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Feeding an infant with Down syndrome: mothers' experiences of support from NHS and charities.

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Abstract

Objective

To understand the experiences of mothers of babies with Down syndrome regarding infant feeding support provided by the NHS and charitable organisations.

Methods

The study took a qualitative approach using semi-structured one-to-one interviews. Following data collection, a six-step reflexive thematic analysis was undertaken. To be eligible for inclusion, participants had to be 1) a mother, father, or primary care giver 2) to an infant aged between 0-12 months with a positive diagnosis of Down syndrome and 3) live within the UK. Six mothers who had babies with Down syndrome were interviewed; three were first-time mothers and three also had other children.

Results

The following four themes were identified: 1) will I ever feel happy about this pregnancy?; 2) charities changed everything; 3) these are my feeding choices; 4) feeding intervention using a nasogastric tube. The first theme explores mothers' journeys through grief following a Down syndrome diagnosis. Mothers experienced an array of emotions that varied in intensity including sadness, worry, guilt, and anxiety, and focused mainly on the unknown journey ahead with a baby with Down syndrome. The second theme focused on mothers seeking the support of a charity to access timely advice for infant-feeding problems. The third theme discussed mothers feeling that healthcare professionals lacked the ability to support, communicate and offer positive encouragement around breastfeeding a baby with Down syndrome. The final theme explored the conflicting information given to mothers about nasogastric tube feeding.

Conclusion

Mothers of babies with Down syndrome face challenges with infant feeding and require compassionate care and increased support. NHS support may not meet all women's needs and some women find additional, improved quality support from charities. NHS support needs to be improved, and women signposted to charities.

Background

Many parents anticipate that having a baby with Down syndrome (DS) will result in significant physical and intellectual disability (ID), with limited quality of life. Many healthcare professionals (HCPs) hold similar attitudes and beliefs (Frizell, 2021). Babies born with DS have a higher chance of physical co-morbidities such as congenital cardiac conditions and respiratory disorders, including common phenotypes such as hypotonia, pinna abnormalities and macroglossia (Bull, 2020; NDSS, 2022; Tracey, 2011). Global developmental delay is also associated with DS and individuals often have mild to severe ID (Parizot, 2019). However, advances in medical and social care partnerships and the movement to a social model of disability, have improved quality of life, advocacy, and independence for people with DS (Bull, 2020; Botha et al., 2021). This is reflected in the numerous DS charities within the UK that support new parents.

Breastfeeding is recommended by the World Health Organisation (WHO) as the optimum feeding method from birth to two years of age (World Health Organisation, 2021). The long and short-term benefits of breastfeeding have long been established for both mothers and infants. For babies this includes reduction in respiratory infections, sudden unexpected infant death syndrome (SUIDS) and improvement in cognitive development (Victoria et al., 2016). For mothers, long-term health benefits include reduction in reproductive cancers and lower risk of cardiovascular disease (Schwarz et al., 2009). Initiating breastfeeding at birth, facilitates mother-infant bonding and evidence suggests that breastfeeding mothers are more receptive to their baby's cry and emotions (Kim et al., 2011). This is important for babies who have DS as the mother-infant attachment during the breastfeeding experience can decrease maternal stress and anxieties that are commonly associated with a diagnosis of DS (Lewis and Kritzinger, 2004).

Having adequate support contributes to a positive feeding journey (Lewis and Kritzinger, 2004). However, the support that parents receive from the NHS has been reported as substandard for mothers of babies who have DS (Hielscher et al., 2022; Cartwright and Boath, 2018). Mothers feel they are given generic breastfeeding information, that lacks acknowledgment of their baby's additional support needs and

results in mothers feeling confused and doubting their ability to breastfeed (Barros da Silva, 2019). Lack of knowledge amongst HCPs relating to infant-feeding for babies with DS is evident, particularly around breastfeeding (Barros da Silva et al., 2019; Zhen et al., 2021; Coentro et al., 2020). While there are studies on the breastfeeding experiences of mothers who have a baby with DS (Magenis et al., 2020; Sooben, 2012) there is limited literature on the support received by mothers by relevant charities.

This research aimed to understand the experiences of mothers of babies with DS of infant-feeding support from the NHS and charities:

- 1) What support do mothers need regarding feeding a baby who has DS?
- 2) What are the experiences of infant feeding support from HCPs for mothers of babies with DS?
- 3) What are the experiences of infant feeding support from charities for mothers of babies with DS?

