

What are the needs and challenges of breastfed medically complex infants and children in the paediatric setting?

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Submitted to Swansea University in fulfilment of the requirements for the Degree of Doctor of Philosophy

Swansea University

2023

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Thesis abstract

Breastfeeding is known to provide optimal nutrition and immunological support to young children. There are many systems in place to facilitate and protect breastfeeding, such as policies, training programs and specialist practitioners employed within certain settings. However, the support and training are weighted towards the initiation of breastfeeding in healthy newborns, as well as supporting the preterm population. Paediatric settings do not have the same investment in training, policy, or staffing. Within paediatrics, different breastfeeding challenges exist, meaning that not only do staff often not have a baseline level of breastfeeding knowledge, but they also require more nuanced training to effectively support families to overcome difficulties. There is a paucity of research on this sub-population, especially within the UK, therefore a systematic review was conducted and used to focus the research studies on the identified gaps.

Two studies were conducted to identify the knowledge and skills of professionals, and the experiences of mothers breastfeeding their medically complex child in the paediatric setting. The first study was a national survey of 409 multidisciplinary healthcare and allied health professionals working in paediatrics. The second study recruited 30 mothers of children who had been inpatients on paediatric wards or paediatric intensive care units and explored their challenges, barriers and views using semi-structured interviews.

The research found that many paediatric professionals have significant gaps in their knowledge and skills, reported several obstacles in terms of unsupportive ward cultures, and identified that current breastfeeding training does not meet the needs of these professionals working to support sick breastfed children in hospital. Furthermore, while some mothers are strongly motivated to breastfeed their sick child, they encounter a range of institutional, clinical and environmental barriers to breastfeeding.

The findings suggest that nuanced paediatric-focused breastfeeding training along with a focus on providing family-centred, compassionate care and supportive environments is clinically justified to support families to reach their personal feeding goals and optimise health outcomes for children.

Declarations and Statements

DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed:  (candidate)

Date: 22nd March 2023

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Where correction services have been used, the extent and nature of the correction is clearly marked in a footnote(s). Other sources are acknowledged by footnotes giving explicit references. A reference list is appended.

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STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

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Acknowledgements

Firstly, I would like to express my sincere thanks to my supervisors, Professor Amy Brown, and Dr Janice Lewis whose constructive feedback and encouragement has been invaluable. I am particularly indebted to Amy, for inspiring a greater respect for research and critical thinking in the first place, and for her ability to predict, respond to and calm my quarterly bouts of existential crisis. Without her patient input and judicious use of humour and light-heartedness just when I needed it, the threats of throwing this work in the bin might have come to fruition!

Secondly, I am hugely grateful to the participants of my two research studies. To the healthcare professionals who took time out of busy clinical roles to honestly report on the current state of care in paediatrics – thank you. To the hundreds of parents who applied to be part of the second study, and to the thirty mothers I eventually had the privilege of interviewing, I hope I have accurately conveyed the highs and lows in a way that can challenge practice.

Finally, while nobody wishes life-threatening illness on their child, in this case hopefully one positive outcome has arisen from personal trauma. So, to my daughters, but particularly Filly, thank you for allowing me to tell *your* story too. I hope I did it justice.

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Abbreviations

AHP	Allied Health Professional
BF	Breastfeeding
BFC	Breastfeeding Counsellor
BFHI	Baby Friendly Hospital Initiative
BFI	Baby Friendly Initiative
CHD	Congenital Heart Defect
CICU	Cardiac Intensive Care Unit
CPAP	Continuous Positive Airway Pressure
DHM	Donor Human Milk
ED	Emergency Department
FCC	Family Centred Care
GMC	General Medical Council
GP	General Practitioner
GT	Gastrostomy tube
HCA	Health Care Assistant
HCP	Healthcare professional
HDU	High Dependency Unit
HFNC	High Flow Nasal Cannula
HV	Health Visitor
IBCLC	International Board Certified Lactation Consultant
MDT	Multidisciplinary Team
NBM	Nil by mouth
NG	Nasogastric
NICU	Neonatal Intensive Care Unit
NMC	Nursing and Midwifery Council
NNU	Neonatal Unit
NNS	Non-Nutritive sucking
PEG	Percutaneous Endoscopic Gastrostomy
PICU	Paediatric Intensive Care Unit
PS	Peer Supporter

SLT	Speech and Language Therapist
SNS	Supplemental Nursing System
TPN	Total Parenteral Nutrition

Introduction

Breastfeeding is justifiably a global public health priority (Victora et al., 2016) yet it is also a learned skill (Harrison et al., 2021) that requires support from multiple sources (Marcon et al., 2019) at key times (Fraser et al., 2020). Breastfeeding rates in the UK are some of the lowest in the world (Victora et al., 2016), with many women stopping breastfeeding before they are ready (McAndrew et al., 2012). There are numerous reasons for the reduction in exclusivity and duration of breastfeeding, including a lack of translation of key information to practice (Pérez-Escamilla et al., 2022) and lack of prompt support that is attuned to the different stages of lactation and associated challenges (Fraser et al., 2020).

Because of the identified challenges of increasing breastfeeding rates to improve public health outcomes and reduce the resulting economic impact of suboptimal infant feeding (Rollins et al., 2016), many initiatives have been introduced in recent decades which have invested in training and support interventions targeted at increasing the initiation of breastfeeding in healthy term newborns and scaling up breastfeeding rates in preterm infant populations (Renfrew et al., 2012).

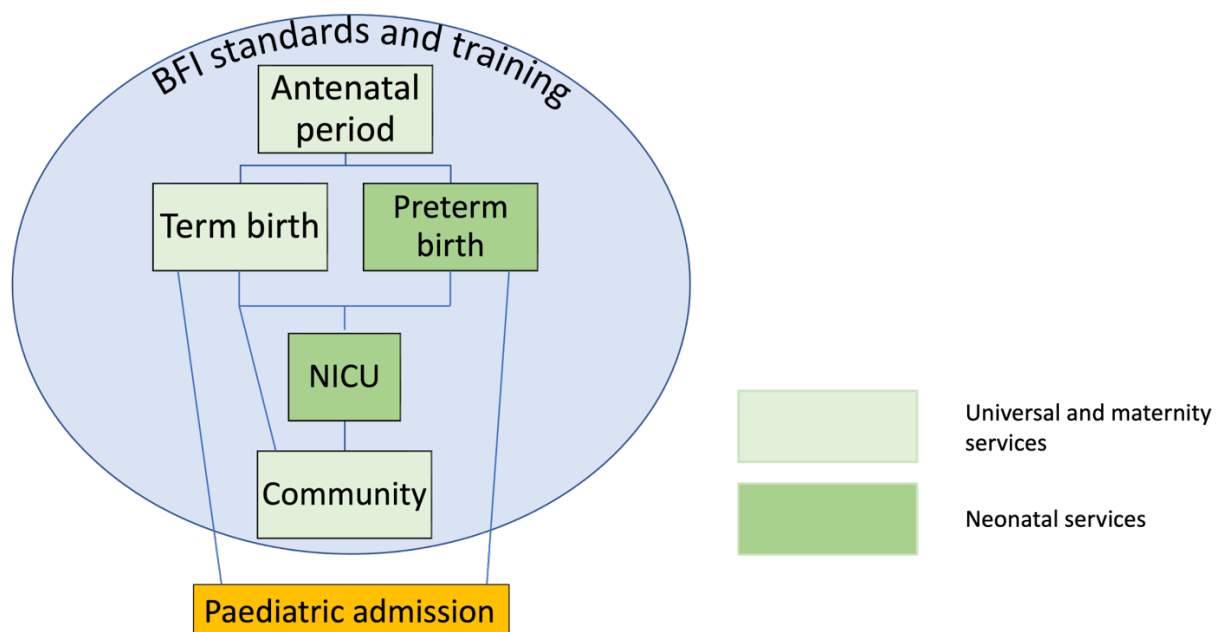
However, modelling of the economic and public health justification of optimising breastfeeding only accounts for the prevention of acute infections and chronic illness in otherwise healthy infants and mothers, with no inclusion of sick children or those with medical complexity (Mavranouzouli et al., 2022). Furthermore, the initiatives to provide support, training and protection for breastfeeding focus on clinical settings that care for healthy newborns and families, as well as preterm and critically sick neonates. The paediatric population is largely absent from any organisational infrastructure designed to protect and promote breastfeeding.

The Baby Friendly Initiative (BFI) is an accreditation program designed to support healthcare organisations to achieve a basic level of competence in the protection and promotion of breastfeeding. The first UK implementation in 1994 was in maternity services, and later adapted and expanded to include community settings, children's centres, neonatal units and some universities that train midwives and health visitors. The BFI sets standards, provides

consistent training, and audits progress with the aim of improving the quality and consistency of evidence-based care to families (Lubold, 2017). Healthcare settings can apply to become accredited as Baby Friendly through a standardised process of commitment, training, audit and assessment of staff and parent experience, and then retain their accreditation by ongoing service development, re-audit and additional awards. The expansion of BFI has been shown to increase the rates of initiation of breastfeeding (Fallon et al., 2019; Fair et al., 2021) but there has not been a similar investment in paediatrics in terms of specific nuanced standards, training at undergraduate level, bespoke postgraduate training, or audit of staff skill or parent experiences in paediatrics. In a very recent positive move, the BFI have published their proposed pilot standards for children’s services, which include similar stages leading towards baby friendly accreditation, but they do not specify how the training might need to be nuanced for this different clinical group.

While the problem may not seem immediately obvious to those unfamiliar with the organisational systems of healthcare departments in the UK, paediatrics is a separate clinical department to the maternity and neonatal settings. Figure 1 illustrates paediatrics as an ‘island’, organisationally isolated as a clinical environment.

Figure 1: Paediatrics as an ‘island’



As Figure 1 illustrates, breastfeeding intervention may be delivered antenatally, at birth either in the maternity unit, by community midwives, or in the neonatal unit. If a child becomes unwell, develops a condition, or requires diagnostic or interventional treatment following discharge from the maternity or neonatal setting, they are likely to be reviewed, assessed, treated, or admitted into paediatrics. In reality, this equates to children with an age range from the first week of life to approximately sixteen years.

Given that mothers may require breastfeeding support at any point in their breastfeeding journey, but particularly in the first few weeks (Fraser et al., 2020), it is logical that paediatrics should be included in any provision of training and practical support.

Unfortunately, there has been a lack of investment in paediatrics, and while progress has been made in many other clinical disciplines regarding research evidence, policy, training and audit, paediatrics lags behind. Indeed, while many policy documents and research studies discuss the impact of increasing breastfeeding to reduce health inequalities and negative health outcomes for healthy children and preterm neonates, sick children are often excluded from the data (Renfrew et al., 2012; Mannion et al., 2013; Schlatter et al., 2019; Kair et al., 2019; Feldman-Winter et al., 2020; Chesnel et al., 2021; Mavranouzouli et al., 2022). This means that while we have an ever-increasing body of knowledge about which interventions support breastfeeding in both healthy and preterm infants, the population that we know least about are the infants and children seen in the paediatric department, including paediatric intensive care (PICU) and the paediatric emergency department.

This significant gap in policy, research, training and practical support leaves breastfeeding mothers, children and families at risk of suboptimal infant feeding care and potentially premature breastfeeding cessation or reduction in exclusivity. There is no logical reason why any of the common challenges that are known to affect healthy infants and mothers would not also be problematic for sick and medically complex children. Indeed, medical complexity is likely to add further challenges to breastfeeding that are unique to this population. Thus, not only is this population vulnerable to not receiving appropriate care and information relating to common breastfeeding challenges due to the widespread lack of support and training, but they may face *additional* threats to breastfeeding due to the nature of their illness or condition. Furthermore, it is likely that breastfeeding specialist professionals in the

surrounding clinical disciplines within the community, voluntary and private sector services, maternity and neonatal care are less familiar with the unique difficulties experienced by mothers of children with a wide age range and vast array of conditions in paediatrics. This means that their skills and knowledge may not always enable mother-child dyads in paediatrics to overcome their specific challenge.

In terms of an identified research gap, the rationale for researching this population is that there is a dearth of literature focused on breastfeeding challenges and support in paediatrics, leading to poor awareness of the problems, as well as lack of skills and knowledge to overcome the challenges. Given that many mothers do not breastfeed for as long as they had planned, often due to encountering challenges or lack of support (Brown, 2018), there is a need to invest in the populations who may be more likely to encounter difficulty. Since many of the children in the paediatric clinical environment are under the age of two years (Keeble and Kossarova, 2017; Ghazaly and Nadel, 2018; Reeves et al., 2019), and therefore a proportion of them may still be breastfeeding at the time of hospital admission, investment in this population is clinically justified. Greater understanding of the unique lactation needs of the paediatric population would support more targeted training and efficient use of resources to protect and promote the maintenance of breastfeeding during paediatric hospitalisation.

Research motivations

It is common for researchers to bring their personal beliefs or relevant experience to their work, since they tend to research that which interests them. However, it is important to acknowledge these potential tensions and biases and consider how they may positively or negatively influence the research design and data collection.

I first became interested in this research topic during my paediatric nursing training. I qualified as a nurse in 2004 and immediately noticed that almost all my patients were under the age of two years, and many of them were milk fed to a greater or lesser extent. Relatively few of my patients were breastfed, but when they were, there existed a tension between providing support for infant feeding choices and providing clinical care. I noticed

repeatedly that mothers were often advised to express milk rather than directly breastfeed, so that volumes could be measured accurately. Mothers were frequently encouraged to supplement breastfeeding with infant formula, even when there was no obvious concern about milk supply or weight gain. There seemed to be little understanding of how breastfeeding and lactation works, how to support mothers to meet their personal feeding goals or enable them to overcome breastfeeding problems. Rather, bottle and formula feeding were often presented as the solution to breastfeeding problems. Many of my nursing and medical colleagues did not seem able or willing to support mothers with breastfeeding if that was their choice. This was partly because there was very little training on offer, and partly because many of them did not feel it was part of their job. As far as some of my colleagues were concerned, while nutrition was an important part of illness management and recovery, the nuances of that nutrition were deemed less significant than clinical care and counting calories.

In common with many of my colleagues, I had received just two hours of training in infant feeding as part of my undergraduate degree. I frequently overheard advice that was not evidence based, and as I began to study in my own time, I realised how much professionals in paediatrics did *not* know. Family centred care was and remains a key principle of caring for children in hospital, and it seemed particularly relevant when sick children were having breastfeeding difficulties. However, when it came to these real-world situations, the theory and practice did not always gel. Keeping families together, valuing parents as partners in care, upholding and respecting the customs and traditions of families, shared responsibility, and valuing their wisdom and opinion are all important tenets of family centred care (Mikkelsen and Frederiksen, 2011; Dennis et al., 2017). I felt that these concepts applied perfectly to protecting a mother's choice to breastfeed, and yet, this did not seem to be universally valued in the paediatric setting.

I worked for a few years as the regional family centred care coordinator for a large perinatal network covering four neonatal units but primarily located at a major tertiary referral centre. The difference between the neonatal and paediatric setting in terms of the acceptance of breastfeeding as the biological norm was stark. Breastfeeding was not only accepted, but expected, and valued as part of the immunological, developmental, and

emotional support for extremely preterm neonates, as well as critically unstable term neonates with congenital anomalies and other life-threatening medical complexity.

After several years within the in-patient paediatric and neonatal setting, I moved into the community, trained as a health visitor, and became more exposed to the challenges of infant feeding within the context of public health nursing, I sub-specialised in lactation and qualified as an International Board Certified Lactation Consultant (IBCLC) in 2011. I became increasingly aware of the gap between clinical paediatrics and optimal breastfeeding support, noticing that many lactation supporters, including clinicians with maternity and adult nurse backgrounds, have limited knowledge of how to support very sick children, and paediatric clinicians have limited knowledge of how to support lactation. Very few professionals have dual skill sets in paediatric clinical care *and* lactation.

This journey became much more personal when my second breastfed child became critically sick with sepsis at the age of three years and was subsequently diagnosed with acute lymphoblastic leukaemia (ALL). We breastfed through 26 months of chemotherapy, multiple painful procedures, and hospital admissions, and experienced tolerance but no encouragement for breastfeeding. On completion of her treatment, I established the *Breastfeeding the Brave* project – which started as a small online support group hosted on Facebook for other parents breastfeeding through serious, chronic, critical, or palliative illness, but quickly grew. The group now has several hundred members, all regularly sharing challenges, inspiration, experiences, and support with each other. I have informally acted as an advocate for many mothers who have received opposition to continuing to breastfeed their very sick children. As awareness has grown of the gap in knowledge and support within paediatrics, professionals have also joined the group to learn, and thus my personal journey has merged with my IBCLC skill set, teaching experience and clinical paediatric nursing experience.

Throughout the last twenty years of clinical nursing experience, providing specialised lactation support on the paediatric ward, neonatal unit, in community health visiting, and infant feeding lead roles, I have drawn on both my nursing and IBCLC training skills and knowledge, and have observed how breastfeeding mother-child dyads are cared for within

multiple settings. I saw the need for a closing of the gap between clinical paediatrics and infant feeding support, and hope that this research can illuminate the gap between two distinct disciplines.

Aim of this thesis

The aim of this thesis was therefore to identify the needs and challenges of breastfed medically complex infants and children in the paediatric setting. In order to address this, five research questions were developed, and two studies designed to explore the central aim.

Research questions (RQ):

- RQ1. What is the current breastfeeding training provision at undergraduate level for healthcare professionals in the UK, and is this felt to be adequate?
- RQ2. What are the skill and knowledge gaps of professionals, do the gaps differ by professional qualification, and would these be addressed by currently available training?
- RQ3. What are the barriers to providing lactation support that meets the needs of families?
- RQ4. What is the importance and meaning of breastfeeding when a child is sick or medically complex?
- RQ5. What are the breastfeeding challenges of medically complex children in the paediatric setting?

The following seven chapters of this thesis are comprised of a background chapter providing an overview of why this population is a research priority, a systematic review of the literature, a chapter explaining the underpinning research methodology for the studies, two chapters presenting the findings of the research studies, a discussion chapter and conclusion.

Chapter 1 outlines the importance of and known barriers to breastfeeding in the general population, before exploring in a theoretical sense, the implications of breastfeeding for sick children, and why this population is unique.

Chapter 2 presents a systematic review of the available literature which identified eleven studies globally which met the inclusion criteria. A narrative synthesis generated seven themes relating to challenges and barriers of breastfeeding sick children in paediatrics.

Chapter 3 outlines the underpinning methodology of the thesis, including the theoretical justification for the choice of overall study design, as well as a section on researcher reflexivity and the epistemological and ontological position of the researcher.

Chapter 4 details a national survey of healthcare professionals (n = 409) including doctors at all grades (n = 103), paediatric nurses (n = 245) and allied health professionals (n = 45) identifying their skills, knowledge, experience and attitudes around supporting breastfeeding in the paediatric setting.

Chapter 5 presents a qualitative interview study with mothers (n = 30) of breastfed medically complex children exploring their challenges, motivations, and views of breastfeeding their sick hospitalised children.

Chapter 6 is a discussion of the combined findings, triangulating the studies to answer the five research questions.

Chapter 7 presents recommendations for practice, along with the limitations of the thesis, areas for future research and conclusion.

Terminology

It is recognised that not all parents who lactate identify as mothers, and some prefer to use the term chestfeeding as opposed to breastfeeding. There are many compelling arguments to choose additive and inclusive language, particularly in parent-focused documents

(Dinour, 2019). In face-to-face contacts with parents, it is always appropriate to use the words that a parent prefers and feels most comfortable with (Bartick et al., 2021). However, to avoid cumbersome or confusing use of language, and to accurately reflect the identities of the parents represented in this thesis, the words 'mother' and 'breastfeeding' have been used except where the use of 'parent' is intended to describe the involvement of or impact on a parent of any gender, whether lactating or not.

Secondly, this thesis frequently refers to medically complex infants and children. For clarity, 'medically complex' includes children with mild, moderate and severe acute or chronic illness, congenital anomaly and disability who are treated in the paediatric setting.

Chapter 1

Background

This background chapter funnels the vast body of knowledge related to breastfeeding, into some of the specific ways in which it is relevant to medically complex children in paediatrics. Thus, this narrative review moves from the macro towards the micro issues for the population of interest. While this review was not systematic, the Critical Appraisal Skills Program (CASP) checklists (2018) were considered when sifting the literature to appraise the quality of available research. A systematic review of the literature relating to the challenges of breastfeeding medically complex children follows in Chapter 2.

Literature searches were performed regularly throughout the period of writing this thesis (2019-2023), to include new and emerging theories on this topic. Search engines used were Google Scholar, PubMed, iFind and the Cochrane library. A search was also made within the UNICEF UK Baby Friendly website, the Nursing and Midwifery Council, General Medical Council and the Health and Care Professions Council to review educational competencies and training requirements.

Search terms used included: infant; child; p(a)ediatrics; PICU; CICU; HDU; p(a)ediatric ward; skin-to-skin; mother; parent; breastfeeding; donor human milk; infant feeding; medically complex; disability; chronic illness; palliative care; trauma; supplementation; PEG feeding; NG feeding; complex feeding; BFI; BFHI; children's hospital; p(a)ediatrician; p(a)ediatric nurse; allied health professional; dietitian; speech and language therapist; physiotherapist; peer supporter; breastfeeding counsellor; IBCLC; lactation; health professional training; economics; preventative healthcare; public health outcomes; feeding tool; feeding assessment; feeding guideline; milk composition; immunology.

Papers were included if they were published in English, and no date limits were set given the paucity of information on this topic. Older papers were treated with caution regarding practice guidelines, given that clinical knowledge is influenced by newer research around best practice. However, some older papers were included if they presented novel findings,

particularly related to identification of previously undiscovered components of human milk. No geographical limits were placed on the searches because both childhood illness and innovative practice are not limited to a specific location. Given that healthcare systems and healthcare professional training differs around the world, the limitations relating to the applicability of the research in a UK setting were considered at all times.

1.1 Normality and importance of breastfeeding on a global scale

Breastfeeding is the biologically standard way to feed human infants and children until the age of two years or beyond (Dettwyler, 2004; WHO, 2014). Human milk - like all mammalian milks - is species-specific, providing the right composition of macro and micronutrients as well as having an important role in the adaptation from intrauterine to extrauterine life via many biochemical components and processes (Lönnerdal, 1985; Bernt and Walker, 1999; Hassiotou et al., 2013). Human milk contains host defence factors, growth factors, biologically specific proteins (Guerrero et al., 2014) and hormones that control the programming of many bodily functions, such as appetite regulation which aids optimal development (Mazzocchi et al., 2019). Feeding infants with non-species-specific milk in the form of infant formula, while nutritionally complete, does not provide optimal immunity or the same targeted programming. Thus, breastfed infants have a lower risk of many infectious and autoimmune diseases, obesity, dental caries and malocclusion (Victora et al., 2016) as well as some malignancies (Amitay and Keinan-Boker, 2015) and sudden infant death syndrome (SIDS) (Hauck et al., 2011).

Breastfeeding can be important for individuals, communities, wider public health outcomes and economies (Rollins et al., 2016; Perez-Escamilla et al., 2023). Ensuring that all children are exclusively breastfed for the first six months of life and then alongside appropriate introduction of complementary foods until the age of two years or beyond would prevent more than 800,000 global deaths in children under five per year (Holla-Bhar et al., 2015). Not all findings are consistent, mainly due to methodological differences in studies, but overall, *not* breastfeeding has been found to increase rates of disease and the associated costs of treating disease and therefore increases the burden on community and hospital healthcare facilities (Rollins et al., 2016). One of the global Sustainable Development Goals

is to reduce poverty and improve prosperity. Scaling up breastfeeding may reduce inequality, optimise health and reduce disease burden. Thus, it is an obvious public health intervention that would potentially have significant economic impact, as well as individual benefits (Hansen, 2016).

However, much of the focus has been around prevention of disease. The language around breastfeeding has historically discussed the 'benefits' of breastfeeding, and the reduction in risk of disease if a child is breastfed. Although a subtle point, it is not strictly accurate to describe breastfeeding as having benefits. As Stuebe (2009) points out, this language may inadvertently present formula feeding as the baseline, and breastfeeding as a 'bonus'. Although formula is an essential and sometimes lifesaving part of infant feeding, it is not the biologically normal way to feed human infants. Therefore, it is more accurate to acknowledge that there may be increased risks associated with formula feeding and reduced breastfeeding exclusivity and duration.

More accurate and nuanced use of language is particularly important when considering medically complex children. Breastfeeding cannot be reduced to merely its immunological protection and nutritional content when there are numerous other positive aspects of the breastfeeding relationship. However, when we specifically consider illness and medical complexity, describing breastfeeding as an intervention to reduce the risk of disease or certain conditions could arguably present several problems in understanding:

1. That if children become sick, breastfeeding could be perceived to have 'failed' to offer the protection that we expected. Many may argue that if children *are* sick, the fact that they are breastfed may mitigate the severity of their condition, but there is no way of quantifying this.
2. Breastfeeding has no role in preventing congenital conditions, disabilities, anatomical anomalies, or accidents and trauma. Therefore, this can feel irrelevant to families of children who present with these conditions.
3. If breastfeeding is seen as a public health intervention which prevents disease, the focus may be on prevention of illness, rather than supporting mothers to

continue through medical challenges, with all the associated non-nutritional benefits of comfort and connection also being overlooked.

4. Not all illnesses and diseases have the same risk reduction with breastfeeding. Some conditions are only less prevalent when breastfeeding is exclusive, or with certain durations of breastfeeding (Victora et al., 2016). Therefore, breastfeeding does not prevent all illnesses in the same way, or to the same extent. For example, breastfeeding provides a dose-response effect on the risk of developing pneumonia, with more risk observed in less exclusively breastfed infants (Lamberti et al., 2013) and a systematic review found that breastfeeding reduces the risk of acute lymphoblastic leukaemia by 14-20% when children are breastfed for six months or more (Amitay and Keinan-Boker, 2015). Clearly, there are some parameters around duration that are relevant, because only a minority of infants are breastfed beyond six months.
5. Some mothers who find breastfeeding difficult or expressing unmanageable (sometimes *because* of their child's medical challenges) may feel the added burden of guilt if they are unable to meet their breastfeeding goals.
6. This mindset also arguably positions breastfeeding as a medical intervention which can be quantified and analysed rather than a developmentally, relationally and socially normal part of mothering and parenting.

This is also important on a human level, because sometimes mothers have been taught that breastfeeding 'reduces the risk' of those negative health outcomes. This may be upsetting or confusing for families of sick children, as they may be optimally fed, and yet still have a serious illness. Some mothers have felt 'short-changed', yet the reason for their child's illness wasn't that breastfeeding failed to prevent it, but that breastfeeding, while associated with lower rates of illness, does not guarantee immunity from these illnesses and conditions (Binns and Lee, 2019).

It is therefore arguably more helpful both to clinicians, but also families, to acknowledge and specify that breastfeeding confers a normal rate of *acquired* disease and conditions in both lactating mothers, infants and children. Despite optimal infant and young child feeding, some breastfed infants and children do still develop illnesses that are seen at higher rates in

their formula fed peers. Therefore, the needs and challenges of breastfed infants and children who become unwell, as well as those with anatomical anomalies, accidents and trauma, disability and congenital conditions are an important consideration that has not been adequately addressed in the literature.

1.2 Human milk immunological specificity

Formula fed infants are more likely to become unwell because while nutritionally complete, formula milk does not contain the specific immunological factors present in human milk. Human breastmilk contains active immunity in the form of immunoglobulins. In particular, Secretory Immunoglobulin A (SIgA), first described by Lars Hanson (1961), coats the lining of the gastrointestinal epithelium, protecting it from invasive pathogens, and is present in a dose-response amount in human milk for about the first four months of life. It continues to be present for as long as breastmilk is produced (Donald et al., 2022). SIgA provides protection against infection in the mucous membranes of the respiratory and gastrointestinal tract. Given that infants do not make significant amounts of IgA until after six months of life, their only detectable IgA is from human milk. Human milk also contains IgG, and IgM and although the latter remains fairly constant throughout lactation, IgG and SIgA increase in concentration to reach their peak levels after the age of two years (Czosnykowska-Łukacka et al., 2020).

Some evolutionary studies have found that the primary purpose of milk was for immunologic support, as well as optimising gut health (Bode, 2012). This makes sense of some of the components found in milk – such as indigestible human milk oligosaccharides (HMOs) whose primary function is to feed the probiotics in the gut (Bode, 2015). Some of these probiotics, such as *Bifidobacterium infantis*, serve to protect the infant from respiratory and gastrointestinal infections. These HMOs compete with the gut epithelial surface for the attachment of pathogens which cause serious gastrointestinal infection such as rotavirus, norovirus, *E. coli* and *Campylobacter*. The HMOs attach to these harmful pathogens which are then excreted harmlessly in stool rather than causing disease. The HMOs have no nutritional value and seem to be purely present for the purpose of immunological protection (Bode, 2009).

Human milk contains stem cells at a rate of several thousand to millions of cells per feed, capable of differentiating into specialised cells and seeding infant organs (Cregan et al., 2007). Human milk contains billions of cells, and when both the mother and child are healthy, the proportion of leukocytes is less than 2% of this number (Hassiotou and Hartmann, 2014). However, breastfeeding is a dynamic process and one of the mechanisms by which it is responsive is the retrograde inoculation theory – commonly known as ‘backwash’ (Perez-Escamilla et al., 2023). Infant saliva causes microbial cross talk with the mammary microbiome, effectively causing the milk to be altered in response to the infant’s environmental exposure. This theory was first proposed by Hinde and Lewis (2015) and supported by evidence discovered by the CHILD study team (Moossavi et al., 2019). It was later expanded (Beghetti et al., 2019) though it remains a hypothesis. Essentially, during suckling, the theory suggests that a child’s saliva enters the mammary tissue and via the entero-mammary pathway, affects the microbiota of the milk produced, meaning that the milk can be compositionally changed in response to infant exposure to pathogens.

The relevance to childhood illness is obvious - when either the mother or infant are unwell, leukocytes are actively recruited from the maternal bloodstream and make up a vastly increased proportion of these billions of cells in milk, evidencing the ability of the human breast to dynamically alter the composition of milk to adapt to the acute needs of the child for immunologic protection (Hassiotou and Hartmann, 2014). At times of acute infant infection, human milk has specifically been found to contain more leukocytes, macrophages, and tumour necrosis factor- α (TNF α), with these components returning to lower levels in the recovery phase (Riskin et al., 2012). SIgA specific antibodies are also present in human milk during times of acute infection, and these appear to remain for several months after the illness (Juncker et al., 2021). Like HMOs, SIgA is virtually unabsorbed, and its primary function is immunologic support, making sense of the increased concentrations found during acute illness.

1.3 The importance of breastfeeding for mothers and families

Breastfeeding is indisputably significant for infants and children, but it is also protective for the mother. Not breastfeeding is associated with higher rates of invasive breast cancer, ovarian cancer, diabetes and overweight (Victora et al., 2016). Among women who intend to breastfeed, rates of postnatal depression are lower when they meet their own self-defined breastfeeding goals. Rates of depression in the first six weeks are lower the longer and more exclusively they breastfeed their children (Borra et al., 2015).

Breastfeeding causes oxytocin to be released which improves maternal mood (Moore et al., 2016) and facilitates sleep (Avidan, 2007; Astbury et al., 2022). This response continues for as long as the child is held in skin-to-skin contact or breastfed, and is thus a mediating factor in postnatal mood (Kendall-Tackett, 2015), as well as eliciting a calming effect on mothers and children. Breastfeeding reduces blood pressure and cortisol levels and has long term impacts on cardiovascular health, reducing women's risk of heart disease and stroke (Stuebe, 2015). A recent study has also suggested that breastfeeding may improve cognitive functioning in postmenopausal women. The study found that women who had breastfed performed better on tests of their memory, learning, executive functioning and processing speed. One possible hypothesis is that breastfeeding leads to improved stress regulation and the results suggest that breastfeeding protects against cognitive decline in later life (Fox et al., 2021).

It is thus valid and relevant that professionals invested in public health consider not only the impact of reduced breastfeeding duration and exclusivity on infants and children, but also their mothers. Mothers who do not meet their breastfeeding goals may experience sadness, grief, disappointment and symptoms of trauma (Brown, 2018).

1.4 Factors that are protective of breastfeeding

There are many known protective factors that enable mothers to achieve their breastfeeding goals. Good preparation and antenatal education have been found to support breastfeeding self-efficacy (Maleki et al., 2021). More breastfeeding knowledge has been

found to be associated with longer and more exclusive breastfeeding rates (Zhang et al., 2018). Alongside knowledge of how breastfeeding works, and how to overcome common hurdles, realistic expectations of normal infant behaviour, frequency of feeding, and feeding responsively are also supportive (Brown and Arnott, 2014). Intention and motivation to breastfeed is a significant buffering factor. Mothers who believe that breastfeeding is important for their child were more likely to want to breastfeed exclusively, and the higher the level of motivation, the more likely they were to achieve this goal. Motivation has also been found to be predictive of longer duration of breastfeeding (Martin et al., 2021).

Having a supportive partner is known to be an important factor in the establishment and maintenance of breastfeeding (Clifford and McIntyre, 2008), as well as the influence of the maternal grandmother. Higher rates of breastfeeding are seen in families where the mothers were themselves breastfed (Negin et al., 2016). Higher rates of breastfeeding exclusivity and duration are also seen when there is a positive culture of breastfeeding – whether this comes from peers, religious institutions, the community, wider family members, healthcare professionals, media influencers or the workplace (Chang et al., 2021). Community support is well-known to have a positive impact, and this support should be universally offered but individually tailored, ongoing, and ideally face-to-face (McFadden et al., 2016). Although support is often offered by professionals, lay or peer supporters have been shown to successfully augment services by providing friendly, accessible, positive interactions with breastfeeding mothers (Trickey et al., 2018).

Previous breastfeeding experience appears to have a mixed effect on breastfeeding duration and exclusivity. Studies have found that a previous positive experience of breastfeeding predicts longer breastfeeding duration with subsequent children (Sutherland et al., 2012). However, in general, unsuccessful attempts to breastfeed a first child, breastfeeding less exclusively or for a shorter duration is strongly predictive of shorter breastfeeding duration or non-initiation of breastfeeding with a subsequent child (Bai et al., 2015).

There are numerous demographic characteristics that have been studied in relation to their respective effects on breastfeeding duration and exclusivity. Mothers who are older than

30, have higher socioeconomic status, and higher educational level are most likely to breastfeed in the UK (Simpson et al., 2019; Sarki et al., 2019). One cohort study found that mothers younger than 26 had a rapid decline in breastfeeding exclusivity and duration after birth, particularly in the first ten weeks, but then rates of decline slowed, with the effect that younger mothers who were still breastfeeding at 10-12 weeks then had a slower rate of decline than the older mothers (Grimshaw et al., 2015). There are many potential reasons for these discrepancies, including peer pressure and lack of social precedent (Dyson et al., 2010; Giles et al., 2010) but they may also be related to lack of compassionate, nuanced support, the need to return to work or school, and misconceptions about normal infant behaviour (Hornsby et al., 2019).

Ethnicity also has an influence on breastfeeding rates, and in the UK, non-white mothers are more likely to breastfeed (Simpson et al., 2021), though second and third generation immigrants have been shown to increasingly adopt the local customs, causing a decline in culturally normal breastfeeding rates (Marvin-Dowle et al., 2021). This finding contrasts with data from other countries that suggests that Black, Asian and Mixed-race mothers are less likely than their white peers to meet their personal feeding goals due to complex issues of institutional racism, prejudice and inequitable access (Hamner et al., 2021).

There are many known protective factors surrounding the birth and immediate postpartum that can affect breastfeeding. Being born in a BFI accredited hospital has been found to increase the rates of initiation of breastfeeding and breastfeeding in the first two weeks of life, though this has not been clearly shown to have a sustained impact (Fair et al., 2021). Training health visitors in the community has been found to reduce breastfeeding cessation, as does adopting a hands-off approach to breastfeeding support (Fallon et al., 2019). The type of birth has also been shown to impact breastfeeding, with higher rates of breastfeeding seen among women who had a vaginal rather than a caesarean birth (Zhang et al., 2019; Chen et al., 2018). Early and prolonged skin-to-skin contact has long been known to facilitate breastfeeding, as well as optimise infant physiological adaptation to the stress of birth (Bergman et al., 2019). Skin-to-skin contact has no upper time limit, and an abundance of literature points to this intervention being appropriate for sick and low birth weight neonates, and those undergoing painful needlestick procedures, and may

additionally enhance weight gain (Johnston et al., 2009; Blomqvist and Nyqvist, 2011; Salim et al., 2021; Charpak et al., 2021).

Keeping mothers and infants together as much as possible is a key part of facilitating effective breastfeeding and optimising a mother's milk supply (WHO, 2018), with no separation unless it is clinically necessary. Even when mothers are hospitalised, current best practice is to allow the infant to remain with their mother (Bartick et al., 2021). Beyond the immediate postpartum period, discussions around proximity and infant sleep location remain important. It is known that mothers who sleep in close proximity to their infants are better able to respond promptly to early feeding cues, supporting more cue-based care which is protective of optimal feeding (Brown and Arnott, 2014; Ventura, 2017; Little et al., 2018). Bedsharing while breastfeeding, coined 'breastsleeping' (McKenna and Gettler, 2016) often facilitates more rest and thus makes breastfeeding for longer durations more sustainable for mothers (McKenna et al., 2007; ABM, 2008).

Considering how all these protective factors might apply to the sick child in hospital, clearly some are difficult to achieve when a sick child is admitted to hospital. While some protective interventions may be possible to maintain, several are hindered by the staff, logistics, culture or environment of the paediatric ward - particularly in relation to paediatric healthcare professional training, proximity measures, peer support and community interventions.

1.5 The impact of having a sick child on parents and families

Although there is a lack of research relating to the specific impacts of illness on breastfeeding, there is plentiful literature relating to the impact of child illness and hospitalisation on families in general. One qualitative study found that both children and parents reported shock, sadness, confusion, frustration, and anger. Parents additionally experience feelings of numbness and worry (Gannoni and Shute, 2010). Stress, trauma and anxiety are also frequently described by parents in the literature (Mortensen et al., 2015; Muscara et al., 2015; Foster et al., 2017) and other research recommends that parents are provided with adequate psychological support during hospitalisation of their child for a life-

threatening condition (Smith et al., 2015; Pelentsov et al., 2015). Some parents develop post-traumatic stress disorder after watching their child becoming profoundly unwell, witnessing their child's resuscitation, or receiving a diagnosis of a life-threatening disease or condition (Woolf et al., 2016).

Some evidence suggests that chronic conditions lasting more than three months and requiring multiple hospitalisations or medical treatments are more stressful for families. However, interestingly, the severity of a child's illness does not always seem to be a factor in predicting parental stress (Franck et al., 2010), suggesting that there may be individual, contextual or environmental stressors which may add to the stress. Childhood illness can be very disruptive to family life. Indeed, some research has found that it is the disruption to the normal activities of daily living that causes the most distress, rather than the uncertainty of diagnosis. One study exploring the stressors experienced by children with a cancer diagnosis and their parents found that both children and parents found the disruption to normal life more stressful than the diagnosis itself (Rodriguez et al., 2012). This study also found that parental stress was significantly higher in children aged five and younger - mainly due to the uncontrollability of some of the aspects of caregiving. Providing care to a child who is chronically unwell presents many psychological difficulties, but it can also have a profound effect on parenting confidence and self-efficacy, as well as limit setting and discipline (Mitchell et al., 2020).

One of the interventions proposed to mitigate some of the stress of paediatric hospital admission is family centred care. Family centred care (FCC) is at the heart of paediatric healthcare delivery including within the critical care environment (Young et al., 2006), but, both in practice and according to the literature, this is sometimes hard to achieve. FCC involves positioning the parents as the experts in their child's care, collaborating with the family as partners, and sharing information. Some studies have found that parents do not feel as involved as they would have liked when their child is in a critical care environment (Ames et al., 2011; Butler et al., 2014; Hill et al., 2019). There are also additional pressures relating to parenting in a very public environment – especially when a child is in intensive care, where the clinical environment is usually very open (Rempel et al., 2013).

There are also many practical and logistical problems associated with having a sick child, such as needing to have time off work, adaptations to lifestyle, relationship strain and loneliness and isolation for the parent resident with the hospitalised child. While the resident parent and child are on the ward, they are unable to access their usual sources of companionship, support, activities, entertainment and exercise, and it is often harder or impractical for other siblings to visit – causing parents to make difficult choices about which child they have most contact with (Ivany et al., 2016; Belanger et al., 2017). Some research has also found that the parents of chronically unwell and disabled children are also themselves more likely to experience poor health (Vonneilich et al., 2016) possibly due to chronic stress, and exacerbated by delaying seeking personal support and care due to prioritising caring for their child.

It is common for parents to struggle with finances and income, and this affects those with lower incomes disproportionately (Beck et al., 2017). While admitted to a ward or PICU, parents often have to purchase food for themselves or their child, and the on-site hospital shopping facilities are usually more expensive (Thomson et al., 2016). Some parents may need to give up paid employment to care for their child (Kish et al., 2018), while others must make adaptations or rely on understanding employers – which adds to their stress. On top of this, parents may have to pay for transport, parking, travel for other family members and associated costs of being away from home. It is hard to maintain usual duties such as laundry, housework and caring for other children while resident on the ward. Juggling work, wider family members, a partner, the home and pets is difficult and stressful, and has an indirect effect on parental mental health and coping ability (van Oers et al., 2014).

1.6 The importance of breastfeeding for sick children

Considering the importance in general of human milk as the norm for young children, it is obvious that this is also true during illness. There are several properties of breastmilk and aspects of breastfeeding and human milk that are especially relevant. As well as immunological protection, human milk also contains endorphins, opioid peptides and beta casein (Kaur et al., 2020). These factors provide effective pain relief, and breastfeeding has been found to provide good pain relief during procedures such as routine immunisation

(Shah et al., 2015; Harrison et al., 2016). Breastfeeding has not been evaluated for pain relieving efficacy with other procedures, such as blood tests and cannulation, but anecdotally it appears to provide excellent post painful-procedure comfort. The differences in the microbiome of a breastfed infant are also related to the low levels of antibiotic resistance genes (Perez-Escamilla et al., 2023), which may be particularly relevant to sick children.

A mother's motivation for breastfeeding a sick child is individual. Some mothers pragmatically decide to continue doing what was previously working well, while others feel an increased desire to provide immunologic factors to buffer them from additional disease burden (Matthews et al., 1998). Breastfeeding may also be a way for mothers to feel more integrally involved in their child's care. There is a lack of research into this aspect within the paediatric setting but literature from the neonatal intensive care setting can offer insight into the value that breastfeeding may have in terms of increased self-efficacy, involvement and sense of agency (Butler et al., 2014; Mortensen et al., 2015). Emotional connection, comfort and stress-reduction through breastfeeding are also valid and important reasons to preserve it and may be a way of connecting back to normality and home routines (Ekstrom and Nissen, 2006; Murray et al., 2007; Moberg and Prime, 2013).

Breastmilk contains numerous immunological components including SIgA, lymphocytes, macrophages, lysozyme and lactoferrin (Lawrence, 2022), and reduces exposure to foreign proteins (Järvinen et al., 2019). Human milk also contains proteins that promote the growth and integrity of oral and intestinal epithelial cells (Perez-Escamilla et al., 2023). Breastfed infants with severe pneumonia in one study had fewer days of ventilation, less iatrogenic infection and fewer days in hospital (Laguna-Cruz and Becina, 2017). Other studies find that breastfed children have fewer complications and less severe illness overall (Rodriguez et al., 2005; Quigley et al., 2009). It is therefore possible that many of the components of human milk may modulate disease trajectory, reduce the number of iatrogenic or opportunistic infections, or decrease the length of hospital stay.

While the importance of breastfeeding for maternal and child health is well understood in a general sense, and for preterm infants, there is very little research exploring how and why it

is harder to breastfeed medically complex infants and children beyond the neonatal period. This group of children may particularly benefit from the immunological components of human milk, and breastfeeding can be a physical and emotional comfort to both mothers and children. We also know that among mothers whose breastfeeding journey ends before they planned, many experience feelings of sadness and disappointment (Brown, 2018).

There are a small number of studies that have explored the challenges of breastfeeding within very specific groups – for instance Down syndrome (Barros da Silva et al., 2019; Colon et al., 2009; Lewis and Kritzinger, 2004), phenylketonuria (Banta-Wright et al., 2015), cardiac defect (Lambert and Watters, 1998; Barbas and Kelleher, 2004) and cleft palate (Madhoun et al., 2020), but no study has looked at this in a general sense and, therefore, it is hard to make recommendations for practice change. There is also only one UK study which has researched this subject, and this involved 5 participants (Ryan et al., 2013).

Around half a million children under the age of four years are admitted to hospital every year in the UK (Keeble and Kossarova, 2017), and given that the WHO recommendations are for exclusive breastfeeding for the first 6 months and then alongside complementary foods for the first two years and beyond (WHO, 2018), it is not unreasonable to expect that many of these children will be breastfed, or that their mothers would have liked to have breastfed.

1.7 How and why might breastfeeding medically complex children in the paediatric setting be different?

Infants and children are cared for in a variety of clinical environments that are not always integrated. Maternity and neonatal units may be physically linked or nearby, though they usually have separate nursing and midwifery staff and separate infant feeding teams. Paediatric wards are often geographically, managerially and organizationally separate from both maternity and neonatal units. Some hospitals do not have all three directorates in the same building. Infants born on the maternity ward who deteriorate are usually taken to the neonatal unit, rather than paediatrics. The paediatric ward usually admits children who have *ever* been discharged home. This means that the paediatric ward may admit infants who are

days old, and yet are considered an entirely separate clinical directorate to both the maternity and neonatal directorates. Furthermore, despite caring for children with a wide age range from days to sixteen years, the staff in paediatrics do not usually attend infant feeding training as their maternity or neonatal colleagues would be expected to.

Admissions to the paediatric setting – whether a general ward, paediatric intensive care unit (PICU), specialist ward or day surgery unit will include children with a variety of illnesses and conditions. There is one study that found that breastfeeding was severely negatively impacted by admission to the ward with acute bronchiolitis (Heilbronner et al., 2017). We therefore have some tentative evidence that breastfeeding may be more challenging, or difficult to achieve, when children have a disability, condition or illness, but there are no general studies that explore why this is so, or the impact of this on mothers.

Across many health care settings – including maternity, neonatal intensive care, health visiting, children’s centres and some universities, the BFI UK standards protect and promote breastfeeding through training, audit and culture change (Perez-Escamilla et al., 2016). However, the standards were only published for paediatrics in late 2022 and, as yet no paediatric specific training is available; and there are no Baby Friendly accredited children’s wards or hospitals, though piloting the standards will occur in 2023. Staff within paediatrics are not provided with breastfeeding training as standard, and the experiences of mothers are not audited with respect to breastfeeding. There has also been no research to ascertain whether the current breastfeeding training provided as part of BFI accreditation and audit would meet the needs of staff and families caring for medically complex children on the paediatric ward. What works in one clinical setting and with one population cannot be assumed to work as effectively in another.

1.8 What aspects of medical complexity could affect breastfeeding?

While some children who present to the paediatric ward may have previously been admitted to the neonatal unit, many children in paediatrics have conditions that are diagnosed beyond the neonatal period, and paediatric units see a vast variety of clinical conditions which will obviously affect breastfeeding in multiple ways (Goday et al., 2019;

Milano et al., 2019; Green and Resnick, 2021). 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. Table 1 summarises some of the aspects of medical complexity that affect feeding.

Table 1: Specific potential effects of medical complexity on feeding

Body system	Required function	Examples of conditions which could affect function
Central/Peripheral nervous system	Alert, intact reflexes, neurological coordination	Spina bifida, intraventricular haemorrhage, hypoxic ischaemic encephalopathy (HIE), epilepsy, brain/spinal cord tumour, encephalopathy, meningitis
Musculoskeletal	Normal muscle tone, stability, proprioception, balance	Spinal muscular atrophy (SMA), muscular dystrophy, cerebral palsy, Down syndrome, stroke, Prader-Willi syndrome, Angelman syndrome
Oropharyngeal	Intact palate, patent airway, coordination of suck-swallow-breathe, intra-oral pressure, unrestricted normal tongue function	Fistula, oesophageal atresia, tracheal stenosis, laryngomalacia, tongue tie, vocal cord palsy, endotracheal tube placement during critical illness, cleft lip/palate, tracheostomy tube placement, aspiration, dysphagia
Cardiovascular and respiratory	Heart rate, respiration rate, oxygen saturation, energy expenditure	Cardiac conditions, respiratory compromise, Down syndrome, bronchopulmonary dysplasia, apnoea, pulmonary hypertension, congenital diaphragmatic hernia, sepsis
Gastrointestinal	Endocrine function, intact gastrointestinal tract, normal digestion, normal metabolic function and rate, normal elimination	Anorectal malformations, gastroschisis, exomphalos, short gut syndrome, liver disease, lactose intolerance, allergy, severe gastroesophageal reflux disease (GORD), kidney disease, pyloric stenosis, intussusception, malrotation, Hirschsprung's disease, nausea, diarrhoea, vomiting, high fluid losses
Craniofacial	Sensory-oral feedback, anatomical function, pharyngeal functioning, patent nose and mouth	Cleft lip/palate, craniosynostosis, micrognathia, facial palsy, Apert syndrome, Treacher-Collins syndrome, Pierre Robin sequence, macroglossia
Psychosocial	Mother-infant synchronicity, correct interpretation and response to hunger cues	Feeding/oral aversion, paediatric feeding disorder, avoidant restrictive food intake disorder (ARFID), sensory processing disorder

While not exhaustive, the conditions outlined in Table 1 illustrate the diversity of breastfeeding complications that could be predicted on the paediatric ward. Notably, these conditions are all in *addition* to any problems of prematurity or, indeed, any breastfeeding complications that are not directly related to childhood illness. Essentially, paediatrics represents heterogenous, unpredictable and evolving breastfeeding challenges that are unique to this population, and therefore require bespoke intervention.

1.9 Breastfeeding within the paediatric directorate

Breastfeeding may be challenging to any mother-child pair, irrespective of medical complexity. Breastfeeding a preterm or critically sick neonate presents many additional challenges in addition to those encountered by healthy term mother-infant pairs. However, breastfeeding medically complex children within paediatrics is a unique scenario. Medically complex children have some of the same challenges as both healthy term, and sick preterm infants, but they also experience additional and different challenges (see Table 2).

Table 2: Potential challenges for infants and children in the three clinical directorates

Clinical department	Possible challenges
Maternity setting – postnatal ward and community <i>(Healthy newborns)</i>	<ul style="list-style-type: none"> • Positioning and attachment • Realistic expectations • Establishing supply • Maternal breast related problems • Common infant challenges • Poor support • Myths and misinformation • Juggling work, other children, home, pets, finances • Maternal and parental mental health
Neonatal unit <i>(Preterm and sick neonates)</i>	<p>All the above challenges in the maternity setting plus:</p> <ul style="list-style-type: none"> • Shock, trauma and grief • Lack of preparation • Establishing milk supply with a pump • Setbacks • Enteral feeding (NG, PEG) • TPN, NBM, buccal feeds, trophic feeds • Surgery, ventilation, respiratory support, medication, central, arterial and peripheral lines • Using tools – nipple shields, SNS, specialised bottles, DHM, skin-to-skin • Learning to breastfeed
Paediatric setting <i>(Sick and medically complex infants from birth to 16 years)</i>	<p>All the above challenges in maternity <i>and</i> neonatal settings plus:</p> <ul style="list-style-type: none"> • Sudden or unexpected illness • Unpredictable course • Vast variety of illnesses • No standard or paediatric specific breastfeeding training • Fewer resources (no pumps, expressing room, DHM) • May be acute, chronic, recurrent or lifelong • Adaptations to breastfeeding/creative positioning • Pressure to measure fluid volumes • Anatomical problems and disability • Low tone, higher calorie needs, metabolic challenges, medical devices • Developmental challenges (boredom, solids, mobility, psychosocial) and wide age range • Transitioning <i>back</i> to breastfeeding

It is likely that mothers of medically complex children need a different type of support to initiate or maintain breastfeeding that is tailored to the needs of their child. It is also likely that as well as some overlapping similarities with healthy newborns and preterm neonates,

there are different challenges associated with breastfeeding the sick or medically complex population, including older infants and toddlers.

Common challenges among healthy newborns and their mothers include finding an effective and comfortable position, correcting the positioning and attachment, establishing supply, and managing common maternal breast and milk supply problems (Walker, 2021).

Professionals supporting mothers in the newborn period are often able to troubleshoot difficulties such as blocked ducts, mastitis, low supply, and identify tongue tie. New mothers also frequently need support and information about realistic expectations, sleep, normal infant behaviour, adjusting to parenthood and optimising their own mental health (Vanguri et al., 2021).

Infants born prematurely are usually taken to the neonatal unit to be stabilised and provided with appropriate clinical care. The shock and trauma of giving birth to a premature infant is profound (Palmquist et al., 2020), and yet it occurs within an environment which is generally supportive and accepting of breastfeeding as the norm. There is a plethora of research justifying the necessity of human milk (Yang et al., 2020) and human-milk based fortifier (Grace et al., 2021), as well as preferentially using donor human milk instead of formula for preterm infants to prevent diseases including necrotizing enterocolitis. The risk of giving formula to a very preterm infant is indisputable and, therefore, breastfeeding or the provision of donor milk is strongly encouraged to prevent significant bowel disease (Quigley et al., 2019). Undoubtedly, mothers of preterm and critically sick newborns have additional and different challenges compared with establishing breastfeeding in healthy newborns – such as dealing with enteral feeding, surgery, and respiratory support, as well as setbacks and illness.

However, it is argued that medically complex children in paediatrics present a much wider range of potential difficulties. While there is a significant and established evidence base in support of breastfeeding or human milk feeding for preterm infants and healthy newborns in general, this is not so in paediatrics. Meanwhile, breastfeeding medically complex children is different for many reasons.

