FEEDING INFANTS WITH DOWN’S SYNDROME: A QUALITATIVE STUDY OF MOTHERS’ EXPERIENCES

ABSTRACT

**Objective:** Breastfeeding may have general and specific advantages for both mothers and Infants with Down Syndrome (IDS). The experiences and needs of mothers of IDS have not previously been explored. This study explored mothers’ experiences of feeding infants with Down Syndrome. **Design:** Qualitative with data collection via focus groups. Interpretative phenomenological analysis was used to elicit the meanings participants attributed to their experiences **Participants:** eight mothers of infants with Down Syndrome participated in two focus groups. **Setting**: United Kingdom **Findings:** Five key themes emerged from the data:

1. Importance of feeding IDS
2. Guilt regarding feeding IDS
3. Health professionals were “Out of their depth”
4. Lack of recognition of difference of IDS and typical infants
5. Power and control of health professionals

**Key conclusions and implications for practice:** Best practice from existing literature and this study is suggested, alongside the need for future research.

Keywords: Down Syndrome, Trisomy 21, Breastfeeding, Bottle feeding, Infant feeding

INTRODUCTION

Although Down Syndrome (DS) is the most common chromosomal condition in infants (Sharman et al., 2007), only 775 families in the United Kingdom give birth to a child who has DS each year, 0.001% of the total number of births (Morris and Springett, 2014). Supporting mothers with feeding infants with Down Syndrome (IDS) is a rare occurrence for health professionals and those with the expertise in these uncommon circumstances are mainly parents with experiential knowledge (Gribble, 2001).

Individuals with Down Syndrome display a variety of features, including phenotypical appearance, learning disability and hypotonia (Silverman, 2007; Bull et al., 2011) and most often results from trisomy 21. IDS also have a higher risk than infants without the condition of cardiac and gastrointestinal defects, and cleft palate (Dennis et al., 2010; Källén et al., 1996).

The relevant literature on feeding IDS was searched in January 2015 and again in August 2015 using the electronic databases Pubmed, CINAHL, MIDIRS, Cochrane Library, NICE and Google Scholar. Key words and combinations of key words searched included Down Syndrome, Down's Syndrome, Trisomy 21, Breastfeeding, Infant Feeding and Bottle Feeding. This search highlighted the paucity of literature on the subject as summarised below.

Why breastfeeding matters

Infant feeding has short and long-term health impacts for both mothers and babies (Ip et al., 2007). The majority of research into parents' experiences of infant feeding have been conducted in populations with healthy term babies, or preterm and low birth weight babies (King and Jones, 2005; Lang, 2002).

Regarding IDS, Al Sarheed, (2005 p 85) stated that "*The protective effects of breastfeeding against illness and complications are so significant as to interpret breast feeding as medicine for such infants”.* Breastfeeding may have general and specific advantages for mothers of, and IDS (Flores-Lujano et al., 2009; Oliveira et al., 2010; Thomas et al., 2007) yet their experiences and needs have not previously been explored.

Gore et al. (2015) highlight the low breastfeeding rates in infants with intellectual disability, and the adverse impact this may have on health outcomes. Sooben’s 2015 paper further discusses the inequalities in health experienced by those with learning disabilities, and calls for more research to underpin and improve support for mothers of IDS.

Despite an extensive review of the literature using Pubmed, CINAHL, MIDIRS, Cochrane Library, NICE and Google Scholar, with no limitation on the timeframe or language, only three studies specifically addressing health outcomes associated with infant feeding in IDS were identified (Bloemers et al.,2007; Flores-Lujano et al.,2009; Oliveira et al., 2010).

Flores-Lujano and colleagues (2009) highlighted an increased risk of Acute Myeloid Leukaemia in childhood for IDS who are not breastfed. Bloemers et al (2007) similarly identified an increased risk of respiratory syncytial virus (RSV) in IDS if not breastfed, especially in the presence of risk factors such as socioeconomic deprivation, passive smoking and overcrowding. Finally, Oliveira et al., (2010) found that breastfeeding for less than 6 months was positively associated with malocclusion in IDS.

Only one paper by Lewis and Kritzinger (2004) specifically aimed to explore parents’ experiences with regards to feeding IDS. This describes symptoms such as hypotonia linked with slow sucking, poor lip seal, uncoordinated suck/swallow/breathe, aspiration, reflux, coughing and vomiting. However, no discussion is given regarding how these infants were fed.

Around half of live born IDS have congenital cardiac disease (Irvine and Chaudhari, 2012). Marino et al. (1995) found reduced cardiorespiratory stress in breastfed infants, compared to those taking feeds by bottle. Edwards and Spatz (2010) discuss the importance of breast milk feeding for babies requiring neonatal surgery and for babies requiring frequent, prolonged hospitalisation.

