

A phenomenological exploration of infant feeding experiences, the mother-infant relationship and maternal wellbeing in mothers of infants with Down syndrome

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

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ABSTRACT

Introduction: There is an acknowledged association between difficulties with infant feeding and increased maternal distress. It is also purported that difficulties with infant feeding can have the potential to undermine the developing mother-infant bond. Despite a recognised tendency towards initial feeding difficulties in infants with Down syndrome, little is known about how mothers experience feeding and bonding with their infant with Down syndrome, and how they make sense of these experiences. This thesis aimed to bridge existing gaps in the literature on infant feeding in Down syndrome, with potential implications for clinical practice and policy development.

Method: Purposive sampling was used to recruit eight mothers of children with Down syndrome under the age of three. These mothers were interviewed about their experiences of feeding and bonding with their infant, and their perspectives on their personal wellbeing during the infant feeding period. To facilitate inductive, in-depth exploration of a previously underexplored research area, the interviews were analysed using interpretative phenomenological analysis.

Results: Four superordinate themes were identified from analysis of participants' interview data: '*Negotiating control and assertions of power*'; '*It made things feel settled*'; '*It's a real Bonding Experience*' and '*Constructing Maternal Identity through feeding*'.

Discussion: The findings indicate that the experience of feeding a baby with Down syndrome can have multiple emotional facets, and can interact with women's constructions of themselves as mothers. Infant feeding was found to facilitate a sense of stability, security and normalcy when adjusting to having a baby with Down syndrome. The findings were evaluated in relation to available literature and considered within frameworks of psychological and feminist theory. Participants' accounts point to the potential utility of compassion-focused therapeutic intervention for any mothers of infants with Down syndrome that may be facing difficulties with infant feeding. The novel findings of this study were considered in terms of their implications for elements of clinical practice and support interventions, and infant feeding healthcare policy development. The ways in which this study may function as a platform for future research are discussed.

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CHAPTER ONE: INTRODUCTION

Overview

The postnatal period can be physically and emotionally challenging for any mother. Mothering a newborn, navigating the maternal role and contending with changes to one's lifestyle constitutes a demanding stage (Tully, Stuebe & Verbiest, 2017). This period may be accompanied by specific additional challenges if an infant is born with a congenital condition, such as Down syndrome (Wright, 2008). Due to certain oralmotor, gastrointestinal and muscle tone issues often present in new-borns with Down syndrome, difficulties with infant feeding are one potential challenge mothers may face (Lewis & Kritzinger, 2004; Cartwright & Boath, 2018). In general, difficulties with infant feeding are known to be associated with increased maternal distress (Brown, Rance & Bennett, 2016; Park et al., 2016). Yet, despite the associations between infant feeding difficulties and heightened maternal distress, and the actuality that infants with Down syndrome have an acknowledged tendency towards feeding difficulties, there is a dearth of qualitative investigation into the emotional and psychological facets of feeding an infant with Down syndrome. Rather, the majority of the small amount of existing research is in the quantitative domain, focusing on the physiological and immunological aspects of infant feeding (e.g Williams et al., 2017), with maternal experiences not captured. Indeed, little is known about how mothers may perceive and understand their feeding experiences, and personal wellbeing, during this time.

It is often advocated that positive elements of the infant feeding experience contribute to the development of the maternal-infant bond, i.e. the emotional tie between mother and infant (Dieterich et al., 2013). Yet, it appears that no research has examined how the feeding experience might contribute positively to, or compromise, the development of the maternal bond in the mother-infant dyad where the infant has Down syndrome. It is evident that fundamental elements of infant feeding and maternal bonding experiences in the context of Down syndrome require greater understanding. A desire to better understand these mothers' experiences, amplify their voices and identify any clinical needs they might have during the infant feeding period prompted the execution of this research.

The present study uses qualitative methods to endeavour to bridge these gaps in the literature, aiming to explore what it is like to feed and bond with an infant with Down syndrome. It is hoped that new understandings will emerge from this study regarding the psychological dimensions of mothers' infant feeding experiences, and how they reflect on their relationship with their infant during this time. It is additionally hoped that the research may identify any clinical needs that this empirically-overlooked group of mothers may have, with possible implications for clinical psychology and public healthcare practice. Lastly, it is intended that the findings may highlight areas needing further research enquiry.

This chapter will set forth and appraise a range of existing literature, providing a contextual framework and rationale for the execution of this study. The literature review will strive to discuss various methods and practices of infant feeding, both generally and in relation to Down syndrome. Maternal wellbeing in the postnatal period will be considered in the context of both infant feeding and Down syndrome. The concept of the mother-infant relationship will be introduced and the related literature examined. Explorative focus will be applied to consider the interfaces between the mother-infant relationship, infant feeding and Down syndrome. Lastly, a case will be put forward accentuating the need for further qualitative research in this area, and the research aims of this study will be presented.

Terminology

The epistemological underpinnings of this thesis are discussed in Chapter Two. However, it is important to acknowledge here that the study has been shaped by feminist perspectives, and also draws upon some *elements* of social constructionist thinking. For example, while acknowledging the positive corollaries of using diagnostic labelling, and the importance that diagnoses can have for individuals, this thesis adopts a social constructionist position on disability. This perspective views disability as an ideological construction, where individualist societies construct a certain view of disability around social expectations of health and ability, devaluing those who deviate from physical/intellectual norms (Wendell, 2013; Liachowitz; 2010). This model locates disability within an oppressive wider system, rather than in the individual with different physical or developmental needs (Snyder & Mitchell,

2010). In line with this conceptualisation of disability as an ideological social construct, and honouring the language used by participating mothers, the term ‘additional needs’ or disability in inverted commas will be used henceforth when referring to ‘disability’. Additionally, a conscious decision has been made to use the term ‘Down syndrome’ throughout, rather than abbreviating to DS or ‘Downs’. This is to reflect the designation preferred by the communities of support groups from which participants were recruited. This thesis also draws upon elements of constructionist thinking when considering the concept of ‘motherhood’. Which is evaluated in further detail throughout the thesis. Furthermore, the words ‘mothers’ and ‘women’ are used throughout to describe individuals who have given birth. The author has experience in the field of gender identity, and would like to briefly acknowledge the reality that some individuals who give birth may not necessarily identify as female, and that individuals who have not given birth may also be mothers. To summarise, although this thesis draws upon elements of social constructionist and feminist thinking around some of the main research phenomena under investigation, i.e ‘disability’ and motherhood, it is crucial to acknowledge that much of the literature evaluated henceforth is situated within differing epistemologies. The majority of the medical/clinical research cited is grounded reductionism, where individuals are considered chiefly in the context of their biochemistry, microbiology and genetics. Additionally, some of the discussed literature that evaluates constructs/phenomena relating to ‘mental health’ has an individualistic focus, where individuals are considered in largely abstraction to their ideological, socio-cultural context. Hence, while adopting elements of social constructionist thinking, this thesis will also refer to and evaluate literature from a divergent epistemological vantage points, and consider some of the research findings within these frameworks.

A comment on the literature search strategy

To establish the scope of existing relevant literature relating to the research questions, four electronic databases typically publishing psychological and medical literature were searched: Pubmed, Google Scholar, NICE and PsycINFO. To locate literature most closely relating to the anatomy of the research questions, and to determine the gaps in the literature, various combinations of the following subject terms and key

words were searched: *Downs syndrome, DS, Trisomy 21, infant feeding, feeding, breastfeeding, formula-feeding, tube feeding, maternal experience, emotional impact, maternal wellbeing, maternal mental health, mother-infant relationship, maternal bond/bonding, qualitative, IPA, social constructionist, feminist perspective, attachment*. Literature searches were conducted in August 2017, January/February 2018 and in April 2019. Each of these searches highlighted the dearth of existing research, as discussed in this chapter. The first searches yielded some quantitative studies, relating to the autoimmune benefits and health outcomes of breastfeeding for babies with Down syndrome (e.g. Flores-Lujano et al., 2009). Only one study that qualitatively investigated parents' experiences of encountering feeding difficulties in *children* was located (Lewis & Kritzinger, 2004). In 2019, a British study entitled '*Feeding infants with Down's syndrome: A qualitative Study of Mothers Experiences*' (Cartwright & Boath, 2018) was identified. This study had some overlapping research aims and employed a similar methodology; it thereby represents the main comparative point for the present study. However, Cartwright & Boath (2018) focused specifically on breastfeeding mothers, used focus groups as the method of data collection, and there was no explicit focus on the maternal-infant relationship. No qualitative or quantitative studies exclusively exploring maternal-infant bonding in the context of Down syndrome/infant feeding were identified, with the only identified studies focusing on the patterns of interactions between mothers and their *children* with Down syndrome (e.g. McCollum, 2003). Accordingly, the literature search was widened to include studies where mothers of infants with Down syndrome are part of a larger heterogeneous sample. Due to this lack of previous research, almost all of the located studies that had some degree of focus on the phenomena under investigation, i.e. infant feeding, maternal wellbeing and the mother-infant relationship in the context of Down syndrome, are included and evaluated in the literature review below.

Introducing infant feeding

Defining infant feeding

The first year of an infant's life represents a crucial window of opportunity to guarantee their optimal growth and development through feeding (UNICEF, 2001).

The World Health Organisation (2017) defines ‘*infant feeding*’ as the feeding of a child from birth to one year of age, to facilitate nourishment and growth.

Methods of infant feeding

Breastfeeding is hailed as the nutritionally optimum method of infant feeding (León-Cava, Ross & Martin, 2002; Martin, Ling, & Blackburn, 2016). Breastmilk is composed of bioactive agents including antibodies, anti-viruses, anti-allergies, and anti-parasites as well as protein and vitamins (Martin, et al., 2016; Jackson & Nazar, 2006), with this nutritional content having myriad established benefits (WHO, 2009). Meta-analytic investigation substantiates the positive effects that breastfeeding has upon infant health, nutrition and development (Association of Womens’ Health, Obstetric and Neonatal Nurses; AWHONN, 2015; Chung et al., 2007; Leesen & Kavenagh, 2015; Salone, Vann & Dee, 2013). These include immunologic protection against multiple illnesses and infections (Jackson & Nazar 2006; White et al., 2016). The long-term health benefits of breastmilk have been well chronicled by systematic review, even when controlling for confounding factors (Horta & Victora, 2013). The WHO (2017) recommends exclusive breastfeeding up to six months of age, with continued breastfeeding, along with appropriate complementary foods, up to two years of age or beyond. There are also proposed cognitive and developmental advantages to breastfeeding (Girard, Doyle & Tremblay, 2017). However, the literature in this particular area is heterogeneous, with systematic review conversely concluding that breastfeeding does not enhance cognitive development (O’Donnell, 2015). In certain situations, breastfeeding is unsuitable, unsupported, undesired or unfeasible, warranting the use of alternative feeding methods (Martin et al., 2016). When breastfeeding is not possible, breast milk can be expressed for bottle feeding, ensuring the same nutritional content as milk straight from the breast (O’Donnell, 2015; WHO, 2009).

Bottle feeding using formula milk is a globally widespread alternative method to breastmilk and represents the first-choice feeding method for many mothers and their partners worldwide (Appleton et al., 2018; UNICEF, 2011). Formula is an intended substitute for breastmilk, as it aims to mimic its nutritional composition (Martin et al., 2016). When breastfeeding, expressing breastmilk or using donated breast milk is not an option, formula feeding is the best alternative for *infants* (WHO,

2009; Martin et al., 2016). In many western societies, formula feeding has become the norm over past decades, due to its perceived status as having equal nutrition to breastfeeding but superior convenience, and relating to social considerations outlined later in this chapter (Abrahams, 2012; Hatfield 2013).

Some preterm infants, infants with respiratory difficulties or infants with congenital conditions may have various difficulties that can interfere with both breast and bottle feeding (Ellet et al., 2005; Southhall & Martin, 2010; Moore & Greene, 2015). For these infants, who may not have the strength or coordination to feed from the breast/a bottle, tube-feeding by a nasogastric or gastrostomic feeding tube (enteral feeding), may be initiated. Tube-feeding ensures these infants' adequate nutritional intake and growth and prevents asphyxiation (Arvedson, Brodsky & Lefton-Greif, 2019). When the tube is firmly in place, expressed breast milk or formula is inserted with a syringe or through an infusion pump, with infant elevation being crucial to prevent regurgitation of fluid (Simpson, Schanler & Lau, 2002). While it provides essential nutrition, tube feeding an infant can be accompanied by a unique set of emotional challenges for parents (Wilken, 2012), referred to later in this chapter.

Understanding infant feeding practices

The literature identifies assorted social, cultural and attitudinal factors that can shape infant feeding practices (IFPs) (Amir, 2011; Liamputtong, 2010; Steinman et al., 2010). IFPs often pertain to the ideological and economical position and condition of women in their different societies worldwide (Grayson, 2016). IFPs may be influenced by various sociodemographic factors, including: cultural context, perceived supports, access to food, workload, socio-economic background, marital status, age and level of education (Bolling et al, 2007; Brown et al., 2014; Losch et al., 1995; Hodges et al., 2008; Brown, Raynor & Lee, 2012; Oakley et al, 2011). Women may opt to bottle-feed if they are experiencing physical discomfort or breast pain when breastfeeding or expressing, or have a low milk supply (Kanhadilok et al., 2015). Formula feeding is also the preferred choice for many women, selected on the basis of its ease, convenience, and status as more conducive to returning to work after maternity leave (Desmond & Meaney, 2016; Radzyski & Callister, 2016). Women also report alternating between breast and bottle feeding in different social contexts, due to experiencing public attitudes towards breastfeeding attitudes as oppressive,

judgemental and shaming (Brouwer, Drummond & Willis 2012; Nathoo & Ostry, 2009).

Feminist theory perspectives on IFPs

IFPs have been considered from divergent feminist perspectives. Previously, for many second wave feminists, breastfeeding represented another element of the patriarchal scheme, and the embodiment of a wider oppressive narrative, where women were restrained to mothering/nursing roles (Blum, 1993). With the advent of formula feeding, liberation feminism conceived formula as emancipating for women, restoring bodily autonomy by facilitating the detachment of feeding from biological gender, enabling sharing of the feeding burden between partners/societies (Hausman, 2014; Nash 2014). As such, the practice of formula feeding came to symbolise female empowerment, ensuring nursing needs did not impact womens return to work, permitting economic independence, autonomy and control over their own lives (Jung, 2015; Smith, 2013).

The arrival of Difference Feminism in the 1980s, which acknowledges the biological differences between men and women, challenged the view that breastfeeding is oppressive (Hekman, 2013). Instead, difference feminist discourses assert that the *societal structures* around feeding are oppressive (Scott, 1988), and petition for social structures that accommodate womens' biological difference (Gilligan, 1993). This philosophy contends that societies often proclaim a libertarian narrative that communicates to women "you have the right to breastfeed", but political structures, social institutions and lack of institutional supports (accessible, free feeding information, lactation consultants for all echelons of society and abundant feeding spaces) impede women in exercising this right (Hausman, 2004). Ultimately, for many feminist promoters of breastfeeding, the aim is not to have every woman breastfeed but for social and wider organisational conditions to be shaped so that every woman could (Smith, 2013). This essential issue of social injustice is why infant feeding is seen as a feminist issue (Labbok, Smith & Taylor 2008).

Third-wave feminism, in addition to prizing bodily autonomy and choice, strives to protect personally meaningful experiences in women's lives, which extends to encompass infant feeding (Bracken-Hull, 2013). Within this stance, choosing to breastfeed is regarded as confirming womens' bodily autonomy and the decision to

breastfeed affording self-actualisation (Wolf, 2013). Through this feminist lens, the practice of breastfeeding is viewed as challenging medical hegemony by reducing women's dependence on the historically male-dominated medical model (Wolf, 2006). Furthermore, breastfeeding is viewed as engineering self-reliance through empowering women to solely be able to provide all of an infant's nutritional needs (Taylor & Wallace, 2012).

As discussed above, IFPs can be influenced by multiple factors. Ultimately though, feeding is an interactive process, and the feeding situation can be influenced by the characteristics of the infant just as much as those of the mother (Fildes et al., 2015). Feeding experiences and decisions may be influenced when an infant is born with a congenital condition characterised by features that might complicate feeding (Ricci & Kyle, 2009; Ryan, Smith & Alexander, 2013; Sabzevari, & Nematollahi, 2016). Down syndrome (also known as Trisomy 21), a congenital disorder involving chromosomal irregularity, is one such condition where the associated features may impact infant feeding practices.

Down syndrome in context

Down syndrome is a genetic, chromosomal condition, caused when genetic materials fail to separate during fertilisation of the sperm and egg, resulting in an additional copy of chromosome 21 (Trisomy 21) (Lubec, 2013; Antonarakis, 2017). This trisomy usually occurs by chance at conception and results in a constellation of characteristics known as Down syndrome. The associated features of Down syndrome include: developmental delay and learning 'disability', decreased muscle tone, characteristic facial features, increased risk of autoimmune deficiencies, congenital heart and gut defects, infertility and increased risk of developing leukaemia, dementia and Alzheimer's disease (Freeman, 1998; Capone, 2004; Mateos et al., 2015; Hartley et al., 2015; Buckley; 2002). In the United Kingdom (UK) Approximately two babies with Down syndrome are born every day, equivalent to around 1 in every 1,000 live births and 750 births a year (The Down Syndrome Association; DSA, 2018). This number mirrors global figures identifying that 1 in every 700-800 babies worldwide are born with Down syndrome (The Global Down Syndrome Association, 2015). As of 2019, it is estimated that there are 40,000 people living with Down syndrome in the

UK (DSA, 2018). Although maternal age has been determined not to be a causal factor for the occurrence of Down syndrome, the individual likelihood of giving birth to an infant with Down syndrome increases with age, with the odds of giving birth to a baby with Down syndrome increasing to 1 in 100 over the age of forty (Allen et al., 2009; DSA, 2018). Prevalence rates of Down syndrome are not influenced by temporal, racial, geographical or environmental factors; it occurs with equal incidence in all races, classes and countries worldwide (Carothers, Hecht, & Hook, 1999; DSA 2018).

In 2014, The National Down Syndrome Cytogenetic Register for England and Wales (NDSCR) annual report reported that in 65% of all live births of infants with Down syndrome, there had been a prenatal diagnosis (Morris & Springett, 2014) The National Congenital Anomaly and Rare Disease Registration Service (NCARDS; 2018) report that between 2015 and 2017, in 57.6 % of live Down syndrome births in the UK, the trisomy had been detected antenatally. There appears to be no available statistics from 2018-2019. The NDSCR (2014) annual report indicates that 90% of reported cases of prenatally diagnosed Down syndrome were terminated. However, NCARDS report a substantially lesser figure between 2015 and 2017, and record that 85.1% of antenatal detections of Down syndrome during pregnancy screenings resulted in a termination (Morris and Springett, 2014).

Various contextual factors, including cultural and religious reasons, may influence a decision not to terminate a pregnancy where Down syndrome has been detected during screening. For instance, within Islam, abortion is largely viewed as impermissible (Hessini, 2008; Hedayat, Shooshtarizadeh & Raza, 2016), with this often representing the main deterrence against aborting a foetus identified as having a 'disability' during screening (Hessini, 2008). However the majority of existing research has been conducted in Muslim-majority countries, and there is a dearth of investigation into the termination decision making experiences of women followers of Islam in the UK whose pregnancies are identified as 'at risk' for Down syndrome during screening. Perceived attachment to the foetus has also been identified as having the most significant influence on a decision not to terminate after receiving a prenatal diagnosis of Down syndrome (Nelson-Goff et al., 2013), which echoes the wider literature capturing maternal inability to proceed with a termination after experiencing an attachment and connection to their foetus (Brauer et al., 2019).

Maternal-foetal attachment is widely acknowledged as being a predictor of mother-infant attachment and patterns (Atashi et al., 2018). However, despite these associations, there appears to be no existing research investigating how maternal-foetus attachment may shape the mother-infant relationship in the context of either pre or post-natal diagnoses of Down syndrome.

Until 2019, Northern Ireland was the only part of the UK where access to abortion procedures was still illegal and denied. Findings from the Turnaway Study (2019) indicates that mothers who are denied termination of an unwanted pregnancy report that this has adverse impacts on the subsequent mother-infant bond (Dobkin & Foster, 2013). However, this research was conducted with an American sample, where the abortion was denied on the basis of the pregnancy being in a late term, and where foetal abnormalities were not necessarily detected. There appears to be no available research or statistics capturing the previous experiences of women from Northern Ireland who were denied access to an abortion when Down syndrome was detected during screening, nor information on how this contextual experience might have shaped their subsequent relationship with their infant.

McAndrew et al., (2018) acknowledge that newborn infants with Down syndrome are often at increased risk of postnatal complications due to congenital irregularities that require management in hospital neonatal intensive care units (NICUs). However, the exact nationwide figures of how many newborn infants with Down syndrome are likely require NICU admission are unknown. They call for a more detailed understanding of the medical management of infants with Down syndrome, and of which postnatal complications place infants at great risk of an NICU admission. This is so that care-providers and parents alike may be prepared in advance, and have reasonable expectations of what an NICU experience may involve. More defined figures on NICU admission rates and admission time trajectories in the Context of Down syndrome could help mitigate potential postnatal stress and anxiety in parents (McAndrew et al., 2018).

Individuals with Down syndrome are often subjected to a ‘positive personality stereotype’, where they are all thought to have a shared profile of affectionate behaviours and happy dispositions (Gilmore, Campbell & Cuskelly, 2003). However, people with Down syndrome should be considered as individuals rather than thought

of collectively, in acknowledgement of their unique personalities, abilities and aspirations, and in recognition of their idiosyncratic profiles of strengths and difficulties (Cunningham, 1996). While the features of Down syndrome certainly shape aspects of development, it should not be presumed that the Down syndrome alone will exclusively influence the developmental trajectory; although all individuals with Down syndrome have degrees of learning ‘disability’, their development is still a dynamic, interactive and social process (Buckley, 2002). Children with Down syndrome can form the same attachments and respond to parental input to the same degree as ‘typically’ developing children (Skotko, Levine & Goldstein, 2011).

Infant feeding and Down syndrome

Feeding profiles of infants with Down syndrome

Feeding difficulties are common in infants born with congenital and neurodevelopmental conditions (Arts-Rodas & Benoit, 1998), and are reported in infants with Down syndrome (Fish, 2008; Lewis & Kritinger, 2004; Burns & Gunn, 2013). The action of swallowing is complex, involving intricate neurological and aerodigestive synchronisation (Humbert et al., 2009) and infants with Down syndrome often have weaker oral-motor functioning, making them susceptible to feeding difficulties (Jackson, 2016). A combination of other factors can contribute to feeding difficulties in infants with Down syndrome, including: increased incidence of congenital illness, particularly heart defects and hyperthyroidism (Cousineau & Lauer, 1995), gastroesophageal reflux (McCurtin, 1997), low muscle tone - resulting in the presence of suckling difficulties and tongue protrusion - (Pilcher, 2008), sleepiness in the first few weeks after birth (Cooper-Brown et al 2008; Sasaki et al, 2010), respiratory problems, reduced oral space, and narrowed nasal passages that interfere with breathing (McCurtin, 1997). Any combination of these anatomical irregularities could interfere with the feeding process. When bottle or breastfeeding is impeded by these difficulties, infants may require feeding via gastrostomic or nasogastric tubing to ensure nutritional intake (Down Syndrome Ireland, 2012; Moore, 2015).

Breastfeeding infants with Down syndrome

Both empirical and anecdotal data illustrates that historically, breastfeeding was often discouraged or only '*half-heartedly supported*' by health care professionals (HCPs) when a newborn was diagnosed with Down syndrome (Cunningham, 1996, p.187). However, the presence of Down syndrome does not mean that successful breast feeding is unlikely. Evidence repeatedly indicates that with proper support, infants with Down syndrome can be successfully breastfed (Hodges et al., 2008; 2010; Williams et al., 2017; DSA, 2018; Sooben, 2015). The rationale for breastfeeding infants with Down syndrome is especially solid; it provides added fortification against immune, respiratory, bowel disorders and viral infections, to which babies with Down syndrome are susceptible (La Leche League, 2018; Epstein et al., 1995). Breastfeeding also improves mouth and tongue coordination and provides oral stimulation, helpful in rousing sleepy babies (Al-Biltagi, 2015). Despite these proclaimed benefits, only three studies appear to evaluate breastfeeding outcomes for infants with Down syndrome: Breastfeeding for longer than six months has been associated with lower risk of developing respiratory syncytial virus (Bloemers et al., 2007) and Acute Myeloid Leukaemia (Flores-Lujano et al., 2009). The ongoing UK-based, longitudinal, 'Feeding and Autoimmunity in Downs Syndrome Evaluation Study' (FADES; Williams et al., 2017), is aiming to bridge these gaps, by creating a national cohort of infants with Down syndrome, striving to explore associations between early infant feeding and autoimmunity.

Despite indications that breastfeeding is both feasible and beneficial for these infants, research reveals that mothers can still be greeted by the assumption among medical practitioners that they will not breastfeed their infant (Sooben, 2015). Considering that only 750 babies with Down syndrome are born each year in the UK (DSA 2019), HCPs are understandably largely unaccustomed to supporting mothers of infants with Down syndrome to breastfeed (Cartwright & Boath, 2018; Gothard & Stanley 2010). Congruently, maternal narratives depict encountering clinician uncertainty around feeding, with professionals advising against breastfeeding new-borns with Down syndrome (Cartwright & Boath, 2018; Davidson, 2016). In their recent study, Cartwright and Boath (2018) phenomenologically investigated infant feeding experiences and decision making processes within a UK sample of mothers. Three of

the eight participating mothers had breastfed for a sustained period, supporting assertions that breastfeeding an infant with Down syndrome is possible. Worryingly, however, their research illuminated the adverse experience of healthcare professional input, with many participants feeling unsupported around breastfeeding and being pressurised to bottle-feed. Participants also perceived healthcare professionals as being '*out of their depth*' and unable to provide specialist breastfeeding support or specific Down syndrome feeding information, with this vagueness resulting in maternal distress. Participants also relayed the difficult experience of perceiving HCPs to have a disproportionate degree of control over feeding. These findings provide support for Sooben's (2010, 2015) assertions that there is an inadequate level of professional breastfeeding support and advice for mothers of infants with Down syndrome, negatively impacting breastfeeding experiences. The evidence of inadequate feeding support available to mothers of infants with Down syndrome is disquieting, especially considering that both quantitative and qualitative inquiry acknowledges perceived satisfaction with breastfeeding support as being crucial in protecting postpartum maternal wellbeing (Chaput et al., 2016; Trickey, 2013; Taveras et al., 2003). Indeed, better breastfeeding duration outcomes are reported when mothers are supported physically and emotionally during the infant feeding period (Entwhistle, Kendall & Mead, 2010; Renfrew, McCormick & Wade, 2012; Shaw-Flatch, 2002). However, the majority of this research appears to focus on healthy, full-term babies, with little focus being applied to exploring the experiences of feeding support for women with babies with additional needs (See: Mc Fadden et al., 2017).

Feeding policy (or lack thereof)

A weakness of the now discontinued UK National Infant Feeding Survey (Mc Andrew et al., 2010), was that it contained no clear data on the developmental profiles of the infants surveyed. Thus, its findings cannot automatically be extended to infants with conditions such as Down syndrome. A 2019 literature search revealed only two NHS trusts (Nottingham Children's Hospital and University Hospital Leister) to have developed official policies and guidelines for 'the medical management of children with Down syndrome.' Although their guidelines for the neonatal period include ensuring families are visited by a community paediatrician to speak about the

diagnosis, the first mention of infant feeding in the Nottingham document is not until the section covering the three-month medical review (Nottingham Children's Hospital, 2016). However, the University Hospitals of Leister's (2016) official policy includes the recommendation that referrals are made to infant feeding coordinators after both pre *and* postnatal diagnoses of Down syndrome, and that feeding coordinators remain involved until '*feeding is established*' (p.9). While this commitment is encouraging, there remains a clear need for the creation and implementation of hospital policies and guidelines around infant feeding and Down syndrome at a more nationwide level.

Cartwright and Booth's (2018) research has afforded important understandings of some facets of these mothers' feeding experiences. It is also to be celebrated that with the FADES study, a national cohort of Down syndrome feeding data is being created. However, the primary aim of FADES is to establish links between feeding methods/practices and autoimmunity in Down syndrome, without in-depth exploration of maternal feeding experiences and needs. On an empirical level, there continues to be scant knowledge about the experiences, perceptions, emotional adjustments and clinical needs of these mothers during the infant feeding period. Echoing the assertions of Sooben (2015), Cartwright and Booth (2018) attest that the needs of these mothers when feeding are manifest. They make an '*urgent*' call for further research to help inform healthcare practice to better meet the needs of mothers and their infants and enhance maternal and infant wellbeing.

It is becoming increasingly acknowledged that qualitative approaches, with their emphasis on lived experience, are especially apt for conducting healthcare research (Pope & Mays, 2013). By focusing on the meanings that individuals assign to significant healthcare events and perceptions of intervention, qualitative research enables access to perspectives out of reach of quantitative measures, and can aid the development of more intuitive policy and sensitively tailored intervention (Al-Busaidi, 2008). In carrying out this study it is hoped that, in addition to enhancing our understanding of maternal experiences, ways to better support mothers and their infants, and areas for practice guidelines, may become clear.

Postnatal maternal wellbeing

The concept of wellbeing has diverging definitions and conceptualisations within differing fields and theoretical perspectives (See: Slades, Oades & Jarden, 2012). For the purposes of this study, a psychological conceptualisation of wellbeing is used, wherein wellbeing is understood as encompassing positive emotions, life satisfaction, personal autonomy, a sense of purpose and positive relationships (Seligman, 2011). An individual's mental health is defined as a *state of wellbeing*, comprising emotional, psychological and social wellbeing (Galderisi et al., 2015). This study has elected to use the term 'maternal wellbeing' over 'maternal mental health' – for although interdependent concepts, wellbeing is a broader, more far-reaching term (Vera et al., 2012). Accordingly, the wider dimensions of wellbeing, including personal autonomy and sense of purpose, were deemed to encompass a more befitting umbrella term for the current study. Additionally, this thesis recognises the social constructions inherent in the label 'maternal mental health', and its relation to the values and norms imposed upon women by society. Hence, this research would like to distance itself from locating any challenging emotions and cognitions that mothers of infants with Down syndrome may experience within the prescribed category of 'mental health.'

Becoming a mother can be a complex dimension of a woman's life. While most often associated with love and joy, childbirth and new motherhood can represent a potentially vulnerable period, with the associated challenges sometimes initiating physical, social and emotional stress (Coates, Ayres & De Visser, 2014). There is a well-documented identification between pregnancy, childbirth, motherhood and an increased risk of mental health difficulties, especially affective disorders, such as depression (Milgrom, 2017; Wylie et al., 2011). The WHO (2018) identify that globally, around 10% of women experiences emotional difficulties in the postpartum period, most frequently depression. In the UK, one in five sampled women reported emotional difficulties during the first-year post-birth (Royal College of Obstetricians and Gynaecologists, 2017). During pregnancy and the post-partum period, mothers are also at risk of increased vulnerability for the relapse of previous and unrelated psychological difficulties (Biaggi, Conroy & Pawlby, 2016). Poor maternal wellbeing is associated with adverse impacts on infant wellbeing (Rahman et al., 2004) and has been found to adversely impact the later cognitive, emotional and psychosocial

development of their children (Deave et al., 2008; Kiernan & Huerta, 2008; Talge, Neal & Glover, 2007), which has been supported by longitudinal research (Luoma et al., 2001).

Recent empirical investigation reveals that anxiety symptoms and anxiety disorders, including Post Traumatic Stress Disorder (PTSD) are commonly experienced by mothers in the post-partum period (Ross & McLean, 2006; Pawluski, Lonstein, & Fleming, 2017). Experiencing stressful life events during the postpartum period has also been identified as a strong risk factor for experiencing symptoms of depression or anxiety (Biaggi, Conroy & Pawlby, 2016). A stressful life event is conceptualised as an event or situation that causes physical or emotional discomfort, distress, anxiety, concern or fear (Rapoport, & Piccinini 2011; Carmichael et al., 2007). Maternal perceptions of stressful life events during pregnancy and after birth are acquiring intensified research focus, particularly in relation to perceptions of traumatic or unexpected birth outcomes (Staneva, 2015). Experiencing a stressful life event can be a risk factor for women developing both prenatal and postpartum depressive symptomatology, and for overall poorer postnatal wellbeing (Alvarenga & Frizzo, 2017; Cohen, 2004; Ngai & Ngu, 2015).

The receipt of a diagnosis of Down syndrome has been reported as a stressful life event by mothers who receive both a prenatal diagnoses via prenatal screening (Hippman, Inglis & Austin 2009; Georgsson et al., 2004) and postnatal diagnoses after birth (Buckley, 2002). Mothers report feelings of sorrow, guilt, grief, anxiety and devastation when receiving both pre-natal and postnatal diagnoses (Nelson-Goff et al., 2013), all of which are emotions that have been found to negatively impact upon the wellbeing of mothers (Pawluski, 2017; Yelland, Sutherland & Brown, 2010). However, a comb of the literature reveals a lack of research investigating wellbeing in mothers of infants with Down syndrome in the postnatal period. Higher levels of maternal stress have been identified in mothers of children with various developmental ‘disabilities’ (Feizi et al., 2014), and mothers of children with Down syndrome have been recognised as having poorer wellbeing compared to controls (Bourke et al., 2009; Wilmott, 2008). Indeed, the majority of research appears to investigate the wellbeing of mothers of children with Down syndrome when compared to mothers of children with other developmental ‘disabilities’ (Abbeduto et al., 2004;

Richman et al., 2009). Furthermore the findings of studies that focus on Down syndrome are not necessarily transferable to mothers of *infants* with Down syndrome; the Bourke et al., study was questionnaire based, with the experiences of mothers not qualitatively captured, and the mean age of the mothers children was 11.9 years.

Extricating maternal stress relating to having an infant with Down syndrome from the wider postnatal stresses that many mothers can experience would admittedly be an intricate process. But considering that meta-analytic investigation confirms maternal stress and anxiety as possible determinants for postpartum depressive symptomatology (Leigh & Milgrom, 2008; Schetter & Tanner, 2012), and that some mothers experience the birth of the child with Down syndrome as a stressful life event, it seems crucial that further research focus be applied to exploring these mothers' perceptions of their wellbeing during the postpartum period. Gaining insight into these mothers' perceptions may enable awareness of any shortcomings in current provisions of support. From a clinical psychology perspective, enhanced awareness of the psychological needs of mothers of infants with Down syndrome in the postpartum period would aid better tailoring of interventions that benefit the wellbeing of mothers *and* the long-term wellbeing of their infants.

Maternal wellbeing and infant feeding

The psychological benefits of positive maternal feeding experiences are widely reported. Successful breastfeeding experiences have been found to enhance maternal self-esteem (Britton, Britton & Gronwaldt, 2006) and engender feelings of maternal pride, accomplishment and affirmation (Fox, McMulle & Newbern, 2015). In comparison studies, exclusively breastfeeding mothers scored higher on several dimensions of self-concept and self-worth, than their non-breastfeeding counterparts (Britton & Britton, 2008). Responding to subjective wellbeing and objective physiological self-report measures, breastfeeding mothers also report lower rates of depressive symptomatology (Kendall-Tackett, 2016), anxiety and stress (Groer, 2005) and blood pressure and heart rate (Hahn-Holbrook et al., 2011).