Firstly, illness may occur suddenly and unexpectedly. Protecting a milk supply, maintaining milk production, and transitioning back to breastfeeding are completely different breastfeeding scenarios compared with learning to breastfeed for the first time, as is the case with preterm and healthy infants. Illness that occurs after a period of 'normality' presents a different challenge. While sudden or unexpected stress or shock does not 'dry up' a milk supply per se, it can and does have an impact on the milk ejection reflex. Acute or chronic stress raises blood cortisol levels, which inhibits the action of oxytocin (Lawrence, 2022). When infants and children become unwell, have a serious accident or receive a worrying diagnosis, it is highly likely that mothers will be anxious and stressed, which may in turn impair their milk ejection reflex. This makes it much harder for them to protect their milk supply by expressing with a breast pump and requires skilled and sensitive support and breastfeeding counselling to manage. This support should ideally occur within the context of a ward environment that has a culture of supporting, protecting and promoting breastfeeding for all children, and which has access to equipment such as breast pumps.

Secondly, prematurity may present many complications and unexpected setbacks, but in general, the course of prematurity is more predictable, with much known about infant responses, reflexes, behaviours and feeding ability at different gestational ages. In paediatrics, infants and children may present with a vast range of acute and chronic illnesses, conditions and disability, at different ages. Their disease or illness trajectory is therefore far less predictable. Children may be admitted to hospital as an isolated event, experience recurrent admissions, or require lifelong care. The different ages and stages of children admitted will also be directly linked to the stage of lactation, with some time points being more critical to the establishment and maintenance of milk production than others.

Thirdly, there are fewer resources, in terms of training, equipment, and research, meaning that good quality information is harder to access. There is usually no expressing room, unlike in the neonatal unit, and there is no established precedent for access to donor human milk. It is common for healthcare professionals to misunderstand many aspects of normal breastfeeding physiology – leading to inaccurate or misleading advice. There is often intense pressure to measure and record accurate fluid volumes, and direct breastfeeding is

sometimes viewed as a hindrance to this. In short, the environment itself is less conducive to facilitating breastfeeding.

Fourthly, children admitted to paediatrics may have breastfeeding complications that are associated with their development. Older breastfed children may breastfeed much more frequently than usual, or indeed may refuse to feed – both of which may cause confusion and frustration, as well as acute breast related trauma in the case of avoidance of feeding. Holding a distressed one-year-old who is nil by mouth awaiting surgery is a very different experience to comforting a newborn. Trying to encourage a bored toddler to breastfeed, persuade a hypoglycaemic and sleepy infant to feed, or manage a crawling older infant who is in protective isolation are additional and disparate stressors to mothers. As well as developmental challenges, it may also be harder to breastfeed older medically complex children due to central and peripheral lines, drains, casts, stomas, wounds, splints or catheters. Creative positioning may be needed, alongside maintaining their safety and comfort. Medically complex children sometimes have unique challenges related to respiratory needs, low or high tone, higher calorie needs, metabolic complications, anatomical problems, pain and nausea. Layering those challenges over their developmental needs, juggling solid food intake, and maintaining the comfort of familiar home routines presents multiple difficulties for families.

Assuming that a mother has overcome the challenges they have experienced with their child, and maintained their supply, they may need or wish to transition their child back to direct breastfeeding. This is a different clinical scenario to beginning to breastfeed, as some children may struggle to return to breastfeeding. Additional skills are required to support a mother-infant dyad to return to breastfeeding after a pause due to enteral or parenteral feeding, nil by mouth, invasive procedures, mechanical ventilation or other respiratory support. There is far less literature relating to re-establishing oral feeding after either invasive or non-invasive respiratory support in paediatric patients, compared to neonatal populations. The literature that does exist mainly focuses on short term non-invasive respiratory support such as continuous positive airway pressure and high flow nasal cannula oxygen, and mostly for bronchiolitis (Canning et al., 2021). Some studies find that under-nutrition due to lack of enteral feeding is a common problem in children receiving

respiratory support in PICU (Slain et al., 2017; Leroue et al., 2017) even though enteral feeding appears to be well-tolerated and shortens the length of hospital stay (Sochet et al., 2017; Shadman et al., 2019). Feeding difficulties and a delay in establishing feeding may have long term consequences for growth and nutrition, oral development, sensory integration and parent-child bonding. These difficulties may occur as a result of the child's condition, or there may be an iatrogenic cause (Jones et al., 2021). Difficulty establishing or re-establishing oral feeding after surgical procedures have been found to be more common with longer ventilation times (Eggink et al., 2006), thus enteral feeding and respiratory support appears to be interrelated: Lack of feeding is associated with more invasive ventilation and more critical condition but, conversely, children seem to recover faster with earlier oral or enteral feeding.

Occasionally, maternity or neonatal staff try to offer support to a patient on the paediatric ward. Although covering paediatrics is often not part of their job description, anecdotally, many will see paediatric 'outliers' as an act of compassion, although this is ad hoc, and only if they have the capacity after managing their usual workload and patient caseload. However, even when these professionals *do* see mothers and their children on the paediatric ward, this may not always be successful. Maternity staff are often very experienced with supporting the initiation of breastfeeding in the early days, and adept at troubleshooting common breastfeeding challenges. Neonatal staff are often skilled at supporting very small or sick infants or providing education and encouragement to express breastmilk for an infant who is unable to orally feed. However, the reality is that despite these professionals having skill and motivation to help, they may not be experienced with supporting challenges that are unfamiliar to them. Mothers can therefore be caught in a 'skill desert', with neither neonatal nor maternity outreach fully meeting their needs.

Because of the different challenges, lack of training for staff (Dykes, 2006; Holaday et al., 1999; McLaughlin et al., 2011; Gupta et al., 2019), and less widespread acceptance of breastfeeding in the paediatric setting, it is likely that mothers may have unique experiences of breastfeeding on the paediatric ward or PICU.

1.10 Breastfeeding training in paediatrics

A recurring theme of lack of support and insufficient skills and knowledge of health care professionals in the paediatric setting has been identified in the literature in respect of supporting breastfeeding and lactation (Sattari et al., 2013; Radzimirski and Callister, 2015; Colaceci et al., 2017; Michaud-Letourneau et al., 2022). While most healthcare professionals acknowledge the importance of breastfeeding, this does not translate into a working knowledge of how to support it (Rollins et al., 2023). Additionally, much of the breastfeeding education that exists is weighted towards the initiation of breastfeeding for newborns (WHO, 2020). Therefore, even if the existing training was mandatory for paediatric professionals, if not adapted, it may not fully equip professionals to be able to support the varied lactation challenges associated with medical complexity in paediatrics.

Currently, BFI accreditation only exists for some neonatal and maternity units, and not at all in the paediatric setting. Children who are born at full term or have ever been discharged into the community will be admitted to the paediatric unit if they develop a condition that requires medical treatment. The staff these families encounter may have little to no breastfeeding training or knowledge, may default to their own personal experiences (Boss et al., 2021), or formula industry-funded training which is biased and inappropriate (Baker et al., 2023) and the knowledge they do have is unlikely to be standardised across many units. There are likely to be differences between hospital units, types of professional, and between individuals with variable levels of commitment to breastfeeding. Therefore, not only do the paediatric staff not necessarily have the skills required to support families, but the neonatal and maternity staff may lack the necessary skills as well, leaving families at risk of not being able to meet their breastfeeding goals.

Many studies have found that medical complexity is associated with difficulty and lower rates of breastfeeding (Lambert and Watters, 1998; Duhn, 1998; Barbas and Kelleher, 2004; Rivera et al., 2007; Colon et al., 2009; Ryan et al., 2013; Banta-Wright et al., 2015; Torowicz et al., 2015; Helibronner et al., 2017; Madhoun et al., 2020; Barros da Silva, 2019; Coentro et al., 2020) and one hypothesised reason for this could be a lack of health professional training and expertise, as well as a lack of designated and specialised lactation support

within the paediatric setting. One study (Heilbronner et al., 2017) found that admission to hospital with an acute respiratory infection was associated with reduced exclusivity and duration of breastfeeding. In this study, the average duration of hospital stay was only 3 days, and breastfeeding modification was unrelated to severity of illness or invasive ventilation. In fact, the most common reason cited by mothers for reduction or cessation of breastfeeding was medical advice. Other studies also echo the correlation of health professional advice alongside inflexible hospital routines with reduced breastfeeding (Rivera et al., 2007; Sooben, 2012; Torowicz et al., 2015).

It is likely that there are many factors related to the quality of advice provided by health care professionals, including undergraduate training, post-qualification training, personal experience and bias. The World Breastfeeding Trends Initiative (WBTi, 2020) identified many risk factors among the training curriculums of health professionals, noting that there are many gaps (Gupta et al., 2019).

Previous studies with sample sizes between 77-241 have identified gaps in knowledge or attitude of paediatric nurses (Karipis and Spicer, 1999; McLaughlin et al., 2011; Brewer, 2012; Colaceci et al., 2017) but there is no study that has explored the knowledge base of the multidisciplinary team, and there is minimal UK-based literature. There is also no study exploring aspects of health professional attitudes and knowledge within the paediatric setting. Medically complex infants and children will be interacted with by a range of professionals, including doctors, allied health professionals and play specialists, as well as nurses and health care assistants. Therefore, it is important to recognise the role that all health professionals play in supporting breastfeeding, not just nursing staff.

1.11 Undergraduate training competencies

One of the problems of healthcare professional competency is that breastfeeding and lactation is not a core clinical subject covered by undergraduate nursing, medical or allied health professional training programs (see Table 3). Therefore, training in breastfeeding is likely to be patchy and inconsistent, with students relying on clinical placement experience

and tuition by a clinical mentor on the ward or needing to supplement their training with post-qualification courses.

The Nursing and Midwifery Council (NMC) Field specific competencies for Children's Nurses (2014) do not specifically mention breastfeeding or human lactation. There are numerous references to competencies that would be indirectly applicable to breastfeeding if the reader chose to interpret them thus, but the only specific reference to feeding is the competency for enteral (nasogastric [NG] and percutaneous endoscopic gastrostomy [PEG]) feeding (Appendix 1).

Allied health professionals have standards of proficiency that are available on the Health and Care Professions Council. Speech and language therapist standards (2014) have no mention of infant feeding, nor do dietitian (2013), or physiotherapy standards (2013).

Postgraduate medical training is divided into several subspecialties by the General Medical Council (GMC). Doctors who are likely to encounter infants, children and lactating mothers include paediatricians, general practitioners, and obstetricians. The Royal College of Paediatrics and Child Health curriculum (2018) has one mention of nutrition, and it is under the sub-specialty of gastroenterology, hepatology and nutrition, referring to the management of children with complex nutritional needs. The Royal College of General Practice (2019) curriculum has a few generic references to health promotion and preventative healthcare but no specific statement about lactation or infant feeding. Finally, the Royal College of Obstetrics and Gynaecology (2019) has no discussion of infant feeding or breast care at all, even under the postnatal care competencies.

Table 3: Summary of health care professional competencies relating to infant feeding

Health Care Professional	Competencies that mention infant feeding
Paediatric nurse	Enteral feeding only - not oral
Doctor	No mention of infant feeding
Speech and Language Therapist	Ethical implications for withdrawal of feeding
Dietitian	Ethical implications for withdrawal of feeding
Physiotherapist	No mention of infant feeding

Despite oral infant feeding not being taught as a core competency on any paediatric health professional training, many individuals access further training either privately, or through training budgets within the NHS. There are a variety of courses, both in-person and online.

1.12 Additional breastfeeding training options

The most commonly accessed training options are 1–3-day Baby Friendly training, peer supporter training, breastfeeding counsellor training, and IBCLC preparation courses. There are differences in the breadth and depth of these training courses (see Table 4), as well as cost, accessibility, and expected career pathways following completion.

Table 4: Summary of differences between training options:

	Baby Friendly Training	Peer supporter	Breastfeeding counsellor	IBCLC
Primarily accessed by	Health care professionals	Usually women who have breastfed their child	Mothers who have breastfed at least one child for >6 months	Health care professionals and breastfeeding counsellors
Clinical hours required	None	None	None	1000 verifiable and supervised hours
Assessed by	No assessment, but audit annually in accredited areas (none currently in paediatrics)	Completion of training, DBS check	Short answer questions, scenarios and some courses are also accredited	Meeting pre-requisite standards and 4-hour exam
Breastfeeding training hours	Average 15-18 hours over 2-3 days	Average 16-36 hours over about 12 weeks	2 years training part time	Minimum 90 hours lactation specific education after health care professional (HCP) or BFC qualification
Re-assessment	BFI accredited units require annual audit and training update.	Most organisations provide continuing education	Varies, but most organisations offer continuing education	Must attend 75 hours of continuing education to recertify every 5 years
Scope of practice	Health professionals utilise their training within the scope of their role	May volunteer in breastfeeding clinics, or in a paid role in hospital. Refer to health professionals or BFC when necessary	Usually volunteer on breastfeeding helpline, and also may run breastfeeding clinics. May supervise and train peer supporters	Many work in NHS settings, training roles, others work privately. IBCLCs manage a range of feeding issues in predominantly healthy infants

Clinical competencies taught	Basic lactation physiology, common breastfeeding problems, attachment and relationship building, supporting expressing, starting solids.	Basic lactation physiology, common breastfeeding problems, how to support expressing, introducing solids, and basic counselling skills	Extensive counselling skills, supporting a range of breastfeeding problems, expressing, supporting parenting	175 competencies including: Anatomy and physiology of lactation, nutrition, endocrinology, infant and maternal pathology and toxicology, psychology, clinical skills, equipment, counselling skills, research, public health
Any information about sick children?	Some common health challenges such as jaundice and hypoglycaemia of the newborn	None	None	Pathology competencies include palate anomalies, some disabilities, metabolic diseases and general response to illness/surgery

Baby Friendly training is considered the minimum standard for professionals supporting lactation in clinical practice. In paediatrics this is not mandated at present, a risk highlighted by indicator five of the World Breastfeeding Trends Initiative (2016).

While it is clear that when training is provided this could lead to improvements in knowledge and staff attitude (Colaceci et al., 2017), other studies have found that there are significant problems with the way that training is delivered. There is some evidence from a recent systematic review to suggest that the Baby Friendly Standards do not significantly increase the duration of breastfeeding beyond one week (Fallon et al., 2019). However, the same review found that support from health professionals was highly influential to their breastfeeding outcome, suggesting that outcomes may not be wholly about staff skill, but their communication and ability to apply what they know in an individualised way. A synthesis of fourteen systematic reviews similarly found that there may be problems translating BFI guidance in a mother-centred way (Fair et al., 2021). In their descriptive interview study of 53 obstetricians, lactation consultants, nurse-midwives and paediatricians Radzimirski and Callister (2015) found that there was a knowledge-practice gap and lack of hands-on practical skills among the professionals. This may lead to parents feeling that professionals are telling them facts, without the ability to adapt their advice to a nuanced clinical scenario. As well as this, personal bias and beliefs about whether breastfeeding is important may influence the care that health professionals provide. Sattari et al. (2013) conducted a survey of 80 mothers who were physicians, and found that there was a statistically significant association between their personal positive breastfeeding journey and their breastfeeding advocacy of their patients, including associations between their own breastfeeding duration and breastfeeding advocacy, intention to breastfeed and advocacy, and continuing to breastfeed after returning to work and advocacy; suggesting that the clinicians who were more motivated, those who had had met their personal breastfeeding goals and those who had overcome difficulties were more likely to provide clinical advocacy for breastfeeding within their workplace both with their colleagues and also their patients.

A study by Blixt et al. (2014) paired municipalities of similar geographical size and breastfeeding duration in Sweden, and allocated midwives and child health nurses either to 'process-oriented' training or standard training. In this longitudinal study following the

experiences of 584 mothers, they found that when child health nurses and midwives were trained in the 'process-oriented' program to support breastfeeding with healthy term infants, this had a positive outcome not only on breastfeeding duration and exclusivity, but women receiving this intervention had more positive experiences of support and felt better able to overcome challenges. These positive outcomes were sustained at three months. The training included a debrief of healthcare professionals' breastfeeding experiences as well as their attitudes and counselling skills. This suggests that when training is geared towards enabling professionals to individualise the care they provide, this leads to better outcomes. An action research study (Michaud-Letourneau et al., 2022) recruited thirty clinical educators and program directors from three universities in Canada. The educators were drawn from nursing, medicine, midwifery, pharmaceutical, dentistry and nutrition disciplines and the results of the focus groups were validated by working group discussions with 48 students and educators from six universities, as well as representatives from the Canadian breastfeeding training committee, and professional regulatory bodies from the six universities. The study found that a major barrier to supporting breastfeeding was the lack of practical skills training. The researchers found that many professionals knew the theory but did not know how to practically support mothers.

The limited research available suggests that firstly, breastfeeding training is not currently a required competency for those working in paediatrics. Secondly, the existing training is not nuanced enough for supporting children with medical complexity who are beyond the scope of knowledge of those trained primarily to assist with initiation of breastfeeding and troubleshooting common problems. Thirdly, there are significant barriers to providing breastfeeding support that is individualised, and this may be due to practitioners knowing the facts, but not having sufficient counselling skills or practical tools. Fourthly, healthcare professionals may have personal biases and beliefs about breastfeeding that could influence the care and support they provide. Finally, there are no designated paediatric feeding teams in the vast majority of paediatric settings, which means that the care and management of breastfed medically complex children will necessarily fall to those who are likely to have received no training. The risk is that healthcare professionals may not have the skills and knowledge to support families (Baker et al., 2023) and may default to their personal experiences or the experiences of family and friends (Boss et al., 2021).

While it is likely that there are pockets of good practice, the current evidence as well as anecdotal data suggests that this is inconsistent. Current breastfeeding support provision within paediatrics may be ad hoc, patchy and opportunistic. For example, there may be enthusiasm from certain individual practitioners, but this is not a sustainable model as it relies on the advocacy and influence of that individual. The systems, training schemes, policies and culture of supporting breastfeeding are not firmly embedded in a robust and systemic way, leaving families vulnerable to falling between services.

1.13 Impact of childhood illness and inadequate support on breastfeeding outcomes

Breastfeeding rates in the UK and Ireland remain the lowest in the world (Sinclair et al., 2018). As previously mentioned, not meeting breastfeeding goals can cause disappointment, grief and sadness for mothers (Brown, 2018), and it also may place vulnerable children at greater risk. Children with chronic illness and disability are more exposed to clinical environments where they may be more at risk of hospital acquired infection (Alten et al., 2018). Some children have conditions which place them at greater risk of comorbidities, additional illnesses and disease processes. They may also be immunocompromised, less mobile, and struggle to maintain their hydration and nutrition due to higher calorie need, nausea and other complications. Breastfeeding would potentially be an effective form of supportive care for chronically and seriously ill children and children with disability, as well as buffering lactating mothers from some of the negative psychological sequelae of stress and anxiety.

Medically complex children and their families are therefore a vulnerable population who would benefit from investment to enable them to be breastfed for longer and more exclusively. However, breastfeeding can be challenging even without medical complexity, and many mothers need support to overcome challenges and meet their feeding goals. Indeed, it is recommended that all mothers have access to timely support (McFadden et al., 2017) which may be remote (Gavine et al., 2022). There are many factors that are known to protect breastfeeding in general – such as early, skilled, empathic, face-to-face support that is tailored to their individual circumstance and accessible to all, as well as preparation to overcome potential hurdles and trained staff in the community (Brown, 2016).

Of these protective factors, several are challenging or impossible with a chronically or critically sick child. It is unclear to what extent the severity of illness is associated with breastfeeding cessation or introduction of formula supplementation (Heilbronner et al., 2017), so we cannot be sure whether a brief admission with a self-limiting illness may threaten breastfeeding duration and exclusivity more or less than complex illness. However, whether the effect on lactation is minor or severe, mothers who are resident with a breastfed child on the paediatric ward will find it difficult or impossible to get to a community-run clinic.

Keeping infants with their mother is an important facilitator of breastfeeding, so it is logical to suggest that mothers remain with their sick children on the ward. However, this is problematic if assistance with breastfeeding is required and there is no specialised service located on the paediatric ward. In order for a mother who is struggling with breastfeeding to obtain support or advice to overcome a challenge, many would either have to leave their child to attend community-based support or rely on a member of the maternity or neonatal infant feeding teams to see them as an outlying patient if their workload can accommodate this. In a similar vein, parents of children admitted to the PICU are usually not permitted to stay on the ward next to their child, thus rendering it impossible to keep lactating mothers and their children close. A related issue is that breastfeeding is also supported by skin-to-skin and bedsharing. There is an abundance of literature supporting skin-to-skin as a clinically beneficial intervention with sick, preterm and low birth weight neonates, as well as healthy newborns (Moore et al., 2016; Pados and Hess, 2020; Gupta et al., 2021). However, there is no data on the importance of this intervention with older infants. One study of 30 mothers and infants measured cortisol levels before and after skin-to-skin and discussed the benefits of this intervention for attachment and bonding in infants with cardiac conditions in the cardiac intensive care unit (CICU) (Lisanti et al., 2021). However, the focus of this study was on whether skin-to-skin reduced *maternal* stress and anxiety and did not consider the physiological stress of the infants – either with a salivary cortisol sample, or by using clinical measures of stress such as heart rate or respiratory rate. Furthermore, the applicability and acceptability of skin-to-skin in this context should be interpreted with caution when considering how generalisable this is to the wider PICU environment given

that arguably CICU has more in common with NICU than PICU, since infants are often admitted at birth following an antenatal diagnosis.

It is likely that there are significant advantages to receiving skin-to-skin at any age, including physiological stability, pain management, distraction, comfort, bonding and protection of milk supply – but there is simply no literature. Without a robust evidence base, in reality, it is not a common intervention on most paediatric wards or PICU.

Bedsharing is known to facilitate breastfeeding and maximise rest. This may be particularly important for mothers who are resident in hospital with a sick child, as hospitalisation can be very disruptive to sleep (Peirce et al., 2018) and, furthermore, stress can impair the milk ejection reflex. Bedsharing may thus be an important way to maintain closeness, protect the mother-child bond, reduce stress, safeguard the milk supply and facilitate responsive feeding. Bedsharing is also culturally normal for many and may be the family's preferred way of sleeping (Blair et al., 2020). Infants and children who are unused to solo sleeping in a cot beside the mother's bed may find this stressful and re-settling an infant in their own cot may deprive the mother of needed sleep. However, no study exists that discusses or explores bedsharing in a hospital inpatient context (Das et al., 2021). In practice, regulations vary in terms of whether bedsharing is discouraged, tolerated, or actively promoted in paediatrics.

Staff in paediatrics are often not provided with mandatory training in how to support and facilitate breastfeeding (Holaday et al., 1999; McLaughlin et al., 2011; Brewer, 2012; Colaceci et al., 2017). Compounding the problem is the lack of paediatric specific lactation training. While breastfeeding mothers of medically complex children may have some overlap of challenges with mothers of healthy newborns and preterm and sick neonates, they also experience entirely unique problems. These challenges, and how to overcome them, are not currently adequately addressed in training at undergraduate or postgraduate level, and specialised breastfeeding courses do not always teach these skills. From a skills training perspective it makes sense to consider the three main clinical directorates of maternity, neonatal care and paediatrics separately, whilst acknowledging that there is some overlap.

The effects of hospitalisation on families are also well-known. These include stress, shock, sadness, confusion, anger, numbness, trauma, anxiety, and worry. Additionally, parents also may experience financial difficulty, struggles with work, juggling other children and home life, as well as other practical and logistical challenges. They may also find that it is harder to parent in public, causing loss of confidence and difficulty maintaining usual parenting boundaries. Furthermore, all this may be exacerbated by loneliness, relationship strain and a knock-on effect on their own health and wellbeing.

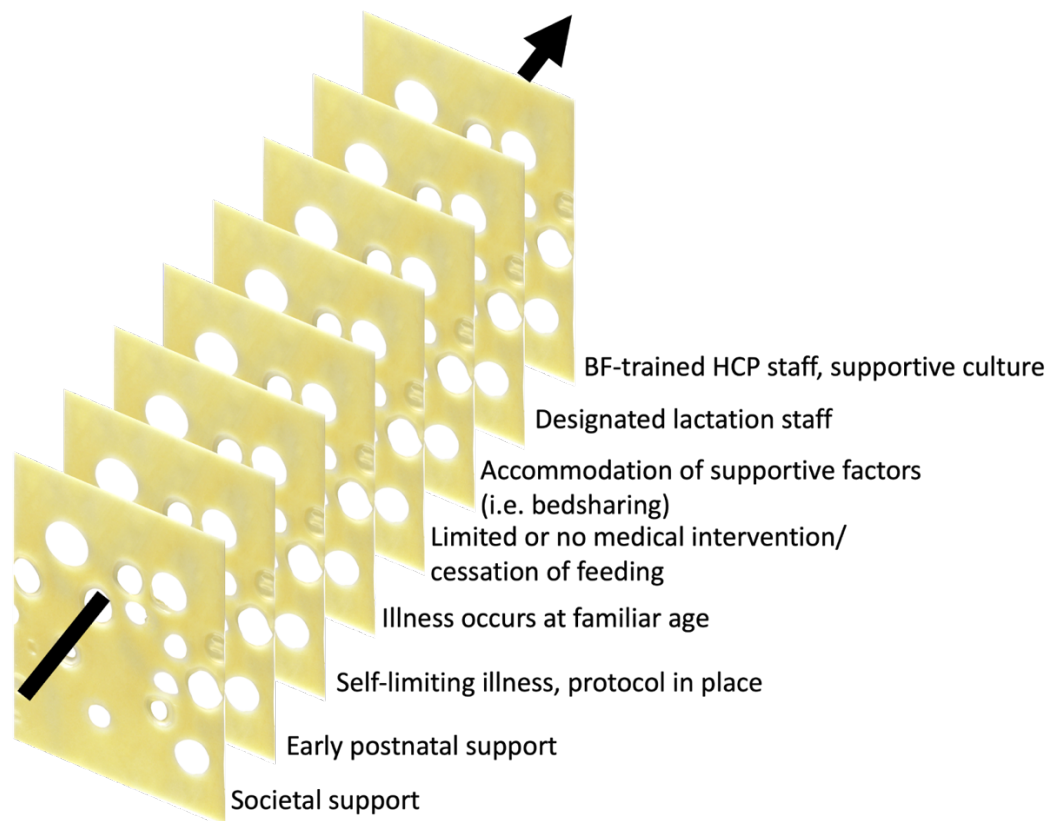
This in turn means that mothers of breastfed medically complex children not only have stressors and challenges due to their child's illness but may have specific breastfeeding difficulties due to the nature of their child's condition that present additional problems. They may not be able to access many of the support options that would be available to them in the maternity, neonatal or community settings; or the support they are able to access may not enable them to overcome their specific paediatric-breastfeeding related problem. This means that not only do they have more and different breastfeeding challenges, but less support to continue to breastfeed and overcome those challenges.

The lack of support, training and additional challenges may pose a threat to the duration and exclusivity of breastfeeding and prevent mothers from meeting their own self-defined breastfeeding goals.

1.14 A systems failure

When all the multiple layers of adversity for families of sick children in paediatrics are considered simultaneously, it is clear that there are multiple opportunities for families to fall through the 'cracks' in the system. Reason's 'Swiss Cheese' model (2000) to explain system-based accidents proposes that in an ideal world, there would be safeguards and barriers to prevent a hazardous situation from occurring. However, in reality, the defences in the system have many holes which, if aligned, will result in families not being prevented from meeting a challenge that will threaten their breastfeeding goal (see Figure 2).

Figure 2: Paediatric lactation barriers, adapted from Swiss cheese model



All families experience either wider societal barriers that impede their breastfeeding intention, motivation, and held beliefs, or conversely, societal support. Next, they are exposed to the challenges common to the general population and may or may not benefit from good postnatal support and early intervention in the community if required. If they get through this barrier and their child is medically complex, they then face a varied range of challenges specific to their child's condition. The best-case scenario is that the child's condition is mild, self-limiting and there is a protocol in place to support optimised feeding through illness. Added to the complication of illness is the fact that medical complexity can affect children at many different ages as well as stages of lactation. Again, the best-case scenario is the child becomes unwell at an age where professionals are familiar with the stage of lactation, and no major adaptations are required. Beyond this barrier are the medical interventions and treatments which themselves can present challenges. Then there are the factors and support systems which may ordinarily protect breastfeeding, but may not be accommodated within paediatric inpatient settings, such as bedsharing, skin-to-skin

and responsive feeding. If a mother struggles to breastfeed her sick child, because she is not able to access usual sources of community support, the ideal ward would have designated paediatric lactation support, but if it does not, the task of supporting lactation will fall to paediatric healthcare professionals who may or may not have received training. Thus, in paediatrics, while there are many layers in the Swiss cheese, the holes in the model are more likely to align; meaning potentially that unless a mother is highly motivated, already has well-established lactation, is able to access additional resources, happens to be buffered by not encountering problems, or her child has less complex illness, it is likely that breastfeeding will be more challenging.

To understand and overcome the potential challenges that families face, it is necessary to know what specific challenges exist for breastfeeding mothers of medically complex children, what interventions help them to maintain breastfeeding during this adversity, and what actions and interventions are less helpful. To this end, a systematic review of the literature was undertaken, to establish the current level of knowledge about why breastfeeding medically complex children may be harder.

The next chapter presents a systematic review of the available literature. The two main aims of the systematic review were:

1. To establish the existing body of knowledge around the challenges and needs of mothers breastfeeding their sick infants or children in the paediatric setting.
2. To identify gaps in healthcare provision that act as barriers to maintaining breastmilk supply and facilitating breastfeeding in the medically complex paediatric population.

Chapter 2

Systematic review of the needs and challenges of medically complex breastfed children and their families

Publication: Hookway, L., Lewis, J., & Brown, A. (2021). The challenges of medically complex breastfed children and their families: A systematic review. *Maternal & Child Nutrition*, 17(4), e13182.

This paper was also presented at four international conferences:

1. Poster presentation at the Lactation Consultants Great Britain conference, May 2020
2. International Lactation Consultant Association, Texas, July 2020
3. Australian Breastfeeding Association conference, August 2020
4. Appalachian Breastfeeding conference, February 2021

The previous chapter reviewed the general literature relating to breastfeeding and conceptualised some of the hypothesised motivations and challenges of breastfeeding sick children in paediatrics. This chapter presents a systematic review of the specific population of sick breastfed children in order to identify the possible areas of known difficulty.

Evidence from studies around the world suggests that breastfeeding duration and exclusivity is lower, and more difficult to achieve among medically complex children for a variety of reasons. For example, one UK literature review found that children with Down syndrome have lower rates of breastfeeding, and those who managed to breastfeed only did so because they had more support (Sooben, 2012). This was echoed in a Puerto Rican study (Colon et al., 2009). A recent case report compared volumes ingested by an infant with Down syndrome with an infant without Down syndrome, and found that low intraoral pressure, large tongue and less effective suckling was clinically significant (Coentro et al., 2020). Meanwhile, Torowicz et al. (2015) studied infants with a congenital heart defect, noting that the high-stress environment makes establishing a milk supply more challenging. Finally, Rivera et al. (2007) explored the complexities of breastfeeding infants with spina

bifida and concluded infant instability after surgery was not the biggest barrier - rather it was the clinical environment, lack of medical staff knowledge, and hospital routines.

It is important to understand how and why breastfeeding is more challenging for parents of medically complex children in order to target services and support to enable them to meet their feeding goals. Understanding the challenges could also lead to more specific training for health care staff so that they are able to support families more effectively and skillfully. Currently, there is little formal guidance for breastfeeding medically complex children. Although the policies of the Baby Friendly Hospital Initiative (BFHI), and the Baby Friendly Initiative (BFI) UK promote, protect and support breastfeeding, their policies do not outline the nuanced care that might be necessary in paediatrics. While children who are diagnosed antenatally with a congenital anomaly will be cared for in the neonatal unit, where staff are likely to have been trained in how to support breastfeeding and maintain milk supply, children cared for in the CICU, PICU, emergency department, or general medical or surgical paediatric ward, may be cared for by staff with very little breastfeeding training. Furthermore, infants who are initially cared for in the neonatal unit may be transferred to one of these paediatric settings, meaning that their experience of breastfeeding support may change.

Despite the known difficulties of feeding medically complex children (Coates and Riordan, 1992), there is no systematic review of their breastfeeding experience within the paediatric setting. A synthesis of studies exploring the experiences of parents breastfeeding their medically complex children may illuminate areas for prioritisation of training and support. The purpose of this systematic review is therefore:

1. To establish the existing body of knowledge around the challenges and needs of parents breastfeeding their sick infants or children in the paediatric setting.
2. To identify gaps in healthcare provision that act as barriers to maintaining breastmilk supply and facilitating breastfeeding in the medically complex paediatric population.

2.1 Methodology

To address the research questions, the search strategy (Table 5) and eligibility criteria (Table 6) were designed in line with the PICOS criteria (population, intervention, comparator, outcomes, study design or setting). This is a modification of the PICO criteria, which omits study design or setting and is more commonly used to search for quantitative studies (Methley et al., 2014). There has been some discussion about whether the PICO, PICOS or SPIDER (sample, phenomenon of interest, design, evaluation, research type) criteria are more appropriate. It has been found that the PICO search strategy is the most sensitive, and tends to yield the most comprehensive results, with some studies being missed when using the more specific SPIDER criteria. Compared with the PICO criteria, PICOS, with the added component of study design and setting, is useful when time or resources are limited and is also more favourable when studies are generally qualitative. (Cooke et al., 2012; Methley et al., 2014).

Table 5: Keywords used in article search

Search number	PICOS component	Search terms (BOOLEAN operator OR)
1	Population	Child, children, babies, baby, infant
2	Intervention	Sick, disease, illness, disability, congenital anomaly, cleft lip, childhood cancer, chronic illness, syndrome, sick children, child with disability
N/A	Comparator	N/A
3	Outcomes	Breastfeeding, breastfeed, breastmilk, human milk, EBM
4	Study design and setting	(Any design, any country) Hospital, PICU, paediatrics, pediatrics

2.2 Eligibility criteria

Both published and unpublished studies using any methodology were eligible if they met the inclusion criteria (see Table 6). Inclusion criteria were that the study was focused on breastfeeding infants or children in hospital, and where the focus was on support for sick

children, rather than preventing disease. Literature was included from anywhere in the world, since there may be examples of good practice, as well as higher breastfeeding rates in resource poor as well as resource rich countries (Victora et al., 2016). In addition, articles that combined the attitudes of health care staff towards breastfeeding parents were also included, as they could have included feedback from parents. No date limits were set as there was no previous systematic review, although where located studies were dated, their results were treated with caution.

All studies whose focused population was breastfed children with acute or chronic illness, disability or congenital anomaly were considered. An acute illness is experienced by a child who is usually healthy, but experiences a brief illness requiring medical treatment, such as an acute infection, sepsis, or accident such as a burn or injury. A chronic illness is a condition which requires observation, monitoring or medical intervention and treatment for many weeks, months, or years, such as diabetes, asthma, epilepsy, or cancer. Chronic conditions may also sometimes require surgery. A disability is a condition that is often diagnosed antenatally or soon after birth, affecting physical, intellectual, or communication abilities, and includes conditions such as Down syndrome, cerebral palsy, or Prader-Willi syndrome. A congenital anomaly is a structural or functional anomaly that occurs during intrauterine life that may or may not have serious medical consequences. Many congenital anomalies will require medical or surgical intervention, such as cardiac defects, cleft lip or palate, spina bifida, or congenital diaphragmatic hernia.

The neonatal intensive care unit (NICU) as a setting was excluded because Baby Friendly standards already apply to this area, and many staff working within the NICU have already received training in supporting breastfeeding and lactation. Combining data from both the NICU and paediatric settings would therefore potentially confuse the data, as parents in different areas may have different experiences of care.

Publication or researcher bias is a significant problem in academic literature and refers to the tendency to favour publication of statistically significant and positive findings, leaving the null results unpublished. This can unfairly skew the data available, and lead to exaggerated emphasis in some subjects (Van Aert et al., 2019). Every effort was made to

both avoid and account for publication bias through not excluding studies with non-statistically significant results, including unpublished data, small studies, and studies conducted in many countries, including low- and middle-income countries (Ekmekci, 2017). It is best practice to have two reviewers to search and sift the literature to ensure inter-rater reliability; however, this was not possible as the work formed part of this thesis, which Siddaway et al. (2019) point out is a common issue, requiring flexibility. Nevertheless, inclusion and exclusion criteria were discussed with a second reviewer, reducing the risk of bias.

Table 6: Inclusion and exclusion criteria

Inclusion criteria	Study written in English
	Original research article
	Mothers, or parents who were directly breastfeeding or providing breastmilk by expressing and bottle feeding, whether exclusive or partial
	Paediatric ward or PICU setting
	Studies that included staff views and training on breastfeeding as well as parent experience
	Studies exploring parental challenges of breastfeeding
	Studies exploring challenges of initiating, maintaining or increasing milk production for sick children
	Studies exploring the challenges of providing breast milk via alternative feeding routes, such as nasogastric tube (NGT) or gastrostomy tube (GT)
Exclusion criteria	Written in another language
	Exclusively formula fed children and formula feeding parents
	Studies focused on another aspect of child feeding – for example solid food
	Community setting
	NICU setting
	Maternity unit or transitional care
	Described a well child with a parent with disability or illness
	Described reasons for cessation of breastfeeding that were not related to child illness
	Compared health outcomes between children who were and were not breastfed in infancy
	Described breastfeeding as a health promotion or preventative strategy
	Described practical or theoretical feasibility of breastfeeding among children with disability
	Expert opinion or theoretical recommendations regarding feasibility without any reference to parental views
	Discussed strategies to increase breastfeeding rates in the general population

2.3 Search strategy

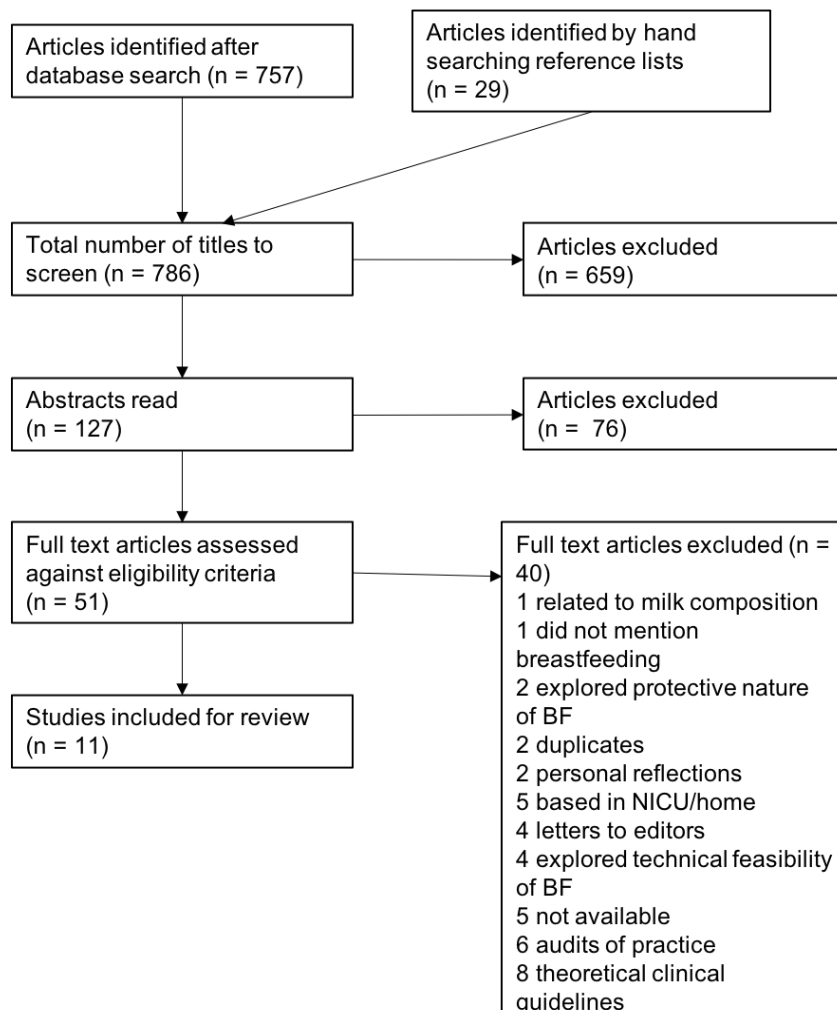
Literature was sought in January- February 2020, using CINAHL, PubMed, Google Scholar, and iFind. Boolean operators (Table 5) were used to blend the keywords, and alternative spellings were used to capture variants of keywords. The literature search yielded 757 studies, dissertations, reports and narrative reviews. In addition, the reference lists of pertinent books and articles were scrutinised to identify further papers which may have been missed.

All retrieved article titles were read initially. Many studies, while including some relevant search terms in the title, were clearly focused on the NICU environment, or on breastfeeding being a preventative intervention against illness. Any article that could not be obviously excluded was kept for further investigation.

After the initial exclusion of articles that did not meet the inclusion criteria, there remained 127 article abstracts to read. Reasons for exclusion are noted in Figure 3. All articles that could not be conclusively accepted or rejected after reading the abstract were kept. After applying the inclusion criteria to the full texts of the remaining papers, 11 articles remained for review (see Figure 3). A narrative synthesis and thematic analysis were then conducted with the eligible studies.

Results are reported in relation to the seven identified themes. To document evidence of the themes within each paper, illustrative quotations have been taken from the mixed methods or qualitative studies. Mixed methods systematic reviews are a newer and emerging approach to research synthesis (Stern et al., 2021) and at the time of undertaking the original systematic review there was limited guidance relating to the methodology of this type of review. Some more recently published mixed methods systematic reviews use quotations to support findings taken from qualitative papers, though there are very few that relate to infant feeding (Baker et al., 2023; Wright et al., 2023) and a decision to follow this style was adopted in the review.

Figure 3: PRISMA flow diagram demonstrating article screening process



2.4 Quality appraisal

A table was created to summarise the main study characteristics and findings to assist with analysis of the remaining eleven papers (Appendix 2). For quality appraisal of the included studies, existing published Critical Appraisal checklists were used – including the checklist for qualitative studies and the cohort study checklist (CASP UK, 2018); and for the cross-sectional studies, an adapted version of the CASP cohort study checklist was designed (Appendix 3). Eight of the studies were qualitative (Table 7). Two studies were cross-sectional in design and there was one cohort study (Table 8).

Table 7: Quality appraisal summary of 8 included qualitative studies

CASP Criteria	Met the criteria? (Yes, Can't tell, No)							
	Banta Wright et al., 2015	Barbas & Kelleher, 2004	Barros da Silva et al., 2019	Moe et al., 1998	Duhn & Burke, 1998	Lambert & Watters, 1998	Lewis and Kritzinger, 2004	Ryan et al., 2013
Q1: Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y
Q2: Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y
Q3: Was the research design appropriate to the aims of the research?	Y	?	Y	Y	Y	?	Y	Y
Q4: Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y
Q5: Was the data collected in a way that addressed the research issue?	Y	Y	Y	?	Y	Y	Y	Y
Q6: Has the relationship between researcher and participants been adequately addressed?	Y	N	?	?	Y	N	N	Y
Q7: Have ethical issues been considered?	Y	N	Y	N	Y	N	N	N
Q8: Was the data analysis sufficiently rigorous?	Y	?	Y	N	Y	?	Y	Y
Q9: Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y
Q10: How valuable is the research?	Y	Y	Y	Y	Y	Y	Y	Y

Table 8: Quality appraisal summary of 2 cross sectional studies and 1 cohort study

CASP criteria	Met the criteria? (Yes, Can't tell, No)		
	Heilbronner et al., 2017	Madhoun et al., 2020	Rendon Macias et al., 2002
Q1: Did the study address a clearly focused issue?	Y	Y	Y
Q2: Was the sample recruited in an acceptable way?	Y	Y	Y
Q3: Was the exposure accurately measured to minimise bias?	N/A	N/A	Y
Q3a: Was the outcome accurately measured to minimise bias?	?	? (Possible response bias. Limited SE and ethnic diversity)	Y
Q4a: Have the authors identified all important confounding factors?	Half the sample did not have socioeconomic background recorded	? (No mention of antenatal education)	Y
Q4b: Have the authors taken account of confounding factors in their design and analysis?	?	?	Y
Q5: Was the follow up of subjects complete enough?	Y	Y	Y
Q5b: Was the follow up of subjects long enough?	N/A	N/A	Y

Q6: What are the results of this study?	Hospitalisation with bronchiolitis is negatively associated with duration and exclusivity of breastfeeding, especially in younger infants, and those who were tube fed	Cleft lip/palate adversely affects BF duration, exclusivity and experience, however, there was a problem with question wording - did not differentiate between exclusive and partial BF. The parents in this sample were well supported by IBCLCs in the hospital setting and achieved a high rate of provision of breastmilk through pumping, and the sample was also biased towards higher socioeconomic (SE) status	Infants with congenital malformations are less likely to BF. Mothers cited many reasons, including medical advice, separation, and infant disease – especially GI disease
Q7: How precise are the results?	N/A	N/A	? (Wide confidence intervals)
Q7a: Do you believe the results?	Some absent data	Y	? (Limitations not discussed)
Q8: Can the results be applied to other populations?	?	? (Limited SE variation)	?
Q9: Do the results of this study fit with other available evidence?	Y	Y	Y
Q10: What are the implications of this study for practice?	Even short hospital durations may pose a threat to breastfeeding outcome, necessitating more support for breastfed dyads in hospital	Infants with clefts are more likely to struggle with breastfeeding, particularly when the palate is involved.	Combined with other research relating to congenital malformations, this study adds to the weight of recommendation for targeted support and multi-disciplinary collaboration

2.5 Search results

Overall, there were eight qualitative and three mixed-methods studies representing a total sample size of 599 (range: n=5-194). All the studies explored the impact on breastfeeding of illness, disability or congenital anomaly. There was a small clustering of studies in 1998, and of eleven included studies, six were conducted in the United States or Canada. There was one UK study, and it was notable how few illnesses or conditions were explored (Table 9).

Table 9: Summary of studies reviewed

Study	Country of study	Sample size	Year of publication	Design	Population
Banta-Wright et al.	USA/Canada	10	2015	Qualitative	Mothers of infants with phenylketonuria (PKU)
Barbas and Kelleher	USA	68	2004	Qualitative	Mothers of infants with congenital heart disease (CHD)
Barros da Silva et al.	Portugal	10	2019	Qualitative	Mothers of children with Down syndrome
Duhn and Burke	Canada	7	1998	Qualitative	Mothers of children with CHD
Heilbronner et al.	France	84	2017	Cross sectional	Mothers of children with bronchiolitis
Lambert and Watters	Canada	12	1998	Qualitative	Mothers of children with CHD
Lewis and Kritzinger	South Africa	20	2004	Qualitative	Mothers of children with Down syndrome
Madhoun et al.	USA	69	2020	Cross sectional	Mothers of infants with cleft lip/palate
Moe et al.	USA/Canada	194	1998	Qualitative	Mothers of children with Rubinstein-Taybi syndrome
Rendon Macias et al.	Mexico	120	2002	Cohort study	Mothers of infants with congenital anomalies
Ryan et al.	UK	5	2013	Qualitative	Mothers of children with Down syndrome, Cleft and CHD

2.6 Study quality

The studies all had clearly defined aims, and recruitment strategies. All of them explored the impact of various medical conditions on breastfeeding outcomes. The studies addressed and commented on a range of potential confounding factors, including socio-economic status (SES), degree of infant illness or disability, and infant age. Only four studies commented on prenatal intention to breastfeed (Lambert and Watters, 1998; Moe et al., 1998; Rendon-Macias et al., 2002; Madhoun et al., 2020), which could be significant, as parental motivation is known to be a factor in breastfeeding duration and exclusivity (Claesson et al., 2019).

Only two studies commented on whether the hospital facility was Baby Friendly accredited (Rendon-Macias et al., 2002; Heilbronner et al., 2017), which may be relevant since BFI/BFHI status is known to positively influence the initiation of breastfeeding, though there is limited data on the correlation between BFI accreditation and maintenance of breastfeeding (Perez-Escamilla et al., 2016), and at the present time Baby Friendly standards do not apply to the paediatric setting.

There were many problems with study quality. Only four studies commented on ethical approval, several studies had missing data, and small sample sizes. Most of the studies only accounted for a limited number of confounding variables, and some of the terms were not explicitly defined – such as what constitutes an ‘expert’ (see Table 10 – Summary of strengths and limitations of studies).

Table 10: Summary of strengths and limitations of studies

Study	Strengths	Limitations	Country	Sample size	Year of publication	Design	Population
Banta-Wright et al. (2015)	<p>Well-designed study meeting all CASP (2018) checklist criteria.</p> <p>Consideration given for the wider impacts of breastfeeding beyond nutrition.</p> <p>Good example of how breastfeeding could work even in a condition that is ever-changing.</p>	<p>Highly motivated sample of mothers with previous experience of breastfeeding, and access to IBCLC may reduce generalisability.</p> <p>Small sample (n=10)</p>	USA/ Canada	10	2015	Qualitative	Mothers of infants with PKU
Barbas et al. (2004)	<p>All infants had a major cardiac anomaly requiring surgery.</p> <p>Parents received education about how to pump, and detail is provided about this teaching.</p> <p>Detail is provided about how exclusivity of breastfeeding changed over time, and why.</p>	<p>Self-selected sample – may have attracted more motivated parents.</p> <p>Mostly high SES and educational status.</p> <p>Half the sample had previous breastfeeding experience.</p> <p>Conflicting remarks about what helped, with no clarification provided.</p>	USA	68	2004	Qualitative	Mothers of infants with CHD

Barros da Silva et al. (2019)	<p>In depth data collection capturing the meaning of breastfeeding as a parenting activity to parents.</p> <p>A range of feeding experiences were represented.</p>	<p>Small sample</p> <p>Confounding variables not commented on.</p> <p>Did not comment on additional needs sometimes co-existing with Down syndrome, so hard to tell if feeding difficulties were due to Down syndrome, or a comorbidity.</p> <p>Possible recall bias due to the ages of children at the time of interview.</p>	Portugal	10	2019	Qualitative	Mothers of children with Down Syndrome
Duhn (1998)	<p>Well-designed study meeting all CASP (2018) checklist criteria.</p>	<p>Small sample size</p> <p>In this sample, all the mothers had stopped breastfeeding by 4-6 weeks, so limited long-term data.</p>	Canada	7	1998	Qualitative	Mothers of children with CHD
Heilbronner et al. (2017)	<p>Focused on acute illness - provides an important comparison to chronic conditions.</p> <p>Relatively larger sample.</p> <p>Separated infant critical illness from environmental factors as a reason for cessation of breastfeeding</p>	<p>Missing demographic data.</p> <p>The study commented that there were difficulties staying in hospital overnight, but no clarification.</p> <p>No definition of 'expertise' despite the study commenting that the 'experts' were not helpful.</p> <p>Sample may have been too under-powered to detect an association</p>	France	84	2017	Cross sectional	Mothers of children with bronchiolitis

		<p>between PICU admission and reduction in exclusivity of breastfeeding.</p> <p>No detail about the extent of breastfeeding modification, despite this being the study focus.</p>					
Lambert and Watters (1998)	<p>Relatively severe CHD in this study, and most infants were breastfeeding at the time of surgery.</p> <p>Parents mostly had breastfed another child, so could separate 'normal' breastfeeding challenges from CHD related challenges.</p>	<p>Small sample</p> <p>Most parents had prior breastfeeding experience.</p> <p>Limited SES, educational variability. Sample recruited via magazine advert, and the infants represented in the sample were born between 1978 and 1993 – potential for recall bias, as well as policy and practice change. Therefore, results should be treated with caution.</p>	Canada	12	1998	Qualitative	Mothers of children with CHD
Lewis and Kritzinger (2004)	<p>This study separated the comorbidities associated with Down syndrome – such as cardiac defect, low tone and poor suck.</p> <p>Explored specific mechanical., growth and emotional challenges.</p>	<p>It is unclear whether the support provided was helpful, as not assessed.</p> <p>No clear lactation support program documented.</p> <p>Study conducted in South Africa where services were noted to be insufficient. It is unclear whether the difficulties experienced were</p>	South Africa	20	2004	Qualitative	Mothers of children with Down syndrome

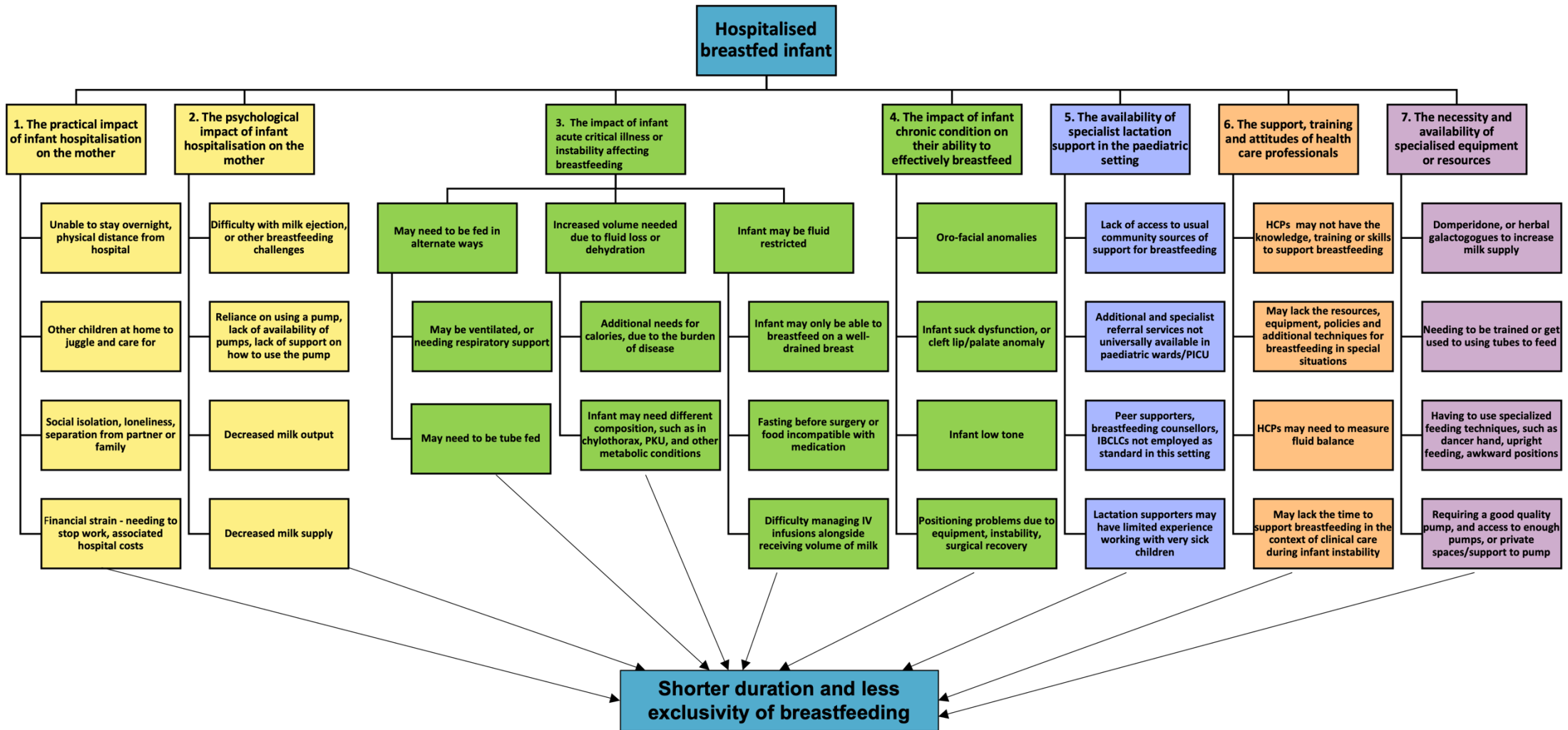
	Authors explored direct breastfeeding, bottle feeding and tube feeding breastmilk	due to inadequate support, or the medical complexity of the infants.					
Madhoun et al. (2020)	<p>Large and relatively wide SES variation, including 28% of participants involved in the WIC (Women, Infants and Children) program.</p> <p>Rates of breastfeeding are similar to national population statistics.</p> <p>Explored both breastfeeding and expressing, and separated barriers to breastfeeding from expressing.</p> <p>Explored the nuances and impact of different severity of cleft.</p>	<p>No differentiation between exclusive and partial breastfeeding.</p> <p>Self-selected sample, so response bias is a risk.</p> <p>Did not separate exclusive breastfeeding from any breastfeeding – it is unclear whether those with more breastfeeding challenges were also those with lower exclusivity.</p> <p>No discussion about how much milk infants received via tube, or whether this was predominantly breast milk or formula.</p>	USA	69	2020	Cross sectional	Mothers of infants with cleft lip/palate
Moe et al. (1998)	<p>Large sample.</p> <p>Initiation of breastfeeding matched national statistics at the time of the study.</p> <p>The condition shares many features of other conditions which may increase the</p>	<p>Very rare condition which may not be generalizable to a broader population.</p> <p>Barriers to breastfeeding not formally assessed but were added as free text comments by parents – therefore the data captured is not</p>	USA/ Canada	194	1998	Qualitative	Parents of children with Rubinstein-Taybi syndrome

	generalisability (with caution).	standardised. Some challenges may have been missed.					
Rendon Macias et al. (2002)	<p>Considers a variety of congenital anomalies.</p> <p>Sample closely followed up for 6 months, limits recall bias.</p> <p>Reasons for cessation of breastfeeding clearly documented and separated by the infant's condition to explore the impact of different conditions on breastfeeding outcome.</p>	<p>May not be generalizable to a wider population due to lack of facilities.</p> <p>Older study – cohort was 1997-1998.</p> <p>Study limitations not discussed.</p> <p>Combined exclusive and partial breastfeeding.</p> <p>Unclear what extent the child's condition had on feeding outcomes as the most significant factor was separation of mothers and infants.</p>	Mexico	120	2002	Cohort study	Mothers of infants with congenital abnormalities
Ryan et al. (2013)	<p>Well-designed study meeting all but one of the CASP (2018) checklist criteria.</p> <p>Explored emotional adjustment and coping mechanisms as well as practical barriers and challenges.</p> <p>Multiple problems and modes of feeding experienced.</p>	<p>Small sample size (n=5)</p> <p>Comments about over-using nasogastric tubes causing stress, but there is no context. Unclear whether this was inappropriate tube use, or the necessity of the tube itself that caused stress.</p>	UK	5	2013	Qualitative	Mothers of children with Down syndrome, Cleft and CHD.