Prevalence of breastfeeding

In the UK, rates of breastfeeding initiation for IDS are lower than for healthy babies (Aumonier and Cunningham, 1983; Martin, 1978). This is not surprising given that only three papers were identified which aimed to offer evidence based guidance around feeding IDS. Ivan and Cromwell’s (2014, p107) guidance for primary care management of IDS states:

*“If the ability to suck or latch on is impaired, consider formula supplementation until a successful breastfeeding pattern is established”*

However, this statement is not evidenced and ignores the option of giving expressed breast milk, which the World Health Organisation (2003) recommends as the next best option for infant feeding and maintaining maternal milk supply.

The clearest clinical guideline is provided by Thomas et al. (2007) in the Association of Breastfeeding Medicine protocols for feeding the hypotonic infant. This paper states that feeding in infants with IDS has not been specifically studied and suggests future research needs around feeding hypotonic infants.

Current literature identified numerical data rather than the lived experiences of participants; the voice of the women is missing. Qualitative descriptions of parents’ experiences are absent from the academic literature, though internet forums, blogs and mother to mother support groups have a number of rich, detailed, personal accounts of feeding an IDS (Dempsey, 2013; Abianac, 2014).

The aim of this study was to explore the experiences of mothers of IDS regarding feeding, and to provide information to better inform health professionals caring for new mothers and their babies.

METHODOLOGY

Mothers of children with Down Syndrome were approached and recruited in 2015 by the first author through parent support groups via Facebook and email. Participants were a self-selected convenience sample and the demographic characteristics and shown in Table 1. All participants who chose to take part in the research participated in the focus groups. Two focus groups were carried out with a sample of eight mothers of IDS. Inclusion criteria were a child under the age of five years, born in the UK, and mothers who were fluent and literate in English. No one who volunteered for the study was excluded. Group data collection allows the most participants to share their thoughts, opinions and experiences.

Ethical approval

Ethical approval was obtained from Staffordshire University Research Ethics Committee. Written, informed consent was obtained from participants prior to data collection. Data was stored in a locked filling cabinet in a locked office. Audio files and transcripts and analysis were saved to a secure, password protected server.

Data collection

Two, one hour long focus groups were held, one in the West Midlands and one in the North West of England. Groups were held at a time and location suitable to the participants and a free crèche was provided for children. Focus groups were audio recorded and transcribed in full by the first author.

Data Analysis

Field notes, initial instinctive thematic analysis and researcher reflection were reviewed immediately after each focus group by the corresponding author. All participants in the focus group were given a pseudonym and any identifying features were removed prior to analysis.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Maternal characteristics |  |  | Infant characteristics |  |
| Ethnicity | 8 White British |  | Ethnicity | 7 white British1 mixed White British / Black |
| Age range at time of data collection | 29 to 44 years |  | Age range at time of data collection | 8 weeks to 3 years |
| Mean age at time of data collection | 35.5 years |  | Mean age at time of data collection | 18 months |
| Area of residence | West Midlands 6North West 2 |

Table 1 Demographics of participants

Interpretative phenomenological analysis (IPA) was used to explore how mothers perceived and explained specific experiences (Smith et al., 1999). Themes were compared and contrasted across full transcripts by the first author and a list of identified themes was produced. The second author independently read the transcripts and identified key themes. These were discussed until agreement was reached. Internal validity was also verified through cross checking the derived themes against the participants’ verbatim accounts. Participants were also given the opportunity to comment on the themes identified, a method of data validation through member checking (Birt et al., 2016) with all concurring that the themes reflected their experiences.

FINDINGS AND DISCUSSION

This is the first qualitative study to explore the experiences and decision making of mothers feeding IDS, using interpretative phenomenological analysis. Pseudonyms are used to ensure anonymity.

The five themes presented here attempt to explain the experiences of participants regarding decision making and care received during feeding their IDS. This is linked to the extant literature. To protect anonymity pseudonyms are used.

Five key themes emerged:

1. Importance of feeding IDS
2. Guilt regarding feeding IDS
3. Health professionals were “Out of their depth”
4. Lack of recognition of difference of IDS and typical infants
5. Power and control of health professionals

The impact of professionals on feeding choices is well documented (Dykes, 2006). In this study participants focused on interactions with health professionals as a more influential factor in feeding decisions than the possible impact of their infant’s condition.

*“Like if they hadn’t panicked me and panicked themselves about the weight gain then I probably would have breastfed”* (Hazel)

Importance of feeding

All the participants said how important breastfeeding felt to them and all planned to initiate feeding with breast milk.

*“I was a bit adamant about breastfeeding”* (Rachel)

The three mothers with an antenatal diagnosis of DS specifically sought out information around breastfeeding from specialists before their child was born.

*“So research antenatally felt like a really important proactive step to at least try to get some control over the situation, to try and almost prevent any problems*” (Jo)

Six mothers stated that they became ‘*obsessed with feeding’*, particularly those who had been given complex feeding plans, possibly including breastfeeding, expressing and using formula and quotes such as the following were typical:

*"Feeding was everything that was all I could think about, all I could focus on, because I knew how much of a struggle we were both having. And I knew that that was the only way he was going to survive, but also, he needed to gain weight so he could have his surgery." (Jo)*

 *“At home I spent about 6 weeks expressing milk, not getting much coming out, spending all my time with a pump attached to me, trying to get him to latch on.” (*Hazel)

All the women identified feeding was a lengthy, time consuming process, whether breastfeeding, expressing or bottle feeding.

