of specific terms may also differ. This situation may be worsened by the fact that the framing of the risks and benefits of the GT procedure may be conducted in various ways by diverse professions on different occasions in a variety of environments. Medical encounters can also be structured in such a way that there may be inadequate space for parents to raise further concerns about risk, meaning that parents must carry out additional interactional work to keep such discussions open. Some parents may lack the skills to approach this effectively and this may create further uncertainty and delay around the decision. It is therefore important that clinicians ensure space for parents to raise further concerns and I will proffer some suggestions for this in the discussion and implications for practice in section 12.3.

Importantly, this research adds to what is now a substantial amount of evidence suggesting that despite decisional dilemma, there is generally a very high level of satisfaction experienced by families once their child has undergone GT placement. However, in contrast to other research there was no suggestion that parents wished they had done it earlier. Instead, parents position themselves as believing that they had agreed to GT when they had reached the point of "no choice". It is also less certain whether these feelings of satisfaction extend into the long-term. It is possible that the early euphoria of being "born again" (*Angela*) which may arise from the feeling of relief after a stressful situation may diminish over time. I suggest this possibility because the benefits of GT feeding do not come without a price. These costs include a medicalised lifestyle, frequent minor treatment complications, physical restriction for the child and the loss of control of natural appetite. Although my research is the first to include children's perspectives, my sample of two children was clearly very small. However, their contributions suggested that children do hold their own viewpoints around GT which may not always tie in with the views of their parents. This is an area of research which needs further investigation.

Finally, one striking finding about my research is its divergence from prior research suggesting that GT provision can lead to a loss of the provision of respite from family and friends (Armstrong et al., 1997; Brotherson et al., 1995; S. W. Smith et al., 1999; Thorne, Radford, et al., 1997). I have postulated that this contrary finding may reflect a strong social and cultural shift in familiarity with smart technology that has occurred over the last two decades. Whatever the reason, potential respite workers talked far more positively about assisting with GT than they did about NGT feeding and were accordingly far more willing to participate in providing respite for the family. In the following section, I will discuss some of the clinical implications of my findings and recommendations for clinical practice.

12.3 Implications for clinical practice

Several issues have arisen from my findings which have implications for clinical practice.

12.3.1 *Greater inclusion of fathers*

Firstly, as I have demonstrated throughout this thesis, fathers' opinions around feeding method may differ from mothers. My research has suggested that some fathers would like to have a greater stake in the decision and the interactional space for them to lend their own voice to the decision may be missing in some encounters. Even where the interactional space exists, there is potentially some evidence to suggest that fathers' views may not carry the same weight as mothers' in the decision-making process. Dealing with this problem requires very sensitive interactional skills. One possible way that this can be managed may be to ensure that strategies are put in place to ensure that both parents are asked for their viewpoints during joint interactions with the clinician rather than giving only one person the opportunity to act as the principal and narrate the feeding story. It could also be useful to offer parents the opportunity to invite other family members such as grandparents who may be needed to provide respite along to these meetings to allow their participation in the decision-making process.

Having the opportunity to discuss and evaluate the risks and benefits in a specific meeting where both parents and a range of professionals are present was highly valued by some of the parents in my study. Greater effort could be made to seek fathers' opinions at these meetings as part of information sharing whenever it is practical to do so. Clinically this may be much easier in the group context where everyone is given the

opportunity to put forward their view. It also gives everyone opportunity to discuss what their hopes may be for feeding at different stages in the child's life.

Having joint meetings also ensures that parents and health professionals are all talking about the same thing when evaluating risk. As my study has highlighted, the risks of having or not have a GT can be presented at different times, in different contexts, by different professional categories. Group meetings where risks and benefits are presented at the same time and debated by everyone would make it easier for families to make sense of the risks and benefits.

Most working parents of children with neurodisabilities in the United Kingdom are entitled to up to 18 weeks unpaid parental leave until the child reaches the age of 18 (UK Government, 2017). Although notice needs to be given to the employer, these days can be taken individually and for some families may be useful for fathers to attend appointments. Although financial constraints may mean that this is not appropriate for all families, it is nevertheless important to ensure that families know of this entitlement and are aware of appointments in good time so that arrangements can be put in place with the workplace.

12.3.2 *Clarity around the maintenance of oral feeding and food pleasure*

Secondly, some parents may be anxious about the effect a GT may have on the child's ability to eat orally, or that they may be restricted from doing so because of the risk of aspiration. This ties in with prior research with mothers which has consistently demonstrated how GT feeding was frequently viewed as a way of depriving the child of the pleasure and socialisation of oral feeding (Calderón et al., 2011; Craig & Scambler, 2006; Craig et al., 2003; Guirriere et al., 2003; S. W. Smith et al., 1999; Spalding & McKeever, 1998).

This is another area where information-sharing around risk could be improved, because the need to cease oral feeding entirely does not apply to the majority of children (Cass et al., 2007). Whenever oral feeding is inadequate, but not prohibited, parents should be made aware of the possibilities for mixed GT/oral feeding from very early on the decision-making process.

The interactions that take place between caregivers and child as they engage in food selection, ingestion, and eating regulation creates a feeding relationship

(Satter, 1990). There are many ways that parents can still help infants develop feeding skills so that oral feeding can be enjoyed alongside tube-feeding where this is allowable. Differences in sensory processing and integration have been shown to affect child participation in many childhood tasks (Edwards et al., 2016). Combined input from the senses including proprioception and body position are all involved in feeding behaviour (Arvedson & Brodsky, 2002; S. Morris, 1989; Sheppard, 2008). For some children, games and activities can be employed that will enable the postural changes to help permit eating in an upright position, develop the co-ordination and integration of swallowing and breathing, and help support swallowing and chewing techniques (Schauster & Dwyer, 1996). Children with neurodisabilities may sometimes struggle to control their responses to new oral-tactile stimuli and may exhibit resistant behaviours as soon as food cues appear (Luiselli, 1994). Parents could be informed that children who are supported in practicing oral-motor movement patterns are more likely to be able to accommodate a variety of foods over time (Schwaab, Niman, & Gisel, 1986; Sheppard, 2008). With the child's nutritional needs safely met, and no NGT in-situ, there may be more opportunities for SALTs to help parents introduce graded sensory input using touch taste and texture to gradually raise the child's tolerance to oral stimulation and hence able to practice oral-motor movement patterns (S. Morris, 1989). This is important because as Mason, Harris, & Blissett(2005) note, an infant's willingness to try unfamiliar foods decreases over the last half of the first year and developmental feeding and swallowing skills are typically fully acquired by age three years (Arvedson & Brodsky, 2002; Gisel & Patrick, 1988).

As I have also demonstrated, even an absence of oral feeding does not necessarily mean that all feeding pleasure is lost. Head (2017) argues that the broad exploration of infant feeding includes temporal, embodied, and emotional dimensions. There is currently untapped value in explaining to parents some of the ways in which some feeding pleasure is learned rather than innate and GT placement may not necessarily represent the same loss to a child as parents might imagine. For children who are not allowed to have tastes, my research suggests the potential for developing feeding pleasure in several ways. Firstly, satisfaction can be derived via the satiety mechanisms of a full stomach

and it is important parents are also made aware of this aspect of feeding pleasure. Secondly, feeding pleasure can also be tied to other senses and may still be obtainable via other means such as sound, touch smell and vision. Parents can also help normalise feeding times by providing sensory cues such as being able to see and smell food at mealtimes and having the child present to socialise at family mealtimes (Schauster & Dwyer, 1996). Using strategies to incorporate other senses into the feeding experience via affectionate touch or fun and games will potentiate these sensory inputs to integrate in the brain to derive pleasure from the feeding experience.

It could be explained to parents that it would still be possible to help prepare a GT fed child for later oral feeding by structuring the regime in such a way as to help develop the child's hunger and satiety cues by offering foods before a bolus tube-feeding (Blackman & Nelson, 1987). It would appear feasible that children who get the bulk of their calories by being fed continuously overnight may become hungrier during the day and increase their oral intake. However, no studies have yet been conducted to test this theory in the paediatric population (Edwards et al., 2016). Theoretically, nocturnal tube feedings have the potential to disrupt circadian rhythms, leading to adverse effects such as lower oxygen consumption, shifts in nitrogen and cortisol balance, and increased aspiration risk (Stenvers, Jonkers, Fliers, Bisschop, & Kalsbeek, 2012). However, one paediatric study has suggested that daytime bolus feeds do seem to decrease oral intake suggesting that continuous night-time feeds may be helpful in increasing oral intake during the day (Wright, Smith, & Morrison, 2011).

The child may also need to be able to communicate both hunger and satiety to the caregiver. Training parents to be responsive and sensitive to the child's feeding cues can lead to significant improvement in the feeding process (Segal et al., 2014). Ensuring the on-going input of a speech therapist post GT may be optimal for helping develop communicating skills (Wolff & Herman, 1994).

Being unable to participate in communal rituals around food and drink could interfere with equality around disability by positioning the disabled person outside of the group. This may be difficult for both the affected children as well as family members. Families may need time to accept that their child's future may differ from their own experiences and they may need support to re-imagine their child's future as one in which commensal

eating and drinking takes on a lesser role. One way that this could be achieved is to develop strategies to develop family bonding rituals which do not centre around the consumption of food and drink but on other types of enjoyment such as special family games, songs and play.

I concur with other researchers who have suggested that suitable counsel may be required to help support mothers in renegotiating their ideas of themselves as good mothers regardless of the feeding method used (Craig & Scambler, 2006).

12.3.3 *Embracing the continuum of SDM as a distributed mechanism*

This research has also shown that parents' wish to participate in shared decision-making around GT placement can be highly variable and clinicians should not assume that parents do or do not want to share in the decision. Offering a degree of participation which parents feel to be inappropriate can fuel parental resistance to the GT procedure and has the potential to cause conflict. It is important that parents do not feel disempowered or that they are sharing their child with clinicians. It is paramount that clinicians ask parents how much they wish to be involved and are aware that preferences for involvement may change over time or with different types of decisions.

Given the evidence from this study that the decision is made across time and possibly in several stages, it is also important to ensure that adequate thinking space is given between consultations. It should not be assumed that parents' viewpoints are constant over time. Opinions may change and develop as the topic is aired with others and new information has been brought to light. This research has highlighted the importance of other family members in helping counsel parents through the decision-making process as well as supporting them implementing the decision. It is therefore important that enough time is given to allow these interactions to occur.

12.3.4 *Recognising the influence of social ideals around being a "good mother"*

Although the high workload around feeding was noted by professionals and other family members this was sometimes positioned by the non-parent participants as something that emerged as a direct result from maternal choice to persist with oral feeding despite their difficulties. Feeding problems, particularly the loss of breastfeeding could lead to a sadness which was noticeably apparent in all my interviews with mothers and in

accordance with the prior work by others (Calderón et al., 2011; Craig & Scambler, 2006; Craig et al., 2003; Guirriere et al., 2003; S. W. Smith et al., 1999; Spalding & McKeever, 1998).

Concepts of risks around the loss of breastfeeding as well as the risks attached to insertion of the GT are important for understanding how women experience infant feeding. Although it is important that mothers understand that breastmilk can be given via the GT, it is also vital to note that one aspect of the “breast is best” message has its roots in scientific claims that formula milk is more “risky” for infants than breastmilk. This underpins discourse around infant feeding where the “good mothers” are those who breastfeed their infants (Head, 2017; Lee, 2011). Faircloth (2010, p. 360) observes that despite formula feeding being statistically normal, even mothers who bottle feed have to engage in “identity work to recreate themselves as moral citizens in the face of ‘deviance’”.

When both breastfeeding and bottle feeding have been unsuccessful, it is therefore even more important to counsel mothers to help reach the understanding that tube use is a pragmatic action and only a tiny proportion of mothers succeed in exclusively breastfeeding for the recommended period of time (Lee, 2011).

Whilst Craig & Scambler (2006) suggest that mothers may need to renegotiate their identity as good mothers, my research strongly suggests that health professionals and significant others have the opportunity to influence the way in which mothers think about infant feeding and what it may mean in terms of being a “good mother”. Taking the stance of protecting mothers from GT discussions on the basis of prior research indicating that these conversations can be difficult, may pay inadequate attention to the social pressures which underpin “good mother” values. For example, Marshall, Godfrey, & Renfrew (2007) found that other’s view of breastfeeding as “good mothering” could only be maintained as long as the recipient infant remained healthy and content. “Breast is best” represented only one potential discourse around infant feeding and mothers were exposed to a diverse range of values and influences across their social networks. Factors that influence the way parents negotiate infant feeding decisions and practices include social and familial networks, the interactions between parents, embodiment, and experiences of public space.

Parents cannot consent to GT placement unless it has been offered. It may be difficult for either parent, but particularly mothers, to proactively request GT placement as it may give the mistaken impression that they are “giving up” on their child and are “unwilling” to put in the effort to maintain oral feeding. It is important therefore that despite the sensitivity of the issue, clinicians should not shy away from offering GT feeding as an option. This may be a question of getting the timing right so that GT is offered when families are willing to hear it. This requires delicate preparatory work to achieve. Clinical information in the form of leaflets and posters including positive messages about lifestyle benefits and not just the procedure and risks alone could be made available in waiting areas so that parents can become gradually familiarised with “GT” and associated terms so that when the topic is eventually raised it is not entirely unexpected. It would be helpful if printed literature included a glossary of terms that might be used in clinical consultations, as my research showed that specific words such as “aspiration” would not always be understood in the same ways by families and their healthcare team.