Methods

Research Design

We adopted an exploratory qualitative approach using semi-structured one-to-one interviews online (Doyle et al., 2020). Following data generation, a six-step reflexive thematic analysis was undertaken (Braun and Clarke, 2022).

Sample

A purposive sampling technique was used (Campbell et al., 2020). The director of the charity Positive about Down Syndrome (PADS) facilitated recruitment through sharing a poster via PADS social media during July/August 2022. To be eligible for inclusion, participants had to be a mother, father, or primary care giver to an infant aged between 0-12 months with a positive diagnosis of DS and living in the UK. Six mothers responded to the poster, and all participated in the study.

Of the six participants – three were first-time mothers, three had other children, and all lived in England. All mothers reported that they were either currently breastfeeding or had breastfed, and one mother was combining breastfeeding and formula-feeding.

Interview Process

Interviews were guided by a topic guide (table 1) allowing participants to answer from their own viewpoint yet allowing any other relevant themes or topics to be discussed (Choak, 2012). The interviews had a mean length of 42 minutes. Interviews were recorded and transcribed using the Microsoft Teams platform and were checked for accuracy by VM, AM and SB. Identifying information was removed.

Analysis

A six-step reflexive thematic analysis was undertaken (Braun and Clarke, 2022). Familiarisation with the data was achieved by repeated listening to each transcript. Through a process of reflection and interaction with the data, coding commenced focusing on the research questions. Coding, focused was inductive; with no predetermined codes (Braun and Clarke, 2019). After the data had been coded and code labels assigned, stage three and four of the analysis involved generating and reviewing themes. Phase five of the analysis focused on defining and naming each

theme (Braun and Clarke, 2019). Phase six of the analysis, incorporates concise presentation of the data in and across themes (Braun and Clarke, 2006).

Ethics

Ethics approval was granted by the University of Dundee in April 2022 [UoD-SoSS-GEO-TPG-2022-202]. Prospective participants were sent a participant information sheet and given at least 72 hours to make an informed decision about participating. Informed consent was taken s commenced. Any identifiable information about the parents', their babies, or healthcare providers were anonymised. Pseudonyms are used to protect anonymity. As the research topic was potentially upsetting. participants were given options to take breaks during the interviews, end the interview early or withdraw from the study. Signposting to charities for support was offered d but no mother expressed the need for this.

Results

The following four themes were developed: will I ever feel happy?; charities changed everything; these are my feeding choices; intervention of nasogastric (NG) tube feeding.

1) Will I Ever Feel Happy?

This theme explores mothers' journeys through grief following a DS diagnosis. Mothers experienced an array of emotions that varied in intensity including sadness, worry, guilt, and anxiety, regarding the unknown journey ahead.

"Being a first-time mum, I was obviously having a certain, you know, anxieties about bringing you know, and then once we have the diagnosis, it's then doing my, well doing my research or getting to know this syndrome and kind of understanding it a bit more. Just because, obviously I'm gonna be bringing up a child and it was, it was scary."

(Catherine)

Three mothers had strong feelings of grief for other family members, in particular worry for what life looked like ahead for older siblings having a sibling with a disability, and the possibility of parents taking on a carer's role.

"My kind of first feelings kind of jumped to my daughter, my, our oldest, and I felt that I'd ruined her life and I kind, like, made a decision to bring another child into the world to give her a sibling and have a life that we shared with our siblings growing up and that had - I had taken away from her..."

(Emma)

Although experiencing her own mental-health challenges, one mother navigated her way through the grief by providing support and contextualising the situation to her husband.

“I was petrified. I was scared, you know, I was upset, but my husband kept saying, I don’t want to be retired and looking after somebody, you know, and I kept saying to him, but our child could have been born with autism, it could fall and hit her head on the curb and need lifelong care, you know, the, the, so many what ifs and it’s such a spectrum.”

(Brynn)

2) Charities Changed Everything

Every mother sought the support of a charity to access timely advice for infant-feeding problems. As well as PADS, mothers also accessed Down Syndrome UK and Down Syndrome Association. Four mothers had a high-chance result of DS from antenatal screening and had researched online, resulting in connecting with a charity prenatally. Of these four mothers, two were signposted by their midwife and two found the charity themselves.

