

Breastfeeding sick children in hospital: Exploring the experiences of mothers in UK paediatric wards

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Abstract

There is a paucity of literature exploring the challenges of breastfeeding sick children in hospital. Previous research has focused on single conditions and hospitals which limits understanding of the challenges in this population. Although evidence suggests that current lactation training in paediatrics is often inadequate, it is unclear where the specific training gaps are. This qualitative interview study of UK mothers aimed to explore the challenges of breastfeeding sick infants and children on a paediatric ward or paediatric intensive care unit. From 504 eligible respondents, a sample of 30 mothers of children aged 2–36 months with various conditions and demographic backgrounds was purposively chosen, and a reflexive thematic analysis undertaken. The study identified previously unreported impacts such as complex fluid needs, iatrogenic withdrawal, neurological irritability and changes to breastfeeding behaviour. Mothers described breastfeeding as emotionally and immunologically meaningful. There were many complex psychological challenges such as guilt, disempowerment, and trauma. Wider struggles such as staff resistance to bedsharing, inaccurate breastfeeding information, lack of food and inadequate breast pump provision made breastfeeding more challenging. There are numerous challenges related to breastfeeding and responsively parenting sick children in paediatrics, and these also impacted maternal mental health. Staff skill and knowledge gaps were widespread, and the clinical environment was not always conducive to supporting breastfeeding. This study highlights strengths in clinical care and provides insight into what measures are perceived as supportive by mothers. It also highlights areas for improvement, which may inform more nuanced paediatric breastfeeding standards and training.

KEYWORDS

Baby Friendly Initiative, breastfeeding, medical complexity, paediatrics, PICU, qualitative methods

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1 | INTRODUCTION

While the importance of breastfeeding is well understood in terms of maternal and child health (Victora et al., 2016), there is very little research exploring the views and experiences of mothers breastfeeding sick infants and children in the paediatric setting. There are a small number of studies that have explored the challenges of breastfeeding among young infants with specific conditions; for instance Down syndrome (Barros da Silva et al., 2019; Colón et al., 2009; Lewis & Kritzinger, 2004; Coentro et al., 2020), phenylketonuria (Banta-Wright et al., 2015), cardiac defect (Barbas & Kelleher, 2004; Lambert & Watters, 1998) and cleft palate (Madhoun et al., 2019), but no study has looked at breastfeeding sick infants and children in a general sense. There is also very little research exploring breastfeeding experiences within paediatrics in UK hospital settings. The United Kingdom has a unique healthcare system, with care being provided free at the point of need and facilitated through community and hospital services. If a child becomes unwell requiring in-hospital care beyond the neonatal period, they will be admitted to a paediatric ward or paediatric intensive care unit (PICU). The paediatric ward or PICU, distinct from the neonatal ward, is staffed by paediatric-trained nurses, who have separate training from adult nurses, midwives or neonatal nurses. The medical support will be provided by paediatricians and trainee paediatricians, who may also provide neonatal cover. At the present time, there is no mandatory breastfeeding or oral infant feeding training on any paediatric nursing, medical or allied health professional core educational competencies (HCPC, 2013a, 2013b, 2014; NMC, 2014; RCGP, 2019; RCOG, 2019; RCPCH, 2018).

A recent systematic review (Hookway et al., 2021) found seven key themes in the available literature. Broadly there were four main parent and child related themes, and three professional and institutional themes. Parent challenges related to the logistical and practical problems of being resident overnight, having to care for other children, juggling paid work and caring for their sick child, difficulties accessing usual community breastfeeding support and practical breastfeeding challenges such as mastitis and low supply that were not adequately managed in the paediatric setting. Parents also struggled with psychological challenges, with many reporting anxiety, depression, stress and impaired milk ejection reflex due to the pressure of needing to produce high volumes under extraordinarily stressful circumstances. Child-related themes were linked to two main challenges—either being critically unwell, or due to adaptations being needed because of the nature of their condition. There are also organisational, resourcing and professional challenges to supporting sick children. Lack of designated lactation support for paediatric departments is a widespread problem globally. Distinctly separate from this is the often insufficient support provided by healthcare professionals. Finally, lack of resources such as breast pumps, inadequate support to use specialised feeding devices, and lack of knowledge about techniques to support more difficult situations are significant problems relating to hospital institutions.

Key messages

- Mothers experienced numerous breastfeeding challenges, including many that are previously unreported.
- Breastfeeding was found to be immunologically meaningful and a source of pain relief and comfort. Mothers were motivated to continue breastfeeding through illness, but also struggled with complex emotions.
- Mothers encountered numerous knowledge gaps from multiple professionals. Apart from some notable exceptions, mothers were often unable to access adequate lactation support, especially when children were more seriously unwell.
- While there were examples of negativity, mothers also described the impact of good care. Providing food, allowing parental presence during procedures, and clinicians taking time to research breastfeeding were all appreciated.

A well-known intervention to support and promote breastfeeding is the Unicef Baby Friendly Initiative (BFI) standards and accreditation process which aim to improve breastfeeding support through training, benchmarking and audit. When BFI is implemented in practice, it has been found to increase rates of breastfeeding initiation (Fair et al., 2021). Comparable support for older infants and children admitted to paediatric care is not yet implemented despite the World Health Organisation recommending that children are breastfed for up to 2 years and beyond (WHO, 2018). There is arguably a greater need for immunological protection in children who are unwell which further amplifies this gap in provision. Therefore, despite breastmilk being potentially beneficial to sick children, the systems that could facilitate this are not in place. Furthermore, children who present with medical challenges—whether self-limiting, or serious and chronic are more likely to require specific breastfeeding support that differs from the currently available support that is weighted towards the establishment of breastfeeding. Children who develop illness later in their breastfeeding journey may have well-established breastfeeding, yet still experience difficulties during illness, regardless of the severity or longevity of illness. Illness, even in established breastfeeding mother-child pairs, may change a child's fluid needs, present specific clinical challenges to breastfeeding, or affect breastfeeding behaviour. While these children may have received quality support in the maternity or community settings during a time of health, each episode of illness represents a risk to breastfeeding either due to the nature of the illness, or lack of support to continue breastfeeding in hospital during illness.

It is also likely that there are different challenges associated with breastfeeding sick children that are as yet unreported or unexplored. Because of the different challenges, lack of training or specific clinical guidelines for staff (Dykes, 2006; Gupta et al., 2019; Holaday et al.,

1999; McLaughlin et al., 2011), and anecdotally, the lack of widespread acceptance of breastfeeding in the paediatric setting, it is likely that parents may have unique experiences of breastfeeding on the paediatric ward or PICU. The aim of the study was to understand the views and experiences of mothers continuing to breastfeed or provide breastmilk to their sick child while they are inpatients on the paediatric ward or PICU. Though there is a positive move to extend BFI into the paediatric setting, the unique challenges of breastfed sick children are currently not considered in policy and clinical guidelines. Thus, the longer-term objective of the study is to use the identified challenges to inform more nuanced care guidelines and training curricula for healthcare professionals, as well as identify current examples of good practice.

2 | METHODS

2.1 | Study design

This was a semi-structured qualitative interview study conducted with mothers of breastfed sick children in the United Kingdom, with all interviews conducted online. While an in-person study was considered, it was found to be impractical due to the challenges of accessing hospital departments during the Covid-19 pandemic. While the Covid-19 pandemic could theoretically have impacted service provision, and thus skewed the results towards a picture of healthcare that did not reflect normal service, this was felt to be unlikely given that nursing and medical staff would not have changed their practice or advice related to breastfeeding purely due to Covid, and no mother in the study mentioned adverse interaction due to personal protective equipment or infection control. Additionally, although community breastfeeding support services were seriously adversely affected during Covid, this was irrelevant to this study as it explored in-hospital services and experiences, rather than community services.