12.3.5 *Offering the opportunity to combine surgery*

Some of the concern around the risk of GT placement for parents is tied to the operation, most notably the anaesthetic itself. Children with CP for example are at greater risk of adverse events from anaesthesia (Havidich et al., 2016; Prosser & Sharma, 2010) and opioid post-operative pain relief (Jay, Thomas, Nandi, & Howard, 2017). One way to reduce risk for some children would be to combine a GT with another “essential” operation should the opportunity for this arise. Little is known about the risks and benefits of combining surgeries in this group. However, several epidemiological studies have been conducted to address the effects of anaesthesia on the neurodevelopment of children. A meta-analysis of these studies has suggested that the number of times of exposure rather than the length of exposure could be a modest risk factor for later neurodevelopmental impairment (Wang, Xu, & Miao, 2014). Combining surgeries is also a successful technique in other medical fields (Ma et al., 2017). If the child has a pending operation, it may be worthwhile for clinicians to broach the possibility of GT placement at this point. This may assist GT decision-making and may also reduce risk, although more research is needed.

12.3.6 Provision of resources with practical advice

Some families engaged in the decision had concerns about practical elements of tube-feeding. Such concerns included physical participation for example, rolling and swimming, as well as longer term concerns such as accessing education. The provision of such information is likely to vary depending on the clinical team so it would be a very useful to compile a practical guide together with parents whose child has already undergone GT placement and who have encountered some of these practical issues. One strong factor to emerge from this study was the desire from parents who had eventually consented to GT placement to offer help and support to other parents who are also making the same decision. The construction of a database of families who would be willing to offer such support, which could be accessed by clinicians, could be helpful.

Some of the extended family members expressed concern about access to GT tube care training as they did not always wish to interrogate parents in case this might alarm the parents in some way or put them under additional pressure. It would therefore be very useful if training around GT feeding and care could be extended to other carers who wish to provide respite and practical support in a similar way to diabetes care.

In contrast with much earlier studies, families in my study did not express concern about the supply of feeding equipment which seem to be successfully managed (Townshley & Robinson, 1999). However, concerns were sometimes expressed regarding the appropriateness of the prescribed milk feeds and feeding regime for their child. The dietetic service was the one service that was sometimes viewed negatively by the participants in my study. As highlighted by Kirk & Glendinning (2002), GT feeding forms one part of the care of a technology dependent child in which the boundary between lay and professional roles can become blurred in the home. Parents are forced into a position where they are taking on feeding as a clinical task but with a much higher degree of emotional investments than might be the case for paid clinicians. This can cause emotional distress and anxiety for some, leading to the need for additional emotional support for families who are providing non-oral feeding for their child (Craig et al., 2003).

In the above section, I have discussed the main clinical implications of my study. However, it is also important to consider some of the limitations of this research.

12.4 The Limitations of the Study

In the following section, I consider some of the limitations of my study. I chose to restrict my written analysis to the areas which I believe have the greatest clinical implications. This means that some of the knowledge generated in the formation of this thesis has been omitted.

12.4.1 *Limitations of the retrospective interviews*

My results need to be considered from the context in which they emerged. Although this study was unique in exploring the perspectives of a wider circle of family members it is important to note that all participating family members resided in North-East England and reflected the local area where 93.6% are of white British origin (Office for National Statistics, 2011). Although their primary and secondary care services differed, all families were cared for by the same tertiary service. This geographical area is not as ethnically diverse as other UK areas but recruitment of participants from other cultural backgrounds would have been desirable. Necessarily restricting the sample to English-speaking parents created an additional barrier for a study in which recruitment was always complex and dependent on the goodwill of clinicians. It is possible that some of the experiences reported by the participants in this study are not representative of other areas.

Secondly, all the women in this study were biological mothers who had nurtured hopes to breastfeed. It is possible that the findings, particularly in relation to embodiment, would have been quite different with adoptive mothers or when breastfeeding had not been the initial feeding method of choice.

Thirdly, the families who were kind enough to participate in this study were all from families where at least one parent was in employment and some were involved in working with children in some capacity. Again, they may not have been representative of non-working families where both parents were at home or where there were lower levels of experience with children.

The findings of this study need to be interpreted with caution. However, I have provided detailed descriptions in my empirical chapters and attempted to relate my findings to existing knowledge emerging from both clinical and sociological literature to provide additional levels of understanding.

12.4.2 *Limitations of the longitudinal study*

Due to difficulties in identifying families who were likely to decide about GT placement early enough in the process, only one family was recruited to the longitudinal study. Studying this family's journey provided lots of rich and unique data but we cannot know whether their decision-making journey was representative of other families' experiences. However, parents of children with disabilities are often greatly stretched with the demands of caring for their children and participating in the longitudinal study is a significant undertaking. The original plan, as submitted for ethical approval, had been to conduct interviews with the parents after each clinical encounter. This family were extremely obliging in allowing me to attend their consultations. However, they did not feel that they could squeeze in the time for additional face to face interviews. I was able to speak to one or other of the parents by telephone between encounters and they were generally content with the consultations that had occurred as well as being satisfied with the GT procedure once it had been carried out.

12.4.3 *Future developments*

This research has highlighted several areas for future study. Firstly, as described above, results of this study are limited by the narrow sampling from the North-East of England. Now that I have highlighted the potential for different values around the importance of oral feeding to mothers and fathers, the next step would be to carry out further qualitative and quantitative work in other areas to see whether these findings are more generalisable. As fathers are increasingly participating in childcare including meal preparation, this is extremely important, not just in relation to GT decision-making, but with respect to feeding children more generally.

Although I included observations of interactions with clinicians, I did not include any observations of family encounters where GT was discussed with family and friends. Given the suggestion in my retrospective study that family members do not always see their supportive stance as contributing to the decision, it would have been useful to explore this further. However, this type of observation is extremely sensitive and may have felt intrusive for families as well as having the potential to ignite conflict. This is another area where a confidential survey could be helpful.

Another area for research would be to expand the inclusion of children. I was very fortunate in being able to recruit two children to my study. However, these interviews were kept deliberately short due to the very young age of one child and the speech problems of another. It would be helpful to seek the views of other children with some verbal ability representing different ages, backgrounds and degree of disability through other qualitative research. This would be enormously beneficial as it may lead to insight for other children who may not be able to express their voices as easily.

12.4.4 Conclusion

In conclusion, my study adds to previous qualitative literature by demonstrating how research around facilitating GT decision-making for children with neurodisabilities needs to move beyond the mother-clinician dyad to be understood as a complex process involving many stakeholders distributed across time and place. The values of fathers, as well as family and friends, are important influences which may differ substantially from mothers, but have not been adequately considered in prior research. Many studies have demonstrated maternal resistance to GT which has sometimes led to delay in placement. By drawing on theories outlining care as a multi-faceted process, I have been able to demonstrate how previous studies may have underplayed the pressures mothers may be under to present themselves as “good mothers” by taking on a disproportionate level of responsibility for ensuring safe and adequate nutrition of their child. This research demonstrates some of the ways in which fathers, family members, and clinicians can support mothers in both decision-making and the provision of feeding care.

Appendices

Appendix A: Systematic Review Protocol

Decision-making around gastrostomy feeding in children with neurodisabilities

Reviewer: Karen Holt

Background and Rationale

Neurodevelopmental Disability and Dysphagia

'Dysphagia' describes any disorder of swallowing and can occur in children with neurodevelopmental disability due to damage and disruption to the central and enteric nervous systems. The prevalence of dysphagia in children with any neurodevelopmental disabilities is unknown. Around 80% of the children seen in specialist feeding clinics have cerebral palsy (CP) (Parr, 2011). CP is a life-long, non-progressive neurodevelopmental disability affecting movement and posture with an approximate prevalence rate of 2/1000 live births (Surman et al., 2006). Dysphagia may result in malnutrition, and aspiration of food or fluid into the lungs leading to recurrent chest infections and chronic lung disease (Sullivan, 2009). Some conditions co-exist with dysphagia, for example, gastro-oesophageal reflux, vomiting and constipation (Sullivan, 2009).

Gastrostomy Feeding

Children with dysphagia may be offered a gastrostomy to augment or replace oral feeding. A synthetic tube, through which feeds and medication can be administered, is inserted through the stomach wall emerging through the skin of the abdomen. Recent systematic reviews (Sleigh and Brocklehurst, 2004; Samson-Fang et al., 2003) indicated that the benefits and risks of gastrostomy feeding in children with cerebral palsy are currently unclear due to a paucity of evidence and more systematic research is needed.

Making the Decision to Insert a Gastrostomy Tube

Quantitative surveys have suggested that parents are generally satisfied with the overall outcome following gastrostomy (Sleigh and Brocklehurst, 2004). However, the measures used to evaluate the health and social outcomes for children and parents may not have

adequately captured feeding related concerns (Morrow et al., 2008). Qualitative studies carried out following gastrostomy placement have suggested that the decision to have a gastrostomy can be difficult and distressing for parents (Craig and Scambler, 2006; Craig et al., 2003; Guirriere et al., 2003). Even when satisfaction with the gastrostomy is reported, parents may continue to feed their child orally against medical advice (Peterson et al., 2006; Thorne et al., 1997).

A recent systematic review consisting only of those qualitative studies that included in-depth interviews or focus groups suggested that the main decisional difficulty for parents relates to 'the meaning of feeding by mouth and feeding through a tube for parents and the values they place on them'(Mahant et al., 2011). The authors concluded that the gastrostomy decision-making theme could be modified by two main factors: 1) child and family characteristics and 2) the quality of information sharing and support. No systematic review of observational or quantitative research around decision-making has been carried out to date.

Evidence suggests that shared decisions are more likely to result in informed choice and consent (Elwyn et al., 2010). The best ways for health professionals to improve information sharing and support around gastrostomy feeding are unknown due to critical limitations in current research. Prior to carrying out further research a full systematic review of both qualitative and quantitative studies needs to be undertaken.

Review Question

What is already known (both qualitatively and quantitatively) about the influences on parents' decisions around gastrostomy feeding for children with neurodevelopmental disabilities?

Location and Selection of Studies

Types of participants

- Parents and/or carers and/or extended family of children of less than 18 years old with feeding difficulties arising from neurodevelopmental disabilities where gastrostomy has been, or is being considered.
- Clinicians involved in gastrostomy tube placement decision-making in children with neurodevelopmental disabilities of less than 18 years old
- Children under 18 where gastrostomy has, or is being considered.

Phenomena of interest

- Decision-making around gastrostomy tube placement in children with neurological disabilities

Types of studies

- Any English-language studies using any type of research method to examine any element of decision-making around gastrostomy tube insertion in children with neurodevelopmental disabilities, even if this was not the primary focus of the study.
- Foreign language studies to be excluded as funding does not allow for translation costs.
- Studies which include data for children who do not have neurodevelopmental disabilities will be excluded *except* when data on children with neurodevelopmental disabilities is recorded separately from the data for other non-neurological conditions.

Outcomes

- Any qualitative or quantitative outcome or factors pertinent to the decision-making process.

Dates of publication

- From 1980 to present (technique introduced 1980)
- Annual updates to follow

Publication Type

- Peer reviewed journals

- Book chapters
- Conference abstracts and posters
- Any on-going study not yet published

Study Selection

- Four subject databases (Medline, Embase, PsychInfo and CINAHL)
- One multidisciplinary database (Scopus)
- One systematic review database (Cochrane)
- Grey/informal materials including conferences
- Snowballing from reference lists

Search Terms

- Gastrostomy and/or feeding tube and/or enteral nutrition
- Neurological disability and/or cerebral palsy and/or developmental disability

Limits

- Child*
- Decision-making (from hand-search only due to multiple descriptions)
- English language
- 1980 to current

Methods for reviewing selected studies

Screening

- Initial screening of titles and abstracts against inclusion criteria
- Full text screening of identified relevant papers.
- Screening to be checked by second reviewer- 20% of papers randomly selected.
- Discrepancies to be resolved by discussion.

Assessment of Methodological Quality

- There are no well-established methods of assessing the quality of qualitative or mixed methods research (Popay et al., 2006) therefore the review will describe

the general quality of the included studies and define any methodological limitations.

- Characteristics of included and excluded studies will be tabulated.