*"It was a slow process, bottle feeding, with him … spent a long time bottle feeding, a lot longer than you’d expect. So it was feeding, feeding, feeding." (*Hazel)

For half of the mothers the demands of caring for and feeding an ill baby were overwhelming. Jo's baby was admitted to hospital at a couple of weeks old with heart failure.

*"And it was only at that stage, that after writing down every single wee and poo and feed for over two weeks, that I stopped writing things down, because I felt like a massive weight had been lifted from my shoulders that I was getting help." (*Jo)

The 2010 UK infant Feeding Survey (McAndrew et al., 2012) found the majority of mothers who stopped breastfeeding in the first few weeks did so due to perceived insufficient milk supply. Similarly, the mothers in this study who stopped breastfeeding earlier than planned found their milk supply to be insufficient to their infant's needs. Mothers reported needing to supplement with formula due to the high energy requirements of their infants who had congenital cardiac defects (Jackson and Poskttt, 1991).

All mothers in this study reported their infants were often sleepy and did not demonstrate feeding cues, which is not reported in the literature regarding typical infants.

*“She was more sleepy, more floppy, should I be waking her, how often should I be feeding her?”* (Hayley)

Guilt

Maternal guilt around formula feeding is reported by Lee and Furedi (2005) and Lee (2007). Even in the current study where formula was advised by health professionals, guilt was an overwhelming emotion for all the mothers.

*“You’ve got this guilt constantly that you’re not doing the right thing, you should be breastfeeding, and obviously he’s getting formula, so there’s so much guilt around*.” (Hazel)

The women all found feeding particularly exhausting and difficult, and got frustrated when the techniques suggested by health professionals did not appear to be working,

 *“I used to sit with it there on maximum trying to get out as much as I can, because there is this bit of guilt that I needed to give her more. And then obviously the more I was doing it the less was coming and the more formula I was giving”* (Steph)

*“It does irritate me a bit that it’s become an obsession with breast is best above everything, above your own sanity, and people made to feel so guilty.”* (Hazel)

Despite the personal time, exhaustion and pain associated with feeding difficulties, mothers all expressed concerned about if they were doing the right thing for their baby.

*“I was still adamant that I wanted to breastfeed him, but he was on a very calorie controlled diet so it was hard to be able to do the two. But he was also on a very fluid restricted diet. So I still don’t know now whether I did the right thing or whether I made his heart failure worse by persisting and trying as much as I could to allow him to have the experience and practice of sucking, whilst trying to minimise the amount of milk that he got from breastfeeding."* (Jo)

*“The internal struggle of like, is it the right thing to do to breastfeed him, because of all the benefits, or is it cruel to make him work for it and to tire him out?” (*Rachel)

This internal battle was described as ‘guilt inducing’ by all participants and there was a fear that they were letting their child down. Five mothers related this back to a lack of support and reassurance from the health professionals on whom they had come to rely.

Health professionals were “Out of their depth”

Despite increased implementation of general best practice in infant feeding across the UK (Demott et al., 2006), families continue to receive inconsistent care regarding infant feeding. Mothers in this study reported being pushed into bottle feeding with long terms feelings of guilt and doubt around what was in the best interest of the child. The main issues in this study were around assumptions by health professionals and the focus on the condition not on the mother / baby. Breastfeeding supporters are often portrayed as overriding the mother’s choice (White, 2013; Cannon, 2014; Faircloth, 2015). In this study breastfeeding was discounted as an option by health professionals in some cases, despite mothers fighting for weeks to make it happen.

Participants were dependant on health professionals for information, support and reassurance, especially if their baby had additional health needs. Mothers described asking for support, but not getting clear answers.

 *“I did have the breastfeeding specialist coming over, it was quite early on so I was trying to breastfeed and bottle feed. I think she felt maybe a bit out of her depth with the whole situation as well possibly, and so she pretty much said the same advice that they said at the hospital just keep doing a bit of everything sort of.”* (Hazel)

Colón et al. 2009 found a third of the mothers with IDS in their study received no support with infant feeding (n=8 mothers), and health professionals seemed unable to offer assistance with specific problems which may have been related to DS.

*“We did have the breastfeeding support woman come out and she was very lovely, and she did say “Oh, I can see he’s latched on really well, but not really sucking” but she offered no solutions.” (*Lily)

Colón et al. (2009) found 84% of mothers who discontinued breastfeeding stated sucking difficulties as the cause for cessation. The lack of skilled help around these issues for IDS caused frustration:

*"[Professionals are] Scared to give any advice in case it’s the wrong advice, and so they choose to give none." (*Hayley)

Four women spoke about their lack of knowledge, and the lack of information provided on feeding and comments such as the following were common:

*“And you think “Am I going to be able to breastfeed him?” Because he’s been in special care for so long, and he’s been tube fed all that time, and he’s not using his mouth, he’s not using any muscles straight away.”* (Jill)

*"… you don’t know what you’re supposed to be provided with, and most of the time my midwives and health visitors didn’t know either."* (Hayley)

One woman stopped taking her child to the health visitor clinic; even though this was a time she could gain support:

*“Because every time I saw someone [about feeding] it was always “It’s a concern, it’s a concern” but they wouldn’t do anything about the concern, they would just be like “We need to monitor it”. And I used to say to them “I don’t know what I need to do if it’s concerning them” and then I ended up not going, and I shut myself off.” (*Steph)

Six of the participants were advised by their health professionals to express milk for their babies, and three organisations even provided suitable breast pumps for these women. However, Lily found the person who provided the breast pump had not given her the correct advice on how to use the equipment.