Breastfeeding rates vary nationwide, different hospitals have varying attitudes to breastfeeding support, and different conditions and lengths of hospital admission are likely to be associated with multiple breastfeeding challenges. Additionally, much of the breastfeeding research in the general population so far has found a predominance of mothers/parents who are white and have higher socio-economic status (Li et al., 2019; Sarki et al., 2019). Previous studies have focused mostly on single conditions, often in one hospital, so one of the advantages of recruiting participants for this study online was a clinically, geographically and ethnically diverse sample.

During development of the interview prompt questions, parents of sick children who were members of a Facebook support group focused on this topic (*Breastfeeding the Brave*) were invited to provide feedback on the approach and proposed questions, and interview questions were piloted to ensure that firstly the questions were acceptable to the parents, and secondly that they elicited meaningful answers.

2.2 | Sampling

The study was targeted at mothers breastfeeding or providing breastmilk—either exclusively or partially—to their sick child. Mothers whose child was previously a patient in the neonatal unit were excluded, because the mothers are more likely to have received support that might have influenced some of their choices when their child is hospitalised in the paediatric setting.

Participants were eligible if their child had been hospitalised within the last 6 months to minimise recall bias. However, it was also recognised that some mothers may not wish to discuss a traumatic admission immediately after discharge, so allowing this time enabled them to reflect on their experience before interview. Mothers who had stopped breastfeeding while their child was an inpatient on a recent admission were eligible for inclusion, as this outcome may be iatrogenic.

Participants self-identified via an online advert which was shared several hundred times on social media, mostly on Facebook, but also on Instagram and Twitter. The researcher and wider research team have very large social media followings, which enabled a large organic reach among numerous generic breastfeeding support groups. Consequently, 849 people responded to the online advert within 48 h and completed a brief initial screening questionnaire hosted on Qualtrics. From these questionnaires, a sample was purposively chosen to achieve a mix of different conditions, as well as ethnic and socio-economic diversity. Initially, a shortlist of mothers who are under-represented in current breastfeeding literature (non-white, disabled, lower educational status) was identified. From this shortlist, a sample of mothers whose children had different conditions, and were admitted for variable lengths of time was chosen. Breastfeeding is a complex process that requires the entire body, and therefore dysfunction with one or more of these body systems will lead to specific complications with feeding (Goday et al., 2019; Green & Resnick, 2021; Milano et al., 2019). Thus, the remainder of the sample included a diverse mix of different conditions and durations of hospital admission to capture the disparate effects on breastfeeding with different illnesses and levels of complexity.

It was recognised that mothers of children who had short, self-limiting conditions may have different experiences to the mothers of children with serious, chronic or recurrent conditions, and therefore, a range of hospital admission durations was chosen, as well as an intentional decision to avoid too much duplication of diagnoses to capture the range of possible experiences.

2.3 | Procedure

Participants completed a brief online screening questionnaire which consisted of both open and closed questions.

The initial questionnaire consisted of:

1. Demographic information: ethnicity, gender, relationship status, educational attainment, disability status and postcode.

- Confirmation of eligibility for the study: participants had to confirm they were the parent of a child who had received UK-based paediatric inpatient care, and they also had to state whether their child had been admitted to the neonatal unit.
- Details about their child's admission and condition: Participants were asked about their child's condition in a free text box, as well as the length of their last admission, how recently they were discharged, and what their current feeding status was.

Participants were invited to provide their contact details if they wished to be considered for the interview study. If selected, participants were emailed further information about the study and invited to an interview at a convenient time. Participants were given appointment times more than 24 h in advance to allow them time to ask any clarification questions. Interviews were conducted on Zoom and all lasted around 1 h (range 30–120 min).

At the start of the interview, participants were reminded of the scope of the research, and informed consent was given in a separate recording to the interview file to ensure anonymity. All transcripts were anonymised and identifying features redacted. There were two children whose conditions were very rare, and their diagnoses have been left intentionally vague to avoid the possibility that they could be identified. Ethical approval for the study was granted by Swansea University School of Health and Social Care Ethics Committee. Ethical considerations were made with respect to the principles for research on human subjects as outlined in the Declaration of Helsinki.

2.4 | Trustworthiness and rigour

There are a number of general principles of rigour that apply to qualitative research. These principles of rigour add credibility to the analysis and increase the trust that others can have in the interpretation (Green & Thorogood, 2006; Lincoln & Guba, 1985). They include transparency, validity, reliability, comparability and reflexive practice. Transparency refers to how clearly the research methods are reported, so that they represent a true and full account of the procedures used to analyse the data, for example explaining how the sample was selected or how codes were developed. The validity can increase the faith one has in the researchers' interpretation of the data. One approach is to look for outlying or contradictory evidence. In this case, both positive and negative experiences were considered. The reliability of the interpretation was enhanced by discussing coding with the second author as the codes and themes were generated (Green & Thorogood, 2006; Lincoln & Guba, 1985). The comparability or generalisability relates to the extent to which the results could be extrapolated to a wider population. This is a problematic concept with qualitative research which seeks not to prioritise widely generalisable findings, but to understand meaning in a specific context (Gough & Madill, 2012; Polit & Beck, 2010). However, some pragmatism is required when conducting research that may inform health and social policy and it is recognised that some concepts may be relevant beyond a specific setting, with caution, and some believe that reflexive thematic analysis may be softly generalisable (Braun & Clarke,

2022). The findings in this study have been clearly situated in the context of the participants' circumstances to offer some suggestions, within the scope of a qualitative study.

2.5 | Data analysis

After the data collection period, the interviews were transcribed verbatim, identifying features were redacted and real names replaced with pseudonyms. The first author immersed themselves in the transcripts and a reflexive thematic analysis was undertaken. The transcriptions were read several times until the transcripts were familiar. Then, each transcript was read through one at a time and codes were developed inductively until no new codes were needed to understand the data. Subthemes and larger overarching themes were developed from these codes (Braun & Clarke, 2021). See Table 1 for an example of how the subthemes and themes were generated.

3 | RESULTS

The study analysis focuses on exploring the experiences and views of mothers breastfeeding their sick children in paediatrics. The impact of the ward culture, healthcare staff attitude and skills, ward environment and equipment and direct impact of illness on breastfeeding all influenced and contributed in some way to the challenges experienced by the mothers.

3.1 | Participants

Thirty mothers with a mean maternal age of 32.3 years (range 19–40 years) and with a mean child age of 15.3 months (range 2–36 months) were interviewed. The mothers were all given a pseudonym using a random name generator app and are summarised in Table 2. Of the 30 mothers, 13 were non-white, with mothers who identified as Asian, Mixed race, and Chinese. The only two Black mothers who completed the screening survey were excluded as their experiences were in the neonatal unit. The sample also included five single mothers, and although the mothers in this sample were mostly educated to graduate level with seven educated to postgraduate level, there were five mothers who were educated to high school level. Two mothers in the sample identified as having a disability and one was homeless.

In total, eight of the mothers were from varied medical, nursing and allied healthcare professional backgrounds, and an additional three mothers were breastfeeding peer supporters. This is an over-representation of the usual proportion of mothers who would be expected to be medically qualified or invested in breastfeeding compared to a random sample on the ward or within the community. However, this was not discovered until the time of interview. It was recognised that these mothers may have been more motivated, better informed or more equipped to persevere with breastfeeding during adversity and this was considered during analysis.

TABLE 1 Example of raw data to subtheme generation.