Conversely, qualitative and quantitative systematic review reveal a strong association between formula feeding and negative emotions including guilt, dissatisfaction, uncertainty and a sense of failure, along with experiencing judgement

and stigmatisation (Labbok, 2008; Taylor & Wallace 2011; Tompson, Burton & Flacking, 2015). However, mothers also describe formula feeding as affording the same positive feelings of intimacy and reciprocity reported by breastfeeding mothers (Bremner & Slater, 2008). Qualitative research also illuminates some women's positive appraisals of themselves as mothers, and their maternal identity, when formula feeding (Ludlow et al., 2012). Additionally, the abundance of online anecdotal evidence substantiates the positive emotional experiences that bottle-feeding can afford (e.g see: 'bottle-feeding stories' on Medium.com or bottle-feeding threads on mumsnet.com).

For some mothers however, the early feeding experience is defined by struggle. Difficulties with feeding an infant are stressful, and can significantly impact upon maternal wellbeing (Chaput et al; 2016; Shaw-Flatch, 2002). When encountering feeding difficulties, the gulf between the idealised image of feeding and reality can be distressing (Hoddinott, Craig, Britten & McInnes, 2012). Various postnatal issues could potentially influence the reality of infant feeding, including: difficulties with infant latching, problems with the milk supply and maternal pain (McAndrew et al., 2010; Brand, Kothari & Stark, 2011). Psychological factors including maternal stress and anxiety, can also impact upon the initiation, frequency and duration of breastfeeding (Doulougeri, Panagopoulos & Montgomery, 2013; O'Brien, Bukistra & Hegney, 2008). Some mothers experiencing difficulties with breastfeeding report significant distress and feelings of disappointment, grief, shame and guilt (Holcomb, 2017; Lawrence & Lawrence 2015, McAndrew et al., 2010). Watkins et al., (2011) identified a positive relationship between early breastfeeding difficulties - resulting in curtailed breastfeeding - and depressive symptoms at two months post-partum. They recommend all mothers contending with feeding difficulties be screened for depressive symptoms. Feelings of inadequacy have also been expressed by women who are unable to meet their imagined breastfeeding goals (Borra, Iacovou, & Sevilla, 2015). Mothers who have been unable or chosen not to breastfeed, report that formula feeding can compromise their positive sense of self as mothers (Lee, 2008).

A grief reaction can also occur in mothers for whom breastfeeding is problematic due to certain physical characteristics or illness in their baby (Lawrence & Lawrence, 2015). Research indicates that mothers who had initial plans to

breastfeed, but were unable to due to their infant's condition, can be at higher risk for developing post-partum depressive symptoms (Borra, Clacovou, & Sevilla, 2015; Chaput et al., 2016). Mothers for whom breastfeeding is disrupted due to their baby being born with additional needs or chronic illness, express feelings of shock, disappointment, helplessness, stress and guilt in their narratives (Ryan, et al., 2013). While tube feeding represents a mode for infants with illness/additional needs to receive necessary nutrition, the meaning attached to oral feeding can make this a difficult experience for mothers (Southhall & Martin, 2010). Qualitative meta-analysis reveals that the tube feeding experience can result in maternal psychological distress, negative self-appraisals and struggles with negotiating maternal identity (Wilken, 2012).

Although literature in this area is limited, contending with unexpected feeding difficulties is also considered a stressful life event by some mothers (Kendall-Tackett, 2016). As mentioned, research indicates that mothers of infants with Down syndrome may be vulnerable to experiencing stressful life events, placing them at risk for post-partum emotional difficulties, which could be compounded by the experience of feeding difficulties. Ryan et al. (2013) qualitatively explored some aspects of the interfaces between breastfeeding difficulties and being a mother of a child with additional needs, with mothers encountering feeding difficulties reporting feelings of shock, disappointment, helplessness, grief and a sense that they were letting their baby down. Mothers in this study also reported that grief surrounding breastfeeding difficulties can compound existing feelings of grief when receiving a postnatal diagnosis of infant 'disability' (Ryan, et al. 2013). The generalisability of these findings is limited, as the sample comprised a heterogeneous group of mothers of infants with various chronic conditions and 'disabilities', with only two participating mothers of babies with Down syndrome. However, more recent investigation has also identified feelings of maternal guilt and blame in mothers of infants with Down syndrome when having to formula feed, with the potential for this guilt to be amplified due to the additional weight assigned to the nutritional value of breastmilk in the context of infant feeding (Cartwright & Boath, 2018).

A feminist perspective on maternal wellbeing and infant feeding

In contemporary culture, infant feeding can be an ideologically and morally charged arena. The empirical landscape is dotted with accounts of women's emotional reactions to infant feeding. Taylor & Wallace, (2012) identify that '*the twin spectres of guilt and shame bookend women's infant feeding practices*' (p.76). Feminist critics purport that current breastfeeding advocacy campaigns, including the moralistic dimensions of the 'breast is best' rhetoric, can inadvertently contribute to women conceiving that not breastfeeding is a '*personal inaction*', inducing feelings of guilt and shame in the non-breastfeeding mother (Smith, Hausman & Lobbok p.16). An apparent paradox is that breastfeeding mothers also report experiencing feeding in public as a shameful act that violates societal standards of modesty (Tompson, Ebisch-Burton & Flacking, 2014). Guilt and shame, regarded as emotions of self-assessment, are consistently observed disproportionately in women (Torstveit, Sutterlin & Lugo, 2016). It is postulated that the different societal and relational paradigms placed upon women in comparison to men – e.g the need to be more nurturing, the need for deeper relational connection – stimulate greater emotions of self-assessment when the prescribed reality of these norms are not met (Brown, 2008; Ferguson & Crowley, 1997). Feminist scholars purport that unreasonable constructions of motherhood and expectations of women contribute to the emotions of guilt and shame that can often accompany IFPs. The social construct of the 'good mother' relates to the socially constructed pressure on mothers to meet certain standards and ideals of motherhood (Holmes, 2006). Contemporary societal constructions of the 'good mother,' view the ideal of the good mother as selfless, devoted and cognizant of the developmental needs of her infant (Goodwin & Huppatz, 2010). Within this construct, breastfeeding is regarded as an act associated with 'good mothering' (Wall, 2001). Feminist theory purports that feelings of maternal guilt associated with formula feeding may be a product of perceived inadequacy during self-comparisons with the socially constructed ideal of the 'good mother' (Taylor, 2012).

As a fundamental commitment of the feminist orientation is to embrace and amplify the voices of those who may be oppressed and disadvantaged, 'disability' is regarded as a feminist issue (Piepmeier, Cantrell & Maggio, 2014), with feminist disability

studies aiming to deconstruct established stereotypes about ‘disability’ (Garland-Thompson, 2005). However, it appears that mothers of infants with additional needs are, as of yet, largely excluded from the feminist feeding discourses. Instead, feminist disability study of maternal experiences focuses largely on *mothers* with a ‘disability’ (e.g. Prilleltensky, 2003). Potentially, mothers who have difficulties with infant feeding due to their infant’s ‘disability’ may perceive themselves as not approximating the paradigm of the ideally-feeding mother, placing them at risk of experiencing the feelings of guilt and shame noted in the literature (e.g. Thomson, Ebisch-Burton, & Flacking, 2015). It bears consideration whether being subject to the same oppressive feeding narratives and feeding ideals as other mothers might be a more acute experience for mothers who are contending with the potentially stressful life event of having given birth to an infant with a socially constructed, visible, ‘disability’. The lack of research discourses in this area evidences the need for new understandings. It seems important that feminist consideration be applied to explore the intersections between feeding, maternal emotional experiences and infant ‘disability’.

The mother-infant relationship

Defining the mother-infant relationship.

The mother-infant relationship denotes the connection between a mother and her infant. The literature regards the mother-infant relationship as comprising of two synergistic components, the maternal bond and infant attachment to the mother (Jansen, de Weerth & Riksen-Walraven, 2008). The current research applies focus to the maternal bond and the maternal perspective within the mother-infant relationship. Infant-mother attachment is not the focus of this study but is discussed briefly within the framework of attachment theory later in this chapter.

The mother-infant bond

Within the mother-infant relationship, the mother-infant bond implies an enduring, loving and affectionate connection that is specific to one’s child (Feldman & Weller,

2007). Jansen et al., (2008) propose the definition of the maternal bond as: *'The tie from mother to infant, that promotes maternal behaviours aimed at mother-infant caregiving'* (p.505). The Mother-infant bond is associated with the mother's perspective and relates to feelings of warmth and devotion towards her infant, protectiveness, concern for her infant's wellbeing and pleasure in contact with her infant (Kinsey & Hupcey, 2013; Kennell & McGrath, 2005). It can be understood that while the term 'bond' denotes the subjective emotional tie between mother and infant, and relates to the affective state of the mother, it is expressed behaviourally by the mother through cuddles, smiles, coos etc. (Moehler et al. 2006). The capability of mothers to form an enduring bond with their infant is identified as a fundamental process, and a secure mother-infant relationship is essential for an infant to thrive in their mother's care. (Bornstein, 2012). The strength of the mother-infant bond has the potential to influence the child's subsequent emotional wellbeing, having been found to relate to better developmental outcomes, including social and emotional functioning (Alhusen, Hayat, & Gross, 2013; Kennell & McGrath, 2005; Winston & Chicot, 2016). It is now widely recognised that mothers begin the process of bonding with their baby during pregnancy (Alhusen et al., 2013; Righetti-Veltima et al., 2005), commonly referred to as 'maternal-foetal attachment'. This initial bond of a mother with their unborn baby has been shown to be a strong predictor of the mother-infant relationship after birth (Alhusen, 2008). Greater maternal attunement to her infant has also been predictive of better social and emotional development in children with 'intellectual disabilities' (Warren & Brady, 2007).

The waters of the maternal-infant bonding literature are slightly murky, with the concept of bonding at times staying superficial, due to flawed and inconsistent use of terminologies. Redshaw and Martin (2013) stress the importance of careful use of terminology and distinct definitions in this area. While they are related, it is important that the term 'bonding' not be confused with 'attachment', for as noted by Benoit (2004), attachment and bonding have acquired colloquial meanings and are erroneously used interchangeably in the literature. Within the developmental tradition, 'attachment' relates to a specific aspect of the relationship formed between infant and their primary caregiver after birth, which if well-formed, supports the infant – and later the child – to feel secure and protected (Bowlby, 1982; Ainsworth, 1978).

Attachment is an independent behavioural system, whereas a bond refers to the *type* of attachment behaviours between individuals (Bowlby, 2005; Brandon et al., 2009).

Conceptualising attachment

Although it is crucial to keep in mind the distinctions between attachment and bonding, attachment theory provides an important theoretical framework within which to consider the concept of bonding, for the theory identifies the importance of the mother-infant bond (Bowlby 1982). First outlined by Bowlby (1969/1982), attachment theory proposes that human behaviour is governed by the instinct to develop attachments with significant others (Bowlby, 1988). The theory describes an attachment behavioural system which denotes the process by which infants seek and maintain closeness to their significant attachment figures (Bowlby, 1988). The quality of the attachment that an infant develops with their primary caregiver is shaped by the caregiver's reaction when the infant's attachment system is triggered, i.e. by feelings of threat to their safety or security (Ainsworth, 1991). Individual differences in attachment quality have been noted and described, with a primary theoretical paradigm being the security of an individual's attachment (Ainsworth & Bell, 1970). Ainsworth (1970) was the first to identify differences between attachment styles, and detail different patterns of attachment behaviour. She described profiles of secure, anxious/ambivalent and avoidant attachment styles, which are configured around internal working models of self and others (Cassidy & Shaver, 2008). A fourth attachment style, disorganised/disorientated, has subsequently been identified. A secure attachment is defined by infants/children feeling protected by and safe their caregivers (a secure base), with the attachment system regulating emotion and pacifying distress (Green & Scholes, 2018). Bowlby (1988) proclaimed that disruptions to the attachment system in early infancy can influence subsequent difficulties with later attachments and relationships. Decades of longitudinal studies and systematic review indicate that the quality of one's attachment security is strongly associated with a range of capacities: social cognition, self-concept, emotion regulation, ego functioning, communication abilities, mentalising abilities and other general facets of development (Waters, Merrick, Treboux, Crowell & Albersheim, 2000; Clark, 2000; Slade et al., 2005; Laible, Carlo & Roesch, 2004; Meins, Fernyhough, Russell & Clark-Carter 1998). Bowlby's initial formulation of

attachment theory was bound by the premise that the mother-infant bond was driven by an innate desire to ensure the survival of the offspring (Bowlby, 1978). Other early assumptions included the idea that women in general and mothers in particular are biologically orientated to form bonds with their infants and better suited to the process of childrearing (Ross, 2011). Attachment theory has since been revised and reconceptualised to encompass attachment figures other than mothers.

It has been asserted that the primary caregiver (the mother in the context of this research) can enable the development of attachment security through *attunement* to their infant's needs/distress, i.e. entering the infant's emotional world to mimic expressions and activities that are 'in tune' with the infant, e.g. facial expressions, soothing tones of voice (Newman, 2015). It can be understood that the security and enhancement of the mother-infant bond relates to the quality of maternal sensitivity to her infant and her attentional processing of its signals (Wright, 2002). As the mother is responding to the infant, this underscores the reciprocal, dyadic architecture of these attuned interactions, with the infant being an active participant (Murray et al., 2016). This synchrony and reciprocity between a mother and her infant are crucial for the development of their relationship (Bowlby, 1982). The proximity of the infant feeding situation provides essential opportunity for synchronous interactions between mother and infant, providing an important context for the infant to develop attachment (Reyna, 2010).

Capturing the mother-infant relationship

There is no universally accepted or standardised measurement of bonding. Evidently, measuring a concept as personal and subjective as bonding has inherent challenges. Various measures exist that aim to capture elements of the mother-child relationship, including the Mother-Infant Bonding Scale (MIBS; Figueiredo et al., 2005), the Postpartum Bonding Instrument (Brockington et al., 2001) and Maternal Postnatal Attachment Scale (Condon & Corkindale, 1998). While the validity and reliability of these scales has been somewhat substantiated (Galindo et al., 2014), predetermined response categories do not facilitate a rich understanding of the maternal bonding experience, nor capture in depth the mother-infant relationship. Qualitative focus has increasingly been applied to exploring the constructs of the mother-infant relationship and bonding (e.g. Flacking et al, 2012). Furthermore, qualitative applications have

also begun to explore the intricate dimensions of the bonding processes between mothers and their infants with complex health needs, such as Congenital Heart Disease (Mellow, 2014). There remains a marked lack of qualitative studies that explore the mother-infant relationship in the context of Down syndrome. However, the findings from previous studies of maternal bonding in the context of complex infant needs, accentuate the clinical significance of such investigation, with the potential for findings to inform the development of tailored interventions to support maternal-infant bonding (Mellow, 2014).

Factors influencing mother-infant bonding

Early research proclaimed that skin-to-skin contact during a critical period after birth was crucial to ensure ‘bonding’, with the absence of this detrimentally impacting the mother-infant bond (Klaus & Kennel, 1976). This damaging claim has since been invalidated and it is now recognised that various physiological, psychological and environmental factors may potentially impact upon mother-infant bonding. Below is an outline of some possible factors that are pertinent to the current study:

Maternal wellbeing

Maternal wellbeing has been recognised as a factor that can influence postnatal bonding, with research identifying that postpartum maternal psychopathology can affect mothers’ sensitivity to their infant (Rossen et al, 2016), placing the developing mother-infant bond at risk. Maternal ability to interpret and respond to signals from their infant is also affected by poor maternal wellbeing (Stone & Menken, 2008). A consistent finding from meta-analytic review is that clinical and subclinical postpartum depression symptomatology poses a significant risk of impeding the maternal bonding process (Dubber, Reck, Zietlow, & Dubber 2016; Kendall-Tackett, 2016). Exploration of mothers’ subjective perceptions of their bonding experiences have revealed that mothers tend to personally view their experiences of bonding with their infant more negatively when experiencing low mood (Noorlander et al., 2008). Maternal anxiety has also been found to negatively correlate with mothers’ perceived ability to bond with their infant (Dubber et al., 2015). Maternal anxiety can influence the maternal contribution to mother-infant interactions during the postnatal year, with mothers with anxiety traits displaying less sensitivity to the dyad and reduced emotional tone (Nicol-Harper, Harvery & Stein, 2007).

Infant illness and additional needs

During pregnancy, women often experience strong feelings and emotions towards the foetus. When these feelings are optimistic and loving, mothers may develop an idealised image of their unborn infant and fantasise about her imagined relationship with the future baby (Gerhart, 2015; Nash 2008). This idealised image may have to be reconciled if the child is born with an illness or ‘disability’ (Barbossa, 2008). Sometimes, giving birth to a child with a ‘disability’ can be experienced as the loss or death of the ‘perfect’ or desired baby (Landsman, 2008; Wright, 2008), with parents describing the experience of a staged-grief process upon learning their child has a ‘disability’ (Lemacks, Fowles, Mateus & Thomas, 2013; Kandel, 2003). The complex emotions associated with giving birth to a child with a condition have been reported to initially impact upon the mother-infant bonding process (Wright, 2008), with mothers sometimes initially finding it difficult to bond with their newborn with a diagnosed ‘disability’ (Sujatha, 2013).

Maternal-infant separation

During the first few hours and days after birth, interactions between mother and baby, as well as the release of oxytocin and other physiological mechanisms, are thought to contribute to the mother’s developing bond to her infant (Kennell & McGrath, 2005). For some mothers, this process is interrupted if their infant needs to be placed in the NICU. Maternal anxiety and fears around disrupted bonding have been detected in women who are separated from their infant in a special care unit (Flacking et al., 2018). For some mothers facing mother-infant separation, their bonding behaviours and thoughts about their infant have been found to decline linearly, with increasing duration of separation from her infant after birth (Feldman et al., 1999). However, the research is heterogeneous, with some studies identifying that the mother-infant bond can withstand the challenges of separation (Mellow, 2014). Again, there is little research focus in the context of Down syndrome, with most investigation appearing to focus on the experiences of mothers of preterm infants. In one qualitative study, mothers of infants with a postnatal diagnosis of Down syndrome perceived mother-infant separation, when the infant was in the special care unit, as negatively affecting

the initial mother-infant bonding process (Muggli, Collins & Marraffa, 2009). However, this research was conducted with parental dyads, resulting in joint-meaning making between partners and less of a focus on women's subjective, individual experiences.

The mother- infant relationship and infant feeding

Feeding is one of the most fundamental and physically intimate ways in which a parent cares for and interacts with their baby (Harding et al, 2016). It has thus been postulated that the act of infant feeding provides optimal opportunity for parent-infant-bonding (Else- Quest, Hyde & Park, 2003). While recognising the role of partners in infant feeding, this review focuses specifically on maternal experience.

Bonding is facilitated by skin to skin contact, physical proximity, mutual visual regard and affectionate dyadic interactions, such as caressing, nuzzling etc., all of which are viable features of feeding interactions (Waller et al., 2015). Accordingly, the close mother-to-infant physical contact during feeding is regarded as important for promoting maternal bonding and affectional ties between mother and infant (Feldman, Weller, Leckman & Kuint, 2009; Kennell & McGrath, 2005).

The '*Breast is Best*' narratives extend to the contention that breastfeeding creates a superior mother-infant bond, with much research purporting that breastfeeding may improve mother-infant bonding (Liu, 2014; Hahn-Holbrook, Schetter & Halselton, 2013). This perception seems often to be shared by expectant mothers, with research indicating that a motivation to bond with their baby can represent mothers' primary reason for breastfeeding (Arora et al., 2000; Radzysinski & Callister, 2016). Ultimately, however, scientific research does not support the assertion that breastfeeding has a superior effect on the mother-infant relationship than other types of feeding (Else-Quest, Hyde, & Clark, 2003; Jansen et al., 2008). In actuality, the bonding process can occur regardless of the feeding method (Hairston, 2019). Formula feeding mothers also report powerful emotions and an awareness of a feeding bond with their baby (Gribble, 2006; Mercer 2006). These findings dilute essentialist perspectives contending that optimal mother-infant bonding during feeding is achieved through breastfeeding. Results indicating that bottle-feeding dyads do not display poorer quality mother-infant relationships are encouraging for

nonmaternal caregivers and mothers who bottle-feed their children (Else-Quest et al., 2003). These findings are also reassuring for mothers who engage in alternative feeding practices with an infant who has a congenital condition or additional needs, such as Down syndrome.

Maternal-infant bonding in the context of Down syndrome

A thorough scour of the literature reveals little empirical investigation into the mother-infant relationship in the context of Down syndrome. The literature notes maternal difficulties bonding with infants displaying visible difference from birth, particularly infants with cleft lip and palate (Bonsu et al., 2018). However, these findings cannot automatically be extended to mothers of infants with Down syndrome, as mothers of new-borns with cleft lip and palate report that it is the shock of facial ‘deformities’ that inhibited their initial bonding process (Bonsu et al., 2018), whereas infants with Down syndrome appear more ‘typical’ than premature infants or infants with facial ‘deformities’ (Grudzinskas, 1994). Early research supposes that the developmental delay in infants with Down syndrome may impact ability to provide emotional cues to their mothers, impeding the reciprocal communication in the mother-infant dyad, ultimately affecting bonding (Biringen & Robinson, 1991). Babies with Down syndrome have been observed to be less communicative at 8 and 20 weeks, compared to ‘typically’ developing babies (Slonims & McConachie, 2006). However, this same paper notes that these babies had ‘caught up’ with ‘typically’ developing babies by one year of age. Research reveals that parental dyads can struggle to bond with their baby with Down syndrome, with some mothers describing initial feelings of embarrassment and revulsion (Buckley, 2002) or a sense of disconnect from their baby (Selikowitz, 2008; Wright, 2008). Mothers disclose that in the initial few days post diagnosis, experiencing uncertainty reduces an awareness of the bonding experience, with one mother describing it thus: *‘Bonding is so tough because you are still struggling to accept the diagnosis, and have no idea what it all means, and are focusing on so many other medical issues’* (Jacob & Sikora, 2015, p.909).

In contrast, anecdotal evidence, as reported in blogs, lay articles and maternal support forums, is rife with positive maternal narratives describing a strong bond with their child with Down syndrome (e.g: downsyndromepregnancy.org). On an empirical

level, in one recent Irish study, only 12% of parents reported initial difficulty bonding with their baby (Smith, 2019), which is lower than the 32% of sampled mothers who reported difficulty bonding with their baby in a 2016 poll conducted by the UK based National Childbirth Trust. However, the data in the Smith (2019) study was collected through a postal survey, with no exploration of the nuances of bonding, and focused on joint parental experience. In another existing study, McCollum and Chen (2003) investigated parent-child interactions in parents of children with Down syndrome in a Taiwanese sample. They identified that mothers had both positive and negative frames of reference when reflecting on bonding with their children, but the mean age of the children in this study was 12.5 months and the underlying focus was on exploring cultural perceptions of disability. Mitchel, Cram & Crossman (2014) compared the dimensions of the mother-infant relationship between mothers of children with Down syndrome and children with other ‘intellectual difficulties’, finding that children with Down syndrome had more positive interactions with their mothers, as captured by a quantitative observational measures. However, this study only captured mother-child interactions at a specific age point, three years, and the comparison group being children with other developmental disabilities inhibits a more general interpretation of findings.

The empirical literature is noticeably scarce and far from conclusive, preventing both a deeper understanding of initial maternal-infant bonding processes in the context of Down syndrome and critical appraisal of the distinct variation between the scant empirical findings and anecdotal narratives. It appears that there has been little investigation of the bonding experiences of mothers of *infants* with Down syndrome. The actuality that factors which could disrupt bonding have been noted in mothers of infants with Down syndrome (e.g. maternal stress/ anxiety and feeding difficulties), signals this as an area needing much further comprehension.

An empirical understanding of the dynamics of mother-infant dyads in the context of Down syndrome is important. Exploring maternal perspectives and identifying any potential early issues within mother-infant dyads may lead to enhanced provision of early intervention that normalises any difficult emotional reactions mothers might initially have towards their infant and promotes mother-infant bonding after birth. Additionally, empirical substantiation of the anecdotal

evidence recounting positive maternal bonding experiences would be vastly important, potentially providing reassurance for future mothers, with possible better associated outcomes for these dyads. Gaining a more in-depth understanding of mothers' reflections on the bonding process in the context of Down syndrome is clearly warranted. Qualitative methods have the potential to provide nuanced and valuable insight into maternal perspectives that quantitative measures might struggle to capture.

Feeding the infant with Down syndrome and the mother-infant relationship

As outlined previously, babies born with Down syndrome may have a predisposition towards feeding difficulties. Some parents of young children with Down syndrome report that feeding times can be source of distress, associated with anxiety in both partners (Sloper & Turner, 1995). In an illuminating study by Lewis and Kritzinger (2004), parents reported enduring emotions of concern, stress, inadequacy, frustration and hopelessness when contending with feeding problems in their infant with Down syndrome. However, again the focus was on joint parental experience and no indication was given regarding the method of feeding. It has been asserted that the potential complexity of early feeding problems in infants with Down syndrome, associated maternal frustration and poor feeding support may impede feeding practices and impact upon the mother-infant relationship (Rynders & Horrobin, 1999). However, it appears that no subsequent research has explored this since the above mentioned 1999 study. Realistically, we know little about the interactions between feeding and the maternal-infant bond in the context of Down syndrome. No research has employed an in-depth qualitative approach to examine the lived feeding experiences of British mothers and their perceptions of their relationship with their baby during the feeding period (ie. first year). Additionally, it appears that there has been no investigation into how feeding patterns in infants with Down syndrome might impact upon mothers' perceptions of the mother-infant relationship during this time, if at all.

Rationale for the current research

The vast majority of Down syndrome feeding related research has a quantitative emphasis, focusing on the physical/physiological aspects of breastfeeding and the immunological benefits of breast milk. The feeding mother herself is often not the focus, and research exploring maternal lived feeding experiences is still very much in its infancy. There have been repeated calls for a more robust evidence regarding the feeding experiences of these mothers, primarily to bridge gaps in healthcare practitioners' understandings of their needs (Sooben, 2010, 2015; Cartwright & Boath, 2018). This lack of focus on and understanding of maternal lived experience shaped the direction of this study and scaffolds the rationale for its execution.

The literature discussed thus far contributes somewhat to understanding the potential emotional dimensions of feeding an infant with Down syndrome. Mothers of these infants may face unique challenges during the feeding period that could potentially impact upon their wellbeing and their perceptions of their relationship with their baby. While Cartwright and Boath's (2018) study has provided illuminating insight into the feeding experiences and decision-making process of these mothers, there is much still to be understood. To the researcher's knowledge, there has hitherto been no study that explored maternal feeding experiences and placed additional focus on mothers' perceptions of how their feeding experiences may have influenced their personal wellbeing and relationship with their infant.

These gaps in the literature and scarcity of existing empirical exploration of subjective maternal experiences provide a concrete rationale for explicitly investigating these phenomenon. Qualitative methods have the potential to offer valuable, nuanced insights into the lived experiences of these mothers that quantitative methods might struggle to capture. Finally, the rationale is further substantiated by the clinical implications of stimulating much needed dialogue about these mothers' subjective experiences – a better understanding of the feeding and bonding processes may reveal ways in which these mothers might be better supported, and positive findings may contribute to the dismantling of current unhelpful empirical narratives around infant feeding and bonding in the context of Down syndrome.

Aims

Given the lack of existing literature, the fundamental aims of this study are to explore the subjective infant feeding experiences of mothers of children with Down syndrome and their reflections on bonding with their infant during the early feeding stages. The present study is also interested in exploring mothers' perceptions of their personal wellbeing during the infant feeding period, by achieving a greater understanding of the thoughts and emotions they experienced during this time. From this exploration, it is conceivable that any identification of unmet needs in this population could inform clinical intervention, ultimately improving outcomes for these mothers and their infants.

It is hoped that the questions below may be answered through conducting this research:

1. How do mothers experience feeding an infant with Down syndrome?
2. How do mothers reflect on the development of the mother-infant relationship in the context of their infant feeding experiences?
3. How do mothers make sense of their personal wellbeing during the infant feeding period?

CHAPTER 2: METHOD

This chapter outlines the study's rationale, methodological framework and underlying epistemological stance. An outline of the steps involved in design and analysis, various methodological principles and pertinent ethical issues are presented. This chapter concludes with a commentary on self-reflexivity.

Methodological approach: Why a qualitative method?

Qualitative methods facilitate in-depth exploration of human perspectives and enable a discovery-oriented approach to uncover the richness of subjective experiences (Crowe, Inder & Porter 2015; Harper & Thompson, 2011). Explorative qualitative approaches are well positioned to explore complex dimensions of human experience that are not easily quantified (Anderson, 2010) and areas that have insufficient research focus (Forrester, 2010). Due to the lack of research in this area, it was important that the research methodology was exploratory in nature – to best generate nuanced understanding of mothers' experiences. As it was supposed that each mother's distinct feeding experience would have unique meaning to them, it was considered that a qualitative approach would best capture the subtleties of any differences and similarities between participants, as opposed to quantitative measures, which can presuppose elements of human experience (Allen, 2019; Willig, 2013). Taking all the above into consideration, an exploratory qualitative approach was chosen to best facilitate a rich exploration of mothers' experiences.

The focus of this study is mothers' feeding and bonding experiences, and how they have come to understand these experiences. As such, interpretative phenomenological analysis (IPA) was deemed the most apt qualitative methodology. IPA is concerned with understanding individuals' unique meaning making processes about experienced phenomenon and their views on their personal reality (Smith & Osborn, 2003). Prior to discussing the rationale for the selection of IPA, below is an explanation of why alternative qualitative methods were discounted.

Possible alternative methods

Narrative analysis

A narrative analysis (NA) methodology could have been applied to understand how mothers construct their personal narratives around feeding an infant with Down syndrome. Both IPA and NA are underpinned by a social constructionist perspective and aspire to make sense of individuals' experiences, by examining their narratives and constructions of meaning across time (Fraser, 2004). Yet the core analytic focus differs slightly, for in addition to exploring what was said, a narrative analytic lens also explores *how* it was said, involving study of the content and structure of individuals' stories (Riessman, 2002). NA is more concerned with how lived experiences are constructed by individuals, by encoding them in their narratives, rather than the placing dominant focus on the subjective meaning making individuals engage in to understand their experiences (Fraser, 2004). The current research is more interested in subjective meaning and the impact of experiences, rather than their narrative structure, making IPA a more apt methodology.

Thematic Analysis

During the early conceptual stages of this project, mixed methods were considered, with the idea of using thematic analysis (TA) to analyse any qualitative data. TA is utilised to identify, analyse, report and interpret patterns within data (Braun & Clarke, 2006). While TA is flexible and can be compatible with a constructionist framework with phenomenological underpinnings, it lacks the ideographic focus of IPA, as it is more focused on collective themes (Forrester, 2010). With the fundamental aim of this study being ideographic exploration of how mothers of children with Down syndrome understand and make sense of their personal experiences, thematic analysis was discounted.

Interpretative Phenomenological Analysis

Specifically developed within the field of psychology, IPA is a qualitative approach that seeks to examine how individuals come to understand their personal lived experience and the meanings they attach to them (Smith & Osborn, 2015; Zahavi, 2003). In essence, IPA is concerned with understanding how a particular group of people make sense of defined phenomenon, in a specific context (Smith & Osborn,

2008) e.g. understanding infant feeding experiences in the context of Down syndrome. An IPA approach is focused on attempting to access individuals' inner worlds and the multiple facets of lived experiences, including their thoughts, feelings, motivations, and systems of beliefs, and understanding how these are shaped by their intersubjective contexts (Eatough & Smith, 2009; Finlay, 2011; Smith et al., 2009). An underlying assumption in IPA is that individuals are 'self-interpreting beings', involved in active meaning making processes with regards the events, objects and other people that shape their existence. To investigate and evaluate these meaning-making processes, IPA draws upon three fundamental philosophical spheres: phenomenology, hermeneutics and ideography, discussed below (Pietkiewicz & Smith, 2012; Smith & Osborn, 2015).

Theoretical underpinnings of IPA

Phenomenology

Phenomenology, the first theoretical axis of IPA, is concerned with eliciting subjective meanings, i.e. human lived experience (Smith et al., 2009; Smith & Osborne, 2015). Phenomenology is interested in eliciting understanding of *how* phenomena are subjectively experienced. Phenomenological approaches develop this knowledge through careful, rigorous examination of everyday human experience (Groenewald, 2004). As it is impossible to entirely access the subjective inner world of the individual, IPA purports that there is no one objective reality to be unveiled, but that the most research can achieve is an '*insider's perspective*' of an individual's experiences and the meanings ascribed to them (Smith et al., 2009, p.16).

Hermeneutics

Hermeneutics, or the 'science of interpretation', represents the second theoretical axis (Smith et al., 2007, p.50). Hermeneutics proposes that individuals instinctively endeavour to understand their experiences, and how they construe their experiences relates to their interpretations of the meanings inherent in any given context (Forrester, 2010; Smith 2005). IPA labels the centrality of the researcher in the analytic process, acknowledging that access to participants' meaning making both depends on, and is complicated by, the researcher's own perceptions and understandings (Smith &

Osborn, 2015). In recognition of the role of the researcher, IPA dictates a two-staged level of interpretation, or a *double hermeneutic*. In that, as the participant tries to relay how they've made sense of their experiences, as shaped by their contexts (first layer of interpretation), the researcher hears this and then processes and understands it through their personal '*experientially informed lens*' (second layer of interpretation) (Smith et al, 2009, p27).

Ideography

The ideographic lens in IPA relates to individuality and is concerned with the uniqueness of subjective human experience (Smith, 2004). Ideographic enquiry is a finely textured focus on how defined phenomena have been experienced and understood by certain people in a particular context (Wilig, 2008). Accordingly, an ideographic focus emphasises interdependence between individuals' specific personal milieus and how their experiences are brought about. IPA's interpretative ideographic status comes from the researcher distilling and illuminating the meaning in participants' narratives (Eatough & Smith, 2008).

Reflexivity in IPA research

As the double hermeneutic is a defining feature of IPA, the researcher becomes a focal, active part of the research process. Smith and Osborn (2008) acknowledge the importance of the IPA researcher maintaining awareness of how their own stance, context, perspectives and assumptions might interact with the research process and shape the interview and analysis phases. Hence reflexivity in IPA refers to '*explicit consideration of specific ways in which it is likely that the study was influenced by the researcher*' (Smith, 2008, p.250). To ensure transparency and address issues of dependability, various reflexive measures – described later in this chapter – were undertaken throughout this research.

IPA and the current research

IPA is acknowledged as being especially useful for investigating topics which are '*multi-dimensional, contextual, subjective and relatively novel*' (Smith & Osborn, 2008 p. 217) and the approach is hailed for its ability to provide a voice to voices not

typically amplified through empirical investigation (Larkin, Watts & Clifton, 2006). These features of IPA are especially relevant for the current study, as the research aims to explore mothers' feeding and bonding experiences in the context of their infant's Down syndrome, currently an underexplored area. Furthermore, IPA provides a practical and theoretical context for exploring participants' perceptions of how processes unfold over time, such as the progressive experience of infant feeding (Brocki & Wearden, 2006; Smith, et al., 2009). From a clinical psychological perspective, phenomenological inquiry represents a pertinent approach to achieve an ideographic understanding how mothers of infants with Down syndrome may engage in meaning making about any psychological impacts of their feeding experiences (Smith et al.,2009).