Data extraction, results and synthesis

- Number of studies screened
- Create list of included studies
- Data to be extracted onto data extraction form (Appendix 1)
- Textual descriptions of study characteristics
- Risk of bias for each study
- Outcomes for each study
- Group studies according to participants -parents/clinicians/children
- Group studies according to timing of data collection - pre/post gastrostomy
- Thematic analysis of extracted data
- Meta-analysis of quantitative data if decision support has been tested. Statistical summary of these to be included in data tables.
- As it is anticipated that the review question dictates the inclusion of a wide range of research designs, producing mainly qualitative with some quantitative findings, an interpretative narrative synthesis, according to ERSC guidelines (Popay et al., 2006) will be used to create a summary of the current state of knowledge about decision-making around gastrostomy feeding for children with dysphagia and neurodevelopmental disabilities.
- If appropriate, concept mapping may be used as visual representation

Discussion

- Summary of current knowledge
- Discuss methodological limitations of included studies
- Relate findings to current practice and other evidence
- Critical reflection of synthesis process
- Direct discussion towards implications for future research

Dissemination

- To be published as part of PhD thesis

References

- Craig, G. M. and Scambler, G. (2006) 'Negotiating mothering against the odds: Gastrostomy tube-feeding, stigma, governmentality and disabled children', *Social Science and Medicine*, 62, pp. 1115-1125.
- Craig, G. M., Scambler, G. and Spitz, L. (2003) 'Why parents of children with neurodevelopmental disabilities requiring gastrostomy feeding need more support', *Developmental Medicine and Child Neurology*, 45 (3).
- Elwyn, G., Laitner, S., Coulter, A., Walker, E., Watson, P. and Thomson, R. (2010) 'Implementing shared decision-making in the NHS', *British Medical Journal*, 341, pp. 971-972.
- Guirriere, D., McKeever, P., Llewellyn-Thomas, H. and Berall, G. (2003) 'Mothers' decisions about gastrostomy tube insertion in children. Factors contributing to uncertainty', *Developmental Medicine and Child Neurology*, 45, pp. 470-476.
- Mahant, S., Joveeska, V. and Cohen, E. (2011) 'Decision-making around gastrostomy - feeding in children with neurological disabilities', *Pediatrics*, 127, pp. 1471-1481.
- Morrow, A., Quine, S., Loughlin, E. and Craig, J. (2008) 'Different priorities: A comparison of parents' and health professionals' perceptions of quality of life in quadriplegic cerebral palsy. ', *Arch. Dis. Child*, 93 (2), pp. 119-125.
- Peterson, M., Kedia, S., Davis, P., Newman, L. and Temple, C. (2006) 'Eating and feeding are not the same: Caregivers perceptions of gastrostomy feeding for children with cerebral palsy', *Developmental Medicine and Child Neurology*, 48, pp. 713-717.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K. and Duffy, S. (2006) 'Guidance on the Conduct of Narrative Synthesis in Systematic Reviews A Product from the ESRC Methods Programme'.

- Samson-Fang, L., Butler, C. and O'Donnell, M. (2003) 'Effects of gastrostomy feeding in children with cerebral palsy: an AACPD evidence report', *Developmental Medicine and Child Neurology*, 45, pp. 415-426.
- Sleigh, G. and Brocklehurst, P. (2004) 'Gastrostomy feeding in cerebral palsy: a systematic review', *Arch. Dis. Child*, 89 (6), pp. 534-9.
- Sullivan, P. (2009) *Feeding and nutrition in children with neuro-developmental disability*. Mac Keith Press.
- Surman, G., Bonellie, S., Chalmers, J., Colver, A., Dolk, H., Hemming, K., King, A., Kurinczuk, J., Parkes, J. and Platt, M. (2006) 'UKCP: a collaborative network of cerebral palsy registers in the United Kingdom', *Journal of Public Health*, 29 (2), pp. 148-156.
- Thorne, S., Radford, J. and McCormick, J. (1997) 'The multiple meanings of long term gastrostomy in children with severe disability', *Journal of Paediatric Nursing*, 12 (2), pp. 89-99.

Appendix B: Data Extraction Sheet

Example citation: Brotherson, M. J., Oakland, M. J., Secrist-Mertz, C., Litchfield, R. and et al. (1995) 'Quality of life issues for families who make the decision to use a feeding tube for their child with disabilities', *Journal of the Association for Persons with Severe Handicaps*, 20 (3), pp. 202-212.

Primary Topic of Exploration	Origin	Theoretical perspective	Children			Adult participants backgrounds and recruitment	Timing of data Collection (pre/post GT)
			Diagnosis	No.	Ages		
Was there a clear statement of the aims of the research?							
Was relevant background literature reviewed?							
Was this research design appropriate to address the aims of the research?							
Was the recruitment strategy appropriate to address the aims of the research?							
Was approval sought from the ethics committee?							
How were ethical issues considered and addressed?							

Brief Overview of Study:	
Data Collection:	
<i>What information were the researchers seeking?</i>	
<i>Was the setting for collecting the data justified?</i>	
<i>Is it clear which methods were used to collect the data? Eg. interviews</i>	
<i>Is the form of data clear? (eg: recordings, field notes)</i>	
<i>Were methods modified during the study?</i>	
<i>Was any modification to methods explained?</i>	
<i>Did the researcher discuss saturation of data?</i>	
<i>Was data collection and analysis simultaneous?</i>	
Data Analysis:	
<i>Is there a description of how the analysis was carried out?</i>	

<i>If thematic analysis is used, is it clear how themes/categories were derived from the data?</i>	
<i>Was any data handling software used eg: NVIVO SPSS</i>	
<i>Was the statistical analysis of quantitative data appropriate?</i>	
<i>Was a statistician consulted?</i>	
<i>Do the researchers explain how illustrative examples were chosen?</i>	
<i>Were sufficient data presented to support the findings?</i>	
Stating the findings:	
<i>Are the findings explicit?</i>	
<i>Is there an adequate discussion of the evidence both for and against the researcher's arguments?</i>	
<i>Has the researcher discussed the credibility of their findings in relation to other research?</i>	
<i>Has the researcher discussed their findings in relation to the original research questions?</i>	
<i>Are the conclusions credible?</i>	
<i>Were contradictory data taken into account?</i>	
Reflexivity:	
<i>Was the relationship between researcher and participants adequately considered?</i>	

<i>Did the researcher critically examine their own role and influence?</i>		
<i>How did the researcher respond to events during the study? Did they consider implications for research design.</i>		
Value of the Research:		
<i>Does the researcher discuss the contribution to existing knowledge?</i>		
<i>Does the researcher identify new areas where research is necessary?</i>		
<i>Do the researchers discuss the generalisability of findings?</i>		
Strengths of study.	Limitations of study	Applicability to proposed research

Appendix C: Search Summary Statistics

SYSTEMATIC SEARCH SUMMARY 2012-2017								
DATABASE	EMBASE	MEDLINE	SCOPUS	CINAHL	COCHRANE	PSYCHINFO	HANDSEARCH	TOTAL
ARTICLES FOUND	282	61	11	4	10	28	17	413
RETAINED AFTER ABSTRACT	12	5	8	4	0	8	13	50
FULL TEXT RETAINED 2012	4	0	1	2	0	4	5	16
ADDITIONAL FULL TEXTS 2017	0	0	1	1	0	0	0	2
TOTAL								18

INCLUDED PAPERS (16)

- Brotherson, M. J., Oakland, M. J., Secrist-Mertz, C., Litchfield, R. and et al. (1995) 'Quality of life issues for families who make the decision to use a feeding tube for their child with disabilities', *Journal of the Association for Persons with Severe Handicaps*, 20 (3), pp. 202-212.
- Craig, G. M. and Scambler, G. (2006) 'Negotiating mothering against the odds: gastrostomy tube-feeding, stigma, governmentality and disabled children', *Social Science & Medicine*, 62 (5), pp. 1115-1125.
- Craig, G. M., Scambler, G. and Spitz, L. (2003) 'Why parents of children with neurodevelopmental disabilities requiring gastrostomy feeding need more support', *Developmental Medicine & Child Neurology*, 45 (3), pp. 183-8.
- Guirriere, D., McKeever, P., LLeWellan-Thomas, H. and Berall, G. (2003) 'Mothers' decisions about gastrostomy tube insertion in children. Factors contributing to uncertainty', *Developmental Medicine and Child Neurology*, 45, pp. 470-476.
- Martinez-Costa, C., Borraz, S., Benlloch, C., Lopez-Saiz, A., Sanchiz, V. and Brines, J. (2011) 'Early decision of gastrostomy tube insertion in children with severe developmental disability: a current dilemma', *Journal of Human Nutrition & Dietetics*, 24 (2), pp. 115-21.
- Morrow, A. M., Quine, S. and Craig, J. C. (2007) 'Health professionals' perceptions of feeding-related quality of life in children with quadriplegic cerebral palsy', *Child: Care, Health & Development*, 33 (5), pp. 529-538.
- Morrow, A. M., Quine, S., Loughlin, E. V. O. and Craig, J. C. (2008) 'Different priorities: a comparison of parents' and health professionals' perceptions of quality of life in quadriplegic cerebral palsy', *Archives of Disease in Childhood*, 93 (2), pp. 119-25.
- Petersen, M. C., Kedia, S., Davis, P., Newman, L. and Temple, C. (2006) 'Eating and feeding are not the same: caregivers' perceptions of gastrostomy feeding for children with cerebral palsy', *Developmental Medicine & Child Neurology*, 48 (9), pp. 713-7.
- Rouse, L., Herrington, P., Assey, J., Baker, R. and Golden, S. (2002) 'Feeding problems, gastrostomy and families: a qualitative pilot study', *British Journal of Learning Disabilities*, 30, pp. 122-128.
- Sleigh, G. (2005) 'Mothers' voice: a qualitative study on feeding children with cerebral palsy', *Child: Care, Health & Development*, 31(4), pp. 373-383.

- Smith, S. W., Camfield, C. and Camfield, P. (1999) 'Living with cerebral palsy and tube-feeding: A population-based follow-up study', *Journal of Pediatrics*, 135 (3), pp. 307-10.
- Spalding, K. and McKeever, P. (1998) 'Mothers' experiences caring for children with disabilities who require a gastrostomy tube', *Journal of Paediatric Nursing*, 13 (4 August), pp. xx.
- Tawfik, R., Dickson, A., Clarke, M. and Thomas, A. G. (1997) 'Caregivers' perceptions following gastrostomy in severely disabled children with feeding problems', *Developmental Medicine and Child Neurology*, 39 (11), pp. 746-751.
- Thorne, S., Radford, J. and McCormick, J. (1997) 'The multiple meanings of long term gastrostomy in children with severe disability', *Journal of Paediatric Nursing*, 12 (2), pp. 89-99.
- Wilson, M., Gosche, J., Bishop, P., Liu, H., Moore, T. and Nowicki, M. J. (2010) 'Critical analysis of caregiver perceptions regarding gastrostomy tube placement', *Pediatrics International*, 52 (1), pp. 20-25.
- Worley, G., Stevenson, R. D., Rosenbloom, L. and Sullivan, P. B. (2007) 'Castang and Novartis Foundation Conference on Undernutrition in Children with Cerebral Palsy: survey of participants about decision-making for enteral (gastrostomy) feeding', *Journal of Nutritional & Environmental Medicine*, 16 (1), pp. 75-81.

PAPER NOT FOUND (1)

- Henry, P. R. (1999) 'Relinquishing the expected: factors influencing caregiver experience of the placement of a permanent feeding tube in their dependent children', *Unpublished thesis: Indiana University School of Nursing*.

ADDITIONAL PAPERS 2017 (2)

- Alsaggaf, A. H., Jan, M. M., Saadah, O. I., & Alsaggaf, H. M. (2013). percutaneous endoscopic gastrostomy tube placement in children with neurodevelopmental disabilities. *Saudi Medical Journal*, 34(7).
- Brotherton, A., & Abbott, J. (2011). Mothers' Process of Decision-making for Gastrostomy Placement. *Qualitative Health Research*, 22(5), 587–

Appendix D: Extracted Data Table

Study	Origin	Participants				Data Collection Timing		
		Mothers	Fathers	Other Carers	Healthcare	Pre-GT	<12 mths Post-GT	>12 mths Post-GT
Alsaggaf et al (2013)	SAUDI ARABIA	30 parents unspecified		0	0		30 (2-144 months, mean 39)	
Brotherson et al (1995)	USA	8	5	0	0	3	2	3
Brotherton & Abbott (2011)	UK	17	0	3 Foster Mothers	0	0	20 (1-132 months)	
Craig et al (2003)	UK	22	0	0	0	22	0	0
Craig & Scambler (2006)	UK	22	0	0	0	22	22	0
Guirriere et al (2003)	CANADA	50	0	FMs included	0	0	50 (< 48 hours)	0
Martinez-Costa et al (2011)	SPAIN	26 caregivers unspecified			0	0	26 Post (timing not stated)	
Morrow et al (2007)	AUSTRALIA	0	0	0	18 paedcs, 15 nurses, 13 Allied	Not applicable		
Morrow et al (2008)	AUSTRALIA	17	2	1 FM, 1 sister	0	9 (No GT)	11 Current GT, 1 past (timing varied)	
Peterson et al (2006)	USA	21	0	3 FM, 2 GM	0	0	26 (3 months to 15 years 9 months)	
Rouse et al (2002)	UK	2 parents unspecified		0	varied	0	2 (timing not stated)	
Sleigh (2005)	UK	9	0	1 GM, 1 GF	0	4 (no GT planned)	6 (timing varied)	
Smith et al (1999)	CANADA	27	1	12 Care Home	0	0	40 (mean 3.5 years)	
Spalding and McKeever (1998)	CANADA	12	0	0	0	0	12 (mean 4 years)	
Tawfik et al (1997)	UK	38 caregivers unspecified			0	0	38 (0.2-3.8 years, median 1 year)	
Thorne et al (1997)	CANADA	3 parents unspecified		4 foster carers	16 nurses	0	23 (several years)	
Wilson et al (2010)	USA	64 caregivers unspecified.			0	45	19 (at least 6 months)	
Worley et al (2007)	UK	0	0	0	17 physicians	Fictional cases		

Appendix E: Favourable Ethical Opinion

NRES Committees - North of Scotland

Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558474
Facsimile: 01224 558609
Email: nosres@nhs.net



17 May 2012

Mrs Karen Margaret Holt
Sir James Spence Institute
Royal Victoria Infirmary
NEWCASTLE
NE1 4LP

Dear Mrs Holt

Study title: Working with parents of children who may have feeding difficulties: Exploring information sharing and support for families
REC reference: 12/NS/0056
Protocol number: 6123

The Proportionate Review Sub-Committee of the NRES Committees - North of Scotland (1) reviewed the above application by correspondence.