*“And then about 4 or 5 weeks in I went to a local place, like a cake and breastfeeding place, and the woman looked at me, and I was probably in bits slightly, and said “How long is expressing taking?” and I told her, and she said “Why is it taking so long?”, and I said I was doing one side then the other, and she said “Why aren’t you doing both at the same time?”, and I was like “I can do both at the same time?! No one’s told me that!”.” (*Lily)

Two participants were however told to purchase their own expressing and feeding equipment by NHS trusts; of interest, these were the mothers in the focus groups who felt they were unsuccessful with breastfeeding.

*“There was nothing, no one could even advise me on a decent pump to get. So in the end I went on which.com and found what they said the best pump was.” (*Hazel)

Chamberlain et al. (2006) found that, for women whose infants were in the neonatal unit, the lack of affordable and suitable breast pumps was a barrier to provision of breast milk and transition to breastfeeding. Bliss (2011) state neonatal units in the UK should provide a breast pump loan service for mothers whose babies require neonatal inpatient stays, a practice which this study suggests is not universal.

In this group, two babies were born preterm and two had complex cardiac conditions. Jill recounted her support from neonatal staff was excellent, and requested the researcher to pass this onto the unit concerned.

*“I went up to neonatal the one day, I think my boobs were literally like this, and the breastfeeding nurse she looked at my boobs first and she says “You need to express.” So she showed me how to express, she stood there, showed me what to do, you know all of this using the electric one. And it was such a relief. … And I could take the breast pump home with me, to pump while I was at home.”*(Jill)

In comparison Rachel felt as a third time mum she was "left to get on with it" but had not received support with breastfeeding. Due to congenital cardiac disease, her child is under the care of a dietician.

*“I mean we’ve been really well supported I’d say sort of nutritionally, but perhaps not so much on the actual breastfeeding if that make sense”* (Rachel)

This reflects the findings of Barbas and Kelleher (2006) who found a common belief amongst health care staff that infants with congenital cardiac defects would not be able to breastfeed. Their study found improved training for staff and lactation support for women dramatically increased breastfeeding rates.

All participants expressed disappointment that where health professionals couldn't provide support, they were unable to refer to someone who could.

*"And I was constantly seeking advice from the health professionals, from my midwife and then later from the health visitor, and then she’d say they just don’t have the access to any information" (*Hayley)

In the United States many maternity units and paediatric clinics have lactation consultants to support families with complex infant feeding issues such as IDS (Manell and Manell, 2006). In the UK, although it is recommended that local specialist services are commissioned, in addition to midwifery and health visiting to support families with more complex challenges (UNICEF UK Baby Friendly Initiative, 2014), this is not universally applied (Brown, 2012).

Four participants reported encouragement by health professionals to bottle feed, but were given little advice or support with this.

*“So we were trying with the bottle, and it was the most frightening experience I’ve ever had. Because I think he wasn’t very well coordinated, so we’d try him on the bottle and he’d be like choking on it and inhaling it.”* (Rachel)

The difficulty babies with hypotonia experience with bottle feeding and milk aspiration was documented back in 1987 by Coulter and Danner, yet the health professionals supporting Rachel's family stated her baby would find it easier to bottle feed.

Overall, it appeared that the assumptions of health professionals regarding the ability of the mother/baby to breastfeed were more of a barrier to successful breastfeeding than the infant's diagnosed condition. Therefore, iatrogenic factors may be the biggest challenge to implementation of parental feeding choices.

Lack of recognition of difference

Participants recognised that for some things, their children may require different care, and sometimes could be treated like a typical baby. Health professionals sometimes got the balance wrong, such as the health visitor's attempts to help Steph with positioning her baby.

*“She was really floppy with hypotonia, I was told “Have a go, come on I’ll help you” and she said “Oh you’re forcing her head, how would you like it if someone forced your head into your plate?” So I used to let go a bit but she would flop back. And she was saying the problem was because I was forcing her head onto me, when if I didn’t hold or support her, her head would fall to one side. So it was kind of like there was no answer for that either, and no one really told me what I should do, or try a different position or anything like that”*(Steph)

All participants struggled to find out about and obtain the correct growth charts for their children, which resulted in unnecessary anxiety and interventions regarding weight gain.