2.7 Study themes

Despite the variable study quality, all included studies contributed to the development of themes since there is so little literature available and all the experiences of the study participants are arguably valid and meaningful. Themes were developed by reading and re-reading the papers to become familiarised with their purpose, methods and results (see Figure 4 for visual representation of themes and subthemes).

Figure 4: Visual representation of themes and subthemes



2.8 Narrative synthesis

A theoretical thematic analysis was chosen because the themes were not necessarily linked to the data being collected in the study in question, although they were explicit within the meaning of the papers. Rather, the data collected was analysed in relation to this research question (Braun and Clarke, 2006). Seven themes were apparent from the literature:

1. The practical impact of infant hospitalisation on the mother
2. The psychological impact of infant hospitalisation on the mother
3. The impact of infant acute critical illness or instability affecting breastfeeding
4. The impact of infant chronic condition on their ability to effectively breastfeed
5. The availability of specialised lactation support in the paediatric setting
6. The support, training and attitudes of health care professionals
7. The necessity and availability of specialised equipment or resources

Eight studies mentioned at least six out of the seven themes, and the most prevalent theme related to the inadequacy of health care professional support – this was identified as a barrier in every study (see Table 11).

Table 11: Study themes

Study	Subthemes	Themes analysed from data
Banta Wright et al. (2015)	Breastfeeding was hard work but important. Mothers had to adapt to infant condition constantly. IBCLCs were hard to find, and healthcare professionals lacked information. Pumps were essential.	1, 2, 4, 5, 6, 7
Barbas and Kelleher (2004)	Breastfeeding increased self-efficacy. Infants were sometimes too sick, and too sleepy to feed. IBCLCs were found to be helpful but too few of them. Nurses were less helpful. Pumps were essential.	2, 3, 4, 5, 6, 7
Barros da Silva et al. (2019)	Practical issues of discomfort and difficulty maintaining supply. Breastfeeding was hard but parents were motivated to persevere. Infants are often too sick to feed, then once better, very sleepy. Very little support available. Pumps essential and not always available.	1, 2, 3, 4, 5, 6, 7

Duhn and Burke (1998)	Parents were exhausted and stressed. Surgery and ventilation were a barrier to success. As infants got better, they continued to be sleepy and struggled with weight. Healthcare professionals often used negative language. Lack of support to use essential equipment.	2, 3, 4, 6, 7
Heilbronner et al. (2017)	Parents struggled with the practicalities of admission to hospital. Illness severity not linked to breastfeeding rates in this sample. Inadequate lactation support. Poor advice from healthcare professionals. Not enough pumps.	1, 3, 5, 6, 7
Lambert and Watters (1998)	Practical milk supply issues. Parents struggled with fatigue and anxiety. Pre-operative fasting and surgery was a barrier. Adaptations for sleepy, slow gaining babies needed. IBCLCs were helpful but not enough of them. Healthcare professionals had little training and were not found to be helpful by parents. Lack of privacy and inconsistent advice about equipment noted.	1, 2, 3, 4, 5, 6, 7
Lewis and Kritzinger (2004)	Parents experienced a range of emotions. Infants were often complex and unstable. Infants often had low tone and adaptations were needed. No IBCLCs, but peer support was helpful. No critique of healthcare professional input. Parents used nasogastric and gastrostomy tubes but no information about how these were managed by parents.	2, 3, 4, 5, 6, 7
Madhoun et al. (2020)	Milk supply struggles. Anxiety and depression were common. Many breastfeeding problems and lower duration of feeding with cleft palate. IBCLCs accessible but not part of the cleft team. Healthcare professionals lacked knowledge and skills. Multiple types of equipment needed.	1, 2, 4, 5, 6, 7
Moe et al. (1998)	Feeding challenges were common. Infant supplementation is common. Breastfeeding was seen as a positive intervention. Many complex swallowing problems are cited, plus low tone and sleepy infants. Lack of lactation support. Healthcare professionals were unsupportive. Specialised techniques were needed	2, 3, 4, 5, 6, 7
Rendon Macias et al. (2002)	Perceived low milk supply was common. Fasting protocols and surgery were barriers. As infants got better, weight problems and poor suck were problematic. Advice to stop breastfeeding was common.	1, 3, 4, 6
Ryan et al. (2013)	Perceived low milk supply was common. Parents experienced stress and anxiety frequently. Needing to know fluid volumes was a barrier. Parents were critical of healthcare professionals' support of lactation but felt conflicted as they needed those professionals to care for their infants clinically. Pumps were essential.	1, 2, 4, 5, 6, 7

2.9 Results

2.9.1 The practical impact of infant hospitalisation on the mother

Infant hospitalisation impacts parents in a very practical way. Eight of the eleven studies found various practical problems, ranging from issues of logistics to practical breastfeeding problems. For example, the way in which the infant was fed breastmilk often had to change due to separation or necessary adaptations due to the illness / disorder. Many mothers had to start expressing milk or work to maintain supply when under normal circumstances they may have been able to directly feed (Lambert & Watters, 1998). This can add in a layer of complication in finding the time to express, store and deliver the milk.

Expressing milk rather than directly breastfeeding is also not necessarily straightforward. It is associated with a higher risk of blocked ducts, mastitis, engorgement (Kvist, 2010), and ultimately low milk supply if the child is not effectively removing milk (Morton et al., 2013). Indeed, Barros da Silva et al. (2018) concluded that breast-related problems and difficulty with milk expression were common, and several studies highlighted the issue of perceived low milk supply, sometimes leading to formula supplementation or breastfeeding cessation (Madhoun et al., 2020; Ryan et al., 2013; Rendon Macias et al., 2002).

However, mothers often feel a desire to persevere with expressing, and this sacrificial aspect was described as a labour of love (Banta-Wright et al., 2015). There were also other more logistical problems that were unrelated to breastfeeding physiology. For example, Heilbronner et al. (2017) noted the challenge of staying overnight in hospital; whilst Rendon Macias et al. (2002) identified difficulties when infants were hospitalised far from home.

2.9.2 The psychological impact of infant hospitalisation on the mother

Nine of the studies explored data relating to the maternal psychological aspects of breastfeeding their hospitalised child. These were both negative and positive. For example, from a negative perspective, Duhn (1998) and Lewis and Kritzinger (2004) found that feelings of exhaustion, overwhelm, disappointment, frustration, inadequacy, loneliness and

sadness were common, though the mothers in the Duhn (1998) study reported mixed feelings as well as distinctly positive and negative.

"I felt the closeness, but it was very hard, I was not in the best of moods. I was tired. But the closeness was there. It's OK, the soothing, calming part. Like ... I could put him back to sleep or breastfeed him but it was just an uphill battle and because there were no answers to anything it made it worse." Duhn (1998) page 54.

Madhoun et al. (2020) identified high levels of anxiety and depression in their sample, with over half the mothers suffering with anxiety and one third struggling with postnatal depression. However, Lambert and Watters (1998) concluded that there were some positive aspects relating to breastfeeding a child with a chronic condition. Some of the perceived benefits of breastfeeding included a greater sense of calm, decreased stress, an opportunity for relaxation, and an increased sense of self-efficacy.

2.9.3 The impact of infant acute critical illness or instability affecting infant ability to breastfeed

Eight of the studies commented on infant instability or severity of illness as a factor affecting their ability to feed easily. Of these studies, one was a study of children with acute bronchiolitis in otherwise healthy children, and the others all described experiences of children with congenital conditions.

Several studies exploring congenital heart defects found infant critical illness or instability to be a barrier to breastfeeding. Duhn (1998) found that infants with heart defects were likely to struggle to feed and gain weight, be too fatigued to feed, and surgery and ventilation were cited as factors affecting an infant's ability to breastfeed.

"... he was very sluggish, very tired [before he went on medication] ... he wasn't gaining enough from breastfeeding ... it was a struggle ... because it tired him out so easily ... I was frustrated, worn out ... I'd have to fight with him ... with him it was a constant battle." Duhn (1998) page 62.

Barbas and Kelleher (2004) found that infants were more likely to be breastfed postoperatively if they had attempted breastfeeding before their surgery. Meanwhile, Lambert and Watters (1998) and Rendon Macias (2002) cited preoperative fasting as a significant barrier to breastfeeding.

Problems were also noted among infants with Down syndrome and Rubinstein-Taybi syndrome, both of which are often associated with comorbidities (Moe et al., 1998). Barros da Silva et al. (2018) found that infants with Down syndrome were more likely to have problems with breastfeeding if they also had a cardiac defect, low tone, and poor suck.

“I had a lot of trouble, he could not grasp the breast, could not suckle, though sucking well in the baby bottle. One difficulty that, now he is in speech therapy we realise, he had hypotonia of the lower lip. He could not make the sealing of the lip and the milk ran around, and so, it was very difficult.” Barros da Silva et al. (2018) page 257.

The only study to explore an acute illness was Heilbronner et al. (2017). The researchers found that admission to hospital for acute bronchiolitis was associated with reduced exclusivity or cessation of breastfeeding, but the reasons for this were multifactorial and mostly unrelated to illness severity.

2.9.4 The impact of infant chronic condition on their ability to effectively breastfeed

All but one paper (Heilbronner et al., 2017) discussed the impact of certain symptoms of the infant’s condition on their ability to breastfeed or the duration of breastmilk provision. Infant conditions generally caused hypotonia, somnolence and poor weight gain in a cluster, or drove a need for feeding adaptations such as frequent short feeds and strategies to increase calories to manage fatigue and growth problems. Banta-Wright et al. (2015) was the exception to the previously mentioned adaptations to feeding. In their study, they found that mothers had to be constantly flexible, in response to their child’s phenylalanine (Phe) levels, not because of their infant’s tone or somnolence, but because of their underlying metabolic condition.

“I breastfed for 7 months. During that time, [how much I could breastfeed] ... fluctuated because we monitored [Phe] levels every week. I would have to increase breastfeeding if levels were too low and decrease breastfeeding if they went too high.”
Banta-Wright et al. (2015) page 731.

Most of the studies exploring the challenges of breastfeeding infants with cardiac defects had many findings in common. Increasing and measuring milk consumption was a common theme. Barbas and Kelleher (2004) focused mainly on the need for more calories, whilst Lambert and Watters (1998) and Duhn (1998) found that many mothers needed to provide small frequent feeds to manage poor weight gain. Meanwhile, a poor suck and subsequent low weight gain was identified by Rendon-Macias et al. (2002) particularly amongst children with congenital anomalies. Finally, in their analysis, Ryan et al. (2012) identified the difficulty of needing to know feed volumes to manage an infant’s clinical condition.

“Sometimes clinical requirements that were deemed necessary, for example knowing how much milk the baby had consumed, were not very compatible with breastfeeding.” Ryan et al., (2013) page 797.

Further studies focused on somnolence and hypotonia, including Moe et al. (1998) and Barros da Silva et al. (2019). Lewis and Kritzinger (2004) concluded that hypotonia, poor and weak suckling, uncoordinated suck-swallow-breathe reflex sequences, macroglossia, small intra-oral space and difficulties achieving a comfortable and effective position due to low tone all impacted breastfeeding.

Finally, Madhoun et al. (2020) studied 150 children with cleft lip and palate. They found that a cleft palate was associated with more problems breastfeeding irrespective of whether there was also a cleft lip. The infants with only a cleft of the lip had the highest rates of breastfeeding. In this study, most of the mothers expressed their milk either long term, or prior to surgical correction of the cleft. The type of cleft made no difference to the duration of expressing – only direct breastfeeding.

2.9.5 The availability of specialised lactation support in the hospital paediatric setting

A total of nine papers commented that lack of specialist lactation support made breastfeeding harder. For example, Banta-Wright et al. (2015) found that although there were designated IBCLCs in the neonatal unit they were not employed in paediatrics. One study participant telephoned every IBCLC she knew to ask for information and managed through this convoluted route to get the help she needed. Meanwhile, in the Barros da Silva et al. (2019) study with mothers of infants with Down syndrome in Portugal., mothers mainly expressed dissatisfaction with the support they received.

“Health professionals who think: Oh, that child has DS and cannot suckle, we will continue to feed with the nasogastric tube, and it was what they said. I picked a poor doctor, also nurses, who felt he had no condition to breast-feed because he had DS.”

Barros da Silva et al. (2019) page 258.

Most reported that there was very little support or information, and they also had little encouragement to breastfeed. Likewise in Ryan et al.’s (2012) study of infants with various chronic illnesses, mothers raised the issue of a lack of reliable, sensitive and accessible breastfeeding support. This was echoed in Lambert and Watters (1998) study where physician support was rated as least helpful. However, when mothers did have access to an IBCLC they found it useful.

Details of who is providing specialist support are often unclear in published research. For example, Heilbronner et al. (2017) studied 84 infants admitted to a hospital without baby friendly accredited status in France with acute bronchiolitis. A total of 51% of the mothers either stopped or reduced the exclusivity of breastfeeding. In this study, each ward had several breastfeeding ‘experts’ among the doctors and nurses, but no specific lactation support service. It is unclear how the definition of expert is made.

Some mothers turn to other sources for information and support instead. For example, Lewis and Kritzinger (2004) found peer support from another mother who had breastfed a child with Down syndrome particularly helpful, although this was not a standardised service.

Meanwhile, Madhoun et al. (2020) and Moe et al. (1998) found that mothers accessed online support groups, and organised breastfeeding support groups were also identified.

When high quality support was provided it had a positive impact. For example, Barbas and Kelleher (2004) studied 68 infants with CHD in the United States, where six years previously they had established a designated lactation support program led by a full-time IBCLC. The IBCLC also had extensive paediatric nursing experience and went on to establish a program of education for all staff. This intervention led to an increase in breastfeeding rates from 14% to 47% in that time. In this study, mothers cited the IBCLCs as very supportive.

2.9.6 The support, training and attitudes of health care professionals

In general, most of the studies highlighted inadequate support. Many of the health care staff were acknowledged as caring, but most parents did not get the breastfeeding support they needed. Some staff were perceived as ambivalent about the importance of breastmilk (Barbas & Kelleher, 2004), or unaccepting of breastfeeding (Barros da Silva et al., 2019).

“Nurses who help prepare breastmilk need to learn NOT to act like the milk is ‘yucky’... this statement and others like it heard often.” Barbas and Kelleher, (2004) page 287.

Duhn (1998) highlighted negative language used by health professionals – for example referring to infants being ‘starving’. Other studies identified a lack of useful support. For example, Heilbronner et al. (2017) attributed breastfeeding cessation or formula use to unhelpful advice, whilst Lambert and Watters (1998) reported that women rated paediatric staff knowledge as poor.

A lack of training and skills was identified by several studies as central to the lack of support (Lambert & Watters, 1998; Madhoun et al., 2020). Moe et al. (1998) found that parents perceived physicians to be theoretically supportive of breastfeeding, but without adequate training to be able to provide support for breastfeeding challenges. Rendon-Macias et al. (2002) found that advice to supplement or stop breastfeeding by a medical professional was prevalent. In the Ryan et al. (2013) study, mothers highlighted various gaps in knowledge.

“They were immensely supportive but obviously lacking in training and knowledge, they had no idea about the impact of bottles.” Ryan et al. (2013) page 797.

Banta-Wright et al. (2015) found that parents had to be creative, finding their own breastfeeding support, or utilising peer and family support.

“When my son was about 2 months old, I talked with another mom who had breastfed her son with PKU... for almost 11 months that encouraged me and definitely kept me going toward the end.” Banta-Wright et al. (2015) page 732.

2.9.7 The necessity and availability of specialised equipment or resources

Finally, all but one study (Rendon-Macias et al., 2002) discussed breastfeeding equipment. Although nearly all the parents required specialised equipment, access to such products was not always universal and support was weak. The participants in the Duhn (1998), Lewis and Kritzinger (2004), Banta-Wright et al. (2015), and Barros da Silva et al. (2019) studies variously used breast pumps, bottles, NGT, GT and syringes but in general did not find adequate support to help them with their breastfeeding journeys, and many found the tubes stressful.

“Having the machinery here, it was just like overwhelming for me. I didn't want to feed him like that but then I got used to it ... I learned how to do it for myself and hook him up and feed him. It became easier for me actually ... but at first, I was afraid of the tube.” Duhn, (1998) page 66.

Lambert and Watters (1998) identified lack of privacy, lack of access to pumps, and inconsistent advice as barriers. Heilbronner et al. (2017) noted that many parents complained of breast pump shortage and that pumping was difficult, creating a significant barrier to expressing.

“Lack of availability of breast pump – number insufficient – lack of privacy in CICU space.” Barbas and Kelleher (2015) page 287.

In the Madhoun et al. (2020) study, there is specific mention of six different specialty feeding bottles, as well as NGT and GT. Some of the mothers were disappointed that the hospital staff did not know how to help the parents use the equipment.

“It would have been extremely helpful if more hospitals were trained on using speciality feeders.” Madhoun et al. (2020) page 6.

Finally, Ryan et al. (2012) identified that some mothers were reliant on practical aids such as a specialised bra that enabled hands free pumping. Three mothers who used NGT felt that these were at times over-used instead of attempting breastfeeding.

2.10 Discussion

This systematic review aimed to establish the existing body of literature relating to the needs and challenges of breastfeeding medically complex infants and children in the paediatric setting and identify gaps in health care provision that may serve as barriers to maintaining lactation and facilitating breastfeeding in this population. There is a paucity of original research in this area, and none relating to older babies and toddlers. Much more work is needed to make specific recommendations for changes in practice. The existing research has focused on specific conditions. This makes generalisation much harder, and therefore less clinically implementable for most paediatric wards admitting children with a range of illnesses. Without extensive background knowledge of how multiple conditions may impact breastfeeding in unique ways, this may mean that unless there is a specific guideline for every condition, health professionals may not be able to apply tools that work for children with disparate conditions, even though the challenges may be similar. Arguably, what would be more useful and user-friendly for practitioners - especially those without extensive lactation training - would be a guideline that provides practical tools and suggestions for challenges by theme, such as low tone, somnolence or higher calorie need, rather than by condition.

However, despite the limited research, seven themes were developed from the available literature, relating to practical and psychological challenges for parents, difficulties associated with clinical instability and physical condition of infants, specialised lactation support, health care professional skills and attitudes, and specialised equipment and techniques.

There are numerous practical problems relating to the hospitalisation of infants and children. These may be practical breastfeeding problems caused by disruption to the normal process of responsive feeding – for example blocked ducts and low milk supply, as well as logistical problems. In the papers in this study, the main non-lactation related practical problems were challenges relating to being resident in a hospital away from home and needing to balance paid work with caring for their child. While the papers in this study only briefly alluded to financial strain, other literature relating more generally to the impact of hospitalisation on families cites the financial burden of transport, parking costs, food and other items that usually must be bought from the on-site hospital shop (Mooney-Doyle et al., 2018). The papers in this study had limited numbers of low SES families, which may be significant as these problems will have the greatest negative impact on vulnerable and low-income families (Thomson et al., 2016; Beck et al., 2017).

Most mothers in this study cited some level of psychological distress surrounding their child's admission to hospital., although some specifically described the positive benefits that breastfeeding brought to the experience. The mothers cited exhaustion, stress, anxiety and depression frequently. The psychological aspects were not all negative however, with many of the mothers describing breastfeeding as something that made them part of the solution, and one mother stated that she felt breastfeeding helped to re-establish trust with her toddler after their surgery. Essentially, breastfeeding was hard work, but the mothers were motivated to continue despite the challenges. The psychological challenges relating to breastfeeding may on the one hand negatively impact a mother's confidence and experience of feeding and caring for their child, but breastfeeding also provides an opportunity to empower mothers to feel included in their child's care. Supporting mothers to be able to overcome a challenge, rather than feel defeated by it may lead to a greater

sense of self efficacy. Throughout many of the papers, there was a sense that the mothers managed to persevere with breastfeeding despite their experience within the paediatric setting, rather than because of it.

There were also infant-related feeding challenges, distinctly different from the practical challenges of maintaining healthy lactation in the parent. Not all congenital conditions affect a child's immediate physiological stability, such as cleft palate or Down's syndrome. However, even when a child is initially stable, their condition can change, or corrective surgery can make them more unstable.

Some conditions necessitate specific breastfeeding adaptations due to the infant's condition, and not their medical instability. These may be related to positioning for breastfeeding, fat or calorie content, specialised techniques or frequency of feeding. Effective breastfeeding involves both the infant and mother. The infant must be able to use their tongue, lips, jaw, and cheeks to stabilise the breast in their intra-oral palate, create negative pressure, and be able to safely suckle and swallow, while also coordinating breathing (Genna, 2013). However, for ongoing successful lactation, milk must be removed from the breast according to the infant's individual metabolic and calorie needs. The infant will need to be positioned sustainably for breastfeeding in a way that supports a safe suck-swallow-breathe sequence.

Some children are born with conditions that require breastfeeding modification. For example, infants with chylothorax cannot receive breastmilk unless it has been separated in a centrifuge to remove the fat (Davis and Spatz, 2019); and infants with PKU cannot breastfeed exclusively because although breastmilk contains less phenylalanine than formula, these infants usually need specialised Phe-free formula to a greater or lesser extent depending on their Phe levels - which must be monitored closely (Gentile et al., 2009). Conversely, infants with hypotonia may not only tire easily, but are also more difficult to hold and position, and they may not be able to effectively create a seal at the breast. Supporting a mother-baby dyad in these specialist cases is more difficult and requires specialist knowledge compared to supporting healthy breastfeeding infants.

In many clinical settings such as maternity or neonatal units, specialist lactation support is a clearly defined sub-specialty. This type of support involves more than simple breastfeeding management in uncomplicated situations and requires the ability to be able to assess and treat complications, at a level far higher than standard breastfeeding training. Globally, the IBCLC credential is currently the recognised leading qualification in breastfeeding support, and IBCLCs have the most comprehensive and robust skill sets (Chetwynd et al., 2019).

However, the number of IBCLCs globally varies, as does the scope of practice. In the United States, IBCLCs are often part of the wider healthcare team, serving neonatal and obstetric departments (Haase et al., 2019). Conversely, in other countries, such as the UK, IBCLCs usually only work in the hospital setting if they are also a health professional. While their additional skills enable them to effectively carry out their role, the credential itself is often incidental, and not formally part of the person specification. Other staff may not always have specialist breastfeeding knowledge and skills, meaning parental experience can differ depending on who they encounter (Holaday et al., 1999; McLaughlin et al., 2011). Additionally, lactation support is often limited to maternity and neonatal care units, hence it is often not routinely present on paediatric units.

Alongside specialist services, we know that breastfeeding is best facilitated when all health professionals looking after a mother recognise its value and have the skills to support her or signpost for more specialist support if needed (McFadden et al., 2017; Thomas, 2020). However, although UNICEF Baby Friendly standards support and protect breastfeeding on the neonatal and maternity wards, these do not currently extend into paediatrics (Carney and Bruce, 2011). Therefore, there are no standardised, mandatory training programs for paediatric nurses, physicians and allied health professionals such as dietitians, speech and language therapists, physiotherapists, and occupational therapists – all of whom are likely to work with medically complex children. The World Breastfeeding Trends Initiative (WBTi, 2020) identified many risk factors among the training curriculums of health professionals, noting that there are many gaps (Gupta et al., 2019).

The support, training and attitudes of health professionals is considered as a separate theme, since some units and hospitals in the review had designated lactation support that

was considered alongside medical treatment. Other units and hospitals had no such identified service, and therefore any lactation support was provided by the medical team – who may or may not have the required knowledge, skills and training to offer support.

When direct, exclusive, responsive breastfeeding is not possible, extra feeding equipment will be needed, both for mothers, and infants. For example, mothers will need to maintain their milk supply with a breast pump – either a hospital-grade double electric pump, single electric pump, manual breast pump, together with hand expressing and breast massage (Morton et al., 2009; Morton et al., 2012, Geddes et al., 2013; Witt et al., 2016). Different approaches work best for individual mothers. Specialised bottles and teats (such as squeeze bottles, one way valve bottles, special needs feeder bottles), cups, spoons, syringes, NGT, nipple shields, palatal prostheses, at-breast supplementers and GT may also be needed (Rudra et al., 2016; Boyce et al., 2019). A thin silicone nipple shield may increase the effectiveness of milk transfer for infants unable to achieve adequate intraoral pressure at the breast (Meier et al., 2017). Mothers will likely need further education around using these products and maximising milk supply.

Very few of the studies specifically studied the use, education or availability of equipment. There are many aspects of using specialised equipment that are missing, such as the possibility of expressing milk at the infant's bedside, how to optimise milk production in difficult circumstances, utilise specialist equipment, and specific techniques for positioning infants with low tone, fatigue, or orofacial anomalies.

2.11 Limitations of this review

A major limitation of this review is that it was conducted by a single reviewer. This was unavoidable as it forms part of this thesis. The process was made more rigorous by an experienced academic checking the criteria used and being involved in the development of the review. This systematic review is also small, so the supervisory team became familiar with the studies analysed.

No study explored the impact of illness in a general sense on breastfeeding. There is a paucity of research related to infant acute illness, and serious conditions that do not specifically affect the head, mouth, palate or face.

The available studies have all explored the relationship between illness/disability and breastfeeding outcome in a disease-specific way, without drawing out more general themes. Since all infant and child conditions will affect breastfeeding differently, with so few conditions studied it is hard to know whether some aspects of infant feeding difficulty have not yet been identified. The initial literature search yielded papers with a disproportionate focus towards conditions that involve orofacial anomalies, decreased muscle tone or increased calorie need, despite the rarity of some of these conditions – for example, Rubinstein-Taybi Syndrome affects approximately one child in every 300,000 (Rana et al., 2017). There is a paucity of research related to infant acute illness, serious conditions that do not specifically affect the head, mouth, palate or face, and indeed, more common conditions.

This is relevant not only because the data generated is not necessarily generalisable, but also because most paediatric wards admit children with a range of diseases and illnesses, both acute and chronic. It is perhaps more useful and user-friendly for health professionals who may not have specific expertise in infant feeding to have general guidelines for best practice when supporting breastfed children and families in the paediatric setting, rather than expecting medical and nursing staff to search for and access numerous disease-specific protocols.

There is also almost no data about how the hospital experience affects the duration and exclusivity of breastfeeding, outside of the disease-specific examples already mentioned. Most children under four years admitted to hospital have an infectious illness (Gill et al., 2013) and half of the total hospital days are accounted for by children with a complex medical condition (Gold et al., 2016). The challenges of being admitted to hospital apply to both parents and children and are in addition to general breastfeeding challenges. The success of breastfeeding may depend on numerous factors, including degree of parental motivation to breastfeed prior to hospitalisation, whether breastfeeding was going well

before, the degree of exclusivity, timely access to support and information, and early initiation of breastfeeding, among many others (Brown, 2016).

The quality, time span and global variation reported in the research included in this review limits the ability to form solid conclusions. Most of the studies were small, and none of them fully addressed all the potential confounding variables. Many of the studies were samples of committed mothers. It is unknown how breastfeeding outcomes would differ among less motivated samples.

The studies included also tended to have limited racial diversity and SES among the included participants. This may be representative of the ongoing higher prevalence of breastfeeding in high SES groups and among predominantly white, married, heterosexual, women with higher levels of education (Bartick et al., 2017). Again, this limits the generalisability of the findings to the wider population.

In addition, the studies came from different parts of the world where healthcare systems are disparate. Half of the studies were conducted in the United States or Canada. This is potentially problematic in terms of exploring healthcare-based lactation support, as the provision of healthcare and IBCLC-led expertise is different around the world. Furthermore, the studies available span twenty years, in which time breastfeeding support and training has evolved, and breastfeeding rates have generally improved. The Baby Friendly Initiative has expanded significantly since its inception in 1991, with more protection for breastfeeding thanks to initiatives such as the World Breastfeeding Trends Initiative and increased awareness of the World Health Organisation International Code of marketing of breastmilk substitutes (WHO, 1981).

Finally, it is likely that other studies exist that explore the challenges of breastfeeding sick children, which did not use terms specific enough to have been identified. However, removing the search terms relating to paediatrics would conversely have limited the sensitivity of the search.

2.12 Conclusions and next steps

There is much we do know about breastfeeding in terms of risk reduction of various illnesses (Victoria et al., 2016), yet we know far less about what it is like to breastfeed a medically complex child. Although breastfeeding reduces the risk of many conditions, it does not eliminate risk. In the important work of continuing to promote breastfeeding in general, we need more specific research about how to support children who are unwell despite having been breastfed.

There are already recommendations for certain conditions, for example cancer (Carney, 2013), cystic fibrosis (Luder et al., 1990), and insulin dependent diabetes (Miller et al., 2017). For this review question, the only conditions explored were Down syndrome, congenital heart disease, cleft palate, PKU and Rubinstein-Taybi syndrome but many suggestions for specific conditions could be adapted and summarised to increase generalisability to other conditions which have not yet been studied.

This review has identified seven themes relating to why breastfeeding medically complex children is more challenging. Breastfeeding difficulties may be parent-oriented, child-oriented, relating to specialist lactation support, healthcare professional support and training, and necessary practical equipment. However, the currently available research is extremely limited in terms of the age range of children, range of illnesses and conditions and ethnic diversity. There is also a gap in the literature relating to the training of healthcare professionals in paediatrics, as well as nonclinical lactation supporters who may also be involved. This review could impact the scope and reach of the Baby Friendly Initiative, and potentially evidence the need for its extension in the paediatric setting, with specific training and audit for staff working in this area.

To address these identified gaps, two research studies were designed. Firstly, a survey explored healthcare professional attitudes and knowledge in paediatrics to gain a more complete overview of the training needs of health care teams caring for sick infants and children in the hospital setting. It is likely that future training needs to be differentiated from current breastfeeding education aimed at the initiation and management of basic

breastfeeding problems in healthy parent-child pairs, but exactly where the clinical knowledge gaps are were not clear from the systematic review. The second research study of mothers of medically complex children was designed to explore what the needs and challenges of children with a wide range of illnesses were in order to expand the current evidence base.

The next chapter will discuss the methodological approach to the studies undertaken, including the theoretical framework chosen to underpin the analysis.

Chapter 3

Methodology

In the previous chapter, a systematic review presented seven core themes generated from the available literature specific to the challenges of breastfed medically complex children. The dearth of literature, limited range of illnesses previously studied, and the narrow age range represented, as well as lack of research conducted in the UK underscored the importance of conducting further research that neatly addresses some of these stark gaps in knowledge. Considering these gaps, the research studies were developed to answer the research questions described in the introduction:

- RQ1. What is the current breastfeeding training provision at undergraduate level for healthcare professionals in the UK, and is this felt to be adequate?
- RQ2. What are the skill and knowledge gaps of professionals, do the gaps differ by professional qualification, and would these be addressed by currently available training?
- RQ3. What are the barriers to providing lactation support that meets the needs of families?
- RQ4. What is the importance and meaning of breastfeeding when a child is sick or medically complex?
- RQ5. What are the breastfeeding challenges of medically complex children in the paediatric setting?

This chapter will outline the theoretical underpinning of the design and methodology of the research topic. Firstly, the rationale for the study setting provides the context for why certain decisions were necessary to study the research question, as well as the reasons for the chosen settings. The chapter will then explore the philosophical assumptions implicit in the study design and provide the rationale for the mixed methods design that was chosen. Finally, researcher reflexivity, the potential impact of researcher motivations on the studies, and how potential bias was managed are discussed. Methods specific to the two studies undertaken are discussed in Chapters 4 and 5.

3.1 Rationale for the UK setting

The systematic review found that there is limited global spread of research both into breastfed medically complex children, and research exploring staff expertise in paediatrics. Most of the research has been conducted in North America, which has a very different healthcare system. In the USA and Canada, most people have healthcare insurance, or pay for their healthcare at the point of need. In the USA, parents also have shorter maternity and parental leave. Both factors may mean that the issues parents face when caring for their medically complex children are different or difficult to compare to the issues that UK parents face with their children. For example, one study (Rendon Macias et al., 2002) found that a significant reason for the difficulty in managing to continue breastfeeding and expressing was the need to return to work. While this may similarly affect UK parents of older children, it is difficult to form solid conclusions regarding the extent to which the stress of expressing and providing human milk is due to a child's illness, or the pressure of returning to work.

The healthcare service provision, policies and issues in the UK are different. We follow the UK Baby Friendly Initiative standards which are subtly different to the global Baby Friendly Hospital initiative. The UK NHS provides healthcare that is free at the point of need, and statutory maternity leave is 40 weeks, although different employers may have slightly different policies in place. This is not to suggest that UK parents would be unaffected by returning to work – because clearly some children will become unwell after their mother has resumed paid work outside the home, and not all parents receive paid parental leave, especially if they are self-employed. However, isolating whether and to what extent it is returning to work, or childhood illness that is the barrier to breastfeeding or continuing to provide human milk is harder with disparate healthcare systems.

It is also much less common for an IBCLC to be employed in a UK hospital. In the USA, many IBCLCs are also nurses, and utilise their IBCLC skills alongside their nursing skills in their clinical environment (Haase et al., 2019; Chetwynd et al., 2019). Since nonclinical professionals are rarely employed as infant feeding leads in NHS hospitals, it is more likely that parents will be supported by nurses and midwives who have accessed up to two days of

training, and their experience and knowledge will vary. This is another important reason why the experiences of parents caring for medically complex infants and children in the USA, Canada and other parts of the world cannot necessarily be compared to the experiences of parents in the UK.

Due to the lack of research from the UK, as well as our unique health systems, to answer the research question the location for the two studies was limited to the UK. Paediatrics is a different healthcare directorate to the neonatal unit and maternity department, which means that, although many maternity and neonatal units are accredited as baby friendly and have infant feeding teams in post, generally the staff who are Baby Friendly trained are not shared with paediatrics. Anecdotally, some maternity or neonatal infant feeding teams will support infants on the paediatric ward as an outreach service, but this is patchy and inconsistent, and it is not clear to what extent this meets the specific needs of parents in the paediatric setting. For this reason, the use of online recruitment enabled data collection from across the UK to develop a clearer idea of the range of experiences in different parts of the UK.

3.2 Philosophical assumptions

This research study was designed after careful consideration of the philosophical assumptions of how and what knowledge exists (ontology) and how we can come to an understanding of knowledge (epistemology). It is important for a researcher to consider their philosophical assumptions to become methodologically self-conscious throughout their work. For a research study to be well-designed and answer the question it sets out to ask, there must be an intentional theoretical underpinning to the methodology (Clough and Nutbrown, 2012).

From an ontological perspective, it is apparent that every mother and family is likely to have a different truth regarding the challenges of medical complexity. These experiences are likely to be unique not only because of the range of medical conditions that exist, but also individual responses to those illnesses and treatments. In addition, there are wider influences on infant feeding decisions and variations in the ages of children at the point that

illness occurs. These variables will all impact breastfeeding in a different way for each family. In terms of the nature of reality with this topic, it is therefore clear that individual experiences, as well as maternal motivation to breastfeed may all affect the breastfeeding experience. It was obviously not appropriate in this study to seek a universally valid truth relating to the challenges of medically complex children. The nature of reality in this case is understood to be influenced by multiple complex intrinsic and extrinsic factors at society, community, hospital, and individual levels, and both unavoidable or unmodifiable contexts as well as individual variations in motivation and choice.

In terms of the underlying epistemology, with this highly heterogeneous group multiple truths were expected to be discovered. Approaching the research with this assumption affected how these multiple truths could most appropriately be understood methodologically. It was likely from the outset that the lived experiences of both health professionals and parents would uncover some unique perspectives, but it was also likely that some of the challenges and buffering factors may overlap between healthcare professionals and mothers, with common experiences being shared between subgroups. Therefore, because there was unlikely to be a single universal truth that can be known, the research was not undertaken with a positivist perspective, which seeks to uncover a 'right' answer. Rather the research was undertaken with the underlying assumption that there would not be one sole outcome that could be generalised to all breastfeeding mothers of sick children, but several. It was felt that while some aspects of the challenges of medically complex children could be measured or quantified, for this research to be sensitive to and cognisant of the variety of experiences, a mixed methods design was utilised to capture the complexity and multifactorial nature of the research phenomenon.

Different researchers may interpret the same data in different ways, choose different methodology to ask the same question, and form different conclusions based on their different epistemological assumptions (Crotty, 1998). It is important not only to acknowledge this reality, but also to justify why a particular research paradigm is felt to be required to answer the research question (Bowling, 2014). When considering the theoretical perspective underpinning the research of medically complex children, both a positivist and an interpretivist approach could arguably cause delimitation of the available data, because

the former would assume there is a quantifiable truth, and the latter may focus too narrowly on highly individual experiences. Neither approach would be likely to generate meaningful and softly generalisable findings that could influence or improve practice. Thus, the epistemological position of the researcher informs the chosen research paradigm. Some researchers believe that research paradigms are distinct (Cohen et al., 2011), and historically, certain approaches were viewed as inherently superior (Crotty, 1998). However, increasingly, many researchers believe they all have unique strengths and limitations (Clough and Nutbrown, 2012). Arguably, while contention remains, there is no perfect research method, only the most appropriate method given the phenomenon under investigation (Rescher, 2013). There are three main well-known paradigms: positivist, interpretivist, and pragmatist.

A positivist approach within the social sciences would assume that human behaviour is a result of external events that can be measured, verified, and objectively analysed using empirical methods. This approach tends to utilise quantitative methods such as surveys, and clinical trials, with use of statistical tests to analyse the results. Quantitative approaches have historically been associated with the concept of robustness, which grows stronger over time as we accrue more verifiable and numeric data. However, the opposing argument posits that this approach may not be as valuable in isolation because human behaviour cannot be understood without reference to the meaning behind their actions (Guba and Lincoln, 1994).

An interpretivist approach, on the other hand, recognises that meaning comes from interaction, and is not standardised across all people and groups. Interpretative researchers understand that the ways in which society functions, and how people behave within society is a result of many variables. Qualitative research could be defined by the type of data it collects, or perhaps more usefully by the aims of the study – qualitative research seeks to understand the reasons for phenomena. Thus, this paradigm more commonly utilises methods such as ethnography, phenomenology, and the use of in depth, semi-structured or unstructured interviews to gather rich data for the purpose of understanding a phenomenon, as opposed to quantifying it (Green and Thorogood, 2018).

Clough and Nutbrown (2012) argue that many social science researchers do not choose one research paradigm, instead many shift between positivist and interpretivist approaches according to what is more appropriate for the research question. The emergence of a third paradigm - pragmatism - is thought to be credited to the American philosopher John Dewey in around 1870 (Brinkman, 2013). Dewey's fundamental assumption was that reality is uncertain, ever-changing, and developing. Humans have evolved to be participants in the developmental change of our reality and norms, with the power to effect change for the benefit of the evolving needs of communities.

Pragmatism would argue that mutually exclusive research paradigms cannot explain how ideas are not always found but are constructed by humans as tools for change in light of the evolving reality (Tashakkori and Teddlie, 1998). An important tenet of pragmatism is that the previously held idea that qualitative and quantitative methods are incompatible is rejected, and instead can be thought of as a partnership (Reichardt and Rallis, 1994). Therefore, pragmatist approaches frequently use a qualitative research method to expand or confirm a quantitative method, or vice versa. Modern transformative, or pragmatist approaches view knowledge as a social construct which is formed by unique experiences and centres the experiences of marginalised communities, or individuals experiencing inequality.

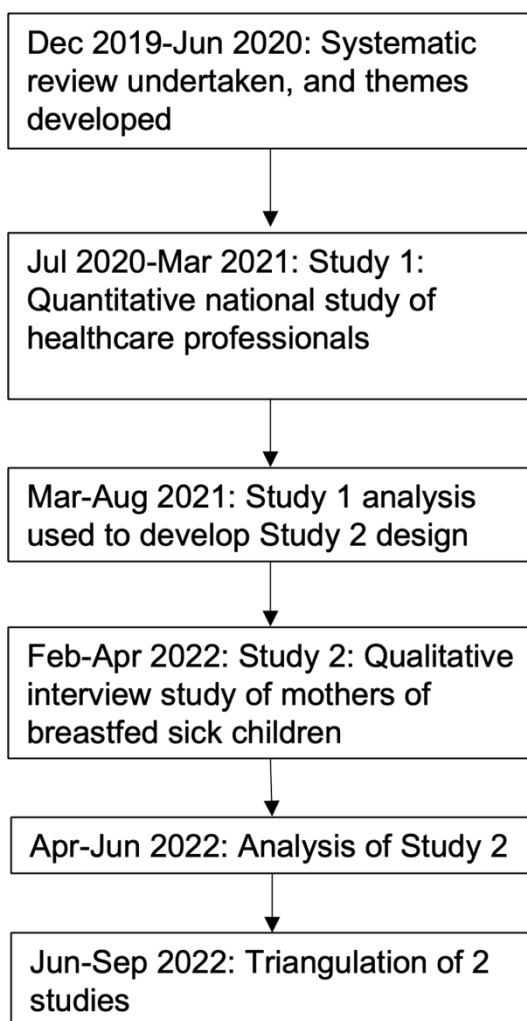
The problem that this research question seeks to answer is an example of an anomaly, or inequality, that has not yet been adequately addressed by science. Thomas Kuhn (1962) coined the phrase 'paradigm shift' when he argued that knowledge does not simply accrue over time but evolves through a series of revolutions in outlook where anomalies are recognised and studied to incorporate and address new solutions to emerging problems. New theories challenge existing paradigms, but for this to occur they must first be recognised as a puzzle that needs to be solved. Kuhn believed that later paradigms are not necessarily 'better' than older ones, because they may be addressing different puzzles. For this reason, a pragmatist approach was felt to be the most suitable research paradigm to answer this question, as it inherently assumes that knowledge may be different for a marginalised or underrepresented group of individuals who have unique experiences that

can add to the body of knowledge around breastfeeding support to form a more complete and inclusive picture.

3.3 Study design and timeline

The overarching methodology for the thesis is an explanatory sequential mixed methods approach. This approach involves using quantitative methods first, followed by qualitative methods (Ivankova et al., 2006; Cresswell, 2014). In this case, the first study was a survey administered to a sample of healthcare professionals, and later triangulated with a qualitative interview study of parents which is discussed in Chapter 5 (see Figure 5).

Figure 5: Overview of explanatory mixed methods sequence



Mixed methods research has become more common in the social sciences because a combination of quantitative and qualitative methods can help to verify and strengthen findings (Tashakkori and Teddlie, 1998). It also allows for confirmation of findings between studies to add rigour. The sequential explanatory approach is particularly popular within the social sciences (Creswell and Plano Clark, 2011). The strength of the design is firstly in its ability to further explain certain phenomena that require more probing, and secondly in its simplicity. With the sequential explanatory design, the quantitative data provides general information about the research problem, and the qualitative data provides clarification (Ivankova et al., 2006). Morse (1991) points out that this approach can be especially helpful when there are unexpected results from a quantitative study. The explanatory sequential design in this case produced useful data from a large sample of healthcare professionals on the general situation within paediatrics in the UK. This approach allowed for different perspectives relating to the research question to be considered and analysed - in this case both healthcare professionals as well as parents, so that their unique realities could be better understood. Before exploring individual experiences of parents on the ward, it was felt that understanding the current culture of breastfeeding support by paediatric professionals would be valuable and informative. This data was analysed in light of the findings from the systematic review, and the qualitative arm of the project was subsequently designed to explore some of the issues raised in more depth.

Mixed methods design acknowledges that neither quantitative nor qualitative methods are sufficient to understand certain phenomena, particularly with the complexity of subjects studied in health and social care research (Ivankova et al., 2006; Östlund et al., 2011). When a mixed methods approach is evident from the design stage, the findings from the quantitative data collection inform the qualitative stage (Fetters et al., 2013). This was important from the perspective that training is likely to have a downstream effect on parent experiences which were later explored in the second study, discussed in Chapter 5. There are three possible outcomes of triangulating data arising from mixed methods research: complementary results, convergent results, and divergent results. The triangulated results of these studies are discussed in Chapter 6. Fundamentally, all mixed methods design uses triangulation techniques, though there is not one consistent approach used, but rather many nuances within mixed methods research. Triangulation enables the researcher to

minimise the biases that are more likely with a single research method (Denzin, 2017). Denzin suggests four main types of triangulation – data triangulation, investigator triangulation, theory triangulation and – as in this study - methodological triangulation. Mixed methods research is arguably most valid when two different data sources point to the same conclusions, which increases the validity of the results (Bowen et al., 2017).

Integrating the results of two different forms of data collection throughout the research is one of the major distinctions between the simple use of mixed methods as separate entities, as opposed to a mixed model. Mixed methods research involves combining the use of quantitative and qualitative methods in the data collection stage, whereas mixed model research combines the approaches across every phase of the research design, from conceptualisation to interpretation and discussion (Tashakkori and Teddlie, 2003). For novice researchers, many suggest that a complex research design is overly ambitious (Creswell, 2014), and so a simple mixed methods approach was chosen for this study.

There are of course disadvantages of a mixed methods research design. One of the risks of mixed methods research is that occasionally, it may be difficult to compare two different data sources if they are inconsistent, or the results are surprising. Also, on a practical level, mixed methods research is time consuming - with a sequential design, the data from the quantitative phase is used iteratively to build the qualitative phase, which adds complexity.

Finally, paradigm purists would argue that quantitative and qualitative research methods are incompatible with each other, fundamentally because the underlying epistemological and ontological perspectives are at odds with each other – with quantitative methods seeking absolute truths, whereas qualitative methods seek clarification and exploration (Smith, 1983). By definition then, mixed methods research may be viewed as a compromise, but also as a practical workaround for complex and under-researched issues that may have multiple perspectives and versions of truth, depending on whose viewpoint is being explored and by whom.

3.4 Theoretical perspectives

The design of the research aims and objectives, the two studies and overall approach was underpinned by the ecological systems theory (Bronfenbrenner, 1979). A theoretical model is essential for the data that is generated from a study to be meaningful, organised, and complete (Evans et al., 2011). Nursing research frequently utilises a theoretical framework to support the conception and structure of the research design, as well as facilitating the cohesion of findings (Sandelowski, 1999). It is also argued that ethical research should acknowledge the fact that it is built on the theoretical work of others. A study that has firm foundations in existing theory also ensures rigour (Clough and Nutbrown, 2012).

There are various models of behaviour used by researchers to assess how people respond to various health or lifestyle events, and several were considered for this research. The health action process model (Schwarzer, 1992) positions self-efficacy as a key factor in determining health behaviour at a motivational and action stage. The action stage acknowledges voluntary, contextual, and behavioural factors which affect health practices. This model has been used in previous breastfeeding research, with one study using the health action process model to explain the predictors of exclusive breastfeeding, particularly related to self-efficacy (Martinez-Brockman et al., 2017). However, this model does not account sufficiently for the wider social factors that may influence breastfeeding among medically complex children. The theory of planned behaviour (Ajzen, 1991), based on social cognition theory (Bandura, 1977) includes elements of control over health behaviours and posits that our intentions and attitudes, together with the perception of social norms will necessarily affect our behaviour. This model has been used effectively to study breastfeeding in terms of exploring factors influencing exclusive breastfeeding (Zhang et al., 2018). However, in terms of personal motivations and attitudes towards breastfeeding, there is insufficient acknowledgement of the role of external influences for this research. The health belief model (Rosenstock, 1974) was also considered. This is a popular model within health sciences, arguing that behaviours are related to the perceived severity and susceptibility of illness. While many mothers are motivated to breastfeed or continue to breastfeed, this model does not fully encapsulate all the timing variables inherent within paediatric medical complexity. It also assumes that more mothers would breastfeed if they knew it was

important, which is not strictly relevant to this work, as the systematic review found that maternal motivation was not the limiting factor in terms of breastfeeding challenge, but rather the environment of paediatrics more widely. Breastfeeding behaviours may also be well-established prior to childhood illness, and so this model, which is more applicable to breastfeeding intention, was thus rejected in favour of the ecological systems model (Bronfenbrenner, 1979).

3.5 Ecological systems theory

To explore why breastfeeding medically complex children leads to more or different challenges compared with breastfeeding healthy children, a theoretical model that accounts for and acknowledges the wider contextual factors and the inter-relationship of the environments surrounding the child and family is appropriate. While there are many social change models, the ecological systems model fits the research question most completely. Bronfenbrenner (1979) originally proposed the ecological systems model to explain the multiple and parallel influences on a child's development. He argued for a framework explaining the behaviour of individuals that encompassed functional systems both within and between settings (Bronfenbrenner, 1986). The model consists of nested structures, starting with the immediate context and moving outward to other settings that affect the developing person. Within this framework, the dyadic breastfeeding relationship can be considered synergistically within the other interactions and influences of the family, community, and society. While at times in this research it has been appropriate to specifically articulate whether a challenge relates solely to the mother or child, by its very nature, breastfeeding is a dynamic, reciprocal, and dyadic interaction between the mother and child (Rasmussen et al., 2017). Therefore, throughout the research, unless otherwise stated, breastfeeding challenges are considered within the context of the dyadic relationship, which makes up the microsystem of the ecological framework.