Method

Design

For the reasons outlined above, this study employed a qualitative design. Semi structured interviews were the mode of data collection, with IPA used as the method of analysis.

Procedure

Sampling

IPA involves thorough analysis of the experiences of a small number of individuals. Smith et al., (2009), assert that while there is no '*right*' sample size, to suitably meet IPA's commitments, between six to eight participants is optimal for professional doctoral research using IPA. This is because only a small sample size permits true, in-depth analysis of the nuances of human experience (Smith & Osborn, 2015). The small sample size enables rich phenomenological insight, while allowing exploration of similarities and differences between participants' experiences. Purposive and opportunistic sampling was used to consciously select participants who had experienced the phenomena under investigation.

Inclusion and exclusion criteria

IPA research requires recruiting a homogenous group of participants, for whom the experience under investigation is familiar and significant. (Smith et al., 2009). Homogeneity in the sample was sought by imposing the following inclusion criteria, depicted in Table 1, below.

Table 1: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none">• Mothers over the age of 18 who gave birth to a child with Down syndrome, who was still living, within the last three years.• Proficient level spoken English was a participant inclusion criterion, to ensure participants' ability to partake in a lengthy, in-depth interview. This was to avoid the additional layer of filtered interpretation that an interpreter might bring, ultimately affecting the hermeneutic.	<ul style="list-style-type: none">• To prevent extended retrospective recall, mothers who gave birth to their child longer than three years ago were not recruited.• Although it was recognised that adoptive mothers can be involved in either bottle or breastfeeding their adoptive children, adoptive mothers were not recruited for this study. It was thought their experiences of infant feeding might have different emotional dimensions and compromise homogeneity.

Recruitment

Participants were purposively recruited from four Down syndrome support groups in a region of Yorkshire. These parent-led groups provide a network of support for children who have Down syndrome and their families. The mothers were all recruited from the '0-3 years' groups, which offer group support to families with children under the age of three. Recruitment began with one support group and gradually three other support groups were approached, until there was a sufficient sample for the research. The support group services all agreed to circulate information sheets to their mailing lists (Appendix I) and publicised abridged information about the project on their websites (Appendix II). I attended three support group meetings to introduce the research and further circulate the information sheets, and any interested mothers were invited to approach/contact me if they wished to participate.

For ethical purposes, it was decided to recruit participants from local support groups rather than from regional paediatric birth or paediatric general registries, as the latter would have involved access to individual medical records. Furthermore, as I attended each support group to circulate the information sheets, this presented potential participants with the opportunity to meet and question me in person, affording additional approachability and transparency for the project. The limitations associated with recruiting from support groups are outlined in the Chapter Four.

Participants

Eight participants were recruited for this study. Four mothers expressed interest to me in person after reading the information sheet when it was circulated at the support group I attended. The other four mothers contacted me after seeing the study publicised by their individual support groups. All the mothers who expressed interest met the inclusion criteria and went on to participate in the research. No additional mothers expressed interest after the eighth participant had been recruited. While the sample of mothers was homogenous in that they all had a baby with Down syndrome aged three or under, the mothers had experienced different methods of feeding their children. Transparency with regards to this element of heterogeneity is achieved by presenting this information in the pen portraits, which are presented in the results section.

Interviews

Smith et al., (2009) cite semi-structured interviews as the optimum method of data collection in IPA research. This is due to their status as a useful forum for the elicitation of richly-detailed first person narratives relating to whatever research phenomenon is under investigation and allow participants to share information that subjectively regard as pertinent and meaningful (Smith et al., 2009). As such, semi-structured interviews were used to collect participant data in the present study. An additional rationale for the selection of semi-structured interviews was their scope for facilitating a more ideographic focus, in comparison to other qualitative interview methods such as focus groups (Willig, 2013). Lastly, as someone who was unfamiliar with the realm of infant feeding and motherhood, the semi-structured element provided me with a subtly helpful scaffold during the interview process. All the

interviews took place in participants' homes and lasted between 45 and 90 minutes. Interviews were audio recorded on an encrypted device.

Interview schedule

The semi-structured interview schedule (Appendix III) was developed in accordance with IPA guidelines, i.e. the interview questions were open-ended, expansive and explorative, with the aim of capturing the richness of participants' lived experience (Smith et al., 2009). The interview schedule was semi-structured and functioned as a flexible guide, so that participants could set the parameters and share any information they regarded as pertinent to their story. The interview schedule was a fluid document and was subjected to refinement throughout the research process. It was hoped that the interview would be piloted with a mother of a child with Down syndrome who did not meet the inclusion criteria. Unfortunately, this proved difficult to organise and the schedule was instead piloted with an extended family member who had breastfed her children. Her feedback prompted some minor changes.

There was no formal collection of feeding information from participants. This was due to concern that using a demographic form might influence participants' experience of the interview, by implicitly conveying that there might be right or wrong answers or 'preferable/superior' feeding practices/experiences. Correspondingly, it was decided not to quantitatively collect information relating to participants previous experiences of distress or any previous postpartum emotional difficulties. This was due to the inductive approach to this research and a desire not to assume what comprises psychological wellbeing for each individual, but rather for the mothers themselves to share the experiences they regarded as pertinent to their own wellbeing. Instead, questions relating to wellbeing were woven throughout the interview, after the interview relationship had been fostered.

Interview Protocol

At the beginning of each interview, the study was introduced and the research aims and rationale described. Prior to commencing, participants were invited to ask any questions and were reminded that they could withdraw from the interview at any time. Participants were advised that there were 'no right or wrong answers' and were invited to talk freely about any aspect of their recalled experience of feeding and bonding

with their baby with Down syndrome, as well as their reflections on their wellbeing during the infant feeding period. Initial reflections were recorded in the reflexive journal as soon as possible after each interview. Ethical issues relating to the interviews are discussed later in this chapter.

Transcription

Transcription of qualitative interviews is regarded as an interpretative activity; hence, it can be viewed as the first step in the analysis process. Researcher transcription is regarded as having analytical benefits, as data immersion at transcription level ensures that nuances of the interview are not lost when transposed to text (Hennink, Hutter & Bailey, 2011). In line with this analytic conceptualisation of transcription, I transcribed six of the interviews myself to facilitate in-depth engagement with the interview data. A university-approved external transcriber was employed to transcribe the final two. All interviews were transcribed verbatim as soon as possible after the interview took place. Upon receiving the two externally transcribed interviews, they were first read with the accompanying audio playing to ensure accuracy. Typical transcription conventions were adhered to, including the practice of writing [name] to indicate when a place or name was omitted to protect anonymity, using a dash (-) to indicate an interruption and using ellipsis (...) to indicate a pause or trailing off.

Data analysis

The interviews were analysed using IPA as described by Smith et al., (2009). IPA boasts a certain flexibility, with Smith et al., (2009) accentuating that IPA should be characterised as having a set of common process or ‘steps’, as opposed to being a prescriptive method with dictated procedures. They advise the following interpretative strategies:

1. Re-reading of the interview transcripts.
2. Initial close line-by-line analysis of the transcripts, at a descriptive, linguistic and conceptual level.
3. Identification of emergent themes (patterns) for each participant.
4. Establishing connections across themes.
5. Moving to the next case and repeating the process.

6. Looking for patterns across cases, at the group level.
7. Development of all this material into a structure, e.g. theme table, which illustrates the relationships between themes.

This is all tied together to develop a fully coherent narrative, supported by transcript extracts, so that the process can be traced from the genesis to the final thematic structure. (Smith et al., 2009). In the present study, analysis was guided by these strategies, as described below.

Individual case analysis

Steps 1-3: Initial re-reading, exploratory noting and developing emergent themes

Corresponding with IPA's ideographic focus, all interviews were first analysed individually. As soon as possible after each interview, the audio recording was listened to and any thoughts and reflections were recorded in the reflexive journal, including any ideas around modifications for subsequent interviews. When returning to the interviews at the analysis stage, recordings were listened to again whilst reading the transcripts, with the aim of re-familiarisation with the interview data. Separate notes were now made on impressions of participants' emotions, tone of voice etc., and any previous entries about the interview in the reflexive diary were re-read. Following this, preliminary interpretations in the form of exploratory linguistic, descriptive and conceptual comments were noted in the column to the left. In the opposite margin, at a higher level of abstraction, these initial interpretative comments were then converted into emergent themes which aimed to capture the '*psychological essence of the data*' (Smith et al., 2009, p .42). This stage of the analysis was initially completed by hand on printed versions of the transcripts and was then typed into word document. This transfer to a digital document provided an opportunity for additional consideration and refinement of themes, as necessary. An interview excerpt with examples of this process can be found in Appendix IV.

Steps 4-5: Looking for connections across themes

The subsequent stage involved looking for connections between participants' emergent themes. For each participant, all emergent themes were written on sticky notes and posted chronologically (the order in which they appeared in the transcript)

on a large surface. This post-it practice was with the aim of achieving a more physical and temporal connection with the emergent themes (Jeong & Ottman, 2016). Parallels between themes were identified and the sticky notes then clustered together in groups of similar meaning, under a preliminary descriptive label, which indicated the conceptual nature of the associated themes. Following Smith et al.'s (2009) suggestions, themes were clustered through the processes of abstraction (putting like with like and creating a new name for the cluster), subsumption (where an emergent theme becomes a superordinate theme with related themes subsumed underneath) and polarisation (clustering themes based on their oppositional relationships i.e. affective/descriptive poles). These theme clusters were then typed into a word document to form a matrix of superordinate and subordinate theme clusters. During this stage, the significance of theme clusters was evaluated in the context of the research questions, with extraneous theme clusters discarded. This was an iterative process and superordinate theme clusters were reviewed and refined multiple times before being finalised. Theme clusters were then placed in a table accompanied by illustrative quotations and page numbers. This process ensured that all themes were grounded in the interview data. This process was repeated for all eight participants. An example of this stage of analysis can be found in Appendix V.

Cross Case Analysis

Steps 6 -7 Cross-case analysis and identification of master themes

Cross-case analysis involved evaluating the superordinate themes across all eight participants and identifying significant thematic convergences and divergences between cases. Superordinate themes were not merely selected based on prevalence within the data. Rather, superordinate themes regarded as being especially potent, illuminating and significant to the research were drawn up in a list for the group (Smith et al., 2009). To maintain accuracy, themes were always traced back to the original transcripts for substantiation. These listed themes were then considered at a psychological level and clustered into higher-order conceptual abstractions i.e. group master themes, with corresponding subordinate themes. Group themes were reappraised, reconfigured and refined multiple times as necessary, with input from the

thesis supervisory team. The finalised themes were placed in a group table – presented in the results section.

Pen portraits

Upon the completion of each individual case analysis, pen portraits were developed for each participant. Pen portraits provide a condensed account of each participants' narrative, whilst preserving the individual nuances and context of their feeding story. The pen portraits enable the contextualisation of participants' individual themes and enable participants' experiences to 'come alive' for the reader at the individual level (Campbell, McNamara & Gilroy, 2004). Pen portraits also provide a thematic backdrop against which the final group themes could be considered. Furthermore, this written portraiture facilitates additional transparency in terms of the heterogeneity between participants' experiences (Holloway & Jefferson, 2000).

Reflexivity

In IPA, the double hermeneutic means that the researcher identifies and interprets emergent themes to participants' accounts (Smith, 2004). It is acknowledged that the researcher can never attain an objective position as they are influenced by the nuanced context of their own experience (Smith, 2004; Smith et al., 2009). Thus on-going self-reflexivity represents an integral and fundamental component of the IPA process, ensuring trustworthiness and transparency of findings (Clancy, 2016). Correspondingly, various reflexive measures were undertaken throughout.

Reflexive measures employed

- Reflexive conversations with my supervisory team were undertaken during the initial stages of the project.
- To achieve iterative 'bracketing' of any preconceived notions and beliefs and assist engaging with the data without a predisposition, a reflexive journal was kept throughout the entirety of research process. This ensured that all my initial assumptions, subjective views, potential biases and emotional reactions to the interviews were recorded and tracked, making my subjectivity explicit and hopefully minimising bias (Smith et al., 2009).

- The use of the first-person voice in this chapter of the thesis was undertaken as part of a reflexive-relational approach, aiming to illustrate my position of intimacy and immersion with all aspects of the study (Smith et al., 2009).
- I took part in a reflexive group with the three other psychologists in clinical training from my cohort also conducting IPA research. During these meetings, we partook in reflexive conversations where we considered our anticipations of what we would find in our analysis. Later, to verify analysis, sections of our anonymised transcripts and the associated interpretations were discussed, along with a sharing of perspectives on each other's emergent themes. This group process identified new angles on certain themes, enabling further refinement. The group level reflections also ensured interrater confirmation of themes to ensure interpretations accurately reflected the interview data.
- At the end of this chapter I situate myself within the research and provide a reflexive statement, capturing how my thoughts and feelings, as moulded by my personal context, shaped this thesis.

Ethical considerations

Ethical approval

Ethical approval for the study was granted by the University of Leeds Research Ethics Committee (Appendix VI). The ethical issues relevant to the present study are addressed below.

Informed consent

An information sheet, detailing the study and outlining what participation would involve, was circulated to mothers associated with the support groups who were eligible for inclusion (Appendix I). Any participants I met in person when attending the groups were given physical copies of the information sheet and advised that they could 'opt-in' to the project and contact me at a later date to express their interest in

participating. Three mothers stated their preference for me to contact them at a later date to arrange an interview. Other participants who heard about the project through their support group and contacted me by email were sent the information sheet before an interview was arranged. After receiving the information sheet, participants were informed that they were welcome to take additional time to consider their participation or ask additional questions. Prior to the interviews, participants signed a consent form (Appendix VII) and were given the opportunity to ask any further questions. The voluntary nature of the study was emphasised again and participants were reminded they could withdraw from the interview at any time.

Privacy, confidentiality and data storage

Participants were informed that their interview responses would be kept strictly confidential between the thesis team and the external transcriber. Participants gave their consent for the interviews to be recorded on an encrypted dicatphone. All of the interview transcripts were anonymised. Participants were made aware that it is planned to publish parts of the thesis in a peer reviewed journal and that the thesis findings will likely be presented at future conferences. It was emphasised to participants that their anonymity will be preserved at all times and they will not be identifiable in the thesis report, or any future publications. This was all outlined in writing in the information sheet. Given that there is a small, inter-linking community of Down syndrome support groups in this study's catchment area, only certain demographic data is reported.

The encrypted interview audio files were stored on the University of Leeds secure M drive, only accessible with my personal login details, in line with the University of Leeds policy for data protection. Participants' contact details were saved in an encrypted document on the university's secure network, which was kept separately to the transcripts. In adherence with the University of Leeds Research Ethics Policy, the encrypted interview audio files and participant details will be kept on the university's secure shared drive for two years after the thesis has been submitted.

Risk

At the outset of the interview, participants were informed about limitations to confidentiality. It was explained that confidentiality would be broken if participants

disclosed anything that indicated there was a significant risk to their safety or the safety of others. Participants' understanding of this was sought before commencing the interview and the parameters of confidentiality were also outlined explicitly in the consent form. A risk protocol was devised to be followed in the event that any concerns relating to risk arose, including a procedure on participant referral to appropriate services if necessary (Appendix IX). This never needed to be invoked throughout the research process.

Potential for distress

It was possible that participants might have found the personal and reflective nature of the interviews emotive/distressing. Therefore, a number of steps were taken to mitigate potential harm to participants and minimise the potential for participant upset. Firstly, participants were informed at the outset of the interview that they may pause or withdraw from the interview at any point, without needing to provide a reason. A debriefing process was followed at the end of each interview, which involved providing participants with a list of sources of follow up support (Appendix X). A local counselling support service affiliated with one of the Down syndrome supports groups agreed to be linked with this research project (Appendix XI). Participants were made aware that they could self-refer this service to access counselling support, free of charge, if they desired to discuss topics raised in the interview further.

Researcher safety

As all interviews took place in participants' homes, the risks associated with being a lone researcher were considered, and a corresponding safety plan was devised and followed, to ensure my safety at all times. This involved alerting my thesis supervisors about the times and dates of interviews, and ensuring I had a charged mobile phone during every interview.

Ensuring research quality

The issues of quality, validity and reliability in qualitative research have been subject to much scrutiny. Mounting frustration with qualitative research being subject to the same criteria for evaluations of validity and reliability as quantitative research has resulted in the generation of various guidelines for assessing issues of quality or validity in qualitative research (Willig, 2013; Easton, 2018). For IPA research, Smith et al., (2009) particularly favour Yardley's (2000) and Elliott, Rennie & Fisher's (1999) guidelines for quality assurance in qualitative research. Elliot et al.'s, (1999) guidelines are recognised as being more comprehensive and were used in the present study. A description of how these guidelines were adhered to in current study is presented in the discussion chapter.

Additionally, as recommended by Smith et al., (2009) an independent audit trail was kept. This involved filing all of the project's interview and analysis data as a 'digital paper trail', which would enable an external individual to follow the chain of evidence from the early stages of the project to the final report.

Reflexive considerations

As IPA involves attempting to understand individuals' experiences through interpretation, the active enmeshment of the researcher with the process of analysis is acknowledged (Clancy, 2016). Before presenting the results of the IPA analysis, it is imperative to support transparency through reflexive consideration of how my positionality and epistemological stance may have influenced the research (Willig, 2013).

Situation of self in the research

An awareness of 'disability' and additional needs is woven throughout the fabric of my life; my mother is a special needs education teacher, my brother has cerebral palsy and I identify as having a neurological 'hidden disability', which has positioned me with an understanding of what difference can feel like. Much of my experience prior to commencing doctoral training was working with adults with learning disabilities and their families, and within the disability charity sector. These experiences have

sharpened my awareness of the ways in which society can marginalise both individuals with additional needs and their family members, sometimes resulting in feelings of being disregarded or unheard. My awareness that people with ‘disabilities’ and their families can sometimes feel overlooked has resulted in an ingrained drive to give a platform to their voices, if they are not usually amplified. I recognise that this may well have been part of my motivation to conduct research on a group not well represented in empirical psychology literature.

Concerning my personal context: I am a white, 29 year old female, and while I am not a mother, I very much hope to have children one day. I do not have any family members nor close friends who presently have young children, and prior to carrying out this research, my understanding and awareness of infant feeding was categorically limited. Thus, I approached this thesis thoroughly unacquainted with the realm of infant feeding and with undefined views. When completing my master’s thesis, I had been an expert by experience on the topic under investigation and felt a shared sense of identity with the participants. Conversely, I recognise that I felt uninformed and perhaps a little fraudulent at the outset of this research process. However, despite coming from a relatively unaware position, I think my ultimate passion for this project stemmed from a genuine interest in the experiences and stories of women, particularly female narratives around phenomena that have the potential to be both empowering and oppressive, such as infant feeding.

Epistemological stance

Epistemology is concerned with the conditions for knowledge, in essence, what we can know about social realities and how we can obtain this knowledge (Guba & Lincoln, 1998; Willig 2012). In a research context, epistemology relates to the relationship between the person with knowledge of a phenomenon (participant), and the person seeking to understand this knowledge (researcher), and what can be known between them (Guba & Lincoln, 1998). Willig (2013) stresses the importance of researchers ‘owning’ their own epistemological stance, so that the research may be evaluated within this explicitly stated position.

Reflexive consideration of my clinical practice and the frameworks I work within aided the uncovering of my own epistemological stance. I recognise that I

unequivocally believe in the validity of clients' subjective experiences or 'truths', and that my thinking is shaped by the integration of ideas from a range of models and theoretical orientations. These include: systemic, third wave cognitive, feminist, narrative, elements of psychodynamic theory and post-modernism. I would describe my *personal* epistemological and ontological stance as predominantly social constructionist. This position compliments IPA's epistemological stance, in recognising that subjective realities are time and context bound. However, as identified in the introduction, although this thesis draws upon elements of social constructionist thinking it is not presented as a social constructionist thesis. This is due to the inclusion of literature that adopts a reductionist and individualistic stance, and to the intrapsychic interpretation and discussion of some of the current study's interview findings, that are not evaluated from a social constructionist perspective.

My identification as feminist aligned most closely with third and fourth wave views, means that I consider gender in relation to power and systemic oppression. Prior to starting this thesis, I did have some familiarity with feminist literature relating to constructions of 'ideal' motherhood, including how this can extend to infant feeding practices. Letherby (2002) emphasises the danger of making one's own voice the loudest when analysing data from a particular political and intellectual position. I am aware my feminist stance may have assembled the frameworks within which I made sense of these mothers' gendered experiences. It is hoped that awareness and transparent acknowledgment of this will enhance the validity of my interpretations.

Reflexive statement

Reflexive conversations with my supervisory team were undertaken during the early stages of the project. These conversations revealed my initial immersion in the literature had resulted in a preconception that the mothers' stories would primarily be ones of difficulty and struggle, potentially impacting the mother-infant relationship. These conversations, recorded as early entries in the reflexive diary, also revealed my expectation that mothers who had breastfed might report a different dimension to their bonding process than those who had used other feeding methods. I additionally held predictions that any difficulties with feeding would have impacted significantly on mothers' wellbeing. Reflecting on this in supervision identified my expectation to

uncover difficult, potentially even traumatic experiences. This is something I cultivated a mindful awareness of, so as to consciously occupy as neutral a stance as possible when approaching analysis.

Conclusion

This chapter has provided the rationale for this study, as well as an outline of the methodological procedures and ethical considerations. IPA analysis always involves close interpretative engagement. Accordingly, my alignment with the above-mentioned theoretical positions, my position as a woman who has not had/fed a baby, my familiarity with disability and ‘difference’, my personal motivation to amplify under-heard voices and my clinical interests and perspectives, will likely have influenced the way in which I approached this thesis and made sense of the interview findings. This premise will be returned to and considered further in the discussion, along with an account of the evolution of my relationship with the project. The following chapter presents the results of the data analysis.

CHAPTER 3: RESULTS

This chapter offers an account of how mothers understand their experiences of feeding and bonding with a baby with Down syndrome. To support a transparent and stepped presentation of the results, this chapter is divided into sections. Firstly the demographic information and participants' pen portraits are presented. The master themes table is then displayed, followed by the results from the group analysis.

Overview of participants

Participants were drawn from a small pool of interlinking support groups within the same geographic region. To protect their anonymity, participants were assigned pseudonyms. Furthermore, their exact ages and ethnicities are not reported, nor are their babies' genders or health conditions. To further ensure anonymity of the mothers and babies, the pronouns 'they/them' are used in quotations where participants had mentioned their baby's gender. All of the participants lived with their partners. Demographic information for participants is presented in Table 2, overleaf.

Table 2: Participant demographics

Participant Pseudonym	Age	Age of baby	Older children	Previous method of infant feeding	Method of feeding infant with Down syndrome	Prenatal diagnosis of Down syndrome	Mother-infant separation after birth (duration)
Jasmine	40-49	2 yrs	Yes	Formula	Formula	No	Yes - Three weeks in NICU
Miriam	30-39	2 yrs	yes	Expressing and formula	Breast and Formula	No	No
Samantha	40-49	2yrs	yes	Breast	Breast	Identified as high risk during screening	Yes – Two weeks in NICU
Jacqui	30-39	3 yrs	Yes	Breast	Breast	Congenital Irregularities detected during screening	Yes - Two days in NICU.
Rachel	40-49	2 yrs	Yes	Breast	Breast	Yes	No
Enid	40-49	1.5 yrs	yes	Formula	Formula	Yes	No
Abbie	40-49	2 yrs	Yes	Breast and formula	Formula	Yes	Yes -Three weeks in NICU
Poppy	20-29	3 mnts	No	n/a	Formula via tube bottle	Yes	Yes - 3 months in hospital (ongoing)

Pen Portraits

The pen portraits provide the unique context for each mother, enabling the reader to evaluate the individual portraits against the backdrop of the final master themes. Due to the degree of heterogeneity between participants' feeding methods, it was decided to include both emergent themes and direct quotations, in line with previous theses (e.g Hunter, 2015). This was to facilitate capturing the nuanced, thematic divergences between participants' stories and permit the evaluation of some individual participant themes in the discussion. Text in bold indicates an emergent theme from the participant's individual analysis, italicised text denotes a direct quotation. Some personal reflective comments are incorporated.

Jasmine

Jasmine's baby was born with multiple health complications that prevented breastfeeding and necessitated them being in the NICU for three weeks post-birth. During these three weeks, her baby was incubated under UV lights at all times and was tube-fed. Jasmine experienced **anxiety around tube-feeding** and described the situation as "*pretty tough because I wanted to breastfeed.*" Jasmine articulated "*feeling low about the Downs*" after receiving a post-natal diagnosis, and relayed that the painful upset of not being able to bottle or breastfeed made her feel '*even more down*'. Jasmine's baby stayed in hospital for a period of weeks, and she articulated her memory of the emotional **distress of separation**, when leaving her baby. Jasmine described feeling **powerless** around feeding and narrated perceiving **others in control of feeding**. She described **feelings of deficiency** stemming from experiencing this lack of control, feeling she "*was not doing enough*" as a mum. Her attempts to express milk at home were unsuccessful, with Jasmine considering her acute **stress as impacting ability to express**.

In hospital, Jasmine contended with enduring **uncertainty** around feeding, as clinicians sought to determine the best method to feed her baby. Towards the end of the hospital stay, Jasmine began making some of the decisions around feeding, such as selecting the bottles, which seemed to afford a sense of **regaining control**. Jasmine spoke of a strong fetal connection during pregnancy and an **immediate bond** with her baby after birth. She described proximity and **maintaining touch as important for the bond** when unable to feed.

As soon as Jasmine was able to bring her baby home and gain control over feeding, she spoke about her sense of **feeding enhancing the mother-infant relationship**, affording a '*bigger bond*' and a new, intimate dimension to their relationship. Jasmine appraised the **tubes as a barrier to relationship**, explaining that '*once [baby] came out from the tubes and everything, I think our bond has grown a lot more... as soon as he was bottle-fed, I was like, I felt like closer to [them]*'. Other themes relating to control were identified for Jasmine including being **territorial around feeding**, with it not "*not feeling right*" when other people asked to bottle feed her baby. Jasmine linked this to wanting to make up for the time they lost together

during the initial mother-infant separation. **Reassurance** in her status as a mother was identified from Jasmine's pleasure that her baby wont "*take the bottle from anyone else*" making her "*feel special.*" Of particular poignancy, was Jasmine's account of a transition from deficiency to capability, with her feeling like she *was "doing something right"* when finally being able to bottle-feed.

The interview with Jasmine was my first, and I was quite anxious. Jasmine was very warm and good humored throughout; I suspect she sensed my anxiety and responded compassionately. Jasmine was still bottle feeding her baby at the time of the interview, which made her meaning making about her infant feeding experiences feel very raw. Her interview was one of the shortest, possibly a product of my nervousness. Upon listening back to this interview, I realised that I had been too much in 'therapist mode,' at times making interpretative summaries of passages of her speech. This realisation prompted greater awareness of this in the subsequent interviews.

Miriam

At the outset of her interview, Miriam spoke frankly about her distressing and "*unpleasant*" breastfeeding difficulties with her older children. Miriam cited this period of breastfeeding difficulties as a time she felt "*closest to depression*". She catalogued some of the psychological impacts of her previous breastfeeding difficulties, including: **low mood, distress, guilt, perceived abnormality and feeling deficient as a mother.** When Miriam received the postnatal Down syndrome diagnosis, she conveyed experiencing a **renewed determination to breastfeed.**

After receiving a crucial degree of breastfeeding support and intervention from student midwives, Miriam was able to successfully exclusively breastfeed her baby for six months. Miriam described breastfeeding as "*wonderful*" and conveyed the unadulterated, "*pure happiness*" and '*overwhelming love*' she experienced during feeding. Miriam described feeding as a "*very bonding experience*" and recounted her perception of **breastfeeding as deepening the mother-infant bond**, describing breastfeeding as "*the closest that it can get.*" Miriam spoke of the pleasurable and **gratifying dyadic intimacy** during feeding. She also narrated her sense of experiencing **stability** through feeding, speaking about her perception of the solidity and '*rhythm*' it provided. Miriam described the feeding moments as **affording**

feelings of normalcy, and diluted anxiety relating to the Down syndrome diagnosis, with the breastfeeding moments having the potential to “*shift your mind away from those worries*”. Miriam narrated the **positive self-to-self relating** that breastfeeding stimulated making her “*felt good about [herself]*” and described feelings of **self-assurance** that she was “*doing the right thing*” for her baby in the context of their additional needs. Miriam had encountered negative feeding narratives from clinicians, and relayed her pride at exceeding expectations around feeding: “*I kept bragging about it, you know and saying don’t say that kids with Down syndrome they can’t, you know*”. Miriam had recounted her “*feelings of failure*” when previously unable to breastfeed. So, a particularly moving, thematic thread related to Miriam experiencing an **evolution from a failing to fulfilled mother**, with her asserting that her positive breastfeeding experience has made her “*kind of a fulfilled mum now*”.

I found the interview with Miriam very moving, and we both became tearful at points as she recounted the emotional magnitude of her breastfeeding journey. I experienced these as moments of connection, contributing to our rapport. Miriam spoke fervently about the depth of meaning her breastfeeding experience and was candid about the emotional impact of her previous feeding difficulties. While Miriam did contemplate the increased weight she assigned to breastfeeding in the context of the Down syndrome, she seemed to mainly make sense of this feeding experience by comparing it to her previous breastfeeding experiences.

Rachel

Rachel received a prenatal diagnosis of Down syndrome and there was a sense of her **preparedness** with regards to feeding, having been “*warned that [they] might struggle to feed*”. Rachel described this **advance information as protective**, stating that “*knowledge had been power.*” Rachel had expressed breastmilk before her baby was born and described the sense of **maternal purpose** this gave her, explaining that she felt she “*was doing something for [baby] before [they’d] even arrived*”. Rachel’s baby was immediately placed in the special care baby unit, and initially fed Rachel’s expressed colostrum by NG tube. Rachel described the strangeness of maternal-infant separation, but acknowledged advance expectation of this was protective, making sense of it thus: “*it was a bit kind of like, no its’s fine...but it would have been shocking*”.

if we hadn't of known what was coming."

Rachel breastfeed shortly after birth, describing it as *"a bit tricky"* initially, due to her baby's floppiness. She described her baby's medical complications as casting a shadow of **feeding worry**, recounting her **apprehension** that she would be *"pushed to bottle feed"* if her baby went into heart failure or lost more weight. Rachel also outlined her **enhanced motivation** to breastfeed in the context of the Down syndrome diagnosis, outlining that *"probably the sort of health benefits and all the rest of it, I think probably em... pushed us a bit more to want to feed."* Rachel described her joyous **relief** at being able to breastfeed and narrated a very positive experience of breastfeeding her baby, exclaiming: *"Oh I loved it! Yeah, very much so."* There was a sense of **acceptance** of the ordeals of breastfeeding in the context of her baby's Down syndrome, with Rachel expressing that she felt *"just accepting it and being happy to do whatever [baby] needed really"*. A sense of Rachel's maternal **affirmation** through the **fulfilment of feeding duty** was identified in her account. When speaking about her relationship with her baby, she identified the role feeding played during the initial separation in hospital, explaining that: *"you're not with them to bond with them, but I think maybe the breastfeeding made a difference there, because he had to come out of the box to be fed."* She went on to describe *"feeling more bonded"* as a result of the breastfeeding process, describing the *"physical closeness"* as an important contributor to the bond.

Rachel in particular spoke very candidly about her emotional journey and process of **making sense of a new normal** as a mum of a baby with Down syndrome. Rachel chronicled her experience of initial **oscillating emotions** and feeling *"up and down"* in the first few months after the baby's birth and her perception of a *"background of anxiety"* during the early months. Rachel relayed the positive emotional impacts of breastfeeding for her: she identified **feeding as stabilising** and **soothing** and something that *"made her feel better."* She also depicted the comforting familiarity and **sense of normality** it afforded, explaining that breastfeeding *"was something that was normal and it was what I'd done with our oldest."* Rachel articulated her sense of **feeling supported around feeding**, expressing her belief that *"a lot of your breastfeeding experience is influenced by the support you get around you."*

Rachel and I developed an easy rapport, possibly contributing to this being the longest interview. Rachel needed little probing to reflect, she spoke openly and honestly about her experiences, providing rich examples from her internal world and meaning making processes. Her interview was a little fragmented due to multiple interruptions, and at times I lost my thread. Listening back to the interview, I noticed that some of the interruptions resulted in us picking back up from a different point and potentially missing aspects of Rachel's story.

Samantha

Due to having multiple health conditions that impeded feeding, Samantha's baby was initially tube fed her expressed breastmilk for a period of weeks before she was able to breastfeed. Samantha's baby also spent an extended period of two weeks in the NICU after birth. Samantha chronicled her sheer **determination to breastfeed**, she relayed her beliefs of breastfeeding as best, and "*what nature intended*". Samantha had a clinical background and was familiar with the literature around the benefits of breastfeeding. She also described **increased dedication to breastfeeding** in the context of the Down syndrome, with her evaluating breastmilk as having "*developmental benefits*". Samantha also acknowledged the importance of feeding for her own "*wellbeing*." Due to the baby's poor oralmotor skills, medical conditions, colostomy bag and various hospital readmissions, breastfeeding was initially difficult. As such, her baby was bottle-fed expressed breastmilk before moving onto exclusive breastfeeding. Although Samantha articulated **feeling supported** by hospital staff around feeding, she described **feelings of failure** during the period where she was unable to breastfeed exclusively.

Samantha described her feeding experience was "*a very difficult journey*". She narrated her **depersonalised experience of expressing**, depicting a mechanised and detached initial feeding cycle: "*wake up, express, go back to sleep, wake up, express.*" Samantha described some of the "*traumatic*" elements of her feeding experience, including **feeling judged** by others in public places when she needed to express: "*you'd be there expressing and you could see the look on some peoples' faces going 'well why aren't you just breastfeeding'*". Samantha described contending with feelings of **self-doubt** around her feeding decisions, explaining that she "*sometimes questioned myself you know, should I give [baby] top ups of formula, because then*

[they] might get fatter quicker. Am I doing the right thing?'". She acknowledged the **protective** element previous feeding experiences stating her belief that she may have *"given up sooner if [baby] had been my first"*.