*“I used to go down to the clinic to get him weighed and they’d be all like “Oh he’s dropped and we want to get him back up here” and then we saw the consultant who noticed that no one had put the Down Syndrome chart in the red book.”* (Lily)

Power and control

*Control by health professionals*

As participants recounted their experiences, it seemed that many decisions made were outside of their control. Some of these decisions had to be made without the choice of the mothers due to the child's health needs, but others seemed to be made by health professionals or based on hospital policy.

For example, Rachel knew her son had DS and had been informed that he would go to the neonatal unit for a couple of days for observation of his cardiac condition. She planned to breastfeed as she had with her older children.

*“They were taking him away and they were like, “We’re going to have to give him food, what do you want him to have?” So we had to kind of say “Well, Aptamil, I don’t know” Like what do you say?”* (Rachel)

Rachel subsequently worried about the impact large amounts of formula and feeding by routine would have on her breastfeeding relationship. In comparison, Jo used her knowledge as a health professional to insist that her baby, who also had a cardiac condition, stay with her on the postnatal ward.

*"It was really important to me that Noah wasn’t removed from my care to go to neonatal unit just because of the diagnosis. And that it was really important that there wasn’t that separation unless there was an indication that Noah was poorly and needed to go for a specific reason, and not just for observation and investigation."* (Jo)

This separation of mother and child for observation echo the findings of Pisacane et al. (2003) and Weijerman et al. (2008) of routine admission to neonatal unit for non-medical reasons. Hazel’s son was born preterm and was also cared for in the neonatal unit. She also planned to breastfeed, but states her decisions were overridden by those of the hospital staff.

*“So I was expressing I got pushed from breastfeeding within a few days to expressing so they could see how much was going in. And then after another day or so they decided to put tubes in to feed him, so I could express milk through the tubes. But then they decided that I wasn’t expressing enough milk, and I was trying obviously, like you said, constantly… and then they had to give some formula milk to top up with the expressed milk. And then we kind of carried on with that at home I guess.”* (Hazel)

Interestingly in her account, Hazel states the hospital were more "obsessed" with her son gaining weight, whereas she felt in hindsight the method of feeding had little impact.

*“I felt pushed to formula feed. There was mixed messages. I had the breastfeeding consultant coming over and a little bit of help with the breastfeeding but generally there was more about getting his weight up and using the formula”* (Hazel)

This may indicate beliefs amongst health professionals in the UK reflect the understanding of parents in Al Sarheed’s 2005 study in Saudi Arabia that infant formula contains more calories and babies find bottle feeding easier. Health professionals positioned themselves as gatekeepers to services at times, disempowering mothers in their attempts to access additional support.

*“The health visitor said “There is a group, I’ll pass your number on”, and no one ever called back, and I didn’t know who she’d passed my number onto to chase.”* (Steph)

Those whose child had a postnatal diagnosis of DS found the manner of health professionals and others in the hospital environment resulted in a loss of power; from the mother's location on the ward, to whether she could stay with her new baby. This reflects Sobben’s 2012 review highlighting the focus of health professionals on the medical diagnosis and process, not the needs of the mother/baby.

Routine separation of mother and child within neonatal care appears widespread in the UK, with 56% of parents stating they were not offered overnight accommodation even if they asked to stay with their child (Howell and Graham 2011). This is despite a number of policy documents (Department of Health, 2003; UNICEF UK, 2013; Bliss, 2011) stating the need for partnership care between health care staff and parents, and the need for suitable accommodation to allow parents to stay with their infant. As opposed to best practice, it appears culture and architecture are the main barriers to promoting family centred neonatal care.

*"When I was in the hospital they kept coming to me and saying “Why are you still here?” and I was like "Oh, I’ve just been advised that I need to stay in to make sure his feeding is established." I just felt like I was bed blocking really."* (Jo)

Steph’s baby was admitted to a specialist children’s hospital shortly after discharge from the maternity unit due to breastfeeding difficulties.

*“They gave me the decision whether to stay in and tube feed her and try to get her on the breast, or to go home and express and bottle feed or combination feed.”* (Steph)

Whilst Steph’s perception is that of giving her choice, the options provided by health professionals imply breastfeeding to be difficult, whereas bottle feeding would be easy, and she could do that at home. Despite the encouragement to express, Steph recounted that she was given no practical support with this.

Jo also found that different hospitals had different policies regarding parents staying with their children.

*" So that came as a massive shock to me when we were transferred to* (specialist children's hospital*) and they said I wasn’t allowed to stay with him, and I’d spent the whole four months with him expressing for him every couple of hours, and putting up all of his milk, and doing the majority of his medications"* (Jo)

Specialist children's hospitals which cared for half the babies in this study seemed particularly ill set up to support mothers to continue to breastfeed or express milk for their babies.

*Taking back power*

After the initial period of shock, Lily found information comforting, specifically to support her desire to continue breastfeeding. She found it frustrating that she was doing the research, and therefore knew more than those employed to help her.

 *“When the health visitor used to come to my house and I’d say “Oh I’ve been finding all this online” and she’d be like “Oh that’s really good, can I have a copy?”. And at some stage I was just thinking like, “Why am I doing the research?” I mean I like it, but that’s not the point."* (Lily)

However, other participants found it difficult to find the information they needed. Emotional trauma and exhaustion may prevent advice seeking.