Raw data	Sub theme	Sub-theme description	Theme	Theme description
"...if she's coming off, I know that she's gasping for air. And it's one of the signs. And she typically has a couple of really, really rough nights where she feeds you know, four, six times a night overnight in the days leading up to an admission."	Difficult breastfeeding	There were numerous breastfeeding difficulties and weight challenges as a direct result of child illness, including more frequent feeding, desaturation during feeding and other difficulties	Challenges of breastfeeding a sick child	Participants cited many difficulties including challenges with direct breastfeeding, expressing and their child's behaviour during illness

Sixteen of the mothers had previous breastfeeding experience and in terms of their children's feeding status, seven infants under 6 months were exclusively breastfed, and the remainder were mostly breastfed alongside solids. The two children with severe feeding difficulties ate no solids at all, and two mothers had stopped breastfeeding during their child's last admission. Children who were fed via nasogastric (NG) tube were included as there is no clinical reason why expressed breastmilk cannot be given through an NG tube, and therefore the specific breastfeeding needs of these mothers are also important.

In terms of the children's clinical conditions, 14 had chronic conditions including cardiac conditions, cancers, sensory disorders, bowel and anorectal disorders, and severe airway conditions. Sixteen children were admitted with acute medical or surgical conditions. The children had various durations of hospital admission. Some of the children with chronic conditions were admitted frequently, though not necessarily for long periods, while other chronically unwell or sick children were sometimes admitted for weeks or months, with the longest nonstop hospital admission in the study being 10 months. Ten of the children were admitted for 3 days or less at the last admission, and nine children had been admitted for more than 2 weeks.

The participants were not intentionally selected by geographical location, but because the advert was shared extensively and the eventual sample was large, there was a spread of locations, meaning that 30 different hospitals were represented in this study (see Figure 1).

3.2 | Thematic analysis

Seven broad themes were identified, including the challenges of breastfeeding a sick child, the importance of breastfeeding a sick child, the psychological impacts of persevering with breastfeeding a sick child, how breastfeeding a sick child impacts parenting and family life, the ward environment and equipment, lack of skills and knowledge and the ward culture and staff attitude. Some of the mothers spoke more generally of the impact of their child's illness, but this was always in the context of these stresses either increasing the importance of breastfeeding, or having an impact on their psychological wellbeing and indirectly on breastfeeding. See Table 3 for sub-themes and prevalence of each sub-theme.

3.3 | Theme 1: Challenges of breastfeeding a sick child

Participants cited many challenges of breastfeeding or expressing for their sick children. These included challenges with related maternal breast problems that arose as a result of their child's hospitalisation.

3.4 | Additional breastfeeding support required

There were several aspects of breastfeeding that mothers felt they required extra support to overcome. These were chiefly raised by

TABLE 2 Summary of participants.

Mother	Demographic details	Child's age	Breastfeeding status	Child's condition	Length of last hospital admission
Maria	Married Postgraduate education Mixed race	18 months	BF + solids	Croup	2 days
Nicky	Married Higher education White	30 months	NG fed formula, BF + solids	Rare form of cancer	14+ days
Maha	Married Higher education Asian	16 months	BF + solids	Fever	1 day
Anna	Married Higher education White	27 months	NG fed formula + BF (no solids)	Complex feeding difficulty	14+ days
Bex	Married High school education White	20 months	BF + solids	Multiple infections, numerous frequent admissions	5 days
Sila	Single NVQ education White	36 months	BF + solids	Chronic wheeze	2 days
Karin	Married Higher education White	13 months	BF + solids	Supraventricular tachycardia	10 days
Cintia	Single Higher education Mixed race	14 months	BF + solids	Bronchiolitis	1 day
Enora	Living with partner Higher education White	12 months	NG, bottle, solids. Stopped expressing on last admission	Complex needs. Tracheostomy Long term ventilation	14+ days
Samira	Married Postgraduate education Mixed race	3 months	Exclusive BF	Urinary tract infection	5 days
Ashley	Married Higher education Asian	5 months	Exclusive BF	Skin infection	2 days
Judith	Married Higher education White	24 months	PEG, BF + solids	Complex, rare bowel condition + unilateral vocal cord palsy	14+ days
Shayla	Married Higher education White	24 months	NG when ill, BF + solids	Bronchotracheo laryngomalacia + iatrogenic withdrawal	14+ days
Lyra	Single Higher education White	36 months	BF + solids	Immunodeficiency (low IgA—unknown cause)	10 days
Bridget	Married Higher education Mixed race	9 months	BF + solids	Intussusception	5 days
Alana	Single NVQ education White	18 months	NG fed formula + BF (no solids)	Sensory food aversion, seizures + suspected Autistic spectrum disorder	4 days

TABLE 2 (Continued)

Mother	Demographic details	Child's age	Breastfeeding status	Child's condition	Length of last hospital admission
Tova	Married Postgraduate education Mixed race	9 months	BF + solids	Norovirus	1 day
Jan	Married Higher education Asian	24 months	Stopped BF during last admission	Anorectal malformation	10 days
Alissa	Married Postgraduate education White	5 months	NG fed EBM when ill + BF	Broncholyngomalacia + vocal cord paresis	8 days
Georgie	Married Higher education Chinese	3 months	Exclusive BF	Viral meningitis	1 day
Molly	Married Postgraduate education White	12 months	NG formula/EBM when ill + BF and solids	Pneumonia	5 days
Lucy	Married Postgraduate education Mixed race	11 months	BF + solids	Meningitis + urinary tract infection	4 days
Ruth	Married High school education Disability White	34 months	NG fed formula + BF (minimal solids)	Acute lymphoblastic leukaemia (regimen C)	14+ days
Tamsin	Single High school education Disability Homeless White	2 months	Exclusive BF	Jaundice, safeguarding	3 days
Sophie	Married Higher education Asian	4 months	Exclusive BF	Jaundice	2 days
Nephele	Married Higher education Asian	17 months	BF + solids	Inhaled foreign body	1 day
Sian	Living with partner Postgraduate education White	13 months	BF stopped in hospital, formula. Relactated, now BF + solids	Lactose intolerance resulting from severe gastroenteritis	14+ days
Marsha	Married Higher education White	16 months	BF + solids	Transverse myelitis	14+ days
Kayla	Married Higher education White	12 months	NG fed EBM, BF + solids	Complex cardiac + bilateral vocal cord palsy	14+ days
Ali	Married Higher education Asian	3 months	Exclusive BF	Fever	4 days

Abbreviation: PEG, percutaneous endoscopic gastrostomy.



FIGURE 1 Visual representation of participants' location.

mothers of children who were more seriously or chronically unwell.

"Yeah, because there was no, there was no consideration for the fact that [redacted] had a giant mask on his face... she's saying, 'try and do like, nose to nipple'. I was like, 'he's got a massive mask on his face'" (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

"...it caused him to basically be like, he couldn't move his arms and legs, he couldn't sit up. He couldn't. Yeah, he was very floppy." (Marsha, 30, mother of child, 16 months, with transverse myelitis, BF)

"She was too weak to suckle so I just sit there with her with it in her mouth until I get sore essentially." (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

3.5 | Difficult breastfeeding

The mothers reported numerous breastfeeding challenges as a result of their child's illness, including frequent feeding, challenges with weight loss, desaturation during feeding, difficulty manoeuvring around cannulas, painful latch, modifications to positioning, feeding refusal and damage to reflexes or loss of tone.

3.6 | Breast problems

Distinct from breastfeeding challenges were the specific breast-related problems that mothers experienced. These ranged from nipple pain, blebs and engorgement to an infected fissure that was hard to treat.

TABLE 3 Proportion of participants identifying each theme and subtheme.