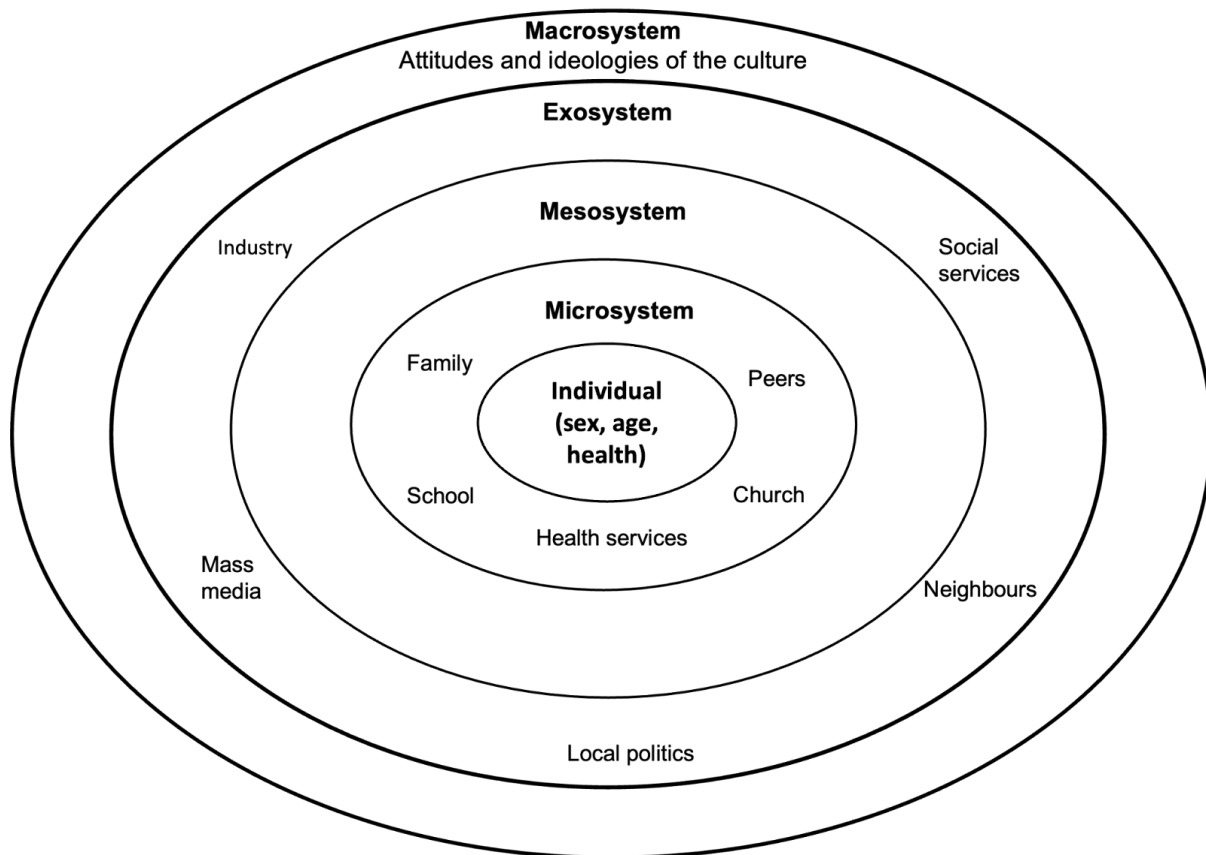
A criticism of the ecological systems model is that the variables within the systems are poorly defined and understood, and it is not clear through the model how various components such as family and peers interact with each other to influence the child (Leventhal and Brooks-Gunn, 2000). However, it was felt that in this relatively unexplored

aspect of lactation care this offered some flexibility with interpretation. Ecological systems theory conceptualises development from an interactive perspective that accounts for multiple contexts that can be thought of like concentric spheres of influence around the child (see Figure 6). Changes in individual characteristics, behaviour or development cannot be adequately explained without consideration of the wider context. This concept meshes well with family centred care theory which argues that children only make sense in the context of the family and environment in which they are being raised (Shields, 2011).

Ecological systems models not only include immediate contexts but also the contexts within contexts. With respect to breastfeeding medically complex children, the challenges are not only of continuing to breastfeed or provide human milk in the hospital setting, but there are wider factors that are simultaneously independent of but also related to the challenges, such as factors relating to the child's condition, the parent and their circumstances, and the hospital environment and culture. The feasibility, likelihood and success of breastfeeding duration and exclusivity is influenced by multiple complex factors from different contexts that are inter-related. All these factors exist within the broader community and societal context of low breastfeeding rates, widespread acceptance of bottle feeding as the dominant way to feed babies, and variable parental leave and inequitable provision of donor milk, among other factors.

This model has previously been adapted for other clinical questions and health improvement studies, such as the model created by Davison and Birch (2001) to propose an ecological systems model of childhood obesity; another adapted to explore the challenges of parenting children with disability (Algood et al., 2013); and more recently a study examining barriers to breastfeeding (Snyder et al., 2021). Due to the multiple complex influences on breastfeeding outcomes, including the duration and exclusivity of breastfeeding, the ecological systems model has been used to provide the context for this research question.

Figure 6: Ecological systems theory model (Bronfenbrenner, 1979)



The Microsystem

In this context, the microsystem consists of the individual factors relating to the child and their medical complexity. While the child and mother are considered simultaneously, it is nevertheless true that many of the aspects of the child's illness relate specifically to the child and the nature of their condition, such as their fluid and calorie needs, level of consciousness, physiological stability, and anatomy, as well as their metabolic rate, cardiorespiratory stability, and level of pain. The truly dyadic part of breastfeeding is the ability of the child to effectively remove milk, as milk removal drives milk supply, and therefore the maternal milk supply is situated at the microsystem level. These elements are unique to each child because of their individual characteristics including their age, but also the condition they have and the unique ways in which their condition affects them, and their ability to breastfeed.

The Mesosystem

The mesosystem includes interpersonal relationships and factors relating to the milk supply that are entirely maternal or influenced by the health and lactation professional interactions which may have jeopardised or optimised the maternal milk supply. At this level, factors such as partner, family and social support, other children, socio-economic status of the family, and factors relating to the success of breastfeeding, such as privacy, motivation, stress, and anxiety are also considered. The mesosystem is unique to a family, but there may be shared challenges within the family unit, and therefore, the factors in this sphere are related to the unique ways in which the interpersonal relationships affect the breastfeeding dyad.

The Exosystem

The medically complex breastfed child's exosystem refers to the community-level organisation that contributes to the breastfeeding experience. In this case, this is mostly at hospital level. Therefore, these factors include family-centred care, ward culture, staff attitudes, provisions and resources, equipment, bedsharing policy, staff skill, access to interpreters and other considerations such as donor milk, furniture, and training. At the exosystem level, the challenges impacting breastfeeding may be common among many different families with disparate health care problems and different ages and stages of lactation. While the problems and challenges may be uniquely experienced due to factors at the mesosystem and microsystem levels, the systems and structures in place, or absent at the exosystem level will impact families in a broader sense. There may be variations in local and regional practice and skills in different hospitals (Snyder et al., 2021), so while the challenges for several families all cared for on one single paediatric unit may share common ground, it is likely that the challenges vary between wards and hospitals.

The Macrosystem

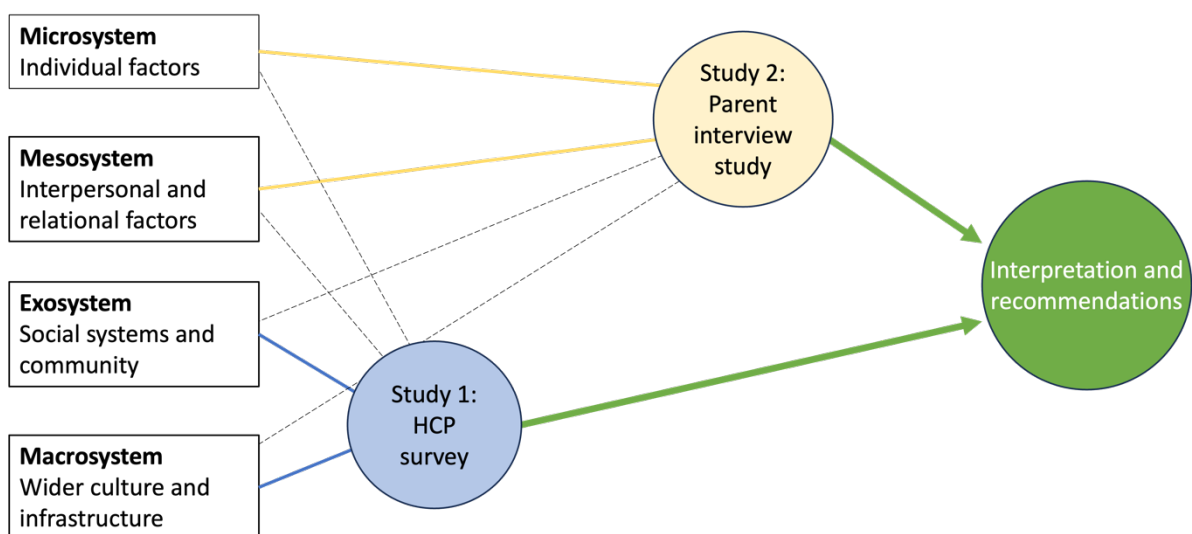
At the macro level, wider societal influences on breastfeeding need to be considered, including the political systems, adherence (or not) to the international code of marketing of breastmilk substitutes (WHO, 1981), maternity and parental leave policies, the protection for breastfeeding in public and in workspaces, as well as social care and financial assistance. At this level, cultural influences on parenting (Banks and Banks, 2019), racism, and the

public perception of breastfeeding all impact upon a mother’s decision-making processes either to interrupt or facilitate her intention to breastfeed, and her motivation to persevere through challenges (Snyder et al., 2021). The macrosystem may impact breastfeeding decisions at any stage of the mother’s journey, from pre-conception through to the cessation of breastfeeding, and there will be shared challenges common for numerous families that are not necessarily related to the specific ward or hospital.

Using the theoretical model to inform study design

The ecological systems model neatly illustrates why a pragmatic approach was most suited to this study, as both the highly individual challenges and factors, the more systemic factors across individual wards and between hospitals, as well as at the wider societal level will have important impacts on the experiences of medically complex children and their families (see Figure 7). The ecological systems model was central to considering the data that would need to be collected, in order to answer the research questions. When planning the studies, the model was used to ensure that each element of the ecosystem was reflected across the studies and during the analysis, and that triangulation between the studies would be achieved. This is further detailed in each study chapter.

Figure 7: How ecological systems theory informed the mixed methods approach



To enable triangulation between the studies, consideration was given to the focus of each study. Given that there are four layers within the ecosystem, each study had a primary focus on two of the layers of the ecosystem, as well as a secondary focus on the other two layers. In this way, the research participants were asked about their lived experience and reality, but were also given an opportunity to reflect on the wider aspects of the ecosystem. This is represented by the dashed and solid lines in Figure 7 – with solid lines indicating the primary focus of the study, and the dashed lines indicating the secondary focus. Study one focused on the macrosystem and exosystem, yet included questions that also related to the child's micro and mesosystem from the perspective of the health care professionals. Study two focused on the microsystem and mesosystem but also included questions relating to the macrosystem and exosystem from the perspective of the parents. This enabled later triangulation between these alternate perspectives to understand how many of the themes were shared across both healthcare professionals as well as parents, and how many perspectives were unique to the individuals involved.

As shown in Figure 7, by utilising a mixed methods approach, the research studies designed were able to elucidate the factors at multiple levels of the ecological model. The chosen theoretical framework provided a navigable route back to the research question at each stage of the process, as well as during the triangulation which found many concurrent themes between the quantitative and qualitative phases. The adherence to the theoretical framework increases the validity and transferability of this research into policy and practice (Evans et al., 2011). In this case, the epistemological assumption that breastfeeding experiences are both highly individual, and yet also influenced by many more universal and generalisable challenges beyond those individual levels was upheld.

3.6 Justification of research design

Two studies were designed to address the main research question:

What are the needs and challenges of breastfed medically complex infants and children in the paediatric setting?

Additionally, the two sub-questions were:

1. What are the skills, knowledge, attitudes and challenges for healthcare professionals providing clinical care and lactation support to families in paediatrics?
2. What are the experiences of mothers breastfeeding their sick child in the clinical paediatric setting?

Borrowing literature from other settings that provide breastfeeding support, it is known that many of the reasons for reduced exclusivity and duration of breastfeeding are because of institutional barriers and societal expectations rather than individual mothers 'failing' at breastfeeding (Brown, 2016). Because of the large body of evidence around the need for adequate training and expertise of professionals supporting mothers with their informed feeding choices (Gavine et al., 2016), it was decided to first consider to what extent this is a comparable problem specifically within paediatrics, and where the clinical knowledge gaps are. The follow up study explored the impact of medical complexity on breastfeeding experiences and outcomes for mothers and children in a more nuanced way.

3.7 Proposed research methods for Study 1

After the systematic review but prior to commencing the research, every higher educational institution in the UK was contacted and asked about whether breastfeeding education was provided despite it not being a core competency. There was a very poor response to this approach, with only approximately 10% of institutions replying. On reflection, the information from this exercise is likely to have had an insignificant bearing on the overall research method, especially given that it is known that breastfeeding training is not part of the medical or nursing curriculum. Although this part of the planning exercise was unsuccessful, it did present an opportunity to share the link for the survey that was eventually developed, which may have improved the recruitment.

The choice of conducting a survey to explore health professional attitudes was made after reviewing the existing literature relating to health professional breastfeeding knowledge.

The research methods exploring this topic are varied, with interview studies (Radzyminski and Callister, 2015), action research (Michaud-Letourneau et al., 2022), studies utilising before and after knowledge tests (O'Connor et al., 2011, Colaceci et al., 2017), and surveys (Holaday et al., 1999) all being used. When deciding between potential research methods the feasibility, potential for generalisability, representative sampling, and the extent to which the methods would appropriately answer the research question were considered. It was felt that with the time and resource constraints implicit within a PhD candidature, action research would be too complex, interview studies would not achieve a large representative sample that would be generalisable, and before and after studies would be impractical for this research question. Before and after studies would certainly be a useful tool if more was known about the right knowledge to test, but previous before and after studies have tested knowledge of basic breastfeeding principles, rather than the gaps that mothers report in the paediatric setting. Therefore, to conduct the research in a meaningful way, the gaps would need to first be identified, and a curriculum written to address those gaps, before disseminating the training. This would not only have been time consuming, but it would also rely on a study that accurately illuminates the knowledge gaps having already been undertaken. This study did not exist for this specific population of healthcare professionals, leading to the rejection of this method as a viable option.

The choice of a survey was a pragmatic one to explore the unknown gaps in knowledge, as well as the skills and attitudes of a large sample of healthcare professionals. Surveys are a practical way of collecting data from large numbers of participants (Check and Schutt, 2011). Some of the disadvantages of using surveys include coverage errors (where there is no chance that particular individuals will be included), sampling errors (where the participants do not represent the general population), measurement errors (where questions in the survey do not reflect the topic of study) and non-response errors (where respondents do not complete the survey) (Dillman et al., 2014).

Selection bias was acknowledged to be a potential problem. This is where the selected participants are not similar to the wider population – essentially, an error arising from the people *not* included as participants (Keeble et al., 2015). The risk with this survey was that it would recruit a disproportionate number of breastfeeding advocates and therefore not

accurately represent the true scale of the challenges and gaps in knowledge among healthcare professionals in paediatrics. There are several potential ways to reduce selection bias, including adjusting for bias (Kleinbaum et al., 1981), predicting the bias (Madigan et al., 2000), and using a propensity score (Rosenbaum and Rubin, 1983). One practical option for reducing selection bias with this study was to predict it, as a propensity score matches cases and controls which was unfeasible for this study and not within the scope of this PhD. The variable (skill) associated with selection was analysed so that the skills between more highly trained breastfeeding advocates were separated from those who had no training – thus some adjustment was undertaken. The gold standard would be to know for certain the true proportion of more highly trained breastfeeding advocates within paediatrics, but this data would be difficult to acquire as breastfeeding skills and training are not a requirement of health professionals, so it would rely on self-report.

Nevertheless, these biases were adjusted for and predicted as far as possible, and questions were designed to account for a skewed sample. For example, questions were asked around the general ward culture, in an attempt to separate a highly skilled individual from a generally under-skilled department. In this way, a skilled individual was not assumed to be a representative sample of the members of the entire ward or department, but it was acknowledged that they may be unique among their colleagues in being invested in supporting breastfeeding.

There are other concerns with surveys, including the fact that internet-based surveys rely on not only internet use but also social media engagement. Reisdorf and Groselj (2017) point out that up to 20% of the population in the UK may not be internet users. However, given that all healthcare professionals are required to use the internet and other computer-based technologies at work, it was felt that this potential error was less likely within this specific population. One suggested way to minimise sampling and coverage errors is to recruit a large sample (Ponto, 2015), therefore the survey was left open until there were more than 400 completed responses and a representative sample of ethnicities recruited.

3.8 Study 1: An online survey of health care professionals working in the paediatric setting

This study was designed to answer research question one, which, as previously stated, mainly focused on the macrosystem and exosystem aspects of breastfeeding in paediatrics. This was a quantitative study utilising a questionnaire (Appendix 5) which was completed by health care professionals who identified as working within the paediatric setting. It included responses from paediatricians of all training grades, nurses, health care assistants and allied health professionals. This study aimed to elucidate the perceived challenges for health care professionals working in the paediatric setting (exosystem), as well as determine some of the issues around training, experience, specialised techniques, and institutional barriers (macrosystem).

Quantitative research involves gathering data to answer a question by using statistical techniques to analyse the results. It has long been viewed as the 'gold standard' method to confirm or test a particular hypothesis (Bowling, 2014). There are many advantages of using a quantitative approach if the issue is unambiguous and can be measured in a reliable way. Quantitative methods allow for large amounts of data to be collected efficiently, and statistically analysed. The results are usually straightforward and objective, allowing researchers to potentially establish causation and correlation, depending on the methods chosen. To gain a more extensive picture of health professional knowledge and skills, large numbers of professionals were needed, which necessitates a quantitative approach.

There are, however, disadvantages of quantitative research methods, especially with relatively unknown areas of investigation where there is little or no established evidence base. Quantitative data may seem more reliable and valid, but numbers can be misleading if the study or researcher is biased, or the study is poorly executed. Data driven research can also be perceived as 'dry' and does not allow for more thorough exploration of individual circumstances or context, which may provide meaning or clarity beyond the numbers (Creswell, 2014). Further details of the specifics of this study are provided in Chapter 4.

3.9 Proposed research methods for Study 2

In terms of the qualitative methodology, the initial plan was an ethnographic approach which would have allowed for immersion in the ward or intensive care setting, to provide rich detail on the lived experiences of parents and their sick children. Ethnographic studies typically require months of data collection and observation, with the researcher participating actively in the field of study, gathering observations, listening, and questioning (Waring and Jones, 2016). However, classic ethnography was inappropriate for this study, for two main reasons. Firstly, it would be impractical as part of the overall scope of this research, requiring more time, funding and resources than were available. Secondly, in the paediatric setting, children are often admitted suddenly, and may only be an in-patient on the ward for 1-3 days in many cases. There is a rapid turnover of patients on most paediatric wards, and even on the PICU, children are escalated and de-escalated quite quickly due to fluctuations in their condition and stability. For these reasons, rapid ethnography would be a more appropriate methodology, and is frequently used in healthcare settings for research aimed at improving care to patients (Annett et al., 1995). Vindrola-Padros and Vindrola-Padros (2018) argue that rapid ethnography allows for timely dissemination of practice-improving findings. Observations of the ward environment, interactions, and activity level could have been recorded in the field notes, and if relevant, could serve as discussion points with participants. Mannay and Morgan (2015) point out that ethnography that relies only on data collected during an interview at an appointed time misses some of the rich detail that can provide as much insight as the interview itself – reiterating the value of being immersed in the environment in question.

However, while this approach was pursued at some length in the early stages of planning, with research sites and gatekeepers identified, this had to be redeveloped in light of ongoing difficulties with access to clinical environments during staffing pressures as a result of the Covid-19 pandemic. While this was initially felt to be to the detriment of the quality of this research study, the redesign of the research method presented an opportunity to address some of the challenges that would have been raised with rapid ethnography, and ultimately recruit a much more diverse sample of mothers.

The eventual choice of semi-structured interviews was justified in the context of the epistemological position that individual realities vary between different people. Yet it was also felt that within the ecological framework, at the exosystem and macrosystem levels, there may be comparable challenges that unite parents with otherwise highly disparate clinical challenges. The challenges elucidated at the microsystem and mesosystem could only be discovered through these conversations with a purpose (Sheppard, 2004), but the data was made more robust through triangulating with the results of the survey and exploring the extent to which the parents and professionals had shared perceptions at each level of the medically complex breastfed child's ecological system (Carter et al., 2014).

3.10 Study 2: Qualitative interviews with mothers of breastfed medically complex children

This study was designed to answer question two, focusing on the microsystem and mesosystem layers of paediatric breastfeeding challenges, and to triangulate some of the perceived barriers identified by the professionals in Study 1. This was a qualitative study that consisted of semi-structured interviews with thirty mothers who were currently breastfeeding or providing their expressed milk to their medically complex infant or child in the paediatric setting. Specifically, this study sought to explore the motivations, experiences, and challenges of breastfeeding medically complex children to better understand what can be done to improve the care of families within the paediatric setting (microsystem), as well as what additional support or resources families would find helpful (mesosystem).

As with quantitative research, there are also many advantages and disadvantages of qualitative research. Qualitative research methods can answer questions that quantitative studies cannot – such as questions relating to why people have certain experiences or find particular situations more challenging. Qualitative studies can add to the body of knowledge around the social sciences, as well as inform policy, by providing a deeper understanding of human behaviour. To understand the unique experiences of mothers breastfeeding their medically complex children, an approach that adds depth and richness through semi

structured interviews was felt to be necessary to explore the challenges and motivations for this under-researched group of people.

Despite the obvious usefulness of qualitative research, there are some disadvantages of this approach. Qualitative data may be difficult to generalise to wider populations because it is by definition asking questions about individual experiences. There is no easy way to be able to determine whether the conclusions drawn from qualitative research can be applied to larger populations. This problem can be reduced with large and diverse samples, but there are inherent challenges with large amounts of qualitative data, including the time-consuming nature of coding and analysing themes, rendering this a possible, and yet impractical workaround. However, arguably, the purpose of qualitative methods is not to produce widely generalisable findings but to understand experiences, and therefore measuring the usefulness of qualitative research by how generalisable it is – an indicator of rigour more appropriate to judge quantitative research - is inappropriate. Moser and Korstjens (2018) suggest a sample size of 25-50 participants to interview for a qualitative study, which is likely to generate sufficient data to code and analyse, and larger samples would likely be unwieldy. Finally, the quality of qualitative data depends significantly on the experience of the researcher – relying on their knowledge of the subject area, and their interviewing and communication skills (Green and Thorogood, 2018). Further details of this study can be found in Chapter 5 and the interview prompt and screening questions can be found in Appendices 6 and 7.

3.11 Researcher reflexivity

Being aware of one's personal experience, motivation and biases is important because given that the researcher is the data collection instrument, they can inadvertently bias their research findings (Green and Thorogood, 2018). Researcher positionality is important to be aware of, and to articulate, since the researcher's epistemological beliefs are likely to influence how they believe the data can most appropriately be collected (Holmes, 2020). The assumptions a researcher has about human nature and behaviour will affect their research position and the ways in which they choose to approach the research question

(Sikes, 2004). It is vital to consider one's personal motives and held beliefs, as well as how these may impact the data and interpretation, and finally how to manage this impact.

In addition to the researcher motivations discussed in the introduction, the most relevant preconceived belief to acknowledge is that fundamentally, my position is that breastfeeding is the normal way to feed infants and children up to the age of two years and beyond. I further acknowledge that my implicit motivation is to increase awareness of breastfeeding and breastfeeding skills among paediatric clinicians, and one of my assumptions is that this is currently not the reality. These assumptions are transparently articulated. Once acknowledged, it was also important to attempt to design the studies, recruit participants, collect and analyse the data with cognisance of these biases to reduce the likelihood that question phrasing, participant selection or analysis would be skewed by my assumptions.

Apophenia is the subconscious behaviour among researchers of perceived pattern recognition of themes or data that are not actually meaningful. Attaching meaning to something that is irrelevant is obviously an undesirable outcome of any research analysis. Buetow (2019) suggests that this behaviour is particularly common among nurse researchers and recommends using reflexivity to prevent these unconscious biases from affecting the rigour of the study. Of course, one of the obvious problems with unconscious biases is that the researcher is not always aware of them. Seale (1999) acknowledges that we cannot possibly be aware of all the ways in which our assumptions shape the research. However, as far as possible, every effort should be made to account for and manage the inter-relationship between the researcher and the research.

The assumptions I acknowledged reinforced the choice of recruiting a large anonymous sample of healthcare professionals and conducting a study that required no researcher interaction. In this way, it was less likely that I could unduly influence the participants, or that they would be susceptible to social acceptability bias (Koelle et al., 2019). Reflecting on my assumptions also led to the decision to develop a mostly objective screening questionnaire for the parent interview study. This served a dual purpose: it enabled purposive sampling to achieve a diverse group of research participants, and it also prevented deliberate selection of participants who had more negative or positive

experiences. I was not aware of any details apart from the child's diagnosis, length of hospital admission, and some demographic variables prior to the interview. While it is acknowledged that those who chose to apply to take part were more likely to have held strong beliefs about breastfeeding, there was less risk of either consciously or subconsciously influencing selection and thus the results of the study.

Green and Thorogood (2018) suggest that there are two extremes of research reflexivity, namely trivial and meaningless dry statements at one end of the spectrum through to using research as a cathartic self-exploration at the other end. Between these extremes there is a useful level of self-awareness that allows the researcher to be methodologically and theoretically open, aware of the social setting of the research interaction, and mindful of the wider context. Attia and Edge (2017) suggest a shift towards not only reflexivity, but also a developmental process of the researcher becoming changed through their research. They view this ongoing personal growth of the researcher as essential to the success of the research. While this might sound counterintuitive, given that the researcher should be a valid and reliable data collection instrument, they argue that the process of conducting research should be viewed with humility, with the researcher acknowledging their own potential to be changed by the interaction between themselves and their participants. Researchers with humility simultaneously acknowledge their own held views, while also being prepared to risk having that view challenged by the research process. The concept of acceptance of ongoing change also aligned well with the overarching pragmatic approach to the research design.

In terms of managing researcher and research interaction, Edge (2011) suggests that reflexivity can be both prospective and retrospective. Essentially, researchers can anticipate the likely effect of the researcher on the research, and the effect of the research on the researcher. In other words, the held views and experience of the researcher may affect both the development of the research question and the data collection itself. But the research may affect the researcher developmentally, which also may affect the interpretation of the data. Personally, I was acutely aware that my extensive clinical experience within paediatrics and lactation, as well as my 'insider' experience as the parent of a sick breastfed child was likely to shape certain beliefs and perceptions about what problems exist. It was therefore

important not only to acknowledge this, but also take several steps to mitigate the possible biases.

There are several potential problems that were anticipated prospectively:

- Asking leading questions in Study 1
- Over-identification with the participants in Study 2
- Issues around boundaries with participants who might ask for clinical or lactation advice

Given my background in clinical paediatrics and my exposure to hundreds of parents who have reported poor care, I was conscious to develop questions for the quantitative arm of the study that did not assume or imply a certain level or lack of care. I was also mindful that the most likely people to volunteer for participation in the survey would be those with some exposure, interest, or investment in infant feeding. With this in mind, I also included several questions that were intended to draw out the culture of the overall clinical environment, in case this was distinctly different from the individual experience of the participants. Most of the questions included Likert scales to enable quantification of the responses. The survey was developed with the oversight of my supervisors, and the questions refined under their guidance and with the input of the ethics committee.

My background as the mother of a breastfed sepsis and cancer survivor is likely to have made me more empathic and insightful about some of the issues facing parents. Sharing characteristics with participants can be helpful to gain their trust and understand the issues identified. Reyes (2020) argues that while a researcher cannot choose whether to reveal their visible characteristics of race and appearance, they can choose whether and when to reveal invisible characteristics, and that these choices inherently affect the interaction between researcher and participant. I therefore had the choice to reveal more or less of these invisible characteristics depending on whether the participants needed encouragement. During the interviews, I chose not to reveal *any* of those characteristics, in order to focus solely on the participants. It transpired that some of the participants knew of my work through my social media presence, but in those cases, this was not raised until the

completion of the interviews when they chose to tell me, or converse on a more personal level after recording had ended.

My background as a nurse and an IBCLC has taught me much about individualised care and remaining open minded. I recognise that my experience, like everyone else's, is unique. Just as every infant feeding journey provides a learning opportunity for the IBCLC, each sick child and their parent provides a unique opportunity to learn from another experience, and not assume shared experiences. For this reason, I chose to include multiple open and general questions, to allow the participants to tell their story freely (Moser and Korstjens, 2018). I also avoided discussing my personal story or giving my opinion about the care being described, choosing to listen and probe for further detail when appropriate instead (Sheppard, 2004).

Finally, as user involvement in the development of research is becoming increasingly common (Nilsen et al., 2006), I gave the parents in my support group (Breastfeeding the Brave) the opportunity to provide feedback on the set of questions prior to making a final decision. To avoid tokenism, their perspectives and criticisms were valued and taken seriously, and then additionally, they were piloted (Romsland et al., 2019). The questions, as well as prompts were then included in the interview guide (Kvale and Brinkman, 2009). The parents were not involved beyond this stage, as there is a limit to how much user involvement can add value in a highly clinical research topic in which the patient or parent is not a clinical expert with broad awareness of the bigger picture (Malterud and Elvbakken, 2020).

Some of the existing literature has pointed to a sense of the perceived power that health professionals have over parents. Ryan et al. (2013) identified this as an issue for the parents in their study. Parents were unhappy about the level of breastfeeding knowledge of the healthcare professionals yet felt indebted to their clinical expertise in caring for their critically unwell children. This research observation was one of the reasons that during the redesign of the study, it was decided that the interviews would all be online and may explain why the parents all chose to participate from home. In this way, the parents were not conscious of being overheard in the busy clinical environment of the ward or intensive care

unit. One potential area that I was acutely aware of was to separate my role as a researcher in this context, from my clinical background both as a nurse and an IBCLC. It would have been natural and understandable for parents to ask for clinical or lactation advice during the second study, so my position had to be clear from the beginning to manage expectations.

3.12 Ethical considerations

Specific ethical considerations are expanded in Chapters 4 and 5, but the overarching ethical principles pertaining to the research studies are summarised in this section. The moral and ethical implications of both conducting ethical research for the right reasons (Farrimond, 2012), as well as the practical aspect of gaining ethical approval are important from both an academic and a professional nursing perspective (Guillemin and Gillam, 2004). A duty of care, principles of confidentiality and responsibility of nonmaleficence is tightly bound up with professional nursing registration as well as the legal imperative to conduct ethical research when it involves children, whether directly or indirectly (Green and Thorogood, 2018). Therefore, the following broad principles were considered and adhered to.

Consent

Informed consent is the underlying mechanism by which it is intended that people should not be persuaded or feel obligated to participate in research unwillingly. They should, according to the Declaration of Helsinki (WMA, 2004) consent to take part by their own volition, after the opportunity to understand the implications of being involved. This means that firstly, they must be given the information they need to make a decision, and also that they are able to understand the information. For both studies, informed consent was sought after the participants were provided with a participant information sheet (Appendix 4) and given the opportunity to ask clarifying questions – though this opportunity was not taken up by any participant across either study.

In these research studies, the participants were both the healthcare professionals and parents of medically complex children. The children represented were not active participants, but data directly pertaining to them was collected during the interview study, and the parents were therefore made aware of the purpose and scope of the research, as

well as how their data would be anonymised, used, stored, and analysed. In both studies, the participants were provided with information about their right to withdraw.

Confidentiality

The privacy of the participants was of utmost importance in both studies. It was vital for the healthcare professionals that their anonymity was protected to respect their right to confidentiality (WMA, 2004). It should not be possible to identify participants, and therefore IP addresses were not recorded, and no professional was asked to provide personal data which might have identified them. The data was also presented in a way that did not link geographical location with professional qualifications for example. This was important, because relatively few of the professionals were trained to breastfeeding counsellor or IBCLC level, so the results have been carefully treated to avoid unintentional identification.

In qualitative research, true anonymity is harder to achieve. Indeed, Saunders et al. (2015) argue that anonymity is a construct that exists on a continuum from absolute anonymity to approaching potential identification. In the parent study, several measures were taken to protect the identities of the participants. The mothers provided their email address in order to provide a summary of the research. Following this, their email threads were deleted, and their email addresses stored on the university secure server. The first part of their postcodes was used to plot their approximate geographical location, but these were not connected in any way to any other demographic or clinical data. The consent recordings containing the name of the mother were created separately to the main interview file and both files were stored on the university One Drive. The two children with exceptionally rare conditions did not have their disease named, as it would be potentially possible for a clinician involved to identify them - therefore, their diagnoses were kept intentionally vague. During transcription, the mothers were all given a pseudonym using a random name generator app and all references to their geographical location, any medical professionals, the hospitals and their children and partner's names were redacted. While some research has found that some parents of children with cancer do not wish to be anonymous (Grinyer, 2002; Marshall et al., 2018), in this study, the mothers all felt more comfortable knowing that only the researcher knew their identity. Finally, the recording for the mother who was interviewed

for the pilot interview was deleted, not transcribed and no reference to any of the details of that conversation have been referred to (Green and Thorogood, 2018).

Impacts on research participants

The impacts of participation in the studies were considered, and harm arising from participation in either study was judged to be unlikely. However, the parent study had the potential to trigger traumatic and distressing memories. These emotional consequences were not considered to be trivial, and because of the inherent respect for the participants, several steps were taken. Firstly, the participants were given advance access to the interview prompt sheet (Appendix 6) as well as the participant information sheet (Appendix 4), prior to seeking consent. Secondly, the participants were invited to tell their story in the way they wanted to, with prompts only being used to clarify meaning or gently probe for further explanatory detail. They were assured that they could leave out anything they did not feel comfortable disclosing. Thirdly, the participants were provided with post-interview written support, including some resources relating to wellbeing, breastfeeding practical support, and breastfeeding grief. Fourthly, the participants were all emailed following the interview to thank them for their participation. Finally, all the participants were given the choice about whether they wished to be written to and provided with a plain English summary of the results. This moral obligation to share the findings is part of the principle of transparency and integrity (Farrimond, 2012) and while some participants may not have wanted to be reminded of a distressing life event, in this case, all the participants were keen to be kept informed of the results.

Data handling and storage

For Study 1, the survey was hosted on Qualtrics, and the data stored on their secure server. When the data set was uploaded to SPSS no IP addresses were recorded. Participant location and date of birth was not recorded, though ethnicity, years of post-qualification experience, profession and gender were collected. This data was stored securely on the server, and no files were downloaded to personal computers. For Study 2, the interview participants' video recorded interview files were deleted once transcription had taken place. The transcripts were stored on the university One Drive and saved under a pseudonym. The master file with identifying features was printed for ease of reference during the study and

then analysis to ensure that the pseudonyms were correctly attributed to the right participant, and then this master copy was securely shredded.

This chapter has outlined the theoretical assumptions which have influenced the methodological choices and research design. Researcher positionality and assumptions have been reflected upon and the decision-making process leading to the eventual research studies has been summarised, with reference to the broad ethical principles adhered to within the research. The next two chapters outline the specific details of design, data collection and results of the two studies.

Chapter 4

Study 1: Experience, perceived skills and attitudes of multi-disciplinary paediatric professionals supporting breastfed medically complex children: A national survey

Publications:

- Hookway, L. & Brown, A. (2023). The lactation skill gaps of multidisciplinary paediatric healthcare professionals in the UK. *Journal of Human Nutrition and Dietetics*, 36(3), 848-863.
- Hookway, L. & Brown, A. (2023). Barriers to optimal breastfeeding of medically complex children in the UK paediatric setting: A mixed methods survey of healthcare professionals. *Journal of Human Nutrition and Dietetics*, 36(5), 1857-1873

This work has also been presented at four international conferences:

1. Ohio Lactation Consultant conference, November 2021
2. Poster presentation at Royal College of Paediatrics & Child Health conference, May 2022
3. United States Lactation Consultant Association, November 2022
4. Poster presentation at Maternal Infant Nutrition and Nurture conference, April 2023

This chapter presents the first study that was part of the overall mixed methods approach – a national survey of healthcare and allied health professionals in the paediatric setting.

4.1 Introduction

As discussed in earlier chapters, medically complex breastfed children may need support to enable them to continue breastfeeding or to receive breastmilk on the paediatric ward or PICU. Yet the systematic review found that unlike the maternity and neonatal departments, there is rarely a designated lactation team for paediatrics. However, the clinical staff may not be adequately trained to be able to effectively provide this support (Baker et al., 2023). Some studies have highlighted gaps in knowledge among paediatric nurses (Holaday et al., 1999; McLaughlin et al., 2011; Brewer, 2012; Colaceci et al., 2017), though there is also a

lack of clarity about which breastfeeding education programmes lead to improvements in staff skills and knowledge (Gavine et al., 2016). Notably, there are very few studies that have explored breastfeeding support competency within a multidisciplinary team, which is significant, because infant feeding support is likely to be provided not only by nurses, but also allied health professionals and doctors at various grades. One study of 181 dietitians in Ireland conducted a questionnaire of breastfeeding knowledge and skills and found that three quarters of the dietitians reported that much of their knowledge comes from their personal experience, 20% report attending formula industry-funded training, and many of them identified that they would benefit from further training (Becker et al., 2021). Another study of speech and language therapists (SLTs) in the United States used a pre and post-test survey design to establish the impact of training on attitudes and knowledge. In this study, 36 SLT students took part in case-based learning using the stories of breastfeeding mothers experiencing feeding difficulty and it was found that after the teaching, their attitudes and positivity towards breastfeeding had significantly increased (Mahurin-Smith, 2018).

There are no specific paediatric multidisciplinary team studies of breastfeeding support competency, which is problematic as many of the existing studies explore attitudes and knowledge across wider healthcare teams including those from maternity departments (Sattari et al., 2013; Radzyminski and Callister, 2015; Colaceci et al., 2017). This means that the results may be skewed by some professionals having accessed statutory breastfeeding training because they work in a department that upholds Baby Friendly Initiative (BFI) standards. Thus, it is hard to elucidate the current state of breastfeeding competency specifically within paediatric multidisciplinary teams.

The systematic review highlighted seven themes, three of which were specifically related to healthcare professionals and the hospital environment. The three healthcare themes were a lack of specific skilled lactation support; poor or insufficient healthcare support of breastfeeding; and lack of resources, specialist skills and techniques to support families. This study was therefore designed to explore these themes which exist in the ecological exosystem and macrosystem levels, within a sample of healthcare professionals working with children in the paediatric setting.

As previously discussed, there are no oral feeding competencies included within paediatric nursing, medical or allied health professional training. The often inadequate undergraduate training in infant feeding means that professionals are dependent on postgraduate training opportunities – either accessed privately, or via their healthcare organisation. These training opportunities are not mandatory and are variable in terms of breadth and depth of content. In addition, access to additional training is often dependent on the discretion of managers and budget holders, so it is likely that further barriers exist in terms of professionals being able to attend training. At the present time, training is also not tailored towards the unique challenges experienced by sick and medically complex children, but towards establishing breastfeeding in healthy newborns, or sick neonates. However, the specific gaps in clinical knowledge are not known, and therefore there are many unanswered questions about who accesses training, the ease of accessing training, whether training is fit for purpose, and what knowledge and skill gaps remain even *after* training.

In addition to establishing current gaps in skills and knowledge, the study sought to understand, from the healthcare professionals' perspective, what resource and equipment barriers to breastfeeding exist. Within the maternity and neonatal units there are facilities such as expressing rooms, breast pumps, access to donor milk, and many members of staff will have received some training as BFI accreditation and neonatal standards become more widely adhered to. The systematic review found that access to breast pumps and other practical resources was one of the factors implicated in more breastfeeding challenges for medically complex children. However, given that many of the studies reviewed were dated and not UK-specific, it was necessary to establish whether these practical barriers still exist in the UK, in order to form conclusions about whether this is a legitimate priority for change.

Objectives

This study was designed to gauge the current state of healthcare professional experience, training and perceived skills in terms of breastfeeding support in the paediatric setting. Using the ecological systems theory model, the study aimed to primarily explore challenges and barriers that exist at the macro and exosystem layers of the model.

More specifically, the study aimed to address the following research questions:

- RQ1. What is the current breastfeeding training provision at undergraduate level for healthcare professionals in the UK, and is this felt to be adequate?
- RQ2. What are the perceived skill and knowledge gaps of professionals, do the gaps differ by professional qualification, and would these be addressed by currently available training?
- RQ3. What are the barriers to providing lactation support that meets the needs of families?

RQ1 was partially answered by searching the educational competencies for the relevant healthcare professionals, but the extent to which professionals in the UK access non statutory training at either under or postgraduate level, and whether they felt this was fit for purpose, was unknown. Therefore, questions around undergraduate training were included to elucidate this. RQ2 relates to the current perceived skill and knowledge gaps, and therefore several questions were designed to establish where these clinical gaps were, and for the staff who had some experience with managing those clinical scenarios, what their self-defined level of skill was. RQ3 aimed to understand what professional barriers existed for the healthcare staff, as well as their perception of what the barriers for parents are, in order to triangulate this with the later results of the parent study which would go on to primarily focus on the challenges at the micro and mesosystem layers.

4.2 Methods

To answer the research questions, a quantitative approach was used because it was important to explore associations between level of training and staff confidence and skill, to establish whether there is evidence that more training and/or more extensive breastfeeding training credentials is associated with higher perceived skill. While it is logical to assume that this would be the case, there is no study that has measured this with respect to breastfeeding skills in healthcare professionals, and no study has differentiated between acquired skills after different levels of training in any setting. Quantitative research also enables the researcher to look at large data sets and generate inferences, which is important for this novel topic which could be used more widely to develop future training.

Study design

This study used a self-report online questionnaire consisting of closed and open questions to explore staff attitudes, skills, and confidence level, as well as their perceptions of barriers for families. The data was gathered using an online survey. A survey is a tool that efficiently gathers data in a standardised way, by asking participants the same questions, in the same order, without influence by the researcher. They can include either quantitative strategies such as the use of numerically rated scales, or qualitative strategies such as utilising open-ended question boxes (Ponto, 2015). Surveys are sometimes conducted over the telephone or completed on paper. Increasingly, online surveys have become a popular and cost-effective way of reaching a large sample within a population of interest, partly because technology has become more accessible, and many people are familiar with taking online surveys.

There are advantages and disadvantages of using online surveys and there is some criticism related to the problem of over-representation and bias (Ball, 2019). However, a lot of the criticism of online surveys is from more dated literature (Eysenbach, 2004; Ritter et al., 2004; Evans and Mathur, 2005), and the use of social media and online learning has developed rapidly in recent years. The advantages include relative ease and low cost of production, potential for gathering large amounts of data, and automation. The survey is convenient to complete at a time that suits the respondent – which is particularly relevant for health care professionals as they often work shift patterns and long hours, so this may increase the response rate (Callegaro et al., 2015). Online surveys are a useful way of gathering data from a specific population group, and can be shared easily via social media, as well as through the hospital intranet. Finally, online surveys were a necessary workaround during the Covid-19 pandemic when access to clinical departments was very difficult, and this approach avoided person to person contact entirely.

The disadvantages include the lack of opportunity for a researcher to clarify questions, survey fraud, and the bias towards people who can access the internet (Bohannon, 2016). The main disadvantage, especially with relation to this survey, is that the survey could be shared among professionals who are already invested in breastfeeding, leading to self-selection sampling bias. Selection bias can be mitigated by predicting it and understanding

that those most invested in making a phenomenon better are more likely to complete a survey relating to the phenomenon (Keeble et al., 2015). Predicting this selection bias influenced the choice of questions to increase the generalisability of the results.

Participants

The survey was open from November 2020 to March 2021, to all UK health care professionals working in the paediatric setting. The survey was timed to be open during a historically busy time of year within paediatrics. While this is likely to have meant that the survey needed to be completed during a time when staff were busy, it was important to time it thus because the Winter months usually see a spike in hospital admissions for infants and very young toddlers for respiratory illnesses. It was therefore likely that this period would capture the maximum number of young infants who are by definition more likely to still be breastfed. Given that exposure to breastfeeding is more likely at times when younger infants are likely to have been admitted, many of the respondents were more likely to have had recent experience of caring for breastfed children. Respondents both from local as well as regional specialist hospitals were recruited.

Inclusion criteria were:

- Participants aged 18 or over
- Resident and working in the UK
- Able to complete the questionnaire in English
- Medical, nursing, or allied health professional currently working within paediatrics (not neonatal/maternity unit)
- Able to give informed consent

The working patterns, patient allocations, scope of practice and training between doctors, nurses and midwives, and allied health professionals vary considerably, so some differentiation was required to ensure maximum paediatric specificity while also capturing all relevant experiences. Midwives, neonatal nurses and health visitors were excluded because midwives receive breastfeeding education as part of their core training and all

these professionals may have received post-qualification ongoing breastfeeding training since health visiting, maternity and neonatal services have long-established BFI accreditation pathways. However, medical and allied health professionals commonly work with larger caseloads across both paediatric and neonatal departments so were not excluded. Furthermore, apart from those who worked exclusively in maternity or neonatal departments, no professional was excluded on the basis of their clinical area. This was because while certain areas may not have much opportunity to support breastfeeding – for example theatre and recovery, this does not mean that these professionals would not or should not have a good working knowledge of how to support optimal breastfeeding.

Ethical approval was sought and granted by the Swansea University School of Health and Social Care Ethics Committee. All participants gave consent prior to completing the survey. Ethical considerations were made with respect to the principles for research on human subjects as outlined in the Declaration of Helsinki (WMA, 2004). All participants were provided with information about the study, informed of their anonymity and secure storage of their data and had the opportunity to ask questions prior to taking part. Upon completion of the survey, a page loaded to thank the participants for their response and to provide them with further sources of information and support.

Measures

The questionnaire was developed to ask healthcare professionals working in the paediatric setting a range of questions relating to their experience, knowledge, and attitudes towards breastfeeding, as well as the general ward environment where they work. The questionnaire validity was improved by being reviewed by a nurse, IBCLC colleague, paediatrician and two senior academics and their feedback refined the questions. The questions were also reviewed by three parents of sick children to check that the issues that were pertinent to their experience were covered.

The questions were developed in light of the findings from the systematic review to test the hypothesis that lack of training and expertise may be one explanation for reduced breastfeeding exclusivity and duration among medically complex infants and children. Previous research (Lambert and Watters, 1998; Lewis and Kritzinger, 2004; Barbas

and Kelleher, 2004; Colon et al., 2009; Banta-Wright et al., 2015; Barros da Silva et al., 2019; Madhoun et al., 2020) has highlighted that most paediatric settings do not have a designated infant feeding team, enough breastpumps, expressing room, or access to donor milk; furthermore many parents have found that when they requested lactation support it was not available. Anecdotally, many parents and professionals rely on ad hoc support borrowed from other wards and departments – for example asking a midwifery or NICU colleague to visit the paediatric ward in between their own workload. Thus, questions were included that asked participants about the access to resources, lactation support, and some of the support structures available in their unit – such as knowledge of resources to refer to, and what facilities would help them to support lactation on the ward.

Poor or insufficient support of breastfeeding by healthcare professionals has also been highlighted as a significant challenge. One study (Heilbronner et al., 2017) found that admission to the paediatric ward was associated with high rates of breastfeeding cessation and modification, mostly because of medical advice. Because of this, questions about professionals' attitudes to breastfeeding, whether they felt it was their job to support breastfeeding goals, and several questions about whether there was a general culture of support of breastfeeding on the unit in which they worked were included.

Lastly, most of the studies in the systematic review found that parents complained about the lack of specialist skills to support their complex children. To explore this theme further, several questions relating to specific perceived skills that were highlighted as gaps by parents in the systematic review were written. Participants were also asked about their training needs, their confidence with dealing with breastfeeding challenges and what they perceived as barriers both for parents and professionals.

The questionnaire comprised six sections, mapped to the layers of the ecological system to ensure that each layer theoretically informed the questions (see Table 12) with a total of 39 questions. Responses were via tick box, Likert scale and open-ended free text boxes. Questions relating to the clinicians' perceived clinical lactation skills as well as perceived ward culture scores were measured using a five-point Likert scale from strongly disagree (1) to strongly agree (5). This enabled questions to be added together to give an overall skills

score (i.e., how extensively professionals felt they were skilled in supporting breastfeeding) and culture score (i.e., how well participants through the culture of the ward supported breastfeeding). Some of the questions had sub-parts to explore the section more fully. A full copy of the questionnaire can be found in Appendix five and contained:

Table 12: Survey questions and their relation to the ecological systems model

Healthcare professional survey question content	Layer of ecosystem
Questions relating to the professional’s role and demographics (9 questions) which included ethnicity, gender, profession, clinical area of work and length of time since qualifying.	Exosystem
How professionals feel about supporting breastfeeding infants and children (3 questions) which included a Likert scale asking professionals how experienced they felt they were supporting breastfeeding as well as asking them about thirteen different areas of perceived skill.	Macrosystem Exosystem Microsystem
Training and experience (7 questions) which included questions around additional breastfeeding credentials, additional responsibility for infant feeding on the ward, and any additional breastfeeding training, as well as their confidence answering clinical lactation questions.	Macrosystem Exosystem
Post-registration training and continuing professional development (9 questions) which included whether the professionals are required to attend mandatory breastfeeding training, and whether they felt different skills are required to support sick breastfed children compared to healthy children.	Macrosystem Exosystem
Barriers to breastfeeding and ward culture (5 questions) which included questions about whether the professionals felt there was enough support for families on their ward, and their perceived barriers to families breastfeeding, as well as professional barriers and awareness of further resources.	Macrosystem Mesosystem Microsystem
Organisational structures (6 questions) which included questions about their knowledge of the infant feeding lead, and breastfeeding policy.	Exosystem Macrosystem

Procedure

Potential participants were invited to take part in the study via an advert containing brief details of the study purpose and inclusion criteria, which was posted on Facebook, Twitter and Instagram. The advert included a link to the questionnaire which was hosted on Qualtrics and shared on several groups used by healthcare professionals on Facebook, as well as on Twitter. The researcher and supervisor have a combined social media following of over 200,000 which enabled a large organic reach. The post was shared over 170 times. If professionals were interested, they clicked on the link in the post, which contained details of the inclusion and exclusion criteria, along with further information about the study. If

they met the inclusion criteria and agreed to take part having read the relevant information, they proceeded to the survey.

It was recognised that if breastfeeding advocates shared the survey with lots of fellow advocates, the risk is that the survey responses may over-represent good practice, and not be a representative sample of average paediatric breastfeeding support and provision. To overcome potential sampling bias, several strategies were considered. Firstly, the survey was sent to a large defined population of interest – in this case currently practising paediatric health care professionals within related social media support groups. Secondly, the survey was sent to infant feeding network leads and link lecturers at 57 UK universities that provide undergraduate nursing training to try to avoid over-sampling in one region or interest group. This was to attempt to avoid the problem of a poor-quality convenience sample. Thirdly, although this has limitations, the survey was developed in line with the recommendations in the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) to ensure rigour and validity (Eysenbach, 2004). Finally, in anticipation that this survey would be likely to have an over-representation of committed and motivated individuals, general questions were included in the survey which attempted to differentiate between the skills and attitudes of the respondent and the skills and attitudes of the wider unit in which the respondent worked. Questions were also asked about the parent experience to attempt to gauge the wider culture of the setting.

Data Analysis

Descriptive and inferential statistical analysis was performed using IBM Statistical Package for the Social Sciences (SPSS) 28.0. Examples of the quantitative analyses are included in Appendix 8. Frequencies and percentages of demographic data including gender, ethnicity, profession, and post-qualification years of experience as well as several other descriptors were calculated. Correlations between variables were calculated using Spearman's and Pearson correlation coefficients, as well as one-way ANOVA, ANCOVA, MANCOVA and Chi squared tests to establish whether there were statistically significant differences between groups. Cronbach's alpha was calculated for any combined scale scores (see reliability and validity below). For calculations exploring differences in experience by professional group, the four participants who identified as 'Other' roles were included in the Health Care

Assistants group. Both of these groups were made up of professionals without medical, nursing or allied health professional training, and in each group, there was only one professional who was a peer supporter, making the groups similar in characteristics.

Given that a substantial number of professionals chose to include further details in the free text boxes, the qualitative data collected was analysed using a simple descriptive thematic analysis (Sandelowski, 2000). Themes were generated from the qualitative data relating to reasons for not undertaking further breastfeeding training, as well as the perceived barriers. To develop the themes, the comments were read and re-read, then each comment was assigned a code until no new codes were required to understand the data. Subthemes were developed from these codes and were discussed with the supervisory team to improve rigour (Braun and Clark, 2022). Ecological systems theory was used to consider how the different themes were situated in each layer of the child's ecological system.

Reliability and validity

Validity – whether a tool measures what it is intended to measure, and reliability – whether the tool is consistent in its measurement, are important aspects to consider when designing a questionnaire for a survey (Drost, 2011). There was no pre-existing validated tool fit for purpose, as previous surveys have used a pre and post-test measurement after specific training (Colaceci et al., 2017), or have measured very specific breastfeeding knowledge (Karipis et al., 1999). Neither of these tools were appropriate for the purpose of the study. The questionnaire was designed to expand on themes from the systematic review: a lack of specific skilled lactation support; poor or insufficient healthcare support of breastfeeding; and lack of resources, specialist skills and techniques to support families. Using these identified themes from the systematic review, questions around specific areas of clinical lactation challenge raised by research participants in previous studies were developed to gauge both the self-defined level of skill and awareness, but also to differentiate between levels of perceived skill that might be dependent on prior training. These skills were not possible to assess objectively as this would have required a different research approach, involving practical skills assessment using an audit tool or clinical skills stations, in order to quantify the level of skill of the participants. As previously discussed, there is no specific training on the clinical challenges highlighted by the systematic review so the participants

were asked to rate their *perceived* level of clinical skill or knowledge of the identified areas. This also ensured that HCP did not feel potentially judged or anxious in relation to their skills being directly measured, changing the 'tone' of the research. To test the reliability for both the combined skills score and the culture scores in the survey, a Cronbach's Alpha was performed for each and found to have excellent internal consistency.

4.3 Results

The study recruited a large sample of professionals from various backgrounds around the UK. It explored various associations between confidence and skill, as well as attitudes towards breastfeeding support on paediatric wards and departments. This study also identified specific skill gaps amongst professionals, and some areas in which professionals have identified more training and support is required.

Participant demographics and location

A total of 496 professionals with unique IP addresses started the survey. On reviewing the initial data, three participants were excluded because they were midwives or neonatal nurses and therefore, they did not meet the inclusion criteria of working within paediatrics. A further 84 people started the questionnaire but only completed the initial non-clinical questions. Therefore, the decision was made to exclude those responses. In total, 409 professionals completed all or most of the questionnaire. Those who answered 80% of the questions as identified by the completion tool in SPSS were included, but as responses to individual questions were not compulsory the overall participant response rate for each question varies slightly. (See Table 13). The 'other' professionals self-defined as play specialists (n=2) and nursery nurses (n=2).