Despite some difficult experiences, Samantha passionately narrated the meaningful aspects of her feeding journey, also describing feeding as **normalising** and **stabilising**. There was a sense of her **gratification** and **reassurance** from being able to **fulfil the feeding role**, in *"providing everything that your child needs."* Samantha articulated her **self- assurance** in her belief that she had *"done the right thing"* by persevering with breastfeeding, and described **positive self-evaluations** that successful breastfeeding afforded, including feelings of **pride** and **self-belief**. Samantha described a close, loving bond with her baby. She had a defined perspective on **breastfeeding as strengthening the mother-infant bond**, expressing her belief that there is *"a stronger bond when you breastfeed."*

Samantha was informed and articulate and I appreciated her spirited honesty and willingness to share facets of her feeding experiences. I must also admit to finding myself thinking about how the non-breastfeeding mothers might have experienced hearing Samantha's somewhat purist 'breast is best' beliefs, particularly her views around its superior contribution to the developing bond. Samantha contacted me about taking part in the study, explicitly stating the lack of empirical research on maternal perspectives as her motivation: *"That's exactly what I was looking for, is what you're looking for, is maternal experiences really more than anything. There isn't anything out there, it's just blogs, it's just people on Instagram saying a few bits."*

Jacqui

Jacqui made an immediate attempt to breastfeed after birth, but her baby had difficulty latching on and soon afterwards was *"scooted off"* to the NICU, and they were separated for two days. Jacqui described the **distress of separation**, recollecting the associated sense of **isolation**. Jacqui described encountering healthcare professionals' pessimistic attitudes around feeding: *"Everybody saying at the start that your child won't feed."* During the time that her baby was in the special care unit and unable to be breastfed, Jacqui expressed her breastmilk. She described the sense of **incongruence** she felt, explaining that *"expressing is the last thing you're wanting to*

be doing when your baby isn't with you." Jacqui communicated the **detachment** she felt at having to express without her baby, describing almost a mechanised experience of expressing, becoming quite "*robot-like*" with it. Jacqui relayed her **rationalisation** of this expressing experience, with it instilling a sense of purpose and belief that she was fulfilling a maternal duty: "*I had a job to do with the milk and maybe that helped keep me focused.*" Jacqui also narrated her increased devotion to breastfeeding in the context of the Down syndrome identifying her belief in the superiority of breastmilk as underpinning this: "*especially with [baby] having that diagnosis and supposed lower immune system, I think it's even more important.*"

There was a sense of Jacqui's **relief** and **validation** when her baby began breastfeeding successfully. Jacqui regarded breastfeeding as an integral part of being a mother, viewing it as "*part of my role.*" Tying into this belief, there was a sense of her **affirmation** and **reassurance** that by breastfeeding, she had been able to "*give [baby] that start in life*". Jacqui described her breastfeeding experience as uniquely special, asserting that there is "*nothing else like it.*"

Jacqui described experiencing an "*emotional outburst*" when she got home from hospital, feeling assailed by emotions as she began to process the diagnosis of Down syndrome. In the midst of this, she reflected on "*feeling happy to be feeding*", describing the sense of comfort she derived from the **stability** that feeding afforded. Jacqui spoke about the easy formation of her bond with her baby, describing her experience of having "*bonded with [them] in the womb*" with this extending after birth. Although describing that she has "*never had a difficulty bonding*" with her baby, she also spoke about **feeding as intensifying the bond**, stating that she "*felt a lot closer*" during feeding, describing the **gratification** and **fulfilment** from "*having [baby] so close and being able to give my milk directly*". Jacqui narrated that her breastfeeding experience was "*not as long as I would have liked*", and ended prematurely due to a medical complication. There was a sense of her lamenting this perceived premature end of breastfeeding, and she conveyed a sense of **remorse** and of internalised **disappointment** around this. Upon moving on to bottle-feed her baby, Jacqui described "*snuggling with the bottle*", to **stimulate the same closeness as breastfeeding**, and spoke about ultimately enjoying bottle-feeding too, explaining that she "*enjoyed bottle feeding. It was still enjoyable, do you know what I mean? It's just different I suppose.*"

I remember feeling very struck by Jacqui's stoicism and resilience throughout her interview. I experienced Jacqui as more matter of fact and rational in the telling of her story than the preceding mothers, and I didn't experience some of the emotional contagion that featured in earlier interviews. Jacqui shared a clear motivation to take part in the interview, expressing: "*I was quite willing to share because I feel like I've had a very positive feeding experience, even though he had a difficult start and [baby] didn't feed initially... the outcome, do you know what I mean, was brilliant. So I would hope that other mums sort of feel inspired give it a go.*"

Enid

Enid had wanted to breastfeed her older child, however the baby had difficulty latching on, and after an extended period of difficulty, she and her partner ultimately decided to use formula. Enid detailed her "*horrible and unpleasant*" experience of feeding intervention from a midwife around this, and spoke about **feeling unheard** and **pressurised to breastfeed**. Enid relayed that she experienced feelings of **guilt** and **distress** at perceiving that she had "*let [baby] down*" due to the difficulties with feeding.

Despite this difficult introduction to infant feeding, Enid described her reived **determination to breastfeed**, after receiving the prenatal diagnosis of Down syndrome in this baby, feeling "*determined to give [baby] a chance with breastfeeding.*" Enid was not able to produce the amount of milk her baby needed and received some involvement from a breast feeding support worker, whom she found "*abrasive,*" and **shaming** when she was unable to follow her instructions. She then described an encounter with a paediatrician who proclaimed that because of the breastfeeding difficulties her baby would need to be tube fed. After establishing that formula feeding would be possible, Enid recounted **regaining control** by asserting herself and announcing to the clinicians "*right that's it then...formula is what we're doing*". From that point onwards, Enid has formula fed her baby.

In her narrative, Enid relayed reassurance in her feeding decisions, describing that feeding has felt like the "*right thing to do*" and ultimately she has "*never looked back.*" Enid's account of her infant feeding experience was emphatically positive, and she chronicled a happy and meaningful feeding journey, describing it as "*plain sailing*

with [baby] in terms of feeding. [They've] gone from strength to strength." Enid described feeding as a *'real bonding experience'*. She recounted perceiving "trust" and "closeness" and an awareness "just how much you love them" during feeding. There was a sense of Enid **connecting with her maternal identity** and her feeling of **accomplishment** during feeding. Enid spoke about feeding providing moments of **stability** during the "fraught" moments of general motherhood. Although Enid stated her belief that she at the time formula feeding felt like "the right thing to do", twice in the interview she shared some **retrospective regret** that she missed the breastfeeding experience and "didn't try harder to breastfeed...because [baby]'d got Downs." The only time Enid mentioned any anxiety relating to feeding was with regards to weaning, explaining that she "there's just an element of worry now that [baby] needs to develop further and wean" but went on to clarify that "other than that it's still very positive".

The interview with Enid was the shortest one. She voiced that she wasn't sure she had "much to say", and at one point described her feeding journey as "probably quite a boring, typical story. As in, you know, [baby] was able." Upon consideration, I wonder if her repeated emphasis of her story being unremarkable subconsciously influenced my approach to the interview, and its consequent duration. However, towards the end of the interview, Enid began to acknowledge the importance of contributing her positive story to the research: "maybe what some people need to remember about Down's children, with feeding, and with all aspects of them, that they're just a little person. I know it can be very different. But, it can also be a very positive story." Compared to the other mothers, Enid spoke less about her identity as a mother of a baby with additional needs, and her baby's Down syndrome felt less of a context from which she evaluated her feeding experience.

Abbie

Abbie's infant feeding story was infused with strain and anxiety. Abbie had breastfed her older child and reflected on **yearning for the breastfeeding experience** with this baby, relaying that she regarded breastfeeding as "the best thing" and "wanted a nice bond". However, Abbie's baby had difficulty breastfeeding and was tube-fed for almost three weeks. During this period her baby was placed in the special care unit

and she was separated from her baby for this extended period. Abbie had difficulty expressing, attributing this to the distress of **mother-infant separation**, when her baby was in the special care unit. She described experiencing **exasperation** when unable to express.

Abbie narrated some maternal attachment anxieties during their separation: *“I was worried like [baby’s] not even going to know that I’m [their] mum.”* When in hospital, Abbie relayed her perception of **others in control of feeding**, resulting in feelings of being **redundant** and **useless**. After repeated failed attempts to get her baby to latch on, Abbie began **asserting control** over the feeding situation, by making the decision to formula feed. Abbie’s baby was tube fed in hospital for three weeks with bottles gradually being introduced, and he was subsequently bottle fed at home. Abbie narrated a fraught, **anxious** feeding journey: *“[baby’s] weight was a big thing, a big worry, cause [they] was losing weight. It was quite stressful. I got really stressed about it”*. She described developing anxious practices around feeding, including **catastrophizing** and **ruminating**. Abbie depicted the enduring nature of this, explaining that it was *“really stressful for months actually”*. She explained her anxiety centred around the prospect of the baby *“ending back up in hospital on a feeding tube”*. Abbie also described **hypervigilance** around feeding, with her being alert and watchful, in case baby became sleepy. **Obsessive/fixated thinking** with feeding was also detected in her account, with Abbie describing that *“all me thoughts . . . basically just revolved around how much [baby] was gonna have the next time [they] was gonna feed.”* There was a sense Abbie’s **unpreparedness** for feeding difficulties, with her saying she had not taken advance information around potential feeding difficulties *“on board.”*

Although Abbie described feeling supported and reassured by postpartum midwife involvement, she recounted that their reassurance would not last, with stress *“creeping back in”* soon after they left. There was a sense of her having felt trapped in an **unending cyclical feeding anxiety**. Abbie described feelings of uncertainty around feeding a baby with Down syndrome, and how this maintained the feeding anxiety. Abbie described that this feeding uncertainty stimulated a discomfiting feeling of **retrogression to new motherhood**, describing that: *“It felt like totally new . . . like I hadn’t had a baby before... Like a new mum again.”* She described **chastising** herself for this and spoke about accompanying feelings of

embarrassment. Abbie did not describe experiencing a feeding bond or feeding as enhancing the relationship, but described “*a very close bond*” with her baby since birth.

Abbie’s enduring Resilience was evident as she narrated her story, and I felt in awe of her fortitude. Abbie got tearful at times throughout the interview, and I was aware it was painful for her to revisit some of her memories from being in hospital. The interview seemed to provide a meaningful space for Abbie to process and make sense of some of her difficult feeding experiences, with her stating that had been “*good to actually talk over like that...I haven’t really had a chance to.*”

Poppy

Poppy’s interview differed from the others as her baby was three months old and still in the hospital when we met, due to his multiple medical needs. Poppy was a first-time mum, and she and her baby were also separated after birth. She narrated the “*absolutely horrific*” **anguish** and **distress** of this separation. Poppy’s baby had been fed by NG tubes for the first 7 weeks, with bottle-feeding gradually introduced. Poppy described feeding as “*a hurdle*” and chronicled a difficult feeding journey. She described feeding difficulties as an “*emotional whirlwind*”, depicting the associated feelings of **disorientation** and **anxiety**. Poppy made sense of her tube-feeding journey in the interview, describing initially feeling **apprehensive** (“*hesitant*”) around having to tube-feed. There was a sense of her lamenting the close contact that a different method of feeding might afford, expressing her certainty that she would “*feel happier if it was all bottle, we’d be closer*”. By the end of the interview, Poppy described **tube-feeding as meaningful**, expressing that being able to be involved was “*wonderful*” and identifying that without tube-feeding she “*wouldn’t have had a feeding bond*”. Poppy described the unique pain she experienced at being unable to feed her baby- she recounted feeling **inadequate** and **disappointed**, and conveyed her belief that by not feeding she has not “*done what I should be doing for [baby]*” and consequently **not fulfilling her maternal role**. She also described **disconnecting from maternal identity** when unable to feed, expressing that she “*Just felt like [baby] wasn’t mine ...Especially cos I wasn’t breast-feeding.*” The theme of **unpreparedness** was identified in Poppy’s narrative, she described being unprepared

for the feeding difficulties, with her having assumed that her baby would feed “*perfectly fine.*”

Poppy reported still contending with **feeding uncertainty**, explaining that she and her partner were still “*not sure what to do when it comes to feeding and bottles*” and were awaiting clarification from clinicians about various feeding issues. Poppy also spoke at length about **feeling unsupported**, asserting that “*from a feeding point of view...there’s no support really*”. She described the **isolation** they felt as a result of this lack of support: “*feeling out on our own.*” Salient themes relating to **lacking and acquiring feeding control** were identified in Poppy’s account. She relayed the meaning she ascribed to becoming more involved in tube feeding, with it leading to **increased parental autonomy**, explaining that: “*Now we can do all the feeding, they’re not coming in as much now cause they know we can do it.*” For Poppy, becoming more involved with feeding facilitated **fulfillment of maternal duty**.

When exploring the development of Poppy’s relationship with her baby, poppy recounted that although she was **aware of a strong prenatal bond**, she “*didn’t feel a bond at first*” when her baby was born and was concerned that bonding would not happen after the mother-infant separation. Poppy depicted **autonomous mothering as important for relationship**.

I found the interview with Poppy particularly affecting, as her experiences of feeding difficulty and distress were so current, and being made sense of in real time. She relayed everything very rapidly and I was left with the impression of it all bursting out of her. I had the sense that she hadn’t really been able to speak to anyone about what she had been going through since the birth, and it seemed that she might have experienced a degree of relief in being able to recount and process her feeding experiences. Poppy’s partner was in the house at the time of the interview, and at one stage joined in. It seemed important for him to speak too, and it took me about five minutes to feel confident to remind him gently that Poppy was the focus of the interview. However, even when her partner moved to a different room, she continued to pluralise her reflections, perhaps an indication everything feeling so jointly experienced. I remember feeling very moved, and also a mounting sense of indignation, at Poppy’s descriptions of feeling isolated and unsupported.

Group Analysis

Analysis then moved from an individual to group level. Cross case analysis identified four superordinate themes and ten associated, and interrelated subthemes in the interview data. These themes are depicted graphically in figure 1, below. The identified themes capture the ways in which the mothers perceived and understood their experiences of feeding and bonding with their baby with Down syndrome, and their perspectives on their personal wellbeing during this time. In presenting the findings, the aim is to illuminate the parallels and divergences among these mothers' experiences. Verbatim quotations are used to exemplify the themes and ground them within the mothers' lived experiences.

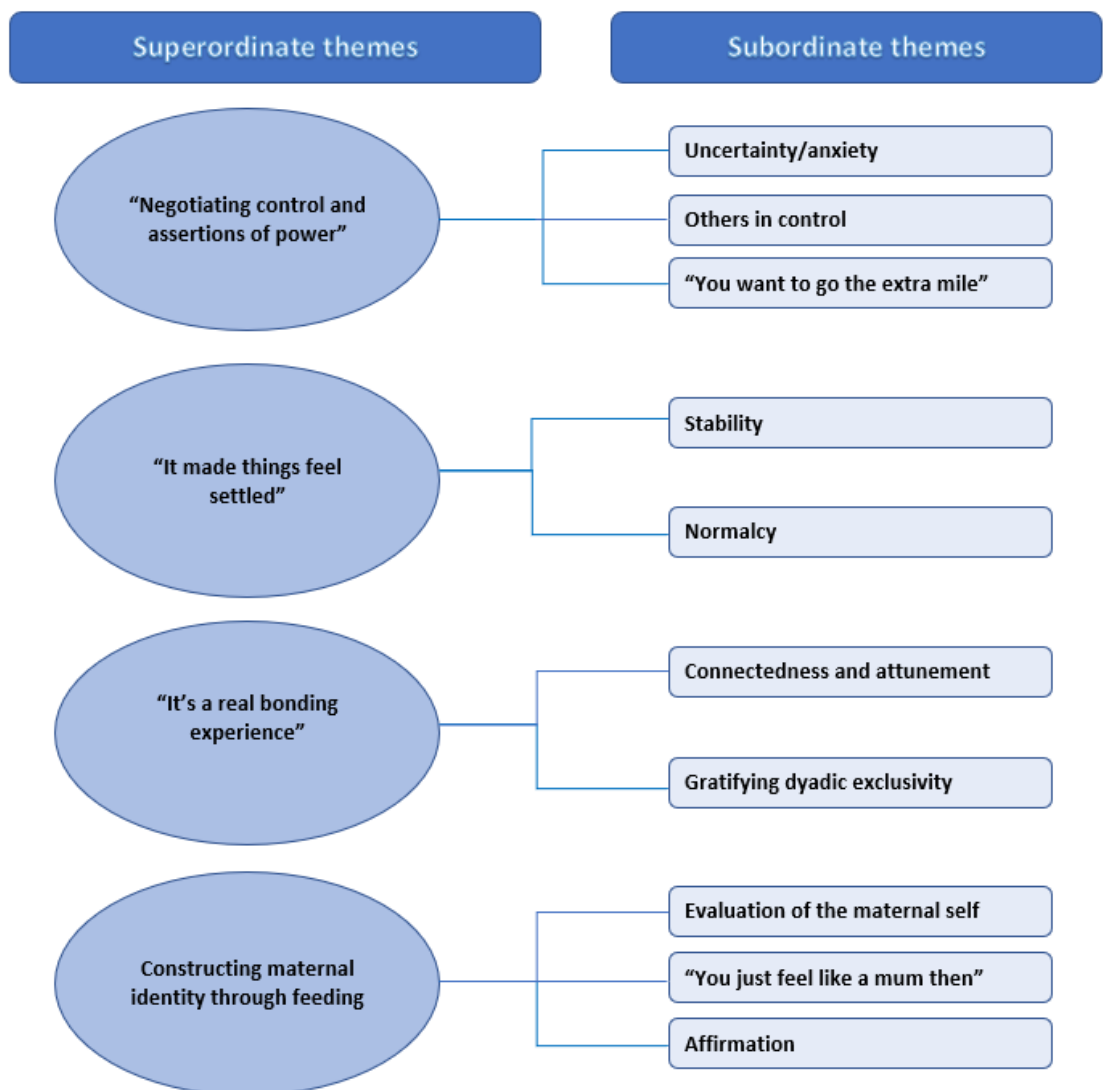


Figure 1: Graphic depiction of themes

Superordinate theme 1: Negotiating control and assertions of power

This first superordinate theme encapsulates the mothers' accounts of their perceived power and control over the feeding situation, their experiences of navigating and negotiating these dimensions of control and the emotional experiences associated with this. Within this superordinate theme, three interlinking subthemes were identified: *Uncertainty & Anxiety*, *Others in control* and *"You want to go the extra mile."*

Uncertainty & Anxiety

While uncertainty and anxiety are different affective states, difficulty mitigating uncertainty relating to a current or future threat, can often result in anxiety (Grupe, 2013). Correspondingly, uncertainty and anxiety have been linked together as a subordinate theme. This is because for some mothers, encountering initial uncertainty around feeding subsequently progressed into a more threatening and intense feeding anxiety.

All eight mothers recounted the various degrees of stress, uncertainty and anxiety experienced during the post-natal period in hospital, and in the early months of adjusting to having a baby with Down syndrome. So, while this subordinate theme relates specifically to feeding-related uncertainty and anxiety, it must be considered in the context the other life stresses and adjustments mothers were contending with. It is conceivable that wider postnatal anxieties may have interacted with, and compounded, any feeding anxiety and vice versa. Thematic threads relating to maternal *resilience*, *perseverance* and *fortitude* were identified in all eight mothers' accounts. These threads are not included in the final group analysis, as they related to the wider experience of coping with transitioning to having a baby with Down syndrome, and not feeding specifically, but it may be helpful for the reader to hold these in mind whilst considering the results.

Five mothers narrated their feelings of uncertainty during the initial stages of their feeding journeys, communicating the feelings of hesitancy and insecurity around how to feed a newborn with Down syndrome, and conveying the lack of control inherent in this state of uncertainty. Some mothers also identified that their experience of uncertainty could stem from clinicians' lack of clarity around feeding. For example,

Jasmine relayed encountering a sense of vagueness from clinicians around feeding, and recounted the impact of this:

“They were trying to work out which milk was right for [baby], for [them] to gain weight ‘cos [they] wasn’t gaining weight. So they had to go through this trial and error of feeding, em through a tube so [baby] wasn’t even having the bottle... they were like ‘oh we have to see, because it could be going down the wrong way and if it’s going the wrong way, we’ll have to do an x-ray and after that [baby]’ll have to have this operation and all this... and it’s was like, well I don’t know what’s going on”

Her use of the words “*trial and error*” indicate a collective uncertainty, with clinicians having to experiment around feeding. Her concluding words of “*well I don’t know what’s going on*” highlights the degree to which clinicians’ vagueness and lack of certainty around feeding could be experienced as perplexing, and even disorienting, insinuating Jasmine’s perceived lack of control over her situation. Jasmine’s baby had received a postnatal diagnosis of Down syndrome, and perhaps this uncertainty magnified a wider feeling of overwhelmedness.

Rachel had breastfeed confidently before, but described feelings of doubt and hesitation around breastfeeding her baby after a heart operation:

“I do also remember first feeding [baby] after the heart op, ‘cause I was so scared of hurting [them], because you have to hold them, you know, you have to support them don’t you, and I thought you’ve just had your chest all broken to pieces, you poor thing, how can I feed you?”

Rachel’s imagery of her baby’s chest here is graphic, and her words imply that uncertainty around feeding can result in feelings of doubt and insecurity, and perhaps indicate a need for specific direction and instruction from clinicians.

Poppy relayed the sense of uncertainty that shrouded her initial introduction to feeding. She conveyed a sense of vagueness stemming from the lack consistent information from the clinicians around feeding her baby, and their inability to answer questions about feeding:

“We was asking the questions is it Downs Syndrome that’s causing this, like breathing, or [baby’s] trouble feeding and they weren’t sure” (p.10)

“One of the nurses would say [baby’s] fine on this milk; and then another one would say no [baby’s] not” (p.53)

She also described encountering the clinicians’ uncertainty around future feeding practices:

“What happens if we come home with that? [feeding tube] And we still haven’t got the answer for that”

These quotations transmit the degree of uncertainty defining Poppy’s initial encounters with feeding and convey a sense of her feeling alienated around feeding. Considering that Poppy was adjusting to motherhood for the first time, it is conceivable that experiencing this vagueness and doubt may have exacerbated an already uncertain time.

For some mothers, a sense of anxiety and powerlessness around feeding accompanied this initial uncertainty. Jasmine reflected back upon her initial worry that she would have to tube feed her baby at home, with there almost being a sense that the tube feeding apparatus represented a technological intrusion, making her feel deskilled:

“I was really anxious about it, because there were too many wires, all the things, all the apparatus”

Poppy described feeling *“all over the place”* during the *“whirlwind”* of feeding difficulties, as her baby’s multiple medical difficulties meant they needed to be tube-fed. She too reflected on the overwhelming nature of feeding difficulties:

“I was a bit like, ‘oh my God, it’s the end of the world”

There is a sense that the scale of these feeding difficulties felt catastrophic to Poppy, suggesting that the feeding and wider hospital stress may have stimulated ‘worst-case outcome thinking’ and that things were being perceived as beyond her control. She also described anxious fear being instilled around feeding:

“It was quite scary really, ‘cause after they’d said [baby] might aspirate, we were a bit afraid [they]’d start choking”

Although Rachel narrated a breastfeeding journey of ease, she also described initial anxious thoughts around feeding and weight gain in babies with Down syndrome.

“You don’t know how much you’re feeding a baby do you, when you’re breastfeeding? And if you’re bottle feeding you know exactly how much you’re giving them, and I was a bit concerned when [baby’s]weight gain stopped”

Poppy’s baby was still in hospital at the time of the interview, and she described how anxiety around feeding pervaded into their time at home:

“We were sat at home thinking, worrying, you know”

This signifies how relentless and permeable feeding anxiety can be, and accentuates how isolated Poppy and her partner felt from their baby.

The initial anxious uncertainty around feeding did not abate for two mothers, and germinated into a more severe and enduring anxiety. When contemplating her “difficult journey” with feeding, Samantha expressed that it had “*really stuck in my head that these children do better with breast milk.*” Samantha viewed that breastfeeding her baby would provide them with the best nurturance, nourishment and sustenance they would need to recover from an impending bowel surgery. She relayed experiencing a corresponding sense of ongoing, prospective anxiety around having to finish breastfeeding before her baby’s surgery date:

“I was so stressed and I think I got a little bit more stressed towards you know the surgical date, and kept thinking just another month, just another month, just another month and actually we got well beyond that point”

Here, Samantha conveys significant anxiety and high levels of arousal around feeding, underpinned by as desire to ensure the best health outcomes for her baby heading into surgery. She later described contending with ruminative anxious thoughts, illuminating the potential for the anxiety to become an excessive, chronic manifestation, that was immune to her attempts at positive-self talk and encouragement:

“It was really real hard .There would be times when you’d express and think that’s not very much, it’s not enough, it’s not- but then I kept

thinking 'relax, you still have that freezer full, that you keep topping back up'. And you know, it will be fine and stop stressing about it. But it was quite stressful, I think that the last 3 months were the worst"

Abbie recounted the acute stress, exhaustion and anxiety she experienced during the initial uncertainty-laced days of alternating between attempting to breastfeed her baby and them being tube fed in hospital. When her baby was brought home, they were overly sleepy and there were concerns around sleep apnoea. Her baby also struggled putting on weight, seemingly contributing to a hyper-vigilant feeding stance:

"[baby] was very tired feeding. We used to be like, 'Wake up! Finish feeding' and that. It was quite stressful. I got really stressed about it"

The following two passages have been selected to illustrate the intense, overriding and enduring feeding anxiety that Abbie described. Her narrative conveyed a significant degree of hypervigilance, prospective and ruminative anxiety, fixated thinking and overall acute feeding-related stress:

"We had a diary every time he fed, how much he was having; how much then he was having over 24 hours. It was extremely stressful because then every day I'd be like going through, adding it up, 'Right, [baby's] had this much. So that's fine.' And if [baby] wasn't having that much the day after, like... it was really stressful. Stressful for months actually"

"I was doing all right with everything else but when it came to actually then feeding [baby] at feed time, I could feel like getting stressed during that time umm, that [baby] wasn't going to stay awake, that [baby] wasn't going to take the amount, and they didn't... I think I was constantly stressed with that at the time... I mean, yeah, all me thoughts . . . basically just revolved around how much [baby] was gonna have the next time they was gonna feed and writing it down, continually looking through the diary...It, yeah, it did kind of take-over, take over your life a bit for the first few months"

Here, Abbie seems to be apprehending, possibly for the first time, how consumed she had felt by feeding during this period in her life. In reflecting that she was coping vis-à-vis with “*everything else*”, Abbie illuminated how undermining the feeding difficulties were. Perhaps for Abbie, the fear of weight loss taps into a more profound worry that her baby isn’t thriving, and the fear of tube feeding looming again potentially internally represents something that would dilute her precarious sense of control.

Others in control

This subordinate theme encapsulates the degrees to which mothers perceived that others were initially in control of feeding, and captures the differences between how they experienced and assigned meaning to the perception of others being in control. Six of the participants divulged experiences which fit within this theme. It is crucial that this theme is considered against the backdrop of the broader initial hospital events; many participants narrated their wider experiences of perceiving a loss or lack of control during the initial postnatal period. Notably, five of the eight participants were separated from their babies after their birth, and recounted the acute agony and distressing loss of control this triggered.

Poppy described having to endure watching the nurses do the “*important stuff*” and feed her baby for six weeks before she and her partner “*finally got shown how to tube-feed*”. She recounted the discomfort of this:

“I was finding it really hard just watching the other nurses sitting and doing it like it was nothing...So we was like, ‘Ughh’, so we’ve just got to sit and watch you do it” (p.25)

“It’s hard for parents still in hospital to say, no, we want to try [baby] on the feeds” (p.54)

Poppy’s words capture how difficult it can be for a mother to tolerate watching others assuming the feeding role, her ‘*Ughh*’ conveys the extent of this almost repulsive discomfort and unease. The above quote also poignantly captures how incapacitated parents can feel when clinicians assume control of feeding and do not involve them. Poppy went on to describe how undermining this felt, almost detracting from their parental status:

“It’s a really weird feeling . . . cause we know - and they know we’re mum and dad but they just, it felt like they just pleased themselves”

While it is to be assumed that the clinicians involved in Poppy’s baby’s care were acting in her baby’s best interests when making decisions around feeding, Poppy’s words illuminate how disregarded she felt as parent when she perceived her own feeding wishes to be overlooked. Despite being a first time mum, with no previous experiences of infant feeding, Poppy had previously described elsewhere an innate instinct and desire to feed her baby. Her identification of this lack of feeding control being “*a really weird feeling*” perhaps indicates how inherently incongruous and alien it can feel to experience this as a mother.

Similarly, Abbie also described feelings of peculiarity or abnormality when not able to feed her baby at night, during the three weeks they were in intensive care:

“It was strange the fact that I wasn’t doing the night feeds”

Again there is a sense of how disconcerting and odd it may feel for mothers not to be involved in the role of feeding. Overall, Abbie emphatically described her support around feeding in hospital as “*fantastic*” but also acknowledged that the nursing staff could end up assuming control of feeding:

“But sometimes . . . they would take over, you know just, cause they were tryin’ to help to get [baby] to take the bottle, instead of doing the tubing feed, but sometimes I would just be like, saying to the nurse you do it, cause you’re better at it than me”

This quotation conveys that the stressful feeding situation made Abbie willing to relinquish her cherished feeding role to those seeming more expert and in control, potentially out of fear and concern for her baby’s wellbeing. Abbie had described her enjoyable and successful feeding experience of breastfeeding her older child. Here her appraisal of others as being as “*better*” than her at feeding suggests that the complex intricacies of her baby’s feeding needs may have diminished her confidence around feeding, stimulating a feeling of redundancy.

Jasmine too recounted her sense of others controlling the feeding situation, with the rigorous monitoring of her baby’s incubation and tube feeding resulting in her feeling unable to take her baby out to cuddle and feed them:

“There were times when I wanted them to take [baby] out of there so that I could feed and cuddle [them], and they did that for me. But, it was only for like, say, 20 minutes and then they needed to put [baby] back under there, so I felt like I couldn’t really breastfeed”

When describing how this perceived lack of control made them feel, it appeared to instil a sense of *powerlessness* and *incapacity* in some of the mothers:

“Feeling helpless really” - Jasmine

“It made me feel... pretty useless” - Abbie

For Poppy, it appeared that mingled in with the powerlessness, was the feeling of being superfluous and unneeded:

“We just sat there because we couldn’t feed [baby] because we didn’t know how to do it” p.4

“We just felt there was no point in us being there...It was a bit like third-wheeling like” p.17

Her use of the words *“third wheeling”* convey a sense of exclusion and isolation, with her almost feeling like an intruder when not involved in feeding. As a first time mum, who unlike the other mothers had no comparative experiences to draw upon, it is possible that feeling redundant like this may have undermined her self-appraisals as a mother and her maternal identity.

Enid’s previous difficult experience of feeling unheard and unsupported around feeding her firstborn resulted in her responding proactively as soon as she perceived others attempt to control the feeding situation:

“This paediatrician came in, and she just, she was the only one who was doing anything remotely doom and gloom...she was stood there like Dr. Death saying you might have to feed [baby] through a tube. And the midwife was stood there, and I said to her would [baby] have to have tube feeding if we used formula, and she said no...And I just said “right, that’s it then!” and I had rehearsed it this time, so I couldn’t be bullied. And I just said: “I think it’s best for us as a family, including [baby], if we switch to formula milk”

Enid's use of the word "bullied" imparts the extent to which she had previously felt intimidated around feeding. Her assignation of the title of 'Dr. Death' to this paediatrician conveys powerfully how clinicians' negativity can feel like a spectre of pessimism in the immediate postnatal period. It is possible that by having existing negative associations around clinicians involvement with infant feeding, Enid's felt threatened by this paediatrician's domineering attempt to control feeding, resulting in an immediate protective response.

Disparately though, Miriam's experience of others managing and directing the initial feeding situation was experienced positively, and she credited the student midwives involvement with making her successful breastfeeding experience possible:

"I don't know whether it would have happened if there had just been regular midwives...But because there was those girls who, em, had more time to sit and were more flexible than regular midwives can be, they were wonderful, absolutely wonderful. So they just sat with me and they explained things to me and they took time, they didn't rush me. We were trying to, you know, endlessly. I remember at the beginning there was so much milk flow, so we were trying the little pipes. And they would sit there with me for like half an hour, despite me getting flustered, saying why is not coming, but they kept going."

This passage accentuates the extent to which Miriam regards the degree of containing direction and intervention she receive as being instrumental in her successful breastfeeding, providing a resounding rationale for extended, intensive support. It prompts consideration that Enid might have had different experience with similar intervention.

Although not spoken about specifically in relation to feeding, four mothers chronicled the loss of control and the acute distress they experienced upon being separated from their baby after birth. For Abbie and Jasmine though, this distressing experience seemed to influence their subsequent feeding behaviours. Jasmine described feeling territorial over the feeding role, experiencing discomfort when others requested to feed her baby:

"When my mother in law said "oh can I feed [baby]!" I didn't want her to. It was strange, because when my [older child] was born, I didn't mind

anyone feeding them or anything. But because [baby]’d been through sort of a lot, because [baby]’d been in hospital and had the operation and we were apart, and [they] was ill quite a lot, I think I wanted to be more closer to [baby], because I think missed out, I sort of felt that. I think I missed out on that feeding bond right at the beginning. So I want to be the only one to feed [them], I don’t want anyone else”

Jasmine made sense of how distinct her possessiveness over the feeding role is, using her previous experience of feeding her older child as a comparison point. It appears that her ownership over feeding has afforded her the sense of the control she felt she lacked at the beginning of their journey together, and perhaps enables her to make reparations for their time apart.

Abbie also reflected upon the “*shock*” of being separated from her baby after birth and how “*difficult*” and “*scary*” it had been. Abbie expressed that she “*wouldn’t put [baby] down . . . because of being away from [them] in the hospital.*” She referred to the longitudinal impact this separation has had, with her struggling to tolerate separation from her baby two years later, as it stimulates a reminder of her previous loss of control during the initial mother-infant separation:

“I didn’t want to be apart from [baby] . And I haven’t. We’re looking into um, nurseries and pre-schools for next year and the stress and anxiety being apart from them again is already kicking in”

It also seemed that remaining the dominant person in control of feeding felt crucial for Abbie. She discussed finding it difficult to tolerate watching her partner bottle-feed her baby:

“I would interfere . . . to the point sometimes where he would give me [baby], and say ‘You feed them then’”

However, this of course must be considered in the context of Abbie’s enduringly stressful feeding experience. Also, personality factors must not be discounted, with Abbie at one point remarking that she is “*a bit of a control freak sometimes.*”

“You want to go the extra mile”

This subordinate theme captures the mothers heightened motivations in relation to feeding. The mothers reflected on determinedly making feeding decisions in the

context of their baby's diagnosis, with a strong devotion to their infants' needs underpinning this dedication to "go the extra mile". There was a sense that for some mothers, underpinning this drive was a need to regain and exert some control over the both the feeding situation and their wider circumstances.

For the four mothers who breastfed, their perceptions of '*breast is best*' were evident in their accounts, with them all sharing a belief in the superiority of breastmilk. They described their increased determination to breastfeed after receiving the diagnosis, citing their beliefs in the nutritional advantage of breastmilk and the enhanced significance of breastmilk in the context of the additional autoimmune and developmental needs associated with Down syndrome.

Jacqui referred to her breastmilk as "*the good stuff*" a total of four times in a short passage, possibly highlighting a subconscious reassurance that she alone as mother provided the best possible sustenance. Jacqui also articulated the augmented importance she assigned to breastmilk, in the context of the Down syndrome:

"I think it's really important, and especially with [baby] having that diagnosis and supposed lower immune system, I think it's even more important"

Jacqui expressed her breastmilk whilst her baby was in the special care unit, describing this process as "*The last thing you're wanting to be doing when your baby is not with you.*" Despite this innate disinclination and challenging situation Jacqui persevered so as to provide what she regarded as the best possible nourishment:

"I think I just sort of went through the motions a bit and got on with the expressing...you're sort of more focused on them being okay and pulling though if you know what I mean"

Rachel similarly seemed to view breastmilk as something protective and inoculating:

"It felt like this poor little scrap needs whatever they can have that will be the best they can have you know [chuckles].[Baby] had a bit of reflux and all that sort of jazz, and it's like, do you know what, you know, breast milk has all these supposed medical benefits, so [baby] needs whatever is the best for

[them]. Em, therefore I wanted to do my, my best to do what's best for[baby] really."