Ethical opinion

On behalf of the Committee, the Proportionate Review Sub-Committee gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Appendix F: Favourable opinion for Study Amendment

NRES Committees - North of Scotland

Summerfield House
2 Eday Road
Aberdeen
AB15 6RE

Telephone: 01224 558458
Facsimile: 01224 558609
Email: nosres@nhs.net



21 March 2013

Mrs Karen Margaret Holt
Sir James Spence Institute
Royal Victoria Infirmary
NEWCASTLE
NE1 4LP

Dear Mrs Holt

Study title: Working with parents of children who may have feeding difficulties: Exploring information sharing and support for families
REC reference: 12/NS/0056
Protocol number: 6123
Amendment number: AM02
Amendment date: 21 March 2013
IRAS project ID: 100145

Thank you for your letter of 21 March 2013, notifying the Committee of the above amendment.

The amendment has been considered by the Ethics Co-ordinator.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

Documents received

The documents received were as follows:

Document	Version	Date
Participant Consent Form: Parent	1.0	21 March 2013
Participant Information Sheet: Parent	1.0	21 March 2013
Notification of a Minor Amendment	AM02	21 March 2013
Covering Email		21 March 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

12/NS/0056: Please quote this number on all correspondence

Yours sincerely



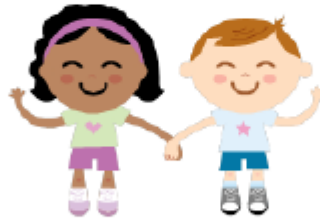
Lisa Shearer
Assistant Ethics Co-ordinator

Copy to: Mr Sean Scott, Research Management and Governance Manager,
Newcastle upon Tyne Hospitals NHS foundation trust.
Dr Gillian Gatenby

Appendix G: Example Information sheet

Working with parents of children who may have feeding difficulties

Information Letter for Children



What is this about?

Some children have problems eating and drinking. We are doing a research project about feeding children through a tube in their tummy. We are asking you if you would like to take part in the project. It will help us find out how parents decide that their child should have a tube put in their tummy.

This letter tells you about the research. Please read the letter and talk to your family about it, if you want to.

Why have I been chosen?

You have been chosen because you had some problems eating or drinking. Someone in your family has told us that you helped decide the best thing to do about your eating and drinking.

If I take part, what will I be asked to do?

A researcher, Karen Holt, will talk to you about the things that you thought were important when choosing what to do about putting a tube in your tummy. It will take about half an hour.

Do I have to take part?

No. It is up to you whether or not you take part. If you agree to take part you can stop at any time. You don't have to say why. We won't mind!

Where will I do the talking?

Karen will come to your house to talk about the project. Or you can come to the hospital if you like.

Who will know that I am taking part?

Only the people doing the research and your family and medical team will know that you are taking part. However, if you tell us something that makes us worry about you, then we may have to tell your parent or a member of the hospital team.

Can I talk to someone before agreeing to take part?

Yes, you can talk to your parents or to us if you like. If you or your parents have any questions you can contact us by phone or e-mail. Our contact details are:

Karen Holt PhD Student Telephone: 0191 282 3762 E-mail: k.m.holt@newcastle.ac.uk
Dr. Lindsay Pennington Speech and Language Therapist Telephone 0191 282 1360 E-mail: Lindsay.Pennington@ncl.ac.uk
Dr. Jeremy Parr Paediatrician Telephone 0191 282 5966 E-mail: Jeremy.Parr@ncl.ac.uk

If you want to take part in this project please fill in the form. You can send the form back to us in the envelope. The other copy of the form and the letter are for you to keep. We will then get in touch to arrange a time to meet with you.

Thank you for reading this letter

Appendix H: Example Consent Form

Working with parents of children who may have feeding difficulties

Mrs Karen Holt, Dr Jeremy Parr, Dr Tim Rapley, Professor Richard Thomson, Dr Lindsay Pennington

PARENT CONSENT FORM

Institute of Health and Society
 Sir James Spence Institute
 Royal Victoria Infirmary
 Newcastle upon Tyne
 NE1 4LP
 Tel: 0191 282 3762
 Email: k.m.holt@newcastle.ac.uk

For research team use:
 Centre number:
 Study number:
 Clinician ID Number:

Please initial each of the boxes below if you agree with the statements

1. I confirm that I have read and understand the Parent Information Sheet dated 10 th December 2012 (version 1.0) for the above study and have had adequate opportunity to consider the information and ask questions	
2. I understand that relevant sections of my child's medical notes such as letters and reports that relate to my child's feeding may be requested by the research team. I give permission for the research team to have access to my child's medical records and for them to be allowed copies of relevant letters and reports.	
3. I understand that relevant sections of my child's medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS trust, where it is relevant to this research. I give permission for these individuals to have access to my child's medical records	
4. I understand that my participation is entirely voluntary. I am free to withdraw at any time and do not have to give a reason. My child's care will not be affected.	
5. I agree to take part in interviews about making decisions around gastrostomy feeding.	
6. I agree that interviews about decisions around gastrostomy feeding can be audio- recorded for this research.	
7. I understand that the things I say during the research may be quoted in reports about the study. However, any quotes used will be anonymous and no personal information which could identify me will be used.	
8. I agree to help identify the people who were important to my decision about gastrostomy feeding.	
9. I agree to take part in the above study.	

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

References

- Aberegg, S. K., Arkes, H., & Terry, P. B. (2006). Failure to adopt beneficial therapies caused by bias in medical evidence evaluation. *Medical Decision Making*, 26(6), 575–582.
- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities*, 33(6), 2122–2140.
- Allwood, R., Pilnick, A., O'Brien, R., Goldberg, S., Harwood, R., & Beeke, S. (2017). Should I stay or should I go? How healthcare professionals close encounters with people with dementia in the acute hospital setting. *Social Science & Medicine*, 191, 212–225.
- Alsaggaf, A. H., Jan, M. M., Saadah, O. I., & Alsaggaf, H. M. (2013). Percutaneous endoscopic gastrostomy tube placement in children with neurodevelopmental disabilities. *Saudi Medical Journal*, 34(7), 695–700
- Andrew, M. J., Parr, J. R., & Sullivan, P. (2012). Feeding difficulties in children with cerebral palsy. *Archives of Disease in Childhood: Education and Practice Edition*, 97(6), 222–229
- Archibald, M. M., Caine, V., Ali, S., Hartling, L., & Scott, S. D. (2015). What is left unsaid: an interpretive description of the information needs of parents of children with asthma. *Research in Nursing & Health*, 38(1), 19–28.
- Ardiel, E. L., & Rankin, C. H. (2010). The importance of touch in development. *Paediatrics & Child Health*, 15(3), 153–156.
- Armstrong, E. A., Radford, M. J., & Thorne, S. (1997). Long-term gastrostomy in children: caregiver coping. *Gastroenterology Nursing : The Official Journal of the Society of Gastroenterology Nurses and Associates*, 20(2), 46–53.
- Arvedson, J. (2008). Assessment of pediatric dysphagia and feeding disorders: Clinical and instrumental approaches. *Developmental Disabilities Research Reviews*, 14(2), 118–127.
- Arvedson, J. (2013). Feeding children with cerebral palsy and swallowing difficulties.

European Journal of Clinical Nutrition, 67 Suppl 2, S9-12.

Arvedson, J., & Brodsky, L. (2002). *Pediatric Swallowing and Feeding, Assessment and Management*. (Second). 2nd ed. Albany, NY: Singular Publishing Group.

Arvedson, J., & Delaney, A. (2011). Oromotor disorders in childhood. In M. Roig-Quilis & L. Pennington (Eds.) (pp. 25-41). Bracelona: Viguera.

Avis, M. (2003). Do we need methodological theory to do qualitative research? *Qualitative Health Research*, 13(7), 995-1004.

Avitsland, T., Kristensen, C., Emblem, R., Veenstra, M., Mala, T., Bjørnland, K. (2006). Percutaneous endoscopic gastrostomy in children: a safe technique with major symptom relief and high parental satisfaction. *Journal of Pediatric Gastroenterology and Nutrition*, 43(5), 624-628.

Åvitsland, T. L., Birketvedt, K., Bjørnland, K., Emblem (2013). Parent-reported effects of gastrostomy tube placement. *Nutrition in Clinical Practice*, 28(4), 493-498.

Åvitsland, T. L., Faugli, A., Pripp, A. H., Malt, U. F., Bjørnland, K., Emblem, R., Emblem, R. (2012). Maternal psychological distress and parenting stress after gastrostomy placement in children. *Journal of Pediatric Gastroenterology and Nutrition*, 55(5), 562-586.

Bahr, D., & Johanson, N. (2013). A family-centered approach to feeding disorders in children (Birth to 5-Years). *SIG 13 Perspectives on Swallowing and Swallowing Disorders (Dysphagia)*, 22(4), 161-171.

Bailey, D. B. (2007). Introduction: Family adaptation to intellectual and developmental disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(4), 291-292.

Bar-Yam, N. B., & Darby, L. (1997). Fathers and breastfeeding: a review of the literature. *Journal of Human Lactation*, 13(1), 45-50.

Barnes, C. (1991). *Disabled people in Britain and Discrimination. A case for anti-discrimination legislation*. London: Hurst and company.

Barrera, M. E., & Maurer, D. (1981). recognition of mother's photographed face by the

- three-month-old infant. *Child Development*, 52(2), 714–716.
- Bellou, T. F. (2011). Skinfold measurements enhance nutrition assessments and care planning for children with developmental delays and disabilities. *ICAN: Infant, Child, & Adolescent Nutrition*, 3(3), 158–170.
- Benjasuwantep, B., Chaithirayanon, S., & Eiamudomkan, M. (2013). Feeding problems in healthy young children: prevalence, related factors and feeding practices. *Pediatric Reports*, 5(2), 38–42.
- Berridge, K. C. (1996). Food reward: Brain substrates of wanting and liking. *Neuroscience & Biobehavioral Reviews*, 20(1), 1–25.
- Berridge, K. C., Ho, C.-Y., Richard, J. M., & DiFeliceantonio, A. G. (2010). The tempted brain eats: Pleasure and desire circuits in obesity and eating disorders. *Brain Research*, 1350, 43–64.
- Blackman, J. A., & Nelson, C. L. (1987). Rapid introduction of oral feedings to tube-fed patients. *Journal of Developmental and Behavioral Pediatrics* 8(2), 63–67.
- Brackett, K., Arvedson, J., & Manno, C. J. (2006). Pediatric feeding and swallowing disorders: General assessment and intervention. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia)*, 15(3), 10–14.
- Braegger, C., Decsi, T., Dias, J.A., Hartman, C., Kolacek, S., Koletzko, B., Koletzko, S., Mihatsch, W., Moreno, L., Puntis, J. and Shamir, R. (2010). Practical approach to paediatric enteral nutrition: a comment by the ESPGHAN committee on nutrition. *Journal of pediatric gastroenterology and nutrition*, 51(1), 110-122.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brotherson, M. J., Oakland, M. J., Secrist-Mertz, C., Litchfield, R., & Larson, K. (1995). Quality of life issues for families who make the decision to use a feeding tube for their child with disabilities. *Journal of the Association for Persons with Severe Handicaps*, 20 (3), 202–212.
- Brotherton, A., & Abbott, J. (2011). Mothers' Process of Decision Making for Gastrostomy Placement. *Qualitative Health Research*, 22(5), 587–594.

- Brotherton, A., Abbott, J., & Aggett, P. J. (2007). The impact of percutaneous endoscopic gastrostomy feeding in children; the parental perspective. *Child: Care, Health and Development*, 33(5), 539–546.
- Brotherton, A., Abbott, J., Hurley, M., & Aggett, P. J. (2007). Home enteral tube feeding in children following percutaneous endoscopic gastrostomy: perceptions of parents, paediatric dietitians and paediatric nurses. *Journal of Human Nutrition and Dietetics : The Official Journal of the British Dietetic Association*, 20(5), 431–439.
- Brown, A., & Davies, R. (2014). Fathers' experiences of supporting breastfeeding: challenges for breastfeeding promotion and education. *Maternal & Child Nutrition*, 10(4), 510–526.
- Brown, J. M. (2013). Recurrent grief in mothering a child with an intellectual disability to adulthood: grieving is the healing. *Child & Family Social Work*, 21(1), 113–122.
- Bruce, E. J., Schultz, C. L., & Smyrniotis, K. X. (1996). A longitudinal study of the grief of mothers and fathers of children with intellectual disability. *British Journal of Medical Psychology*, 69(1), 33–45.
- Bruce, E. J., Schultz, C. L., Smyrniotis, K. X., & Schultz, N. C. (1994). Grieving related to development: A preliminary comparison of three age cohorts of parents of children with intellectual disability. *British Journal of Medical Psychology*, 67(1), 37–52.
- Bryant - Waugh, R., Markham, L., Kreipe, R.E. and Walsh, B.T.(2010) Feeding and eating disorders in childhood. *International Journal of Eating Disorders*, 43(2),98-111.
- Bryman, A., Becker, S., & Sempik, J. (2008). Quality criteria for quantitative, qualitative and mixed methods research: a view from social policy. *International Journal of Social Research Methodology*, 11(4), 261–276.
- Byrne, P. S., & Long, B. E. (1976). *Doctors talking to patients: a study of the verbal behaviour of general practitioners consulting in their surgeries*. London: H.M.S.O.
- Calderón, C., Gómez-López, L., Martínez-Costa, C., Borraz, S., Moreno-Villares, J. M., & Pedrón-Giner, C. (2011). Feeling of burden, psychological distress, and anxiety among primary caregivers of children with home enteral nutrition. *Journal of Pediatric Psychology*, 36(2), 188–195.