Table 13: Participant demographic data

Variable		n	%
Gender	Female	385	94.1
	Male	15	3.7
	Nonbinary	1	0.2
	Prefer not to say	8	2.0
Ethnicity	White/White British	359	87.7
	White/White Irish	10	2.4
	Gypsy/Traveller	1	0.2
	Asian/Asian British (Bangladeshi)	1	0.2
	Asian/Asian British (Indian)	10	2.4
	Asian/Asian British (Pakistani)	3	0.7
	Asian/Asian British (Chinese)	1	0.2
	Asian/Asian British (Other)	2	0.5
	Black/Black British	2	0.5
	Mixed race	9	2.2
	Other self-defined	8	2.0
	Prefer not to say	3	0.7
Profession	Paediatric nurse	245	59.9
	Paediatricians	103	25.2
	Allied health professional (AHP)	45	11.0
	Health care assistant (HCA)	12	2.9
	Other	4	1.0
Post qualification years of experience	<2 years	23	6.6
	2-5 years	59	16.4
	5-10 years	98	26.5
	10-15 years	79	20.6
	15+ years	108	29.9

Most of the participants were female (94.1%) and the most common profession represented was paediatric nursing (59.9%), followed by paediatricians (25.2%), AHPs (11%) and HCAs (2.9%). Other professionals made up 1% (n = 4) of the sample and self-identified as play specialists and nursery nurses. Approximately half (50.5%) of the sample had been qualified within their role for more than ten years. A chi square found a significant association between length of post qualification experience and professional group [$X^2 = 43.927$, $p = <0.001$]. Overall, 69.4% of AHPs had ten years or more experience, followed by 56.7% of paediatric nurses, 41.6% of HCAs, and just 27.7% of paediatricians. Length of experience was

therefore controlled for in any further analyses exploring differences in attitude or experience between professional groups.

Participants were also asked about what type of hospital they worked in, the clinical specialty if applicable, and their geographical location. Overall, there was a varied spread of geographical location and clinical environment which is important because while breastfed children are more likely to have more significant input from a general ward or PICU, they may be seen in any clinical area (Table 14).

Table 14: Hospital, clinical area, and location

Variable		n	%
Type of hospital	Local hospital	202	50.2
	Specialist (tertiary referral) centre	200	49.8
Clinical area	General medical/surgical ward	274	55.6
	PICU/HDU	105	21.3
	Outpatients	69	14.0
	Emergency department	68	13.8
	Ambulatory/rapid assessment	52	10.5
	Other (Community, oncology etc.)	16	3.2
	Cardiac intensive care/HDU	28	5.7
	Theatre and recovery	3	0.6
Geographical location	England – North	161	39.4
	England – South	34	8.3
	England – East	13	3.2
	England – South West	75	18.3
	England – Central	37	9.0
	England – London	45	11.0
	Scotland	12	2.9
	Wales	28	6.8
	Northern Ireland	4	1.0

There was an almost even split between people identifying as working in a specialist hospital and people working in a local hospital (49.8% specialist/tertiary referral hospital, 50.2% local hospital). The most common clinical area was the general paediatric medical or surgical ward (55.6%), but many respondents reported working in the high dependency unit (HDU) or paediatric intensive care unit (PICU) (21.3%). 3.2% selected the other category,

which included the neonatal intensive care unit for professionals who worked across all paediatric and neonatal directorates, oncology and other specialist wards, and the community setting. There were also three people who worked in a senior clinical role across all departments, or in an educational capacity.

4.3.1 Experience and attitudes towards working with breastfed infants and children

The professionals were firstly asked how often they care for young children under the age of two, to determine the likelihood that they had regular contact with the population group most likely to need breastfeeding support. They were also asked specifically how often they care for breastfed infants and children. There were two questions relating to professional attitudes towards breastfeeding – whether they personally felt that breastfeeding was important, and whether they felt that supporting parents to achieve their breastfeeding goals was part of their job (Table 15).

Table 15: Experience working with breastfed infants and children on the ward

Variable	Responses	n	%
How often do you care for children <2 years	Every shift	233	57.1
	Nearly every shift	136	33.3
	Sometimes	33	8.1
	Rarely	5	1.2
	Never	1	0.2
In an average week, how often do you provide clinical care to a breastfed child?	Every shift	23	6.2
	Most shifts	126	34.0
	Sometimes	161	43.4
	Rarely	51	13.7
	Never	10	2.7
I believe that breastfeeding is important for all children, whether healthy or medically complex	Strongly agree /agree	339	95.7
	Neither agree nor disagree	14	4.0
	Strongly disagree / disagree	1	0.3
I believe that supporting parents to meet their breastfeeding goals is an important part of my job	Strongly agree /agree	335	94.3
	Neither agree nor disagree	14	4.0
	Strongly disagree / disagree	6	1.7

As shown in Table 15, most of the professionals in this sample felt that breastfeeding was important for all children, whether they are unwell or healthy. Most of the participants (94.3%, n = 335) also agreed that supporting parents to achieve their breastfeeding goals is an important part of their job. A MANCOVA, controlling for length of experience, found that there was a significant difference in belief that breastfeeding was important for all children by professional role [F (1,3) = 5.554, p = <0.001]. Although almost all professionals agreed that it was important, post hoc Bonferroni tests showed that paediatricians (p = .002) and AHPs (p = .031) agreed less strongly than paediatric nurses. There were no significant differences in beliefs that supporting breastfeeding was important [F (1,3) = .622, p = .601] between professional roles.

4.3.2 Training and qualifications

When asked about their undergraduate training via a tick box, 66.5% (n = 246) reported not having any training at all in breastfeeding, and a further 25.7% (n = 95) had just 1-2 hours of training. Only 3.2% (n = 12) had a whole day or more as part of their training. There was no significant association between professional group [$X^2 = 13.797$, p = .314] or length of experience [$X^2 = 15.072$, p = .519] and extent of training. In terms of whether the health professionals felt that their undergraduate training had equipped them to be able to support families with breastfeeding in the paediatric setting, 71% (n = 264) felt that they had not been equipped. 13.7% (n = 51) felt ambivalent about their undergraduate training preparation, and 15.3% (n = 57) felt they had been adequately equipped by their training.

4.3.3 Breastfeeding credentials, perceived skills, and training

The professionals were asked about whether they had undertaken any additional training or had specific breastfeeding qualifications or credentials (Table 16).

Table 16: Post-qualification training and breastfeeding credentials

Question	Variable	n	%
Do you have any breastfeeding credentials?	IBCLC	8	1.9
	BFC	20	4.9
	Peer supporter	47	11.49
	None	334	81.6
Have you attended any breastfeeding training?	Extensive (PS and above)	75	18.3
	Some	71	17.3
	None	263	64.3
Have you been provided with breastfeeding training?	It is mandatory	59	16.6
	It is offered, but not mandatory	114	32.1
	It is not provided	165	46.5
	Not sure	17	4.8
I feel I need or could benefit from breastfeeding training	Strongly agree /agree	294	81.8
	Neither agree nor disagree	52	14.9
	Strongly disagree / disagree	13	3.3
Have you asked for breastfeeding training from your manager?	Asked, and received	71	20.2
	Asked, but refused	38	10.8
	Not asked	243	69.0
In paediatrics, you need different or additional skills, compared with healthy children	Strongly agree /agree	331	93.3
	Neither agree nor disagree	23	6.4
	Strongly disagree / disagree	1	0.3

In terms of further credentials gained, whilst breastfeeding training is not a core competency of health professionals in paediatrics, some choose to pursue additional training – either funded and facilitated by their healthcare institution, or self-funded. A variety of breastfeeding training is currently available, including short courses lasting between one and three days. Peer supporter training involves approximately twelve weeks of study with supervised practice, and opportunities thereafter to work in paid or voluntary roles in a variety of clinics, community and maternity settings. Breastfeeding counsellor training usually lasts approximately two years and has a broader curriculum than that of a peer supporter. Breastfeeding counsellors, like peer supporters, have a nonmedical, counselling focus. IBCLCs must meet the criteria of having provided at least 1000 verifiable

hours of supervised breastfeeding support, and complete 95 hours of lactation specific training before sitting an exam.

Some of the professionals reported having completed the BFI e-learning or had accessed some other training lasting 1-3 days. Several professionals had accessed peer supporter training though fewer numbers identified as peer supporters – so it may be that although they had taken peer supporter training, they did not feel they were working in a peer support capacity in hospital. Far fewer had undertaken breastfeeding counsellor training and even less had accessed IBCLC preparation courses or other extensive breastfeeding training providing 50-90+ hours of tuition.

Some of the professionals had additional breastfeeding qualifications/credentials and training. In total, 11.49% (n = 47) were trained peer supporters, 4.9% (n = 20) were breastfeeding counsellors and 1.9% (n = 8) were IBCLCs. Because of the small numbers of professionals who had more extensive training, particularly at BFC and IBCLC level, training was coded as 'extensive' at peer supporter level and up. Professionals who had attended between 1-3 days face to face or online training were considered to have had 'some' training, and those who had not attended any were coded as 'none'. To explore whether there was any association between who had achieved additional qualifications and professional group, a crosstabs between breastfeeding qualifications and professional groups was computed (Table 17). Excluding the 'Other' group due to low numbers, AHPs were the most likely to have additional qualifications, followed by the paediatric nurses and the paediatricians. However overall, the majority of participants did not hold additional qualifications.

Table 17: Lactation credentials by professional group

	IBCLC		BFC		PS		No credential	
	N	%	N	%	N	%	N	%
Paediatric nurse	3	1.2	11	4.5	34	13.9	197	80.4
HCA	0	0	0	0	1	8.3	11	91.7
Paediatrician	0	0	6	5.8	6	5.8	91	88.3
AHP	4	8.9	3	6.7	5	11.1	33	73.3
Other	0	0	0	0	1	25.0	3	75.0

To explore whether those who did have qualifications were associated with professional groups a chi square calculation was performed. Due to very low numbers in the 'Other' group which may have skewed the data, these participants were combined with the AHPs. A significant association was found between qualification and professional group ($X^2 = 20.603$, $p = .015$). IBCLCs were most likely to be AHPs (57.1%, $n = 4$) and paediatric nurses (42.9%, $n = 3$). Breastfeeding counsellors were most likely to be paediatric nurses (55%, $n = 11$), followed by paediatricians (30%, $n = 6$) and AHPs (15%, $n = 3$). The majority of peer supporters were also paediatric nurses (72.3%, $n = 34$), followed by paediatricians (12.8%, $n = 6$) and AHPs (10.6%, $n = 5$).

As noted above, there was a significant association between professional group and post qualifying experience, with AHPs being the most likely to have over ten years' experience and paediatricians the least. However, a chi square found no significant association between years of experience and having a breastfeeding qualification, potentially due to low numbers in the sample with any breastfeeding qualification ($X^2 = 6.993$, $p = .858$). Despite this it is important to note that 75% of those with IBCLC qualifications had over 10 years' experience (compared to 50.5% of the full sample), although this only represented eight participants. The percentage of the remaining breastfeeding qualification groups were closer to the full sample average: BFC 52.7%, Peer supporter 57.4% and no qualification 48.8%.

Considering whether they would benefit from additional training, most of the sample (81.8%, n = 294) felt they needed more training in breastfeeding, with 14.4% (n = 52) feeling ambivalent about this, and just 3.6% (n = 13) saying that they did not feel they needed or could benefit from training. A MANCOVA, controlling for length of experience, found a significant difference in perceived need for training between professional groups [$F(1, 3) = 9.910, p = .009$]. Post hoc Bonferroni tests found that paediatricians were significantly less likely to feel that they needed further training than paediatric nurses ($p = .03$) and HCAs ($p = .01$). Despite the high numbers of professionals agreeing that they need training, 69% (n = 245) had not asked for it. The majority (93.3%, n = 334) of the professionals surveyed felt they need different skills to support families with breastfeeding in the paediatric setting. 6.5% (n = 23) were ambivalent about the necessity of this, and just 0.3% (n = 1) disagreed.

To further explore why professionals did not ask for breastfeeding training, a free text box (see Table 18) enabled professionals to provide reasons. In total, 165 professionals left comments, which were coded into 16 themes.

Table 18: Reported reasons for not asking for breastfeeding training

Reasons	Examples
1. Lacking confidence to ask	<p>“My manager isn’t approachable” (Paediatric nurse)</p> <p>“Know they wouldn’t think it was important enough” (Paediatrician)</p>
2. Unaware	<p>“Don’t see it often on PICU so rely on my own experiences, and didn’t know courses exist.” (Paediatric nurse)</p> <p>“Didn’t know it was available.” (Paediatrician)</p>
3. Not invested	<p>“It does not particularly interest me.” (Paediatric nurse)</p> <p>“One expects that the training one is given is already appropriate and complete. I don’t think trainees should be expected to know what the gaps in their training are – this should come from deaneries/trainers/supervisors.” (Paediatrician)</p>
4. Limited exposure to breastfeeding	<p>“Very rare to have a breastfed baby on the ward.” (Paediatric nurse)</p> <p>“Don’t see it often on PICU so rely on my own experiences” (Paediatric nurse)</p>
5. Hostility	<p>“Because it is not my job! Would rather not have the breastfeeding police infiltrating paediatrics!” (Paediatrician)</p> <p>“Current unit not pro-breastfeeding.” (Paediatrician)</p>
6. Not felt to be necessary	<p>“Most children are established with breastfeeding already or are receiving other methods of feeding (i.e., enteral).” (Paediatric nurse)</p> <p>“Always ‘got by’ without it.” (Paediatric nurse)</p>
7. Already feel skilled	<p>“Not needed as previous role was Health Visitor.” (Paediatric nurse)</p> <p>“Have had lots of BF training in previous role as an infant feeding lead” (AHP)</p>
8. Cessation of training due to Covid-19 pandemic	<p>“Asked and was due to attend but it was cancelled as it was during lockdown. It has not been rescheduled.” (AHP)</p> <p>“Started my job during COVID times with no training taking place” (Paediatric nurse)</p>

9. Training isn't helpful	<p>"The course we get put on isn't helpful and my own knowledge from teaching myself and feeding my babies is more than the course gives." (Adult nurse working in paediatrics)</p> <p>"There is a short course available and I didn't feel I would benefit" (Paediatric nurse)</p>
10. Being newly qualified	<p>"Only qualified for year and a half, unaware of what is extra training." (Paediatric nurse)</p> <p>"Only recently started" (Paediatric nurse)</p>
11. Delegate to midwives/neonatal team	<p>"I feel that if I ever have a problem that I need sorting with breastfeeding, I contact NICU and the midwives there and they can give advice and come help the mum personally. So, there is expertise available, it just may not be me." (Paediatric nurse)</p> <p>"We would rely on health visitors and SALT to help with feeding" (Paediatric nurse)</p>
12. Lack of time, or the training would be undertaken on annual leave	<p>"Breastfeeding training is available but in your own time and very limited availability." (Paediatric nurse)</p> <p>"Lack of time/opportunity." (Paediatrician)</p>
13. Existing training focuses on establishing feeding in healthy newborns and sick neonates	<p>"Some is provided via neonatal training, but breastfeeding seems relatively forgotten about in the paediatric setting." (Paediatrician)</p> <p>"Only basic training available (1/2 day)." (AHP)</p>
14. Not felt to be applicable to their role	<p>"Not obligated for role." (Paediatrician)</p> <p>"Not applicable to job role." (AHP)</p>
15. Other clinical priorities	<p>"Often we don't have time, and more pathological conditions take precedent." (Paediatrician)</p> <p>"Too many other priorities" (Paediatric nurse)</p>
16. Rely on personal experience of breastfeeding to get through any questions that arise	<p>"Personal experience of breastfeeding difficulties I feel I have a good knowledge. Breastfeeding training (in neonates) roughly every 6m focuses on the benefits of BF rather than how to overcome any of the difficulties." (Paediatrician)</p> <p>"I have learnt a lot through my own breastfeeding journeys." (Paediatrician)</p>

4.3.4 Confidence and experience

Participants were asked to rate how strongly they agreed that they were experienced at supporting breastfeeding, as well as how confident they felt, whether they had any additional responsibility for infant feeding on their ward or unit, and the source of their knowledge (Table 19). In terms of how experienced the professionals feel they are at supporting parents to breastfeed, around half felt they had a lot of experience with the remainder split between ambivalence, and those who felt they did not have a lot of experience. A similar number of professionals felt confident to answer questions that arose on a shift about breastfeeding. A MANCOVA controlling for length of experience found no significant difference for either experience [$F(1,3) = 1.554, p = .200$] or confidence [$F(1,3) = .981, p = .551$] between professional groups.

Table 19: Confidence, responsibility for and experience supporting breastfeeding

Question	Variable	n	%
How much do you agree that you have a lot of experience supporting breastfeeding?	Strongly agree /agree	205	53.6
	Neither agree nor disagree	81	21.2
	Strongly disagree / disagree	96	25.2
Do you have any additional responsibility for infant feeding on your ward/department?	Yes	64	17.9
	No	293	82.1
On an average shift, I feel confident about being able to answer any questions about breastfeeding?	Strongly agree /agree	198	53.2
	Neither agree nor disagree	88	23.6
	Strongly disagree / disagree	86	23.2
Is there someone who has been identified as having additional expertise on the ward?	Yes	229	64.5
	No	84	23.7
	Not sure	42	11.8
On an average shift, there is enough support for families trying to breastfeed	Strongly agree /agree	80	23.3
	Neither agree nor disagree	95	27.7
	Strongly disagree / disagree	168	49.0

When exploring what factors might be associated with confidence, those with higher breastfeeding credentials (such as IBCLC) felt more confident (Spearman's $r(373) = .322, p < .001$) and had a higher level of perceived experience supporting breastfeeding (Pearson's r

(371) = .376, $p < .001$). However, those who were more confident also have a desire for more training (Pearson's r (354) = .209, $p < .001$).

Professionals were also asked whether there was an identified person with additional knowledge and skills on their ward, and whether there was generally enough support for families who wish to breastfeed. When asked whether they feel there is enough support for families, almost half of the professionals felt that there is not enough support for families. An ANCOVA controlling for length of experience found a significant difference by professional group [$F(1,3) = 3.002$, $p = .017$]. Paediatric nurses were significantly less likely to feel that there was enough support compared to paediatricians ($p = .014$) and AHP ($p = .013$).

Additionally, participants were also asked about the source of their breastfeeding knowledge. Some of the professionals (12.6%, $n = 62$) had personally funded additional training, whereas others reported that their training came from their personal experience (44.4%, $n = 219$), another colleague on the ward (27.8%, $n = 137$), NHS funded training (25.4%, $n = 125$), and websites or books (25.8%, $n = 127$). 12.4% ($n = 61$) reported that their undergraduate training was the source of their knowledge, and 5.9% ($n = 29$) felt they didn't have any specific knowledge.

4.3.5 Specific perceived skills

Based on many of the areas of challenge elucidated from the systematic review, professionals were asked if they felt they had any experience supporting thirteen specific breastfeeding skill areas [response options yes lots, yes some and none] (Table 20).

Table 20: Perception of extent of breastfeeding clinical skills

Specific breastfeeding skills	Lots (3)		Some (2)		None (1)	
	N	%	N	%	N	%
Providing encouragement to breastfeed	193	50.8	152	40.0	35	9.2
Supporting parents to express milk	152	40.0	162	42.6	66	17.4
Able to identify adequate milk intake	123	32.5	160	42.2	96	25.3
Able to provide information about the benefits of non-nutritive sucking	116	30.4	176	46.2	89	23.4
Helping parents to protect or increase their milk supply	111	29.1	170	44.6	100	26.2
Improving latch to reduce nipple pain	96	25.2	170	44.6	115	30.2
Supporting infants with high calorie need	78	20.4	145	38.0	159	41.6
Helping parents to restart breastfeeding after tube feeding	75	19.8	158	41.7	146	38.5
Supporting common breastfeeding challenges, e.g., mastitis	70	18.4	150	39.4	161	42.3
Experience with hypotonic/sleepy infants	68	17.9	151	39.8	160	42.2
Identifying poor milk transfer through a feed assessment	60	15.8	145	38.2	175	46.1
Experience supporting infants with orofacial anomalies	34	8.9	121	31.7	227	59.4
Supporting relactation (restarting bf after stopping)	33	8.7	91	23.4	257	67.5

As shown in Table 20, in general, the respondents were more likely to identify having lots of experience in simple aspects of breastfeeding support – such as providing encouragement to breastfeed. Most of the sample had at least some experience supporting parents to express milk, providing information about the benefits of non-nutritive sucking, identifying adequate milk intake, and helping parents to protect or increase their milk supply. Many had at least some experience with improving latch to reduce nipple pain, though only a

quarter reported having lots of experience with this. Slightly fewer professionals reported that they had some experience helping parents to restart breastfeeding after tube feeding.

The areas that professionals felt they had generally less experience with included supporting infants with high calorie needs. Over 40% (n = 159) of the professionals had no experience with this clinical challenge. Almost half the sample of professionals (46.1%, n = 175) had no experience identifying poor milk transfer through a feed assessment. Most of the professionals had limited or no experience with hypotonic infants (82.1%, n = 311) and supporting common breastfeeding challenges, such as mastitis (81.6%, n = 311). Less than 9% (n = 348) had lots of experience supporting infants with orofacial anomalies and supporting relactation.

To calculate an overall level of perceived skill, responses to individual skills were scored with lots = 3, some = 2 and none = 1 and combined to give an overall skill score with the potential to range from 13 – 39. To test the internal consistency of these items as a combined scale, a Cronbach's alpha was computed ($\alpha = 0.916$) demonstrating excellent internal consistency across these items. The range of the scores was 13-39, with a median score of 23, and mean score of 24.544 (SD \pm 6.622).

Perceived skill was again examined by professional group but also by considering broader experience in terms of qualifications, training and responsibility. Table 21 shows that increased skill was significantly associated with higher additional qualifications, greater training, more years of experience, perceived own greater experience and for those who had additional responsibilities. No difference in perceived skill was found for professional group or amount of undergraduate training.

Table 21: Comparisons of perceived skill scores by sub-groups

Question	Variable	Mean skill score ± SD	N (368)	%	
Skill by credential	IBCLC BFC PS None	36.125 ± 3.136 30.842 ± 5.510 27.717 ± 5.698 23.328 ± 6.198	8 19 46 295	2.17 5.16 12.5 80.16	F (3, 364) = [24.730], p = <.001 (ANOVA)
Skill by level of training	Extensive Some None	29.461 ± 5.929 26.597 ± 6.341 22.429 ± 6.622	65 77 226	17.66 20.92 61.41	r (368) = .423, p = <0.001 (Spearman's)
Skill by profession	Paediatric nurse HCA/other Paediatrician Allied health professional	24.821 ± 6.508 22.111 ± 7.896 23.217 ± 5.217 26.435 ± 8.567	224 9 92 39	60.86 2.44 25.0 10.59	F (4, 362) = [2.226], p = .066 (ANOVA)
Skill by number of years post qualification	<2 years 2-5 years 5-10 years 10-15 years 15+ years	23.826 ± 5.449 23.118 ± 6.028 23.806 ± 6.223 24.683 ± 6.115 24.504 ± 6.588	23 59 98 79 108	6.25 16.03 26.63 21.46 29.34	r (408) = .125, p = .016 (Spearman's)
Skill by extent of agreement of having lots of experience	Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree	32.158 ± 5.562 26.379 ± 5.009 21.739 ± 4.790 19.389 ± 4.069 17.058 ± 6.630	63 137 73 77 17	17.11 37.22 19.83 20.92 4.61	r (386) = .676, p = <0.001 (Pearson's)
Amount of undergraduate training	1 day or more 1-2 hours None	25.833 ± 8.211 24.876 ± 6.353 24.512 ± 6.694	12 89 256	3.36 24.9 71.7	F (2, 354) = .295, p = .744 (ANOVA)
Skill by additional infant feeding responsibility	Additional responsibility No additional responsibility	30.031 ± 5.710 23.413 ± 6.230	63 283	17.11 76.90	F (1, 344) = [59.870], p = <.001 (ANOVA)

4.3.6 Perceived barriers to breastfeeding for professionals and parents

Professionals were asked about their perception of barriers to maintaining or facilitating breastfeeding on the ward via a multiple-choice tick box in which they could select zero, one

or multiple options. These were split into barriers for families who want to breastfeed, and the barriers to professionals being able to support breastfeeding. The most commonly perceived barriers for parents identified by the professionals were stress, lack of support, tube feeding, fluid restriction or needing extra fluids, having other children at home, and feeling scared. For professional barriers the most commonly reported barriers were a lack of knowledge, the need to measure fluid intake, no time, infant instability, adaptations to infant condition, pressure from health care professionals to stop breastfeeding, and feeling that critical care was more important than breastfeeding. (Table 22).

Table 22: Professional and parent barriers and potential solutions

Question	Possible barriers	n	%
Perceived professional barriers to being able to support breastfeeding	Lack of knowledge of how to help	275	55.8
	Need to measure fluid balance	176	35.7
	No time to support	167	33.9
	Infant instability	157	31.8
	Adaptations required to manage child's condition	115	23.3
	Pressure from healthcare professionals to stop	104	21.1
	Critical care is more important than feeding choices	70	14.2
	Other	50	10.1
Perceived barriers for parents trying to breastfeed their sick child	Stress	292	59.2
	Not enough support	242	49.1
	Need to tube feed	211	42.8
	Fluid restricted, or needing additional fluid/calories	185	37.5
	Need to care for other children at home	167	33.9
	Scared to breastfeed their sick child	154	31.2
	Lack of privacy	131	26.6
	Cannot stay with their child	106	21.5
	Cannot find a breast pump	103	20.9
	Advised not to breastfeed by HCP	96	19.5
	Other	29	5.8
What would help you to be able to support more families on the ward?	Specific training relating to sick children	292	59.2
	Having a designated paediatric infant feeding team	206	41.8
	Better undergraduate training	172	34.9
	Leaflets or handouts to give parents	167	33.9
	A breastfeeding policy	129	26.2
	Better facilities for families	65	13.2
	Other ideas	49	10.0
	Not sure	10	2.0

Total perceived professional and parent barrier scores were calculated for each participant by adding the number of barriers identified by each participant. This gave a possible score of 0 – 7 for professional barriers and 0 – 9 for parent barriers. The mean score for professional barriers identified was 2.15 (SD: 1.92), and for parent barriers identified the score was 3.42 (SD: 2.95).

To explore whether perceived barriers differed between professional groups, a MANCOVA was conducted for the four main professional groups (paediatricians, paediatric nurses, allied health professionals and HCAs/other). A significant difference was found for professional barriers [$F(3, 401) = 4.634, p < 0.001$]. Post hoc Bonferroni tests found that the HCA/other group identified significantly fewer barriers than paediatric nurses ($p = .008$) and paediatricians ($p = .003$). No further significant differences were found. A significant difference was also found for parent barriers [$F(3, 401) = 5.776, p < 0.001$]. Post hoc Bonferroni tests found that HCAs/others identified significantly fewer barriers than paediatric nurses ($p = 0.047$) and paediatricians ($p = 0.002$). Paediatricians also identified significantly more barriers than paediatric nurses ($p = .036$).

In addition to selecting perceived barriers, there was an optional free text box for what they perceived as professional barriers to supporting optimal breastfeeding. For the barriers for parents, 29 participants left comments. These were coded into eight themes (Table 23).

Table 23: Perceived barriers for parents

Possible barriers for parents	Examples
1. Rest/sleep prioritised for parents	<p>“Parents are often encouraged to rest, and nurses give formula instead.” (Paediatric nurse)</p> <p>“I think when a parent has a sick child in PICU, despite their best efforts this can impact the milk supply. It’s important not to make the mother feel more stressed or guilty for the lack of milk.” (Paediatric nurse)</p>
2. Implication that bottle feeding is easier	<p>“Not explicitly told not to breastfeed, but rather implied that it is easier/less time consuming/able to tell how much an infant is taking when you don’t breastfeed.” (Paediatrician)</p>

	<p>“Often professionals think. Bottle feeding is easier and will get the family home quicker” (AHP)</p>
3. Medication confusion	<p>“Medications the mothers may be on and medical/pharmacy confusion surrounding this.” (AHP)</p> <p>“Inadequate analgesia for mothers.” (Paediatrician)</p>
4. Large volumes of bottle/tube feeds prescribed	<p>“Often told to offer 150ml/kg first, meaning the infant isn’t hungry and doesn’t want to take the breast after.” (Paediatric nurse)</p> <p>“Pressure to meet demand of expectations of volumes” (Paediatric nurse)</p>
5. Struggling to express	<p>“Being told their child is dehydrated, being told they need to top up after a feed with EBM or formula, struggling to get anything on expressing and then having to give formula, becoming obsessed with how much they are taking as this is what the doctors focus on.” (Paediatric nurse)</p> <p>“Too busy with doctors and therapy to have time to pump” (Paediatric nurse)</p>
6. Professional advice	<p>“Pressure from professionals to switch to formula for a variety of reasons.” (Paediatric nurse)</p> <p>“Biased and under trained staff.” (AHP)</p>
7. Assumptions	<p>“The implication that if the baby can’t exclusively breastfeed there is no point doing it at all.” (Paediatrician)</p> <p>“Extra glucose needed” (Paediatrician)</p>
8. Lack of knowledge about specific clinical scenarios	<p>“Advised against breastfeeding patients who have received chemotherapy as can be excreted in saliva putting mum at risk.” (Paediatric nurse)</p> <p>“Their child being temporarily unable to directly breastfeed and no support to get them back to the breast as they recover.” (Paediatrician)</p>

For the ‘other’ text box for barriers for staff, 50 participants left comments. These were thematically analysed and seven barriers were identified (Table 24).

Table 24: Perceived staff barriers

Possible barriers for staff	Examples
1. Staff deferring to their own negative experiences of breastfeeding	<p>“Some think it’s not important and bring their own negative experiences with them.” (Paediatric nurse)</p> <p>“Staff potentially dealing with their own breastfeeding grief and the ‘I used formula, it was fine’ mindset.” (Paediatrician)</p>
2. Not prioritised	<p>“It is low priority and undermined by health professionals – BMS* industry links and lack of code adherence/awareness.” (AHP)</p> <p>“Little to no thought given to maintaining lactation amongst other goals of treating a sick child.” (Paediatrician)</p>
3. Lack of understanding	<p>“Not understanding how breastfeeding works.” (Paediatric nurse)</p> <p>“Lack of basic knowledge about breastfeeding and we seem to always compare breastfeeding and formula as though formula is the default and breastfeeding is an inherent risk.” (Paediatrician)</p>
4. Interplay between other clinical settings	<p>“Lack of community support before they present.” (Paediatrician)</p> <p>“In emergency department we are with the family for a short time. Sometimes the child is beyond help - very low BG, severe jaundice as the mother has not had enough support before they reach us.” (Paediatric nurse)</p>
5. No general paediatric infant feeding team	<p>“We are not specifically funded to support BF when there isn’t a dysphagia concern.” (AHP)</p> <p>“No designated team on paediatrics and the maternity staff don’t have time to visit the ward.” (Paediatric nurse)</p>
6. Strict fluid intake	<p>“Dr insistence on fluid intake measurement rather than looking at output and growth.” (Paediatric nurse)</p> <p>“Strict fluid intake for faltering growth is a main issue.” (Paediatric nurse)</p>
7. Intrusive ward routines/ward culture	<p>“Ward routines e.g., obs***, ward rounds etc. not supporting responsive feeding. Limited/no visiting from partners during Covid to allow mothers a rest. Poor levels of nutrition/fluid offered to mothers” (AHP)</p> <p>“BF parents are there more and ‘in the way’. BF babies are more ‘needy’ and so harder work” (Paediatric nurse)</p>

* BMS = Breast milk substitutes **BG = Blood glucose *** obs = clinical observations (temperature/pulse etc)

Participants were given the option to write their suggestions for what would help them support more families with breastfeeding on the ward. The most commonly selected option was having paediatric specific breastfeeding training (59.2%, n = 292) and having a paediatric infant feeding team (41.8%, n = 206). Undergraduate training (34.9%, n = 172) and having leaflets or handouts to give families (33.9%, n = 167) were also suggested. Better facilities were selected by 13.2% (n = 65) of the participants. Too few left additional comments in the 'other' section for meaningful descriptive analysis, and many of these matched the perceived barriers and could be classified under the options provided, such as their suggestions for more breast pumps, private spaces, leaflets, and more training. Other suggestions included:

- Breastfeeding chairs and pillows
- Feeding spaces in the emergency room
- Expressing rooms
- Facilities to store pumped milk
- Support to re-establish feeding after medical or surgical problems

4.3.7 Ward culture and organisational structures

Participants were then asked a range of questions relating to the general attitudes and culture on the ward, as well as their knowledge of additional resources to refer to. (Table 25).

Table 25: Perceptions of ward culture that may influence breastfeeding support provision

Statement	Strongly agree / agree		Strongly disagree / disagree	
	N	%	N	%
Our unit values breastfeeding for its nutritional, immunological, relational, and psychological impacts	207	60.5	50	14.7
Supporting families to reach their goals is something we try to do	222	64.9	46	13.5
The staff on our unit are adequately trained to support most breastfeeding challenges	66	19.3	169	49.5
Breastfeeding families generally have a good experience on our unit	139	40.8	51	15.0
The MDT generally work together to find solutions that enable breastfeeding to continue alongside clinical care	146	42.7	89	26.0
Our unit is a good example of how to support breastfeeding in challenging circumstances	90	26.3	109	31.9
I am one of just a few people on my unit who advocates for breastfeeding	150	43.8	88	25.8

Regarding the general attitudes towards breastfeeding on their ward, unit, or department, most agreed that their unit values breastfeeding for the nutritional, immunological, relational, and psychological impacts that it has. Similarly, most agreed that their unit tries to support parents' breastfeeding goals. Less than half agree that in their unit, the multidisciplinary team works together to try to find solutions that enable breastfeeding to continue alongside clinical care or that breastfeeding families generally have a good experience in their unit. Only around a quarter feel that their unit is an example of how to support and protect breastfeeding in challenging circumstances. Less than 20% agree that the staff on their unit are adequately trained and are able to support most breastfeeding challenges. Finally, just under half say they are one of just a few breastfeeding advocates on their unit, which suggests - as suspected - that the survey was completed disproportionately by those already invested in breastfeeding.

An aggregate ward culture score was calculated by adding responses to each of the statements together (where strongly disagree = 1 and strongly agree = 5) apart from the last item (*I am one of just a few people on my unit who advocate for breastfeeding*). This last item was omitted from the ward culture score as it may be just the individual completing the survey who felt they were a lone advocate for breastfeeding, within an otherwise less supportive environment. This gave a possible score from 6 – 30 with a lower score indicating a culture where support, training, collaboration and positivity for breastfeeding was low with a high score representing a more supportive environment. To test the internal consistency of these items as a combined scale, a Cronbach's alpha was computed ($\alpha = 0.89$) demonstrating good internal consistency across these items.

The minimum ward culture score - indicating an environment where there was low support, training, collaboration, and positivity for breastfeeding – was 6. The highest possible score was 30 with few wards or departments receiving a very low or very high score. The range was 6-30, with a median of 19.5 and a mean ward culture score of 19.373 (SD \pm 4.514). An ANCOVA controlling for years of experience found no significant difference in perceived ward culture score amongst professional groups [F (3, 333) = .788, p = .507]. Ward culture score was, however, significantly negatively correlated with the number of perceived professional (r (339) = -.277, p = .001) and parent (r (339) = .250, p = .001) barriers to breastfeeding.

4.3.8 Ability to refer to other sources of support

Professionals were asked how many resources, websites, organisations, and support groups they were aware of (Table 26). This is important because if the professionals are not able to answer a question or provide the advice needed by a parent, they should be able to refer the family to a reputable source of support. Given that over 40% of the sample agreed that they were one of a few breastfeeding advocates on the ward, the awareness of these sources of support was surprisingly low.

Table 26: Awareness of other resources and sources of information

Variable – resource/source of support	N	%
Baby Friendly Initiative	224	45.4
La Leche League	214	43.4
Breastfeeding Network	187	37.9
Hospital Infant Feeding Network	123	24.9
Kellymom	113	22.9
Drugs in breastmilk factsheets	104	21.1
Association of Breastfeeding Mothers	95	19.3
LactMed	65	13.2
Academy of Breastfeeding Medicine	34	6.9
Breastfeeding the Brave support group	24	4.9

Participants were most likely to have heard of the Baby Friendly Initiative and La Leche League and least likely to have heard of the Academy of Breastfeeding Medicine which has a repository of evidence-based guidelines for the management of numerous conditions relevant to paediatrics, and the Breastfeeding the Brave support group.

4.3.9 Organisational systems and structures

The next questions related to some of the organisational and support infrastructure, such as the infant feeding team if applicable, whether they knew who to refer to if they needed to provide a family with more sources of support, and whether there was a breastfeeding policy available and easy to locate (Table 27).

Table 27: Awareness of organisational support systems

Variable	Response	n	%
Do you know who the infant feeding lead is?	Yes	154	45.0
	No	105	30.7
	There isn't one for paediatrics	45	13.2
	Not sure	38	11.1
Do you know of any helplines to give families?	Yes	194	56.7
	No	100	29.2
	I'm not sure	48	14.0
Do you know of any websites to refer to?	Yes	217	63.5
	No	77	22.5
	I'm not sure	48	14.0
Do you know where the breastfeeding policy is?	Yes	181	52.9
	No	109	31.9
	I'm not sure	52	15.2
Was the BF policy part of your orientation?	Yes	37	10.9
	No	274	80.4
	I'm not sure	30	8.8
Is the BF policy somewhere accessible to families?	Yes	35	10.3
	No	152	44.6
	I'm not sure	154	45.2

In most paediatric units there will not be a designated paediatric infant feeding team, but there is likely to be an infant feeding team and infant feeding lead for maternity or the neonatal unit, who may provide ad hoc cover for paediatrics. Just under half of the professionals knew who the infant feeding lead was. Most of the professionals reportedly knew of helplines or websites to provide to families. Just over half of the sample knew where the breastfeeding policy was but only a minority reported the breastfeeding policy was part of their orientation to the ward, and it was only accessible to families in about 10% of the units represented in this sample.

A chi square found a significant association between referral knowledge and professional group [$\chi^2 = 12.702$, $p = 0.048$]. Allied health professionals were the most aware (77.8%), followed by paediatricians (61.8%), paediatric nurses (51.4%) and finally HCAs/other

(50.0%). No significant association was found for years of experience and knowledge of helplines [$\chi^2 = 9.759$, $p = 0.242$].

A chi square found a significant association between awareness of the infant feeding lead and professional group [$\chi^2 = 14.067$, $p = 0.048$]. Allied health professionals were the most aware (77.8%), followed by paediatricians (61.8%), paediatric nurses (51.4%) and finally HCAs/other (50.0%). For knowledge of availability of the breastfeeding policy there was a significant association [$\chi^2 = 16.384$, $p = 0.012$] with paediatric nurses (59.6%) and allied health professionals (58.3%) having greater awareness than paediatricians (37.1%) and HCAs/other (33.3%). No significant association was found for it being accessible [$\chi^2 = 4.667$, $p = 0.770$].

No significant association was found for years of experience and knowledge of infant feeding lead [$\chi^2 = 14.067$, $p = 0.296$]. However, a significant association was found between knowledge of there being a breastfeeding policy and years of experience [$\chi^2 = 22.713$, $p = 0.004$]. With increased experience, participants were more likely to know that there was a breastfeeding policy with 33.3% of those with less than 5 years' experience knowing about a policy compared to 67.0% of those with ten or more years' experience. No significant association was found however in accessibility of the policy to families [$\chi^2 = 4.837$, $p = 0.775$].

4.4 Discussion

This study explored the perceived skills, training, experience and attitudes of professionals working in in-patient paediatric wards and units in the UK, as well as the institutional barriers and ward culture within those areas in order to explore factors affecting breastfeeding in the child's macrosystem and exosystem. It recruited over 400 healthcare professionals, including paediatric nurses, doctors at all grades, and allied health professionals such as dietitians, speech and language therapists and physiotherapists. This sample was generally supportive of breastfeeding, as evidenced by 40% of the sample reporting that they are one of the few advocates on their unit, and nearly 18% having some additional responsibility for infant feeding within their ward or department. The skewing of

the sample was also reflected in several of the professionals having extensive breastfeeding credentials, and the sample was also generally clinically experienced, with the nurses and allied health professionals being particularly likely to have been qualified more than ten years in this sample. The paediatricians were less experienced within their role in general, which may have been because more experienced paediatricians were too busy, or it may be representative of a changing culture and evidence of the clinical observation that there are more support groups for medics who are interested in supporting breastfeeding. The relatively high levels of positivity towards breastfeeding were anticipated given that this was a self-selecting sample exploring breastfeeding – therefore it may have disproportionately appealed to more professionals who were convinced of the importance of breastfeeding. Nevertheless, despite this being a motivated sample, there were many identified gaps in knowledge, with very few being confident and experienced to support a full range of clinical lactation challenges.

Some of the skills could be classified as specialist – for example supporting the return to direct breastfeeding after tube feeding. It could therefore be argued that not all staff would be expected to be competent in all skills. However, the sample included 133 professionals who worked in an intensive care environment and therefore could reasonably be expected to have some exposure to this scenario. Additionally, more than half the sample reported that they would feel confident to answer any questions that arose during their work with breastfeeding families, yet this was not borne out when they were subsequently asked about specific clinical skills. This may suggest that these scenarios and clinical needs had not occurred to them prior to being asked, or that they were unaware of their own gaps in knowledge.

Concerningly, the gaps in skill were not limited to more complex clinical scenarios, but also to breastfeeding fundamentals. For example, only about 15% of the sample felt they had lots of experience identifying poor milk transfer through undertaking a feeding assessment – which is far lower than might have been expected for a sample that self-identified as being relatively experienced and having additional infant feeding responsibilities. The concerning aspect of this is that the sample was generally motivated and likely to have an over-representation of more informed and skilled professionals. If these professionals have major

skill deficits, the implication is that a more representative sample is likely to have even greater skill and knowledge gaps as well as more negative attitudes.

The sample included representation from many clinical areas, and the free text boxes allowed for the health professionals to expand on some of the barriers they perceived to be present. It was notable how many felt that breastfeeding was not something that they were exposed to frequently on their ward, and thus was not a clinical training priority. However, from a clinical perspective, many breastfeeding mothers may perceive a lack of knowledge or acceptance on the ward negatively. Support for breastfeeding should be positive, consistent, and evident across multiple clinical areas (Gianni et al., 2019), since parents may be exposed to emergency department waiting areas, outpatient departments and theatre recovery areas – all places where staff may feel breastfeeding is not something they frequently see, and therefore feel is irrelevant.

There was clear evidence of institutional and cultural barriers, lack of training that was fit for purpose, and negative and biased attitudes among some staff. The data can be grouped into six main areas of challenge, which can be mapped to the child’s ecosystem as shown in Table 28. There were clear connections between themes, and these are presented in a naturally flowing order which mirrors the sequence of questions in the survey.

Table 28: Challenges mapped to the ecological systems theory model

Challenges	Ecosystem layer
Attitudes, confidence and experience with breastfeeding support	Exosystem
Undergraduate training	Macrosystem
Credentials, perceived skills and post-qualification training	Exosystem
Breastfeeding clinical skills	Microsystem
Barriers to breastfeeding	Macrosystem/Exosystem/ Mesosystem/Microsystem
Ward culture	Exosystem

While many of the areas of challenge were related to the skills, attitudes and experiences of the individual participants, many of the reported issues had much broader impacts into the systems at the macrosystem layer. Participants also commented on clinical skills which are

related to the individual clinical challenges experienced by paediatric patients at the microsystem layer, factors affecting parents and families within the mesosystem, and they commented on their perceptions of patient and parent experiences. The challenges, grouped into these six areas, are discussed below.

Attitudes, confidence, and experience with breastfeeding support

In this sample of professionals, there was predominantly a positive attitude towards breastfeeding. More than half the sample felt that they were experienced with supporting breastfeeding, and a similar number agreed that they felt confident about addressing most questions that arose on their shift. Many of the professionals reported that their experience comes from their own personal breastfeeding journey, or reliance on colleagues to know the answer. This was also reflected in many of the comments left in the free text boxes, with several professionals stating that they didn't feel the need for training as they had their own personal experience. This has previously been highlighted by several other studies exploring training and attitudes of general practitioners (Finneran and Murphy, 2004; Brodribb et al., 2008), obstetricians and gynaecologists (Gonzalez et al., 2014) medical students (Moukarzel et al., 2018) and paediatricians (Pound et al., 2014; Baker et al., 2021). However, many of these studies have also found that knowledge is lacking, clinicians do not feel confident, and practice may not be evidence-based (Boss et al., 2021). This is problematic because parents are more likely to receive conflicting or inaccurate information which may make achieving their breastfeeding goals harder. Biases and negative attitudes can be hard to change, and studies in other clinical settings have found that personal experience of breastfeeding can not only impact the care provided, but also highlight the differences between theory and practice (Michaud-Letourneau et al., 2022; Stolar et al., 2022).

In terms of more general attitudes towards breastfeeding, almost all the participants agreed that breastfeeding is important for all children, and that supporting parents to meet their breastfeeding goals is an important part of their job. Health professional support of breastfeeding is highly influential on breastfeeding outcomes (Sikorski et al., 2002; Taveras et al., 2004) therefore these positive attitudes, where they exist, are protective. Positive attitudes towards these variables were significantly associated with more extensive training, higher breastfeeding credentials, desire for more training, confidence in being able to

answer any questions that arose, and higher skill scores. This suggests that although this was a sample of professionals who were generally convinced of the importance of breastfeeding, those who believe breastfeeding is more important are more likely to seek to improve their skills and knowledge even further.

Notably, there were some hostile comments and some professionals who felt strongly that breastfeeding support was *not* part of their job, or that it was not important for children. While these attitudes were relatively rare overall, they are concerning given that this study is likely to have an over-representation of those who are invested in breastfeeding. It is therefore unknown how truly prevalent these more hostile attitudes are in a broad sense in UK paediatric settings. Hostile and negative attitudes are potentially very damaging to families, given that hospitalisation can have a profoundly negative impact on breastfeeding (Heilbronner et al., 2017; Bartick et al., 2021). One study found that nurses' attitudes towards breastfeeding were strongly influenced by whether they themselves were breastfed in infancy, and many nursing students felt that encouraging mothers to breastfeed is somewhat synonymous with pressurising them (Cricco-Lizza, 2006). Some of the participants in this study did not demonstrate hostility, but ambivalence - with 4% of the sample selecting the 'neither agree nor disagree' option for the questions relating to the importance of breastfeeding. Although this attitude may be intended for positive reasons, ambivalence has previously been found to discourage breastfeeding (Odom et al., 2014).

Active support and encouragement are known to promote breastfeeding, especially when this comes from a health professional (Taveras, 2004; Sattari et al., 2013) and thus the attitude of not appearing to have an opinion on infant feeding may have a detrimental impact on the maintenance of breastfeeding during illness. Support or undermining of breastfeeding also applies to the insidious promotion of formula. Unfortunately, the lack of mandatory provision of breastfeeding education presents an opportunity for formula industry funded training to fill the gap, threatening the quality, validity and objectivity of breastfeeding information made available to health professionals (Rollins et al., 2023; Baker et al., 2023). Cricco-Lizza (2006) found that nursing students had very poor awareness of the WHO international code of marketing of breastmilk substitutes (WHO, 1981) and could not understand how their participation with code violating companies was a conflict of interest.

This was similarly highlighted by some participants in the free text boxes who felt that there was poor awareness of the scope and application of the code.

Undergraduate training

It is important to consider undergraduate training as the first potential exposure to information that may shape practice. Ideally, infant feeding training would be integrated with clinical training, rather than compartmentalised, or seen as an extra. Because feeding decisions impact clinical care and vice versa, professionals need to know how to assess breastfeeding efficacy, as well as support breastfeeding, or the maintenance of lactation when children are receiving clinical care. Yet very few respondents had received at least a whole day of training on breastfeeding, with the majority expected to learn on the job. Yang et al. (2018) found that a common issue is that most health professional students learn from supervising colleagues or mentors in the clinical setting. Given that, a further complication of not being provided with embedded undergraduate breastfeeding training is that breastfeeding education is likely to be influenced by the attitudes of the mentor. A minority of respondents felt that their undergraduate training had adequately prepared them for supporting families on the ward. It may be that the professionals who felt it was adequate work in a clinical area where they do not encounter many breastfeeding children – for example theatre and recovery, but some of the sub-groups were too small to accurately demonstrate this.

On a question relating to the source of any breastfeeding expertise, only a small proportion of respondents cited their undergraduate training as being the source of their knowledge. This could mean that they consider this amount of information satisfactory to support them in their role because they are not often required to support breastfeeding. It could also mean that these professionals are not motivated to either learn more or support breastfeeding, which is partly explained by the correlation between desire to have more training and agreement that supporting breastfeeding goals is part of their job. The sense that undergraduate training is insufficient to prepare clinicians for the practicalities of supporting breastfeeding was echoed in a study by Brzezinski et al. (2018), which similarly found many skill gaps and lack of confidence among paediatric nurse practitioners despite them having a positive attitude towards breastfeeding.

The low rates of provision of breastfeeding training to undergraduate healthcare professional students are unsurprising given the absence of oral infant feeding on any clinical competency but are nevertheless concerning and are likely to be contributing to the widespread lack of confidence among practitioners (Esselmont et al., 2018; Biggs et al., 2020; Baker et al., 2021; Mulcahy et al., 2022).

Credentials, skills, and post-qualification training

In terms of post qualification training, only a small number had extensive breastfeeding training, defined as peer supporter and above, and similarly, very few had accessed 1-3 days of in-person or online training. The majority had not received any training at all in breastfeeding. The more extensive the breastfeeding training, or the higher the credential, the higher the skill score. Breastfeeding credentials provided by different training organisations are varied, with different curricula and inconsistent assessment or accreditation procedures (Dodgson, 2020). It is also recognized that training may be provided by lay breastfeeding counsellors and other nonclinical lactation professionals, but there are no studies that have explored the effectiveness of this training by lay professionals, or indeed joint training (Spiby et al., 2009). The skill sets of clinical and nonclinical lactation supporters are likely to be different, even though they may attend similar lactation training. This is because clinicians' breastfeeding knowledge and how to apply or adapt this to sick children is likely to be augmented by their clinical training and experience. It is therefore important to acknowledge that while many nonclinical lactation professionals provide effective support to lactating mothers, it is unclear currently where *their* skill gaps are.

Both across, and within different disciplines, professionals also have various levels of knowledge, and these inconsistencies cause frustration for families (Blixt et al., 2019). Only 15% of the participants in this study were health care professionals who also held a lactation credential, though the ones that did had consistently higher levels of skill. There is a paucity of research on these dual qualified professionals, but one study found that compared with visiting a paediatrician, parents had more confidence and trust when receiving support from a dual qualified paediatrician and IBCLC (Glassman et al., 2022). Other areas in the UK have established specialist clinics within health visiting and midwifery services that are staffed by

health professionals who are also IBCLCs (Fox et al., 2015; Judd, 2019; Spiro, 2019; Lopez-Bassols et al., 2021). However, extensive breastfeeding training requires significant motivation, time and sometimes finances. For peer supporters and breastfeeding counsellors, there is an expectation of voluntary unpaid work, and IBCLC preparation represents gathering evidence of a significant number of hours of breastfeeding support, which is not always realistic alongside clinical work. Having 1-3 days of training does not increase skill scores as significantly, however, this is likely to be a much more realistic time commitment, and one that is easier to attend alongside busy NHS roles.

Most respondents felt that they needed or would benefit from training, and nearly all the sample felt that different skills were needed to be able to support breastfeeding in the paediatric setting. In the section of the questionnaire asking about what would help professionals support parents better, more people selected specific training relating to sick children than any other intervention. Interestingly, professionals with higher skill scores were more likely to agree that they need or would benefit from training. Indeed, this awareness of the need for training has previously been found among studies of junior doctors (Esselmont et al., 2018) and medical students (Biggs et al., 2020). Despite the clear perception that training would be beneficial, most of the respondents had not asked their manager for training. When asked why, although this revealed some hostile, anti-breastfeeding attitudes, there were also many clinical and practical reasons for not asking for training. The responses suggest that professionals have not asked because the training is not easy to access, pitched at an inappropriate level, not fit for purpose, or hard to prioritise in the face of so many other competing clinical needs. Interesting, in this study, the paediatricians were less likely to feel they needed more training, though there was no evidence that the doctors were more skilled in providing lactation support, and they did not overall have more qualifications in infant feeding. This may be due to cultural perceptions within this professional group, or a recognition that as a doctor, they are less likely to be providing hands-on care, and therefore perhaps do not feel they need more practical training.

A small study in a large children's hospital found that many professionals identified that current training focuses on healthy infants, rather than supporting breastfeeding in complex

cases (Baker et al., 2021). Another study found that there is a lack of practical skills-based training provided to healthcare professionals (Mulcahy et al., 2022). This issue was raised numerous times by the participants of this study, with many pointing out that their knowledge of breastfeeding from their own experience of overcoming challenges had provided more information than that which would be gained from currently available training. While this assumption may be flawed, many professionals highlighted that existing breastfeeding training is focused on establishing breastfeeding in healthy newborns, and others commented that parents are not supported to transition back to breastfeeding after their child has been critically unwell as bottle feeding is seen as a route to faster discharge, or they lack the skills to be able to support this transition. This was backed up in the skills questions where very few reported having lots of experience supporting babies to restart breastfeeding after tube feeding.

Breastfeeding clinical skills

Despite relatively high numbers of professionals having additional training and credentials, there were many skill gaps, and these clinical skills are not currently addressed in mainstream breastfeeding training. While *any* training was associated with having skill scores above the mean, all participants were able to select 'some' experience in terms of their perceived skill, which does not necessarily equate to full competence.