*"I didn’t access support from the charity or the Down Syndrome Association. The first time I contacted them was when Noah was eleven or twelve weeks old. And that was because I’d had such a difficult pregnancy, and I was told that he wasn’t going to survive, I still was clinging onto this fear that I didn’t belong to that club."*(Jo)

Limitations of the study

This study only represents the participants’ perception of their experiences and cannot be transferable to all mothers of IDS (Pringle et al., 2011). Results and findings are suggestive, not conclusive. Participants were self-selected and recruited via parent support groups; they may therefore represent a group of mothers who differ from other in that they actively seek support from a group. Accounts were retrospective and the salience of evidence may be skewed by memory, though some research suggests women's recall of events around birth are highly valid (Tomeo et al., 1999; Natland et al., 2012). Within focus groups the full exploration of emotions and personal meanings may be limited by time and the impact of others (Jayasekara, 2012).

Further research is needed to explore the factors which affect women around feeding infants with additional needs.

RECOMMENDATIONS AND BEST PRACTICE POINTS FOR HEALTH PROFESSIONALS

* Review NHS protocols - do mothers and babies need to be separated? Ensure access to equipment for expressing both in hospital and at home.
* Signpost to local peer support services for both Down Syndrome and infant feeding.
* Have current written information for parents to keep.
* Refer to infant feeding specialists if the care needed is beyond your knowledge and skills

CONCLUSION

This study adds to the very small body of existing research around feeding IDS and demonstrates the limitations of what is currently known about this area. Iatrogenic factors played a major role in the decisions mothers made, or felt forced into making, regarding feeding their IDS. Those mothers of infants born with associated congenital conditions, who would benefit most from breastfeeding, faced more barriers to reaching their feeding goals than those with healthy, term babies. Further research is urgently needed to improve the care around feeding support and advice provided to mothers of IDS to enhance infant and maternal health and wellbeing.