Although some of Rachel's language and her chuckle here may seem almost a bit flippant, her words convey her intensified drive to provide what she regards as the best possible nourishment to her vulnerable baby. Rachel had enjoyed her experience of breastfeeding her older child, but reflected that sometimes a degree of weariness could set in. However, with this baby, Rachel recalled also being willing to go the extra mile and feeling "*a bit more em, just accepting it and being happy to do whatever [baby] needed really.*" This quotation may reflect how mothers' of infants with Down syndrome may experience enhanced tolerance or acceptance of the ordeals of feeding, in the comforting reassurance that they are fortifying their child and nurturing their development.

During a readmission to hospital, a videothoracoscopy detected that Samantha's baby was aspirating when he was breastfeeding, due to oral-motor difficulties. Despite this, Samantha trusted in her instinct that this would resolve with time, and continued to "*breastfeed against advice,*" referencing the supposed health and developmental benefits as underlying her motive for breastfeeding:

"And the reason I was so adamant about that, is partly to do with em, the whole, the sucking is very different to when you're bottle fed and its developing those oral motor skills for later on, and to strengthen [baby's] mouth for being able to eat later on as well....and also because of the bowel defect, the, the surgeon said if at all you can, continue breast milk of any form, until [baby]'s had his bowel repaired, because it will be the best thing for [them]"

Through breastfeeding, Samantha implied that she was aiming to procure the best outcome for her baby. She distinctly conveyed exerting her control over feeding by acting as her own counsel in the face of alternative advice. The advice that Samantha received from her surgeon appears to have had a reinforcing impact on her dedication to breastfeeding, with her later remarking that she had "*really held on to*" the surgeon's advice. Deciding to disregard the advice not to feed over the surgeon's instruction indicates the extent of her drive, and the degree to which she may have

assimilated his advice around feeding. In addition to her determination, a note of hope is detectable in Samantha's visions of her baby's future developmental attainments.

Miriam had chronicled her distressing previous experiences of trying to breastfeed, and the negative psychological impacts these difficult experiences had for her. Despite these previous adversities, Miriam spoke about her renewed determination to breastfeed:

“It was this feeling that you want to go the extra mile and make a bit more effort because it might be more important for [baby]...If there's anything extra that you can do, to help [baby] grow better, develop better. You just want to do it”

There is a sense of Miriam's devotion to her baby stimulating her resolve. Miriam conveys a sense of heightened responsibility or duty, or perhaps even accountability, in this passage. Perhaps “*going the extra mile*” was also a way of making reparations in the context of the diagnosis.

Miriam spoke about her experience of encountering pessimistic feeding narratives around breastfeeding an infant with Down syndrome:

“They keep telling you – another common misconception is that, you know kids with Down syndrome they don't always feed well. And if that's the first bit of information being given when you have, you know, that little chipmunk with Down syndrome, then you know, you kind of feel like that's not a good starting point, if you know what I mean. And I thought, no, you know, despite this I'm going to try. I'm going to see how it's going to work. And it did work, it worked very well!”

This illuminates how dispiriting it can be for “*the first bit of information*” received about feeding to be negative or discouraging. Despite this, Miriam was able to assert her control over the situation, almost defiantly, in turn reclaiming some power after the initial projection that feeding might be difficult.

The mothers who did not breastfeed also spoke about making decisions in the context of their babies' Down syndrome and related health complications. There was a sense of these mothers easily forgoing their own feeding wishes to prioritise their infants' needs. Abbie and Jasmine had wanted to breastfeed, however they had difficulty

expressing and their babies were initially tube-fed. Both ultimately decided not to continue attempting to breastfeed, with this decision appearing to be their way of ensuring they were helping their babies, mirroring the breastfeeding mothers' drive to nourish and protect their babies through feeding. Potentially, it was also a way for them to also feel more involved with feeding, in turn restoring a modicum of control:

“I didn't so much feel like I'd let [baby] down by putting [them] on formula, because I wanted the feeding tube out; so it just made sense to me; the only way - I can't help [them] with the oxygen, but I can help with the feeding, and that we're not tiring [baby] out trying to get breast; put [baby] on formula ... getting [them] built up, and fed was my aim” - Abbie

“I think em because of how ill [baby] was I think the focus was just on that really. And breastfeeding [them] then at that point wasn't my main concern anymore” – Jasmine

To summarise, the superordinate theme '**Negotiating power and assertions of control**' comprises of three subordinate themes (*Uncertainty & Anxiety*, *Others in control* and *“You want to go the extra mile”*) that relate to mothers' perceptions of lacking and acquiring/asserting control around the feeding situation, their experiences of navigating and negotiating these dimensions of control and their subjective appraisals of the affective/emotional facets of these experiences, particularly the anxiety and uncertainty that could be engendered around feeding.

Superordinate theme 2: “It made things feel settled”

This superordinate theme relates to mothers' perspectives of how feeding became a soothing, stabilising and steadying force in their lives, affording a sense of equilibrium and control. In the interviews, the majority of mothers also made sense of how the stabilising experience of feeding in turn instilled a sense of dyadic and wider normalcy, in the context of coping and adjusting to having a baby with Down syndrome.

Stability

This subordinate theme captures participants' perceptions of how 'successful' feeding became a stabilising, soothing and steadying force against the backdrop of worry that was present when adjusting to having a baby with Down syndrome.

Rachel described her personal milieu as being defined by a "*backdrop of anxiety*" during the initial months of adjustment: "*a lot of those early months were spent worrying.*" She reflected on the sense of stability that feeding afforded in relation to this:

"I wonder if it might have helped actually, it made things feel settled"

Jasmine recounted the assuaging abatement of anxiety and sense of security and stability she experienced when her son was brought home and she was finally able to feed:

"When [baby] came home and I could feed [them], it was just a relief. That I could do it all the time and [baby] was like close to me, and not somewhere in some incubator somewhere and I'm not having to worry about [them]"

Miriam referred to the stabilising role of breastfeeding in her life, acknowledging the "*rhythm*" it brought and describing it as "*the heart of our routine, part of our day. It brings some sort of solidity and you fit it into your daily routine*"

There is a sense that in becoming the locus of Miriam's day, feeding became emotionally regulating and the scaffold for feelings of stability. She also went on to speak about the sense of equilibrium feeding afforded, it turn possibly stabilising her own mood:

"So, it was very helpful as well to kind of balancing things out later on. This is what we're doing, healthy baby, happy baby, breastfeeding baby you know. Let's live in the moment."

In the passage, there is a sense that feeding was almost meditative, providing a soothing, affirmative mantra that enabled her to engage positively with the present moment, diluting the focus on the diagnosis. Samantha and Enid also described the containing, calming and stabilising influence of a feeding routine in their lives.

Samantha further reflected on feeding affording some mutual dyadic stability, by calming and soothing both her *and* her baby, intimating dyadic reciprocity:

“It’s that calm time, where you feel like it’s a good time” - Enid

“It was so nice. But that’s because of getting [baby] into that routine of like, we’re going to do this now, we’re going to that. So, [baby] got into that routine and when we went home we just continued it, ‘cos it worked for [baby] and it worked for us, it terms of keeping us calm and keeping [baby] calm.” – Samantha

When reflecting on the time before she was able to breastfeed exclusively Samantha reflected that her *“my emotions would have been better if I had been able to do that [breastfeed]”*. This makes the above quote particularly illustrative of the stabilising impact of consistent breastfeeding on her emotional state.

Although Jacqui’s referred to the stabilising influence of feeding less explicitly, her words also convey how feeding became a soothing, steadying routine, and protected time for her to make sense of, and begin to emotionally process the diagnosis:

“I think it just hit me, do you know what I mean, the diagnosis and everything and you’re still sort of coming to terms with it now some days, do you know what I mean. I probably always will. But I was happy to be feeding. I used to quite enjoy it, I’d set myself up on the sofa with something to watch, my phone on this side, do you know what I mean, and it was a bit of an event almost”

She also relayed the solid focus that feeding provided for her, enabling her to fulfil what she regarded as her maternal duty:

“I just got on with it. I was, I suppose that I had a job to do with the milk and maybe that helped keep me focused”

Having become accustomed to her baby’s feeding routine in hospital, Poppy appeared to take solace from envisioning that feeding would provide a comforting, familiar practice during the massive adjustment of bringing her baby home:

“Obviously it’s not gonna change when we come home. So it’s just so nice to know that it’s cause we’re doing something at hospital that we’re actually gonna do at home.”

A notable point of contrast is Abbie’s case. In addition to her enduring feeding anxiety, Abbie also described more general anxiety relating to the Down syndrome, describing the first months as *“all a bit of a worry due to the unknown”*. Abbie did not convey the soothing, regulating effect of feeding that the other mothers articulated. Instead, in the absence of this, she seemed to describe self-regulating practices in response to any mounting feeding anxiety, explaining that she would:

“Have a word with myself and just say, ‘just, just stop it”

She also described:

“Getting a cup of coffee to pull myself together”

While Abbie implied that implementing these adaptive practices had a regulating effect for her, her tone here almost seems exasperated or self-critical, which could be conceived as having the potential to maintain a sense of being under threat, and impeding her ability to feel soothed.

Normalcy

Closely linked to the theme of stability, this subordinate themes encapsulates mothers’ recounting of the sense of normality and normalcy that feeding instilled. There was evidence of the mothers perceiving feeding as having the potential to normalise the experience of having a baby with Down syndrome, allowing the mothers to view their infants as ‘normal’ babies, in turn alleviating some of the wider anxieties around having a baby with a ‘disability’.

For Rachel, there was a comparative element to her construing the meaning around her feeding experience, as she reflected on the parallels it evoked with her firstborn. She perceived that having a *“normal”* experience of feeding inoculated her from experiencing her situation more negatively, accentuating the protective function of feeding:

“The fact that [baby] just drank like a fish just like [sibling] was something normal of having a baby in an environment where things weren’t quite as normal as they should have been... I think it definitely made me feel better. I think if [baby] hadn’t had fed and [they] were very little, I think I’d have done whatever was needed, to be okay, but I wonder whether I would have got more, probably some more negative feelings about the situation if I wasn’t feeding [them]. You know, the normality, we were, we were doing what we had planned to do, and [baby] was feeding and that bit was lovely and yeah, [baby] wasn’t very well, but actually from a day to day experience, it was very similar to [sibling] really.

Perhaps the normalcy of the feeding experience provided Rachel with some prospective reassurance that raising her baby with Down syndrome will be a familiar experience i.e something that she has been able to do before. Samantha reflected on how the ‘normal’ process of feeding made her feel like she was caring for her baby like any other baby:

“You know, now I can look after [baby] the way you look after every baby. So that, yes it’s a much more pleasant feeling”

Similarly, both Jacqui and Jasmine considered (Jacqui retrospectively, Jasmine in the present) on how feeding dismantled the lens of disability:

“It was just [name], my baby I suppose and it was just them I was feeding”- Jacqui

“I look at [baby] now [when feeding], to me they’re just like any other baby” – Jasmine

Miriam spoke about the comfort she derived from the universality of breastfeeding, and its alleviating capacity over the “non-stop” worry she had been experiencing:

“At the beginning when you find that your child has got a disability, you’re overwhelmed with this news and you worry non-stop, and it’s sort of, you see this disability and bring, the whole package of disability comes in, you know. Em, but just doing simple things that

every mother and every child are doing, like breastfeeding. It just makes you, it shifts your mind away from those worries and you just see the baby as [they] are, it's a baby."

In addition to affording situational normalcy, Miriam also seems to reflect on how feeding depathologised having a baby with a disability, affording a sense of dyadic normalcy and enabling her to perceive and relate to her son as a 'normal' baby.

Possibly, the sense of normalcy inherent in a stabilised feeding, in addition to enabling the above mothers to perceive their infants as 'normal' babies, may have empowered them to see themselves just as 'normal' mums.

Although her infant feeding situation was distinctly different (and current), Poppy spoke about habituating to the tube-feeding role, and the sense of a norm that tube-feeding provided:

"I think it's the only thing at the minute that's just the norm for us now"

She too spoke about how being involved in feeding normalized the hospital situation, facilitating a sense of normalcy for them in the midst of the stressful clinical environment:

"Feeding [baby] - just the things you would do at home and probably take for granted"

In summary, the superordinate theme "**It made things feel settled**" encapsulates the mothers' perspectives of how infant feeding restored (or maintained) a sense of stability, balance and control. This superordinate theme also captures mothers' perceptions of the sense of personal and dyadic normalcy that feeding afforded, when adjusting to having a baby with down syndrome.

Superordinate theme 3: "It's a very bonding experience"

This superordinate theme captures the ways in which participants made sense of how elements of their feeding experience may have shaped the mother-infant relationship/ contributed to the process of bonding with their baby with Down syndrome.

Profound connectedness and attunement

This subordinate theme relates to participants' descriptions of the profound feelings of connection to their baby that they experienced during feeding. Six of the mothers spoke about feeding as contributing to harmonious feelings of mother-infant connection and attunement, fostering the mother-infant bond. Four of these participants further conceived feeding as enhancing the mother-infant relationship. There was no difference between how the mothers who breastfed and bottle-fed described the quality of the mother-infant relationship, with both the bottle and breastfeeding mothers acknowledging the formation of a feeding bond. Poppy, whose baby was mostly tube fed, had slightly divergent experiences.

Participants acknowledged their awareness of distinct feeding bond and a sense of connection to their infant during feeding. Participants articulated the emotional magnitude of feeding and the pleasurable sensory aspects of feeding, particularly eye contact, identifying it as a 'bonding experience':

"And it is a real bonding experience; it tugs at your heartstrings. You know, you can feel it, you can feel those things here...It is just how much you love [them]. I mean don't get me wrong, your mind wanders sometimes [laughs] but its - when you're focused in and you look at [them], it's normally when I catch [baby's] eye and [they're] staring intently at me" - Enid

"Whether its love or bond or closeness, or whatever you want to call it, it's overwhelming you know, during the breastfeeding" – Miriam

In their meaning making, some of the mothers attributed the feeding interactions with enhancing the mother-infant bond, stimulating greater closeness and connection:

"You certainly, when you're feeding your child, you feel a lot closer to them" - Jacqui

The feeding experience appeared to be at the very crux of the mother-infant relationship for Miriam and Samantha, almost an extension of the pregnancy bond:

"Yes we have a very good bond me and [baby], and I think, em, that the feeding experience is possibly part of that... It's a togetherness and

closeness and almost like [baby's] right back inside you. [Baby's] part of me and that we'll always be together. So that's the closest that it can get, when you breastfeed" – Miriam

"I do still feel like they're part of me and they were part of me, I think breastfeeding is an extension of that ... I do think that you have a stronger bond when you breastfeed" – Samantha

Jasmine described commencing bottle feeding as enriching the mother-infant bond, stimulating a new depth of closeness:

"As soon as [baby] was bottle-fed, I was like, I felt like closer to [baby] and I think [they] felt close to me, because [baby] was always looking at me and smiling."

With her descriptions of her baby's gaze and smiles, Jasmine's quotation conveys a sense of solid dyadic attunement, potentially indicative of the synchrony of their interactions during feeding. Other mothers also conveyed a sense of attunement during the intimate dyadic interplays during feeding, describing an enhanced awareness of mutual engagement and learning:

"It's the time to engage with each other fully" - Enid

"Well at the beginning you're sort of learning, you see, from each other" –Miriam

While the majority of the mothers reflected on the distinct nature of the feeding bond, and its contribution to the development of the mother-infant relationship, there was a unique trajectory to the way Poppy made sense of her feeding and bonding experiences. She reflected on her perception of the initial absence of a feeding bond:

"Like I say, I couldn't feed [baby] at all so there was no bond over feeding"

At multiple points throughout the interview, Poppy went on to express her belief that her connection with her baby would be enhanced if they had been bottle or breast fed e.g: *"If [baby] was breast-feeding... we'd get a stronger bond" (p.19)*. However, later on in the interview, despite initially regarding tube-feeding it as *"daunting"*, she also credited it with providing a feeding bond:

“Without it we wouldn’t have had a feeding bond”

When prompted to contemplate how feeding stimulates awareness of an enhanced mother-infant connections and emotional closeness, the mothers conveyed that the proximity, intimacy and skin to skin closeness during feeding as contributing to this, with mothers using words such as ‘snuggle’ and ‘cuddle’ to capture the unique intimacy of this:

“I suppose its em, it’s such an intimate thing isn’t it, breastfeeding and having [baby] so close ...the snuggling down and getting ready for bed.”-
Jacqui

“But you do feel like an instinctive, you know, you want to bring them in and you want to, have them close– Enid

“It’s like having a cuddle at the same time” – Jasmine

As a first time mother, Poppy’s instinct that her emotional connection with her baby would be enhanced if there was more physical closeness during feeding, highlights the innate maternal desire for this physical closeness:

“I do just think it would be easier if we didn’t have the tube, and then we could have a bit more close contact as well for feeding”

She went on to articulate that increased amount of ‘cuddles’ and involvement in feeding has enriched the bond, accentuating the contributory role that physical contact plays in stimulating feelings of closeness:

“Getting [baby] out and just having cuddles and doing all the care...the bond’s a lot stronger now”

In contrast, Abbie made sense of how disparate her feeding experience was in the absence of the closer physical contact:

“Well, it was different from the other two, cause usually you snuggle. I’d have [baby] in my arms and feed [them] and look at [them] and that; but that position was making [baby] too snuggly so then we had to hold [them] like that, which was the best way from behind, and feed like that. So you’re not getting them lovely snuggles . . . Umm, it was still, I don’t

know. Looking back, was it nice? It was nice but I think the anxiety of keeping [baby] awake, kind of took the shine off that a bit.

She clearly conveys how the vigilant feeding stance and lesser degree of closeness took the “*shine off*” her feeding experience, illuminating how profound the physical closeness during feeding can feel. Abbie described simulating the closeness of feeding at other times instead. There was a sense of reassurance in her exclamation at the end:

“So we had . . . lots and lots of snuggles plenty of other time! Yeah!”

Although participants made sense of the contributory role of feeding to the bonding process, all of the mothers except Poppy expressed feeling immediately bonded with their baby after birth. (Poppy linked her initial difficulty bonding with the two day period where she did not see her baby after the birth due to C-Section complications and her baby’s medical needs). It seems important to acknowledge that many of the mothers reflected on feeling bonded with their baby in utero, with this bond continuing and deepening postnatally. Two of the mothers who had received the prenatal diagnosis of Down syndrome acknowledged the additional layer of caring protectiveness constituting their bond:

“I think I knew carrying [baby] that [they] were different. [Baby] was a [gender] and we so wanted a [gender]. So I was, I felt like I bonded more with [baby] in the womb when I was carrying them, then I did with my other pregnancies” – Jacqui

“I’ve never had a problem bonding with [baby]” - Jacqui

“Probably, I think I felt more bonded in pregnancy. I think it was probably a bit more of a protective determination there, possibly” - Rachel

“I think you bond as well when you’re pregnant and that” – Abbie

“Well to be carrying em your baby around for so long, that helps”– Jasmine

“I think it was probably just a continuation of what had started [in pregnancy] really” – Samantha

Rachel voiced her awareness of a ‘protective determination’ upon learning of the Down syndrome diagnosis and Jacqui detailed her sense that her baby was ‘different’. Other than these remarks, participants did not seem to evaluate their relationship and bond with their baby in the context of the Down syndrome or infant ‘disability’. Perhaps the findings are suggestive of feeding having the potential to enhance and enrich the mother-infant bond in the context of feeding a baby with Down syndrome, but that for these mothers, who all reported strong prenatal bonds, feeding was *not* the foundation of the mother-infant bond.

Gratifying dyadic exclusivity

This subordinate theme captures mothers’ descriptions of the gratification and pleasurable sense of control that they experienced through the maternal exclusivity of the feeding role. This was either through the exclusivity inherent in breastfeeding, or by exerting exclusive ownership over the bottle-feeding role. Miriam spoke about the pleasurable dyadic intimacy that breastfeeding afforded, referring to feeding as “*very mummy-baby moments*”. She also relayed the gratification she derived from being the sole provider of her baby’s nutritional needs:

“Pretty much everyone can feed the baby with the bottle. It can be grandma, it can be dad, it can be anyone. But it’s nice that with the breastfeeding it has to be yourself”

Perhaps this satisfaction was stemmed from her maternal status being strengthened, in contrast to her previous experiences. Miriam went on to verbalise that the cessation of breastfeeding after six months, and the loss an exclusively maternal feeding role, resulted in a difficult dilution of her ownership over her baby:

“ I did feel like I was losing moments with [baby]. Like you know, like [baby] was more mine than anybody else’s up until then ”

Jasmine too spoke about the pleasure she derived from being the sole provider of milk to her baby:

“[baby] never drank milk off of anybody else. So like, when [husband] tried to feed [baby], they wouldn’t feed off [husband]. And then my

mother in law tried to feed [baby], and they wouldn't feed off her, just me. [baby]'d just look at me and just want me to feed"

Here, Jasmine conveys a sense of the powerful reassurance being derived from her baby refusing to feed from anybody else. Perhaps this reassurance is particularly potent for Jasmine in the context of their extended separation and receiving a postnatal diagnosis i.e feeding is subconsciously confirming that her baby's attachment to her was not affected by their separation or the developmental delay. As such, there was a sense of Jasmine needing to prolong her control over the exclusive intimacy of this experience:

"Well I was just thinking, [baby] should be like holding the bottle and having a go at drinking, but I think [baby] prefers me, cos it's like having a cuddle at the same time"

Samantha described experiencing the potential for others to be involved in feeding as a debilitating loss of control:

"I felt like things were taken out of my hands, because it meant, as awful as it sounds and I don't want to take that away from my husband, he could do a lot more. He could provide too, he could – for him that was a great bonding moment, but for me that was like it was taken out of my hands and you feel like a failure, and you know - those feelings again"

Her words poignantly suggest that others' involvement in feeding deprived her of a role that was calibrating her sense of control during the fraught postnatal period, and may have diminished the assurance she derived from being the primary provider of nourishment to her baby with additional needs.

However, some of the other bottle feeding mothers reflected that their partner's involvement in feeding becoming meaningful for them at a **later** stage. The meaning mothers assigned to their partners' involvement appeared to relate to the pleasure of observing them develop a feeding bond with the baby, and the respite associated with feeding being a dual role:

"He has supported it at night and that kind of thing, so I'm very lucky really." - Jacqui

“I had to share. I couldn’t do it all by myself . . . I couldn’t. Sometimes it was nice just to hand over. Like, will you try [baby] please because [baby]’s falling asleep, and I’m getting stressed and that’s not good for the three of us” - Abbie

“I suppose feeding allows him just to focus on [baby] and have that time with him, you know. They get to connect really” – Enid

“It definitely helped, yeah, yeah. They’ve got a lovely bond” -Jacqui

Perhaps this is indicative of the importance of an initial period of dyadic exclusivity, for the mothers to experience the solidification of the feeding bond and recalibration of control, before feeling able to tolerate inviting others in to the feeding situation.

To synthesise, the superordinate theme **‘It’s a real bonding experience’** relates to the mothers’ attributions of how elements of their feeding experience may have contributed to the process of bonding with their baby with Down syndrome. The subthemes *‘connectedness and attunement’* and *‘gratifying dyadic exclusivity’* capture the ways in which six of the mothers made sense of how the defining features of the feeding situation may have enhanced or shaped their relationship with their baby.

Superordinate theme 4: Constructing maternal identity through feeding

This superordinate theme encapsulates how mothers negotiated, constructed and made sense of their maternal identity when feeding their infant with Down syndrome. Nestled within this superordinate theme were three associated subthemes *Evaluation of the maternal self*, *“You just feel like a mum then”* and *Affirmation*.

Evaluation of the maternal self

This subordinate theme is associated with the self-evaluative processes that mothers described in relation to feeding. Seven of the participants described judging and appraising themselves as mothers, in relation to their evaluations of their feeding experience. Typically, within most the mothers’ accounts was a proneness to evaluate or judge themselves negatively during feeding difficulties. For example, Samantha described feelings of failure and a sense of shortcoming as a mother when she was initially unable to breastfeed:

“I mean it’s hard not to feel like a failure. It is hard to feel like it’s not your fault that you can’t get them to feed”

Samantha went on to reflect her awareness that these feelings of failure had been self-imposed:

“The failure thing, it’s self-driven. As I said, the Surgeon had always said ‘if you can it will be best’ and I did hold on to that a lot, but he never would have said to me, ‘you’ve failed because you didn’t do it’, you know [laughs]. So, but for me, that’s what I kept thinking that I have got to. I don’t want [baby] to have problems. I didn’t want [baby] to start having sores, I didn’t- you know, lots of different things, em because of it, so that is why I felt that something that I was providing and it would have been, you can only kind of blame yourself, don’t you, there’s nobody else you can blame for that.”

There is a sense of Samantha having an amplified inner self-critic. Perhaps her critical voice is particularly amplified when she perceives that she falling short by not achieving something she has previously accomplished, such as breastfeeding. Other mothers also conveyed critical self-appraisals when not being able to feed their baby with Down syndrome. For Jasmine, this appeared to instill feelings of worthlessness, potentially impacting upon her maternal self-concept:

“Feeling so down about yourself...Because you feel like there’s nothing you can do” (p.10)

“As a mum, you’re still like, you know, you’re not doing enough for them”
– (p.15).

Jacqui described the emotional difficulty of having to finish breastfeeding earlier than she would have liked, and depicted evaluating herself harshly after this, seemingly placing the onus of blame on herself:

“I felt really disappointed in myself I think, I really wanted to carry on. But everybody was like ‘well you’ve done amazing’ and all that, but I think I wanted to carry on really, it was a bit of a shame”

This passage seems infused with a sense of remorse at ceasing breastfeeding. She later qualified that this disappointment lasted for “*a few months maybe.*” While the supportive and encouraging comments from others are perhaps indicative of a solid support network, Jacqui’s reflections highlight that in the context of this internalised disappointment, empathetic encouragement didn’t resonate. Jacqui went on to convey how this acute sense of disappointment was augmented due to her more lengthy previous experiences and her belief in feeding being an integral part of the maternal role:

“I think because I had done it so well with the [siblings], for so long, it was more a feeling of this is what I should be doing”

Poppy also spoke about feeling that she was not fulfilling a core maternal role by being unable to feed her baby

“I just felt like I wasn’t doing my job and . . . it was, it was really bad. It was really bad ” (p.11)

“Quite upset um, like I’ve not, not done what I should be doing for [baby] . . . eh disappointed.” (p.25)

The repetition of “*really bad*” and the verbalization of disappointment emphasizes her distress and pain. As a first time mum, Poppy made sense of the unique pain of not feeding, by differentiating it from previous upsets and disappointment:

“It just feels a totally different upset and . . . and hurt than anything else . . . I don’t know. It’s hard to describe because you don’t feel like that any other time”

Abbie encountered difficulty when attempting to express her breastmilk, citing the distress she was experiencing at being separated as impeding her ability to express:

‘I was tryin’ to express as well during the night, we’d keep doing during the night. I think that could’ve been part of the problem because obviously stress, not having your baby with ya. They gave me-I had a picture, I used to look at the picture on my phone and the little hat [baby]’d had on cause with the smell and everything [chuckles]. I felt ridiculous!... I was annoyed that I couldn’t do it and I was like, ‘What’s wrong, why can’t I express, at least!’

Although Abbie did not speak about failing her baby or not fulfilling her maternal role by being unable to feed, this passage seems to still convey felt inadequacy. Abbie exclaimed that she '*felt ridiculous*' when unable to express, and her concluding sentence suggests an exasperated critical evaluation of herself.

Miriam's evaluative basis as a mother differed from the other participants. Her previous experiences of labouring to breastfeed her children resulted in a "*feeling of failure*", where she felt that she had been "*failing the baby as a mother*". With this distinctly negative feeding comparison point, she described a journey from feeling like a failure, to feelings of affirmation and fulfilment as a mother, when successfully breastfeeding her baby with Down syndrome:

"I was failing before but I'm doing very well now, yeah"

She went on to express feelings of personal and dyadic pride, self-belief, and positive maternal self-concept e.g:

"Wohoo" you know, we're making it now. I'm not such a dreadful mother"

Enid described her feeding journey as difficulty free and "*plain sailing*." She also described feeding as instilling a sense of confidence and positive self-appraisal:

"It was something I could do successfully"

When feeding commenced without difficulty or when initial feeding difficulties stabilised, participants described more positive self-evaluations in the context of feeding:

"You feel like you're doing something right"- Jasmine

Poppy had asked me some questions about my doctoral studies prior to the interview commencing and I had relayed some of the stressful hurdles of final year. When reflecting on what learning to tube-feed has meant for her, Poppy tried to make her meaning relatable to me, perhaps to accentuate how much of a mammoth hurdle feeding has felt, and how momentous being involved in feeding feels for her:

"I don't know really . . . maybe doing something for the first time and you've achieved it. So probably like for you passing your exams, I would've assumed!"

“You just feel like a mum then”

This subordinate theme encapsulates the mothers’ perceptions of how their positive infant feeding experiences enabled them to connect with their maternal identity. The mothers seemed to describe their maternal identity and sense of the maternal self as being inextricably linked with feeding, and depicted that successful infant feeding conferred a concreted maternal identity. For example, after not being able to feed her baby for an extended period, Jasmine appeared to experience a validation of her maternal identity upon commencing feeding herself:

“You just feel like a mum then”

Enid also reflected on feeling aware of her identity as a mother when feeding:

“I felt like I was just being a mum”

Jacqui spoke about feeding being an integral part of motherhood for her, and implied feeding was one of the foundational constructs of her maternal identity:

“I think for me as a mum, with a new baby, I’ve always seen it as part of my maternal role, if you like. It’s part of something that I should do.”

Poppy initially described feeling disconnected from her maternal identity when she was not involved with feeding her baby, perceiving others in the maternal role:

“I just felt like [baby] wasn’t mine cause I couldn’t, you know I couldn’t do anything. Especially cos I wasn’t breast-feeding, you know, I thought at least if I, if I could do it then it would be- but no, we couldn’t do anything. So we were sat there and I did feel a bit like I wasn’t [baby’s] mum and that, you know. We had same nurse quite a lot so it was more like [baby] was hers, rather than mine cause she was doing all the feeding and stuff.”

Poppy went on to describe the evolution of her maternal identity; after advancing to being more involved in her baby’s feeding and general care, she conveyed a greater degree of assurance in her maternal self, and a more solidified maternal identity:

“Finally like I’m actually a mum; like before I was a part-time mum”

In contrast, Samantha did not explicitly verbalise that feeding enhanced her connection with her maternal identity. However, her meaning making conveys that

perhaps her maternal identity was diluted during the stage of clumsily expressing, with her perceiving her baby as “*somebody else’s*” during this period:

“Whereas if you’re constantly thinking: ‘right, it’s time to get this equipment out to do this, it’s time to get this equipment out to do that’, then it doesn’t – [baby] doesn’t really feel like yours, [they] feel like somebody else’s”

In contrast, she described her baby feeling more like her own during breastfeeding:

“As soon as we could start doing that [breastfeeding] I, it just felt [baby]’s mine, [they’re] not everybody else’s baby”

Again, Abbie’s case is an interesting inverse of this theme and comparison point. For Abbie, the difficulties and uncertainty she encountered when feeding her baby with Down syndrome, appeared to stimulate a discomfiting sense of retrogression to a state of new motherhood, illustrated in the two passages below:

“I’d had two babies before so I kind of think, yeah, I know all this feeding stuff and kind of the weaning. But with [baby] it felt like totally new . . . like I hadn’t had a baby before, you know if I was asking questions ‘I know I’ve had two kids before. This could be a stupid question to ya,’ but, you know [chuckles] so yeah, it was like, yeah starting again. Like being a new mum again”.

Hard to explain really, yeah, how it feels to be a new mum who’s had two kids; but that’s kind of how it felt . . . like I hadn’t done it before [chuckles] strange, yeah, it was just, I did feel silly at times. It’s like why amn’t I just cracking on with this, why am I questioning that like a new mum, I’ve done it twice before.

For Abbie, there is almost a sense that the uncertainty and self-doubt she experienced around feeding compromised her maternal identity and it felt odd and difficult to make sense of. This is perhaps an indication of how unsettling and deskilling it can feel when trying to adapt to the new intricacies of feeding her baby with Down syndrome.

Affirmation

This subordinate theme captures the sense of reassurance in their status as mothers, and the affirmation that the mothers described when they were able to fulfil what they perceived as one of the most fundamentally important maternal roles - infant feeding.

The breastfeeding mothers reflected on this affirmation occurring due to their belief that nourishing their baby with breastmilk fulfilled a key maternal duty. They communicated the additional significance they attributed to this because their baby had additional developmental needs:

“I felt that I was doing something most important, as a mother, you know, a very important job for [baby’s] development, for [their] wellbeing” - Miriam

“I’m just grateful that I was able to give [baby] that start in life, do you know what I mean” – Jacqui

Rachel described the psychological impact of this reassurance, and it appeared to have a protective function for her wellbeing:

“So I think actually, I think it helped... I think psychologically it probably helped me, because it felt like something that was the best thing for him and quite natural”

Samantha had previously voiced the affirming gratification she received from “*providing everything that your child needs*” when feeding, and she too conveyed a sense of assurance in her feeding decisions and affirmation in fulfilling her perceived duty as a mother:

“I think when I made that conscious decision to feed [baby] against advice, em, I was quite nervous about it. I think I’d made an informed choice, and as I progressed feeding and [baby] didn’t get any chest infections and [they] didn’t show any signs, I felt a little bit like actually it was the right decision”

The mothers who didn’t breastfeed also seemed to convey a similar sense of reassurance and affirmation. Abbie experienced some initial frustration and distress when encountering breastfeeding difficulties. In deciding to stop attempting to breastfeed and take her baby off the feeding-tubes, Abbie appeared to feel reassured

that she had also aided her baby's development, and fulfilled her perception of her maternal role:

“Just knowing I was just helping [baby] by stopping that, it was gonna help [them] in the long-run”

Enid reflected on the feelings of wistfulness she experiences when contemplating missing out on breastfeeding, and its supposed benefits:

“Sometimes I'm a bit wistful about it. And I know that it's good in terms antibodies and protecting them and that kind of thing, but you know, I fed [baby] and [they're] fit and alive and I did the right thing”

However, Enid also appears validate her feeding decision, and a note of affirmation is detectable, in that that she too has fulfilled the maternal role of nourishing and protecting her developing baby, keeping them 'fit and alive'.

Poppy also spoke about how her increasing involvement in tube feeding has felt affirming, and facilitated fulfillment of her maternal role:

“But now I can do the important thing, keeping [baby] healthy like I was doing when [baby] was still inside... I was doing everything, you know I was feeding [baby] and everything... now [baby]'s been born, I can still, I can still deliver that”

To recapitulate, the superordinate theme '**Negotiating maternal identity through feeding**' encapsulates how mothers negotiated, constructed and made sense of their maternal identity when feeding their infant with Down syndrome. The three associated subthemes *Evaluation of the maternal self*, *“You just feel like a mum then”* and *Affirmation* capture these constructions of identity and relate to how the mothers described processes of self-evaluation in the context of their feeding experiences. The findings related to this superordinate theme imply that perhaps it is not the method of feeding, but rather the symbolic act of feeding and supplying nourishment, that stimulates this reassurance, resulting in the sense of affirmation for these mothers.

As word count parameters prevent including illustrative quotations from every participant, additional transparency is achieved through presenting the frequency of themes across participants, depicted in Table 3, below.

Table 3: Frequency of themes across participants.