- Callery, P. (1997). Maternal knowledge and professional knowledge: co-operation and conflict in the care of sick children. *International Journal of Nursing Studies*, 34(1), 27-34.
- Cans, C., De-la-Cruz, J., & Mermet, M.-A. (2017). Epidemiology of cerebral palsy. *Paediatrics and Child Health*, 18(9), 393-398.
- Carpenter, B., & Towers, C. (2008). Recognising fathers: the needs of fathers of children with disabilities. *Support for Learning*, 23(3), 118-125.
- Carter, S. M., & Little, M. (2007). Justifying knowledge, justifying method, taking action: epistemologies, methodologies, and methods in qualitative research. *Qualitative Health Research*, 17(10), 1316-1328.
- Cass, H., Wallis, C., Reg, M. R., Reilly, S., & McHugh, K. (2007). Assessing pulmonary consequences of dysphagia in children with neurological disabilities: when to intervene? *Developmental Medicine & Child Neurology*, 47(5), 347-352.
- Castro, D. C., & Berridge, K. C. (2014). Advances in the neurobiological bases for food 'liking' versus 'wanting'. *Physiology & Behavior*, 136, 22-30.
- Chang, W.-K., & Hsieh, T.-Y. (2013). Safety of percutaneous endoscopic gastrostomy in high-risk patients. *Journal of Gastroenterology and Hepatology*, 28(S4), 118-122.
- Charles, C., Gafni, A., & Whelan, T. (1997). Shared decision-making in the medical encounter: What does it mean? (Or it takes, at least two to tango). *Social Science and Medicine*, 44(5), 681-692.
- Charles, C., Gafni, A., & Whelan, T. (1999a). Decision-making in the physician-patient encounter: Revisiting the shared treatment decision-making model. *Social Science and Medicine*, 49(5), 651-661.
- Charles, C., Gafni, A., & Whelan, T. (1999b). Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49(5), 651-661.
- Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. London: SAGE Publications.

- Coad, J., Toft, A., Lapwood, S., Manning, J., Hunter, M., Jenkins, H., Sadlier, C., Hammonds, J., Kennedy, A., Murch, S. and Widdas, D., (2016). Blended foods for tube-fed children: a safe and realistic option? A rapid review of the evidence. *Archives of disease in childhood, Archives of Disease in Childhood*, 102(3):274-278.
- Coley, R. L. (2001). (In)visible men. Emerging research on low-income, unmarried, and minority fathers. *The American Psychologist*, 56(9), 743-753.
- Cooke, L., & Fildes, A. (2011). The impact of flavour exposure in utero and during milk feeding on food acceptance at weaning and beyond. *Appetite*, 57(3), 808-811.
- Corbin, J., & Strauss, A. (2008). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (third). Thousand Oaks, CA: Sage Publications.
- Craig, G. M. (2013). Psychosocial aspects of feeding children with neurodisability. *European Journal of Clinical Nutrition*, 67 (S2), S17-20.
- Craig, G.M., Carr, L.J., Cass, H., Hastings, R.P., Lawson, M., Reilly, S., Ryan, M., Townsend, J. and Spitz, L. (2006). Medical, surgical, and health outcomes of gastrostomy feeding. *Developmental medicine and child neurology*, 48(5), pp.353-360.
- Craig, G. M., & Higgs, P. (2012). Risk owners and risk managers: Dealing with the complexity of feeding children with neurodevelopmental disability: Negotiating and communicating health risk. *Health, Risk and Society*, 14(7-8), 627-637.
- Craig, G. M., & Scambler, G. (2006). Negotiating mothering against the odds: Gastrostomy tube feeding, stigma, governmentality and disabled children. *Social Science & Medicine*, 62(5), 1115-1125.
- Craig, G. M., Scambler, G., & Spitz, L. (2003). Why parents of children with neurodevelopmental disabilities requiring gastrostomy feeding need more support. *Developmental Medicine & Child Neurology*, 45(3), 183-188.
- Crotty, M. (1998). *The Foundations of Social Research: Meaning and Perspective in the Research Process*. Thousand Oaks, CA: SAGE Publications.
- Dahlseng, M.O., Andersen, G.L., Da graca andrada, M., Arnaud, C., Balu, R., De la Cruz,

- J., Folha, T., Himmelmann, K., Horridge, K., Júlíusson, P.B. and Pålman, M., (2012). Gastrostomy tube feeding of children with cerebral palsy: variation across six European countries. *Developmental Medicine & Child Neurology*, 54(10), 938-944.
- Daly, M., & Lewis, J. (2000). The concept of social care and the analysis of contemporary welfare states. *The British Journal of Sociology*, 51(2), 281-298.
- Davison, K., Charles, J., Khandpur, N., & Nelson, T. (2017). Fathers' perceived reasons for their underrepresentation in child health research and strategies to increase their involvement. *Maternal and Child Health Journal*, 21(2), 267-274.
- Day, S. M., Strauss, D. J., Vachon, P. J., Rosenbloom, L., Shavelle, R. M., & Wu, Y. W. (2007). Growth patterns in a population of children and adolescents with cerebral palsy. *Developmental Medicine & Child Neurology*, 49(3), 167-171.
- De Montigny, F., Girard, M.-E., Lacharité, C., Dubeau, D., & Devault, A. (2013). Psychosocial factors associated with paternal postnatal depression. *Journal of Affective Disorders*, 150(1), 44-49.
- de Montigny, F., & Lacharité, C. (2004). Fathers' perceptions of the immediate postpartal period. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 33(3), 328-339.
- Delaney, A. L., & Arvedson, J. (2008). Development of swallowing and feeding: prenatal through first year of life. *Developmental Disabilities Research Reviews*, 14(2), 105-117.
- DeMarle, D., & Le Roux, P. (2001). The life cycle and disability: experiences of discontinuity in child and family development. *Journal of Loss and Trauma*, 6(1), 29-43.
- Doucet, A. (2006). 'Estrogen-filled worlds': Fathers as primary caregivers and embodiment. *The Sociological Review*, 54(4), 696-716.
- Douglas, M. (1966). Purity-Danger excerpts. *Purity and Danger: An Analysis of the Concepts of Pollution and Taboo*. London Ark
- Earle, S. (2017). Why some women do not breast feed: bottle feeding and fathers' role. *Midwifery*, 16(4), 323-330.
- Edwards, S., Davis, A.M., Bruce, A., Mousa, H., Lyman, B., Cocjin, J., Dean, K., Ernst, L.,

- Almadhoun, O. and Hyman, P., (2016). Caring for tube-fed children: a review of management, tube weaning, and emotional considerations. *Journal of Parenteral and Enteral Nutrition*, 40(5), 616-622.
- Elwyn, G., Edwards, A., Gwyn, R., & Grol, R. (1999). Towards a feasible model for shared decision making: focus group study with general practice registrars. *BMJ (Clinical Research Ed.)*, 319(7212), 753-756.
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S. and Edwards, A., (2012). Shared decision making: a model for clinical practice. *Journal of general internal medicine*, 27(10), 1361-1367.
- Emanuel, E. J., & Emanuel, L. L. (1992). Four models of the physician-patient relationship. *Jama*, 267(16), 2221-2226.
- Estrem, H. H., Pados, B. F., Park, J., Knafl, K. A., & Thoyre, S. M. (2016). Feeding problems in infancy and early childhood: Evolutionary concept analysis. *Journal of Advanced Nursing*, 73(1), 56-70.
- Faircloth, C. (2010). 'What Science Says is Best': Parenting Practices, Scientific Authority and Maternal Identity. *Sociological Research Online*, 15(4), 4.
- Fantz, R. L. (1961). The origin of form perception. *Scientific American*, 204, 66-72.
- Ferluga, E. D. E. D., Sathe, N. A. N. A., Krishnaswami, S., & Mcpheeters, M. L. (2014). Surgical intervention for feeding and nutrition difficulties in cerebral palsy: A systematic review. *Developmental Medicine and Child Neurology*, 56(1), 753-756.
- Fiese, B. H., Foley, K. P., & Spagnola, M. (2006). Routine and ritual elements in family mealtimes: Contexts for child well-being and family identity. *New Directions for Child and Adolescent Development*, (111), 67-89.
- Fiks, A. G., & Jimenez, M. E. (2010). The promise of shared decision-making in paediatrics. *Acta Paediatrica (Oslo, Norway: 1992)*, 99(10), 1464-1466.
- Fiks, A. G., Localio, A. R., Alessandrini, E. A., Asch, D. A., & Guevara, J. P. (2010). Shared decision-making in pediatrics: a national perspective. *Pediatrics*, 126(2), 306-314.

- Fischer, K. W. (1980). A theory of cognitive development: The control and construction of hierarchies of skills. *Psychological Review*, 87(6), 477–531.
- Fisher, B., & Tronto, J. (1990). Toward a feminist theory of caring. In E. K. Abel & M. K. Nelson (Eds.), *Circles of care: Work and identity in women's lives* (pp. 29–54). Albany New York: State University of New York Press.
- Flynn, D., Knoedler, M. A., Hess, E. P., Murad, M. H., Erwin, P. J., Montori, V. M., & Thomson, R. G. (2012). Engaging patients in health care decisions in the emergency department through shared decision-making: a systematic review. *Academic Emergency Medicine*, 19(8), 959–967.
- Fox, D., Campagna, E. J., Friedlander, J., Partrick, D. A., Rees, D. I., & Kempe, A. (2014). National trends and outcomes of pediatric gastrostomy tube placement. *Journal of Pediatric Gastroenterology and Nutrition*, 59(5), 582–588.
- Fox, N. J. (1993). Discourse, organisation and the surgical ward round. *Sociology of Health & Illness*, 15, 16–42.
- Fröhlich, T., Richter, M., Carbon, R., Barth, B., & Köhler, H. (2010). percutaneous endoscopic gastrostomy in infants and children. *Alimentary Pharmacology & Therapeutics*, 31(8), 788–801.
- Fung, E.B., Samson-Fang, L., Stallings, V.A., Conaway, M., Liptak, G., Henderson, R.C., Worley, G., O'Donnell, M., Calvert, R., Rosenbaum, P. and Chumlea, W., (2002) Feeding dysfunction is associated with poor growth and health status in children with cerebral palsy. *Journal of the American Dietetic Association*, 102(3), 361-373.
- Gabe, J., Olumide, G., & Bury, M. (2004). 'It takes three to tango': A framework for understanding patient partnership in paediatric clinics. *Social Science and Medicine*, 59(5), 1071–1079.
- Gamble, D., & Morse, J. M. (2017). Fathers Of Breastfed Infants: Postponing and Types of Involvement. *Journal of Obstetric, Gynecologic & Neonatal Nursing*, 22(4), 358–365.
- Gantasala, S., Sullivan, P., & Thomas, A. G. (2013). Gastrostomy feeding versus oral feeding alone for children with cerebral palsy. In S. Gantasala (Ed.), *Cochrane*

Database of Systematic Reviews. Chichester, UK: John Wiley & Sons, Ltd.

Garfinkel, H. (1967). *Studies in Ethnomethodology*. Englewood Cliffs, NJ: Prentice-Hall.

Gauderer, M. W. L., Ponsky, J. L., & Izant, R. J. (1980). Gastrostomy without laparotomy: a percutaneous endoscopic technique. *Journal of Pediatric Surgery*, 15(6), 872–875.

Gerstein, E. D., Crnic, K. A., Blacher, J., & Baker, B. L. (2009). Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. *Journal of Intellectual Disability Research*, 53(12), 981–997.

Gewolb, I. H., & Vice, F. L. (2006). Maturation changes in the rhythms, patterning, and coordination of respiration and swallow during feeding in preterm and term infants. *Developmental Medicine and Child Neurology*, 48(7), 589–94.

Gisel, E. (2008). Effect of food texture on the development of chewing of children between six months and two years of age. *Developmental Medicine & Child Neurology*, 33(1), 69–79.

Gisel, E., & Patrick, J. (1988). Identification of children with cerebral palsy unable to maintain a normal nutritional state. *The Lancet*, 331(8580), 283–286.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. London: Prentice-Hall.

Goffman, E. (1981). *Forms of Talk*. Pennsylvania: University of Pennsylvania Press.

Goffman, E. (1990). *The Presentation of Self in Everyday Life*. Garden City, New York: Doubleday.

Gomes, C. A., Andriolo, R. B., Bennett, C., Lustosa, S. A., Matos, D., Waisberg, D. R., & Waisberg, J. (2015). Percutaneous endoscopic gastrostomy versus nasogastric tube feeding for adults with swallowing disturbances. In C. A. Gomes Jr (Ed.), *Cochrane Database of Systematic Reviews*. Chichester, UK: John Wiley & Sons, Ltd.

Goode, D. (1994). *A World without Words* Temple University Press: Philadelphia

Graham, H. (1991). The concept of caring in feminist research: the case of domestic service. *Sociology*, 25(1), 61–78.