Theme	Subtheme	N	%
1. Challenges of breastfeeding a sick child	Additional breastfeeding support required	10	33.3
	Difficult breastfeeding	26	86.6
	Breast problems	9	30
	Enteral feeding	11	36.6
	Expressing	16	53.3
	Fatigue	14	46.6
	Fatigue	11	36.6
	Fluid charts and balance	12	40
2. Importance of breastfeeding a sick child	Milk supply problems and anxiety	12	40
	Breastfeeding feels like a buffer	18	60
	Breastfeeding for comfort	24	80
	Breastfeeding as a parenting tool	13	43.3
	Maternal motivation as a buffer	16	53.3
3. Psychological impacts of persevering with breastfeeding a sick child	Difficult emotions/guilt/conflict	13	43.3
	Disempowerment/doubting themselves	11	36.6
	Loneliness	6	20
	Poor care has put them off seeking help	6	20
	Trauma and distress	7	23.3
	Vigilance	7	23.3
4. How breastfeeding a sick child impacts parenting and family life	Bedsharing	24	80
	Change in breastfeeding behaviour is a sign	15	50
	Difficult choices and juggling	14	46.6
	Difficult choices and juggling	9	30
	Impact on family	10	33.3
	Intuition	17	56.6
	Responsive parenting not supported	17	56.6
5. Ward environment and equipment	Covid made things harder	13	43.3
	Food provision and basic needs	23	76.6
	Furniture/pillows	9	30
	PICU	4	13.3
	Privacy	17	56.6
	Pumps	14	46.6
6. Lack of skills and knowledge	Advice didn't meet needs	19	63.3
	Breastfeeding assessment	20	66.6
	Feed schedules and rules	7	23.3
	Formula	12	40
	Inaccurate/inadequate information/errors	14	46.6
	Procedures	10	33.3
7. Ward culture and staff attitude	Ambivalence from staff	20	66.6
	Awkwardness	6	20
	Breastfeeding is inconvenient to staff	8	26.6
	Encouragement/kindness	13	43.3
	Helpful BF interventions	15	50
	Helpful BF interventions	9	30
	Hero	14	46.6

TABLE 3 (Continued)

Theme	Subtheme	N	%
	Hostile/lack of compassion/outrageous comments	5	16.6
	Ignored by staff	10	33.3
	Love for the National Health Service (NHS)	10	33.3
	Staff interaction	23	76.6
	Support not provided		

"I was given a pump, the hospital grade one. But with the wrong size flange. And there were no others available in the hospital, so had to use it with the wrong ones. And I ended up with a fissure that got infected. And long story short, I had four months of an open wound. And three different rounds of antibiotics to clear this horrendous fissure, it was awful." (Judith, 30, mother of child, 24 months, with rare complex bowel condition, PEG/BF)

3.7 | Enteral feeding

Feeding children with NG or percutaneous endoscopic gastrostomy tubes was found to be stressful. Not only were the tubes sometimes inconvenient but ensuring that children received the correct amount of fluid was also difficult.

"...we would literally like you know, we'd have to aspirate his tube, put the feed on, sit indoors for two hours while it went on. Take it off, wait two hours, put another one on. And it was just, it dominated the whole day." (Ruth, 32, mother of child, 34 months, with ALL, NG/BF)

3.8 | Expressing

Expressing was often accompanied by mixed emotions for participants. Many mothers saw it as an act of sacrifice, but some found it logistically challenging or intensely disliked it. Expressing was part of a broader experience of support and prioritisation for breastfeeding, and valuing breastmilk, as well as the stress and challenge of expressing during a difficult time and to provide their children with breastmilk.

"I hated expressing... every part of it... every single time. I hated it, it was the worst thing ever." (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

"To me as well, I think it like it gave my day purpose..."
(Kayla, 36, mother of child, 12 months, with complex cardiac condition, NG/BF)

didn't happen. And that was the end of our breastfeeding there." (Jan, 34, mother of child, 24 months, with anorectal malformation, stopped BF)

3.9 | Fatigue

Many mothers described intense fatigue resulting from caregiving and more frequent feeding, as well as iatrogenic factors.

"...it's just like, more intense. So in itself, having a sick child is quite stressful. If you count that you will normally wouldn't sleep properly, because you're like, constantly checking on them and whatever. But the fact that he would be feeding more often, it makes it even harder."
(Maria, 35, mother of child, 18 months, with croup, BF)

3.10 | Fluid charts and balance

Attempts to maintain accurate fluid balance using fluid charts caused anxiety for mothers. Many were frustrated by the lack of understanding of breastfeeding which is difficult to quantify, as well as sometimes feeling demoralised by the unachievable amounts of milk that they would be required to produce to balance the fluid chart.

"They kept trying to ask me how much has he had? Because I think it was very much tailored towards you know, formula fed babies and while he's had this many ml or whatever, but I kept trying to say, well, I don't I don't know... I couldn't really give them kind of like the amounts that they were trying to document." (Maha, 34, mother of child, 16 months, with fever, BF)

"...the input-output – it's a big stress for people, which I understand; she's got a high output obviously, we've been in with massive dehydration before. She was at one point, you know, she was nine kilograms, and she was losing 1.5 litres a day out of her stoma." (Judith, 30, mother of child, 24 months, with rare complex bowel condition, PEG/BF)

3.11 | Milk supply problems and anxiety

Many mothers had concerns about their milk supply. This was sometimes due to shock and stress, and sometimes an iatrogenic cause, such as failure to provide a pump in a timely fashion.

"...it was just so stressful. It was kind of probably partly the delay in actually getting the time and finding someone to come and bring the breast pump around then trying to express while she was so poorly, it just

3.12 | Theme 2: Importance of breastfeeding a sick child

Almost all the mothers described breastfeeding as being a comfort to their child and described a sense of breastfeeding against the odds—the idea that breastfeeding was not easy, but worth it.

3.13 | Breastfeeding feels like a buffer

Buffers identified by the mothers included prevention of more aggressive disease, as well as providing calories, fluids, and pain relief. One mother described her post-operative child's pain from being in ileus as unmanageable despite morphine and ketamine, yet breastfeeding provided effective pain relief. Another managed her child's emergence delirium by breastfeeding. Two children were on high-dose chemotherapy and yet unusually had no mucositis.

"... while he does get sores on the outside of his lips, he doesn't get any on the inside of his mouth at all. And a lot of the kids on the ward have. I don't know if it's anything to do with breastfeeding, but I like to think that possibly..." (Nicky, 32, mother of child, 30 months, with rare childhood cancer, NG/BF)

3.14 | Breastfeeding for comfort

Several mothers cited comfort as a major reason to persevere with breastfeeding. As well as providing comfort to children, breastfeeding was also comforting to mothers and created opportunities to calm down after procedures.

"It's a comfort and helps them with pain but the way he was talking about it he was saying it's comfort but also it stops it hurting on a very physical level." (Lyra, 31, mother of child, 36 months, with low IgA, BF)

"...there's just an immediate sort of relaxation that comes over them... and with me, it honestly it helped a lot." (Ali, 34, mother of child, 3 months, with fever, BF)

3.15 | Breastfeeding as a parenting tool

Breastfeeding was clearly a 'cure-all' for many parents, giving them a tool to soothe children who were bored, scared, hungry, sore or angry.

"...it just means I can give her you know... comfort and... nutrition and everything else that comes with it. You... think that at six months that don't need that as such. But for me, it's been my ace card when she's not well..." (Bex, 34, mother of child, 20 months, with multiple admissions, BF)

3.16 | Maternal motivation as a buffer

Several mothers were motivated by a desire to maintain something that was within their control.

"...we're really lucky that we're still doing it. But I felt that all of that was down to me, educating myself after the fact... So you know, reading, reading the books, and then doing the peer support training and... all of that sort of stuff that ensured that we got through it" (Molly, 33, mother of child, 12 months, with pneumonia, NG/BF)

3.17 | Theme 3: Psychological impacts of persevering with breastfeeding a sick child

The third theme related to various psychological impacts of breastfeeding children through illness. There were many emotions identified, including guilt, loneliness, isolation, self-doubt, disempowerment, trauma, distress and hypervigilance.

3.18 | Difficult emotions/guilt/conflict

There were numerous examples of complex and difficult emotions. Several mothers also described feeling torn between wanting to stop breastfeeding and feeling compelled to continue.