Superordinate	Subordinate	Jasmine	Miriam	Rachel	Jacqui	Samantha	Enid	Abbie	Poppy
Negotiating control and assertions of power	Uncertainty and anxiety	✓	X	✓	✓	✓	X	✓	✓
	Others in Control	✓	✓	✓	X	✓	✓	✓	✓
	"You want to go the extra mile"	✓	✓	✓	✓	✓	✓	✓	X
"It made things feel settled"	Stability	✓	✓	✓	✓	✓	✓	Counter experience	✓
	Normalcy	✓	✓	✓	✓	✓	✓	X	✓
"It's a very bonding experience"	Connectedness and attunement	✓	✓	✓	✓	✓	✓	X	✓
	Gratifying dyadic exclusivity	✓	✓	✓	✓	✓	✓	X	X
Constructing maternal identity through feeding	Evaluation of the maternal self	✓	✓	✓	✓	✓	✓	✓	✓
	"You just feel like a mum then"	✓	✓	✓	✓	✓	✓	Counter experience	✓
	Affirmation	✓	✓	✓	✓	✓	✓	X	✓

CHAPTER FOUR: DISCUSSION

There is a current lack of empirical understanding of the feeding and bonding experiences of mothers of infants with Down syndrome. Given this fact, the fundamental aims of this study were to explore the subjective infant feeding experiences of mothers of children with Down syndrome and their reflections on bonding with their infant during the early feeding period. The present study was also interested in exploring mothers' perceptions of their personal wellbeing during the infant feeding stage, by achieving a greater understanding of the thoughts and emotions they experienced during this time. Aims of the research included using the findings to stimulate insight into the clinical needs of these mothers during the infant feeding period, with potential implications for clinical practice and policy development.

The research questions were:

1. How do mothers experience feeding their infant with Down syndrome?
2. How do mothers reflect on the development of the mother-infant relationship in the context of their infant feeding experiences?
3. How do these mothers make sense of their personal wellbeing during the infant feeding period?

The current study sought answers to these research questions by interviewing eight mothers of infants with Down syndrome. Interpretative phenomenological analysis was used to analyse the data, the application of which identified four superordinate themes and eleven subordinate themes (Figure 1).

Summary of key findings

To synthesise, analysis of the interview data indicated that mothers may experience a range of emotions when feeding an infant with Down syndrome. Mothers recounted that the outset of the infant period could be defined by uncertainty around how to feed

their infant – resulting in increased anxiety, which had the potential to be further compounded by encountering clinicians’ uncertainty around feeding. High levels of maternal drive regarding feeding were identified, with both breast and formula-feeding mothers experiencing a heightened drive to ensure their babies received nourishment through feeding, which had augmented importance in the context of their infant’s diagnosis of Down syndrome. For those who encountered difficulties feeding their infants, the mothers described being prone to negative self-evaluations, including self-criticism and self-blame, and recounted feelings of failure. The mothers seemed to convey that the sense of failure during feeding difficulties was exacerbated by the additional significance that was assigned to feeding and nourishing the baby in the context of the Down syndrome. Mothers narrated the debilitating loss of control that can be experienced as a mother when not initially in charge of feeding. Four of the mothers spoke about how this perceived loss of control can undermine maternal identity.

The mothers conveyed the sense of restored control, stability and normalcy that was instilled in them when feeding ‘stabilised, i.e when tube feeding ceased or when a steady breast or bottle-feeding routine was established. The ‘stabilisation’ of feeding often occurred as a product of the infant’s health becoming more stable, permitting them to be removed from tube-feeding apparatus. The majority of the mothers conveyed that stability in the feeding situation enabled them to perceive themselves and their baby as a ‘normal’ mother-infant dyad, in turn diluting wider anxieties associated with adjusting to having a baby with Down syndrome. However, for Abbie, the initial feeding difficulties were sustained, lasting for a year and did not ‘stabilise’, resulting in enduring stress and anxiety.

The majority of the mothers spoke about the positive meanings they assigned to their infant feeding experience, and the sense of connection and attunement they felt with their baby when feeding. Six mothers articulated their awareness of a distinct feeding bond, and four of these expressed their belief that the feeding experience enhanced the mother-infant relationship. Although Abbie relayed a sustained period of feeding difficulty and anxiety, she did not convey that this had any impact upon her relationship with her infant.

While there were qualitative differences in the language used by the breastfeeding mothers when describing their feeding experiences, the mothers who

formula-fed reported equally strong feeding bonds and as secure mother-infant relationships as the mothers who breastfed. When speaking about their bond with their baby all mothers reported strong prenatal bonds, which endured past birth and withstood incidences of mother-infant separation and feeding difficulties and the accompanying difficult emotions. However, there was a sense in Poppy's narrative that for her, re-establishing the bond after mother-infant separation, subsequent loss of control and lack of inclusion in her infant's care was a more incremental process. Although the mothers reported that the feeding situation could normalise the experience of having a baby with Down syndrome and stimulate an awareness of relating to their baby as a 'normal' baby, mothers did not otherwise appear to make sense of their bond with their baby through the lens of Down syndrome or 'disability'. In the interviews, mothers made sense of how the construction of maternal identity can be shaped by the feeding experience, with positive feeding experiences enabling mothers to connect with a maternal identity and evaluate themselves positively as mothers. Mothers described the sense of affirmation that feeding afforded and the reassurance derived from being able to fulfil the role of providing nourishment to their babies. It appeared that it was the symbolic act of feeding that provided this assurance for these particular mothers, rather than the method.

An attempt will now be made to use these results to answer the research questions and evaluate the findings against the backdrop of the relevant literature and existing theory. The strengths and limitations of the study will be outlined, followed by a discussion of the potential clinical implications of the findings, and how these may function as a platform for future research. This chapter will conclude with some final reflections.

Question 1: How do mothers experience feeding an infant with Down syndrome?

The findings relating to the first research question indicate that mothers can experience a range of emotions when feeding an infant with Down syndrome, with different stages of feeding creating distinct emotional states. This section will begin by chronicling some of the difficult emotional experiences associated with infant feeding that these mothers described, and will conclude with the more positive dimensions of their infant feeding experiences.

Loss of control

Salient themes relating to perceptions of lacking and acquiring/asserting control were detected in the mothers' accounts. The majority of the mothers described a threatening sense of diminished personal control and associated threats to individual agency in the immediate postnatal period, particularly in relation to mother-infant separation post birth and perceptions of others being in control of feeding.

Conceptualised as a cognitive attribute, perceptions of control are central to human cognition and motivation (Jonas & Mühlberger, 2017). Copious studies have identified that a perception of personal powerlessness or lack of control puts one at risk for psychological distress (e.g Frazier, Steward & Mortensen, 2004; Keeton, Perry-Jenkins & Sayer 2008). Conversely, a sense of control is acknowledged as a protective psychological mechanism, with perceptions of personal control and personal agency and efficacy repeatedly identified as strong correlates with subjective emotional wellbeing (Diener & Suh, 2003; Vargas, 2019). An extensive body of qualitative studies have also linked mothers' perceptions of a loss of control in the postpartum period to increased distress (Coates, Ayres & Visser, 2014; Elmir et al., 2010). Systematic review detects higher levels of distress and trauma symptoms in mothers of infants admitted to NICUs as compared to mothers of healthy infants (Shaw, et al., 2013), with many mothers attributing this to a perceived loss of personal control and feelings of powerlessness when feeling excluded from their infant's care (Obeidat, Bond & Callister, 2009). Mothers have also described a debilitating perception of a loss on control and sense of incapacity when unable to feed their infant in the NICU (Weiss, 2016). Six of the mothers in the current study narrated their perception of a lack of control and autonomy around infant feeding in the initial postpartum stage, and recounted the significant distress associated with this perception. While there is a scarcity of previous Down syndrome-related research with which to compare this finding, it echoes themes relating to perceptions of loss of control around feeding, and associated upset, which were identified in Cartwright and Boath's (2018) study, and mirrors the above-mentioned wider literature detecting maternal perceptions of a loss of control when unable to feed their infant.

Mother-infant separation after birth is acknowledged to represent a colossal sense of threat for mothers, resulting in high levels of anxiety (Flacking, 2012). This was

echoed in the accounts of all the mothers who experienced mother-infant separation post-birth, as detailed in the pen portraits. Jasmine and Abbie were the only mothers who linked experiencing mother-infant separation, and the associated loss of control, to their subsequent feeding behaviours. These included feeling territorial over the feeding role, difficulty tolerating others' involvement in feeding, and in Jasmine's case, using the feeding moments as opportunities to make up for the time she felt they missed together during their initial separation. Their narratives link with findings from previous research identifying more 'protective' maternal-infant patterns of engaging, as a way of mothers compensating for guilt around feeling unable to mother and feed their infants as they would have wished during early separation in the NICU (Forcada et al., 2006; Ionio et al., 2016).

Rachel had been warned in advance of the likelihood of postnatal mother-infant separation, which she described as ultimately having a protective function, and her reflective account of the initial postpartum period was less infused with memories of anxiety and powerlessness. No research appears to investigate the potential mitigating influence of advanced preparation for the possibility of mother-infant separation when a condition is diagnosed prenatally, but Rachel's disparate experience provides a solid rationale for the merit of enhancing the potential for a perception of control in the postpartum period by preparing mothers who receive a prenatal diagnosis of Down syndrome for the possibility that mother-infant separation might occur after birth.

Uncertainty and anxiety

It appears that in addition to the sense of threat associated with a perceived loss of control, mothers could also experience an undermining uncertainty and anxiety around feeding their infant with Down syndrome. Five mothers narrated the sense of worry that characterised their initial infant feeding experiences, particularly fear of asphyxiation and difficulties with weight gain, mirroring existing previous empirical inquiry into these mothers' experiences of feeding anxiety (Cartwright & Boath, 2018; Lewis & Kritzinger, 2004). Two mothers reported having to be more vigilant during feeding due to their baby's sleepiness and associated concerns around choking, a characteristic more specific to infants with Down syndrome; as noted by Cartwright & Boath (2018) the need for this particular vigilant stance is not reported in the wider

infant feeding literature. This potentially indicates that there can be a distinct dimension of stress to the Down syndrome infant feeding experience.

‘Failure to thrive,’ is the term assigned to infants who have difficulty gaining weight. Due to their higher incidence of gastrointestinal difficulties, failure to thrive is often noted in babies with Down syndrome (Das, 2015; Krugman & Dubowitz, 2003). Failure to thrive has previously been linked with heightened maternal anxiety (Lauwers & Swisher, 2005) Indeed, Abbie’s feeding anxieties centred on her infant’s weight gain and were enduring, lasting almost a year, with deleterious impacts upon her wellbeing.

For Abbie, Jasmine and Poppy, whose babies were tube-fed for longer than three weeks, this was initially shrouded in a specific trepidation and prospective anxiety associated with the possibility of extended tube feeding. This is analogous with themes of apprehension previously identified in the narratives of mothers whose babies are tube-fed (Stevens, Gazza & Pickler, 2014). The feelings of redundancy that the mothers voiced in relation to tube-feeding also has parallels with existing literature capturing mothers’ perceptions of compromised self-esteem and agency during the process of neonatal tube-feeding (Park et al., 2016; Swanson, Nicol & McInnes, 2012). (The impact of tube feeding on maternal wellbeing and identity is discussed in greater detail later in this chapter).

A thematic thread of ‘*unpreparedness*’ for the extent of potential feeding difficulties was detected in the accounts of three mothers who had received a prenatal diagnosis of Down syndrome (See pen portraits). Poppy also expressed regret at the amount of expenditure she had incurred purchasing bottles that ultimately were not suitable for her baby. Rachel had a notably divergent experience: she was warned her baby might have difficulty feeding and recounted the protective and preparative function of this. It has previously been recommended that parents be provided with sources of comprehensive feeding information and directed to sources of support following prenatal diagnosis of Down syndrome (Skotko, Kishnani & Capone, 2009). However, the period after a postnatal diagnosis of Down syndrome is recognised as an emotionally stressful time (Nelson-Goff et al., 2013), and the mothers’ narratives suggest that feeding about information may not be assimilated or processed in the period following a diagnosis. This indicates that in addition to disseminating realistic

and pragmatic feeding information, ensuring to clarify mothers' understanding and retention of this is vital, and could have potential emotionally and financially protective functions, in turn mitigating postnatal distress around feeding. For as Rachel articulated, "*knowledge was power.*"

Clinician uncertainty/lack of perceived support

Five mothers described experiencing clinicians as uninformed, vague and uncertain around infant feeding in the context of Down syndrome, which appears to have had a compounding effect on any existing anxiety. These findings are consistent with the perspectives of mothers in Cartwright and Boath's (2018) study, where women experienced HCPs as "*out of their depth*", unknowledgeable and uncertain about feeding an infant with Down syndrome. Previous associations have been found between experiencing unmet feeding information dissatisfaction with aspects of the postnatal care environment (including feeding) and increased maternal distress in the postnatal period (Coates et al., 2016; McKinnon, Prosner & Miller, 2014). Corrigan, Kwasky & Groh (2015) note the associations between postpartum emotional difficulties and poor appraisals of support from HCPs. Lewis and Kritzinger (2004) reported that perceptions of quality of feeding intervention from HCPs/feeding specialists influenced the degrees of breastfeeding initiation and duration in mothers of infants with Down syndrome. This connects to the attribution Miriam made between the extensive breastfeeding support she received from the student midwives and her successful extended breastfeeding experience. Conversely, as soon as Enid felt under threat in relation to infant feeding, she elected not to continue to attempting to breastfeed. Considering that postpartum support from HCPs around feeding is recognised as protective of maternal and infant wellbeing (Stapleton et al., 2012), there is patent need for greater cognizance of the intricacies of feeding an infant with Down syndrome, so that HCPs may be better positioned to provide appropriate intervention and support.

Determination and drive

The subordinate theme '*you want to go the extra mile*' captures the mothers' determination and drive to provide nourishment to their infant through feeding. There was a sense that this determination also permitted mothers a sense of regaining or

asserting control over the feeding situation. This reflects previous identification of heightened maternal drive around feeding in mothers with infants in an NICU, with mothers articulating that being able to feed facilitated a restored sense of control in a stressful postnatal period (Rossman, Greene & Meier, 2014). For the mothers who breastfed, this determination and drive appeared to relate to the incentive of providing breast milk, which they viewed as “*the best possible thing*” for their infant in the context of their additional needs, and their most important contribution as mothers. This determination to provide nourishment and additional fortification through breast milk, echoes the resolve previously noted in mothers of preterm infants in NICUs (Rossman et al., 2014) and in mothers of infants with Down syndrome (Cartwright & Boath, 2018). Mothers of preterm infants report experiencing guilt around their baby’s uncertain health, which can prompt bids for reparation through determination to breastfeed (Obeidat et al., 2009). None of the mothers verbalised the guilt or sense of failure around their infant’s diagnosis, which has been previously observed in mothers of unwell infants (Ionio, 2016; Obeidat et al., 2009), but there was a sense of accountability in some of their narrative passages, with the breastfeeding mothers conveying a sense of responsibility or duty to breastfeed to ensure their infant’s optimal nutritional intake and nourishment.

Samantha’s almost fixated focus on feeding goal attainment, i.e. continued breastfeeding until her infant’s surgery, reflects Cartwright and Boath’s (2018) finding that mothers of infants with Down syndrome can describe becoming ‘*obsessed with feeding*’. Maternal drive to breastfeed and provide best possible nutrition has previously been observed to eclipse other aspects of mothers’ lives (Laney et al, 2015). In the current study, mothers appeared to have acute drive and determination to breastfeed regardless of physical discomfort (Rachel and Samantha) and dissatisfaction with weight gain (Miriam), paralleling with research indicating that mothers will subjugate their own needs to breastfeed their infant (Hausman, 2018). The mothers who formula fed their infants also conveyed their determination to ensure their infant’s optimal nurturance through feeding, even if this meant them forgoing their own feeding wishes. Existing infant feeding research exploring maternal drive and determination in the context of infant feeding focuses predominantly on the experiences of breastfeeding mothers. The findings from this study suggest that in the context of infant ‘disability’, mothers who are not breastfeeding may also experience

heightened drive and determination to assert their power to ensure their infant's optimal nurturance through the feeding method they believe best meets their infant's needs.

Feeding as stabilising and soothing

Bar Abbie, all the mothers can be understood to have conveyed that at varying stages on their journeys, a stabilised feeding situation facilitated a sense of balance and stability. This corresponds with manifold studies identifying infant feeding as an emotionally regulating process for mothers (Benson & Haith, 2009; Heinrichs, Neumann & Ehlert 2002; Krol & Grossman, 2018). Mothers depicted the soothing sense of rhythm and calmness that feeding afforded, which has links with previous research identifying lower levels of anxiety in mothers who had a stable feeding routine with their infants (Lacovou & Sevilla 2013).

The hormone oxytocin, an amino acid peptide and neurotransmitter produced in the hypothalamus, is associated with the diminishment of anxiety, associated feelings of calmness and the regulation of a sense of threat (Lee, 2008; Jones et al., 2017; Gilbert, 2014). Oxytocin has been found to have a role in the formation of social-affiliate behaviours, including bonding (Algoe, 2017). Oxytocin is released within the brain in response to certain sensory stimuli, including skin to skin contact, close physical proximity and physical acts including stroking, holding and physical intimacy (Depue & Morrone-Strupinsky, 2005; Uvnäs-Moberg, Handlin & Petersson, 2014), all of which are viable features of the feeding situation (Gribble, 2006). Mother-infant proximity and touch-mediated interaction during feeding has long been identified as a pleasurable sensory dimension of the feeding situation (Dykes & Hall-Moran, 2009). Indeed, seven mothers described the physical closeness (mostly termed '*snuggling*') as the most pleasurable and calming element of feeding. In contrast, Abbie verbalised that her vigilance to ensure that her baby did not fall asleep and choke, and need to position her baby in a way that prevented him falling asleep, prevented this pleasurable physical intimacy. Although she sought to recreate the physical intimacy of feeding by '*snuggling*' afterwards, her account was void of the soothing stability that the other mothers experienced during feeding.

While both the formula and breast feeding mothers described the soothing and stabilising experience of feeding, and depicted experiencing pleasurable sensory components of feeding, there were qualitative differences in the language the breastfeeding mothers used to describe these experiences. Miriam, Samantha and Jacqui repeatedly used the words “*special*” and Miriam and Samantha used the words “*overwhelming*”, “*ecstasy*” and “*euphoric*” to describe their feeding experiences. These were distinctly different utterances to the formula-feeding mothers. Schmeid and Lupton (2001) also found that women can speak about their breastfeeding experiences with ‘*fervour*’. This finding is considered from a social constructionist perspective later on in this chapter, however it could perhaps also be understood hormonally, for in addition to being released during pleasurable physical proximity, oxytocin is also released in significant doses during nipple stimulation, with babies’ sucking motions during breastfeeding activating increased oxytocin release (Uvnas-Moberg, 2013). This release of oxytocin has been linked to higher levels of elation (Jesso et al., 2011), pleasure and exhilaration (Hiller, 2004), and euphoric affects (Wambach & Riordan, 2016). This may represent one interpretation for the variances in the language the mothers used to construct their perceptions of their feeding experiences. This finding indicates that although a stabilised formula-feeding experience may provide soothing feelings of stability and calmness, breastfeeding mothers may experience access to heightened sensual pleasure, and a different dimension of satisfaction. Further empirical investigation is needed to establish whether this has additional alleviative capacity and provides additional comfort in the context of coping with the adjustment to having a baby with Down syndrome

Question 2: How do mothers reflect on the development of the mother-infant relationship in the context of their infant feeding experiences?

With regards to the interfaces between feeding and the mother infant relationship, six of the mothers in this study identified their awareness of a distinct feeding bond, i.e. awareness of the feeding experience as a conduit to a new dimension of the mother-infant relationship. This supports previous maternal appraisals of feeding as a bonding experience that can add an additional layer of harmonious intimacy to the mother-

infant relationship (Flacking et al., 2006; Palmer & Erikson, 2019). At the outset of her interview, Poppy stated that for her, “*there has been no bond over feeding.*” However, towards the interview’s conclusion she acknowledged that tube feeding had afforded her a sense of a feeding bond, supporting previous research denoting that parental involvement in tube feeding can enhance a sense of connection with infants in NICUs (Flacking, 2012). Although Poppy had initially expressed a lack of a feeding bond, her meaning making was being constructed around current events and had shifted by the end of the interview. This the trajectory reflects the notion that perspectives can unfold and crystallise over time when reflecting on immediate lived events in interviews (Lehmann, Murakami & Klempe, 2009).

As mentioned earlier, six mothers described that the deeply pleasurable physical closeness or ‘snuggling’ during feeding, stimulated awareness of attachment and closeness to their infant. Women have previously described this physical sensuality as stimulating the feelings of unique concord and unity between mother and infant (Swain, Lorberbaum, Kose & Strathearn, 2007). Jacqui, Jasmine and Samantha reported that when they were unable to feed their baby during the initial three weeks of tube-feeding, striving for any physical contact and touch with their infant was important for them to maintain a sense connection when they were unable to be directly involved in feeding. This is analogous to the behaviours of mothers of preterm infants when striving to foster a bond and connection with their in the restrictive environment of an NICU (Phuma-Ngaiyaye & Kalembo, 2016), highlighting the perceived importance of touch and physical closeness for the developing bond.

Maternal-infant interactions and engagement can be negatively impacted when a mother is experiencing postpartum anxiety (Reck et al., 2018), with postpartum maternal anxiety having previously been linked with increased difficulty with self-regulation, that can undermine engagement with their infant (Feldman et al., 1999). However, Abbie’s experience reflects the reality that mothers can bond with their infant despite experiencing considerable anxiety (Figueiredo & Costa, 2009; Mellow, 2014). Abbie’s enduringly difficult feeding experience, diminished confidence around feeding and consistent anxiety, did not impact upon her relationship with her baby. The current small sample size does not allow for generalisations to be made, but it is

possible that for the other mothers, rather than having a protective function for the bond itself, feeding enhanced their perceptions of the mother-infant relationship.

The narrative that breastfeeding is the superior vehicle for promoting maternal-infant bonding is embedded within both the empirical and lay narratives (Dieterich, et al., 2013; See ‘baby bonding’ thread on www.babycentre.com). Many studies infer that mothers who breastfeed demonstrate greater longer-term sensitivity to their children (Britton, 2006) and have greater degrees of maternal responsiveness, i.e. ability to perceive and respond to their baby’s signals, in turn positively influencing the mother-infant bond (Hammad, 2016). In contrast, formula feeding has been associated with lower levels of maternal nurturance (Brown & Arnott, 2014). However, as asserted recently by Ventura (2018), systematic review reveals many of these studies to be methodologically weak, including varied concept definition and retrospective reporting after a long passage of time.

A salient finding from the current study was that there were no qualitative differences between how the breastfeeding and formula-feeding mothers described the strength of their bond in general, their awareness of a feeding bond or their sense of feeling attuned with their infant during feeding. This aligns more with recent research asserting that mother-infant bonding and the strength of the relationship is not associated with feeding type (Hairston et al., 2019). There appears to be no existing literature in relation to Down syndrome against which to compare these findings. Cartwright and Boath’s (2018) feeding study, the primary comparison point thus far, makes no mention of maternal bonding or the mother-infant relationship. While there is limited research investigating formula-feeding mothers perceptions of bonding in the context of infant feeding, this study joins the ranks of research indicating that formula feeding mothers report powerful emotions of dyadic connectedness and awareness of a feeding bond (Else-Quest et al., 2003; Gribble, 2006; Mercer, 2006), paving the way for the bonding experiences of mothers of infants with ‘disability’ to be included amongst this bracket.

Six of the mothers had received a prenatal diagnosis of Down syndrome or high likelihood of Down syndrome was detected during prenatal screening (Table 2). Perceived attachment to the foetus has been identified as having the most significant influence on a decision not to terminate after receiving a prenatal diagnosis of Down

syndrome (Nelson-Goff et al., 2012). Positive and accepting attitudes towards disability in general – and Down syndrome in particular – and conviction in one’s own ability to cope with a child with Down syndrome have been identified as other significant factors in deciding not to terminate (Lawson & Walls-Ingram, 2010). In the present study, all of the mothers, including those who received a prenatal diagnosis, reported feeling attached to their baby during pregnancy. Maternal-foetal attachment has been regarded as an independent predictor of the subsequent quality of the mother-infant bond (Petri et al., 2017; Rossen et al., 2016), so it is conceivable that a strong attachment to their foetus with Down syndrome may have been a determinant in these mothers forming bonds that were impervious to the impact of any feeding difficulties and accompanying anxieties. As both Miriam and Jasmine, who received postnatal diagnoses, described intensely close relationships with their infants in utero, after birth and during feeding, further research is needed before conclusive inferences can be made around the protective influence of mother-foetal attachment on the development of the maternal-infant relationship in the context of Down syndrome. However, these findings show preliminary indications that perhaps for mothers who had strong prenatal attachments to their infants and decided not to terminate *and* women whose prenatal attachment is sustained after the receipt of a postnatal diagnosis, feeding can be a conduit to the enhancement of the mother-infant relationship but may not represent the foundation of the mother-infant bond. Indeed, for *these* mothers, bonding was initiated independently of feeding, and the mother-infant bond was able to withstand the potential threat to attachment and bonding that initial/sustained feeding difficulties are said to represent (e.g. Lau, 2018).

Question 3: How do mothers make sense of their personal wellbeing during the infant feeding period?

The above discussion contends that when feeding an infant with Down syndrome, mothers can experience uncertainty, anxiety and hyperarousal/ increased drive, all of which are variables that have been found to impact negatively upon the wellbeing of mothers of ‘typically developing’ infants (Bennet, 2018), mothers of preterm infants (Padovani et al., 2009; Ionio et al., 2016) and mothers of infants with Down syndrome (Cartwright & Boath, Lewis & Kritzinger , 2004). Stabilised infant feeding was

described as having a soothing, stabilising impact for the majority of the mothers, aligning with previous research capturing the influence of perceptions of emotional and situational stability in positive subjective appraisals of wellbeing (Eid & Larsen, 2008), and more specifically, with research linking infant feeding with maternal emotional stability (Bick & Chang, 2015).

As these previously discussed findings indicate the seeming interrelatedness of maternal wellbeing and infant feeding experiences, they contribute in part to answering research question three. Hence, the below section will instead discuss maternal wellbeing as it relates to maternal identity.

Feeding, self-evaluation and maternal identity

A positive maternal identity is considered a core component of postnatal maternal wellbeing (Luthar & C, 2015). There is a well-established literature base that explores the associations between constructions of maternal identity and infant feeding, with feeding experiences often representing an arbiter for women's capacity as mothers (Wall, 2001), becoming a 'measure of motherhood' (Lee, 2008).

Clusters of themes relating to negotiating maternal identity in the context of infant feeding were detected in the mothers' accounts, with feeding experiences seeming to have profound implications for sense of self and maternal identity. Both the breast and formula-feeding mothers conceptualised feeding as an intrinsic, integral part of their maternal role. The mothers described how being unable to feed in the way they wished could stimulate critical self-evaluations, undermining their maternal status and compromising maternal identity. This reflects previous research detecting a compromised sense of maternal identity in mothers encountering breastfeeding difficulties (Símonardóttir, 2006), and has links with studies indicating that mothers can construct either positive or negative identities around their breastfeeding experiences (Fowle, 2015; Lee, 2008). 'Milk Pride', the gratification and pride associated with the provision of breastmilk to one's infant, is regarded as a form of positive self-identity for mothers (Mecinska, 2018). It can perhaps be understood that 'milk pride' may have contributed to some of the positive identity constructions and self-evaluations made by the breastfeeding mothers in this study, as they all voiced

the gratification experienced through their provision of breastmilk, which had an additional layer of meaning in the context of their infant's Down syndrome.

Women who formula feed have been found to score lower on measures of self-concept, self-worth and maternal gratification than breastfeeding mothers (Britton & Britton, 2008). As breastfeeding is considered nutritionally superior, guilt, stress and shame have been associated with the experience of exclusively formula feeding (Fallon et al., 2006; Radzimirski & Callister, 2016). Mothers often report having to conduct 'identity work' to reconcile their identity as a formula-mother with their identity as a 'good mother' (Murphy, Parker & Phipps, 1999). However in this study, themes of initial maternal guilt identified in the Jasmine and Abbie's accounts appeared to relate to their being unable to be involved in feeding to the degree they wished during the initial tube-feeding. These feelings of *guilt* appeared to subside when a stabilised formula-feeding routine had commenced. This diverges from the findings of Cartwright and Boath (2018), who detected 'overwhelming' and lasting maternal guilt relating to the use of formula, due to breast milk being regarded as nutritionally superior and more vital for infants with Down syndrome. However, in the current study, Jasmine and Abbie's babies had previously been tube-feed for a period of weeks. Mothers have previously described anxiety, apprehension, fear and trepidation around tube-feeding their infant in an NICU, and a sense of relief upon the cessation of tube-feeding (Stevens et al., 2014). It is possible that for the current mothers, the relief at tube-feeding ending neutralised any of negative emotions of self-assessment that can be associated with formula feeding.

Additionally, the subordinate theme of "*affirmation*" conveys the sense of reassurance and affirmation of maternal status, and the gratifying sense of role attainment that was achieved through the act of feeding, regardless of feeding method. Positive breastfeeding experiences have previously been linked to self-affirmation of mothering abilities (Fox, McMullen & Newburn, 2015) and maternal identity (Ogbonna, 2018). The literature investigating the experiences of mothers who formula feed is limited, with most qualitative and quantitative exploration focusing on the breastfeeding experience. This study provides a preliminary basis from which to contend that in the context of infant 'disability', mothers who formula feed can also be reassured in their status as mothers and experience as sense of affirmation that they

have done the best thing for their child. As Jasmine, Enid and Poppy, who did not breastfeed at all, also conveyed a sense of reassuring affirmation, it appears that it was the symbolic *act* of providing nourishment through milk that stimulated more positive constructions of maternal identity, not the method.

Poppy's story contradicts a wide narrative that feeding a child orally is a key part of the development of maternal identity (e.g. Wilken, 2012). She described a greater connection with her maternal identity upon becoming more involved in her baby's tube-feeding and general care, and articulated awareness of a tube-feeding bond. This supports previous research indicating that a shift from a passive to active caring role results in greater maternal confidence, more engaged and confident mothering, augmented sense of control, enhanced connection with the infant (Broedsgaard & Wagner, 2005). Again though, this research was conducted with mothers of pre-term infants and further substantiation of the current findings is needed before this can be extended to mothers of infants with Down syndrome.

Normalcy

This study also illuminated the normalising function that feeding had for these mothers, who reported experiencing a sense of dyadic and wider normalcy when their feeding difficulties stabilised.

Wellbeing is essentially a matter of self-perception (Bellini et al., 2006), and so too can 'normality' be considered a subjectively perceived state (Dodge, et al., 2012). How normality is perceived relates to social, cultural and temporal constructions in any given context (Marinescu, 2017). Discomfort with the assessments one makes about one's own experience/life situation is associated with increased distress, with this extending to appraisals of abnormality, difference or deviation from the norm (Eid & Larsen, 2008). Equally, research indicates that for many individuals, subjective wellbeing can be associated with perceptions of both normalcy and normality (Joronen & Åstedt-Kurki, 2005). Dominant constructions of normal motherhood locate infant feeding as a core maternal responsibility, in which both bottle and breast feeding can be experienced as affiliation with or deviation from the norm, depending on societal and cultural contexts (Holmes, 2006).

As articulated by Landsman (2008), the mothering of babies who do not

coincide with cultural and social standards of ‘normal’ represents a valuable arena for gleaning insight into constructions of motherhood in different contexts. Notions of normality are often challenged in mothers of babies with ‘disabilities’ or additional developmental needs (Watterson, 2000). When their threats to normalcy were threatened by the arrival of their baby with a ‘disability’, feeding appeared to bestow a sense of dyadic normalcy for the current mothers, becoming a fundamental component of their maintenance of normality. Decidedly little research appears to investigate the potentially normalising function of feeding in the context of infant ‘disability’. One qualitative study (Ryan et al., 2013) also detected that stabilised feeding enhanced coping by instilling a sense of typical motherhood and normalcy in mothers of infants with ‘disabilities’, including two mothers of infants with Down syndrome.

In this study, mothers expressed their relief at tube-feed ceasing, and at one point Rachel remarked that she was relieved not to have had the visibility of extended tube feeding, expressing her belief that tube feeding would have signalled a sense of difference that she was pleased not to have to contend with. The visibility associated with tube feeding and the accompanying ‘stigmatised’ identity of infants who are tube-fed, has been found to instil social anxiety in mothers when having to contend with reactions from the ‘uniformed public’ (Craig & Scambler, 2006; Ferguson & Paul, 2007). It is possible that for some of these mothers, their relief at their baby not being tube-fed may have enriched and augmented the experience of normality afforded by the feeding experience.

The normalising influence of stabilised feeding suggests that the act of feeding, regardless of the feeding method, may represent a vehicle for enhancing perceptions of normalcy, in turn enhancing coping for these mothers.

Theoretical considerations of the findings

In this section, the associations between infant feeding and maternal wellbeing are considered from social and feminist theoretical perspectives.

The finding that mothers linked the stabilising of infant feeding with validations of their maternal identity and self-worth can perhaps be considered within the framework of Social Identity Theory (SIT; Tajfel, 1978; Tajfel & Turner, 1979). SIT refers to the

facets of an individual's self-concept that are derived from their perceived membership in a particular group. One's social identity represents the link between the internal representations of the self and the social self, as it is embedded within different groups (Sedikides & Brewer, 2015). When situating social identity within a constructionist perspective, it is acknowledged that identity is intrinsically social, where sense of self and identity are constructed (and reconstructed) in relation to others (Michael, 1996).

One's constructed social identity is acknowledged as having implications for psychological wellbeing (Haslam et al., 2009; Sharma & Sharma, 2010). When individuals consider specific group membership to be key to their self-concept, affiliation with said group confers enhanced self-esteem and wellbeing, and sustaining of the desired social identity (Leaper, 2011). SIT also posits that the sense of belonging achieved by identification with a group can facilitate perceptions of normalcy (Kruglanski & Stroebe, 2012). With regards to this study, stabilised infant feeding perhaps enabled perceived affiliation with the grouping of 'normal mothers' or mothers of 'normal' babies, and in turn increased self-esteem and consequent positive self-evaluations were afforded (Smith & Leach, 2004).

Parameters of normality/normalcy are crucial in considering what group affiliation constitutes. Indeed, *'expectations for behaviour, skills or roles often define parameters of "normality"'* (Rao, 2007, p 170). As noted in the introduction, the construct of the 'good mother' relates to the socially constructed pressure and expectation that mothers meet certain 'normal' standards and ideals of motherhood (Johnson & Swanson, 2006). Feminist perspectives contend that successful breastfeeding has become one of the representations of 'good mothering', with the potential for a sense of inadequacy to accompany the perception one has fallen short of the socially constructed ideal of the 'good' breastfeeding mother (Taylor & Wallace, 2012). A feature of the good mothering ideology is the willingness of mothers to subjugate their own need for those of their infant, for example continuing to breastfeed in the face of discomfort or pain being regarded as an expression of devoted mothering (Lee, 2011). In this study, the breastfeeding mothers voiced an enhanced willingness to go above and beyond to provide breast milk, even in the face of discomfort, gaining a fundamental sense of reassurance from nurturing their baby through feeding. Exposing one's children to risk is not considered acceptable within

the good mother paradigm (Knaak, 2010), and the breastfeeding mothers appeared to receive affirmation from the perceived protective role of their breast milk. Perhaps the breastfeeding mothers in this study subscribed, both consciously and subconsciously, to this premise, perceiving that the provision of optimal nourishment to their baby affiliated them with the ‘good mother’ group, with affirmative implications for maternal identity and sense of self. This may have particular resonance for mothers of infants with a ‘disability’, whose identities may be under reconstruction when making sense of and adapting to being a mother of a child with a ‘disability’ (Landsman, 2008).