|  |
| --- |
| REFERENCESAbianac K (2014) Breastfeeding a Baby with Down Syndrome. [Online] Available at www.parkersplaces.weebly.com/1/post/2014/01/breastfeeding-a-baby-with-down-syndrome.html [Accessed 17 January 15].Al-Sarheed M (2005) Feeding habits of children with Down's Syndrome living in Riyadh, Saudi Arabia. Journal of Tropical Pediatrics 52(2) p 83-86.Aumonier M F and Cunningham C C (1983) Breastfeeding in infants with Down's Syndrome. Child: Care Health and Development. 9 p 247-255.Barbas K and Kelleher D (2006) Breastfeeding success among infants with congenital heart disease. Pediatric Nursing. 30(4) p 285-289.Birt L, Scott S, Cavers D, Campbell C and Walter F (2016) Member checking: a tool to enhance trustworthiness or merely a nod to validation? Qualitative Health Research. 26(3) p 1802-1811.Bliss (2011) The Bliss Baby Charter Standards 2nd ed. Bliss: London[Bloemers](http://pediatrics.aappublications.org/search?author1=Beatrijs+L.P.+Bloemers&sortspec=date&submit=Submit) B, [van Furth](http://pediatrics.aappublications.org/search?author1=A.+Marceline+van+Furth&sortspec=date&submit=Submit) A, [Weijerman](http://pediatrics.aappublications.org/search?author1=Michel+E.+Weijerman&sortspec=date&submit=Submit) M, [Gemke](http://pediatrics.aappublications.org/search?author1=Reinoud+J.B.J.+Gemke&sortspec=date&submit=Submit) R, [Broers](http://pediatrics.aappublications.org/search?author1=Chantal+J.M.+Broers&sortspec=date&submit=Submit) C, [van den Ende](http://pediatrics.aappublications.org/search?author1=Kimberly+van+den+Ende&sortspec=date&submit=Submit) K, [Kimpen](http://pediatrics.aappublications.org/search?author1=Jan+L.L.+Kimpen&sortspec=date&submit=Submit) J,  Strengers J and [Bont](http://pediatrics.aappublications.org/search?author1=Louis+J.+Bont&sortspec=date&submit=Submit) L (2007) Down Syndrome: A Novel Risk Factor for Respiratory Syncytial Virus Bronchiolitis— A Prospective Birth-Cohort Study. Pediatrics. 120 p 1076-1081.Brown S (2012) Working at the interface between the art and science of breastfeeding: A qualitative study of International Board Certified Lactation Consultants’ experiences. A thesis submitted in fulfilment of the requirements of Bournemouth University for the degree of Doctor of Philosophy September 2012 Bournemouth University.Bull M and the Committee on Genetics (2011) Clinical report: health supervision for children with Down Syndrome. Pediatrics. 128(2) p 393-406.Cannon E (2014) How I was hounded by 'Breastapo' and why we MUST stop bashing mums who choose the bottle: She was branded 'a bitch who needs kicking' by online trolls, but our GP insists breast ISN'T always best. Daily Mail 2 March 14 [online] Available from  <http://www.dailymail.co.uk/health/article-2570925/How-I-hounded-Breastapo-MUST-stop-bashing-mums-choose-bottle.html#ixzz3iyVwRKFU> [Accessed 8 August 15] Chamberlain L, McMahon M, Philipp and Merewood A (2006) Breast pump access in the inner city: a hospital based initiative to provide breast pumps for low-income women. Journal of Human Lactation. 22(1) p 94-98.Colón E, Dávila-Torres R R, Parrilla-Rodríguez A M, Toledo A, Gorrín-Peralta J J and Reyes-Ortiz V E (2009) Exploratory study: barriers for initiation and/or discontinuation of breastfeeding in mothers of children with down syndrome. Puerto Rico Health Sciences Journal. 28(4) p 340-344.Coulter M and Danner S (1987) Sucking Disorders in neurologically impaired infants: assessment and facilitation of breastfeeding. Clinics in Perinatology. 14(1) p 109-130.Dempsey L (2013) Milo’s Feeding Journey [online] Available at http://sunshineandtheberry.blogspot.co.uk/2013/08/milos-feeding-journey.html [Accessed 17 January 15] Demott K, Bick D, Norman R, Ritchie G, Turnbull N, Adams C, Barry C, Byrom S, Elliman D, Marchant S, Mccandlish R, Mellows H, Neale C, Parkar M, Tait P and Taylor C (2006) Clinical Guidelines And Evidence Review For Post Natal Care: Routine Post Natal Care Of Recently Delivered Women And Their Babies. London: National Collaborating Centre For Primary Care And Royal College Of General Practitioners.Dennis J, Archer N, Ellis J and Marder L (2010) Recognising heart disease in children with Down syndrome. Archives of Disease in Childhood: Education and Practice Edition. 95 p 98-104.Department of Health (2003) Getting the Right Start- National Service Framework for Children: Standard for Hospital Services. London: Department of Health.Dykes F (2006) Breastfeeding in Hospital; Mothers, Midwives and the Production Line. Routlidge, Oxford.Edwards T M and Spatz D L (2010) An innovative model for achieving breastfeeding success with in infants with complex surgical anomalies. The Journal of Perinatal and Neonatal Nursing. 24(3) p 246-253.Faircloth C (2015) Breastfeeding doesn't determine a child’s future, so we should stop pretending like it does. The Independent. 11 June 15 [online] Available at http://www.independent.co.uk/voices/comment/breastfeeding-doesnt-determine-a-childs-future-so-we-should-stop-pretending-like-it-does-10313616.html [Accessed 8 August 15].Flores-Lujano J, Perez-Saldivar M L, Fuentes-Pananá E M, Gorodezky C, Bernaldez-Rios R, Del Campo-Martinez M A, Martinez-Avalos A, Medina-Sanson A, Paredes-Aguilera R, De Diego-Flores Chapa J, Bolea-Murga V, Rodriguez-Zepeda M C, Rivera-Luna R, Palomo-Colli M A, Romero-Guzman L, Perez-Vera P, Alvarado-Ibarra M, Salamanca-Gómez F, Fajardo-Gutierrez A and Mejía-Aranguré J M (2009) **Breastfeeding and early infection in the aetiology of childhood leukaemia in Down syndrome. British Journal of Cancer. 101 p** 860-864.Gore N, Emerson E and Brady S (2015) Rates of breastfeeding and exposure to socio-economic adversity amongst children with intellectual disability. Research in Developmental Disabilities. 