Professionals with more extensive breastfeeding training – defined as peer supporter and above have at least 12 weeks of training, and their combined aggregate skill score is significantly higher than those with 1-3 days of training, or no training. Higher skill scores are also positively correlated with perception of experience and level of confidence at supporting breastfeeding challenges, suggesting that professionals are realistic in their breastfeeding skill self-assessment. Finally, professionals with higher skill scores were more likely to hold positions of additional responsibility for infant feeding. This matches with what we know about the impact of training on skills and downstream positive impacts on families, and it was encouraging to see that those with infant feeding positions of responsibility were more likely to hold additional qualifications to enable them to carry out their role more effectively.

Many studies have previously found that breastfeeding training improves clinical skills and knowledge of health care professionals (Holaday et al., 1999; Cattaneo and Buzzetti, 2001; Durand et al., 2003; Blixt et al., 2014; Colaceci et al., 2017; Boss et al., 2021). One randomised controlled trial found that a 14-minute educational DVD significantly increased professionals' skills in positioning and attachment and hand expressing (Ma et al., 2018). Another study was a follow up to an earlier cohort study (Heilbronner et al., 2017) which found that breastfeeding modification occurred in over 50% of the mothers following hospitalisation for bronchiolitis. To try to reduce the levels of breastfeeding modification, a program of training, as well as investment in more breast pumps and better signage and health promotion posters was implemented. The researchers found that following this program, only 20% of mothers had unwanted breastfeeding modification following discharge from hospital (Gueriba et al., 2021).

More training has been clearly shown to increase skills in a general sense, but no study has so far explored the impact of different levels of training on skills. In this study, different levels of training had a clear impact on subsequent perceived skill. There was more consistency and breadth of skill with higher credentials. The skill scores were higher in the IBCLC group compared to the other groups, yet this was not statistically significant, possibly due to the low numbers of professionals with this credential. The higher skill scores among IBCLCs could be because the combination of their clinical training alongside extensive lactation training with more complex breastfeeding scenarios equips them more substantially. In this sample, it could also be explained by the fact that the only professionals who hold an IBCLC credential were the AHPs and nurses, who are also the most likely to have hands-on experience with families compared with paediatricians and HCAs. However, because the number of IBCLCs in this sample was small, their scores were combined with those of the breastfeeding counsellors and peer supporters.

No significant correlations exist between self-defined level of skill and profession, although some groups such as allied health professionals may be too small to see differences. In this sample, while all the IBCLCs were AHPs and paediatric nurses, at breastfeeding counsellor and peer supporter level training, there were a number of paediatricians as well. The extensively trained professionals were not isolated to one professional group which may

explain why there was no significant difference between perceived skill and profession. There were several comments in the free text boxes specifically suggesting that doctors needed training *most* urgently. However, this was not reflected in this population. While caution is required as this may not be representative of the broader situation on paediatric wards, it suggests that multi-disciplinary learning may be a valid option, as there may not necessarily be a professional group that stands out as being significantly more or less clinically competent with breastfeeding support. It may be fairer to infer that the existing biases, attitudes and opinions of professionals are not wholly attributable to their profession but are likely to be affected by other factors.

In this study, *any* breastfeeding credential or training significantly increases perceived breastfeeding skills above the mean. However, there was no statistically significant difference in skill score between immediately adjacent credential bands, apart from the no credential group. The professionals' perception of their level of experience accurately matched their perceived skill scores, suggesting they were realistic about their level of competence supporting parents. The difference between the professionals who felt they were the most experienced versus the least experienced represents a significant clinical skill shortfall which has the potential to impact the care a breastfeeding family receives on a very practical level. Additionally, these skill gaps are likely to impact children with more serious illness disproportionately since the clinical skill scores were generally lower for more complex lactation challenges. A recent position paper by the European Society for Paediatric and Neonatal Intensive Care (Tume et al., 2020) extensively reviewed the evidence for various aspects of feeding and nutrition for critically ill children in PICU and there is no mention of breastfeeding or breastmilk within the systematic review. The feeding needs of critically ill children are under-researched, and this is also evident within this study. It is particularly notable that breastfeeding competence with critically sick children is lacking because feeding intolerance is known to be a significant problem (Tume and Valla, 2018; Eveleens et al., 2020), as well as both fluid overload (Mitting et al., 2021) and undernutrition (Canning et al., 2021), and human milk may be easier to digest (Bonner et al., 2015; Beck et al., 2019).

Barriers to breastfeeding

There were numerous barriers identified from the sample, and many of them correspond with the results from the systematic review. Again, with this motivated sample, the concern is that the gaps in knowledge and training are likely to be much more widespread and problematic in a more representative sample. Lack of knowledge of how to help was the most commonly selected barrier for professionals, and the need to measure fluid balance was also common. Barriers such as lack of knowledge (Zhang et al., 2018; Snyder et al., 2021), accurate fluid balance management (Bartick et al., 2021), conflicting information (Schmied et al., 2011), inconsistencies with medication advice (McClatchey et al., 2018), time constraints (Swerts et al., 2019), breastfeeding not being a clinical priority (Anstey et al., 2018), and lack of knowledge of wider resources and sources of support (Brzezinski et al., 2018), have previously been highlighted in the literature, though these studies have largely related to the maternity setting. These professional barriers point to a more systemic problem of a fundamental lack of support for breastfeeding.

There is a clear need for both more general knowledge around breastfeeding, as well as some specific clinical teaching – such as how to ensure safe fluid balance and hydration while also prioritising responsive breastfeeding, the safety and compatibility of maternal medication and breastfeeding, and overcoming simple practical breastfeeding challenges such as painful latch.

Interestingly, while most of the participants reported that they knew of helplines and websites to refer to, when they were later asked if they had heard of some specific resources the majority were unfamiliar with them. The professionals' knowledge of websites or helplines to provide to families was significantly correlated with feeling confident to answer any questions. This suggests that those who are most likely to be able to help a family are the most likely to be able to refer families to helplines or websites. Conversely, those with the least confidence are also the least aware of resources to refer a family to for more support. Allied health professionals were the most likely to be aware of sources of support to refer to, and the most likely to know where the breastfeeding policy was, and the HCAs/others were the least aware. In this sample, this may be due to additional training, given that the HCAs/others had the least number of professionals with

additional credentials, and also the fact that allied health professionals such as speech and language therapists and dietitians may be more likely to be involved where there are specific feeding concerns.

Years of post-qualification experience was also associated with knowledge of the breastfeeding policy, which may be related to mandatory training and familiarity with ward protocols and guidelines. However, greater awareness of the existence of the policy did not translate into greater public availability of the policy to families, so awareness does not necessarily demonstrate commitment. It is likely that those who are more invested in breastfeeding have more exposure to sources of information because people who find a topic interesting tend to spend more time learning about it (Tassone and Heck, 1997; Govranos and Newton, 2014; Mukhalalati and Taylor, 2019). Families may thus be falling between skill and knowledge gaps, not only being unable to find the answer to a challenge from their healthcare professional, but also not being provided with a resource or source of more knowledgeable breastfeeding support.

Being able to refer to other sources of support is important, firstly to ensure that families access timely and high-quality support to overcome challenges, and secondly because busy clinicians may not have time to undertake lengthy breastfeeding support. Thus, knowledge of and the ability to refer to other sources is pragmatic. However, the sample was relatively ill-informed about sources of other information and support. For example, very few had heard of the Drugs in Breastmilk factsheets, and even fewer had heard of LactMed, a major international database of drug contraindications specific to breastfeeding. The lack of knowledge of maternal medication and pharmacy confusion was highlighted by several professionals as a barrier in the free text box as well as in wider research. This is an obvious area for awareness-raising and information sharing (McClatchey et al., 2018; Jones, 2019).

The organisation most likely to be familiar to the professionals in the sample was the Baby Friendly Initiative, but it was surprising that less than half the sample had heard of this resource; possibly because BFI standards are not yet embedded in paediatrics and there is no BFI accredited children's ward or hospital. The new BFI children's standards outline a staged accreditation process aiming to improve the standard of breastfeeding support in

paediatrics through training, benchmarking and audit. They were released in late 2022 and are due to be piloted in paediatric settings, but at present, BFI training, accreditation and resources are more well-known in the neonatal and maternity environments. The resources listed – major breastfeeding support charities – are excellent sources of ongoing support for families, with high quality resources available on their websites. The fact that so few professionals are aware of them means that families are potentially not being referred to evidence-based support – which would also be more efficient and would relieve some of the burden and time pressure on hospital staff (Brown, 2016).

The professionals were also asked, based on their experience, to speculate about what the barriers for parents were. In the wider literature, there is very little research on these parent-perceived barriers. Much of what we currently know relates to the challenges and barriers of breastfeeding healthy term infants, or preterm infants in the NICU. Therefore, the challenges cited by the healthcare professionals are distinct from the current literature and are likely to be based on their clinical observations. In this sample, there were some identified differences in the perception of professional and parent barriers by participant profession. This may be related to which professionals are carrying out ongoing care or developing management plans for children on the ward, because HCAs/others identified fewer barriers than either paediatricians or paediatric nurses, and paediatricians identified more barriers than nurses. This could also be explained by paediatricians and paediatric nurses working with children who were more acutely unwell, given that HCAs and the other professionals, which included nursery nurses and play therapists, would not be expected to care for unstable children.

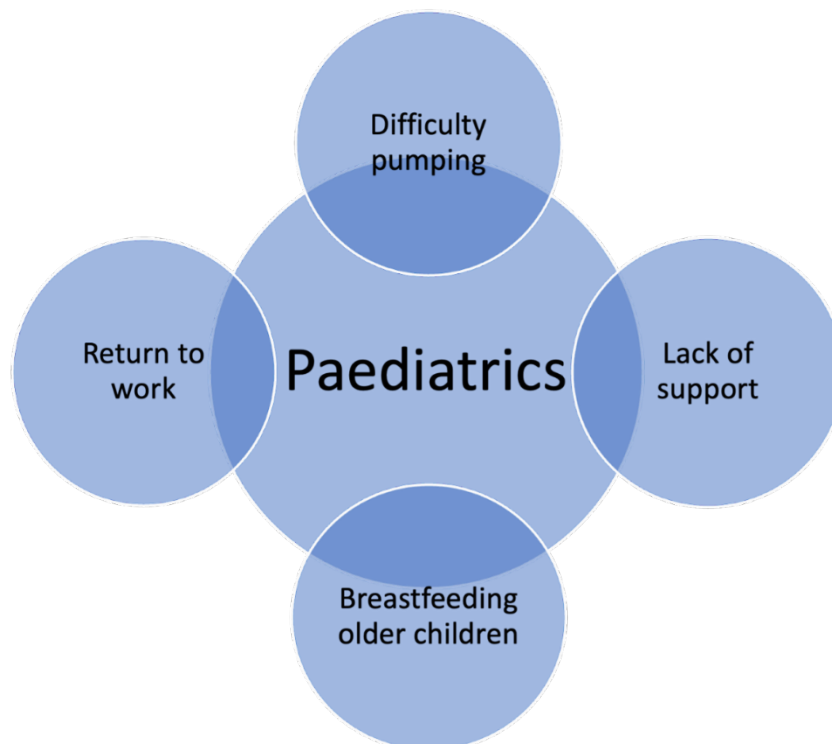
The perception of parent barriers to breastfeeding was negatively correlated with years of experience, which may suggest that as professionals develop more clinical experience, they realise that many of the perceived barriers can be overcome. In healthy term infants, the most cited barriers include perceived or actual low milk supply (Brown et al., 2014; Morrison et al., 2019; Gianni et al., 2019; Moss et al., 2021; Perez-Escamilla et al., 2023), stress after birth in general (Ayers et al., 2019), as well as a sense from mothers that their infant is not satisfied on their milk (Li et al., 2008). Additional barriers often found in studies exploring reasons for breastfeeding cessation include lack of support, including lack of support for

breastfeeding older children (Jackson and Hallam, 2021; Morse and Brown, 2022), difficulties with maintaining milk supply and returning to work (Hornsby et al., 2019; Gianni et al., 2019), and breastfeeding in public (Hauck et al., 2021). There is an increasing amount of literature relating to expressing with some research finding that exclusive pumping is a risk factor for early cessation (Pang et al., 2017), further studies finding that more women wish to know that exclusive pumping is a viable option (Jardine, 2019), and others commenting that pumping can present difficulties of its own (Odom et al., 2013).

Some of these identified barriers among healthy infants may overlap with the challenges of breastfeeding a sick child in paediatrics. For example, the lack of support identified among mothers breastfeeding older children may be directly relevant since there is a paucity of information about the needs of mothers breastfeeding children beyond the age of one, and some evidence that mothers attempt to conceal this - including from healthcare professionals (Thompson et al., 2020; Jackson and Hallam, 2021). Another area of overlap may be the struggles mothers have with combining breastfeeding and returning to work. Some of these difficulties may be similar when they are trying to juggle work and breastfeeding with the additional challenge of their child's hospitalisation and may feed into the conversations around struggling to express milk.

Struggling with expressing is also a common challenge cited by mothers trying to maintain lactation for a preterm infant in the neonatal unit. While many mothers report the NICU as being an environment that encourages breastfeeding (Gianni et al., 2018), many struggle with milk supply or breastfeeding challenges (Kair and Colaizy, 2016; Gianni et al., 2018). Indeed, many mothers in the NICU report feeling intense pressure to produce milk and have strongly negative feelings about pumping despite it being an important way for them to feel a sense of self-efficacy (Brockway et al., 2020). While the challenges of expressing for and breastfeeding both healthy term and preterm infants are very different from breastfeeding sick children of a wider age range, there may be some areas of similarity (see Figure 8).

Figure 8: Areas of overlap between healthy infant, preterm neonate, and paediatric breastfeeding challenges



As illustrated in Figure 8, whilst there may be some areas of overlap there is very little literature that explores whether, and to what extent, these challenges apply to paediatrics, and it is likely that there are many other challenges as yet unidentified. This also has relevance for when neonatal or maternity infant feeding leads see infants on the paediatric ward as a favour to their paediatric colleagues, although this is unresearched. While most paediatric wards do not have a designated infant feeding lead, many of the paediatric professionals reported in the free text boxes that they ask their neonatal or maternity colleagues for support with breastfed patients on the paediatric ward. These areas of overlapping clinical competence mean that the likelihood that a non-paediatric professional has the required skill and experience to effectively support a lactation challenge on the paediatric ward depends on the nature of the child's underlying clinical condition. For example, both midwives and neonatal nurses will have experience supporting sleepy infants and those with jaundice. A neonatal nurse will have experience with respiratory support needs. However, neither midwives nor neonatal nurses necessarily have experience with older infants and toddlers, or indeed many conditions that usually occur beyond the

neonatal period. A useful and logical next step would be to repeat this study with both a nonclinical lactation advocate population, as well as a clinical non-paediatric population, to establish whether these individuals have additional or different areas of skill deficit.

Many of the perceived barriers in this study were not related to the physical challenges of breastfeeding but were mostly about the wider difficulties of maintaining milk production in the context of hospitalisation. For example, lack of support was the most commonly suggested barrier, as well as enteral feeding, fear, lack of privacy and inability to locate a breast pump. Interestingly, in this study, the paediatric nurses were less likely to feel there is enough support for families. This may be because the nursing staff are likely to be providing the most hands-on one-to-one care. Both paediatricians and AHPs have larger caseloads but do not spend as much time with individual families on a shift as nurses, which may affect their perception of how much support is required for families, as well as the knowledge they have about overcoming practical problems.

In the limited, mostly dated literature that exists around hospitalised infants in the paediatric setting, reported barriers include inadequate healthcare professional knowledge. Heilbronner et al. (2017) found that significant barriers to maintaining breastfeeding when a child was admitted with acute bronchiolitis included not being able to stay, needing to look after other children, and advice from health professionals. Other barriers included child critical illness and instability, parent psychological challenges and physical adaptations due to a chronic condition (Lambert and Watters, 1998; Lewis and Kritzing, 2004; Barbas and Kelleher, 2004; Colon et al., 2009; Banta-Wright et al., 2015; Barros da Silva et al., 2019; Madhoun et al., 2020). However, there is very little research exploring these challenges in more depth, and no data on the challenges of breastfeeding sick children beyond the first few weeks.

Ward culture

Cultural and societal influences within the breastfeeding macrosystem are significant (Rollins et al., 2016; Brown, 2021) especially in areas where historically breastfeeding has been under-represented or less well-supported (Leahy Warren et al., 2017). It is known that it is more difficult to overcome breastfeeding problems when there is no surrounding

culture of breastfeeding as this means that many have unrealistic expectations of child behaviour and feeding, and it is harder to continue to breastfeed with inadequate support (Scott and Mostyn, 2003). Other studies have demonstrated that a cultural shift is needed (Christopher and Krell, 2014) in order to build a supportive community that values breastfeeding (Brown et al., 2011). This is particularly important when mothers continue to breastfeed beyond the first few weeks, as it is known that mothers encounter more negativity with longer durations of breastfeeding, and healthcare professionals in this situation should accept and promote the normality of longer-term breastfeeding (Dowling and Brown, 2013).

In terms of the culture of the paediatric ward there is very little research. However, there are many studies of healthcare professional attitudes towards breastfeeding, and some literature points towards the impact of personally held beliefs on patient interactions (Taveras, 2004; Sattari et al., 2013; Yang et al., 2018; Michaud-Letourneau et al., 2022; Stoliar et al., 2022). Negative personal experiences can lead to a denial of the positive aspects of breastfeeding which may be evident in healthcare professionals' interactions with parents (Azad et al., 2021). Equally, a positive attitude can be a supportive influence on a mother's feeding experience, though this may not compensate for lack of knowledge (Brzezinski et al., 2018). From a clinical perspective whether a parent encounters a positive or negative culture of breastfeeding on the ward remains something of a postcode lottery, and their experience is additionally impacted by external factors outside the hospital's influence, such as intrinsic motivation to breastfeed, and wider sources of support.

In this study, several questions were asked that attempted to gain a sense of ward culture, as this has not been widely explored. Part of the rationale for these questions was that the study was anticipated to have an over-representation of breastfeeding advocates. However, anecdotally, these advocates are often isolated, and their views may not be widely held by their colleagues across the entire department. This means that families on the ward are likely to have a mixed experience depending on who they see. Additionally, feeling like a lone advocate within a generally unsupportive culture is likely to have a negative impact on the wellbeing of those professionals (Brown, 2022). The question that was excluded from the ward culture combined score asked professionals how much they agreed that they were

one of just a few people who advocate for breastfeeding on their unit; this was to separate their personal breastfeeding attitude from the wider attitudes of the ward. About half the sample indicated that they agreed they were one of just a few breastfeeding advocates, potentially because this was a motivated sample. This may mean that some professionals feel like they are alone or unsupported by colleagues in their unit. Anecdotally, many breastfeeding advocates feel demoralised by the sense that they alone speak up for breastfeeding families within a wider, less supportive culture.

Six ward culture descriptors were combined to give an aggregate ward culture score out of 30 and very few of the 340 departments represented received a score at the extremes of positive or negative culture. Most of the units represented by the participants could therefore have some improvement in terms of positive culture and attitudes towards breastfeeding support. In this sample, there was no difference in perceived ward culture between professional groups or years of post-qualification experience. However, identification of more barriers was strongly associated with lower perceived positive ward culture. This may suggest that the barriers identified on a particular ward are an intrinsic part of a less supportive ward culture, whereas an environment where there is a more positive culture of breastfeeding support may be one where barriers are reduced or overcome. Having an improvement in the general support on the ward or unit is likely to have a positive impact on the experiences of families who are hospitalised, though attitude and culture alone will not be enough to overcome some of the hypothesised clinical lactation challenges experienced by sick children.

4.5 Limitations

There were several limitations of this study. Firstly, this study recruited healthcare professionals via an online advert. This method was chosen as it was the most practical option during the Covid pandemic and was also a simple way to reach a large sample of professionals from around the UK. Nevertheless, there are inherent problems with studies that recruit participants in this way – namely that only those most interested were likely to have been invested to take part, leading to an over-representation of breastfeeding advocates. However, although this was a sample skewed towards those who were more

likely to be more experienced and supportive of breastfeeding, self-defined levels of skill were still generally low, which highlights a major gap within paediatrics and a risk for breastfeeding families. The second major limitation of this method of recruitment is that only those with the time to complete the survey would have taken part. Thirdly, those with internet access and who are active on social media would have been more likely to have seen the advert. This was mitigated somewhat by sending the survey to several academic and clinical leads to disseminate, but it is still likely that busy and less motivated professionals would have been less likely to complete the survey. These limitations were acknowledged and anticipated in the design of the survey, which was why there were several questions alluding to the wider issues within the unit or ward.

Another limitation is the lack of quantification of level of experience with certain clinical skills. Asking professionals whether they had 'some' or 'lots' of experience was a deliberate use of language chosen to avoid professionals being put off answering through feeling embarrassed or unsure. It is also impossible to accurately quantify these skills without a practical skills test or in-depth individual audit, so this study was not an attempt to gauge accurate levels of skills, as this would have been beyond the scope of this PhD candidacy. Thus, the use of the words 'some', and 'lots' were provided for participants to choose between. While these words are subjective, they are also non-threatening, and the completion rate of these questions was high. The usefulness of this question is increased by further questions that have, in combination, suggested that participants were generally honest about their abilities. However, future studies should attempt to quantify this with more objective accuracy.

Finally, not all the data is complete, due to some professionals exiting the survey before completing it or omitting questions. This may have been due to time constraints, bias or antagonism towards the subject matter, or other individual reasons. One of the problems with online research is that the researcher is unable to prompt the participant, ask for clarification or encourage them (Bowling, 2014; Ponto, 2015), but on balance, with controversial topics, online research may enhance the acceptability of the questions because of anonymity.

4.6 Conclusion

In terms of what is important to families, we know that they need timely, accurate support to deal with challenges that arise, and this may sometimes involve support outside the NHS (Brown, 2016). Parents also desire individualised support based on their individual needs (Blixt et al., 2019). The findings of this study suggest that breastfeeding skills are patchy and inconsistent, and particularly lacking in more complex clinical scenarios. This is significant, because it may mean that children who have more serious or complex illness are disproportionately affected by gaps in knowledge and skill. These potential skill gaps may be explained by the fact that in general, most health professionals defer to their personal experience when trying to answer questions about breastfeeding challenges, and the currently available training is focused on healthy term infants.

When a breastfed child and their mother are admitted to the paediatric ward, there are many factors which may influence the success of their breastfeeding journey:

- How well-established breastfeeding is
- Underlying maternal factors influencing milk supply, as well as their ability to express milk if needed due to the child's condition
- Whether and to what extent the child's illness impacts breastfeeding
- Whether there is a supportive culture and positive attitude towards breastfeeding
- Whether the staff know how to overcome particular breastfeeding challenges
- Whether they know about sources of support or further resources to refer to

This study has found that there is considerable room for improvement in staff skill and ward culture. Despite this being a relatively invested sample, there was evidence of some antagonism towards breastfeeding, and many professionals not only did not know how to support families with lactation challenges, but also did not know to whom they could refer.

This study highlighted several areas that influenced the sample selection and questions asked in Study 2. This integration of quantitative and qualitative data is needed at the design stage in addition to the analysis to ensure that the phases are connected and related (Ivankova et al., 2006). Hence, when designing the qualitative study, firstly, given that the general skill levels were lacking, it was important to recruit parents of children with a wide variety of illnesses who may need a range of clinical feeding support. Secondly, many professionals suggested that their lack of skill in supporting breastfeeding was not a significant problem because they could refer to maternity and neonatal infant feeding teams. It was therefore relevant to find out whether this is happening, and also whether this is found to be helpful. Thirdly, while there was relatively little hostility demonstrated in this sample, it was suspected that true levels of both hostility and ambivalence may be higher in the general population of paediatric professionals; therefore, this was important to ascertain from parents. Fourthly, the awareness of resources and information was low, so parents were asked specifically whether they were provided with any adjunct sources of support. Purposive sampling in this way ensured that a spread of illness was represented, and the issues and challenges raised in this study could be confirmed, elaborated on, or refuted by triangulating with the qualitative study. The next stage of the research was therefore designed to explore the child's micro and mesosystems to establish how gaps in lactation knowledge within paediatrics affect the downstream provision of support and thus parent experiences, and whether and to what extent these lived experiences matched the perceptions of parent barriers held by professionals. The next chapter will present the findings from a qualitative study of UK mothers of breastfed medically complex children.

Chapter 5

Breastfeeding Sick Children in Hospital: Exploring the experiences of mothers breastfeeding their medically complex child in the paediatric setting

Publication: 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(2), e13489. <https://doi.org/10.1111/mcn.13489>

This research has also been presented at six international conferences:

1. Neonatal Infant Feeding Network, October 2021, and March 2022
2. The London School of Speech Therapists, March 2022
3. Maternal and Infant Nutrition and Nurture conference, April 2023
4. La Leche League, Italy, April 2023

The previous chapter presented a national survey of paediatric healthcare professionals exploring their skills, training and attitudes towards supporting breastfeeding. The survey sought to understand some of the issues and challenges mostly at the exosystem and macrosystem levels of the medically complex child, though it also asked professionals for their opinion about what some of the challenges and barriers at individual levels could be. This chapter details the study that followed, aiming to fill in some of the missing knowledge of the child's ecological system at the individual level, as well as add rigour through triangulating the results against parents' experiences.

5.1 Introduction

While the importance of breastfeeding is well understood in terms of maternal and child health, there is very little research exploring how and why it is harder to breastfeed medically complex infants and children. Around half a million children under the age of four years are admitted to hospital every year in the UK (Keeble and Kossarova, 2017). Given that the World Health Organisation (2018) recommends exclusive breastfeeding for the first 6

months and then alongside complementary foods for the first 2 years and beyond, there is clearly a large gap in the literature. Admissions to the paediatric setting – whether a general ward, PICU, specialist ward or day surgery will include children with a variety of illnesses and conditions. One study found that breastfeeding was severely negatively impacted by admission to the ward with acute bronchiolitis (Heilbronner et al., 2017). There is, therefore, some limited evidence that breastfeeding may be more challenging or difficult to achieve, when children have a disability, condition or illness; but there are very few general studies that explore in depth why this is, or the impact of this on mothers and families.

It is possible that mothers of medically complex children experience different challenges and need a different type of support to initiate or maintain breastfeeding that is tailored to the needs of their child. Because of the different challenges, lack of training for staff (Dykes, 2006; Holaday et al., 1999; McLaughlin et al., 2011; Gupta et al., 2019), and lack of widespread acceptance of breastfeeding in the paediatric setting, it is likely that mothers may have unique experiences of breastfeeding on the paediatric ward or PICU.

The systematic review found seven themes relating to the difficulties experienced by mothers breastfeeding their medically complex children. These were:

1. Practical problems relating to breast care, associated with reduced, ineffective or absent feeding, such as blocked ducts, mastitis, fullness, and milk supply problems.
2. Psychological problems relating to logistics of managing a hospital admission, alongside work, other children at home, and being resident in hospital overnight.
3. Infant/child critical illness or instability meaning that they were unable to breastfeed due to respiratory distress, ventilation, or intensive care.
4. Infant/child chronic conditions that necessitated adaptations to breastfeeding due to anatomical challenges, milk absorption or metabolism problems or difficulties related to positioning due to injury, medical intervention, or equipment.

5. Lack of specific lactation support because paediatrics is a separate directorate to the postnatal ward and neonatal units where there is usually better provision of lactation supporters and services. It is also difficult for mothers to access their usual community lactation support services due to being resident in hospital.
6. Lack of skilled support for lactation and encouragement to maintain breastfeeding through a child's illness by health care professionals, in part due to lack of training, policy and paediatric baby friendly standards.
7. Inadequate provision of, and training to use equipment necessary to support the maintenance of lactation through child medical complexity – such as breast pumps, and specialised feeding equipment.

The seven themes highlighted multiple potential problems at every level of the medically complex breastfed child's ecosystem and thus form an integral part of the overall design of the research studies, which aim to explore, clarify and provide guidance and next steps for the development of policy to improve care for mother-child dyads in the paediatric setting.

Objectives

The intention was for this research study to provide rich insight into the experiences and challenges of mothers of medically complex breastfed infants and children. This in turn will facilitate the generation of more user-friendly recommendations to support lactation in the paediatric clinical setting and bring about practice change. Along with the results from the quantitative study, areas for future training in order to improve outcomes and experiences for families will be identified. The data will also enable recommendations for policy, and changes to facilities and resources for families.

As a relatively under-studied area of lactation support, there are many unanswered questions that justified the need for this research study. The study was designed to build on the healthcare professional survey, in order to expand on RQ3, and answer RQ4 and RQ5:

- RQ3. What are the barriers to providing lactation support that meets the needs of families?

RQ4. What is the importance and meaning of breastfeeding when a child is sick or medically complex?

RQ5. What are the breastfeeding challenges of medically complex children in the paediatric setting?

RQ3 was partially answered by Study 1, but in that study, professionals were asked to give their views on what they perceived to be parent barriers. Therefore, one aim was to find out from mothers whether the professional perceptions matched their lived reality. To answer RQ4, questions were asked to draw out some of the intrinsic motivations of mothers who persevere with breastfeeding through medical complexity. Finally, to address RQ5, the mothers were asked about the clinical lactation challenges they encountered while admitted to the paediatric ward or PICU. It was also important to separate the lactation challenges from the more institutional barriers, as well as supportive interventions, to find out where changes to practice and training could make a positive impact for families. Thus, this study primarily focused on individual challenges at the child's microsystem, as well as complexities that influenced their mesosystem. However, it also sought to explore wider challenges that are related to the child's exosystem, such as ward culture and staff knowledge, and factors at the macrosystem level, such as attitudes and policies.

5.2 Methodology

The health care professional survey was the first phase of an explanatory sequential approach and identified that most professionals felt that they needed training in breastfeeding, and that families do not generally have a good experience on their unit in terms of support for breastfeeding outcome. This qualitative study was thus informed by the systematic review and the quantitative study and aimed to confirm, refute, explain, or expand on the findings from the national survey. It was particularly important to establish whether there was congruence between the perceptions of barriers for parents and health professionals, as well as the importance and meaning of breastfeeding to them.

Study design

This was a national online study utilising semi-structured interviews. While an in-person study was considered, it was found to be impractical due to the challenge of accessing hospital departments during the Covid-19 pandemic. The second reason for the decision to interview mothers remotely is that breastfeeding rates vary nationwide, and some areas have much lower rates of breastfeeding, which makes it more challenging to recruit a large enough sample. Different hospitals have different attitudes to breastfeeding support, and varying conditions and lengths of hospital admission are likely to be associated with distinct breastfeeding challenges. Previous studies have focused mostly on single conditions, often in one hospital; so one of the advantages of recruiting participants for this study online – especially with a very large social media following - was a geographically varied sample to generate meaningful data.

Another reason for this approach is that much breastfeeding research so far has found a predominance of mothers who are white and have higher socio-economic status. A large study of 167,842 infants found significantly higher levels of breastfeeding among white mothers (Li et al., 2019). This may, in tandem, partly relate to the fact that women who have higher levels of education are more likely to breastfeed (Sarki et al., 2019). Isherwood et al. (2018) refer to the differences in breastfeeding rates between areas of high income and low income as the 'local landscapes of breastfeeding', highlighting the inequalities in breastfeeding rates in an urban area with neighbourhood variations of wealth. Smith (2018) argues that social injustices such as racial and gender inequality, poverty and violence, as well as inequitable systems and structures work to position breastfeeding as a parenting practice of privilege, and that these injustices must be addressed to support non-white parents to achieve their breastfeeding goals. Other research has found generally lower rates of breastfeeding among Black, Asian and Indigenous populations despite equally high levels of intention to breastfeed and suggests that there may be different barriers and disadvantages including racism and discrimination that need to be overcome in order to meet their breastfeeding goals (Hamner et al., 2021). Hospital treatment of breastfeeding mothers also appears to differ by race (Sipsma et al., 2019), suggesting that for some women the barriers to achieving their breastfeeding goals are iatrogenic, which is very relevant to this study. For this reason, it was postulated that if breastfeeding is challenging

for white mothers of medically complex children, there may be *additional* or different challenges affecting Black, Asian and Indigenous mothers, as well as mothers from lower socio-economic backgrounds. Therefore, recruiting from different areas, including areas with more socio-economic and/or racial diversity was important for this study to improve the generalisability of any findings to a wider population.

Participants

The study was targeted at mothers breastfeeding or providing breastmilk – either exclusively or partially – to their medically complex child, either through direct breastfeeding, or expressing and providing breastmilk via tube, bottle or specialised feeding device. The study explored experiences in the paediatric setting only, as there is already plentiful literature and policy provision in the neonatal unit (Maastrup et al., 2019). The study was particularly geared towards the effect of hospital admission on breastfeeding choices, outcomes and management, so mothers of children solely treated in the emergency department, day surgery, or outpatients were ineligible to participate, as their experiences of a brief/transient visit to hospital may be different to those who are admitted overnight. Mothers whose child was previously a patient in the neonatal unit were also excluded, because neonatal units have a greater degree of support for, and expectation of breastfeeding, and neonatal and paediatric units are organisationally separate. The support mothers receive in the neonatal unit might therefore influence and buffer some of their choices when their child is hospitalised in the paediatric setting.

Mothers were eligible if their child had been hospitalised within the last 6 months. This was to allow for a time lag from the completion of the screening questionnaire to data collection, to minimise recall bias. However, it was also recognised that some mothers may not wish to discuss their child's admission immediately after discharge due to a traumatic experience, so allowing this time enabled them to reflect on their experience prior to interview.

There were no specific criteria for the type of child illness or level of medical complexity because this study aimed to explore general experiences that are not necessarily related to the specific condition. Previous research has found that severity of illness is not necessarily

related to breastfeeding outcome (Heilbronner et al., 2017), so the study aimed to explore what aspects of hospital admission and care make breastfeeding more challenging. Mothers of children who were not expected to recover or receiving palliative care were not excluded if they wished to take part, but this situation did not arise.

There were also no age specifications for the breastfed child, as breastfeeding is recognised to have a variable duration, and by giving an age range for the study, this might have inadvertently suggested that breastfeeding is only appropriate until a certain age, or that challenges with breastfeeding are only meaningful until a certain age. It was important to gather experiences from mothers of children at varying ages, as different challenges are more common at different ages, and sometimes mothers have experienced more hostility when breastfeeding an older child.

Mothers who had previously breastfed their sick child but were not currently breastfeeding were excluded because decision-making about breastfeeding duration and exclusivity is not limited to hospital experience and medical complexity (Matthews et al., 1998; Scott and Colin, 2002). The reasons for breastfeeding cessation outside of those that are iatrogenic or related to illness, while important and meaningful, were not relevant to this study.

However, mothers who had stopped breastfeeding while their child was an inpatient on a recent admission were eligible for inclusion if they consented to take part; as were mothers who had chosen to relactate for their child after a period of cessation of breastfeeding, as these decisions may be related to the child's illness. In the final sample, there were two mothers who had stopped breastfeeding during their last hospital admission as a direct result of breastfeeding management or their child's condition, and one mother who relactated after a period of exclusive formula feeding on medical advice.

The intended sample size was 20-30 mothers. After interviewing 15 mothers, the decision was made to interview a further 15 as some of the early interviews included children who had only been admitted to hospital for a short duration, and more diversity of experiences was desired. A sample size of 30 is within the commonly cited range for qualitative research (Moser and Korstjens, 2018) and was felt to generate sufficient detail in relation to the topic of study, based on participants having high levels of information power (Malterud et al.,

2016). The choice of semi-structured interviews allowed for in-depth discussion and exploration of the issues, within a diverse range of families dealing with a variety of medical challenges, different ages of children, and different ethnicities.

Ethical approval for the study was granted by the Swansea University School of Health and Social Care Ethics Committee. All participants gave consent prior to completing the online screening questionnaire and then verbal consent was given prior to the interviews of selected participants. Ethical considerations were made with respect to the principles for research on human subjects as outlined in the Declaration of Helsinki (WMA, 2004). All participants were provided with information about the study, informed of their anonymity and secure storage of their data and had the opportunity to ask questions prior to taking part.

Recruitment procedure

Participants were recruited via an online advert which was shared several hundred times on social media, in numerous breastfeeding support groups, national organisations and on several large social media pages. The researcher and supervisor both have significant social media followings across Facebook, Instagram and Twitter and numerous professional contacts in the related field of research so a large reach was achieved quickly. Mothers self-identified through the recruitment poster and 849 people responded to the online advert within 48 hours. Interested mothers were invited to complete a brief initial screening questionnaire (Appendix 7); and from these questionnaires a sample was chosen to achieve a mix of different levels of paediatric service provision, conditions, racial and socio-economic diversity. Those not selected for interview were all contacted individually, thanked for their time and informed that they had not been selected.

By clicking the advert, they were taken to a survey hosted on Qualtrics which provided information about the study and eligibility criteria. Contact details for the researcher and supervisor were provided, and after completion of the brief questionnaire a thank you page with resources and useful sources of further support and information loaded. Only 504 completed enough of the screening questionnaire, which gathered basic demographic data, to be considered for interview. 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; Milano et al., 2019; Green and Resnick, 2021). 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.

Using this approach, a sample of mothers was initially selected, representing a broad range of childhood illness and duration of hospitalisation, and the remainder of the 849 applicants were all individually informed that they had not been selected and thanked for their time. After the first 15 interviews, a further 17 were invited to participate, two of whom did not attend at the agreed time. The interviewed participants were all given a £20 voucher as a token of appreciation for their time.

Measures

The interview prompt guide (Appendix 6) was developed after asking several mothers in the Facebook support group *Breastfeeding the Brave* about the acceptability of such a study, and what they would have liked to be asked when they were resident with their children in hospital. A total of 21 mothers responded, all positively (Figure 9).

Figure 9: Sample of study feedback comments

"I would have absolutely spoken to you. But... probably giving lots of notice and a heads up to the questions first may have helped those difficult times when the simplest request seems challenging."

"Breastfeeding mums are not the norm in the hospital environment, and anyone paying attention to us, and interested in our experience is welcome. "

"My daughter is an oncology patient, and I would have loved to be able to talk to someone about breastfeeding through the toughest time ever."

"My daughter suffers from very severe and complex pain, and I have been involved in a research study looking at pain in paediatric palliative care and have found it so nurturing for me. I felt less alone and would say it's been a very positive experience."

"I have been in since last week and would have happily spoken to someone, in fact would have loved a chat as you go a bit stir crazy in these places. However, on Monday we were told our baby only had hours left to live so if you had come at the wrong time, you might not have got the same response from me. Thankfully my daughter is still here, and we have actually been discharged!"

Summary of key points that were identified by parents, which shaped the objectives and interview prompt:

- Mothers identified that talking about their child may make them tearful.
- Some mothers suggested that advanced notice may be helpful – to allow them to mentally prepare, but also to manage any procedures that their child is due.
- A few mothers said that having the questions in advance would be beneficial – so a list of the broad areas of discussion was provided to participants.
- Many mothers mentioned that being listened to was important. This may be because the focus is often on their child, or it could be that they feel breastfeeding is undervalued.
- One mother of a child whose condition was palliative discussed how being part of a research project was nurturing for her as a parent.

- Several mothers felt that being interviewed about something that was meaningful to them would alleviate the sense of isolation they felt on the ward.
- Two mothers whose children were critically unwell with conditions that had a sudden onset mentioned the rapidly changing clinical situations that their children were experiencing and being willing to be flexible about timing.
- Many mothers said that talking to someone who shared an understanding of the importance of breastfeeding would be a welcome change as they felt that it was largely unnoticed or sometimes dismissed.
- Several mothers identified that being interviewed about breastfeeding their children would leave them feeling validated. This might be due to the relatively little support or encouragement they receive.

It was also decided to pilot the interview questions to ensure that firstly the questions were acceptable to the mothers, and secondly that they elicited meaningful answers. A mother who was ineligible for the study due to the length of time that had elapsed since her child's discharge was interviewed and her feedback about the process was positive. However, some additional questions related to bedsharing were reworded on the interview prompt sheet as a result of this pilot interview.

Participants completed an 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.
2. Confirmation of eligibility for the study: participants had to confirm they were the mother 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.
3. 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.

From these responses, a sample was chosen to give a range of conditions, socio-economic and ethnic diversity and length of admission. From the stated condition and length of admission it was possible to gauge the severity of illness in some cases – for example, a child who was admitted with fever for one night was assumed to have had a milder condition than a child who was admitted due to sepsis for 14+ nights. This information proved reliable in terms of obtaining a clinically diverse sample.

The selected participants were then invited via email to an interview hosted on Zoom. The interview prompt sheet included some closed and several open-ended questions, but the participants were encouraged to tell their story in the way they wished. Prompts were used only to expand certain details, provide clarification or fill in important missing information. Examples of the questions can be seen in Table 29.

Table 29: Closed and open questions on interview prompt sheet, and how these related to the ecological systems theory model

Closed questions	Layer of the ecological systems model
Have you previously breastfed a child?	Microsystem
Do you feel like breastfeeding was valued on the ward?	Exosystem/Macrosystem
Have you been provided with food and drinks on the ward?	Exosystem
Did you have the privacy you needed?	Mesosystem/Exosystem
Do you feel the staff had enough knowledge to be able to support breastfeeding?	Exosystem
Were you given any websites, helplines, leaflets or specific information to support you to reach your breastfeeding goals?	Exosystem/Microsystem
Have you had enough emotional support while your child was struggling to feed?	Mesosystem/Exosystem

Open questions	Layer of the ecological systems model
Can you tell me about your child's condition?	Microsystem
How has your child's illness affected their feeding?	Microsystem
What support have you needed for breastfeeding while your child has been unwell?	Mesosystem/Exosystem
Has the importance or meaning of breastfeeding changed for you since your child has been unwell?	Microsystem/Mesosystem
How have you felt supported by the staff in hospital?	Mesosystem/Exosystem
Can you tell me about the facilities available in hospital, such as pumps?	Exosystem

The questions were developed from themes that were identified in the systematic review – such as psychological challenges, the specific difficulties of breastfeeding a child with more complex needs, lack of specific lactation support, inadequate healthcare professional support, and scarce resources such as pumps. The health professional survey also suggested that professionals themselves can identify their lack of knowledge and need for training, and many of them felt that parent-related barriers to breastfeeding included stress and lack of support. The questions were therefore designed to increase the validity of those findings through triangulation between the two studies (Carter et al., 2014).

Data Analysis

After data collection, the interviews were transcribed verbatim, identifying features redacted and real names replaced with pseudonyms. The transcriptions were then 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. While software such as NVivo to organise and manage analysis was considered, due to researcher preference, this was not utilised. Subthemes and larger overarching themes were developed from these inductively developed codes (Braun and

Clarke, 2022). During the process of coding, the ecological systems model provided a framework in which to contextually situate each of the identified themes and subthemes to better understand how the identified challenges affect breastfeeding at individual, community, ward and societal levels.

Saldaña, (2014) asserts that themes are outcomes from the process of coding, allowing patterns of similar observations to be amalgamated and organised to better understand their meaning. Themes may capture an abstract idea or concept but can usually be evidenced with specific data in the form of participant quotations. Through the process of developing themes, larger portions of data can be summarised into their inherent meaning. This approach to coding allowed for this relatively new phenomenon to be explained in the parent’s own words and with the meaning of their words intact (Sandelowski, 2000); or in other words, produce an analysis that is an accurate representation of the data (Sandelowski, 2010). See table 30 for an example of how the subthemes and themes were generated.

Table 30: Example of how themes were developed from raw data

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

Thematic analysis is a method that allows for identification and reporting of themes in a data set and follows a six-phase process – dataset familiarisation, coding, theme generation, theme development, theme refining and naming, and writing up (Braun and Clark, 2006).

There are several approaches to thematic analysis; Braun and Clark (2021) are clear in their

assertion that thematic analysis is not atheoretical, and lack of understanding of the precise method of thematic analysis can lead to a confusing mix of approaches to analysis. Reflexive thematic analysis can be understood as a method of analysis that positions the researcher with their acquired experience and knowledge, as a co-creator with the participant. In this way the background position of the researcher is not viewed as bias to be minimised but is an inherent strength of the resulting data (Gough and Madill, 2012). One of the features of reflexive thematic analysis is that single researchers usually develop codes, as the idea that another researcher with a different background could strengthen the development of codes is inherently a flawed concept (Braun and Clark, 2022).

One of the aims of this research is to better understand the challenges breastfeeding mothers face, to make recommendations to address various identified difficulties, and therefore reduce some of the systemic barriers to breastfeeding sick children in hospital. Therefore, although Braun and Clark (2022) argue strongly for avoiding counting responses to report theme frequency, in this analysis it was felt that flexibility was required. The argument against quantifying qualitative data in this way is that it misunderstands the purpose of qualitative research, and each incidence of that code or theme may be context-specific, fleeting and not comparable. In this case it could be argued that the experiences of just one person are meaningful and significant and having more participants concurring does not necessarily strengthen the argument. However, concurrence is relevant in this study because it represented thirty different hospitals. The fact that experiences are shared across multiple sites suggests that these experiences are not isolated to one rogue encounter or hospital environment but are more systemic. Furthermore, when the codes were developed, many of the mothers were not describing feelings or situations that were transient. They clearly and articulately expressed strong emotions, some of which they had held for many months, and the challenges they described were also often concrete, specific and distinct. For these reasons it was decided to include information about the frequency that the mothers were reporting certain themes as this may add weight to any recommendations made for improvements to care. This approach to analysis will allow the concepts and themes of the mothers' stories to be more focused and useful for making recommendations to practice (Denscombe, 2014) which will make the output of this research more applicable and user friendly in practice.

Trustworthiness and rigour

There are several 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 reported (Lincoln and Guba, 1985; Green and Thorogood, 2006) and 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, or credibility, of an interpretation of qualitative research is contestable as truths are held to be socially constructed and are not necessarily a fixed reality. However, there are other aspects of validity in this type of research that 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, rather than only including the most interesting or powerful quotes. Another approach, which is controversial in reflexive thematic analysis, is to count the number of responses. As previously stated, there were many carefully considered reasons why this approach was eventually included in the analysis.

The reliability, or dependability, of the interpretation refers to the likelihood that the results would be repeated. Again, this is a contested landscape in reflexive thematic analysis as the researcher and their experience are integral to the co-creation of the codes. However, there are certain features of this study that do increase the reliability, such as various aspects of good practice in fieldwork – including note taking, accurate transcription, and discussing coding with the supervisory team as the codes and themes were generated.

The comparability refers to the ability we have to compare cases to look for similarities and differences within the data set. Comparisons have been tentatively made with this analysis, though this is deliberately cautious, and with reference to the uniqueness of the experiences of the participants in the study. Other qualitative researchers also refer to generalisability or transferability which 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 (Polit and Beck, 2010). Furthermore, some pragmatism is required when conducting research that may inform health and social policy and it is recognised, with caution, that some concepts may be relevant beyond a specific setting; and some believe that reflexive thematic analysis may be softly generalisable (Braun and Clark, 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.

5.3 Results

Thirty mothers were interviewed over Zoom, with each conversation lasting approximately an hour. After the data collection period, the interviews were transcribed verbatim, identifying features were redacted and real names replaced with pseudonyms using a random name generator app. The researcher immersed themselves in the transcripts and a reflexive thematic analysis was undertaken. The study analysis focuses on exploring the experiences and views of mothers breastfeeding their sick or medically complex 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. The mothers are briefly summarised in Table 31. There were two children whose conditions were so rare that naming them could potentially have identified them, so their diagnoses are deliberately vague.

Table 31: Summary of participants

Pseudonym	Demographic details	Child's current age	Breastfeeding status	Child's condition	Length of last hospital admission
Maria	Married Postgraduate education Mixed race	18 months	BF + solids	Croup	2 days (6 months prior)
Nicky	Married Higher education White	30 months	NG fed formula, BF + solids	Rare form of cancer	14+ days (2 days prior)
Maha	Married Higher education Asian	16 months	BF + solids	Fever	1 day (6 months prior)
Anna	Married Higher education White	27 months	NG fed formula + BF (no solids)	Complex feeding difficulty	14+ days (1 week prior)
Bex	Married High school education White	20 months	BF + solids	Multiple infections, numerous frequent admissions	5 days (2 weeks prior)
Sila	Single NVQ education White	36 months	BF + solids	Chronic wheeze	2 days (1 month prior)
Karin	Married Higher education White	13 months	BF + solids	Supraventricular tachycardia	10 days (5 months prior)
Cintia	Single Higher education Mixed race	14 months	BF + solids	Bronchiolitis	1 day (4 months prior)
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 (2 weeks prior)
Samira	Married Postgraduate education Mixed race	3 months	Exclusive BF	Urinary tract infection	5 days (2 months prior)

Ashley	Married Higher education Asian	5 months	Exclusive BF	Skin infection	2 days (4 months prior)
Judith	Married Higher education White	24 months	PEG, BF + solids	Complex, rare bowel condition + unilateral vocal cord palsy	14+ days (2 weeks prior)
Shayla	Married Higher education White	24 months	NG when ill, BF + solids	Bronchotracheo laryngomalacia + iatrogenic withdrawal	14+ days (6 months prior)
Lyra	Single Higher education White	36 months	BF + solids	Immunodeficiency (Low IgA – unknown cause)	10 days (1 month prior)
Bridget	Married Higher education Mixed race	9 months	BF + solids	Intussusception	5 days (5 months prior)
Alana	Single NVQ education White	18 months	NG fed formula + BF (no solids)	Sensory food aversion, seizures +? Autistic	4 days (1 week prior)
Tova	Married Postgraduate education Mixed race	9 months	BF + solids	Norovirus	1 day (5 months prior)
Jan	Married Higher education Asian	24 months	Stopped BF during last admission	Anorectal malformation	10 days (6 months prior)
Alissa	Married Postgraduate education White	5 months	NG fed EBM when ill + BF	Broncholaryngeomalacia + vocal cord paresis	8 days (1 month prior)
Georgie	Married Higher education Chinese	3 months	Exclusive BF	Viral meningitis	1 day (2 months prior)
Molly	Married Postgraduate education White	12 months	NG formula/EBM when ill + BF and solids	Pneumonia	5 days (6 months prior)
Lucy	Married Postgraduate education Mixed race	11 months	BF + solids	Meningitis + urinary tract infection	4 days (3 months prior)

Ruth	Married High school education Disability White	34 months	NG fed formula + BF (minimal solids)	Acute lymphoblastic leukaemia (regimen C)	14+ days (1 week prior)
Tamsin	Single High school education Disability Homeless White	2 months	Exclusive BF	Jaundice, safeguarding	3 days (2 weeks prior)
Sophie	Married Higher education Asian	4 months	Exclusive BF	Jaundice	2 days (4 months prior)
Nephele	Married Higher education Asian	17 months	BF + solids	Inhaled foreign body	1 day (5 months prior)
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 (6 months prior)
Marsha	Married Higher education White	16 months	BF + solids	Transverse myelitis	14+ days (4 months prior)
Kayla	Married Higher education White	12 months	NG fed EBM, BF + solids	Complex cardiac + bilateral vocal cord palsy	14+ days (6 months prior)
Ali	Married Higher education Asian	3 months	Exclusive BF	Fever	4 days (2 months prior)

The mean maternal age was 32.3 years with a range of 19-40 years, and the mean child age was 15.3 months with a range of 2-36 months. The age of the child at the time of interview in some cases differed from the age they were at the time of their last admission. In some cases, up to six months had elapsed since their last or only admission to hospital, while other children were discharged just days before the interview. Since there was considerable variability in the amount of time elapsed, and some of the children had chronic conditions requiring recurrent episodes in hospital, for consistency, their age at the time of interview

was recorded, but the time since their last admission is noted in Table 31, as this may have a bearing on whether they would have been exclusively breastfeeding at the time of the admission. In all cases, their breastfeeding status at the time of the interview was also recorded, with any relevant details about the differences in feeding behaviour being noted explicitly during the interview.

The participants were not selected by geographical location, but probably because the advert was shared hundreds of times and the eventual sample was large, there was a wide spread of participants by location, meaning that thirty different hospitals were represented in this study (see Figure 10).

Figure 10: Visual representation of participants' locations



The map clearly demonstrates a geographically dispersed sample, with no obvious clustering, and representation from England, Wales and Scotland. The conditions of the children studied are also diverse. There are a few duplications – for example, there were two children each admitted with jaundice, severe feeding difficulty, fever and meningitis, but overall, 26 different conditions were represented, and a wide number of challenges were identified by their mothers.

After familiarisation with the transcripts, keywords or phrases were assigned a code. For example, ‘feeds more when ill for comfort’ was assigned the code ‘Breastfeeding for comfort’. Codes were developed inductively by reading one transcript at a time. In subsequent transcripts, keywords that matched an existing code were added to that code in a partially deductive way, but novel or unique keywords and phrases were given a new code. All transcripts were read and coded this way until no new codes were required. Codes were then grouped into subthemes, under seven broader themes. The seven themes are summarised in Table 32 below, considering also how these themes related to the different layers of the ecological systems model.

Table 32: Themes mapped to the ecological systems theory model

Theme	Ecosystem layer
Challenges of breastfeeding a medically complex child	Microsystem/Exosystem
Importance of breastfeeding a medically complex child	Microsystem
Psychological impacts of persevering with breastfeeding a medically complex child	Microsystem/Mesosystem/Exosystem
How breastfeeding a medically complex child impacts parenting and family life	Mesosystem/Exosystem
Ward environment and equipment	Mesosystem/Exosystem/Macrosystem
Lack of skills and knowledge	Exosystem/Macrosystem
Ward culture and staff attitude	Mesosystem/Exosystem/Macrosystem

Across these seven themes, 47 sub themes were identified. The sample size of 30 enabled the proportion of mothers who raised each sub theme to be considered. These sub themes, connections to their themes and frequency are show in Table 33.

Table 33: Proportion of participants identifying each theme and subtheme

Theme	Subtheme	N	%
1. Challenges of breastfeeding a medically complex 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
	Fluid charts and balance	11	36.6
	Milk supply problems and anxiety	12	40
2. Importance of breastfeeding a medically complex child	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 medically complex 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 medically complex 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
	Impact on family	9	30
	Intuition	10	33.3
	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 breastfeeding interventions	15	50
	Hero	9	30
	Hostile/lack of compassion/outrageous comments	14	46.6
	Ignored by staff	5	16.6
	Love for the National Health Service (NHS)	10	33.3
	Staff interaction	10	33.3
	Support not provided	23	76.6

The majority of mothers identified that breastfeeding a child who was unwell or medically complex was challenging, and most mothers also highlighted a lack of support, problems with food provision while on the ward, and difficulties with bedsharing. However, most mothers also emphasised the importance of breastfeeding as a comfort measure. Many of the subthemes had an opposite theme – for example 13 mothers spoke about the kindness or encouragement from some staff, but 14 mothers spoke about hostility, lack of compassion and outrageous comments or suggestions. Within some of the themes, such as bedsharing, a minority of mothers had a positive story, but the majority of the 24 mothers who mentioned bedsharing did so in a negative sense.