“It would have been really nice to get some, you know, just some talking through support kind of stuff, and then my partner actually did quite a lot of research online and found PADS and, um, they were our main sort of source of support.”

(Annie)

All the mothers commented positively about being involved with a charity. Mothers felt charities provided them with a safe and non-judgmental environment, and an opportunity to connect with those who had similar experiences.

“So charities seemed like a reliable source and then seemed the most forthcoming and open with lots of sources of information, but, but not just kind of lists and tick lists like you know real life experience, and I think that was probably the most useful for me to kind of see other families, families that were similar to us, so many families kind of living it and that’s kind of what has helped me.”

(Emma)

Charities mainly used social media to provide mothers with timely breastfeeding support, through private Facebook groups and live videos.

“So, I guess it would probably be PADS the Facebook Group, so it’s you know Positive about Down Syndrome Breastfeeding Group Supports, just mums in that one which is, which is nice. I quite like it when it’s just the mums, and so on there like I said they did a Facebook live that I’d watched after it had been recorded, which was different mums talking about different aspects of feeding and their journeys.”

(Danielle)

3) These are my Infant Feeding Choices

Mothers felt that HCPs lacked the ability to support, communicate and offer positive encouragement for mothers’ choices around breastfeeding a baby with DS.

“Yeah feeding, I, I should go into the feeding issues we had since birth, but it wasn’t, wasn’t the feeding issue for us, it was the lack of support, the, the lack of communication, um, you know, so he’s now 16 weeks, we’ve managed to, we’re in a reasonably good place with breastfeeding.”

(Brynn)

“No, we didn’t get the, the support we got postnatally was awful. We got none. So that’s why I’m so glad, you know, I only received help with my breastfeeding on day three of him being in NICU.”

(Brynn)

Some mothers commented on HCPs not believing that babies with DS can breastfeed.

“I think we really need to move away from a message that children with DS struggle to feed because I think that people should say is any child, you know,

baby, can struggle to feed. I think that it's a really hard message. I mean I took [baby] for her RSV jab the other day, and as I was feeding, I was being told by a special care nurse that babies with DS can struggle to feed."

(Danielle)

Many of the mothers discussed that their feeding decisions were for their baby not to receive formula-milk but felt pressured to do so by midwifery staff. Mothers expressed their feeding choices prenatally, but these were often dismissed postnatally.

"I think I said to them, you know, my wishes that I will not be, that my baby they won't have formula. I will be breastfeeding. And, and, I specifically said, you know, I don't want an NG tube placed unnecessarily, I will be harvesting colostrum, I don't want any formula and, and [the doctor] was very pro, pro-choice with that. He was like that's fine. And I said I would rather my baby have donor milk than formula again he said that was fine, we can talk about that later but that didn't happen."

(Brynn)

One mother highlighted the lack of understanding around DS when requiring weaning support, often being met with no guidance or signposting.

"The charities have been amazing. Where I was trying to get some support through NHS, but it was literally just like waiting lists and long waiting lists and all I needed to, I just needed to see someone or speak to somebody, a SALT [speech and language therapist] or someone just to advise me, but all I would get is we don't really specialise in [DS], because I, when I was asking my health visitor like can you even point me in the direction of someone who can help me and they were like oh we don't really know, we don't really deal with this, or they were like acting like [baby] was the first DS child that they ever come across and it's like I'm sure that's not true, but there you go."

(Catherine)

4) Feeding Intervention using a Nasogastric Tube

Mothers were presented with conflicting information around NG tube feeding. Three mothers experienced HCPs not explaining why tube feeding was needed. One mother's baby was feeding well with expressed breastmilk in a bottle, one mother felt the intervention lacked medical reasoning, and another mother's baby had an NG tube inserted without any involvement in the decision.

"You know, I said to them, but she's taking milk fine out of a bottle, obviously we want to her breastfeed but she's having my breastmilk out of a bottle, I don't, they said, oh yeah but she's had some syringes and quite often babies with DS tube feed, and I was like but maybe they end up tube fed because [the doctor] suggested it unnecessarily."

(Annie)

"When he was in there [NICU], they placed an NG tube without, without my consent, which upset me."