"...some days, I'm really grateful. And some days, I feel like I'm kind of trapped. Because if it wasn't for the cancer, I think I would have weaned by now." (Ruth, 32, mother of child, 34 months, with ALL, NG/BF)

3.19 | Disempowerment/doubting themselves

Eleven mothers felt a profound sense of disempowerment on the ward and many parents doubted themselves even when they knew they were right.

"I felt very insecure... you can read as much about... babies and... child health as you like, but... when it's your child sort of in front of you, and you're not exactly sure what's going on. I think... it's quite a different sort of experience in a way... I sort of parked any of my brains at the door..." (Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

3.20 | Loneliness

Another subtheme was that of loneliness and isolation. Some mothers admitted they wanted someone to talk to but found the staff were task-orientated and busy.

"...it can be quite like, an isolating experience in hospital... And I mean, I'm a single parent as well. So every time that I do go into hospital, I'm always there on my own." (Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

"...they're long and lonely nights sitting in hospital, because... she would go on her feed at about seven o'clock at night. And so, I'd have to put her in the cot and trap her in there. And so, I couldn't do anything..." (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

3.21 | Poor care has put them off seeking help

Some mothers felt put off seeking help because of poor care, and others downplayed or actively withheld information from healthcare providers because they did not trust that they were going to be given accurate advice.

"...she's very much: 'He's 18 months, he doesn't need feeding at night now... you should stop feeding him at night'. So, to be honest, I do tell a little porky pies and I just say he wakes up once or twice for a feed." (Alana, 39, mother of child, 18 months, with severe complex feeding, NG/BF)

"...it's actually... it's prevented me from ever wanting to go into hospital again. There was one time I was on the borderline, kind of the cusp of taking him in again, where again, he had very high fever wasn't really coming down. And I was thinking do I need to take him in? And but the thought of that kind of was just like, 'You know what.... I can care for him better at home?'" (Maha, 34, mother of child, 16 months, with fever, BF)

3.22 | Trauma and distress

Some parents described distress, grief and vicarious trauma which was distressing to witness, but also placed them in a moral dilemma about where to pump without causing further stress to bereaved parents. Other mothers commented on how profoundly stressful it was to be told to stop breastfeeding.

"I remember one, one day very sadly, the child in the bed next to her passed away. And I was tied to the ward to pump but, the parents next to me very clearly needed me to just bugger off... And so I kind of just disappeared. But I was so uncomfortable. And I didn't really know what to do..." (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

"It was honestly the most grief I've ever felt [being told to immediately stop breastfeeding] I can't. Like I can't explain to you..." (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

3.23 | Vigilance

Many mothers of children with chronic conditions felt unable to relax or feel at ease about their child once they were home due to the severity of their condition or rapidity of deterioration. Mothers who raised this also felt that this was one reason they could not stop breastfeeding even if they wanted to, due to the immunological protection they felt it provided. Many were anxious about opportunistic infections and felt worried about exposing their child via nursery or school.

"I'm terrified of colds - my son's at school, and that's our weak link... you should see the medical plan we've sent the nursery; it just looks really bleak... Yeah, it's just really stressful." (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

"You know, she could die if she caught a cold, you know, so we were like really scared when we came home." (Kayla, 36, mother of child, 12 months, with complex cardiac condition, NG/BF)

3.24 | Theme 4: How breastfeeding a sick child impacts parenting and family life

The fourth theme related to wider aspects of the impact on family life, including finances, siblings, juggling work, parenting style, and intuition.

3.25 | Bedsharing

Most parents cited bedsharing as being an issue to a greater or lesser extent. In some cases, bedsharing was facilitated, but the majority encountered opposition which caused stress. While there may have been bedsharing policies, these were not shared with the families who were denied this opportunity, and the mothers often felt distressed at the way in which this was handled.

"They gave me a room with a cot and chair. And I said I breastfeed and co-sleep... So is there any room with a bed or anywhere I can feed him I said, he's not feeding that often in a chair, I can't get him a good position. Can I try feeding lying down... And I was told no. So I ended up just laying my coat out on the floor of the room and feeding him on the hospital floor." (Lyra, 31, mother of child, 36 months, with low IgA, BF)

3.26 | Change in breastfeeding behaviour is a sign

Changes to feeding efficiency, frequency or refusal to feed were often correctly interpreted by mothers as signs of their child's condition either deteriorating or improving.

"...if they don't eat and just want to be on the breast or cuddling it's like definitely a sign that he is not well..." (Maria, 35, mother of child, 18 months, with croup, BF)

3.27 | Difficult choices and juggling

Many of the parents described a sense of having to juggle children and make difficult choices.

"...to get three kids out the door and at school and food and you... get them on the breast whilst you're NG feeding. It was... it was a challenge, it really is..." (Alissa, 32, mother of child, 5 months, with bronchotracheolaryngomalacia and vocal cord paresis, NG/BF)

3.28 | Impact on family

Distinct from juggling children, some mothers described the financial strain of having a child in hospital, while others spoke about how they had to give up work to care for their child.

"I haven't actually returned back to work yet, because all of my focus was on him and his rehabilitation."

(Marsha, 30, mother of child, 16 months, with transverse myelitis, BF)

3.29 | Intuition

Several mothers felt that breastfeeding enabled them to tap into their intuition and become more responsive.

"I knew he was hungry. I knew his cues. Like I hadn't known him that long, three days. But at that point, I'd started to pick up on the little things, because being around him literally 24/7. And, you know, I'm recognizing these things and everyone's telling me. And no, no, that's not what that is. And I'm like, yes, yes, it is..." (Tamsin, 19, mother of child, 2 months, with jaundice, BF)

3.30 | Responsive parenting not supported

Numerous mothers cited examples of responsive parenting and responsive feeding not being understood or valued by the staff.

"...they were actively dissuading me from holding him and touching him and having him on me, every time they came in and saw that I was holding him, they're like, 'You need to put him down. So what I was doing was kind of putting him down. And then, you know, when they went away, kind of picking him up again, but I just felt like I was naughty and doing something wrong.'" (Maha, 34, mother of child, 16 months, with fever, BF)

3.31 | Theme 5: Ward environment and equipment

The fifth theme related to the ward environment, resources, provisions, equipment and processes. Some parents did have examples of good care and plentiful provisions, but the majority were frustrated by ward-level under resourcing.

3.32 | Covid made things harder

Many of the mothers were affected by restrictions imposed during the Covid-19 pandemic. Several mothers were unable to have their other children present, even when they were also breastfed, and many partners were unable to visit, even during critical illness.

"...obviously COVID: One parent only... So it wasn't like I could just ring my husband and say, Oh, can you drop the breast pump round or anything like that, but it's those kind of things... There was no consideration to - well if you're a breastfeeding mum, you can't leave her for 24 hours." (Jan, 34, mother of child, 24 months, with anorectal malformation, stopped BF)

3.33 | Food provision and basic needs

Most of the mothers in this sample expressed anger, frustration and disappointment that they were not provided with sufficient food.

"The first day we were in nobody fed us at all. We had to go and ask if there was a canteen or something because we were really hungry..." (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

3.34 | Furniture and pillows

Many of the mothers commented on beds, chairs and pillows. Many of the chairs were difficult to feed in, especially for an older, larger child.

"...the space was awkward. Because... it's hard to feed her in the armchair and you had like a camp bed for overnight, but she... didn't want to sleep in the cot. So I had to keep kind of bringing her into the camp bed and not fall off and also feed her there. So it was uncomfortable." (Nephele, 39, mother of child, 17 months, with inhaled foreign body, BF)

3.35 | PICU

There were several comments about the intensive care environment where children were mechanically ventilated via endotracheal tube, tracheostomy, or received continuous positive airway pressure. Specific challenges were not being able to be present overnight, a lack of acceptance of skin to skin on PICU, and how traumatic the environment itself was.