Broadly, support from healthcare staff was identified by the mothers as positive, neutral or negative, and they elaborated on how the cultures of the ward made them feel about continuing to breastfeed. The themes and subthemes are discussed in more detail below.

5.3.1 Theme 1: Challenges of breastfeeding a medically complex child

Participants cited many challenges of continuing to breastfeed or provide breastmilk for their children while inpatients on the paediatric ward or PICU. These were mainly in response to questions such as, ‘How has your child’s illness affected their feeding?’, ‘How is your child currently being fed?’, and ‘Have you had to adapt your feeding goals?’. The mothers spoke not only about what challenges they had experienced with direct breastfeeding but also with expressing and related maternal breast problems that arose as a result of their child’s hospitalisation. They also spoke about some of the direct impacts of

breastfeeding challenges – such as fatigue and milk supply problems. Overall, there were eight subthemes.

Additional breastfeeding support required

There were several aspects of breastfeeding medically complex children that mothers felt they required extra support to overcome. These were chiefly raised by mothers of children who were more seriously or chronically unwell. Specific examples included the need for more support post-operatively, supporting infants and children with various challenges after extubation or following a period of enteral feeding, supporting complex conditions, and supporting very sick children.

“Yeah, because there was no, there was no consideration for the fact that [redacted] had a giant mask on his face. It was like, so you know, 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)

“You kind of feel like you shouldn’t be the one that’s having to ask and check. Because you’re already in a state of kind of worry and thinking about her. If someone would have said, ‘Oh, if you’re breastfeeding, you can just feed her now’. Because you don’t know, do you, whether it’s a certain time that she has to wait or....?” (Jan, 34, mother of child, 24 months, with anorectal malformation, stopped BF)

“...after this most recent op, she was on TPN, but she was only NBM for three and a half days. And then TPN for another week, because it took us that long to kind of get back on track with feeding.” (Judith, 30, mother of child, 24 months, with rare complex bowel condition, PEG/BF)

Difficult breastfeeding

The mothers in the study reported numerous breastfeeding difficulties and weight challenges as a direct result of their child’s illness, including more frequent feeding, desaturation during feeding, difficulty manoeuvring around cannulas, children who only feed on one breast due to the position of their PEG, implanted central line or wounds,

painful latch modifications to positioning, feeding refusal and damage to reflexes or loss of tone.

“So, we went from going to like, maybe two feeds a day and however many night feeds to him feeding constantly nearly for those first two weeks. He didn’t want anything else. And then after that when his weight had dropped, and it dropped fast, because he was always a very big boy. He was 99th centile on his charts before he got sick. And so yeah, he stopped eating, he lost a lot of weight and we had to put the tube in. Then yeah, he’s actually only just stopped having NG feeds...” (Ruth, 32, mother of child, 34 months, with ALL, NG/BF)

“...he’ll ask for boob more, so during the night because his asthma usually gets worse during the night so he’ll kind of he’ll wake up a bit more and he’ll want to be on the boob a bit more.” (Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

“...cannulas were a pain because they were just, they were everywhere.... So, he’d, they’ve been in his feet and things which are just a little bit awkward to manoeuvre around.” (Lucy, 35, mother of child, 11 months, with meningitis, BF)

“...by that point, she still wasn’t feeding very much. Just not interested in, in feeding in the slightest. So, we took her back. And at that point, she was admitted for an NG tube...” (Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

“I fed him every three hours for seven weeks and it was a breastfeed, a bottle feed. And then I would express. So, by the time that was all done, there was only about an hour and a half left before the next feed. And he wouldn’t even wake up – it was hideous, was squeezing milk into his mouth most of the time.” (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

“...she was very grumpy, and wanted to suckle all the time, not necessarily feed and so she’d get really annoyed when there was milk...” (Georgie, 33, mother of child, 3 months, with meningitis, BF)

“...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)

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.

“I had those white bleb things, which I haven’t had recently. But yeah, I remember having lots when I was in hospital...” (Ashley, 40, mother of child, 5 months, with skin infection, BF)

“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)

“During that time my milk came in, the day we went into the hospital for his jaundice. So, my milk was coming in, I was very heavy and engorged.” (Tamsin, 19, mother of child, 2 months, with jaundice, BF)

“I needed to pump because at that point she became nil by mouth while they wanted her to be assessed for the intussusception because they didn’t know whether they’re gonna operate that night. Obviously, they didn’t need to operate at all in the end. But I

became quite sore.” (Bridget, 32, mother of child, 9 months, with intussusception, NG/BF)

Enteral feeding

Feeding children with nasogastric (NG) or percutaneous endoscopic gastrostomy (PEG) tubes was often found to be stressful and difficult for mothers alongside maintaining their milk supply. Not only were the tubes sometimes felt to be invasive and 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)

“I think it’s really difficult to get into a routine with [redacted] and his NG. Because some days he tolerates it. Some days, he doesn’t. Sometimes I can put 200mls down the NG. Sometimes I can put 60 and he starts throwing up, or he basically just doesn’t want me to do it. And he pulls at his tube, or he cries. If he cries too much it won’t go down. It’ll all come straight back up. So, every day is a challenge...” (Alana, 39, mother of child, 18 months, with severe complex feeding, NG/BF)

“And she got her tube placed.... That is traumatic and it’s horrendous having to hold your child down.” (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

Expressing

Expressing milk for their children was often accompanied by mixed emotions. Many mothers saw it as an act of sacrifice, and they did it because providing breastmilk was important to them. However, some found it confusing, logistically challenging or even had intense dislike for it.

"I hated expressing... every part of it.... Every single time. I hated it, it was the worst thing ever. And to do that for such a long time, and then get the impression that the easy option was to just can the breastmilk and put more formula in." (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 because I think when the nurses are looking after your child... you almost feel like a bystander looking after your child. It's kind of a really weird experience. For me, I was like, that was the thing I did, you know? I provide the milk. I'm expressing. That's my thing. But I think if she'd been fed another way I would have been like, what well, what do I do?" (Kayla, 36, mother of child, 12 months, with complex cardiac condition, NG/BF)

"I couldn't express and at the time, like, you know, I was never told that... like, expressing isn't a sign of low supply so I just thought 'oh I can't express so maybe he's not getting that much' "(Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

"I think the thing that I found difficult at that point was trying to comfort her and finding the time to express was quite... was quite challenging." (Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

Fatigue

Many mothers in the study described intense levels of fatigue and sleep deprivation. This resulted sometimes directly from the aspects of caregiving and more frequent feeding, as well as iatrogenic factors. For example, sometimes the fatigue was related to the time of admission on to the ward, or the frequency of routine observations and checks overnight.

"...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. That means that I don't get like a rest in between." (Maria, 35, mother of child, 18 months, with croup, BF)

"I couldn't possibly physically do my baby's feeds every two hours overnight, as well as in the day as well as express and I was so exhausted and drained. And... the nurses would come on and say, 'Okay, let's negotiate your feeds, because we hear that you're clearly... not coping to do them all'. I was like.... I'm human." (Alissa, 32, mother of child, 5 months, with broncholaryngeomalacia and vocal cord paresis, NG/BF)

"...by the time we got there it was, I think it was about 11 pm or 11:30pm. And it took a long, long time. So, I think we finally settled in at about half past one, at which point, the nurse in charge overnight then wanted to restart all the swabs and the MRSA and... all the COVID swabs and everything else. I just wanted to go to bed!" (Bridget, 32, mother of child, 9 months, with intussusception, NG/BF)

"...by the end of that 24 hours when I finally got him back out of the hospital the second time I was drained to high hell, like there was nothing left of me..." (Tamsin, 19, mother of child, 2 months, with jaundice, BF)

Fluid charts and balance

Fluid charts and maintaining accurate fluid balance caused anxiety and stress for many mothers. There was often pressure to record specific volumes on the fluid chart. Many mothers were frustrated by the lack of accommodation for and understanding of responsive breastfeeding which is difficult to record in terms of millilitres. One mother was also stressed by fluid charts because her child had vast losses from their stoma. Volumes of feeds cannot be sensibly quantified by recording the number of minutes spent feeding, and some staff seemed to want to overcome this by asking mothers to express and bottle feed against their wishes. Mothers sometimes felt demoralised by the unachievable amounts of milk that they would be required to produce in order 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)

“...they were asking me, you know, how many feeds he’d had? How many he’d kept down? How much I thought he’d had, which is an impossible question to answer when you’re breastfeeding.” (Molly, 33, mother of child, 12 months, with pneumonia, NG/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)

“...straight away, they’re like, ‘do you want us to just get you a pump and you can bottle feed him right now?’ I was like ‘no, I don’t want to do that’. 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)

Milk supply problems and anxiety

Many mothers in the study had concerns about their milk supplies. This was sometimes due to acute shock and stress, and sometimes due to iatrogenic causes, such as failure to provide a pump in a timely fashion. One mother felt lucky that due to her child’s critical condition they were not able to tolerate large volumes, so the only reason her dwindled milk supply was sufficient was because of these lower required volumes.

“I felt that my milk supply definitely dropped while we were there, because I was just so exhausted and stressed...” (Molly, 33, mother of child, 12 months, with pneumonia, NG/BF)

“I was stressed, I was tired. I wasn’t even allowed to drink in the same room as her, it was just awful. And I think it was day two, I was trying to pump in the morning, I was not even getting a drop.” (Karin, 33, mother of child, 13 months, with supraventricular tachycardia, NG/BF)

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

“I was quite lucky. Because they were only giving [redacted] very, very small volumes of milk at that time. So, what I was pumping – even though it was small volumes, it was actually a lot for her at that time.” (Karin, 33, mother of child, 13 months, with supraventricular tachycardia, NG/BF)

5.3.2 Theme 2: Importance of breastfeeding a medically complex child

The second theme identified was how important breastfeeding was to mothers of sick children. Almost all the mothers described breastfeeding as being an important source of comfort to their child. This was often positioned as being more important than any nutritional or immunological benefits, though these were also cited as reasons to persevere. Many of the mothers described a sense of breastfeeding against the odds – the idea that breastfeeding was not easy, but worth it. There were eleven mothers who were either healthcare professionals or breastfeeding peer supporters who felt that their training buffered them in some way against some of the ambivalence they encountered from staff on the ward. Overall, there were four subthemes.

Breastfeeding feels like a buffer

There were many buffers identified by the mothers, including prevention of more aggressive disease, side effects and iatrogenic infection, as well as providing needed calories and fluids. Many mothers also described it as offering excellent pain relief and aiding faster recovery. Two children were on high-dose chemotherapy and yet, unusually, had no mucositis.

“...he breastfeeds more, which is quite comforting. Like he doesn’t eat much solid food. So, knowing that at least he’s having some, something else. It’s, it’s reassuring...”
(Maria, 35, mother of child, 18 months, with croup, BF)

“...she recovers from operations faster than anybody would expect her to do. And I’ve brought her out of ileus before by giving her breastfeeds and I genuinely believe it’s kinder on her bowel...” (Judith, 30, mother of child, 24 months, with rare complex bowel condition, PEG/BF)

“You know, she could die if she caught a cold, you know, so we were like really scared when we came home. So, I was like, breastfeeding was like, literally my one saviour – it’s like this thing I’m doing, you know, to really help her immune system...” (Kayla, 36, mother of child, 12 months, with complex cardiac condition, NG/BF)

“There are about three chemo drugs where mouth sores are very common. He’s on five different chemo drugs, but he’s on the three worst ones that you could possibly be on together. And so, 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)

Breastfeeding for comfort

Several of the mothers cited comfort as a major reason to persevere with breastfeeding. Breastfeeding also seemed to be comforting just as much to mothers as it was to their children and provided an opportunity for connection and to calm down after unpleasant procedures.

“The fact that I could, I could comfort her that way. And I knew that she was still getting nutrition. She was still, you know, getting lots of cuddles.” (Georgie, 33, mother of child, 3 months, with meningitis, BF)

“The consultant... she was like the top consultant for him, and a couple of times when they were wanting to do some, like tests and stuff, she’d said, ‘Why don’t you like pick him up, give him a feed, and it’ll chill him out a bit’. And then we’ll try again in like 15-20 minutes...” (Marsha, 30, mother of child, 16 months, with transverse myelitis, BF)

“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)

“...sometimes when he’s feeling really low, I think that he will breastfeed to sleep.... He did for his nap today. And he doesn’t need a nap every day. So, I think it’s just when he’s feeling particularly anxious, or unwell.” (Nicky, 32, mother of child, 30 months, with rare childhood cancer, NG/BF)

Breastfeeding as a parenting tool

As well as providing comfort, breastfeeding was clearly a ‘cure-all’ for many mothers, giving them a tool to soothe children who were bored, hungry, in pain or angry. It was also a way for one mother to connect with both children at once through tandem feeding.

“And that was something that I can definitely do that will help her rather than just maybe putting her in a swaddle and giving her a cuddle is so much more than that, when you’re breastfeeding your baby. There’s just more, they get more out of it. And there’s just an immediate sort of relaxation that comes over them.” (Ali, 34, mother of child, 3 months, with fever, BF)

“...it just means I can give her, you know, what she needs really, the comfort and, you know, the nutrition and everything else that comes with it. You know, 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)

“He still occasionally likes a bit of a tandem feed – that’s a bit tricky now with the size of both of them. But they, they’re very cutchy. They do like to cuddle each other.

They're very.... He loves his sister a lot." (Nicky, 32, mother of child, 30 months, with rare childhood cancer, NG/BF)

"...it is the, you know, the top way of just settling her at the moment. So, if she's been angry, like, we'll just put on the boob or anything like she's a bit hungry, angry, hangry if she's not eating, or is, you know... it's just such a reliable way of providing comfort to her." (Nephele, 39, mother of child, 17 months, with inhaled foreign body, BF)

Maternal motivation as a buffer

Several mothers were clearly very confident and able to defend themselves when challenged. As well as this, some mothers were motivated by a strong desire to maintain something that was within their control. One mother specifically mentioned a family history of atopic disease.

"...sometimes with an unwell baby, there's so much that's out of your control. And it's just nice to know that you still have that part. There's still, there's still that part of being a mum there that you have. Nobody else can, you know, step in and kind of do it for you, I suppose. (Karin, 33, mother of child, 13 months, with supraventricular tachycardia, NG/BF)

"...it's just easier to just feed them you know, yeah. And the benefits – we've got eczema and asthma within the family." (Bex, 34, mother of child, 20 months, with multiple admissions, BF)

"I'm one of them people who will speak out. So, if I did need something like that, and if I was really uncomfortable, I don't really mind asking." (Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

"I will do it because he's my son. And without it, it has consequences. It's hard work, especially with my other son as well. I'm a single parent as well. Yeah. Yeah, it's difficult, but at the same time, it's very rewarding. It's very rewarding. Yeah, it's tough." (Alana, 39, mother of child, 18 months, with severe complex feeding, NG/BF)

“...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, that we that we got through it” (Molly, 33, mother of child, 12 months, with pneumonia, NG/BF)

5.3.3 Theme 3: Psychological impacts of persevering with breastfeeding a medically complex child

The third theme that was apparent in many of the participants' responses was related to various psychological impacts of continuing to breastfeed their child through illness. There were many negative emotions identified, including guilt, loneliness, isolation, self-doubt, disempowerment, trauma, distress and hypervigilance. There were six subthemes identified.

Difficult emotions/guilt/conflict

There were numerous examples of complex and difficult emotions. Some mothers were buffered by being a health professional, and they were able to identify that this was an advantage, enabling them to overcome barriers. At the same time this sometimes provoked feelings of conflict over whether they were chiefly a parent, or a professional. Several mothers also described a sense of feeling torn between wanting to stop breastfeeding and also feeling trapped or compelled to continue.

“I feel I can’t stop. I feel that if I were to stop, it would be me being selfish. Because she needs my antibodies. Would she be worse if I wasn’t feeding her? Because she’s getting to that age where... I’m done. And I go through moments where I’m absolutely, absolutely done.” (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

“I think that helped kind of feel like I was being able to be an advocate for [redacted] from that point of view. In hospital, I think. Yeah, so I think I was treated with respect. And I think some things that were easier with me being a medic than if I hadn’t been...” (Nephele, 39, mother of child, 17 months, with inhaled foreign body, BF)

“And the doctor that we also saw, you know, was my junior before so then he would, I think he was then kind of swayed by my thoughts or my opinions and things which is always very tricky, because actually, sometimes I don’t want to be the doctor. I want to be the mum.” (Georgie, 33, mother of child, 3 months, with meningitis, BF)

“...she’d be miserable all the time. And I was miserable thinking about her. And I didn’t want to feed her, I don’t want to touch her. I don’t want her to touch me. And I really resented her. I really resented her. And I resented feeding her. I resented my husband because he couldn’t feed her.” (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

“...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)

“I know it sounds really illogical, but I was really angry when he was diagnosed with cancer. Because obviously, everyone lauds the benefits of breastmilk and we definitely saw them in that first year. Like he was never sick, no colds, he was robust as hell. And I was just like, how have I breastfed from like day one pretty much, and he still got cancer.” (Ruth, 32, mother of child, 34 months, with ALL, NG/BF)

Disempowerment/doubting themselves

Several of the mothers were highly educated or experienced – either academically, professionally, or as mothers - and yet felt a profound sense of disempowerment on the ward. Many mothers doubted themselves even when they knew they were right, and some described a clear sense of feeling gaslit – they were made to feel that their protectiveness of breastfeeding was irrational or that they were not seeing what the professionals were.

“I felt very insecure. And... you can read as much about sort of babies and sort of child health as you like, but when you know, 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 a different, 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)

"And it makes you question yourself when someone says she wouldn't be in this mess if she wasn't breastfeeding." (Judith, 30, mother of child, 24 months, with rare complex bowel condition, PEG/BF)

"Whilst I was confident this was the right thing to do, it still came with feelings of guilt and made me question myself..." (Alissa, 32, mother of child, 5 months, with broncholaryngomalacia and vocal cord paresis, NG/BF)

"...because for so long, you start doubting yourself like, Am I over feeding him? Is it breastfeeding? I knew in my heart it wasn't." (Nicky, 32, mother of child, 30 months, with rare childhood cancer, NG/BF)

"...you start to doubt yourself, I would say,' is this right? Is this important? Like, is this worth it? Am I making too much of a thing?" (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

Loneliness

Another prevalent subtheme was that of loneliness and isolation. This was especially pronounced among some of the single mothers in the sample, but almost all mothers were alone on the ward due to either Covid restrictions, or their partner having to remain at home to care for other children or go to work. Many spoke of how they just wanted someone to linger for a moment to talk to them but found that the staff were task-orientated and busy.

"...it can be quite like, an isolating experience in hospital, especially now you've got COVID, 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)

“I felt like I was quite left to it when it comes to sort of emotional support. There wasn’t anything, no one to talk to, you know, no one sort of came in to check on me unless I pressed my buzzer. No one came to have a chat or anything.” (Samira, 31, mother of child, 3 months, with urinary tract infection, BF)

Poor care has put them off seeking help

Although not many mothers described this, a distinct subtheme for six mothers was that of feeling put off seeking help in the future because of perceived poor care. Some mothers actively downplayed or withheld information from healthcare providers because they did not trust that they were going to be given quality advice or care.

“I didn’t dare mention the lower volumes I was giving him to the nurses in fear of the team pushing formula. Being aware of the risk of formula as well knowing that formula would further lower my supply, I felt it would do more harm than good, so I just told the nurses I’d given the full volume when they needed to update their charts.” (Alissa, 32, mother of child, 5 months, with broncholarynomalacia and vocal cord paresis, 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 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)

“...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 poriky 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)

Trauma and distress

Overall, seven mothers described distress, grief and trauma, including vicarious trauma. Trauma and distress, even if not directly breastfeeding related, may have indirect effects on breastfeeding and ability to express. One mother was describing several symptoms of post-traumatic stress disorder and this arose not only from observing her child being intubated following a respiratory arrest, but also the child next to them dying. This was distressing to witness but also placed her in a moral dilemma about where to pump without causing further distress 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 bugga off. They didn’t need the sound of my pump going. 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 I can’t. Like I can’t explain to you...” (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

“...in my husband’s family, they’ve had childhood cancer before – it took his brother when his brother was nine. So obviously being told that our child had cancer is awful. Like, I mean, it’s awful for anyone but with the family history as well...” (Ruth, 32, mother of child, 34 months, with ALL, NG/BF)

“I don’t feel like they considered that telling me to just stop feeding would have an impact on me, my mental health, and my physical well-being. I don’t feel like anybody considered that.” (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

"I was devastated because they've said about putting it [EBM] in the fridge. And then when I went and said, 'Oh, can I get my milk?' They were like, 'Oh, well, we can only store.... We don't have the space and it's gone'. They said, 'you should have asked to put it in the freezer'. Well, I wasn't aware of that. So, I'd lost this expressed milk, which was all labelled up and that. (Lucy, 35, mother of child, 11 months, with meningitis, BF)

Vigilance

Many mothers of chronically unwell children who were frequently in and out of hospital felt unable to relax or feel at ease about their child due to the severity or unpredictability of their condition or rapidity of deterioration. Many were anxious about iatrogenic or opportunistic infections with a child with compromised immunity or vulnerability and felt worried about exposing their child via nursery or school.

"...it's quite hard because, you know, thinking about going back to work and trying to explain to child minders or nurseries, that, you know, just look out for her you know, going a bit of a strange colour or kind of, being off her food..." (Karin, 33, mother of child, 13 months, with supraventricular tachycardia, 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)

"And it just really scares me how fast she can go downhill. So, I'm really vigilant with her now. I used to be so cool... I've spent quite a bit on alarms, and you know, monitors for her... But when she's poorly I use this alarm, just in case you know she becomes unresponsive again..." (Bex, 34, mother of child, 20 months, with multiple admissions, BF)

"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)

5.3.4 Theme 4: How breastfeeding a medically complex child impacts parenting and family life

The fourth theme was related to some of the wider aspects of the impact on family life, including finances, connecting with other children and juggling work. Other mothers described the impacts that illness has on their parenting style, intuitive behaviour and ability to detect through observation of their child's subtle signs that something is wrong. There were also some subthemes identified around practical and emotional aspects of parenting, such as the value placed on responsive parenting in general, making difficult choices and bedsharing. Overall, there were six subthemes.

Bedsharing

Most mothers cited bedsharing as being an issue to a greater or lesser extent. In a few cases, bedsharing was facilitated or encouraged, but most participants encountered opposition to bedsharing which caused various degrees of stress. Some mothers were angry and frustrated. One mother became tearful as she spoke of how distressing it was to have to place her screaming child in a cot rather than hold him close or share a bed with him.

"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)

"I wanted to co-sleep. And they were quite against that. So, I didn't sleep for the first night, he slept on the bed, and I just sat on the bed watching him. And then by the second night, one of the bank nurses took pity on me, and was like, 'You need to get some sleep, let me go get you a barrier' and she put a bumper down the side of the bed for me so I could feed him in the bed, which was so much easier..." (Samira, 31, mother of child, 3 months, with urinary tract infection, BF)

“So, when, when they’ve told me you can’t breastfeed your child in a certain way, you can’t co-sleep with them. To me that’s basically telling a mother that she has to choose between breastfeeding her child and getting sleep. So, for that reason, I felt like that it was really unsupported.” (Ali, 34, mother of child, 3 months, with fever, BF)

“I’ll bring her to bed with me. And I’ll sort of lay down and feed her because obviously, it’s exhausting. It’s exhausting... and the nurses are like ‘It’s ok, it’s your baby, you know what you’re doing. You know... we check on her all the time with a temperature and you know, her blood pressure and everything. So, we would always check in on her so you can rest’” (Bex, 34, mother of child, 20 months, with multiple admissions, BF)

Change in breastfeeding behaviour is a sign

Many of the children represented in the sample had a marked change in their breastfeeding behaviour in the lead-up to their hospital admission. 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)

“...there were definite changes. So, when she was really poorly, she just wasn’t feeding. Yeah. She didn’t want to feed. And then normally straight after when she was in recovery, there was normally desperation to feed...” (Jan, 34, mother of child, 24 months, with anorectal malformation, stopped BF)

“I didn’t know anything until that night when he was just on and off all the time. I mean, but he was very hot as well. But yeah, then just these inefficient feeds and know that you’re kind of really uncomfortable because you’re just all engorged and nothing’s transferring.” (Lucy, 35, mother of child, 11 months, with meningitis, BF)

Difficult choices and juggling

Many of the mothers, but particularly those with other children, described a sense of having to juggle children, and make difficult choices. Some mothers felt torn between a younger child at home and their sick older child. Lack of flexibility around visiting often meant that mothers could not have both children on the ward, even when they were both breastfed. Another mother continued to work full-time, and juggled caring for a sick child in hospital with her husband.

"...to get three kids out the door and at school and food and you feed your baby, breastfeed them and 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 broncholyngomalacia and vocal cord paresis, NG/BF)

"I said you shouldn't ask me to be picking between my unwell child, and my exclusively breastfed child." (Nicky, 32, mother of child, 30 months, with rare childhood cancer, NG/BF)

"I've obviously got another child at home; he was two when it all kind of started. I think a lot of mums perhaps would have just given up with the breastfeeding at that point to try and manage being there for both children." (Jan, 34, mother of child, 24 months, with anorectal malformation, stopped BF)

"I stay overnight, feed through the night. And then I go to work at about nine in the morning when my husband finishes the school run, not because I have to but it's distraction. So, I go and do six out of my eight hours for the day, do the school run, take my son home, give him his dinner, log on for another couple of hours and then go back to the ward at six o'clock and swap with my husband again." (Shayla, 33, mother of child, 24 months, with bronchotracheolyngomalacia, NG/BF)

Impact on family

Distinct from juggling children, was the subtheme of wider impacts on family life. Some mothers described the financial strain of having a child in hospital, while others spoke about how they have had to give up work to care for their child.

“And you make stupid purchases when you’re stressed. Because you’re stuck in a room with no Wi-Fi by yourself away from your family. So, things like that. Yeah. Like, £200-300 out of pocket easily and my husband was on benefits at the time. And there’s no support. You just have to deal with it?... Money was a horrendous worry.” (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

“So, I’ve had to, I have to stop work. Because you know, at sort of nine months when I was supposed to return, he didn’t have his NG. He didn’t have anything but breastmilk. And I have no choice but to take time off work. And I still haven’t been able to return yet. So yeah, my life has been put on hold.” (Alana, 39, mother of child, 18 months, with severe complex feeding, NG/BF)

“I haven’t actually returned back to work yet, because all of my focus was on him and his rehabilitation. And actually, like, he wasn’t letting me leave the room to go to the loo, let alone go to work.” (Marsha, 30, mother of child, 16 months, with transverse myelitis, BF)

Intuition

Many mothers felt that breastfeeding was a way of tuning into their maternal instincts more. Several were not only intuitively drawn to continue breastfeeding for the sake of their child’s health and wellbeing, but also were able to discern their child’s feelings, cues, and even impending deterioration. One mother intuitively knew when her child needed a transfusion or was about to become symptomatic through the close breastfeeding relationship.

“My instinct was, he needs breastmilk. I totally understood the calorie deficiency and that he needed the calories, it was really important that he got calories on board. But

my instinct was I have to get breastmilk into this baby.” (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

“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)

“...sometimes I know when his numbers have dropped like his blood counts, because he starts asking for milk a bit more in the day.” (Ruth, 32, mother of child, 34 months, with ALL, NG/BF)

Responsive parenting not supported

Numerous mothers cited examples of responsive parenting and responsive feeding not being understood or valued by the staff. Nurturing activities and closeness were sometimes actively discouraged, and there was an unwillingness to facilitate responsiveness for many families. Some mothers were frustrated that the staff did not seem to understand the non-nutritive aspects of breastfeeding, or that the advice on the ward contradicted previous advice they had received to feed responsively.

“No one ever encouraged skin-to-skin. No one. No one. It was something that seemed completely alien to them.” (Kayla, 36, mother of child, 12 months, with complex cardiac condition, NG/BF)

“...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)

“The first time that the tube was presented to me it was: I would stop feeding and they would feed her by tube instead. And I said absolutely not. We’re not doing that. You’re not taking away one source of nutrition, but that also gives her comfort and support and security and providing her with the tube. No.” (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

“...we weren’t given any other ways to comfort her... I couldn’t get in her cot... And then trying to get a baby to sleep who you’ve always just nursed. And then it’s like, oh, so she started getting better. It kind of felt like I was trying to drown her to sleep with some other milk from a bottle and it was just so awful.” (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

“I was feeding on demand. I was... whenever he’d give me cues that he was hungry, I’d feed him, or I’d offer him the breast if he seemed distressed or anything like that. Then when we got into the hospital, obviously, him having to be under the blue lights. The advice completely changed. They were just like, no, you can’t keep bringing him out to feed him. And I’m like, Yeah, but he’s hungry. He needs food, he’s three days old...” (Tamsin, 19, mother of child, 2 months, with jaundice, BF)

5.3.5 Theme 5: Ward environment and equipment

The fifth theme identified from the interviews related to the ward environment, resources, provisions, equipment and processes. Challenges between equipment and staff related themes were distinct, though often interrelated. Some mothers did have examples of good care and plentiful provisions, but the majority were frustrated by under provision or resourcing on the ward. The PICU environment was considered a separate subtheme as some of the issues arising in that environment are unique to intensive care. Overall, there were six subthemes within this theme.

Covid made things harder

Many of the mothers were affected by isolation and visiting restrictions imposed during the Covid-19 pandemic. Several were able to identify that life on the ward was made specifically

more challenging because of these rules. Several mothers were unable to have their other children present, even when they were also breastfed, and many mothers were more fatigued and isolated because their partner was unable to visit, even during critical illness. One mother had considerable professional expertise as a virologist and found the rules frustratingly illogical.

“They’d taken a COVID swab, and they put us in a separate room. But they refused to let us come out of the room until the COVID Swab was negative. And they refused to let my husband into the room. So, they sent him home. And it was just her and I in the room. And I’m a virologist, right, I was like, this just doesn’t make total sense to me.”
(Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

“...because of all the COVID restrictions, it was only like one parent allowed to be in with the kid. Yeah. And, and oftentimes, it was my husband, and I would stay with my other kid.” (Maria, 35, mother of child, 18 months, with croup, BF)

“...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... I guess it goes right down to as well again, hospital rules, then with one parent 24 hours at a time. 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)

“And I wasn’t allowed to leave and swap with my husband. Because of the isolation rules, I wasn’t allowed to see my son, I didn’t see my son for all December. You have to have a nurse escort to go to the toilet. I also found pumping [in a mask] made me feel nauseous and hot, but the nature of the ward and mask requirements made that tricky to manage.” (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

Food provision and basic needs

Most of the mothers in this sample expressed anger, frustration and disappointment that they were not provided with food. This was made even more frustrating by the pandemic, because it was also difficult or impossible for partners to deliver food, and often the canteen had closures or restrictions as well. It was very difficult for mothers to leave the ward because they were alone, caring for their child. Two participants commented on the lack of food options for people with allergies. Effectively, not being provided with food meant that many went hungry. Several mothers ate their child's food when it was clear that their child was not going to eat. Some mothers were told to use the parent's kitchen, but this was often impractical because it would have meant leaving a mobile child alone and unattended, and children were not allowed into the kitchen. One mother was not allowed water in the intensive care unit. Sometimes there were rules about only feeding mothers of babies under six months, which was felt to be unfair by many of the mothers whose toddlers were only consuming breastmilk and feeding more frequently than a newborn. Only a minority were given sufficient or plentiful food.

"...that's the only time we've ever been offered food. And that was because it was Christmas Day. So, they got... he got offered food then, and I got a sandwich. Um, and I have to always, every time we go there, I always have to ask for water." (Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

"...they literally just didn't have anything, and they gave me a meal with soya in. And so even though I said I wasn't having cow's milk protein, they gave me a vegan meal. And it had soya in, and I couldn't eat it because luckily, I read the labels. But it was just completely unfeasible." (Alissa, 32, mother of child, 5 months, with broncholyngomalacia and vocal cord paresis, NG/BF)

"...they quite frequently forgot to bring me food so because I'm boarding with her, I'm supposed to be fed, and they would forget to feed me...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 and had been in for like eight hours and we've not eaten." (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

“...no, it was just that. Yeah, it was just breakfast in the morning. Yeah... Luckily, I’d taken in kind of some snacks and things with me. So, they also did obviously provide some food for him. But he didn’t eat any of it. So, I just kind of had bits given to him.” (Maha, 34, mother of child, 16 months, with fever, BF)

“...they bring you cups of tea all day in a flask so she can’t get burned. They bring you food, you get breakfast, you get dinner, you get your tea. You get sandwiches. I’ve been brought sandwiches two in the morning.” (Bex, 34, mother of child, 20 months, with multiple admissions, BF)

Furniture/pillows

Many of the mothers commented on beds, chairs and pillows. A common problem was that for many mothers, their children fed more effectively lying down. This was difficult and sometimes unsafe on the parents' pull-out beds, and if the child was not provided with a full-sized bed because bedsharing was not facilitated then they were forced to feed in awkward positions. Sometimes the bed folded into a chair in the day, or the parent beds were put away early in the morning which again meant that lying down to feed was impossible. Most of the chairs were felt to be difficult to feed in, especially for an older, larger child. Finally, there seemed to be a chronic lack of pillows which was problematic.

“You know those hospital chairs aren’t conducive to breastfeeding a baby particularly a postoperative baby with a big abdominal wound trying to feed in one of those chairs is awful. Access to more pillows – you get your one little, tiny flat pillow so yeah more pillows.” (Judith, 30, mother of child, 24 months, with rare complex bowel condition, PEG/BF)

“...it was just like a metal bed and put against the wall. So, when I was feeding, I was basically sitting up against this hard wall with this pillow, which was floppy, I only had one pillow. So actually, that was really awkward. It was, it was actually a very uncomfortable experience for three days.” (Ashley, 40, mother of child, 5 months, with skin infection, BF)

"...you can't sit on the chair because the chair is so upright and what can you do? Yeah, it was a really rigid, small chair. So, if I'd been big, you know, you wouldn't have fitted in. It wasn't comfy anyway. Because, yeah, even elbows and trying to sort round you're like banging with the elbow." (Lucy, 35, mother of child, 11 months, with meningitis, BF)

"...it was just not having somewhere to feed properly... Even if it had been just, even, like a reclining chair, rather than a futon bed. At first glance the room looked really fully equipped and very sensible. But actually, when you're then trying to feed in it, it was almost impossible. It was just so uncomfortable." (Bridget, 32, mother of child, 9 months, with intussusception, NG/BF)

"...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 wouldn't. 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, it was uncomfortable." (Nephele, 39, mother of child, 17 months, with inhaled foreign body, BF)

PICU

There were several comments made specifically about the intensive care environment where children were mechanically ventilated via endotracheal tube, tracheostomy, or received continuous positive airway pressure (CPAP). Some of the common difficulties were around not being able to be present overnight on the PICU with their child, a lack of acceptance of skin-to-skin and nurturing care on PICU, and how traumatic the environment itself was.

"Awful. I almost lost my milk supply because of it completely... I was offered to go to a hotel, to obviously stay the night. And I had said, you know, I'm breastfeeding. So, am I able to take a pump with me? ... And they said they couldn't give me a pump. And the hotel wasn't too far away. It was roughly about half an hour's walk. So, they wanted me to be walking back and forward in the middle of a city in the middle of the night. It

was wintertime. And I said no". (Karin, 33, mother of child, 13 months, with supraventricular tachycardia, NG/BF)

"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)

"...very little knowledge of having a stepped down child from PICU isn't an everyday occurrence... it was just traumatising and exhausting... Seeing her in PICU. And the deterioration and then the lack of progress with recovery. I think I naively thought you'd only be in PICU for a day." (Shayla, 33, mother of child, 24 months, with bronchotracheolaryngomalacia, NG/BF)

"...she was in PICU. And I found it, I found it awful leaving to go to bed." (Kayla, 36, mother of child, 12 months, with complex cardiac condition, NG/BF)

Privacy

A common subtheme was the idea of enforced privacy. Many women felt angry and confused about why staff members closed curtains, shut doors and turned lights off when they were comfortable feeding in public. Many women felt that the implication was that breastfeeding was something to be hidden away from public view. In a few cases, staff saw that a mother was breastfeeding and left the room. This was often frustrating because this delayed them hearing clinical updates on their child's care. The mothers expressed a wish that the staff would simply ask their preference, rather than making assumptions. A few mothers commented on the lack of privacy, though this was not always related to breastfeeding, and in two cases this was an issue mostly confined to the emergency department or clinic waiting areas.

"I tended just to kind of like, put, like, cover him up with my coat or something when he was having a feed. But it's not like, like, they're not the warmest of places in A&E because people are constantly coming and going... There was a room that you could

have asked I could have asked to go into, but I was more focused on not missing somebody coming to get us. Yeah. But on the ward.... I just tended to keep the curtain round.” (Marsha, 30, mother of child, 16 months, with transverse myelitis, BF)

“...feeling that I have to hide away with my sick child who... might have a snotty nose and he’s on the boob. And then he’s off the boob and on the boob and off the boob. And then I’ve got to do this in a room full of people who... have nowhere else to look, other than watching me and my sick child with my boob out, you know?” (Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

“...they wouldn’t stand and talk to me whilst I was breastfeeding, they’ll be like, ‘I’ll come back, I’ll give you some privacy now and they’d shut the door and turn the lights off’” (Nicky, 32, mother of child, 30 months, with rare childhood cancer, NG/BF)

“...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)

“...whenever I was feeding because I had my hands full, I wouldn’t go and close the door and people would come by and say, ‘let me just close this for you’. I think there was that thing of like, ‘keep it private’ was sort of instilled passively. And they didn’t really want me out roaming around with my boob out... And I was in there for five days, I didn’t see outside for five days, I was like in a little prison room basically...” (Samira, 31, mother of child, 3 months, with urinary tract infection, BF)

Pumps

There were numerous comments made about pumps. A few mothers were promptly given pumps, but the majority experienced delays in obtaining a pump, or failure to provide a pump. Most of the time, the pumps were not situated on the paediatric ward or PICU, and staff had to try to locate one. Other times, pumps were missing, broken, or there was one pump to be shared between all the patients. A few mothers had to source their own pump,

or bring their own from home, often because of delays in finding a pump on the ward. Almost all the mothers who were given a pump had no instructions or tips for how to use it.

"They tried to find a pump, but they didn't. The one that they had was broken. I think they had two and one was sort of missing in action. And one was, one was broken. So, at that point.... And in a way it was sort of my fault for not bringing in." (Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

"...one time when his surgery got delayed, and I was there, like, feeling like my boobs were gonna pop and there was just no help.... You'd think someone could have rung up maternity or something and be like, 'Can we borrow a breast pump?' But apparently not." (Ruth, 32, mother of child, 34 months, with ALL, NG/BF)

"I told that I'm very, very engorged, my pump is not working, then I think that's the time she told me you want me to bring a pump? We got a pump here. Then I said to her, of course I need to pump. You know, I had no idea that the hospital had a pump." (Sophie, 31, mother of child, 4 months, with jaundice, bottle/BF)

"...there wouldn't be anything for me to be able to pump or anywhere to even store my milk. So even if they gave me a pump, I would have nowhere to store my milk that I was expressing overnight." (Karin, 33, mother of child, 13 months, with supraventricular tachycardia, NG/BF)

"...I asked for a pump, and then one morning I woke up and it was gone and there was a mum and baby who was still a newborn who was still being breastfed. And so, she got the pump..." (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

"...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, 3 years, with low IgA, BF)

5.3.6 Theme 6: Lack of skills and knowledge

The sixth theme specifically related to staff skills and knowledge. Within this theme there were very few positive comments made. Mothers frequently found that nobody was able to help them, or even to find someone else who could help them. The comments about lack of knowledge and skills were not confined to paediatric clinical staff, there were also many issues with maternity infant feeding specialists and non-clinical lactation specialists who had little or no awareness of the challenges or adaptations sometimes required by medically complex children beyond the neonatal period. There were six subthemes within this theme.

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. A few participants accessed private nonclinical IBCLC support in the community which also did not meet their needs, and some wards called a maternity infant feeding lead whose advice was felt to be unhelpful. There was also a perception among a few mothers that paediatric nurses were not experts in caring for infants.

"And I couldn't settle her, and it hadn't been explained to me at that point that she was suffering from withdrawal, and they hadn't noticed that they haven't given her the medicine – like methadone.... 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)

"...the infant feeding coordinator in the tongue tie clinic was like, 'Oh, he's fine. Look at him. He's growing. He's latching'." (Alissa, 32, mother of child, 5 months, with broncholaryngomalacia and vocal cord paresis, NG/BF)

"...the one breastfeeding question I did have was about her safety with [redacted] breastfeeding and with chemo drugs, and they said there was no information on that."

And so, they couldn't answer that question. I'm not entirely sure where I would take that question. If I couldn't ask an oncologist. I'm not even sure that, like, a breastfeeding consultant would know... Everything I've read about breastfeeding and cancer has been anecdotal evidence." (Nicky, 32, mother of child, 30 months, with rare childhood cancer, NG/BF)

"...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?... some of the nurses would talk to you about it because they'd breastfed. But it was kind of more, it wasn't their specialist area and babies weren't their specialism as such – they were paediatric trained..." (Kayla, 36, mother of child, 12 months, with complex cardiac condition, NG/BF)

"...none of the nurses were experts in babies. They were just general, paediatric nurses..." (Ashley, 40, mother of child, 5 months, with skin infection, BF)

"...you're trying to like, 'look at pictures of your baby', and I'm like, 'Well, my baby's over there half dead'" (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

"I sort of said I need help to position this baby to feed. How do I do this? And both these ladies just kind of stood in this cubicle and just watched me pick him up and try this. And they said 'oh, like, maybe turn around... Have you thought about just maybe doing that'. And I was like, you're just standing there watching me I've got no clothes on, like, this is really awkward. And then obviously he didn't feed – he's never fed orally, really. So, it was really the point when I thought 'I'm never going to feed this baby again'. And neither of them helped..." (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

"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)

Breastfeeding assessment

None of the mothers had a breastfeeding assessment, and this included children whose primary reason for admission was directly related to feeding. There were a few examples of a speech and language therapist assessing feeding, but this was from the perspective of establishing whether a child had a safe swallow. 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.

"...no one assessed the breastfeed..." (Bridget, 32, mother of child, 9 months, with intussusception, NG/BF)

"...not a single nurse did a breastfeeding assessment obviously they could see we were struggling with feeds..." (Alissa, 32, mother of child, 5 months, with broncholyngomalacia and vocal cord paresis, NG/BF)

"It was not like a breastfeeding assessment. Obviously, when the paediatric doctor asked, they asked me like, whether you are breastfeeding or bottle feeding..." (Sophie, 31, mother of child, 4 months, with jaundice, bottle/BF)

"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)

"...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'. Yeah. So, when I've kind of been like, 'Oh, I'm not sure he's latching okay', they've gone. 'Yeah, that's fine'. It's like, I know it's not because I'm his mum." (Lyra, 31, mother of child, 36 months, with low IgA, BF)

Feed schedules and rules

Many of the mothers were upset or frustrated by some of the imposed schedules or limits placed on their breastfeeding. It was common for mothers to be asked to feed every three

to four hours, and to try to stretch infants' feeds out. 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 the implied suggestion that a strict schedule is preferable to responsive feeding.

"...when he was under the lights, and with the jaundice, there was times when I'd sit there looking at him. Like he's showing signs that he's hungry. And they just were like oh, no, you've got to wait for him to start crying. And I'm like, I don't want to wait for him to start crying. I want to feed him when he's hungry." (Tamsin, 19, mother of child, 2 months, with jaundice, BF)

"...when you come first off from the NBM, she's only allowed dioralyte. And then after dioralyte, like the dioralyte, like, had to increase a certain amount of mls before then moving to breastfeeding. So, there was some nurses that were a bit unsure about kind of how soon to allow that to move on." (Jan, 34, mother of child, 24 months, with anorectal malformation, stopped BF)

"...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)

"...she was sort of you have to give a minimum of 100 mls per kilo but that was like 1200 mls or something ridiculous. And the other thing I had to argue, so I was giving him a two hourly amount, but I didn't want to ever give him more than 60 mls by the NG tube. So, I'd rather feed him more frequently..." (Alissa, 32, mother of child, 5 months, with broncholarynomalacia and vocal cord paresis, NG/BF)

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. This meant that the default position was often to feed formula even when there were no

concerns about maternal milk supply. This was especially common when children were NG fed, and rather than find a pump so that a mother could express, or teach them hand expressing, children were given formula. Formula was also often the go-to intervention among critically ill children. Giving formula was often something that mothers were very upset about and caused many conflicting feelings.

“And she said, ‘What would you like us to give him – we’ve got Aptamil, we’ve got Cow & Gate, we’ve got...’ whatever the other one is, and I just burst into tears. It was, it was awful. I just kind of, I felt like someone had cracked me open.” (Molly, 33, mother of child, 12 months, with pneumonia, NG/BF)

“...she was 100% infatrini [high calorie formula] ... because that’s what they do. That is the process. And they do infatrini because it’s high nutrients or whatever. 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)

“...it was horrible. Hated every second of it, everything to do with it... I thought the stuff itself was disgusting. And like, very functional as opposed to like, like, like you’d have to be hungry to eat it...” (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

“...every night, I have to feed her formula that is made from God knows what. And I’m grateful for it because she’s gaining weight... I don’t want her to starve to death.... I feel so many emotions about how she’s fed at the minute.” (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

“...when you’ve got a child who might be just a generally sickly child, one of the first things is – put them on formula, put them on a bottle, so you can have a break... And I’m like, but yes, I need a break, but it shouldn’t be then putting him on a bottle. You know.... That shouldn’t be my answer.” (Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

Inaccurate/inadequate information/errors

Many participants described incidents where they were not provided with the information they needed to maintain their milk supply or breastfeed effectively. Other times they were given inaccurate or inappropriate information. There were also several examples of expressed breastmilk errors. One mother was given the wrong baby's expressed breastmilk, and two mothers were upset when their breastmilk was thrown away either due to lack of storage facility, or because of a minor omission on the labelling. One mother was given a prefilled bottle of formula and told to rinse it out which is inappropriate.

"...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.... Urgh, like it's grim." (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

"...she had brought me a bottle of breastmilk that said... so my baby's name is [redacted], and the bottle she'd bought me said [redacted], cubicle 23. And we were in cubicle 25. And I was like, I don't want to use this milk." (Alissa, 32, mother of child, 5 months, with broncholaryngomalacia and vocal cord paresis, NG/BF)

"I confirmed that that was mine. And then I said, 'Well, can I at least have it back so I can take it home?' They were like. 'We've got to dispose of it'... Yeah, it was dreadful. I was heartbroken." (Molly, 33, mother of child, 12 months, with pneumonia, NG/BF)

"...she bought me those Aptamil one. They're very tiny bottle with 70 ml of Aptamil. And she said to me, you can throw that out, wash it and use that bottle with that teat." (Sophie, 31, mother of child, 4 months, with jaundice, bottle/BF)

Procedures

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

pain relief. Conversely, one parent was frustrated that staff kept trying to get her to breastfeed during procedures against her will.

"...they try to use feeding as well as, like a tool to do tests on him and stuff as well... And I didn't really want to do that. Because it's like a calming time for him at a time where everything's really chaotic... I didn't want him to associate feeding with, like, more procedures. I just made them wait until he was done feeding." (Samira, 31, mother of child, 3 months, with urinary tract infection, BF)

"...that was couched as 'people find it quite distressing when we put the tube down and when we swab them. So, it would be better for you if you went out of the room'. And, again, I wish in hindsight, I said, 'Well, actually, I'd rather be there for that'" (Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

"...they often would take him away to put all those and I could hear him crying and screaming. I think they really struggled with his cannulas anyway. And they had so many attempts." (Lucy, 35, mother of child, 11 months, with meningitis, BF)

"...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. And every time I suggested something I was just ignored." (Bridget, 32, mother of child, 9 months, with intussusception, NG/BF)

5.3.7 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. There were positive and negative comments made, and often these were from the same parent – for example it was common to describe a generalised culture of hostility, with one hero standing out and defending their right to breastfeed. It was also common for mothers in this study to describe ambivalence or neutrality. While this might sound benign, it was always interpreted negatively by the mothers in this study. Their perception of this passive

response was that staff didn't care about breastfeeding. Notably, the parent who had the most positive experience of all was given the link to complete the screening questionnaire by a health professional on her local ward. There were eleven subthemes within this theme.

Ambivalence from staff

The sense from most mothers about the attitudes towards breastfeeding was that staff were ambivalent. This was often accompanied by other identified challenges such as lack of proactive or anticipatory guidance. Many mothers also perceived this ambivalence as offensive because maintaining breastfeeding during illness was hard and felt like an achievement. The passive responses were unwelcome in this regard because they felt their efforts were undermined or undervalued, and breastmilk and formula milk were inadvertently implied to be equivalent.

"They weren't necessarily encouraging. But they weren't discouraging either." (Cintia, 35, mother of child, 14 months, with bronchiolitis, BF)

"Then they were like, 'Oh, wow, he's a big boy. He must be doing a good job with his milk'. And that was, that was pretty much it. No one sort of, you know, said well done to me for actually feeding him whilst I was there or anything... I don't really take it as a positive reinforcement." (Samira, 31, mother of child, 3 months, with urinary tract infection, BF)

"Just very neutral. So, it was the same throughout different parts of the hospital. So, we've done HDU, we've done the ward and we've done PICU... no one really batted an eyelid because some mums breastfed some mums didn't. But then at the same time, nobody cheered it on either. It was just like, meh, like breastfeed if you want or don't if you don't..." (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

"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. It was more like it was just non-

existent. I don't think anyone else even really asked about it or anything to be honest."
(Maha, 34, mother of child, 16 months, with fever, BF)

Awkwardness

Several mothers described staff awkwardness. The sense that staff were embarrassed to 'catch' them breastfeeding sometimes made mothers feel ashamed or confused, as breastfeeding in front of others was not something that they were bothered by. It also sometimes delayed them receiving test results or hearing clinical updates if they were breastfeeding on the ward round. One doctor tried to insist upon a chaperone if a mother continued to breastfeed.

"I said to him, 'can I breastfeed him while you're doing it?' And he said, 'No, no, there's no need'. And I was like, 'No, I'm going to breastfeed him while he was doing it'. And he was like, 'no, no, because then I need somebody else in with me'. I was like, 'Why? You just concentrate on him and his hand and his Bloods? And just ignore me, I'll just breastfeed him'. But no." (Alana, 39, mother of child, 18 months, with severe complex feeding, NG/BF)

"...the second one came in, she was like, 'Oh, my God, I'm so sorry', like, turned away, and refused to do his observations whilst I was feeding. I was getting a bit worried. They were sort of making me feel a bit shameful for feeding him." (Samira, 31, mother of child, 3 months, with urinary tract infection, BF)

"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)

"I felt like because they came in and they walked out, I felt like they looked through the window to see that I was feeding, and they maybe felt a little bit uncomfortable about that." (Sila, 32, mother of child, 36 months, with chronic wheeze, BF)

Breastfeeding is inconvenient to staff

Several of the mothers described a sense that breastfeeding made nurses or doctors jobs harder. This was mostly related to the challenges of recording accurate fluid balance and, without a positive culture and true understanding of the way that breastfeeding works, the lack of quantifiable milk volumes left many staff feeling uncertain.

"I think to them, it was much more a barrier because yeah, it was then difficult for them to measure, you know, fluid input and output. It all just seemed to make things more difficult I think for them." (Maha, 34, mother of child, 16 months, with fever, BF)

"...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)

"...that clinical environment was not set up to be supportive and understanding of a breastfeeding mother and their child. And it was, it was set up for something that, that's much more quantifiable and easy to measure." (Molly, 33, mother of child, 12 months, with pneumonia, NG/BF)

"There was absolutely no culture at all of supporting breastfeeding. It was kind of a nuisance to them that I was breastfeeding." (Alissa, 32, mother of child, 5 months, with broncholyngomalacia and vocal cord paresis, NG/BF)

Encouragement/kindness

Many of the mothers, irrespective of whether they had also expressed frustration with their experience, acknowledged the kindness of some of the staff. Some mothers were also grateful for the encouragement provided, even if the staff were not able to support them with breastfeeding on a practical level. Kindness, acts of compassion, thoughtfulness and encouragement were often observed to come from non-clinical staff such as cleaners, housekeeping staff and porters.

"...only words of encouragement I got were from a lovely lady that came to take my order for my meal. This was one person who I saw one day, and I wish I'd taken her name because she was so, and she was like, 'You need to eat more than that. You're breastfeeding'. She was just basically so supportive of breastfeeding and said, 'I breastfed my baby until they were two. And the best thing... your baby will love you forever'. It was really nice. It was the only positive thing I had." (Alissa, 32, mother of child, 5 months, with bronchologyngomalacia and vocal cord paresis, NG/BF)

"...even a domestic coming in and noticing that you're, you know, your water's far away from where you're sitting, feeding, and just pushing the table close to you. Just the thought that people have is just incredible at times, it really is." (Karin, 33, mother of child, 13 months, with supraventricular tachycardia, NG/BF)

"...they said that because of all of his, because he got all of his plasma took out, by continuing on breastfeeding for a bit longer, he'll then build up antibodies, because all of them were just been took out." (Marsha, 30, mother of child, 16 months, with transverse myelitis, BF)

"...most like, nurses are very, very supportive and very, like, kind asking, like, what you need? Are you okay? Are you comfortable? Are you warm enough?" (Maria, 35, mother of child, 18 months, with croup, BF)

"...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, 36, mother of child, 12 months, with complex cardiac condition, NG/BF)

Helpful breastfeeding interventions

Some of the mothers were able to identify helpful strategies that supported them in their efforts to continue breastfeeding or expressing. This was sometimes related to how they managed to get their NG-fed child back to breastfeeding or stop breastfeeding; and at other

times it related to proactive 'permission' to breastfeed so that mothers were not in any doubt about whether that was 'allowed'. There were also some specific clinical interventions cited as supportive of breastfeeding through managing their child's condition.