However, this premise is less applicable to the bottle-feeding mothers, who also conveyed a sense of affirmation and confirmation of their maternal status and identity when feeding their baby. As previously noted, this may be related to the experience of transitioning from tube to bottle feeding and the assuaging impact this had on levels of distress and disrupted identity formation. Feminist theory may now need to consider the potential for mothers of infants with ‘disability’ to be more impervious to the considerable burdens of guilt, stress and regret that can often accompany formula feeding (Lee, 2007).

Implications of the research findings

This section considers the implications for practice, policy/guideline development and existing feeding and bonding narratives that have emerged from this study.

Implications for medical healthcare professionals

Mothers of infants with Down syndrome may have specific needs during the infant feeding period. However, many neonatal settings may be unaccustomed to providing specialist feeding support to these mothers (Cartwright & Boath, 2018; Sooben, 2015). HCPs including midwives, nurses, paediatricians and infant feeding practitioners are well positioned to better support these mothers, as discussed below.

Four of the mothers in this study were able to breastfeed their infant, offering further substantiation for the reality that infants with Down syndrome can successfully be breastfed, with potential positive impacts on mothers wellbeing and maternal identity.

Unlike the findings of Cartwright and Boath (2018), none of the mothers in this study voiced feeling dissuaded or discouraged against breastfeeding. However they narrated the dispiriting experiencing of HCPs dispensing unhelpful feeding narratives after their birth of their infant. HCPs involved in the care of these mothers should be cognizant that breastfeeding an infant with Down syndrome is possible, but may be accompanied by specific challenges, and be able to provide balanced feeding information to these mothers. In line with the protective function that advance information about feeding had for Rachel compared to the other mothers, practitioners should provide realistic feeding information to parents in receipt of a prenatal diagnosis of Down syndrome, and should ensure parents' retention/understanding of this.

It is evident from the mothers' accounts that interactions with HCPs can shape women's initial feeding experiences, both positively and negatively. Miriam perceived that extended, intensive support was critical for her breastfeeding success, but five participants reported the difficulty of encountering clinicians' vagueness and uncertainty around feeding infants with Down syndrome, with this being a sustained experience for Poppy. Cartwright and Boath (2018) assert that HCPs should refer mothers to infant feeding specialists if the feeding intervention needed is beyond the level of own knowledge and ability. This study adopts the position that instead, there is a need for a general upskilling of neonatal practitioners involved in infant feeding, so that they make be equipped with specialist knowledge of infant feeding in the context of conditions such as Down syndrome, as recommended in the Unicef Baby Friendly Initiative (2015).

Two mothers whose babies spent an extended period in the NICU relayed their belief that the stress of the situation impacted their ability to express breast milk, and Poppy was not offered any support around expressing. Previously, mothers of preterm infants have reported that providing their expressed breast milk fostered a greater sense of connection to their infant during physical separation, reduced distress and facilitated affirmation of maternal status (Sweet, 2008). In line with this, there is a need for greater supports that are individually tailored to aid mothers of infants with Down syndrome who wish to express during periods of separation from their baby.

The potential for distress and the loss of control associated with mother-infant separation to be further compounded by perceived lack of control around feeding was a notable finding from the mothers' accounts. Evidence repeatedly indicates that higher perceptions of personal control have a protective function for general wellbeing (Frazier, Steward & Mortensen, 2004; Keeton et al., 2008) and maternal wellbeing in the postpartum period (Coates, Ayres & Visser, 2014; Elmir et al., 2010). While Neonatal wards are typically overstretched and under-resourced (Baby Bliss Report, 2015), clinicians should endeavour to enhance mothers' perceptions of control around feeding. This could be achieved via consulting them around feeding decisions and facilitating as much maternal involvement in feeding, and overall infant care, as possible. The positive emotional implications of such practices have been substantiated in research with mothers of preterm infants (Obeidat, 2009). It is likely that measures to increase perceived control for these mothers would also have an emotionally protective function.

The themes identified in the accounts of the three mothers whose babies were tube fed for over three weeks, mirror those identified in previous studies evaluating maternal experiences of tube feeding (Wilken, 2012). Psychoeducation for parents on the potential for tube-feeding experiences to conflict with fundamental expectations about mothering has previously proven efficacious in reducing maternal distress (Stevens et al., 2014). Research indicates that if mothers are consulted about – and have an active role in – the tube feeding process, it is viewed as a component of their mothering role (Wilken, 2012). Accordingly, HCPs should endeavour to support mothers of infants with Down syndrome who are tube-fed, to positively integrate the tube feeding experience with their maternal identity.

Implications for clinical psychology

Implications for practice

Social constructionism offers the perspective that values and ideologies are 'human made', i.e. constructed through social and cultural discourse (Galbin, 2014). Some therapy approaches with postmodern, social constructionist underpinnings aim to challenge models of normalcy that other therapies may have historically embraced (Atwood, 2008). Instead, more constructionist therapies endeavour to instigate change

through deconstructing clients' experiences of the impacts of cultural and societal narratives, followed by the co-construction of new life meanings and narratives (Burr, 2015). Examples of such therapeutic approaches include NA (previously discussed in Chapter Two), systemic therapy, Solution Focused Therapy and Collaborative Language Systems approach. For example, Solution-Focused Therapy operates in opposition to deficit-based methods, instead focusing on competencies, strengths and resources (O'Connell, 2012), may be helpful for mothers of infants with Down syndrome who find themselves engaging in unhelpful self-evaluations. NA interventions, with a non-blaming, externalising focus, could guide mothers to externalise feeding difficulties, preventing internalisation of problems that might result in lowered self-concept and compromised identity and sense of self (Morgan, 2012).

Considering a Compassion Focused framework

Following further reflection on the interview findings, Compassion Focused Therapy (CFT) was identified as a fitting psychological conceptual framework within which to consider the implications of results. Developed by Gilbert (2010), CFT is a system of psychotherapy that amalgamates techniques from Cognitive Behavioural Therapy with concepts from evolutionary psychology, developmental psychology and neuroscience. I acknowledge that applying an evolutionary, biopsychology framework to evaluate the results may seem like an odd departure from the thesis' inclination towards considering social constructionist perspectives. For evolutionary psychology is often conceptualised as the 'theoretical rival' of social constructionism – it adopts the more realist perspective that human perception is an evolved, species-specific architecture of cognition, comprised of systems that are responsible for shaping emotional reactions, motivations, beliefs, and inter and intrapersonal behaviours, stemming from genetic adaption to ancestral environments (Mallon, 2000; Wilson, 2005). Historically, social constructionists have viewed this position as dismissive of the socially and culturally constructed attitudes, norms and beliefs that influence societal exhibitions, for example: racism and sexism, which consecutively stem from social constructions of race and gender (Rosenblum &

Travis, 1996). In turn, social constructionism has been criticised for ignoring evidence from physical and biological science (Sokal & Bricmont, 1999).

However, the decision to apply a CFT framework to evaluate the findings was influenced by the mounting expressions of belief in the theoretical compatibility of social construction perspectives and evolutionary psychology (Mallon, 2000; De Block & Du Laing, 2007). Indeed, Mallon (2005) asserts that the two orientations are not mutually exclusive, are less antagonistic and adversarial than once thought, and can actually be understood to complement each other. Wilson (2005) proposed the integration of both fields to form 'evolutionary social constructionism'. 'Evolutionary social constructionism' acknowledges that as a species, humans are dependent on information that is transmitted socially and "must respond to the social constructions of localised reality", but also that human tendency towards social constructionism represents a significant component of our evolved psychology as a species (Aranguren, 2018, Jost & Kruglanski, 2013; Mallon, 2005). In uniting the stances on emotions in both paradigms, the result is the broader framework of 'evolutionary social constructionism', which acknowledges both that emotions can be sculpted both by culture-specific social constructions, *and* have an evolved, adaptive basis (Mallon, 2005). This theoretical perspective created the rationale for the application of a CFT framework within which to consider the current research findings.

A core tenant of CFT is its Three Circles Model of emotion, which contends that there are three basic affect regulation systems: the threat system, the drive system and the safety system (attachment system) (Gilbert, 2010). These systems relate respectively to evolved threat responses, motivation to seek out resources/achieve goals and feelings of safeness/security. This model postulates that there are patterns of interaction between the three systems, and imbalance between the systems results in psychological distress, usually due to the under-regulation and under-development of the soothing system (Gilbert, 2010, 2014). Wellbeing is associated with balanced regulation between the three systems, as depicted in Figure two, overleaf.

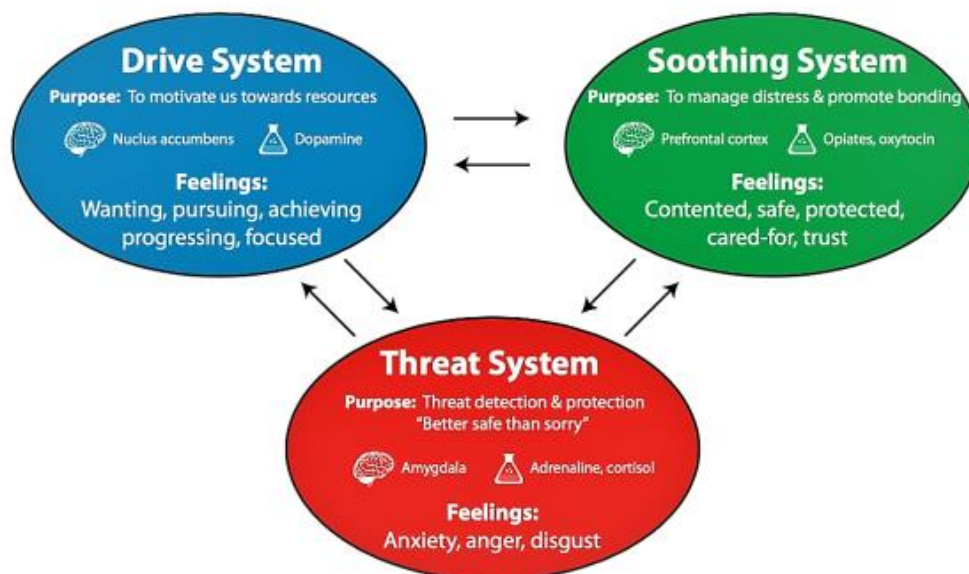


Figure 2: The three affect regulations systems as conceptualised in Compassion Focused Therapy (© Gilbert, 2010).

Presented below is a brief explanation of the three emotional regulation systems, as conceptualised in CFT, along with contemplation of how many of the interview themes can be considered as fitting within the three circle model. Social constructionist consideration is also given to how these three systems can be shaped by an individual's socio-cultural context.

The threat system

The threat system is involved with detecting and responding to threat, and is operated by the release of the hormones cortisol and adrenaline (Bezdek, 2017). Both external (perceived danger) and internal (self-criticism/self-attack) experiences can activate the threat system (Gilbert, 2009). An activated threat system is associated with emotions such as fear, anxiety and disgust and threat-focused cognitions. The threat system is reactive to both lived traumatic events and more symbolic threats, such as a perceived loss of control (Abelson et al., 2008). Some of the themes identified from the data analysis can be considered as affective or cognitive states that can be understood as being indicative of the mothers experiencing heightened threat systems,

including loss of control, conditions of uncertainty and anxiety, a sense of threat to self/ maternal identity and negative appraisals of the self (Hoeffler et al., 2015 Grupe, 2013).

Social constructionism contends that emotions are socially and culturally constructed and transmitted (Burr, 2015). Within this premise, the social construction of the individual self has also been considered. This perspective contends that people define themselves in comparison to others, with the self being distinguished as unique through interpersonal comparison (Sedikides, & Brewer, 2015). As such, our narrations of our own identity and the construction of our sense of self are a product of our social and relational interactions (Gergen, 2011). Accordingly, as much as one's situatedness is a product of social relations, so too is the attitude one takes towards oneself and resultant patterns of self-to-self relating (Sedikides, & Brewer, 2015). Relatedly, self-criticism can be a result of unfavourable social comparisons, creating feelings of inadequacy and impoverishment of the constructed self (Duarte, 2009). Hence it can be understood that the constructed wider social situation can have sway in determining our beliefs and attitudes towards ourselves. From this perspective, the self-attack or self-criticism that these mothers experienced in relation to their appraisals of their feeding experience, may have been stimulated through interpersonal and social comparison with other mothers, potentially women whom they perceived as better approximating the social construction of the 'good mother' (See: Johnston & Swanson, 2006).

Drive system

Typically a resource acquisition system, the drive system relates to motivation for goal attainment (Kolts, 2016). The drive system is maintained through the release of the neurotransmitter dopamine, which functions to alert and maintain focus on the pursuit of goals and resources (Gilbert, 2014). An activated drive system is associated with high arousal, simulation, anticipation, incentive-based focus and a mind-set attuned to achieving/realising goals (Gilbert, 2010). An individual's drive system can have a regulatory function, in that it be activated and maintained to restore a sense of control in response to perceived threat (Gilbert 2010, 2014). The mothers' heightened drive, determination and motivation to nourish their babies through feeding can be

understood as representative of an activated drive system, oriented on the attainable goal of infant feeding and pursuit of restoration of control. A hyper-active drive system is powerful, sometimes to the detriment of individual needs (Kolts, 2016; Gilbert 2010). As discussed previously, the breastfeeding mothers in particular conveyed a sense of heightened drive around feeding, potentially in response to a heightened sense of threat.

Individual motivation can also be conceptualised as a state that is interpersonally driven, and an enactment of socially transmitted and constituted schema (Eccles, 2009). Anderson and McShea (2001) put forward a case for motivation being shaped by culture, in addition to by nature. In that, the resources or goals that humans desire and are motivated towards are influenced by social factors which represent the motivational sources of human behaviour. Gergen (2011) argues that motivation or 'drive' must be considered within the individual's conception of self and others, which is intersubjectively constructed. His stance contends that arousal and motivation can be heightened in specific contexts, by experiences that have been assigned importance due to socially constructed norms and dialogues. As such, it is potentially also possible to conceptualise the womens' motivation to breastfeed, or to be involved in feeding to the degree they wished, as being a product of one of the dominant constructed ideologies of motherhood, i.e the mother who 'successfully' feeds her child.

The soothing system

The soothing system is the social affiliation and attachment system, and functions as a regulator of the threat and drive systems (Gilbert, 2014). Activation of the soothing system is linked with the stimulation of the neuro-hormone oxytocin (Ellingson, 2015; Gilbert 2010, 2006; Uvnäs-Moberg & Peterson, 2014), which is associated with the diminishment and regulation of threat (Lee, 2009; Jones, 2017), in turn mediating the soothing system (Algoe et al., 2017; Gilbert, 2014). As outlined previously, oxytocin is released neutrally in response to certain sensory stimuli, including close physical proximity. All of the mothers, bar Abbie, can be understood to have conveyed that at varying stages on their journeys, feeding eventually restored balance and instilled a sense of soothing stability. It can potentially be understood that for these mothers, stabilised feeding became a regulator of the threat and drive systems, facilitating

access to their soothing systems and more balance between the affect regulation systems. Meta-analytic review of CFT has established the link between activation of the soothing system and feelings of safety, calmness, security and stability (Wilson, 2019), all of which were affective dimensions of feeding described by six of the mothers, and to a lesser degree by Poppy, who was at an earlier stage of her feeding journey.

The concepts of security and safety have also been framed as socially constructed, conceptualised as products of culturally and socially constructed narratives, that stem from socialisation and collective agreement (Simpson, 1996). Similarly, the concept of contentment is regarded as being rooted in social experience, founded by culturally specific ideals that are constructed intersubjectively (McKensie, 2016). In that, these ideals provide a framework for individual appraisals of personal experience, wherein individuals evaluate the degree to which their experiences approximate culturally and socially constructed ideals (Feinman, 2013). Motherhood is also recognised as a site of socially constructed discourses, which are underpinned by the cultural and moral norms and orders of individual societies (Lindley, 2013), e.g the pervasive discourses around the ‘ideal mother’ that can result in increased weight and social meaning being assigned to the mother who ‘successfully’ feeds her infant. Hence, from a social constructionist perspective, the feelings of stability, safety and contentment that the mothers described in relation to feeding, may have resulted from the assuaging reassurance, and sense of security afforded through perceiving to be fulfilling the ideal of the feeding mother.

Considering the findings within a CFT framework, for the majority of the participating mothers, the experience of feeding an infant with Down syndrome can be understood as having the potential to overstimulate both the maternal threat and drive systems, in turn maintaining anxiety and a heightened motivational state. However, stabilised feeding appears to have a soothing influence, ultimately regulating the threat and drive systems, permitting mothers greater feelings of stability and access to their soothing systems. While CFT purports an evolutionary basis for these systems, the above discussion offers a social constructionist consideration of the three systems.

Compassion-focused interventions

The soothing system is underactive in those experiencing a stimulated threat system through self-criticism. Accordingly, a CFT therapeutic approach supports individuals to cultivate a warm, accepting and compassionate stance towards the self and others, with the aim of diminishing shame and self-criticism, in turn stimulating the soothing system and creating a more adaptive, regulated balance between the three affect systems (Gilbert, 2010; 2014).

CFT is thus well placed to address any issues of self-criticism, guilt and blame that may arise if mothers encounter difficulties when feeding their infants with Down syndrome. Clinical psychologists working with these mothers could apply CFT intervention to challenge any unhelpful appraisals of the self, cultivate positive self-talk and foster more positive patterns of self-to-self relating, thereby enhancing self-soothing during periods of heightened threat. Similarly, any mothers with analogous experiences to Abbie, for whom infant feeding might not become a soothing experience, could be equipped with substitutory self-soothing skills to help modulate anxiety and the sense of threat (Gilbert, 2009). The applications of CFT for maternal distress is still evolving, but has been found to be efficacious in reducing maternal wellbeing and enhancing mother-infant relating in mothers who were referred to a perinatal mental health service (Cree, 2010). Again this research was conducted with mothers of ‘typically’ developing babies, but provides a preliminary justification for the application of a CFT approach with mothers experiencing a heightened sense of threat and the associated difficult emotions during the postnatal period.

Implications for consultancy and wider systemic influence

The remit of clinical psychologists within the NHS continues to expand, with there being a shift from working with an exclusive therapeutic focus to leadership and consultancy roles. Clinical psychologists working in hospital settings would be well positioned to disseminate CFT ideas and principals to hospital staff and provide training on how to cultivate a compassion-focused approach when working with mothers of infants with Down syndrome who may have an overstimulated threat

system during the infant feeding period. Health-care professionals should be versed in the detection of high levels of self-criticism, and be trained to provide brief compassion-focused intervention, or make referrals to clinical psychology as appropriate. This could also have a wider systemic focus, with clinical psychology facilitating team formulations around how to eliminate or soften potential sources of threat during the initial postpartum period.

‘Psychological First Aid’, originally developed for survivors of ‘disaster trauma’ are collective techniques used to foster short and longer term adaptive coping in the aftermath of trauma, with the aim of reducing the manifestation of PTSD after a traumatic event (Shultz & Forbes, 2014). Psychological First Aid is increasingly being applied by clinical psychologists working in major trauma wards in hospital settings, often utilising brief psychoeducation centred on CFT’s Three Circles model, and mindfulness techniques (National Child Traumatic Stress Network and National Center for PTSD, 2006). Mothers described the acute distress of being separated from, and unable to feed their baby, and as discussed, these mirrored themes in the wider literature capturing maternal NICU experiences. Accordingly, there is potential scope for applications of psychological first aid to move away from a sole presence on major trauma wards, and be extended to neonatal settings, with the preventative aim of minimising current distress, and mitigating the potential for any mothers who are separated from their infant and unable to feed to develop future trauma symptoms and sustained distress.

Implications for policy/guideline development

The Baby Friendly Initiative for Neonatal Units (Unicef UK, 2015) sets out specific guidelines to improve infant feeding in healthcare settings. However, no guidance is issued around infant feeding in the context of Down syndrome.

There is potential for this study’s findings to initiate the development of policies and interventions, which could considerably improve the experiences of mothers of infants with Down syndrome. The Marce Society for Perinatal Mental Health, (MSPMH) an international society dedicated to understanding, treating and preventing prenatal and postpartum difficulties, for men and women, advocate for universal psychological and social assessment in perinatal care settings – of which infant feeding is a component

– as part of an integrated model of care (MSPMH, 2015). There is no national healthcare policy or guidance around infant feeding tailored to the needs of mothers of infants with Down syndrome. There is patent need for standardised guidelines around preparing mothers for possible feeding difficulties, training requirements for healthcare staff and practice-based guidelines around the provision of tailored feeding support. The findings from the current study could potentially contribute to the development of neonatal guidelines to be tailored to best meet the needs of these mothers and babies.

Implications for Down syndrome support services

‘New parent packs’ such as the ‘Tell it right’[®] brochure, containing accurate and balanced information about Down syndrome, are distributed by Down syndrome support services nationwide (DSA, 2019). Both the finding that infants with Down syndrome can be breastfed successfully, and that formula-feeding does not appear to impact the mother-infant relationship, represents valuable information for Down syndrome support services to include in information packs and on websites.

Research indicates that peer support during the transition to motherhood has positive impacts on maternal self-esteem and role attainment for mothers of ‘normally developing’ infants (Leahy-Warren, McCarthy & Corcoran, 2010) and new mothers of infants with disabilities (Bray et al., 2017). Feeding-specific peer support, perhaps with a home visit element, could be a valuable initiative for Down syndrome support services to develop, with HCPs being able to signpost mothers to regional peer support services accordingly.

Implications for mothers

Lastly and importantly, the findings of this study may potentially have crucial implications for mothers of infants with Down syndrome. Three of the mothers explicitly stated that their decision to take part stemmed from their desire for more empirical understanding around maternal feeding experiences, which this research has afforded. The findings confirm that infants with Down syndrome can be breastfed successfully and highlights the significance that this can have for mothers’ sense of

self and overall wellbeing. It may likewise be helpful for mothers to be cognizant that feeding an infant with Down syndrome can be accompanied by a specific set of stressors. However, significant reassurance may be derived from the finding that feeding difficulties appear to often stabilise, with a resultant sense of stability and soothing and normalising impacts.

This study offers a counter stance to the narrative that breastfeeding represents the superior mode of feeding for mother-infant bonding, and offers a *preliminary* position from which to dismantle some of the lore around ‘breast is best’ for the developing bond. This may have potent reassurance for mothers of infants with Down syndrome who are unable to breastfeed as they had hoped to, or for mothers whose infants are tube fed for an extended period. While replication of the study’s findings by future research is needed before generalisations can be made, it is possible that dissemination of this information may have a reassuring, assuaging and encouraging utility for mothers, ultimately protecting maternal wellbeing. Three of the mothers who were separated from their infant detailed experiencing attachment anxieties during this period, and worries that the infant-mother bond would be compromised, reflecting previously noted concerns of mothers of infants with Down syndrome during mother-infant separation (Muggli et al., 2009). However, these mothers reported that separation did have any lasting impact on the mother-infant relationship, which may also be valuable information for mothers to receive.

Strengths and limitations

The study contained both strengths and limitations; presented below is a general critique of the research.

Design and methodology

The use of qualitative methods, and IPA in particular, represents a strength of this study, as it enabled an ‘insider’s’ access to participants’ phenomenological worlds, allowing the rich and diverse experiences of each individual mother to be privileged. A fundamental rationale for using qualitative methods was to capture aspects of experience that are not easily quantified. However, mixed methodology and the use

of quantitative measures (e.g on wellbeing or bonding) might have enabled illuminating supplementary information to be gathered, in turn triangulating the qualitative findings (Onwuegbuzie & Teddlie, 2003). However this study was ardent in its desire not to presuppose around elements of lived experiences, or to implicitly infer that dimensions of experience are preferable or better than others, which qualitative measures may have imposed.

Sampling, recruitment and participants

A primary limitation of IPA research is the typically small sample size, meaning that robust generalisations cannot be made, as the themes identified in the narratives of these eight mothers are not necessarily representative of all mothers' views and experiences. However, it is argued that the specialized, in-depth insights afforded by IPA have the potential for development of more nuanced clinical implications (Reid, Flowers, & Larkin, 2005). Additionally, identified themes relating to the first research question overlap to a degree with findings from Cartwright & Boath's (2018) study, indicating that thematic experiential trends may be present in this populations' experiences. The sample were recruited from community networks in one region of Yorkshire. Casting the participant net further afield to more urban or remote areas would permit greater generalisation of findings. As participants were purposively sampled, the potential effect of self-selection bias must be acknowledged (Willig, 2013). All mothers self-selected to take part and were recruited from Down syndrome support groups that they were in a position to attend during the day. As the mothers were recruited from support groups, it is possible that they may have had disparate experiences to mothers with different resources, who less actively sought or had less access to support, with this representing a research bias that could further hamper generalisability (Newington, 2014). Furthermore, it is conceivable that some of the women who volunteered to take part in this study had enough confidence in their relationship with their child, and in the solidity of their identity as a mother, to make taking part a non-threatening, tolerable experience.

Although all participants had a baby with Down syndrome under the age of three, the homogeneity of the sample could be questioned due to the variance of feeding methods. This variation between methods resulted in a need for greater thematic

abstraction at the group level analysis. A uniform sample in terms of feeding practices may have resulted in a more distinct thematic profile for that particular method, potentially increasing the degree to which findings could be generalised. Despite this methodological limitation, the inclusion of differing feeding methods has the potential for wider clinical inferences to be made from this study; the findings indicate the overlapping needs these mothers may have but also identify feeding method-specific needs.

The inclusion of Poppy may also have undermined the homogeneity of the sample. For although she met the inclusion criteria, she was the youngest by a decade, the only first-time mother and her baby was still in hospital at the time of the interview, making her meaning making less retrospective than the other mothers'. Poppy relayed that her relationship with her baby was still actively developing and evolving at the time of the interview, which also positioned her differently to the other mothers who reflected upon longer-established bonds with their children. The formation of maternal identity is acknowledged to be a dynamic, intrapsychic, multi-faceted process that can develop over time (Laney et al., 2015), and Poppy did not transmit the sense of a fully consolidated maternal identity, but rather one that was still under construction. While these elements of Poppy's experiences and the current nature of her meaning making differentiated her from the other participants, the inclusion of her account provides nuanced and illuminating clinical insight into the real-time experiences of a new mother of an infant with Down syndrome who is facing current difficulties with infant feeding, and how they make sense of the impact of this on their developing relationship with their infant, their maternal identity and their personal wellbeing.

Interviews

The in-depth, semi-structured, explorative interview is the optimum method of data collection for IPA, allowing participants to speak in detail about aspects of their experience they deem meaningful (Smith, 2007). Conducting Face-to-face, one-to-one semi structured interviews also enabled me to make supplementary observations beyond participants' oral reporting – such as body language and the emotional potency of various reflections.

Participants were interviewed at varying stages of their infant feeding journey (Table 2), and hence were either engaged in current or retrospective meaning making, implying different perceptual vantage points. As human memory is fallible, a possible consequence of this may have been ‘recall bias’, with the potential for participants reflecting on a longer time ago having a skewed memory of events (Althubaiti, 2016). However, the durability of women’s memories of childbirth and early feeding experiences has been noted (Li, Scanlon & Serdula, 2005; Takehara et al., 2014). Additionally, the different vantage points offered possibly enhances the utility of the findings; in addition to permitting access to the more ‘hot cognitions’ associated with current meaning making (Kret & Bocanegra, 2016), the varied participant time points provide a panoramic temporal perspective on how feeding events, and the associated emotional experiences, may unfold over time. This time-infused data potentially allows inductive inferences to be made about the feeding experience as it unfolds, representing a singular strength of the study.

I occupied a ‘non-expert’ position during the interviews, for I am not a mother, and this was something that I disclosed to participants. This revelation may have positively influenced how much information participants shared, as research indicates that individuals may be more likely to perceive greater anonymity with, and disclose personal truths to researchers/interviewers with a greater degree of perceived demographic dissimilarity (Oltmann, 2016). By not having much familiarity with infant feeding, I occupied a curious, almost naïve stance, which was highlighted when I asked in one early interview what colostrum was. It is possible that my naive positionality equalised the inherent power imbalance between the interviewer and the interviewee that is typically present in research and was perceived as less threatening to participants (Råheim, et al., 2016).

My position as a clinical psychologist and its potential impact on the research must also be acknowledged (Mercer, 2007). The interview topics were emotive for many of the mothers, and when they became upset, it was a challenge not to convert to ‘therapist mode’. Upon listening back to some of the interviews, I recognise that at times my listening may have been a little ‘active’ or supportive. This represents a possible permeation of the interview boundaries, potentially influencing participant disclosure (Oltman, 2016). However, rapport and empathic engagement with participants is acknowledged as an *ethical* ingredient in research encounters involving

sensitive/emotive topics (Elmir, 2011). The ethical implications of participants' emotional experience of disclosing things for the first time were mitigated by the debriefing process and provision of information about sources of support (Appendix X).

Analysis and general research quality

In line with the recommendations of Smith et al. (2009) regarding quality and rigour in IPA studies, this study adhered to Elliot et al.'s (1999) guidelines for quality assurance in qualitative research. Various measures were taken to ensure the rigour and quality of the study. These are outlined in Table 4, below.

Table 4 . Quality measures undertaken in the research process (informed by Elliot et al., 1999).

Quality Guideline	Measures taken to implement guideline
1. Owning one's perspective	Various reflexive measures were taken throughout the research process. I cultivated a mindful awareness of my own context, position, personal narratives and value framework, and how this may have shaped and interacted with the research. A reflexive journal was kept throughout the thesis and I engaged in various reflexive conversations and activities in order to identify any preconceived ideas and biases I held in relation to the research. A reflexive statement was provided, which outlines my context and epistemological stance.
2. Situating the Sample	The demographics of the sample as a whole are described, while still preserving participant anonymity. Detailed pen portraits of participants provide further context and allow the reader to evaluate who the research findings may be relevant to.
3. Grounding in examples	In all stages of analysis, as evidenced by the audit trail, themes have been substantiated by verbatim quotes from participants. Examples of all of the analysis stages are included in the appendices for additional transparency, allowing readers to make their own conceptualisations of the data and evaluate the fit between the data and my interpretation of it.
4. Providing credibility checks	My thesis supervisors, external IPA supervisor and fellow IPA peer researchers have all provided quality checks for the project. The transcripts and the output from various stages of analysis were shared with all supervisors. IPA peers were conferred with during the development of themes. The theme frequency table means readers may see clearly which participants have contributed to each theme. This can then be considered in the context of participants' pen portraits.

5. Coherence

The structure of the data is organised into final superordinate themes and subthemes for the group and presented in both table and figure format, which forms a coherent narrative relating to the phenomena under investigation. The process of analysis is also described coherently and presented in the appendices so that the reader can follow the thematic development from the initial emergent themes to final group themes.

6. Accomplishing general vs. specific research tasks

As the research was interested in specific, defined phenomena, it was studied, defined and described comprehensibly. The generisability of findings are presented in this chapter; it is evaluated when themes may be generalisable to mothers more generally, and when the exclusively Down syndrome. It is also considered when themes may relate specifically to the experience of feeding a baby with Down syndrome. The limitations of the findings are outlined in the discussion.

7. Resonation with readers

Taking the adherence of guidelines 1-6 into account, it is hoped that the findings will be presented in a way that resonates with readers and results in their understanding of the subject matter/ phenomena being expanded in a meaningful way.

As discussed previously, it is inevitable that this thesis will have been shaped by my own context, biases and assumptions. It is hoped that the above steps and various reflexive measures, as outlined in the methodology, will ensure the transparency of the analysis and allow the reader to draw similar conclusions from the results.

Implications for future research

While this study made a novel contribution to the research base, the findings have also illuminated areas warranting further research focus. It is difficult to draw absolute conclusions from the current findings, due to the scant existence of previous research and comparison points. Consequently, the results have mostly been compared to research carried out with mothers of premature infants. As such there is a patent need for the establishment of a robust, evidence base relating to the phenomenon under investigation here in the context of Down syndrome, which in turn could inform and guide practice. Below are suggestions for future empirical investigation.

The current study has accentuated the need for more qualitative research into the phenomenology of infant feeding experiences with this group of mothers. Additional qualitative investigation to confirm or refute the findings of this study is necessary. It

would also be informative for this study to be replicated with more homogenous samples, in terms of feeding method, to establish whether divergent themes/clinical needs are identified between feeding methods. Quantitative inquiry into maternal wellbeing with a larger sample would enhance the potential for generalisability.

There is also a need for longitudinal investigation of the perceived impacts of feeding difficulties. Poppy's story, for example, represents an interesting case for longitudinal investigation; she referred to her maternal identity as still being fluid and forming at the time of the interview, and her baby had only recently progressed from an extended period of tube-feeding to bottle feeding, with associated positive impacts upon her wellbeing. Longitudinal enquiry into Poppy's experiences could have the potential to evaluate the development of the maternal-infant relationship at intervals across time, and provide useful insight into the longitudinal interfaces between feeding, the developing mother-infant relationship and maternal wellbeing.

The majority of the literature on the interplays between maternal identity formation and infant feeding in intensive care units focuses on the experiences of mothers of preterm infants. Given the weight that Poppy assigned to being more involved with tube feeding in terms of restoring her maternal identity, there is a need for further research to evaluate tube feeding and maternal identity in the context of Down syndrome specifically.

As proposed above, CFT represents a psychological conceptual framework within which difficult maternal feeding experiences could be formulated and understood. The suitability of a CFT framework was only observed after the analysis. Future research with a specific CFT focus and research questions could more explicitly tap into the domains of CFT, meaning more precise implications for feeding-specific, compassion-focused intervention development. In future research, administering the self-compassion scale (Neff, 2003) or the self-attacking/self-soothing scale (Gilbert et al., 2004) could have established participants' current levels of self-criticism, indicating whether patterns of self-criticism are persistent or were particularly activated during the stress of their infant feeding experience. This could have clinical utility in terms of the development of compassion focused, feeding-specific, postnatal interventions.

Fathers can also report a diminished sense of control, heightened distress and hyperarousal and during the placement of a new-born in an NICU (Lefkowitz, Baxt & Evans, 2010). Again, there is scarce research on fathers' NICU experiences when the infant has Down syndrome. These fathers represent a potentially vulnerable group; it would be important for future research to establish any unmet needs for fathers, and to enhance clinical understanding of their experiences of infant feeding. The formula feeding mothers spoke about feeding becoming a bonding opportunity for fathers and facilitating the development of a paternal feeding bond. There is a need for future qualitative research to investigate the meanings that fathers assign to bottle-feeding in the context of the developing relationship with their infant with Down syndrome. The results of such research exploration represent potentially valuable information for parents, clinicians and Down syndrome services alike.

The significance incorporating healthcare practitioners' views into research on healthcare intervention development is long established (See: Hudelson et al., 2008). While some studies have investigated healthcare professionals perspectives on how better to support mothers and the development of the mother-infant relationship in NICUs (e.g. Fleury, Parpinelli & Makuch, 2014), again this focused on the needs of mothers of preterm infants. Future qualitative research should focus on gleaning perspectives from HCPs with regards to their perceptions of the feeding and bonding needs of this population, and their views on any current barriers to care. This could provide illuminating information for commissioners and service development.