Guba, E. G., & Lincoln, Y. S. (. (1994). Competing paradigms in qualitative research. In

- N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (p. 105–117.). London: Sage Publications.
- Guirriere, D., McKeever, P., LLeWellan-Thomas, H., & Berall, G. (2003). Mothers' decisions about gastrostomy tube insertion in children. Factors contributing to uncertainty. *Developmental Medicine and Child Neurology*, *45*, 470–476.
- Halpern, S.D., Ubel, P.A. and Asch, D.A., (2007). Harnessing the power of default options to improve health care. *The New England journal of medicine*, *357*(13), p.1340.
- Harris, R., Noble, C., & Lowers, V. (2017). Does information form matter when giving tailored risk information to patients in clinical settings? A review of patients' preferences and responses. *Patient Preference and Adherence*, *11*, 389–400.
- Hart, R. I., Foster, H. E., McDonagh, J. E., Thompson, B., Kay, L., Myers, A., & Rapley, T. (2015). Young people's decisions about biologic therapies: who influences them and how? *Rheumatology*, *54*(7), 1294–1301.
- Havidich, J. E., Beach, M., Dierdorf, S. F., Onega, T., Suresh, G., & Cravero, J. P. (2016). Preterm versus term children: analysis of sedation/anesthesia adverse events and longitudinal risk. *Pediatrics*, *137*(3), e20150463.
- Head, E. (2017). Understanding Mothers' Infant Feeding Decisions and Practices. *Social Sciences*, *6*(2), 50.
- Higgs, S. (2016). Cognitive processing of food rewards. *Appetite*, *104*, 10–17.
- Hobson, L., & Noyes, J. (2011). Fatherhood and children with complex healthcare needs: qualitative study of fathering, caring and parenting. *BMC Nursing*, *10*(1), 5.
- Jackson, C., Cheater, F. M., & Reid, I. (2008). A systematic review of decision support needs of parents making child health decisions. *Health Expectations*, *11*(3), 232–251.
- Jawadi, A. H., Casamassimo, P. S., Griffen, A., Enrile, B., & Marccone, M. (2004). Comparison of oral findings in special needs children with and without gastrostomy. *Pediatric Dentistry*, *26*(3), 283–288.
- Jay, M. A., Thomas, B. M., Nandi, R., & Howard, R. F. (2017). Higher risk of opioid-induced respiratory depression in children with neurodevelopmental disability: a

retrospective cohort study of 12 904 patients. *BJA: British Journal of Anaesthesia*, 118(2), 239–246.

Johnson, H., Desai, M., & Reddihough, D. S. (2011). Saliva and drooling. In M. Roig-Quilis & L. Pennington (Eds.), *Oromotor disorders in childhood* (pp. 333–348). Barcelona: Viguera.

Johnson, T. W., Spurlock, A., & Galloway, P. (2013). Blenderized formula by gastrostomy tube: A case presentation and review of the literature. *Topics in Clinical Nutrition*, 28(1), 84–92

Kastner, T., Criscione, T., & Walsh, K. (1994). The role of tube feeding in the mortality of profoundly disabled people with severe mental retardation. *Archives of Pediatrics & Adolescent Medicine*, 148(5), 537–538.

Kearney, P. M., & Griffin, T. (2001). Between joy and sorrow: being a parent of a child with developmental disability. *Journal of Advanced Nursing*, 34(5), 582–592.

Kerwin, M. E. (1999). Empirically supported treatments in pediatric psychology: severe feeding problems. *Journal of Pediatric Psychology*, 24(3), 193–214.

Khandpur, N., Blaine, R. E., Fisher, J. O., & Davison, K. K. (2014). Fathers' child feeding practices: A review of the evidence. *Appetite*, 78, 110–121.

Kirk. (1998). Families' experiences of caring at home for a technology-dependent child: a review of the literature. *Child: Care, Health and Development*, 24(2), 101–114.

Kirk, S., & Glendinning, C. (2002). Supporting 'expert' parents-professional support and families caring for a child with complex health care needs in the community. *International Journal of Nursing Studies*, 39(6), 625–635.

Kirk, S., Glendinning, C., & Callery, P. (2005). Parent or nurse? The experience of being the parent of a technology-dependent child. *Journal of Advanced Nursing*, 51(5), 456–464.

Kisler, J. (2014). Parental reaction to disability. *Paediatrics and Child Health*, 20(7), 309–314.

Knight, K. (2013). The changing face of the 'good mother': trends in research into families

- with a child with intellectual disability, and some concerns. *Disability & Society*, 28(5), 660–673.
- Kohler, H., Lang, T., & Behrens, R. (2008). Buried bumper syndrome after percutaneous endoscopic gastrostomy in children and adolescents. *Endoscopy*, 40 Suppl 2, E85-6.
- Kuperminc, M. N., Gottrand, F., Samson-Fang, L., Arvedson, J., Bell, K., Craig, G. M., & Sullivan, P. (2013). Nutritional management of children with cerebral palsy: a practical guide. *European Journal of Clinical Nutrition*, 67(S2), S21–S23.
- Kuperminc, M. N., & Stevenson, R. D. (2008). Growth and nutrition disorders in children with cerebral palsy. *Developmental Disabilities Research Reviews*, 14(2), 137–146.
- Kvello, M., Avitsland, T. L., Knatten, C. K., Pripp, A. H., Aabakken, L., Emblem, R., & Bjørnland, K. (2016). Trends in the use of gastrostomies at a tertiary paediatric referral centre. *Scandinavian Journal of Gastroenterology*, 51(5), 625-632.
- Landsman, G. (2003). Emplotting children's lives: developmental delay vs. disability. *Social Science & Medicine*, 56(9), 1947–1960.
- Landsman, G. (2005). Mothers and models of disability. *Journal of Medical Humanities*, 26(2), 121–139.
- Langridge, D. (2004). *Research methods and data analysis in psychology*. England: Prentice-Hall.
- Lawton, J. (1998). Contemporary hospice care: the sequestration of the unbounded body and 'dirty dying'. *Sociology of Health & Illness*, 20(2), 121–143.
- Leder, D. (1990). *The absent body*. Chicago: Chicago University Press.
- Lee, E. (2011). Breast-Feeding Advocacy, Risk Society and Health Moralism: A Decade's Scholarship. *Sociology Compass*, 5(12), 1058–1069.
- Lefton-Greif, M. A. (2008). Physical medicine and rehabilitation clinics of North America. *Physical Medicine and Rehabilitation Clinics of North America*, 19(4), 837–51.
- Leopold, N. A., & Kagel, M. C. (1997). Dysphagia—ingestion or deglutition?: a proposed paradigm. *Dysphagia*, 12(4), 202–206.
- Licqurish, S., & Seibold, C. (2011). Applying a contemporary grounded theory

methodology. *Nurse Researcher*, 18(4), 11–16.

Linell, P., Adelswärd, V., Sachs, L., Bredmar, M. and Lindstedt, U. (2002). Expert talk in medical contexts: Explicit and implicit orientation to risks. *Research on Language and Social Interaction*, 35(2), 195–218.

Lipstein, E. A., Brinkman, W. B., & Britto, M. T. (2012). What is known about parents' treatment decisions? a narrative review of pediatric decision making. *Medical Decision Making*, 32(2), 246–258.

Lipstein, E.A., Brinkman, W.B., Fiks, A.G., Hendrix, K.S., Kryworuchko, J., Miller, V.A., Prosser, L.A., Ungar, W.J. and Fox, D. (2015). An emerging field of research: challenges in pediatric decision making. *Medical Decision Making*, 35(3), 403–408.

Littman, H., VanderBrug Medendorp, S., & Goldfarb, J. (1994). The decision to breastfeed. *Clinical Pediatrics*, 33(4), 214–219.

Logemann, J. A. (1983). *Evaluation and treatment of swallowing disorders*. Little Brown and Company Boston

Long, T., & Johnson, M. (2000). Rigour, reliability and validity in qualitative research. *Clinical Effectiveness in Nursing*, 4(1), 30–37.

Lorenz, K. (1971). Forward. *Advances in Ethology*, 29(S7), 3–4.

Luiselli, J. K. (1994). Oral feeding treatment of children with chronic food refusal and multiple developmental disabilities. *American Journal on Mental Retardation*. 98 (5) 646-55

Lupton, D. (2013). Infant embodiment and interembodiment: A review of sociocultural perspectives. *Childhood*, 20(1), 37–50.

Ma, I.T., Gray, R.J., Wasif, N., Butler, K.A., Cornella, J.L., Magrina, J.F., Magtibay, P.M., Casey, W.J., Mahabir, R., Rebecca, A.M. and Hunt, K.S. (2017). Outcomes of Concurrent Breast and Gynecologic Risk Reduction Surgery. *Annals of Surgical Oncology*, 24(1), 77–83.

Mahant, S., Friedman, J. N., Connolly, B., Goia, C., & Macarthur, C. (2009). Tube feeding and quality of life in children with severe neurological impairment. *Archives of*

Disease in Childhood, 94(9), 668 -673.

- Mahant, S., Jovcevska, V., & Cohen, E. (2011). Decision-making around gastrostomy-feeding in children with neurologic disabilities. *Pediatrics*. Jun 2011, 127 (6) e1471-e1481; DOI: 10.1542/peds.2010-3007
- Makoul, G., & Clayman, M. L. (2006). An integrative model of shared decision making in medical encounters. *Patient Education and Counseling*, 60(3), 301-312.
- Manikam, R., & Perman, J. (2000). Pediatric feeding disorders. *Journal of Clinical Gastroenterology*, 30(1), 34-46.
- Marchand, V., & Motil, K. J. (2006). Nutrition support for neurologically impaired children: a clinical report of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition. *Journal of pediatric gastroenterology and nutrition*, 43(1), 123-135.
- Marshall, J. L., Godfrey, M., & Renfrew, M. J. (2007). Being a 'good mother': Managing breastfeeding and merging identities. *Social Science & Medicine*, 65(10), 2147-2159.
- Martínez - Costa, C., Borraz, S., Benlloch, C., López - Sáiz, A., Sanchiz, V., & Brines, J. (2011). Early decision of gastrostomy tube insertion in children with severe developmental disability: a current dilemma. *Journal of Human Nutrition and Dietetics*, 24(2), 115-121.
- Martínez-Costa, C., Calderón, C., Gómez-López, L., Borraz, S., & Pedrón-Giner, C. (2013). Satisfaction with gastrostomy feeding in caregivers of children with home enteral nutrition; application of the SAGA-8 questionnaire and analysis of involved factors | Satisfacción con la alimentación mediante gastrostomía en cuidadores de niños con nutri. *Nutricion Hospitalaria*, 28(4).
- Mason, S. J., Harris, G., & Blissett, J. (2005). Tube feeding in infancy: implications for the development of normal eating and drinking skills. *Dysphagia*, 20(1), 46-61.
- Mays, N., & Pope, C. (1995). Qualitative research: Observational methods in health care settings. *BMJ (Clinical Research Ed.)*, 311(6998), 182-184.
- McCann, D., Bull, R., & Winzenberg, T. (2012). The daily patterns of time use for parents of children with complex needs. *Journal of Child Health Care*, 16(1), 26-52.

- McCann, D., Bull, R., & Winzenberg, T. (2014). Sleep deprivation in parents caring for children with complex needs at home. *Journal of Family Nursing*, 21(1), 86–118.
- McGrath, S. J., Splaingard, M. L., Alba, H. M., Kaufman, B. H., & Glicklick, M. (1992). Survival and functional outcome of children with severe cerebral palsy following gastrostomy. *Archives of physical medicine and rehabilitation*, 73(2), 133-137.
- McKeever, P., & Miller, K.-L. (2004). Mothering children who have disabilities: a Bourdieusian interpretation of maternal practices. *Social Science & Medicine*, 59(6), 1177–1191.
- McLaughlin, J. (2006). Conceptualising Intensive Caring Activities: the Changing Lives of Families with Young Disabled Children. *Sociological Research Online*, 11(1), Available at <http://www.socresonline.org.uk/11/1/mclaughlin.html> [accessed 16-October-2017]
- McLaughlin, J., & Coleman-Fountain, E. (2014). The unfinished body: The medical and social reshaping of disabled young bodies. *Social Science & Medicine*, 120, 76–84.
- Mehta, N.M., Corkins, M.R., Lyman, B., Malone, A., Goday, P.S., Carney, L., Monczka, J.L., Plogsted, S.W., Schwenk, W.F. and American Society for Parenteral and Enteral Nutrition (ASPEN) Board of Directors, (2013.) Defining pediatric malnutrition: a paradigm shift toward etiology-related definitions. *Journal of Parenteral and Enteral Nutrition*, 37(4), 460–481.
- Mehta, S., & Farina, A. (1988). Associative stigma: perceptions of the difficulties of college-aged children of stigmatized fathers. *Journal of Social and Clinical Psychology*, 7(2–3), 192–202.
- Mennella, J. A., & Beauchamp, G. K. (1991). Maternal diet alters the sensory qualities of human milk and the nursing behavior. *Pediatrics*, 88(4), 737–744.
- Michaelis, C. A., Warzak, W. J., Stanek, K., & Van Riper, C. (1992). Parental and professional perceptions of problems associated with long-term pediatric home tube feeding. *Journal of the American Dietetic Association*, 92(10), 1235–1238.
- Milanchi, S., & Allins, A. (2007). Early pneumoperitoneum after percutaneous endoscopic gastrostomy in intensive care patients: sign of possible bowel injury.

American Journal of Critical Care , 16(2), 132–136.