"Now, there was lots of other doctors on that intensive care unit. And they were all very much: 'babies that are intubated, don't get held. These babies are staying in bed.'" (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

3.36 | Privacy

A common subtheme was enforced privacy. Many women felt angry when staff members closed curtains, shut doors and turned lights off when they were perfectly comfortable breastfeeding on the ward.

"...you did think....why are you pulling the curtain? Like you can't see through the door anyway. Yeah, it then felt like you were a little bit shut away with the behind the curtain..." (Lucy, 35, mother of child, 11 months, with meningitis, BF)

"I went to a breastfeeding...like a lactation support worker. And I left there feeling probably worse about my experience..." (Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

"I couldn't settle her, and it hadn't been explained to me at that point that she was suffering from [iatrogenic opiate] withdrawal ... They were measuring her withdrawal against neonatal scores, where it talks about checking on the mother. So, it made me feel like I was a second-class citizen. Because what they had wasn't necessarily fit for purpose." (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

3.37 | Pumps

There were numerous comments about pumps. A few mothers were promptly given pumps, but the majority experienced delays or failure to provide a pump.

"...They were trying to get hold of one from maternity because he was refusing to even breastfeed. They were trying to get hold of one for me. It had been a while (since he last fed). But I don't think they managed to get hold of one. And they were looking for hours..." (Lyra, 31, mother of child, 36 months, with low IgA, BF)

3.40 | Breastfeeding assessment

None of the mothers reported having a breastfeeding assessment, and this included children whose primary reason for admission was directly related to feeding. While all the mothers in this sample had already established breastfeeding, their child's illness affected breastfeeding in novel ways, and yet nobody re-assessed milk transfer either to support direct optimal breastfeeding or to ensure adequate hydration.

"Nothing on breastfeeding. No, no, not how to support breastfeeding with a sick child or anything..." (Cintia, 35, mother of child, 14 months, with bronchiolitis, BF)

3.38 | Theme 6: Lack of skills and knowledge

The comments about lack of knowledge and skills were not confined to paediatric clinical staff but also included issues with maternity infant feeding specialists and non-clinical lactation specialists who had little or no awareness of the challenges of sick children beyond the neonatal period.

"...they have no idea how to check a latch. If he's latched in any way, they'll be like, 'yep, that's fine'. I've learned that. Like if he's attached to the boob, that's a 'good latch'." (Lyra, 31, mother of child, 36 months, with low IgA, BF)

3.39 | Advice didn't meet needs

Numerous mothers described care that did not meet their needs. This ranged from nobody knowing the answer to an important question, to advice that was not tailored or nuanced enough for critically sick children in paediatrics.

"...the breast-feeding support worker that was attached to PICU bless her. She...didn't know anything about it really, like she's obviously read the facts, but it's very different, isn't it?... (Kayla, mother of child, 12 months, with complex cardiac condition, NG/BF)

3.41 | Feed schedules and rules

Many of the mothers were frustrated by imposed schedules and three to four hourly feeds. These rules often extended to NG feeding as well despite there being no clinical justification for four-hourly NG feeding. While fully responsive NG feeding may be impractical, some flexibility around feed timings would have been appreciated by mothers. Feeding schedules also risk suggesting that a strict schedule is preferable to responsive feeding.

"...they were feeding her every three I think it might have been every four hours... They wanted to measure the volumes that she was taking and keeping down." (Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

3.42 | Formula

Several of the mothers felt that there was a lack of understanding of breastfeeding and breastmilk, and most of the staff seemed more familiar and comfortable with formula.

“...she was 100% [high calorie formula]... because that's what they do. That is the process... And trying to say, but why am I pumping? And in the end, what really frustrated me is I came home from that visit, with litres of frozen milk that I ended up donating.” (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

3.43 | Inaccurate/inadequate information/errors

Many mothers described incidents where they were not provided with the information they needed to maintain their milk supply or breastfeed effectively.

“...you're just sitting in the dark in the hospital, you can't sleep anyway, trying to pump at five o'clock in the morning because you, you know that you're ... you need to be pumping at these times - you *think* because you've read it on Google, but you're not sure because no fucker's telling you...” (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

3.44 | Procedures

Within this subtheme, there were two main issues; parents not being allowed to be present in the procedure room to offer their child comfort, and breastfeeding not being valued as pain relief.

“...they wouldn't let me. They did allow that in the other hospital. That's exactly how they got the cannula in. ... But yeah, when we got to the other hospital, they were just wanting to do what they wanted to do.” (Bridget, 32, mother of child, 9 months, with intussusception, NG/BF)

3.45 | Theme 7: Ward culture and staff attitude

The final theme was related to the general culture of the ward with respect to breastfeeding and responsive parenting, as well as the attitudes of staff members.

3.46 | Ambivalence from staff

The sense from most parents was that staff were ambivalent. This was often accompanied by other identified challenges such as lack of proactive or anticipatory guidance.

“I would say that that one nurse was definitely hostile. But I would say the others were just ambivalent. Yeah, it wasn't that they were trying to discourage me but they also weren't doing anything to encourage me either...” (Maha, 34, mother of child, 16 months, with fever, BF)

3.47 | Awkwardness

Several mothers described a sense that staff were embarrassed to ‘catch’ them breastfeeding, which was upsetting.

“I've had doctors come in while I was breastfeeding my baby and immediately leave the room saying, ‘Oh, no, I'll come back later’. So I didn't mind breastfeeding the baby in front of the doctors. They shouldn't have left the room immediately, because we were waiting for them.” (Ali, 34, mother of child, 3 months, with fever, BF)

3.48 | Breastfeeding is inconvenient to staff

Several of the mothers described a sense that breastfeeding was inconvenient to staff. This was mostly related to the challenges of recording accurate fluid balance.

“...a lot of them have sort of thought of breastfeeding as a barrier to her eating...they actually mentioned that a few times that it would be easier if she was bottle fed because we could see how much she was getting.” (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

3.49 | Encouragement/kindness

Many of the mothers acknowledged the kindness of some of the staff—often observed to come from non-clinical staff such as cleaners, housekeeping staff and porters.

“...everyone was just always really kind of like, you know, pro, whatever you want to do. You know ‘God, yeah, if you want us to hold her while you do that,

that's fine'. You know, so I think yeah, they were lovely, lovely, lovely people. I just think they just didn't know anything about breastfeeding." (Kayla, mother of child, 12 months, with complex cardiac condition, NG/BF)

3.50 | Helpful breastfeeding interventions

Some of the mothers were able to identify helpful strategies and clinical interventions that supported them in their efforts to continue breastfeeding or expressing.

"...they did suction on her nose to suck out mucus to help her with her feeding..." (Cintia, 35, mother of child, 14 months, with bronchiolitis, BF)

"I did do some feeds when they were accessing her cannula for drugs and whatever. And she was feeding and they just kind of worked around me and her at the time." (Georgie, 33, mother of child, 3 months, with meningitis, BF)

3.51 | Heroic staff member

Several mothers spoke about a standout professional. These 'heroes' were often described as having 'saved' the mother's breastfeeding journey.

"... she would just ring me and she did actually come over and visit me. But that was just because kind of, I don't know, even if that's part of her role, she just kind of did it out of the kindness of her heart. But she did come over to visit from the neonatal unit at a different hospital." (Kayla, mother of child, 12 months, with complex cardiac condition, NG/BF)

3.52 | Hostile staff

The opposite subtheme to the heroes was that of hostility. Almost half the mothers in the sample described interactions or a culture of distinct hostility, including receiving negative comments and being shouted at.

"I felt a bit ganged up on... she compared it to smoking... that she was addicted to breastfeeding, and that it was like smoking and that we had to stop it for her own good." (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

3.53 | Ignored by staff

Some of the mothers felt like they were ignored by the ward staff. Occasionally this was interpreted positively, as a lack of interference, but mostly it was negatively perceived.