39 p 12-19.Gribble K (2001) Mother-to-mother support for women breastfeeding in unusual circumstances: a new method for an old model. Breastfeeding Review. 9(3) p 13-19.Ip S, Chung M, Raman G, Chew P, Magula N, DeVine D, Trikalinos T and Lau J (2007) Breastfeeding and Maternal and Infant Health Outcomes in Developed Countries. Evidence Report/Technology Assessment No. 153 (Prepared by Tufts-New England Medical Center Evidence-based Practice Center, under Contract No. 290-02-0022). AHRQ Publication No. 07-E007. Rockville, MD: Agency for Healthcare Research and Quality. Irvine C and Chaudhari M (2012) Cardiovascular abnormalities in Down's syndrome: spectrum, management and survival over 22 years. Archives of Disease in Childhood. 97 p 326-330.Ivan D L and Cromwell P (2014) Clinical practice guidelines for management of children with Down Syndrome: Part 1. Journal of Pediatric Health Care. 28 p 105-110.Jackson M. and Poskttt E. (1991) The effects of high-energy feeding on energy balance and growth in infants with congenital heart disease and failure to thrive. British Journal of Nutrition. 65(2), pp. 131–143. Jayasekara R (2012) Focus groups in nursing research: methodological perspectives. Nursing Outlook. 60 p 411-416.Källén B, Mastroiacovo P and Robert E(1996) Major congenital malformations in Down syndrome. American Journal of Medical Genetics. 65(2) p 160-166.King S and Jones E (2005) Feeding and Nutrition in the Preterm Infant. Amsterdam: Churchill-Livingstone. Lang S (2002) Breastfeeding Special Care babies 2nd ed. London: Balliere-Tindall.Lee E and Furedi F (2005) Mothers’ experience of, and attitudes to, using infant formula in the early months. Project report. SSPSSR [online] Available at <https://kar.kent.ac.uk/id/eprint/25249> [Accessed 8 August 15].Lee E (2007) Health, morality and infant feeding: British mothers’ experiences of formula milk use in the early weeks. Sociology of Health and Illness. 29(7) p 1075-1090.Lewis E and Kritzinger A (2004) Parental experiences of feeding problems in their infants with Down Syndrome. Down Syndrome Research and Practice. 9(2) p 45-52.McAndrew F, Thompson J, Fellows L, Large L, Speed M and Renfrew M (2012) Infant Feeding Survey 2010. [online] Available at http://www.hscic.gov.uk/catalogue/PUB08694/Infant-Feeding-Survey-2010-Consolidated-Report.pdf [Accessed 23 May 15]Manell R and Manell M (2006) Staffing for hospital lactation programs: Recommendations from a tertiary care teaching hospital. Journal of Human Lactation. 22(4) p 409-417.Marino B, O’Brien P and LeRe H (1995) Oxygen saturation during breast and bottle feeding in infants with congenital heart disease. Journal of Pediatric Nursing. 10(6) p 360-364.Martin J (1978) Infant Feeding 1975: Attitudes and Practice in England and Wales. London :HMSO.Morris J K and Springett A (2014) The National Down Syndrome Cytogenetic Register for England and Wales: 2012 Annual Report. Public Health England: London.Natland **S, Anderson L, Nilsen T, Forsmo S and Jacobsen G (2012)** Maternal recall of breastfeeding duration twenty years after delivery. BMC Medical Research Methodology.**12** p 179. Oliveira A C, Pordeus I A, Torres C S, Martins M T and Paiva S M (2010) Feeding and nonnutritive sucking habits and prevalence of open bite and crossbite in children/adolescents with Down syndrome. Angle Orthodontist. 80(4) p 749–753.Pisacane A, Toscano P, Pirri I, Constinisio P, Andria G, Zoli B, Strisciuglio P, Concolino D, Piccione M, Lo Giudice C and Vicari S (2003) Down Syndrome and breastfeeding, Acta Pædiatrica. 92 p 1479-1481.Pringle J, Drummond J, McLafferty E and Hendry C (2011) Interpretative phenomenological analysis: a discussion and critique. Nurse Researcher. 18(3) p 20-24.Sherman S, Allen E, Bean L and Freeman S (2007) Epidemiology of Down Syndrome. Mental Retardation and Developmental Disabilities Research Reviews. 13 p 221-227.Silverman W (2007) Down Syndrome: cognitive phenotype. Mental Retardation and Developmental Disabilities Research Reviews. 11 p 228-236.Smith J, Jarman M and Osborn M (1999). Doing interpretive phenomenological analysis. In M. Murray & K. Chamberlain (Eds.) Qualitative health psychology. London: Sage.Sooben R D (2012) Breastfeeding patterns in infants with Down's Syndrome: a literature review. British Journal of Midwifery. 20(3) p 187-192.Sooben R (2015) Breastfeeding of newborns with Down’s syndrome. Learning Disability Practice. 18(6) p 26-28.Thomas J, Marinelli K A, Hennessy M and the Academy of Breastfeeding Medicine Protocol Committee (2007) ABM Clinic Protocol #16: Breastfeeding the Hypotonic Infant. Breastfeeding Medicine. 2(2) p 112-118.Tomeo C, Rich-Edwards J, Michels K, Berkey C, Hunter D, Frazier A, Willett W and Buka S (1999) Reproducibility and validity of maternal recall of pregnancy related events. Epidemiology. 10(6) p 774-777.UNICEF UK Baby Friendly Initiative (2014) Guidance of Provision of Additional and Specialist Services to Support Breastfeeding Mothers. [Online] Available at <http://www.unicef.org.uk/BabyFriendly/News-and-Research/News/UNICEF-UK-statement-on-the-provision-of-specialist-services/> [Accessed 8 August 15]UNICEF UK (2013) The Evidence and Rationale for the UNICEF UK Baby Friendly Initiative Standards. UNICEF UK / Baby Friendly: London.Weijerman M E, Marceline van Furth A, Vonk Noordegraaf A, van Wouwe J P, Broers C J M and Gemke R (2008) Prevalence, neonatal characteristic, and first year mortality of Down Syndrome: a national study. The Journal of Pediatrics. 152(1) p 15-19.White A (2013) The Breastapo need to stop nipple gazing. The Telegraph [online] 7 March 15 Available at http://www.telegraph.co.uk/women/mother-tongue/9915446/Breastfeeding-battle-The-Breastapo-need-to-stop-nipple-gazing.html [Accessed 8 August 15]. |

World Health Organisation (2003) Global Strategy for Infant and Young Child Feeding. Resolution WHA55.25. WHO: Geneva.