Conclusion

The present study answered an urgent call for further empirical investigation into the infant feeding experiences of mothers of infants with Down syndrome (e.g. Sooben, 2015; Cartwright & Boath, 2018). This qualitative study appears to be the first of its kind, and makes a singular contribution to the research base through the collection of meaningful data regarding mothers' experiences of feeding and bonding with their baby with Down syndrome, and perspectives on their personal wellbeing during this period. An IPA approach has enabled the emergence of nuanced understanding of the dimensions of these mothers' feeding stories and it is hoped that the interpretation of the interviews affords a voice to the experiences of these mothers. The findings

indicate that feeding an infant with Down syndrome can be a multifaced emotional experience and that infant feeding practices and emotional wellbeing have a reciprocal interaction, which has relevance for clinical practice and potential policy development.

The findings from this study are by no means conclusive, as qualitative inquiry into the feeding and bonding experiences of mothers of infants with Down syndrome is in its infancy. Due to the dearth of literature in the area, the results were often compared to existing research on maternal experiences of feeding and bonding with preterm babies. Accordingly, there is a need for a distinct literature base relating to Down syndrome to be established. This study provides a platform for future research to continue to secure a greater understanding of the interfaces between infant feeding, maternal wellbeing and the mother-infant relationship in the context of Down syndrome.

Final reflections

I attached myself to this thesis due to an interest in ‘disability’ research and womens’ experiences. However, I think initially I felt a little fraudulent carrying out research exploring infant feeding, an area that previously held little personal interest, and resultantly perhaps felt a little bit disengaged from the project at times towards the start. However, I am aware that throughout the research process my relationship with this study has changed; so too has my connection with the subject matter. I’ve come to a greater understanding of the fundamental and almost inarticulable weight assigned to infant feeding, and how feeding experiences can be deeply tied with maternal wellbeing and womens’ constructions of themselves as mothers. Upon concluding this research, I regard that I have been afforded a more attuned awareness of the intricate permeations of infant feeding with sense of self. I imagine this awareness is something I will carry forward in my practice as a clinical psychologist, and potentially in my own conscious awareness if I become a mother.

After my initial immersion in the literature, I began this research expecting to encounter maternal narratives of difficulty and anticipated that mothers would recount that any challenging feeding experiences impacted upon the initial shaping of the

mother-infant relationship. Reflecting back now, I am surprised at how infused with pessimism this perspective is and how differently I would position myself now. To speak with candour, I think I was surprised to hear that feeding difficulties did not impact upon any mother's bond with her child, and I am left with the slightly unpalatable query of whether, at some subliminal level, I too had been influenced by some of the narratives I encountered in the literature around feeding and bonding in the context of infant 'disability'. Reflecting on this again now has prompting musing about how expectant or new mothers of infants with Down syndrome might process and assimilate the same information that shaped my initial views. This has further crystallised my belief that further empirical exploration of these mothers' experience is greatly needed, so that women can be provided with balanced and realistic information about feeding and the mother-infant relationship in the context of Down syndrome.

A closing return to the concept of researcher positioning is pertinent. I am aware that my experiences during clinical training influenced the psychological lens I applied to interpret the data. By chance, I have been on two CFT placements during training, and I regard CFT as the model that I am most confident working within. I recognise that my familiarity with the model will undoubtedly have influenced my application of this framework to the results. There was some momentary discomfort about the shift from mostly considering ideas from social constructionism in the thesis, to considering a model with an evolutionary underpinning. However, uncovering the increasing bid for the recognition of the compatibility of these two paradigms, eased this discomfort. Additionally, the discovery of 'evolutionary social constructionism' has provided me with some novel ways of conceptualising emotion.

While there is far still to come in terms of the development of supports that appropriately meet the needs of these mothers, I feel optimistic that the continued application of research focus in this area will pave the way for greater understanding of maternal experiences, contribute to the development of enhanced supports and facilitate the constructions of more balanced narratives around feeding an infant with Down syndrome. While acknowledging the enduring difficulty of Abbie's feeding-related anxieties and the likelihood that other mothers may experience similar

difficulty and need tailored supports, I would like to conclude this thesis on a note of hope. After the subsiding of initial feeding anxieties and uncertainty, the majority of the mothers recounted positive and meaningful stories of feeding and bonding with their infant. I think it is important to continue to de-pathologise and normalise infant feeding and bonding in the context of Down syndrome. I leave the reader with this quote from Enid, and hope that mothers and practitioners alike may find it helpful to hold this in mind:

“Maybe what some people need to remember about Down’s children with feeding, and with all aspects of them, is that they’re just a little person. I know it can be very different, but it can also be a very positive story.”

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APPENDICES

Appendix I: Participant Information Sheet



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Participant Information Sheet

Introduction

Hello, My name is Ríon O’Farrell-Walsh, as part of my clinical psychology doctoral training at the University of Leeds, I am carrying out a research project exploring the infant feeding experiences of mothers of children with Down syndrome.

Before deciding whether you would like to take part, please take the time to read this information sheet, which outlines why this research is being undertaken and what taking part would involve. If you would like anything clarified please feel free to contact me at any stage - my contact details are provided at the end of this sheet.

What is the purpose of this research study?

The aim of this study is gain an in-depth understanding of the infant feeding experiences of mums of children with Down syndrome. Mums of Down syndrome have varied feeding experiences and babies with Down syndrome are fed in different ways, so we are interested in hearing about all methods of feeding. The study hopes to explore Mums' reflections on their experiences of feeding their child when they were an infant. The study also hopes to explore mothers' perceptions of bonding with their baby during the feeding period and their reflections on their wellbeing during this time. Currently, there is not much research that investigates the emotional aspects of feeding a baby with Down syndrome or the potential difficulties that mums face during this time. It is hoped that this study, which aims to emphasise the voices of mums of children with Down syndrome, will facilitate improved understanding of mums' experiences and enable the development of future postnatal supports.

Why have I been invited to take part?

You have been identified as a potentially participant for this research because you are a mother of a child with Down syndrome under the age of 3 years, whose contact details are registered with a Down Syndrome Support group within the West Yorkshire region.

What will taking part involve for me?

If you decide to take part in this study, you will be asked to meet with me (Ríon) to take part in an interview that will last approximately between 60 and 90 minutes. The length of the interview will vary depending on how much information you feel like sharing. The interview can take place either at your home or a pre-booked room in the University of Leeds. If you decide to come to the university, you will be reimbursed for any travel expenses.

During the interview you will be asked to share your personal experiences and reflections on your experiences of feeding your child when they were an infant, how your relationship with your child developed during this time and your perceptions of how you were feeling during this period. There are no right and wrong answers and you will be welcome to decline to answer any question that you do not feel comfortable speaking about. With your consent, the interview will be recorded so that the researcher will be able to refer back the recording and will not be busy taking notes during the interview.

Will my participation be confidential?

Yes, your participation will be completely confidential. All of the data collected in this study will be anonymised (you will be assigned a pseudonym), so that those who took part cannot be recognised. The interviews will be recorded on an encrypted recording device and will also be stored on a computer network drive that is encrypted. After the research has been completed and the project written up, the recordings will be deleted.

Do I have to take part?

No, taking part in this study is completely voluntary and will not affect your position within the Down syndrome support group that you are associated with. You will be able to change your mind at any stage before or during the interview and ask to stop being a participant in the study. If you change your mind about participating after your interview has taken place, you will be able to request that your interview data be removed from the study. You do not have to provide a reason for withdrawing your participation. It will not be possible to remove your interview once all the interviews have been analysed and written up to submit as a thesis. However your interview data will be anonymous and I will ensure that your privacy will be protected.

If you are interested and decide that you would like to participate in this research, you will be asked to sign a consent form to indicate that you have given your consent to take part. The researcher will keep one copy of the consent form and you will be also be given a copy.

What are the possible risks and benefits for me if I take part in this study?

Risks: Taking part in this study will not put you in direct risk, however some people may find speaking about their personal experiences upsetting or uncomfortable. If you realise that you are finding the interview a difficult experience, we can stop the interview at any stage to take a break, or just stop altogether. After the interview, you will be provided with a list of options for support that you can contact if you think that you would benefit from speaking with someone about how you are feeling.

Benefits: While we cannot assure you outright that there will be any direct benefits from taking part in this study, sometimes people appreciate the opportunity to speak about their personal experiences. By sharing your story you will also be providing valuable information that will be beneficial in helping enhance our understanding of what it is like to feed an infant with Down syndrome. It is hoped the findings from this study will facilitate the development of better post-natal supports for mothers.

What will be done with the findings from this study?

The results from this research study will be written up as a thesis for part of the requirements of the Doctorate in Clinical Psychology, awarded by the University of Leeds. The research will also be presented at a thesis conference and it is intended that the findings will be published in a scientific journal. While direct quotes from your interview may appear in publication, you will not be identified in any of this and all participant quotes and information will remain anonymous. If you would like, we will gladly send you a summary of the research findings.

What if I have concerns?

If you have a concern about any aspect of this study, you can contact either Ríon or Dr . Louise Bryant who is the main project supervisor, they will strive to answer any queries you might have. If you are unsatisfied with their response and wish to express any concerns more formally, you can contact the University of Leeds clinical psychology department on: 0113 343 2732.

Who has reviewed the study?

This study has been approved by the University of Leeds Research Ethics Committee. The project reference number is MREC17-069

Expenses

As participation is voluntary, you will not receive payment for taking part, but any travel expenses will be reimbursed. In recognition of your time and input, we will invite you to make a £20 donation to the National Down Syndrome Association in your name, if you would like.

What do I do now?

If after consideration, you decide that you would like to participate in this study, please contact Ríon within *three weeks* of having received this information sheet. Her contact details are provided below. We are hoping to only recruit between 6-8 mums to take part in this study. This means that if there happens to be a large expression of interest and more than eight mothers would like to take part, the first eight mothers who confirm their interest in partaking will be selected for interview. If you contact Ríon after the first eight mothers have been selected, you

will be invited to leave your contact details with her so that she can contact you if any participants drop out.

Further information and contact details

Ríon O’Farrell –Walsh
Psychologist in Clinical Training
The University of Leeds Leeds
Institute of Health sciences
Level 10, The Worsley Building
Clarendon Way , Leeds, LS2 9NL
0113 343 2732
umrofw@leeds.ac.uk

The telephone number provided will put you through to the University of Leeds Clinical Psychology Administration Office - please leave a message for Ríon with your contact details and I will get back to you promptly.

This project is supervised by:

Dr. Louise Bryant
Associate Professor in Medical Psychology
Faculty of Medicine and Health
The University of Leeds
Leeds Institute of Health Sciences
Level 19, The Worsley Building
Clarendon Way
Leeds, LS2 9NL
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NE77TR
+44 (0)191 215 6115
roz.hadrill@northumbria.ac.uk

Appendix II: Abridged information about the project posted by support groups on their websites

Ríon O'Farrell-Walsh, a trainee clinical psychologist at the University of Leeds, is completing her doctoral thesis on the infant feeding experiences of mums with children with Down syndrome. She is interested in exploring mums' feeding experiences and their reflections on their well-being during this period. At present, there is not much research that explores maternal feeding experiences. Ríon is hoping that her study will bridge this gap, and facilitate a greater understanding of mums' experiences. She would like to invite any mums who have a child with Down syndrome between 0-3 years to take part in the study.

Taking part involves participating in an interview with Ríon, in a location that best works for you. The interviews usually last around 50-60 minutes. As infants with Down syndrome can be fed in lots of different ways, she is interested in hearing about any feeding method.

Anyone interested is welcome to contact Ríon at umrofw@leeds.ac.uk or on [xxxxxxx](tel:xxxxxxx) for further information.

Thank you!

Appendix III: Interview Schedule



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Introductions

- **Setting the Scene** *“Thank you again for volunteering to take part in this research. When we sent the invitation for you to take part in this interview, we also sent an information sheet and consent form. Do you have any questions about those?”*
- **Outline research aims** – Ask participant if they have any questions about the purpose of the study.
- **Remind mother of her right to withdraw** – explain that she has the right to stop the interview at any point, and is able to withdraw from the interview without the need for explanation. Remind mother she can remove her interview data from the study up until the stage of final analysis.
- **Explain confidentiality and its limits (risk)** - Explain to participant that her participation will be strictly confidential, except in the event of any risk concerns:
 - *“Your participation in this study will be confidential, the only exception to this is if you tell me something that makes me concerned that you or someone in your life are at risk. In this case I would have a duty of care for safeguarding and will be obliged to pass this information on to the appropriate supportive authorities, in order to ensure your safety. Do you have any questions about this?”*
- **Participant to complete consent form**
- **Any questions?**

Potential prompts and probing questions to hold in mind before starting

- I just want to make sure I understand your experience fully - Can you tell me more about what that felt like?

- How did you make sense of/understand that experience?
- Could you please tell me what you were thinking during this time?
- Can you reflect upon how that made you feel/ What impact has that had for you/
- How have you come to understand or think about that now?
- What stands out for you in your memory about that?

Semi structured interview questions

- **Opening spiel:** *“I am interested in all aspects of your experiences of feeding and bonding with your child when they were a baby, and how you were doing personally during this time. The aim of this interview is for me to get an in-depth understanding of your experience, so I’m interested in exploring your thoughts, feelings, reflections and perceptions about this time in your life. There are no right or wrong answers, so please feel free to give me as much detail as you feel comfortable sharing.”*

Warm-up question

I’d love to hear more about [child’s name]. Could you tell me a little bit about them?

Core Questions

Infant feeding

Could I ask you to reflect on your memories of what it was like to feed [Child’s name] as a newborn baby?

Possible Prompts

- Did you receive any support/ guidance around feeding your baby? (What was your experience of this?)

The mother-infant relationship (bonding)

Can you please describe what it was like getting to know [child’s name] when feeding them as a baby?

Possible prompts

- How do you think about your relationship with your baby in the context of your infant feeding experiences?

Maternal wellbeing

Could you tell me about any thoughts and emotions you remember experiencing when feeding [Child's name]?

Possible prompts

- How did you personally feel during this time?
- (If difficult experience) Have you ever experienced emotionally difficult periods in your life before?
- Did you experience any changes in your emotions as you continued on your feeding journey?

Present musings

- What are your thoughts now/today after having reflected back on your early experiences of feeding & bonding with [child's name]

Ending the interview

- Is there anything else important to your experience that we have not spoken about?
Or
- Is there anything I haven't asked you that you wished I had?

Debriefing

- How are you feeling after our conversation?
- Discuss with participant the support that is available if needed:
- *“If this interview has brought up anything that you weren't expecting or you think it might be helpful for you to speak to someone else about things we have discussed, I have some information about sources of support.”* [Give debrief information sheet, and explain self-referral pathway to counselling support if needed]

- Thank participant for their time.
- Remind participant about what will happen to their data and the results from the study.
- Invite participant to contact you if they have any further questions about the study.

What to include in notes about my initial response to the interview:

- My reactions to the participant and their account of their experience
- My observations about aspects of the interview e.g. pauses, body language, participant demeanour, emotive segments etc.
- Questions that I wish I had asked, which could be included in subsequent interviews
- Phrasing or prompts that I perceive as being unhelpful, to be omitted from the next interview.

Appendix IV: Example of IPA analysis (steps 1-3)

Interview 8	Exploratory Comments	Emergent themes
<p>I: [baby's] okay, and did you have kind of any expectations around feeding or . . .</p> <p>P: no, not really. We knew he had, he was going to be Down's Syndrome. We found out pretty early umm, but that was it really. We knew we'd be in hospital, we- to be honest, we thought we'd be there a couple of weeks if his feeding would be fine, you know there wouldn't be much but like I say, he came-he was early umm, 35 weeks and 2 days, so he was quite early. [; yeah] Umm, which meant just general things hadn't developed as well as they should've anyway. But obviously coming out early didn't help to that. And to be honest, his feeding was more of an issue because of his breathing. When he was feeding, he was de-saturating quite a lot. So he was needing more oxygen, so that's why we had to tube feed him. But like at first we couldn't do anything. So when we was going we just sat there because we couldn't feed him because we didn't know how to do it, you know we didn't know how to give him a tube feed, so we was just sat there watching. So it's a lot better now, as parents</p>	<p><u>Prenatal diagnosis of DS</u></p> <p>Expectation that baby would spend time in hospital, but not this extended period – preparedness for extended staying in hospital unpreparedness for feeding difficulties.</p> <p>Baby came early -I wonder if there is any impact of this on maternal readiness, and development of maternal identity?</p> <p>Struck by the stress of having to watch your newborn desaturate, especially as a first-time mum</p> <p>'we just sat there' Didn't know what to do as parents. Impact of feeding difficulties on parental roles – almost a sense here of them feeling superfluous.</p> <p>Haven't been instructed how to tube feed? Why? Sense of them being excluded before they were taught how to tube feed</p> <p>It feels better as parents to know how to tube feed – more involved, no longer sitting and observing others care for our child. A sense of relief inherent in this, and greater autonomy for them as parents perhaps?</p>	<p>Expectations vs. reality</p> <p>Unpreparedness</p> <p>'we just sat there': feeling superfluous</p> <p>Involvement in tube-feeding enhancing parental status</p>
<p>I: okay. And what was that like for you as [baby's] mum at the beginning</p> <p>P: we didn't really, well I know me, I'm not sure about dad, but I just felt like he wasn't mine because I couldn't, you know I couldn't do anything. Especially cos I wasn't breast-feeding, you know I thought at least if I, if I could do it then it would be- but no, we couldn't do anything. So we were sat there and I did feel a bit like I wasn't his mum and that, you know. It was quite, and we had same nurse quite a lot so it was more like it was, he was hers, rather than mine cause she</p>	<p>maternal identity impacted by not being involved in baby's care – almost a sense of her feeling disconnected from her maternal identity</p> <p>'I couldn't do anything. Sense of her feeling useless or redundant, almost surplus maybe?</p> <p>Regarding BF as linked with maternal identity/maternal role or enhancing the relationship -added pressure inherent in this belief. Why did this perspective come from?</p>	<p>Disconnection from maternal identity</p> <p>breastfeeding as integral to maternal identity</p> <p>Feelings of uselessness</p> <p>"I felt like I wasn't his mum": undermined</p>

<p>was doing all the feeding and, and stuff</p> <p>I: would you feel comfortable if I asked you a little bit more about, about this . . .</p> <p>P: yeah, that's fine</p> <p>I: . . . one thing I'm looking at in my study is, yeah, maternal feeding experiences. But I'm also interested in looking at like how mums develop their relationship with their baby. And I know you mentioned there that you didn't really feel like [baby] was yours at the beginning. Can I ask how you were kind of I guess understanding your relationship that at the time?</p> <p>P: so, it was quite hard, cause I had an emergency section, so for the first couple of days I didn't see him [I:yeah] Um, and then when I finally did go down he was in an incubator with loads of phototherapy lights. So still, I didn't really get to touch him or, you know like you would if he was at home. And then I was slow- we were slowly bringing him out but it was for maybe five or ten minutes and then he was going back. So we got a little bond but there was nothing like you would if he was at home. And then slowly over time obviously he's got better and he's come out of his incubator; he's in a cot and he's in a big-boy cot now. So we have a lot more interaction which is nice. He's got a little side-room, so it is like being in the front room although there's just nurses and monitors and stuff. So it's a lot, it's a lot nicer than what it was. And it was horrible at first, like I say, it just felt like we was going to visit one of the nurse's, one of the nurse's babies and then coming home. So it has been hard, but I think it's just adapting to it all now, and as much as we don't want him to be there we know he has</p>	<p>didn't feel like his mum when not involved in his care- something fundamental here. Regarding nurse as fulfilling the maternal role because she was involved in the feeding. Appears she is viewing as feeding as integral to maternal role, with her identity compromised when not involved</p> <p>"and stuff" – this utterance almost seems to neutralise or minimise the emotive element of the above passage, a sense of dejection in this</p> <p>Difficulty of M-I separation, isolation from her baby. Deprived of touch with baby when he was in the incubator. A sense of perceived <u>barriers</u> between then, the intrusion of the incubator.</p> <p>Perceiving the differences inherent in her hospital experience</p> <p>Incremental periods of time with baby, a sense of this being controlled and monitored by others. Almost a lack of autonomy as a mother, with the defined limits on the amount of time together</p> <p>'a little bond': regarding that the developing bond was not as deep as if it had been at home gradual element to developing bond increased interaction/touch important for relationship</p> <p>The impact of separation and extended stay in hospital on parental identity- perceptions of others in maternal role during separation. The poignancy of this – their isolation from their infant feels</p> <p>Hospital has been hard - word 'horrible'</p>	<p>identity</p> <p>Perceiving other in maternal role when not feeding</p> <p>Difficulty of M-I separation</p> <p>incremental development of bond</p> <p>Interaction feels important for relationship</p> <p>Perceiving others in maternal role during separation</p> <p>Accepting the situation</p>
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<p>to be there because that's the best place for him</p> <p>oh, it sounds like you guys have had a bit of a journey over the past eight weeks</p> <p>P: yeah, definitely</p> <p>I: and you mentioned there [participant] that feeling of him not really feeling like he was yours. Is there anything that has kinda changed in that feeling or does it still feel like . . .</p> <p>P: no. It feels like he's mine now. Now, now, I can hold him and do what I want with him. Before we was always having to ask the nurses if we could, you know, get him out or if we could do this. But now the nurses are a lot more flexible because he's been there so long and they know that we can, you know we've been trained to do like the NG feeding and stuff now so...</p> <p>and how important has that been to you?</p> <p>P: really important, that we can actually get hands-on and do his personal cares and feed him and just the things you would do at home and probably take for granted: going and get a bottle out of the fridge, you know. We have to walk round the unit to find the milk and the bottle rather than just walk into the kitchen and putting the milk into the bottle</p>	<p>illuminating the extent of this Accepting that hospital is the best place for baby</p> <p>Autonomous mothering with touch and access to baby important for maternal identity – sense of a cemented maternal identity now</p> <p><i>'I can do what I want' – ownership of maternal role now</i></p> <p><i>'having to ask' indicating the extent to which access to baby was monitored, dependent on others.</i></p> <p>Nurses and parents becoming used to each other during extended stay – greater flexibility trained to be involved in baby's care – increased trust from hospital staff?</p> <p>The importance of hands on involvement in baby's care for relationship - contributing to sustaining her emerging maternal identity? Elements of care become more prized/important - there is a sense of regained control here, and of things feeling normalized due to their increased involvement in baby's care</p>	<p>Autonomous mothering enhancing maternal identity</p> <p>Increased ownership of maternal role</p> <p>Regaining control through autonomous parenting</p> <p>Feeding allowing feelings of normalcy</p>
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Appendix V: Example of IPA analysis steps (4-5)

Superordinate themes and subthemes	Quotes or key words and page numbers
<p>Psychological impacts of breastfeeding difficulties</p> <p>Low mood</p> <p>Self-propelled guilt</p> <p>Motherhood overshadowed by BF</p> <p>Difficulties Perceived abnormality and deficiency</p> <p>Emotional disturbance/distress</p>	<p><i>If there was any time, in any way in my life a point where I felt close to depression (p.4)</i></p> <p><i>I think you know, I kind of drove myself to guilt (p.7)</i></p> <p><i>being a mum, is a really lovely, lovely thing. But that was something that was kind of overshadowing it (P.6)</i></p> <p><i>I thought that my breasts were wrong, that there was something wrong with them (p.4)</i></p> <p><i>Definitely more emotionally, you know, disturbing than anything else (p.5)</i></p>
<p>“You want to go the extra mile”: Increased determination in context of DS</p> <p>Renewed devotion to BF after diagnosis</p> <p>Persevering despite negative narratives</p> <p>Revived determination in face of low expectations(robustness)</p> <p>Determination</p> <p>Assigning new import to BF in context of DS</p>	<p><i>I think it kind of clicked in my head, you know, “I’m going to try”. I’m going to try to do it for him. (p.3)</i></p> <p><i>I thought, no. you know, despite this I’m going to try. I’m going to see how it’s going to work (p.4)</i></p> <p><i>I was very, very determined... I’m going to give it a try... I’m so nearly 100% sure that it’s not going to work (p.7)</i></p> <p><i>it was this feeling that you want to go the extra mile (p.7)</i></p> <p><i>... make a bit more effort because it might be more important for him (p.7)</i></p> <p><i>If there’s anything extra that you can do, to help him grow better, develop better. You just want to do it (p.9)</i></p>
<p>Stability through feeding</p> <p>Feeding feels regulating</p> <p>Stability through feeding</p>	<p><i>Everything [mimes slowing down]...it’s a very nice side of breastfeeding, it’s that kind of the rhythm (P.13)</i></p> <p><i>It brings some sort of solidity and you fit it into your daily routine (p.10)</i></p>

<p>BF as locus of day</p>	<p><i>It was the heart of our routine, the heart of our day (p.10)</i></p>
<p>BF as a vehicle for coping and normalcy</p> <p>Feeling of normalcy</p> <p>BF diluting difficulties</p> <p>Enhanced coping with difficulties</p>	<p><i>just doing things that every mother and every child are doing, like breastfeeding....it shifts your mind away from those worries and you just see the baby as he is, it's a baby (p12)</i></p> <p><i>Because the feeding experience was so positive, it was kind of taking me away from the disability worry</i></p>
<p>Positive Self-to-self relating</p> <p>Positive self-concept</p> <p>'I'm doing the right thing': self-assurance</p> <p>Positive self-talk</p>	<p><i>I felt very good about myself (p.18)</i></p> <p><i>I'm doing the right thing (p.19)</i></p> <p><i>I can't remember any thoughts apart from "I'm feeling good"...and "I'm feeling good about it, it's working really good." (P.19)</i></p>
<p>Failing to fulfilled: Enriched maternal identity</p> <p>Perceived failure</p> <p>Feeling like I couldn't fulfil my maternal duty (shame?)</p> <p>Feeling deficient</p> <p>Feeling positive about motherhood</p> <p>I'm no longer failing - achievement</p> <p>Maternal pride</p> <p>Fulfilment</p>	<p><i>A feeling of failure I think. Yes, you know, failing the baby as a mother you know (p.6)</i></p> <p><i>Not being able to you know, fulfil your duty as a mother, because that's how it feels (p.6)</i></p> <p><i>Not doing something right, not knowing what to do (p.6)</i></p> <p><i>Um very positive, very positive (p.11)</i></p> <p><i>I was failing before but I'm doing very well now (P.11)</i></p> <p><i>Very proud as well (p.10)</i></p> <p><i>The breastfeeding times were very proud moments (p.18)</i></p> <p><i>I'm kind of a fulfilled mum, and I feel good about it. (p.18)</i></p>
<p>It's the closest that it can get': BF as intensifying the M-I bond</p> <p>BF contributing to developing bond</p> <p>Baby as extension of self during feeding</p>	<p><i>I think that the feeding experience is possibly part of that [bond] (p.12)</i></p> <p><i>[he's] part of me and that we'll always be together. So that's the closest that it can get,</i></p>

<p>BF extending pregnancy bond?</p> <p>Feels like bond is intensified during BF</p> <p>Feeding felt important for bond</p> <p>BF was a bonding experience</p> <p>perceiving baby's love and trust during BF</p> <p>Awareness of positive bond during BF</p>	<p><i>when you breastfeed p.17</i></p> <p><i>It's a togetherness and closeness and almost like he's right back inside you (p.16)</i></p> <p><i>Whether its love or bond or closeness, or whatever you want to call it. It's overwhelming you know, during the breastfeeding (P.16)</i></p> <p><i>And it's very clear, you know, that you've got a child and you love this child. It's a togetherness and closeness (p.16)</i></p> <p><i>It was a very bonding experience (p.4)</i></p> <p><i>The moment where you're breast feeding and you see them looking up with total trust and loving in their cute baby eyes, it's beautiful, it's absolutely priceless (p.9)</i></p> <p><i>You're feeding the baby and there is a loving bond, you know there is all positives (p.12)</i></p>
<p>The pleasurable dyadic exclusivity of Breastfeeding</p> <p>Maternal exclusivity of BF: ownership</p> <p>dyadic learning</p> <p>Dyadic intimacy</p> <p>BF as protected time for M-I interaction</p>	<p><i>He was more mine than anybody else's up until thenBut with the breastfeeding it has to be yourself (p.13)</i></p> <p><i>you're sort of learning, you see, from each other (p.10)</i></p> <p><i>It's a very intimate moment, a very private moment. It's very mummy-baby moments (p.10)</i></p> <p><i>So even if you're super busy, whatever you're doing you have to leave it. This is the moment when the baby is hungry, you have to do it. (p.13)</i></p>

Appendix VI: Evidence of ethical approval

The Secretariat
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Leeds, LS2 9JT
T: +44 (0) 113 343 1642
Email: FMHUniethics@leeds.ac.uk



School of Medicine Research Ethics Committee (SoMREC)

Rion O'Farrell Walsh
Psychologist in Clinical Training
Leeds Institute of Health Sciences
Faculty of Medicine and Health
Clinical Psychology
Level 10, Worsley Building
Clarendon Way
University of Leeds
LEEDS LS2 9NL

09 July 2018

Dear Rion

Ref no: **MREC 17-069**

Title: An exploration of infant feeding, the mother-infant relationship and maternal wellbeing in mothers of infants with Down syndrome

Your research application has been reviewed by the School of Medicine Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documentation received from you and listed below.

Document	Version	Date Submitted
MREC17-069 SoMREC ethics application V2.0 14.05.18	2.0	14/05/2018
MREC17-069 Evidence of Support From Bradford Support group	1.0	14/05/2018
MREC17-069 Evidence of Support From Phoenix Centre	1.0	14/05/2018
MREC17-069 Evidence of support from Sunshine and Smiles	1.0	14/05/2018
MREC17-069 Fieldwork_Assessment_Form_low_risk V2.0 14.05.18	2.0	14/05/2018
MREC17-069 Information sheet V2.0 14.05.18	2.0	14/05/2018
MREC17-069 Participant Consent Form V2.0 14.05.18	2.0	14/05/2018
Debriefing Information Sheet	1.0	01/03/2018
Interview Guide	1.0	01/03/2018
Participant invitation Letter	1.0	01/03/2018
Research Protocol	1.0	01/03/2018

Please notify the committee if you intend to make any amendments to the original research ethics application or documentation. All changes must receive ethics approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhuniethics@leeds.ac.uk)

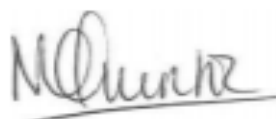
Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, any risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

We wish you every success with the project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Naomi Quinton', written over a horizontal line.

Dr Naomi Quinton
Chair, School of Medicine Research Ethics Committee
University of Leeds

(Approval granted by Dr Naomi Quinton on behalf of SoMREC Co-Chairs)



Participant Consent Form

(v2.0 06-05-2018)

Research project title: *An exploration of infant feeding, the mother-infant relationship and maternal wellbeing in mothers of infants with Down syndrome*

Name of researcher: Ríon O’Farrell-Walsh

Participant Identification Number: _____

Please tick the boxes beside each statement

1. I confirm that I have read and understood the information sheet which outlined the above study.
2. I had the opportunity to consider the project and to ask any questions I had about the project or about what taking part involves.
3. I realise that my participation is completely voluntary and that I can withdraw from the interview at any stage without giving a reason. I realise that I can withdraw my interview data from the study after the interview takes place, but not once it has been written up.
4. I understand that my responses in the study will be anonymous and that the interview data will be securely stored.
5. I understand that my responses will be kept strictly confidential, but that if the researcher thinks that there is a current risk of harm to myself or others, this concern will be shared with relevant parties.
6. I understand that my interview data may be looked at by the researcher’s supervisors. I give permission for this access to my interview data.
7. I understand that direct quotes from my interview may be present in the final thesis and future journal articles. I understand that all quotes will be anonymised and there will be no identifying features in the data. I give permission for inclusion of my quotes.
8. I give permission for my interview to be audio- recorded.
9. I would like to be sent a summary of the research findings upon completion of the research project in 2019. To facilitate this I give my consent for the researcher to store my address until this time.

10. I agree to take part in this study.

Participant signature..... Investigator signature.....

Date.....

Risk protocol

If any mothers disclose any information that intimates that they are at risk of harming themselves, their baby or another person, the following risk protocol is to be followed (as explained to participants on consent form).

1. Explain to the mother why her remarks constitute a safeguarding concern.
2. Explain that it is your duty of care to inform the local crisis team – ensure the mother’s understanding of this.
3. Contact the local NHS crisis support service and the local NHS safeguarding team before parting company from the mother.
4. Provide mother with information around sources of support.
5. If there is a concern of **acute and immediate risk only**: also phone the police, use clinical judgement to deem if appropriate/safe to stay with mother, (remove self from vicinity if the mother poses a risk to me).
6. Phone thesis team immediately after concluding interview.

Appendix X: Debriefing information sheet



Debriefing Information Sheet

This study aimed to explore the feeding and bonding experiences of mothers of infants with Down Syndrome, as well as mothers' reflections on their personal wellbeing during the infant feeding period. I was interested in:

- What it was like to feed your child when they were an infant and any difficulties you may have had.
- Who supported you when you were feeding your baby.
- Your reflections on how you bonded with your baby and your perspectives on your relationship with your baby during the infant feeding period.
- Your reflections on the emotions and thoughts you experienced during this time.

You may have found speaking about your personal experiences upsetting or found that you have felt low after speaking with me. This is a normal and understandable reaction to discussing a sensitive topic and usually these feelings subside after a few days. However, if these feelings persist there are routes to accessing support that you might find useful.

Sources of comfort and help

- ***The Samaritans helpline*** - The Samaritans is a helpline staffed by trained volunteers and offers a safe space to talk anything that is troubling you. The helpline is open 24 hours a day for those who may need to talk. Their number is 116123 or email: www.samaritans.org
- ***The Down's Syndrome Association (DSA) Helpline*** - The DSA operate a helpline to provide information and support to the families of those with Down Syndrome and are able to talk through any concerns you may have relating to your child. The DSA helpline can be reached on 0333 1212 300 and is in operation from 10.00am – 4.00pm, Monday to Friday.
- ***The Phoenix Health and Wellbeing Centre (Leeds)*** - The Phoenix Health and Wellbeing Centre has affiliations with Sunshine and Smiles, the Leeds Down Syndrome support network. This service offers counselling support to anyone

who is struggling emotionally. The director of this service is aware of this research project and that participants may wish to speak to a counsellor after taking part. If you feel that you would benefit from speaking to a counsellor about how you are feeling, you can refer yourself to this service. Their number is: 0113 234 0818. Please quote the code SUN21 to receive support for free.

If you wish to contact me again about any aspect of the study, please feel free to do so. I can be contacted by email at: umrofw@leeds.ac.uk or by telephone on: 0113 343 2732. This will put you through to the University of Leeds Clinical Psychology Administration Office - please leave a message for me and I will get back to you promptly.

A very sincere thank you for making this research possible.

Appendix XI: Letter of support from counselling centre



9th May 2018

Dear Sir/Madam

I am writing to confirm that Phoenix Health and Wellbeing (Leeds), of which I am director, is aware of Ríon O' Farrell-Walsh's doctoral thesis.

We have given our consent for Ríon to direct participating mothers towards our counselling service, should they need follow-up support after partaking in the research interview.

Yours faithfully,

A handwritten signature in black ink, appearing to be "Gill Trevor", written over a light grey rectangular background.

Gill Trevor
Director