"I think they know better than to talk to me about it now, at my local, because they know I will complain. And they'll just leave me alone to get on with what I need to do, which is easier." (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

3.54 | Love for The National Health Service (NHS)

There was a distinct subtheme of discomfort around criticising the NHS. Many participants readily acknowledged that many staff were kind and hard-working.

"...sometimes I think I'm overly excusing of the NHS, having worked for the NHS... And I know how stretched they are and I know how understaffed, and I know how hard is on them. So to a certain extent... we're more forgiving than a lot of parents would be..." (Nicky, 32, mother of child, 30 months, with rare childhood cancer, NG/BF)

3.55 | Staff interaction

There were numerous examples of staff interactions that were noteworthy to parents. It was common among the mothers of older breastfed children to notice obvious shock or incredulity at the fact that they were still breastfeeding, but it was not isolated to older children.

"...the general response that you get is, 'oh, wow, I can't believe you're breastfeeding. And that's very difficult. I couldn't do it. I didn't breastfeed past this... I didn't do it', and you hear that time and time again from people. It's very rare that you get a positive thing that's not reversed back to that person - whoever is talking about their own experience." (Ali, 34, mother of child, 3 months, with fever, BF)

3.56 | Support not provided

The final subtheme identified was around lack of support. Sometimes this was an act of omission, and other times it was more obstructive. For example, some mothers asked for support and were denied it.

"What I needed them to do just in that moment... I just needed some reassurance..." (Samira, 31, mother of child, 3 months, with urinary tract infection, BF)

"...you kind of go to [a coffee shop]... and you're breastfeeding, and you don't need to buy a drink, but they still come up and offer you a drink and they offer you water and everything. But then you do that in a hospital where they're all medical professionals and you don't get that kind of even supportive offer, you know, a drink of water or something." (Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

4 | DISCUSSION

This study explored the experiences of 30 breastfeeding mothers of children admitted to the paediatric setting with a range of illnesses in the United Kingdom. It identified numerous challenges related to breastfeeding, parenting, mental health and staff skill and knowledge gaps as well as challenges in the clinical environment. The study provides insight into what measures are perceived to be supportive by mothers. It also highlights shortcomings that are not consistently addressed within paediatrics. Several parents of children who were profoundly unwell struggled to maintain their milk supply, and found that major adaptations to breastfeeding were required. It was difficult to obtain the support they required to overcome these problems, leading many parents to experience negative breastfeeding outcomes, breast pathology, stress and exhaustion, as well as threatened or actual breastfeeding cessation.

The range of childhood illnesses has illuminated many previously unrecognised breastfeeding challenges—such as high stoma losses, high calorie needs alongside fluid restriction, neurological irritability and opiate withdrawal. This has implications for designing training that meets the clinical needs of this population as well as the staff supporting them. Some of the challenges around maintaining milk supply have previously been reported in other settings, including neonatal intensive care (Alves et al., 2016) and unrelated to breastfeeding, studies of parent experiences in PICU have also reported issues related to powerlessness and exhaustion (Alzawad et al., 2020; Dahav & Sjöström-Strand, 2018).

Breastfeeding was perceived by mothers, especially those whose children were more seriously unwell, to provide immunological support, as well as non-pharmacological pain relief. Current evidence suggests that breastfeeding provides effective pain relief during needlestick procedures and vaccination (Harrison et al., 2016; Shah et al., 2015), but the mothers in this study were describing effective pain relief for their children with cancer, surgical ileus that was unresponsive to morphine and ketamine, and other significant pain. Breastmilk provides immunological support (Hanson et al., 2003; Hassiotou & Geddes, 2015; Moossavi et al., 2019) and for children who were more seriously unwell, this was evident in fewer episodes

of febrile neutropaenia than their non breastfed peers, absence of mucositis, and faster than expected recovery from major surgery. While there are no human studies to validate these clinically significant observations, there was a recent discovery that an oligosaccharide abundant in breastmilk, 2'-fucosyllactose (2'FL), prevents intestinal epithelial cell apoptosis in mice exposed to chemotherapy (Zhao et al., 2022).

Many mothers reported that breastfeeding provided a parenting tool in an environment that was often hyper-clinical and disempowering. Breastfeeding enabled mothers to perceive clinically relevant micro-changes in their child and predicted deterioration or recovery, as their illness behaviour often affected their feeding and vice versa. This was true for mothers of children with both self-limiting and more serious or chronic illness and echoes findings from neonatal settings in terms of breastfeeding leading to increased self-efficacy and sense of agency (Butler et al., 2014; Flacking et al., 2007). Emotional connection, normality, comfort and stress-reduction through breastfeeding are also valid reasons to preserve breastfeeding (Ekström & Nissen, 2006; Moberg & Prime, 2013; Murray et al., 2007).

The psychological impacts of breastfeeding sick children were complex, particularly among the mothers of children with more severe illness. Some experienced conflicting emotions—such as feeling compelled to continue breastfeeding and also wanting to stop. Some of the mothers' motivations to persevere with breastfeeding included wanting to offer additional immunological support and non-pharmacological pain relief, and in some cases, mothers noted that they would not necessarily have breastfed for as long as they had done in the absence of illness. These conflicting emotions have previously been reported in other studies, though not related to sick children (Dowling & Pontin, 2017; Jackson & Hallam, 2021). Others were exhausted and wanted a break but did not want to leave their child. Trying to make sense of opposing feelings, while continuing to persevere with breastfeeding in an environment where it was neither facilitated nor encouraged was infuriating. There was a sense that breastfeeding took so much effort, that when health professionals suggested that stopping breastfeeding would be easier, many mothers felt angry and disregarded. Some mothers had experienced trauma and noticed that this affected their ability to express milk. While trauma has been identified among parents whose children experience life-threatening illness (Foster et al., 2017; Mortensen et al., 2015; Muscara et al., 2015; Woolf et al., 2016), the effects of trauma on breastfeeding in paediatrics are unstudied. The identified challenges of expressing milk may justify the extension of donor human milk provision in the paediatric setting to augment a mother's efforts to keep her child exclusively breastmilk fed, which has been shown to promote parental mental health (Brown & Shenker, 2022).

Breastfeeding is related to many aspects of family life and parenting. Mothers who feed responsively are generally more likely to meet their feeding goals (Brown & Arnott, 2014; Little et al., 2018; Ventura, 2017). Bedsharing while breastfeeding, coined 'breastsleeping' (McKenna & Gettler, 2016) facilitates more rest and thus makes

responsive breastfeeding more sustainable (ABM, 2008; McKenna et al., 2007). This was commonly not facilitated on the paediatric ward, and sometimes resulted in distressed children and mothers who achieved very little sleep. From a clinical perspective, the challenges of supporting bedsharing in paediatrics are longstanding and hospital bedsharing guidelines are inconsistent. While blanket statements are inappropriate due to the variable clinical needs of children in hospital, more clarity is required for families.

Responsive parenting was often felt to be undervalued. Two mothers of infants receiving phototherapy were not told that breastfeeding breaks of up to 30 min do not affect treatment efficacy and were discouraged from holding their infants (Flaherman et al., 2017; Sachdeva et al., 2015). Skin to skin was neither encouraged nor facilitated for two infants in PICU. Skin to skin contact has no upper time limit, and an abundance of literature promotes the intervention for sick and low birth weight neonates (Blomqvist & Nyqvist, 2011; Charpak et al., 2021; Johnston et al., 2009; Salim et al., 2021). There are no studies of skin-to-skin in the paediatric setting, however, there is no physiological reason why this would not be beneficial beyond the neonatal period, and some research points to the positive effect of touch and carrying (Berecz et al., 2020; Pawling et al., 2017).