(Brynn)

Two mothers received conflicting information regarding the opportunity for parents to be trained in the care of the NG tube. These mothers were also given conflicting information from the neonatal intensive care unit (NICU) and transitional care units regarding discharge guidance for NG tube feeding.

"We'd agreed antenatally with again the paediatrician that if [baby] has to come home with the NG tube they would train us to change it. We were confident, we're only 10 minutes from the hospital. My mum works in healthcare, she can be trained up. So, we were confident if he comes home with the tube, fine. [We] go to transitional care and we were told you're not allowed to come home with a tube in and again, as I put it, that's different to what we've been told."

(Brynn)

Discussion

Mothers in our study felt that following a DS diagnosis, HCPs had blanket assumptions of their babies, which left mothers feeling alienated and caused additional stress. These findings align with other evidence that mothers whose babies receive a diagnosis of DS require compassionate support. A study in collaboration with six non-profit DS charities in the USA found that mothers who received a postnatal diagnosis reported feelings of fear and anxiety that were heightened by HCPs focusing on blanket negative assumptions of DS (Skotko, 2005). For example, mothers in our study were often met with resistance from HCPs who assumed that babies with DS would not succeed with breastfeeding. Apart from possible swallowing co-ordination issues, babies with DS have phenotypes such that hypotonia and macroglossia could cause feeding difficulties. Mothers in our study chose breastmilk feeding yet felt there was a culture of formula-feeding amongst HCPs. Mothers were aware of the positive benefits of breastfeeding, for babies with DS (including strengthening oral muscle and protecting against respiratory infections), however, this knowledge was often not shared by HCPs. Our findings are consistent with wider evidence that there is an overall lack of encouragement and support for mothers to initiate and continue breastfeeding (McInnes and Chambers, 2008; Blixt et al., 2019).

The timely support that charities provided was invaluable to the mothers in our study. Building relationships with families who had lived experience created a sense of community and connection. Although the literature on charity support is limited, the significance of peer-support is cited widely as providing parents with emotional wellbeing support and a reliable source for information (Bromley et al., 2004; Sartore et al., 2021). Some mothers in this study faced long NHS waiting lists when they required urgent support. In comparison, charities used social media as an avenue for timely peer support. Mothers discussed the use of private Facebook groups through PADS that were specifically focused on topics such as breastfeeding. Other research supports the value of online informal breastfeeding support, such as Facebook groups and blogs (Jönsson et al., 2022). This is where the NHS and charities can harmonise and complement each other. HCPs could learn from charities in the way they deliver support, including signposting to charities.

The decision to commence NG tube feeding left mothers questioning medical reasoning. Parents were often presented with a blanket assumption that babies with DS are tube fed. Wider literature reports that mothers of babies with DS feel their feeding choices are not respected and that NG tube feeding interventions are carried out based on convenience for HCPs rather than what is best for their baby (Enoch, 2021). While it is recognised that some babies will require NG tube feeding for medical reasons, parents of babies who are in NICU or transitional care should be encouraged and supported to take an active role in that care (UNICEF, 2022). This also includes supporting breastfeeding mothers to express breastmilk, regularly putting their baby on the breast and implementing kangaroo care and ensuring that mothers and babies are routinely kept together (UNICEF, 2022).

Limitations

This was a small, exploratory study with highly selective participants. As the participants were recruited through one charity via social media, their views could be more positive about charitable support than mothers who have not accessed support from charities. Also, mothers who had sought support from charities may have done so because they experienced poor support from the NHS. Furthermore, those who participated in the study had access to the internet and used social media. There may be mothers or parents who do not use social media and did not have the opportunity to participate in our study. While we tried to recruit mothers, fathers, or caregivers, only mothers responded. Although mothers did discuss aspects of the infant feeding journey from the perspective of their partners, further research is needed to explore the experiences of fathers and other primary caregivers. A larger study is needed to further understand of the support needs and experiences of feeding babies with DS. Nevertheless, our study highlights important insights that could lead to better support.

Conclusion

Mothers of babies with DS face challenges with infant feeding and require compassionate care and increased support. Current support provided by the NHS may not meet all women's needs. Some women receive excellent charitable support with infant-feeding, including emotional support and a sense of community. Breastfeeding

mothers of babies with DS benefit greatly from being signposted to charities and this should be promoted.

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