- Moerman, M. (1987). *Talking Culture: Ethnography and Conversation Analysis*. Philadelphia: University of Pennsylvania Press.
- Montori, V. M., Gafni, A., & Charles, C. (2006). A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expectations*, 9(1), 25–36.
- Moore, L., & Kirk, S. (2010). A literature review of children's and young people's participation in decisions relating to health care. *Journal of Clinical Nursing*, 19(15–16), 2215–2225.
- Morris, C., Janssens, A., Tomlinson, R., Williams, J., & Logan, S. (2013). Towards a definition of neurodisability: a Delphi survey. *Developmental Medicine & Child Neurology*, 55(12), 1103–1108.
- Morris, S. (1989). Development of oral-motor skills in the neurologically impaired child receiving non-oral feedings. *Dysphagia*, 3(3), 135–154.
- Morrow, A. M., Quine, S., Loughlin, E. V. O., & Craig, J. C. (2008). Different priorities: a comparison of parents' and health professionals' perceptions of quality of life in quadriplegic cerebral palsy. *Archives of Disease in Childhood*, 93(2), 119–125.
- Morse, J. M. (1989). Strategies for sampling. In J. M. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (pp. 117–131). Aspen, rockville: MD.
- Morse, J. M. (1994). Qualitative research: fact or fantasy? In J. M. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 1–8). Thousand Oaks, CA: SAGE Publications.
- Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods*, 1(2), 13–22.
- Moumjid, N., Gafni, A., Bremond, A., Carrere, M.-O., & Bre, A. (2007). shared decision making in the medical encounter: are we all talking about the same thing? *Medical Decision Making*, 27(5), 539–546.

- Murray, C. D., & Sixsmith, J. (1999). The corporeal body in virtual reality. *Ethos*, 27(3), 315–343.
- National Institute for Health and Clinical Excellence. (2014). Health visiting. Available at: www.nice.org.uk/guidance/lgb22/resources/health-visiting-pdf-60521203534021 [accessed 16-October-2017]
- Naureckas, S. M., & Kaufer-Christoffel, K. (1994). Nasogastric or gastrostomy feedings in children with neurologic disabilities. *Clinical Pediatrics*, 33(6), 353–359.
- Neergaard, M. A., Olesen, F., Andersen, R. S., & Sondergaard, J. (2009). Qualitative description -- the poor cousin of health research? *BMC Medical Research Methodology*, 9(1), 52.
- Nettleton, S. (1991). Wisdom, diligence and teeth: discursive practices and the creation of mothers. *Sociology of Health and Illness*, 13(1), 98–111.
- NHS Improvement. (2017). *Never Events reported as occurring between 1 April 2015 and 31 March 2016 final update*. available from <https://improvement.nhs.uk/resources/never-events-data> [accessed 16-October-2017]
- NICE. (2014). *Maternal and child nutrition: Guidance and guidelines* available from <https://www.nice.org.uk/guidance/ph11> [accessed 16-October-2017]
- Nicklaus, S. (2016). The role of food experiences during early childhood in food pleasure learning. *Appetite*, 104, 3–9.
- Nicklaus, S., & Remy, E. (2013). Early origins of overeating: tracking between early food habits and later eating patterns. *Current Obesity Reports*, 2(2), 179–184.
- Nicolle, A., Fleming, S. M., Bach, D. R., Driver, J., & Dolan, R. J. (2011). A regret-induced status-quo bias. *The Journal of Neuroscience : The Official Journal of the Society for Neuroscience*, 31(9), 3320–3327.
- Office for National Statistics. (2011). *Census: Special Migration Statistics (United Kingdom)* available at <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/migrationwithintheuk/datasets/2011censusdetailedukmigrationstatistics>

[accessed 16-October-2017]

- Office of Technology Assessment (OTA). (1987). *Technology-dependent children: Hospital v. home care a technical memorandum*. Washington D.C. available at [https://doi.org/Publication number OTA-TMH-38](https://doi.org/Publication%20number%20OTA-TMH-38). [accessed 16-October-2017]
- Pahsini, K., Marinschek, S., Khan, Z., Dunitz-Scheer, M., & Scheer, P. J. (2016). Unintended adverse effects of enteral nutrition support: parental perspective. *Journal of pediatric gastroenterology and nutrition*, 62(1), 169-173.
- Parkes, J., White - Koning, M., Dickinson, H.O., Thyen, U., Arnaud, C., Beckung, E., Fauconnier, J., Marcelli, M., McManus, V., Michelsen, S.I. and Parkinson, K. (2008). Psychological problems in children with cerebral palsy: a cross - sectional European study. *Journal of Child Psychology and Psychiatry*, 49(4), 405-413.
- Pascalis, O., de Schonen, S., Morton, J., Deruelle, C., & Fabre-Grenet, M. (1995). Mother's face recognition by neonates: A replication and an extension. *Infant Behavior and Development*, 18, 79-85.
- Pedersen, S. D., Parsons, H. G., & Dewey, D. (2004). Stress levels experienced by the parents of enterally fed children. *Child: care, health and development*, 30(5), 507-513.
- Pelchat, D., Lefebvre, H., & Levert, M.-J. (2007). Gender differences and similarities in the experience of parenting a child with a health problem: current state of knowledge. *Journal of Child Health Care*, 11(2), 112-131.
- Pemberton, J., Frankfurter, C., Bailey, K., Jones, L., & Walton, J. M. M. (2013). Gastrostomy matters-The impact of pediatric surgery on caregiver quality of life. *Journal of Pediatric Surgery*, 48(5), 963-970.
- Pennington, C. (2002). To PEG or not to PEG. *Clinical Medicine* 2(3), 250-255.
- Pennington, L., & Noble, E. (2010). Acceptability and usefulness of the group interaction training programme It Takes Two to Talk to parents of pre-school children with motor disorders. *Child: Care, Health and Development*, 36(2), 285-296.
- Pentiuk, S., O'Flaherty, T., Santoro, K., Willging, P., & Kaul, A. (2011). Pureed by gastrostomy tube diet improves gagging and retching in children with

- fundoplication. *Journal of Parenteral and Enteral Nutrition*, 35(3), 375–379.
- Peräkylä, A. (1997). Reliability and Validity in Research Based on Tapes and Transcripts in Silverman, D. (Ed) *Qualitative Research Theory, method and practice*, 201-220. London: Sage Publications
- Petersen, M. S. C., Kedia, S., Davis, P., Newman, L., & Temple, C. (2006). Eating and feeding are not the same: caregivers' perceptions of gastrostomy feeding for children with cerebral palsy. *Dev Med Child Neurol*, 48(9), 713–7.
- Phares, V., Lopez, E., Fields, S., Kamboukos, D., & Duhig, A. M. (2005). Are fathers involved in pediatric psychology research and treatment? *Journal of Pediatric Psychology*, 30(8), 631–643.
- Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., Britten, N., Roen, K. and Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. A product from the ESRC methods programme Version, 1, p.b92.
- Popay, J., & Williams, G. (2006). Lay knowledge and the privilege of experience. In D. Kelleher, J. Williams, & G. Gabe (Eds.), *Challenging medicine* (pp. 122–145). London: Routledge.
- Prosser, D. P., & Sharma, N. (2010). Cerebral palsy and anaesthesia. *Continuing Education in Anaesthesia Critical Care & Pain*, 10(3), 72–76.
- QSR International Pty Ltd. (2012). NVivo qualitative data analysis software. *QSR International*.
- Quandt, D., Schraner, T., Bucher, H. U., & Mieth, R. A. (2009). Malposition of feeding tubes in neonates: is it an issue?. *Journal of pediatric gastroenterology and nutrition*, 48(5), 608-611.).
- Quill, T. E., & Cassell, C. K. (1995). Nonabandonment: A central obligation for physicians. *Annals of Internal Medicine*, 122(5), 368–374.
- Rapley, T. (2008). Distributed decision making: The anatomy of decisions-in-action. *Sociology of Health and Illness*, 30(3), 429–444.

- Razeghi, S., Lang, T., & Behrens, R. (2002). Influence of percutaneous endoscopic gastrostomy on gastroesophageal reflux: a prospective study in 68 children. *Journal of Pediatric Gastroenterology and Nutrition*, 35(1), 27–30.
- Reeves, S., Perrier, L., Goldman, J., Freeth, D., & Zwarenstein, M. (2013). Interprofessional education: effects on professional practice and healthcare outcomes (update). *Cochrane Database of Systematic Reviews (Online)*, 3(3), CD002213. <https://doi.org/10.1002/14651858.CD002213.pub3> [accessed 16-October-2017]
- Reilly, S., & Morgan, A. (2008). Dysphagia is prevalent in children with severe cerebral palsy. *Developmental Medicine & Child Neurology*, 50(8), 567.
- Reilly, S., Skuse, D., & Poblete, X. (1996). Prevalence of feeding problems and oral motor dysfunction in children with cerebral palsy: a community survey. *J Pediatr*, 129(6), 877–882.
- Ricciuto, A., Baird, R., & Sant'Anna, A. (2015). A retrospective review of enteral nutrition support practices at a tertiary pediatric hospital: A comparison of prolonged nasogastric and gastrostomy tube feeding. *Clinical Nutrition*, 34(4), 652–658.
- Rippon, S. (2012). How to Reverse the Organ Shortage. *Journal of Applied Philosophy*, 29(4), 344–358.
- Risdal, D., & Singer, G. H. S. (2004). Marital Adjustment in Parents of Children with Disabilities: A Historical Review and Meta-Analysis. *Research and Practice for Persons with Severe Disabilities*, 29(2), 95–103.
- Robinson, J. D. (2006). Soliciting patients' presenting concerns. In J. Heritage & D. W. Maynard (Eds.), *Communication in medical care: Interaction between primary care physicians and patients* (pp. 22–47). Cambridge: Cambridge University Press.
- Rommel, N., De Meyer, A.-M., Feenstra, L., & Veereman-Wauters, G. (2003). The complexity of feeding problems in 700 infants and young children presenting to a tertiary care institution. *Journal of Pediatric Gastroenterology and Nutrition*, 37(1).
- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., Dan, B. and Jacobsson, B.,(2007). A report: the definition and classification of cerebral palsy

April 2006. *Dev Med Child Neurol* (Suppl 109), p.8-14.

Rossi, A. (1985). *Gender and the Lifecourse*. New York: Aldine.

Rossi, A. (2015). Gender and parenthood *American Sociological Association*, 1983 Presidential Address, 49(1), 1-19.

Rouse, L., Herrington, P., Assey, J., Baker, R., & Golden, S. (2002). Feeding problems, gastrostomy and families: a qualitative pilot study. *British Journal of Learning Disabilities*, 30(3), 122-128.

Rugiu, M. G. (2007). Role of videofluoroscopy in evaluation of neurologic dysphagia. *Acta Otorhinolaryngologica Italica*, 27(6), 306-316.

Ryan, S., & Runswick-Cole, K. (2008). Repositioning mothers: mothers, disabled children and disability studies. *Disability & Society*, 23(3), 199-210.

Sacks, H., Schegloff, E., & Jefferson, G. (1974). Linguistic society of america a simplest systematics for the organization of turn-taking for conversation Author (s): Harvey Sacks , Emanuel A . Schegloff and Gail Jefferson. *Linguistic Society of America*, 50(4), 696-735.

Saloviita, T., Italinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a Double ABCX Model. *Journal of Intellectual Disability Research*, 47(4-5), 300-312.

Samson-Fang, L., Butler, C., & O'Donnell, M. (2003). Effects of gastrostomy feeding in children with cerebral palsy: an AACPD evidence report*. *Developmental Medicine & Child Neurology*, 45(6), 415-426.

Samson-Fang, L., & Stevenson, R. D. (2000). Identification of malnutrition in children with cerebral palsy: poor performance of weight-for-height centiles. *Developmental Medicine and Child Neurology*, 42(3), 162-168.

Samuelson, W., & Zeckhauser, R. (1988). Status quo bias in decision making. *Journal of Risk and Uncertainty*, 1(1), 7-59.

Satter, E. (1990). The feeding relationship: problems and interventions. *The Journal of Pediatrics*, 117(2 2), 81-9.

- Schauster, H., & Dwyer, J. (1996). Transition from Tube Feedings to Feedings by Mouth in Children: Preventing Eating Dysfunction. *Journal of the American Dietetic Association*, 96(3), 277-281.
- Schegloff, E. (1991). Reflections on talk and social structure.. Zimmerman, DH & Boden, D *Talk and Social Structure: Studies in Ethnomethodology and Conversation Analysis* University of California Press, Berkeley
- Schegloff, E. A., & Sacks, H. (1973). Opening up closings. *Semiotica*, 8(4), 289-327.
- Schwaab, L. M., Niman, C. W., & Gisel, E. (1986). Tongue movements in normal 2-, 3-, and 4-year-old children: a continuation study. *American Journal of Occupational Therapy*, 40(3), 180-185.
- Schwartz, C., Scholtens, P. A. M. J., Lalanne, A., Weenen, H., & Nicklaus, S. (2011). Development of healthy eating habits early in life. Review of recent evidence and selected guidelines. *Appetite*, 57(3), 796-807.
- Schwarz, S. M., Corredor, J., Fisher-Medina, J., Cohen, J., & Rabinowitz, S. (2001). Diagnosis and treatment of feeding disorders in children with developmental disabilities. *Pediatrics*, 108(3), 671-676.
- Segal, D., Michaud, L., Guimber, D., Ganga-Zandzou, P. S., Turck, D., & Gottrand, F. (2001). Late-onset complications of percutaneous endoscopic gastrostomy in children. *Journal of Pediatric Gastroenterology and Nutrition*, 33(4), 495-500.
- Sheppard, J. J. (2008). Using motor learning approaches for treating swallowing and feeding disorders: a review. *Language, Speech, and Hearing Services in Schools*, 39(2), 227-236.
- Sidnell, J. (2010). *Conversation Analysis: An Introduction*. Hoboken New Jersey: Wiley Blackwell.
- Silverman, D. (2011). *Interpreting qualitative data: A guide to the principles of qualitative research*. London: SAGE Publications.
- Singer, G. H. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation*, 111(3), 155-169.