Many mothers remarked that it was hard to meet their basic needs while on the ward, echoed in other studies of parents in PICU (Berube et al., 2014; Shudy et al., 2006). While some hospitals provided food and snacks, others had inconsistent provision. Many had to buy food from the canteen or on-site shop which caused financial anxiety, particularly with longer admissions. The lack of provisions extended into the unavailability of breast pumps. The core issue for most wards was that there were no designated pumps for the paediatric unit. Staff sometimes tried to borrow pumps from the postnatal ward or NICU, but this was only occasionally successful. There were no pumping rooms on paediatric wards and storage was limited, with a few incidents of milk being discarded due to lack of space. Often when mothers were provided with a pump, there were no instructions, which meant that mothers struggled to use them. While literature exploring the challenges of expressing on neonatal units and the reasons for expressing in healthy term neonates is plentiful, no studies explore the challenges of expressing in paediatrics (Bower et al., 2017; Bujold et al., 2018; Johns et al., 2013).

Several skill and knowledge gaps were highlighted. Most paediatric professionals receive little to no breastfeeding training as part of their initial education leading to knowledge deficits (Brewer, 2012; Colaceci et al., 2017; Holaday et al., 1999; McLaughlin et al., 2011). Some professionals access post qualification training but are likely to be those already invested in breastfeeding. Thus, many healthcare professionals who care for breastfed children have no breastfeeding training. It is therefore unsurprising that inaccurate advice was common, and nobody received a breastfeeding assessment.

Current breastfeeding training is weighted towards the initiation of breastfeeding in healthy term newborns (WHO, 2020), with some additional training available for preterm and sick neonates

(Gerhardsson et al., 2023). Most training is not nuanced enough to support children in paediatrics with medical complexity which explains why, when a member of the neonatal or maternity infant feeding team visited a family, the advice was still lacking. In this study, several mother-child dyads experienced problems which the staff had no experience of, such as breastfeeding with airway difficulties, and managing high caloric need with fluid restriction. Many of the mothers reported that the care they received did not meet their needs. With complex feeding challenges in this study, the only effective feeding support was provided by dual qualified lactation and paediatric clinicians.

While parents valued encouragement, when it came to practical advice, very few mothers had a positive experience. The instances when a maternity or neonatal infant feeding lead was 'borrowed' were largely ineffectual, and solutions were also not found among nonclinical lactation advocates. This is unsurprising, as management of many of their challenges would be outside the scope of practice of an IBCLC (International Board of Lactation Consultant Examiners, 2018) because assessment of unwell children would be required—for example iatrogenic withdrawal, loss of reflexes, respiratory compromise, and complex fluid needs. This suggests that nonclinical and non-paediatric lactation supporters may need additional training to be able to support children with more complex health challenges, and equally, paediatric professionals need lactation training to be able to integrate lactation and clinical support for families. Joint training and multidisciplinary working could be an effective option to ensure that families are cared for by professionals with enough skills to both clinically assess children but also protect breastfeeding.

There were numerous examples of positive and negative communication. Ambivalence was common, but there were also examples of exemplary and substandard care. Mothers tended to have more positive experiences when the staff were kind, even if they could not help. Kindness has previously been found to be a buffering factor in the perceived quality of experience on paediatric wards (Tsironi & Koulterakis, 2019). Equally, practitioners who are empathic can improve a patient's psychological condition and satisfaction with care (Howick et al., 2018). Mothers sometimes reported sadness that breastfeeding was viewed neutrally. There is a need for professionals to improve the individualisation of the health and lactation care messages they deliver. This 'agenda matching' leads to more therapeutic communication (Rothman, 2016).

At the negative end of the support scale, practitioners displayed signs of hostility, such as appearing horrified, or making negative remarks. Another common negative response was staring and surprise, particularly among parents of older children. These negative reactions have been previously reported outside of the hospital environment, with mothers of children who are breastfeeding beyond the age of 1 year tending to conceal their 'extended' breastfeeding status, including from medics (Jackson & Hallam, 2021; Thompson et al., 2020). It is more difficult to conceal breastfeeding in hospital where nutrition is an integral part of a child's care, and many mothers were thus subjected to staff reactions.

Encouragement and praise even without practical problem solving was viewed positively and protected self-esteem. Other studies have found that when parents are involved in decision making, they feel more empowered (Ashcraft et al., 2019; Reeder & Morris, 2021). Beyond practical support, some parents were able to find someone who could answer their question. These individuals were not always located on the paediatric ward but were often described as having 'saved' the breastfeeding journey. This support was not proactive though, so this may only be accessed by those who are confident, articulate, persistent or motivated.

4.1 | Limitations and future research recommendations

There were several limitations of this study. First, although 30 participants are within the recommended range for a qualitative study utilising in-depth interviews, it was nevertheless a small sample of mothers who were mostly highly motivated to breastfeed. Only two mothers in this study stopped breastfeeding as a direct result of either the nature of their child's condition, or the support that they received. This may be an under-representation of those who would not be able to continue to breastfeed given that these mothers had access to additional resources or knowledge. It was not within the scope of this study to extensively explore reasons for breastfeeding cessation among mothers of sick children, but future work could consider this, as the reasons may be distinct from those reported in the neonatal and maternity literature. Second, this sample of mothers was recruited via an online advert which limits participation to those with internet access and those who use social media. The disadvantages of online recruitment were mitigated somewhat by a very large social media reach and a large pool of potential participants. The screening questionnaire allowed a purposive sample which was socio-economically, geographically and ethnically diverse, but offered no opportunity for participants to say whether they had a mostly positive or negative experience. This was to minimise unintentional bias and skewing selection towards certain potential participants. Nevertheless, mothers who elected to take part were likely to have been invested in breastfeeding, so this may not have been a representative sample. Third, while this study is unique in exploring the challenges of multiple different conditions among breastfeeding dyads, not every child with these conditions will have the same challenges, and there are hundreds of other conditions not represented by this sample. Further studies could explore other childhood illnesses and recruit larger samples.

5 | CONCLUSION

This study identified numerous challenges related to breastfeeding and responsively parenting sick children in paediatrics. The experiences of mother-child dyads with 26 different conditions and a range of severity of illness and duration of admission were

explored. The impact on breastfeeding and maternal mental health was not necessarily related to the severity of illness, but the types of challenge were affected by illness severity. While not every parent of a sick child in hospital requires complex breastfeeding support and intervention, those who do are more vulnerable to falling between the gaps in paediatric service provision. Thus, mothers and children who require more advanced lactation support may be disproportionately affected by staff attitudes and skills. There were widespread gaps in staff knowledge, and the clinical environment was not always conducive to supporting breastfeeding. This study highlights both strengths and challenges in clinical lactation care of sick children in paediatrics and provides insight into the measures that are perceived as supportive by mothers. The varied challenges identified in this study also hint at the need for further research exploring the breastfeeding needs of children and families in paediatrics. These findings should be used to inform nuanced curricula for paediatric breastfeeding training that more accurately meets the needs of mothers breastfeeding or providing breastmilk to their sick and medically complex children.

AUTHOR CONTRIBUTIONS

Lyndsey Hookway, Amy Brown and Aimee Grant were responsible for study conception. Lyndsey Hookway was responsible for data collection, analysis and draft manuscript completion. Amy Brown was involved with discussions around code and theme generation. Lyndsey Hookway, Amy Brown and Aimee Grant were involved with critical revisions.

ACKNOWLEDGEMENTS

The authors would like to express their sincere thanks to the mothers who took part in this study.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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How to cite this article: Hookway, L., Brown, A., & Grant, A. (2023). Breastfeeding Sick Children in Hospital: Exploring the experiences of mothers in UK paediatric wards. *Maternal & Child Nutrition*, 19, e13489. <https://doi.org/10.1111/mcn.13489>