- Sleigh, G. (2005). Mothers' voice: a qualitative study on feeding children with cerebral palsy. *Child: Care, Health and Development*, 31(4), 373–383.
- Sleigh, G., & Brocklehurst, P. (2004). Gastrostomy feeding in cerebral palsy: a systematic review. *Archives of Disease in Childhood*, 89(6), 534–9.
- Sloper, P., & Statham, J. (2004). The National Service Framework for children, young people and maternity services: developing the evidence base. *Child: Care, Health and Development*, 30(6), 567–570.
- Smith, E. R., Bergelson, I., Constantian, S., Valsangkar, B., & Chan, G. J. (2017). Barriers and enablers of health system adoption of kangaroo mother care: a systematic review of caregiver perspectives. *BMC Pediatrics*, 17- 35.
- Smith, S. W., Camfield, C., & Camfield, P. (1999). Living with cerebral palsy and tube feeding: A population-based follow-up study. *The Journal of Pediatrics*, 135(3), 307–310.
- Snape, D., & Spencer, L. (2003). The Foundations of Qualitative Research. In J. Ritchie & L. J (Eds.), *Qualitative Research practice. A Guide for Social Science Students and Researchers* (pp. 1–23). London, UK: SAGE Publications.
- Soto, D., Heinke, D., Humphreys, G. W., & Blanco, M. J. (2005). Early, involuntary top-down guidance of attention from working memory. *Journal of Experimental Psychology. Human Perception and Performance*, 31(2), 248.
- Spalding, K., & McKeever, P. (1998). Mothers' experiences caring for children with disabilities who require a gastrostomy tube. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, 13(4), 234–243.
- Spiers, G., & Beresford, B. (2017). 'It goes against the grain': A qualitative study of the experiences of parents' administering distressing health-care procedures for their child at home. *Health Expectations*, 1–9. available at <http://dx.doi.org/10.1111/hex.12532> {accessed 16th October 2017}
- Spiers, G., Parker, G., Gridley, K., & Atkin, K. (2011). The psychosocial experience of parents receiving care closer to home for their ill child. *Health & Social Care in the Community*, 19(6), 653–660.

- Stenvers, D., Jonkers, C., Fliers, E., Bisschop, P., & Kalsbeek, A. (2012). Nutrition and the circadian timing system, *Progress in Brain Research* 199, 359–376.
- Stevenson, R.D., Conaway, M., Chumlea, W.C., Rosenbaum, P., Fung, E.B., Henderson, R.C., Worley, G., Liptak, G., O'Donnell, M., Samson-Fang, L. and Stallings, V.A. (2006). Growth and health in children with moderate-to-severe cerebral palsy. *Pediatrics*, 118(3),265.1010-1018.
- Stoeckli, S. J., Huisman, T., Seifert, B. A. & Martin--Harris, B. J.. (2003). Interrater Reliability of Videofluoroscopic Swallow Evaluation. *Dysphagia*, 18(1), 53–57.
- Strauss, A. L. (1987). *Qualitative Analysis for Social Scientists*. New York: Cambridge University Press.
- Sullivan, P. (2013). Nutrition and growth in children with cerebral palsy: setting the scene. *European Journal of Clinical Nutrition*, 67 S3–S4,
- Sullivan, P.B., Juszczak, E., Bachlet, A.M., Lambert, B., Vernon-Roberts, A., Grant, H.W., Eltumi, M., McLean, L., Alder, N. and Thomas, A.G. (2005). Gastrostomy tube feeding in children with cerebral palsy: a prospective, longitudinal study. *Developmental Medicine and Child Neurology*, 47(2),77-85.
- Sullivan, P., Juszczak, E., Bachlet, A. M. E., Thomas, A. G., Lambert, B., Vernon-Roberts, A., ... Jenkinson, C. (2004). Impact of gastrostomy tube feeding on the quality of life of carers of children with cerebral palsy. *Developmental Medicine and Child Neurology*, 46(12), 796–800.
- Sullivan, P., Juszczak, E., Lambert, B. R., Rose, M., Ford-Adams, M. E., & Johnson, A. (2002). Impact of feeding problems on nutritional intake and growth: Oxford Feeding Study II. *Developmental Medicine & Child Neurology*, 44(7), 461–467.
- Sullivan, P., Lambert, B., & Rose, M. (2000). Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. *Developmental Medicine & Child Neurology*, 42, 674–680.
- Sullivan, P., Lambert, B., Rose, M., Ford-Adams, M., Johnson, A., & Griffiths, P. (2000). Prevalence and severity of feeding and nutritional problems in children with neurological impairment: Oxford Feeding Study. *Developmental Medicine and Child*

Neurology, 42(10), 674–680.

Sullivan, S. A., & Birch, L. L. (1994). Infant dietary experience and acceptance of solid foods. *Pediatrics*, 93(2), 271–277.

Suri, G., Sheppes, G., Schwartz, C., & Gross, J. J. (2013). Patient inertia and the status quo bias. *Psychological Science*, 24(9), 1763–1769.

Sweet, L., & Darbyshire, P. (2009). Fathers and breast feeding very-low-birthweight preterm babies. *Midwifery*, 25(5), 540–553.

Tahhan, D. A. (2008). Depth and space in sleep: intimacy, touch and the body in Japanese co-sleeping rituals. *Body & Society*, 14(4), 37–56.

Tanner, D. C. (2006). *Case studies in communication sciences and disorders*. Pearson/Merrill Prentice Hall.

Tawfik, R., Dickson, A., Clarke, M., & Thomas, A. G. (1997). Caregivers' perceptions following gastrostomy in severely disabled children with feeding problems. *Developmental Medicine and Child Neurology*, 39(11), 746–751.

ten Have, P. (1991). Talk and institution: a reconsideration of the 'asymmetry' of doctor-patient interaction. In D. Boden & D. Zimmerman (Eds.), *Talk and social structure: studies in ethnomethodology and conversation analysis*. (p. 138–163.). Cambridge: Polity Press.

ten Have, P. (2007). *Doing Conversation Analysis A Practical Guide*. (second). London: Sage Publications.

The American Academy of Pediatrics. (2010). Prevention of Choking Among Children. *Pediatrics*, 125(3), 601–607.

Thomas, C. (1993). De-Constructing Concepts of Care. *Sociology*, 27(4), 649–669.

Thorne, S. (2008). *Interpretive description*. Walnut Creek, CA: Left Coast Press.

Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20(2), 169–177.

Thorne, S., Radford, J. M., & McCormick, J. (1997). The multiple meanings of long-term

- gastrostomy in children with severe disability. *Journal of Pediatric Nursing: Nursing Care of Children and Families*, 12(2), 89–99.
- Thorne, S., Reimer Kirkham, S., & O’Flynn-Magee, K. (2004). The analytic challenge in interpretive description. *International Journal of Qualitative Methods*, 3(1), 1–11.
- Todd, S., & Jones, S. (2003). ‘Mum’s the word!’: maternal accounts of dealings with the professional world. *Journal of Applied Research in Intellectual Disabilities*, 16(3), 229–244.
- Tong, A., Lowe, A., Sainsbury, P., & Craig, J. C. (2010). Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child: Care, Health and Development*, 36(4), 549–557.
- Townsley, R., & Robinson, C. (1999). More than just a health issue: a review of current issues in the care of enterally-fed children living in the community. *Health and Social Care in the Community*, 7(3), 216–224.
- Trevena, L. J., Barratt, A., Butow, P., & Caldwell, P. (2006). A systematic review on communicating with patients about evidence. *Journal of Evaluation in Clinical Practice*, 12(1), 13–23.
- Tronick, E., Als, H., Adamson, L., Wise, S., & Brazelton, T. B. (1978). The infant’s response to entrapment between contradictory messages in face-to-face interaction. *Journal of the American Academy of Child Psychiatry*, 17, 1–13.
- Trute, B., Benzies, K. M., Worthington, C., Reddon, J. R., & Moore, M. (2010). Accentuate the positive to mitigate the negative: Mother psychological coping resources and family adjustment in childhood disability. *Journal of Intellectual & Developmental Disability*, 35(1), 36–43.
- Turner, J., Abobo, M., Blatz, D., Hartfield, D., & Mager, D. (2016). Prolonged nasoenteral tube feeding in children contradicts best practice guidelines. *Paediatrics & Child Health*, 21(5), E90.
- Tversky, A., & Kahneman, D. (1981). The Framing of Decisions and the Psychology of Choice. *Science*, 211, 30.
- Uday, S., Shaw, N., Krone, R., & Kirk, J. (2017). Hypopituitarism in children with cerebral

palsy. *Archives of Disease in Childhood*, 102(6), 559–561.

UK Government. (2017). Unpaid Parental Leave. available from from <https://www.gov.uk/parental-leave/entitlement> [accessed 16-October-2017]

Vermilyea, S., & Goh, V. L. (2016). Enteral Feedings in Children: Sorting Out Tubes, Buttons, and Formulas. *Nutrition in Clinical Practice*, 31(1), 59–67.

Walker, J. L., Bell, K. L., Boyd, R. N., & Davies, P. S. W. (2012). Energy requirements in preschool-age children with cerebral palsy. *The American Journal of Clinical Nutrition*, 96(6), 1309–1315.

Walton, G. E., Bower, N. J. A., & Bower, T. G. R. (1992). Recognition of familiar faces by newborns. *Infant Behav Dev*, 15, 265–269.

Wang, X., Xu, Z., & Miao, C.-H. (2014). current clinical evidence on the effect of general anesthesia on neurodevelopment in children: an updated systematic review with meta-regression. *PLoS ONE*, 9(1), e85760.

Ward, C., Glass, N., & Ford, R. (2014). Care in the home for seriously ill children with complex needs. *Journal of Child Health Care*, 19(4), 524–531.

Whiting, M. (2013). Impact, meaning and need for help and support: The experience of parents caring for children with disabilities, life-limiting/life-threatening illness or technology dependence. *Journal of Child Health Care*, 17(1), 92–108.

Whitney, S. N., Ethier, A. M., Frugé, E., Berg, S., McCullough, L. B., & Hockenberry, M. (2006). Decision making in pediatric oncology: Who should take the lead? The decisional priority in pediatric oncology model. *Journal of Clinical Oncology*, 24(1), 160–165.

Wiernicka, A., Popińska, K., Szlagatys-Sidorkiewicz, A., Chlebowczyk-Grzybowska, U., Toporowska-Kowalska, E., Gębora-Kowalska, B., Borkowska, A., Sibilska, M., Więcek, S., Hapyn, E. and Kierkuś, J. (2012). Indications for gastrostomy feeding in Polish children—Multicenter retrospective analysis of ten years period (2000–2010). *Pediatrics Polska*, 87(6), 560–563.

Wilk, R. (2010). Power at the Table: Food Fights and Happy Meals. *Cultural Studies ↔ Critical Methodologies*, 10(6), 428–436.

- Willig, C. (2001). *Introducing Qualitative Research in Psychology*. Maidenhead: Open University Press.
- Wilson, M., Gosche, J., Bishop, P., Liu, H., Moore, T., & Nowicki, M. J. (2010). Critical analysis of caregiver perceptions regarding gastrostomy tube placement. *Pediatrics International : Official Journal of the Japan Pediatric Society*, 52(1), 20–25.
- Wolff, R. P., & Herman, C. J. (1994). Management of behavioral feeding problems in young children. *Infants & Young Children*, 7(1), 14–23.
- Wood, E. G., Bunchman, T. E., Khurana, R., Fleming, S. S., & Lynch, R. E. (1990). Complications of nasogastric and gastrostomy tube feedings in children with end stage renal disease. *Advances in Peritoneal Dialysis. Conference on Peritoneal Dialysis*, 6, 262–264.
- Worley, G., Stevenson, R. D., Rosenbloom, L., & Sullivan, P. (2007). Castang and Novartis Foundation Conference on Undernutrition in Children with Cerebral Palsy: Survey of participants about decision-making for enteral (gastrostomy) feeding. *Journal of Nutritional & Environmental Medicine*, 16(1), 75–81.
- Wright, C. M., Smith, K. H., & Morrison, J. (2011). Withdrawing feeds from children on long term enteral feeding: factors associated with success and failure. *Archives of Disease in Childhood*, 96(5), 433–439.
- Wu, F.-Y., Wu, J.-F., & Ni, Y.-H. (2013). Long-term Outcome After Percutaneous Endoscopic Gastrostomy in Children. *Pediatrics and Neonatology*, 54(5), 326–329.
- Wyatt, K. D., List, B., Brinkman, W. B., Prutsky Lopez, G., Asi, N., Erwin, P., ... LeBlanc, A. (2017). Shared decision making in pediatrics: systematic review and meta-analysis. *Academic Pediatrics*, 15(6), 573–583.
- Young, M. E., Norman, G. R., & Humphreys, K. R. (2008). The role of medical language in changing public perceptions of illness. *PLOS ONE*, 3(12), e3875.
- Zheng, H., Lenard, N., Shin, A., & Berthoud, H. R. (2009). Appetite control and energy balance regulation in the modern world: reward-driven brain overrides repletion signals. *International Journal of Obesity*, 33(Suppl 2), S8.