"...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)

"...she just became a massive cheerleader. And that just completely changed everything then. And then when I decided that I needed to stop expressing... she was really supportive of that and just kept cheering me on really and saying how good it was... So, she really turned it around for me actually even when I was stopping. I didn't feel like I was quitting. I didn't feel like I was giving up." (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

"...as soon as she was in recovery, they called us and they called us in, and because she was really upset, and one of the nurses was holding her... and just as I was thinking, you know, kind of just gonna try to offer her like a breastfeed and see how she does, one of the nurses said, Why don't you have this chair and you can feed her, like, just in the bay there. And I thought that was really kind of nice for them to say that just because it just meant that, you know, I didn't feel like, you know, kind of like Earth Mama trying to breastfeed my toddler. They just - it was just kind of taken as normal..." (Nephele, 39, mother of child, 17 months, with inhaled foreign body, 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)

"...they were happy with sort of how she was doing. And so, the plan was that they'd leave the tube in place and see if she could tolerate sort of small breastfeeds." (Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

Hero

Several mothers spoke about a standout professional, often this was one advocate among the predominant stance of either ambivalence or hostility. These heroes were often spoken about with great warmth and were described as having 'saved' the mother's breastfeeding journey. The heroes were variously nurses, doctors, and occasionally domestic staff. The heroes sometimes provided practical advice that was successful, other times encouragement, and sometimes the hero status was achieved through the staff member being kind and emotionally available. One of the heroes was not based at the hospital but was a visiting paediatric/neonatal nurse and IBCLC from outside the department.

"...I love her, and she would come and sit with me for like half an hour every day to just watch [redacted] and have a chat with us and it was.... it really.... it felt like really caring medicine. Like she would come and actually spend time with us..." (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

"She (IBCLC/NICU nurse) was amazing. And she was actually attached to the neonatal unit at a different hospital. And 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, 36, mother of child, 12 months, with complex cardiac condition, NG/BF)

"I was so upset. And it was actually a doctor... came into the room. And she just saw how upset I was. And she went away and kind of said, 'you know, somebody yesterday should have given you like tokens for the canteen... You know, they should have been encouraging you in every way to be pumping every two hours, to be allowing you to even bring in water'... I don't know - she was quite angry at the situation. And I think if it wasn't for her, it would have... yeah, would have went very downhill." (Karin, 33, mother of child, 13 months, with supraventricular tachycardia, NG/BF)

"...actually, when I spoke to the IBCLC she was hugely validating as well. And because she was just so knowledgeable and knew so much that, that she kind of backed me up,

and she also made me feel good when they were trying to up the formula. She was sort of saying, 'you know, as long as he gets X amount of breastmilk in a day, he's got all of those good things that he gets from your milk, as long as we've got that goal, anything above that is great'. So, she was, she really helped me pick myself up again and start, you know, cheering that on." (Enora, 30, mother of child, 12 months, with long term ventilation and complex needs, NG)

Hostile/lack of compassion/outrageous comments

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. This was sometimes in the form of outrageous comments that caused hurt or anger. Other times mothers were shouted at or told off. Several mothers described a discernible sense that breastfeeding was not welcome on the ward.

"...he came in and said 'You're in with dehydration? She's breastfeeding, you can't keep up with her sodium requirements, she wouldn't be in this mess if she wasn't breastfeeding'. And I kicked back immediately. And he went on to say, 'Why do you want to continue breastfeeding when it's harming her? This is the reason she's in hospital'" (Judith, 30, mother of child, 24 months, with rare complex bowel condition, PEG/BF)

"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)

"...she was just horrible. And she pretty much yelled at me and said, 'well I'd rather him be screaming and crying and in a cot, than you cause him to have a febrile convulsion by having him sleep with you in the bed'. So, yeah, so I put him in the cot. And he obviously, he was just screaming..." (Maha, 34, mother of child, 16 months, with fever, BF)

"...having a member of male staff tell you to cover up and pull the curtains on you. That's quite hostile. I don't feel that's ok..." (Lyra, 31, mother of child, 36 months, with low IgA, BF)

"There was a level of it that felt patronising. A lot of people tend to assume that because I'm a younger mum. I won't breastfeed... I know I'm a very young mum. But that doesn't mean I don't know what I'm doing..." (Tamsin, 19, mother of child, 2 months, with jaundice, BF)

"Actually, they made me feel like I was being selfish." (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

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. Feeling ignored was often experienced in tandem with a lack of a plan or waiting for care. Sometimes mothers were left alone because they had made a complaint and they sensed that staff had backed off.

"...the time that I felt unsupported was when, like I said, we were just shut in the room. I'd been told I couldn't feed her. It wasn't clear when she was going to get the first dose of milk in the tube. And so, there was about probably 40 minutes where I was just alone in a room with a screaming, screaming baby. That wasn't great. And that there wasn't really any clear sort of this is what's going to happen." (Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

"Because I was like... they're not coming to do my baby's feed. So, I just got up and did it myself. And then my nurse came in and said, 'Why did you do it?' I said, 'well, the feed was just left there. And it's 25 minutes late... and I did it' and she said, 'Oh, I decided not to go on my break because everyone else is too scared to come in here'." (Alissa, 32, mother of child, 5 months, with broncholaryngomalacia and vocal cord paresis, NG/BF)

“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)

“Just the staff not being in the way of me. Yeah. I think I mean; it is 100% I needed the reassurance and the.... how can I say like, the guidance and the tests, and everything that was done at the hospital? Just to make sure that he was okay. And that there was nothing more dangerous than, than what we can see. Right? But at the same time, it was like, Yeah, I’m pretty sure that I’m capable of taking care of my kid.” (Maria, 35, mother of child, 18 months, with croup, BF)

Love for the National Health Service (NHS)

There was a distinct subtheme of unwillingness or discomfort around criticising the NHS. Many participants readily acknowledged that many staff were kind and hard-working. They also acknowledged that the COVID-19 pandemic had placed additional strains on an already stretched system. Several mothers, though frustrated or disappointed with their care, criticised the NHS almost unwillingly and acknowledged that they were perhaps forgiving of care that was at times substandard.

“Yeah, I have to say, the NHS is wonderful. And yeah. And I think we were lucky that it worked – she recovered...” (Tova, 40, mother of child, 9 months, with norovirus, NG/BF)

“...sometimes I think I'm overly excusing of the NHS, having worked for the NHS. And also having my sister is an NHS manager in [redacted]. And I know how stretched they are, and I know how understaffed, and I know how hard it is on them. So, to a certain extent I was a little bit like, you know, if they leave us waiting a little bit too long, etc, then we're more forgiving than a lot of parents would be...” (Nicky, 32, mother of child, 30 months, with rare childhood cancer, NG/BF)

"I feel bad saying it because obviously I work in the NHS, so I don't want to, you know, be criticising them, but it was a particularly bad experience for me." (Maha, 34, mother of child, 16 months, with fever, BF)

"I wasn't allowed to go and make myself a cup of tea. And so, I have to ring for a cup of tea. And again, I feel incredibly guilty about asking nurses - they're not maids." (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

Staff interaction

There were numerous examples of staff interactions that were noteworthy to the mothers. Most of these were negative. It was more common among the mothers of older breastfed children to notice obvious shock, surprise, or incredulity at the fact that they were still breastfeeding; however, this reaction was not isolated to the mothers of older children. Many mothers felt 'unusual' and sensed that staff had formed a judgmental opinion of them based on their breastfeeding status. Some mothers were frustrated by nurses projecting their own, mostly negative, breastfeeding experiences onto mothers, rather than being objective.

"...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)

"...if you do long term breastfeeding, then you get looked at like you're some kind of hippy nutter who doesn't know what shoes are... I think in the hospital, they can all look at you like you're a bit weird because you're breastfeeding an older child." (Anna, 36, mother of child, 27 months, with severe complex feeding, NG/BF)

"...feel like I was the crazy one, to the point where they sent in a female doctor to be like, why is this so important to you? And I'm like, why the fuck is it not important to you? Like, why is it not important to you? I'm not a badgering, like, weirdo here. And

even if I was, you should still be treating me with more respect.” (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

“Some nurses have been like ‘oh yeah, I fed mine until they stopped themselves’, and there are others who are like, ‘Oh...are they meant to still feed at that age, like, is it okay’, and so yeah, really, really mixed.” (Lyra, 31, mother of child, 36 months, with low IgA, BF)

Support not provided

The final subtheme identified was related to a 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. Other times support was given that was not required, and so it was perceived to be invasive. Often, what mothers craved most was just someone to listen to them and provide reassurance. The mothers in this sample mostly had established milk supplies, and primarily needed help to overcome the specific breastfeeding challenge related to their child’s clinical condition. One mother eloquently summed it up by observing that she had received more breastfeeding support in a coffee shop than she had when attending hospital with her sick child.

“...nobody asked me like, how, how are you breastfeeding? Like, is it going well, or it's not going well? Or do you need any support with breastfeeding? There wasn't much chatter about breastfeeding.” (Sophie, 31, mother of child, 4 months, with jaundice, bottle/BF)

“I had asked if the maternity hospital, if the team from maternity hospital who would support with breastfeeding there, could come and help or even phone me or anything and that wasn't possible.” (Sian, 33, mother of child, 13 months, with severe lactose intolerance, bottle/BF)

“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)

"...at one point, because they were saying, oh, how's he feeding? And I said, well, he's not feeding as well, I said, but obviously, we're in hospital and he's not well. So, they offered us some breastfeeding support. And I was like, I don't need any breastfeeding support." (Lucy, 35, mother of child, 11 months, with meningitis, BF)

"...you kind of go to Costa... 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)

5.4 Summary of analysis

Most of the mothers in this study described a range of issues arising from their child's hospital admission. Almost all the mothers found that breastfeeding was more challenging in one or more ways during their child's illness, and nearly all the mothers described breastfeeding as being a positive, nurturing interaction that provided comfort. There were many psychological challenges that were complex and related not only to breastfeeding, but the impact of their child's illness on breastfeeding. These two issues often converged to impact maternal mental health and coping in some way.

The challenges of the ward environment were related to personnel as well as equipment and resources. For some mothers, the ward was poorly resourced as well as being staffed by clinicians who were unsupportive. At other times there were buffering effects of plentiful food or pillows, or encouragement from someone. Breastfeeding a sick child not only affected breastfeeding, and the mother, but there were wider impacts on family life, finances, relationships and work that were sources of stress and struggle for families. These struggles often existed against a backdrop of staff ambivalence which made many mothers feel angry or confused that their efforts and perseverance were invalidated.

Finally, many mothers observed that there simply wasn't a solution to be found for their situation. Several mothers were resourceful and tapped into their contacts, personal

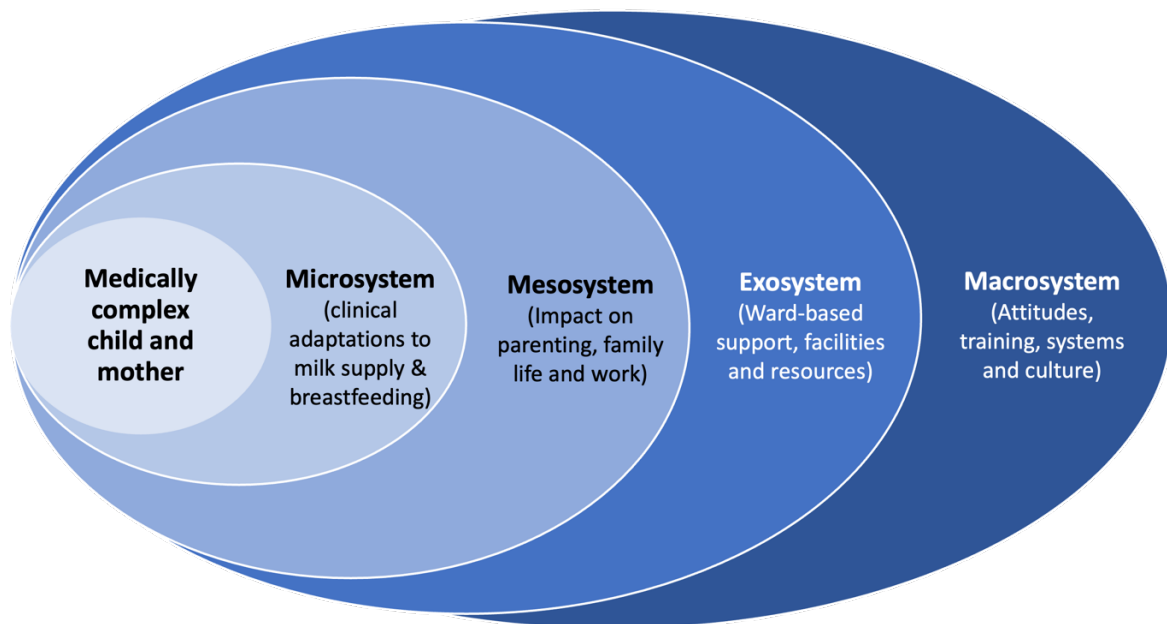
knowledge or had the financial means to source additional help. Yet the help they managed to creatively curate was not necessarily fit for purpose as nobody had a complete picture. The nonclinical lactation staff were often unaware of how to support seriously ill children, or specific clinical scenarios, and the clinical staff did not have enough skill to support breastfeeding. This left many mothers unsure of how to proceed, and a sense that they were alone in working out a plan. Some mothers were buffered by having had a previous breastfeeding experience, and a few were not only breastfeeding mothers but also peer supporters which gave them some additional knowledge which increased their confidence. A minority were experienced breastfeeding mothers and also healthcare professionals. These mothers most often described a pattern of disregarding the advice they were given by paediatric staff and falling back on their own knowledge – yet this was often accompanied by feelings of guilt.

While many mothers expressed understanding and patience for the current lack of staff and equipment resourcing in the NHS, they were frustrated at the impact this had on their care. Many mothers were able to separate lack of understanding and knowledge around breastfeeding, from the kindness of staff. However, for many mothers, the kindness of one or two staff members was not enough to cancel out the negative interactions and ambivalent or hostile culture of the ward environment.

5.5 Discussion

This study explored the experiences of thirty breastfeeding mothers of children admitted to the paediatric ward or PICU with a wide range of illnesses in the UK. It identified numerous challenges within all four layers of the medically complex child's ecosystem related to breastfeeding, parenting, mental health and staff skill and knowledge gaps as well as the clinical environment (see Figure 11).

Figure 11: Identified challenges within the medically complex child's ecosystem



While there were numerous challenges at each of the layers of the child's ecosystem, many of the challenges spanned more than one layer, and are complex and affected by multifactorial systemic issues. Therefore, while Figure 11 identifies challenges that might appear to exist in one layer of the ecosystem, the reality is that the problem is more complex than this. For example, within the first theme of the challenges of breastfeeding a medically complex child, a child's clinical condition may be defined at the surface as a microsystem factor, and yet the impact on breastfeeding is influenced by the wider family and factors at the mesosystem layer. How the condition is managed and whether breastfeeding is facilitated or obstructed is affected by the staff skill, as well as resources at the exosystem layer; and staff training, ward culture and attitudes of fellow parents on the ward are all factors that exist at the macrosystem layer. Thus, the ecological model was used not only to identify where these challenges exist in order to understand the needs of parents and children, but also to understand how the layers of the ecosystem inter-relate, which will be further discussed in the following chapter. This clearly demonstrates how factors at different layers of the child's ecological system can interact and influence each other (Onwuegbuzie et al., 2013).

The study highlights some strengths and successes in caring for families and provides insight into what measures are perceived to be supportive by mothers. It also highlights several shortcomings that are not currently addressed within paediatrics in a consistent or universally accessible way.

There were numerous challenges at the microsystem level associated with breastfeeding a sick or medically complex child. These included supporting children with serious, chronic and life-threatening illness. Several mothers of children who were profoundly unwell have struggled to maintain their milk supply, found that major adaptations to breastfeeding were required, and that there were associated problems as a result of their child's illness – such as loss of tone, challenges with positioning, changes in appetite, abnormal reflexes, respiratory compromise, iatrogenic withdrawal and fatigue or weakness. It was difficult to obtain the support they required to overcome these problems, leading many mothers to experience negative breastfeeding outcomes, breast pathology, stress and exhaustion, as well as threatened or actual breastfeeding cessation.

This aspect is supported by the findings of the systematic review which also identified many challenges associated with breastfeeding children with illness or chronic conditions, though the conditions previously studied were limited. There are several studies discussing Down syndrome (Barros da Silva et al., 2019; Colon et al., 2009; Lewis and Kritzinger, 2004). One literature review found that children with Down Syndrome have lower rates of breastfeeding and required more support (Sooben, 2012). Another study (Rivera et al., 2007) explored the complexities of breastfeeding infants with Spina Bifida and concluded it was environmental factors and lack of medical staff knowledge that interfered with breastfeeding, rather than infant instability after surgery. There have been a few studies that have explored the challenges of breastfeeding babies with cardiac defects (Lambert and Watters, 1998; Barbas and Kelleher, 2004). Torowicz et al., (2015) also studied infants with a congenital heart defect (CHD) noting that the high-stress environment makes establishing and maintaining a milk supply more challenging. There have also been some studies exploring phenylketonuria (PKU) (Banta-Wright et al., 2015) and cleft palate (Madhoun et al., 2020). Interestingly, many of the conditions previously studied are rare, such as Rubinstein Taybi syndrome and phenylketonuria. The spread of illnesses in this study was

more typical of the range of illnesses seen on paediatric wards and reflects the reality that many paediatric professionals care for children with a variety of illnesses, rather than one single condition.

In this study, the broad range of childhood illness has illuminated many previously unrecognised challenges that affect breastfeeding – 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. Many of the frustrations around breastfeeding a medically complex child were related directly or indirectly to their child's condition – for example, weight concerns, struggling to express milk, nasogastric tube feeding and exhaustion. Some of the challenges around maintaining milk supply have previously been reported in other settings, including neonatal intensive care (Alves et al., 2016). Unrelated to breastfeeding, other studies of parent experiences in PICU have also reported issues related to powerlessness and exhaustion (Dahav and Sjöström-Strand, 2018; Alzawad et al., 2020). However, there were also challenges that were related to institutional factors and lack of awareness, such as fluid charts that were incompatible with responsive breastfeeding.

The second identified theme related to the wider importance of breastfeeding a sick or medically complex child. Breastfeeding was perceived to provide immunological support, as well as non-pharmacological pain relief, post-procedure comfort, and connection. One mother described her postoperative child's pain from being in ileus as unmanageable despite morphine and ketamine, but breastfeeding provided effective pain relief. Another mother managed her child's emergence delirium by offering close contact and breastfeeding. Two children in the study were on multiple types of chemotherapy and yet had no mucositis which is normally extremely common among immunocompromised children with cancer, affecting up to 100% of patients (McCulloch et al., 2018; Zhao et al., 2022). Many mothers expressed frustration that there was no research to validate clinically significant observations such as pain relief or prevention of mucositis, though their lived experience was enough to convince them that breastfeeding was clinically important. While some literature supports breastfeeding as a tool for pain relief (Shah et al., 2015; Harrison et al., 2016) this is currently limited to needlestick and vaccination pain relief; whereas the

mothers in this study were reporting effective pain relief from more invasive and painful procedures and post-surgical pain.

Beyond the observable benefits of continuing to breastfeed, such as pain relief, many mothers reported that breastfeeding provides a link to normality and provided a parenting tool in an environment that was often hyper-clinical and disempowering. Other positive aspects included a sense that breastfeeding enabled mothers to perceive clinically relevant micro-changes in their child. Breastfeeding was also a way to observe whether their child was improving or deteriorating, as their illness behaviour often affected their feeding and vice versa. This echoes findings from the neonatal intensive care setting in terms of breastfeeding leading to increased self-efficacy, establishing an identity as a mother, involvement and sense of agency (Flacking et al., 2007; Butler et al., 2014). Emotional connection, normality, comfort and stress-reduction through breastfeeding are also valid and important reasons to preserve it (Ekstrom and Nissen, 2006; Murray et al., 2007; Moberg and Prime, 2013).

Notably, many of the mothers in this study could be described as motivated – due to their duration of breastfeeding, and in many cases fairly extensive knowledge of breastfeeding. Several also had qualifications as peer supporters or were health professionals. Therefore, many of the mothers had knowledge that would not be reasonably expected of all breastfeeding mothers. In addition, several had breastfed a child before and most had been breastfeeding the child in the study for a significant length of time, and thus had extensive and intimate knowledge of their child's feeding patterns and illness behaviour. Only two mothers in this sample stopped breastfeeding either because of their child's condition, or due to an iatrogenic cause. This may be an under-representation of the true proportion of mothers who would find it impossible to persevere through medical complexity given that these mothers were particularly motivated and most of them were well-informed and had access to further resources. However, despite the high levels of motivation seen among the mothers in this sample, most of them specifically commented that they needed help to overcome their breastfeeding challenge. Some of them persevered through significant challenges at considerable cost to their physical or mental health, whilst others were able to curate their own package of support from numerous sources which was convoluted. Many

of the mothers commented that they were concerned about parents who were less confident, motivated or resourceful. The implied concern here is that if breastfeeding a medically complex child in paediatrics is difficult for a motivated and well-informed mother who may have medical or lactation knowledge, the challenges may be insurmountable for those without this knowledge as a buffer.

The third theme related to the complex psychological impacts of breastfeeding sick children particularly among the mothers of children with more severe or long-term illness. Some experienced conflicting emotions - such as feeling compelled to continue breastfeeding and also wanting to stop. These conflicting emotions and difficult decisions have previously been reported in other studies, though not related to sick children (Dowling and Pontin, 2017; Jackson and Hallam, 2021). Others were exhausted and wanted a break but did not want to leave their child. Trying to make sense of opposing feelings whilst also continuing to persevere with breastfeeding in an environment where it was neither facilitated nor encouraged was infuriating. There was often a sense that breastfeeding took so much effort to achieve, that the insinuation from health professionals that stopping breastfeeding was the easier option led to many mothers feeling unsupported. Some mothers had experienced trauma, often not just once but on multiple occasions and noticed that this affected their ability to express milk. While trauma has previously been identified among parents whose children experience a life-threatening illness or event (Mortensen et al., 2015; Muscara et al., 2015; Woolf et al., 2016; Foster et al., 2017), the effects of trauma on breastfeeding in paediatrics are unstudied. The identified challenges of expressing milk in this stressful environment may support the extension of donor human milk provision into the paediatric setting as a measure to augment a mother's efforts to keep her child exclusively breastmilk fed, which has been shown to promote parental mental health (Brown and Shenker, 2022).

Guilt was a frequently occurring emotion, especially when mothers acknowledged their frustration with their situation, or were honest about their mixed feelings about stopping breastfeeding versus continuing. They sometimes felt guilty for wanting to stop because they were convinced of the immunological benefits as well as the comfort that it provided their child. During significant illness, breastfeeding was felt to provide a layer of protection and the thought of withdrawing that made some mothers feel like this would be a selfish

decision. Many of the mothers were extraordinarily stoical and resilient. Some of the children were seriously unwell – including long PICU admissions, multiple surgical procedures, serious and profound medical complexity, uncertain prognoses and multiple invasive interventions and treatment. Yet, despite this, most of them had very positive outlooks, were fierce advocates for their children, and were patient and tolerant of extremely disruptive healthcare that affected nearly every aspect of their personal and family life. Notably, although this resilience was obvious, the mothers spoke honestly about how difficult their children's conditions were and the impact that this had on their mental health to a greater or lesser extent.

Many mothers described profound disempowerment and a sense that they could not challenge poor care or illogical advice. Several mothers in this study were highly educated or qualified and *still* felt powerless to challenge the advice or care provided. One mother was a virologist and found the isolation rules nonsensical; and yet in this position of being in receipt of care for her child who was acutely unwell, she felt disempowered and blamed herself unnecessarily for factors that should not have been her responsibility to address. Another mother was a doctor and identified as a confident woman yet when faced with extremely inappropriate communication, although she was able to challenge the doctor, she was angry with herself for crying.

One worrying indictment of the care that some of the mothers had received was that it had put them off seeking help for their child in the future, or moderated the information they chose to share with healthcare professionals. A few mothers were deeply distrusting of their care providers and have either delayed seeking care, or have omitted details because they were worried about what advice would be given to them if they were honest. This selective filtering, or modification of information-sharing was twice mentioned by healthcare professionals, and it is unclear to what extent these mothers felt buffered in their decision making by their clinical training, or how likely this behaviour would be among non-clinical breastfeeding mothers. One mother did clearly express a sense of doubt and guilt over this withholding of information, but still felt that ultimately it was clinically appropriate.

Finally, within the theme of psychological impacts, some mothers had clearly experienced traumatic events, often not just once but on multiple occasions. While trauma has previously been identified in other literature among parents whose children experience a life-threatening illness or event, the effects of trauma on breastfeeding within that clinically traumatic environment have not been studied. Stress, trauma and anxiety are frequently described by parents (Mortensen et al., 2015; Muscara et al., 2015; Foster et al., 2017) and other research recommends that parents are provided with adequate psychological support during hospitalisation of their child for a life-threatening condition (Smith et al., 2015; Pelentsov et al., 2015). Some parents develop post-traumatic stress disorder (PTSD) after watching their child becoming profoundly unwell, witnessing their child's resuscitation, or receiving a diagnosis of a life-threatening disease or condition (Woolf et al., 2016). Indeed, one mother in this study was describing several symptoms of PTSD and remarked that had several months not elapsed between her child's respiratory arrest and the interview, she probably would not have been able to discuss it. Several mothers described not being able to express milk until the crisis was over, and a few mothers found that breastfeeding only really returned to normal once they were home. The literature has clearly identified trauma as a potential problem for parents of very unwell children. In the neonatal intensive care unit it is common for trauma to be acknowledged – which means that mothers sometimes access targeted support to assist them with pumping. However, the effect on lactation has never been studied within paediatrics; and within the neonatal setting the focus is usually on supporting mothers to express milk. The impact of paediatric trauma specifically on direct breastfeeding is an unstudied area of lactation support.

The fourth theme highlighted many ways in which breastfeeding affects and is affected by family life and parenting at the level of the child's mesosystem. This theme had many positive and negative subthemes. Breastfeeding is often facilitated by bedsharing and, indeed, this aspect of parenting was raised as an issue by numerous mothers in this study. It is known that mothers who sleep in close proximity to their infants are better able to respond promptly to early feeding cues, supporting more cue-based care which is protective of optimal feeding (Brown and Arnott, 2014; Ventura, 2017; Little et al., 2018). Bedsharing while breastfeeding, coined 'breastsleeping' (McKenna and Gettler, 2016), facilitates more rest and thus makes breastfeeding for longer durations more sustainable for mothers

(McKenna et al., 2007; ABM, 2008). Bedsharing also reduces the time it takes to settle infants and young children and keeps them calmer. This was commonly not facilitated on the paediatric ward and sometimes resulted in very upset children and distressed mothers who achieved very little sleep as a result. From a clinical perspective the challenges of supporting bedsharing in paediatrics are longstanding and what has been illuminated in this study is the inconsistent nature of guidelines around bedsharing. While blanket statements are inappropriate due to the variable clinical needs and vulnerabilities of the children on paediatric wards, more clarity is urgently required for families.

Sometimes there was a blanket ban on bedsharing and at other times this seemed to relax when children were older, though there was no clear cut off age; and the policies around this decision making were inconsistent between hospitals. Some mothers were intensely angry about the opposition to bedsharing especially when the alternative was a screaming child, or having to sit up all night in a chair which they knew was unsafe. Their outrage was heightened by the contradictions between what they were aware of within research around safer sleep, and the lived experience on the ward. Furthermore, many mothers ended up taking their child into the parent pull-out bed which was universally felt to be less safe than a large hospital bed with solid bed rails.

The challenges of bedsharing were closely related to the sense that responsive parenting was not valued or understood in general. Many mothers were discouraged from holding their children. Two mothers of infants receiving phototherapy were not told that breastfeeding breaks of up to 30 minutes do not affect treatment efficacy and were discouraged from holding their infants (Sachdeva et al., 2015; Flaherman et al., 2017). Two other infants in the study were critically unwell on PICU, and skin-to-skin was neither encouraged nor facilitated. Skin-to-skin contact has no upper time limit and an abundance of literature points to this intervention being appropriate for sick and low birth weight neonates (Johnston et al., 2009; Blomqvist and Nyqvist, 2011; Salim et al., 2021; Charpak 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 (McGlone et al., 2014; Pawling et al., 2017; Berecz et al., 2020).

Another issue raised by many mothers was the challenge of juggling children, work, and all their other commitments. There was often a sense of 'life on hold' for an uncertain amount of time while their child's condition evolved with an uncertain course. Many participants were stoical about this and yet it was clear that juggling, especially when it involved other children, was a source of stress that was not well supported.

The fifth theme was distinctly related to the ward environment and equipment, which alludes to challenges that may exist at the exosystem, but also affect functioning at the mesosystem level. Many mothers remarked that it was hard to meet their basic needs while resident on the paediatric ward with their child. Some of the children were cared for in isolation rooms which had the advantage of having a private toilet and often a shower, as well as affording more privacy. The downside of those facilities was that mothers often felt more isolated. One parent described her room as a 'prison'. For the mothers whose children were nursed on open bays, there were shared facilities, but this often meant that they had to ask a nurse to watch their child while they went to the toilet. Many mothers felt guilty for asking nurses to do this, and yet there was no practical alternative. One mother found showering and using the toilet extremely stressful because there were no locks on the bathroom doors. Another mother was worried about needing to use the toilet which would have meant leaving her child, so she avoided drinking fluids while waiting in the emergency department. As a result, she was profoundly thirsty and dehydrated by the time she arrived on the ward and felt that her milk supply had suffered.

A closely related issue was the discrepancy of food provision. While some hospitals provided abundant and unrestricted food and snacks, others had complicated rules or inconsistent provision. While some had food brought in from home, other mothers described having to sustain themselves on their children's leftover discarded food supplemented by snack foods available in vending machines. Many described being hungry often; and having to buy food from the hospital canteen or on-site shop caused frustration, as well as financial anxiety, particularly with longer admissions. The problem of overlooking basic needs is a finding echoed in other studies of parents in the PICU setting (Shudy et al., 2006; Berube et al., 2014) and suggests that clearer provision for families whose children are unwell in the paediatric setting is needed.

Several mothers were frustrated with the furniture on the ward or PICU, which was usually not conducive to comfortable breastfeeding. Several commented that their child fed more effectively lying down, but this was difficult on very low, flimsy and narrow parent beds. Sometimes the parent beds converted from chairs, so when children fed best sitting up their mother had to dismantle her bed in the middle of the night, convert it to a chair to feed and then turn it back into a bed to sleep in. One mother whose child was admitted for safeguarding concerns unrelated to the mother felt like she was being watched and so did not feel able to bring her baby into her bed anyway for fear that this would be frowned upon. Other mothers complained about the chairs generally not being comfortable due to armrests being in the way, or the chairs being very hard. Some of those problems could have been overcome by the provision of more pillows to render the chair more comfortable, or to position larger children, or those with large wounds more comfortably. Yet pillows were often in short supply and thus this was not an option for many.

The lack of availability of pumps was an extensive problem for numerous mothers. The core issue for most wards was that there were no designated pumps for the paediatric unit. Staff sometimes tried to obtain a pump by calling the postnatal ward or NICU, but this only occasionally resulted in a pump being made available. Sometimes there was just one pump for the whole department, or the pump was broken. Many mothers brought their own pumps in from home to overcome the frustration with lack of equipment. There were no pumping rooms on paediatric wards either; and often the storage was limited, with a few incidents of milk being discarded due to lack of space and lack of knowledge of human milk storage guidelines. Often when mothers were provided with a pump there were no instructions for its use and sometimes this meant that mothers could not use the pump. While literature exists exploring the challenges of pumping on neonatal units and the reasons for pumping in healthy term neonates, there are no studies that explore the challenges of pumping on paediatric wards or the shortage of breast pumps in paediatrics (Johns et al., 2013; Bower et al., 2017; Bujold et al., 2018).

Finally, within this theme, a recurrent issue of privacy was raised by many of the participants in this study. As mentioned, privacy was sometimes achieved through children and their mothers being in isolation rooms due to clinical vulnerability, or infection control policies

and mostly they valued having their own space. Some members of staff were courteous and respectful asking whether they had permission to enter. These examples were notably most common among domestic and housekeeping staff, though there were one or two clinicians who also behaved in this way. However, some of the mothers remarked that staff members would peer through the blinds on the outside of the room and if they noticed the mother breastfeeding, they immediately left. Similarly, some members of staff entered the room, saw a mother breastfeeding and turned around. This was frustrating to mothers on two counts. Firstly, most of the mothers had no reservations about feeding in public and this treatment of them made them feel ashamed and angry. Secondly, they were often waiting for test results or news of their child's condition or treatment, so it was doubly frustrating to see the staff member, knowing that whatever results they were about to deliver would be further delayed for reasons that were, in their eyes, unnecessary.

There was also a distinct occurrence of 'enforced privacy' for several mothers. This code was used whenever mothers described staff shutting curtains without asking, closing doors, turning lights off, or leaving the room. It was frustrating for mothers as it was privacy they had not asked for and didn't feel they needed or wanted. One mother was mid-conversation with a mother on the opposite side of the ward when a staff member closed the curtains around her because she was breastfeeding. Conversely, there were also times when mothers wanted privacy, but this was not respected or provided. There is clearly a need for nuanced and individualised provision of privacy that is offered, but not enforced, so that it meets the needs of families.

The sixth theme around lack of skills and knowledge highlighted several interesting and important aspects around the gap between paediatric support and lactation support. These issues represent challenges that occur at the exosystem (ward) level but are directly influenced by policies, national training programs and attitudes within the macrosystem. Considering some of the challenges of breastfeeding medically complex children identified in theme one, it was clear that mothers needed support that met their unique needs. There are several problems with provision of breastfeeding training that were identified in the first study of health professionals. Most paediatric professionals receive little to no breastfeeding training as part of their undergraduate education and many studies have

highlighted gaps in knowledge among paediatric nurses (Holaday et al., 1999; McLaughlin et al., 2011; Brewer, 2012; Colaceci et al., 2017). Thus, many healthcare professionals who have clinical oversight for breastfed children have no training in how to support breastfeeding or maintaining lactation. It is therefore unsurprising that no mother-child dyads received a breastfeeding assessment in this study, and many received inaccurate or inappropriate advice. It also explains why there was little to no awareness of breastfeeding for non-pharmacological pain relief and little encouragement for responsive parenting.

Current breastfeeding training is weighted towards the initiation of breastfeeding in healthy term newborns (WHO, 2020) with some additional training available for those providing care to 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, in this study, even when a member of the maternity infant feeding team visited the family the advice was still lacking. In this study several mother-child dyads experienced problems for which the staff had no experience or training, such as breastfeeding with respiratory support and airway difficulties, large fluid and stoma losses, and challenges of managing high calorie need and fluid restriction. These challenges would not be adequately addressed by current training. This was evident in many of the mothers reporting that the care they received did not meet their needs. With complex feeding challenges, the only effective feeding support was provided by dual qualified lactation and paediatric clinicians. Mothers sometimes tried to access support from community resources, non-clinical IBCLCs, and infant feeding leads from other departments, but this was rarely successful.

While many mothers valued encouragement in any form, when it came to practical advice that was fit for purpose 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 non-clinical lactation advocates. This is unsurprising as management of many of their challenges would be outside the scope of practice of an IBCLC (IBLCE, 2018) because assessment of unwell children would be required to curate a care plan – for example iatrogenic withdrawal, loss of reflexes, respiratory compromise, and complex fluid needs. These findings suggest that non-clinical and non-paediatric lactation supporters may need additional training to be able to support children with more complex

health challenges; equally paediatric professionals need lactation training to be able to integrate lactation and clinical support for families. It also suggests that 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 uphold their feeding goals.

The mothers whose children had significant feeding challenges had good outcomes when they were seen and assessed by dual qualified lactation and health care professionals, one time this was a paediatric and neonatal nurse who was also an IBCLC, and another time it was a paediatrician who had researched and worked extensively with breastfeeding dyads. This confirmed the views of healthcare professionals who identified their own need for training that is targeted towards meeting the needs of medically complex children in paediatrics. Without this nuanced training it is somewhat understandable, though frustrating, that many professionals default to suggesting formula. When they do not have the ability to manage or support breastfeeding, and they are trying to treat unwell children, one of their first priorities is to ensure they have enough fluids. Unfortunately, if breastfeeding becomes problematic, and there are no pumps immediately available with the knowledge of how to use them, the only option for many families will be formula.

Finally, in relation to ward culture and staff attitude there were numerous examples of both positive and negative communication. Ambivalence was common, but there were also examples of both exemplary and substandard care. Mothers tended to have more positive experiences overall 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 and Koulierakis, 2019). Equally, it has been found that practitioners who are empathic can improve a patient's psychological condition and satisfaction with care (Howick et al., 2018). Mothers sometimes reported feeling as if their feeding choices did not matter – either clinically, or to the staff. This was often interpreted as the professionals being uncaring, or not acknowledging the effort of breastfeeding. While these mothers' efforts were not actively sabotaged, they were not encouraged either, and some described sadness that something they had worked hard to achieve was viewed so neutrally. There is a need for professionals to improve the individualisation of the health and lactation care

messages they deliver. This has been termed 'agenda matching' in other settings, and leads to more therapeutic communication (Rothman, 2016).

Fundamentally many of the children were experiencing specific breastfeeding challenges that often required expert clinical and lactation knowledge to solve. However, a good starting point was compassion and listening. Beyond this, families seemed to appreciate being encouraged in their breastfeeding efforts even if they could not find an answer to their specific problem. For some families represented in this study, their experience of care might have been perceived as more positive because they did not actually have any specific need for tailored breastfeeding advice or support. In this sense, all the staff had to do for a mother's experience to be perceived positively is provide food, offer encouragement, and show compassion. None of those aspects of care are directly related to breastfeeding and yet they form a baseline from which more meaningful interaction can take place.

There are therefore many ward and culture related variables that can affect the experience on the ward – provision of basic care, privacy and dignity, kindness, and treating people with respect. Layered on top of this is the attitude of staff towards breastfeeding and, beyond that, whether they have any additional skills and knowledge in breastfeeding support. Arguably the biggest variable is how complex the parent and child's breastfeeding needs are and how much support they require.

Within the theme of ward culture, there were several levels of support or lack of support described. At the extreme negative end of the scale practitioners occasionally displayed signs of open hostility, such as appearing horrified, sneering, or making negative remarks. Expressions such as 'starving your baby' or being 'selfish' for wanting to persevere with breastfeeding were coded under the theme of hostility. While not all were openly hostile, some professionals had a negative attitude towards breastfeeding that was obvious from the advice they gave. Inaccurate information is coded as a negative, because it could derail breastfeeding if it is followed.

Another common negative response was staring, surprise, and doing a 'double take'. This was particularly common among mothers of older infants and children. These negative

reactions have previously been reported outside of the paediatric clinical environment, with mothers of children who are breastfeeding beyond the age of one year tending to conceal their 'extended' breastfeeding status, including from medics (Thompson et al., 2020; Jackson and Hallam, 2021). It is of course much more difficult for mothers to conceal their feeding status in hospital where nutrition is an integral part of a child's care, thus many mothers were subjected to the reactions of staff. There were also subtle nods to this with mothers being offered formula before being asked how they were feeding their infant, and at other times staff asking questions that made it clear that they felt formula feeding was the norm. For example, being asked how many bottles they drink, or whether their child was 'off their bottles' because of illness.

Mothers sometimes reported feeling invisible, as if their feeding choices did not matter, or that professionals had a neutral opinion about their feeding choice. Rather than this being perceived as accepting, this can be interpreted as the professionals being uncaring, or not acknowledging the effort and work of breastfeeding. There was a sense from many mothers that the professionals did not seem to validate or encourage the additional effort they often made to persevere with breastfeeding. Many felt that the staff did not want to pressurise women into breastfeeding and had perhaps been told to be neutral in order to prevent giving offence. But this is an example of how paediatrics is different from the maternity setting. While some mothers who have just given birth and feel ambivalent about breastfeeding interpret encouragement to breastfeed as 'pressure', in paediatrics breastfeeding is more likely to be established. This is a different context, requiring a different approach. If the mother is already breastfeeding, then supporting them to continue is not pressurising but facilitating an existing and meaningful parental feeding decision.

Passive acceptance can be damaging because the absence of criticism in and of itself is not necessarily a positive. Many mothers were grateful not to have suggestions to stop breastfeeding, but equally this response was interpreted by some as uncaring. Examples of ambivalence included asking questions such as 'is your child bottle or breast fed', with no further comment, question, or validation. While these mothers' efforts were not actively

sabotaged, they were not encouraged either, and some described sadness that something they had worked hard to achieve was viewed so neutrally.

Encouragement and praise without having any practical problem-solving was viewed positively. Simply being told 'well done' meant a lot to the mothers, even when they had to find breastfeeding support elsewhere. Being kind and reassuring was protective of parental self-esteem, even in the absence of any breastfeeding information. Other studies have found that when parents feel like they are more involved in collaborative decision making and valued for their input, they feel more empowered (Ashcraft et al., 2019; Reeder and Morris, 2020). Whilst being kind in general should be the minimum standard, it should additionally become part of a ward culture of kindness to actively listen to mothers' feeding choices with more open-mindedness. Beyond practical support such as food provision, some mothers were able to find someone who could answer their questions. These individuals were not always located on the paediatric ward but were often described as having 'saved' the breastfeeding journey. This type of support was not proactive though and mothers had to look for it, so this may be a level of support that is only accessed by those who are confident, articulate, persistent or motivated.

Whilst this was not described by any of the mothers in this study, the logical next step to improving care for families would be to enquire about feeding status on admission to the ward; with clear documentation of breastfeeding and an individualised approach to advice and support to meet the needs of the nursing dyad. In practice this means aligning clinical care and management with the feeding goals of the parent and being willing to be flexible about how care on the ward is managed in order to protect, accommodate and value breastfeeding as an important intervention and supportive measure in its own right. The best-case scenario would be support that is not only reactive, as in the previous level of support, but proactive. This means that infant feeding is considered as an equally important part of clinical and family centred care and informs all future decision making. Potential problems are considered in advance and efforts to reduce the likelihood of these problems having a negative effect on intended feeding goals are made. Agenda matching is an intervention where a parent's level of knowledge is established, rather than assumptions made about what information the parent needs and scripted care being offered by rote.

Rather, the parent is listened to and any gaps in care, support, or knowledge are filled in to meet the needs of the individual parent. As part of this proactive approach, information about potential future problems is provided to equip mothers to overcome likely hurdles as they transition from one ward to another, one stage of treatment to another, or from hospital to home.

5.6 Study limitations

There were several limitations of this study. Firstly, although thirty mothers were within the recommended range for a qualitative study utilising in-depth interviews, it was nevertheless a small sample of mostly highly motivated mothers. Any speculative assumptions about whether breastfeeding challenges would be more difficult among less experienced or motivated mothers must be cautiously suggested. Secondly, this sample of mothers was recruited via an online advert for numerous reasons as discussed in Chapter 3 and the Design section of this chapter. The disadvantages of online recruitment were mitigated somewhat by a very large social media reach and hundreds of initial potential participants. The screening questionnaire was also intentionally vague about the experiences of families and 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. However, mothers who elected to take part were more likely to have been invested in this subject and so this may not be a representative sample. Thirdly, while this is the only study that has explored the challenges of multiple different medical and surgical conditions among breastfeeding dyads in several different paediatric wards in the UK, understandably not every child with these conditions will have the same challenges – and there are hundreds of other conditions *not* represented by this sample. Whilst it is useful to have a more varied sample, further studies could explore other childhood illnesses and recruit larger samples.

5.7 Conclusion

This study identified numerous challenges at every level of the child's breastfeeding ecosystem. The experiences of mother-child dyads with 26 different conditions, in 30

different UK hospitals, and a range of severity of illness and duration of stay 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 clear gaps in service provision that exist in paediatrics. Thus, mothers and children who require more advanced lactation support may be disproportionately affected by the ward culture and staff attitudes and knowledge. There were widespread gaps in staff skill and 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. It is clear from triangulating Studies 1 and 2, that both mothers and professionals have a strong level of consensus over what the challenges of breastfeeding medically complex children are. There was convergence in themes around the need for additional skills, as well as some of the barriers to breastfeeding sick children. Professionals often identified that which mothers eloquently described – breastfeeding is not generally well-supported in paediatrics. The next chapter will discuss how Studies 1 and 2 can be interpreted, the implications for practice, and recommendations for future research and practice change.

Chapter 6

Discussion

This thesis sought to more fully understand the challenges of continuing to breastfeed or provide breastmilk when a child is sick or medically complex in the paediatric setting. Two related studies were designed to establish the skills, knowledge and attitudes of paediatric healthcare professionals, identify what the gaps and barriers are; and ascertain how both the barriers as well as specific lactation challenges affect the experiences of mothers trying to maintain lactation with their sick children. The studies found that health professionals have many gaps in knowledge, and there were also numerous breastfeeding challenges for mothers of sick children, including several that are previously unreported. Overall, this suggests that the paediatric setting is poorly equipped to support breastfeeding.

6.1 Triangulating the studies

Because of these gaps identified in the systematic review, two related research studies were designed which together aimed to address the research questions and identify challenges and barriers at every level of the medically complex child's ecosystem. The first study sought to understand the knowledge, self-identified skills, perceived barriers and attitudes of healthcare professionals working in paediatrics. The second study recruited mothers of medically complex children to explore their specific breastfeeding challenges, their motivation to breastfeed their sick children, and the institutional and environmental barriers they encountered. There were many areas of concordance between the two studies and the findings are triangulated below to answer the five research questions.

6.1.1 RQ 1: What is the current breastfeeding training provision at undergraduate level for healthcare professionals in the UK, and is this felt to be adequate?

Several studies have found that breastfeeding training for physicians and nurses is inadequate (Holaday et al., 1999; McLaughlin et al., 2011; Brewer, 2012; Sattari et al., 2013; Radzyminski and Callister, 2015; Colaceci et al., 2017; Michaud-Letourneau et al., 2022),

particularly regarding practical breastfeeding support skills (Biggs et al., 2020) and many healthcare professionals default to their own experiences of breastfeeding (Finneran and Murphy, 2004; Brodribb et al., 2008; Gonzalez et al., 2014; Pound et al., 2014; Moukarzel et al., 2018; Baker et al., 2021; Boss et al., 2021; Stoliar et al., 2022). However, much of this research has taken place in the maternity or neonatal setting with only a limited amount of data relating specifically to paediatrics (Holaday et al., 1999; McLaughlin et al., 2011; Pound et al., 2014; Baker et al., 2021), and no data has previously been gathered that reflects the multidisciplinary nature of the paediatric environment. This was a crucial gap because dietetic and speech and language involvement is common among children with medical complexity (Orton et al., 2018; Stute et al., 2020; Garvey et al., 2020; Fazel et al., 2021). Thus, the first study was designed to elucidate the skills and knowledge of as many healthcare professionals who would be likely to be involved in the care of a medically complex child as possible. The study included doctors at all grades, paediatric nurses, allied health professionals and healthcare assistants with a variable amount of experience post qualification.

In terms of undergraduate training, 66.5% of the healthcare professionals did not have any breastfeeding training and almost all the participants who had received undergraduate training felt that their training had not equipped them to provide lactation support to families on the ward. This was mirrored in many of the mother's experiences in the second study. In this second study, 63.3% of the mothers felt that the advice they were given did not meet their needs; many found that nobody on the ward was able to answer their questions, or support breastfeeding in a meaningful way. Some professionals felt that in certain clinical environments they did not need to know about breastfeeding as they rarely encountered the need to support a mother and child. However, some of the mothers found these intermediate areas such as accident and emergency, clinic waiting rooms, outpatient departments and theatre and recovery to be stressful. This was in part due to the lack of awareness of breastfeeding, lack of anticipatory guidance, and lack of welcome for breastfeeding in these environments. All these basic problems could potentially be addressed through a simple training curriculum at undergraduate level for all healthcare and allied health professionals.

There was some hostility noted regarding whether breastfeeding was important, whether it was felt to be part of the core role of a paediatric healthcare professional, and whether specific paediatric breastfeeding training would be welcomed. Hostility around breastfeeding is not a new phenomenon, with reports of breastfeeding in the workplace and in public being unwelcome, despite the widespread public narrative of the advantages of breastfeeding (Grossman, 2012; Brown, 2015; Gatrell, 2019; Huang et al., 2020; Čatipović et al., 2022). However, most participants were positive about breastfeeding and recognised that specific paediatric specific training was necessary to help them overcome the challenges faced by their patients and families. Indeed, some of the mothers in the second study found that healthcare staff were generally positive about breastfeeding, yet they often did not know the answer to their questions. The general positivity combined with ineffectiveness, while supportive to some extent was perceived to be, on balance, frustrating. This was more pronounced among the mothers whose children were more seriously unwell or had more complex feeding difficulties and led to a sense that they were on their own.

Most of the professionals further recognised that their knowledge of breastfeeding largely comes from their personal experience; this was also evident in many of the mothers' experiences, with most of them reporting that staff would often ask around to see if any of their colleagues had breastfed or deferred to their own experiences of breastfeeding – whether good or bad. It is clear that undergraduate training is mostly either too brief and ineffective, or non-existent for medical practitioners, paediatric nurses and allied health professionals. Furthermore, undergraduate training of healthcare professionals would be welcomed by the majority. This could lead to more integrated development of clinical care plans that dovetail with appropriate feeding management. The development of undergraduate integrated infant and young child feeding training within the clinical curriculum would avoid breastfeeding feeling like a 'bolt-on' where advice needs to be reverse-engineered to accommodate or prioritise clinical care.

6.1.2 RQ 2: What are the perceived skill and knowledge gaps of professionals, do the gaps differ by professional qualification, and would these be addressed by currently available training?

There was no significant difference in breastfeeding skills and knowledge between different professional groups. The main factor that affected the depth and breadth of clinical lactation skills was training. A small percentage undertook further training in their own time post-qualification, ranging from short courses in breastfeeding, to more extensive training as peer supporters, breastfeeding counsellors and IBCLCs. Generally, the more extensive the breastfeeding training, the higher their skill score. This was reflected in the few instances where mothers had positive experiences of an encounter with a dual qualified paediatric clinician and lactation advocate. Without exception, mothers described these interactions positively and valued having someone who could address both their child's clinical needs, but also their feeding needs, and simultaneously support them with the psychological and emotional aspects of feeding and parenting their sick children. However, these encounters were rare, which matched the findings in the first study. The survey of health professionals found that 70.4% of health professionals had no breastfeeding training at all, and only 13.6% of this generally motivated sample had extensive breastfeeding training – classified as peer supporter, breastfeeding counsellor or IBCLC. So, while these professionals were effective and demonstrated high levels of skill and knowledge both on the health professional survey and with mothers, this combination was uncommon.

Many of the healthcare professional participants commented that the training currently provided is not paediatric specific, focused on establishing breastfeeding in newborns and would not significantly add to what they already know. This may have led to a high proportion of professionals not seeking breastfeeding training because they could not see the value at the present time. Previous research has found that breastfeeding training is often lacking in practical information, focuses more on theory (Radzynski and Callister, 2015; Biggs et al., 2020; Mulcahy et al., 2022) and that currently available training is not specific to the needs and challenges of medically complex children in paediatrics (Baker et al., 2021). Most professionals recognised that different skills were needed and wanted specific training and a paediatric infant feeding team; this recognition of their skill gap was

reflected in the skill scores. While many professionals had basic skill gaps that would be addressed by mainstream breastfeeding training, there are also identified gaps that are specific to paediatrics and these skills were generally lacking amongst the participants, except for those with additional training who scored higher and more consistently the more extensive their training.

Again, there was concordance with the parent study in this regard, because many of the mothers were frustrated that evidence of knowledge of relatively simple breastfeeding fundamentals was missing from healthcare professional advice and care plans. This was apparent with a widespread practice of asking mothers to write down how long their child had been feeding at the breast to attempt to quantify fluid balance. The mothers in this study were often upset that this arbitrary measure of milk intake was being relied upon, rather than the clinician undertaking a breastfeeding assessment and demonstrating knowledge and understanding of the principles of responsive feeding. While there is no research on the unsuitability of recording infant feeding duration in minutes on fluid charts in paediatrics, there is substantial literature on the inadequacy of measuring feeding using infant feeding tracker applications which record no more meaningful data than that which would be captured on a fluid chart (Meedya et al., 2019; Dienelt et al., 2020).

Very few professionals felt confident assessing milk transfer with a breastfeeding assessment, this was also reflected in the parent study where none of the mother-child dyads had a breastfeeding assessment. Many of the mothers felt that there was a strong culture of using formula and recommending inappropriately large feed volumes due to a fundamental lack of understanding of breastfeeding and normal fluid intakes of breastfed children. This is likely to be due to a combination of anxiety over insufficient intake particularly when it is unquantifiable, but it may also be because they are unaware of, or not trained to use a breastfeeding assessment tool. A recent systematic review of breastfeeding assessment tools for malnourished infants noted that none of the 29 tools reviewed met all the needs of an at-risk infant being assessed, and all measured outcomes in different ways (Brugaletta et al., 2021). This reflects the uncertainty of how best to record and measure the effectiveness of breastfeeding – and this may be even more true for the heterogeneous population in paediatrics. The default position to either provide infant formula, give large

feed volumes, or request mothers to express and give their breastmilk by bottle or NG tube may reflect not only fear of poor infant outcomes such as dehydration, but also a wider lack of confidence not only related to measuring breastfeeding, but also the tools with which to do so. In the absence of a clear consensus on how to accurately assess breastfeeding to maintain clinical safety, perhaps it is inevitable that practitioners who lack experience in observing normal feeding patterns would choose an option that, on the face of it, appears to safeguard against adverse outcomes.

Many of the mothers in the second study also described frustration that nobody was able to help them with more complex problems. Children with severe airway conditions, major cardiac and gut conditions, vocal cord palsy, complex fluid needs, and cancers appeared to encounter the biggest knowledge gaps and were the most likely to be exposed to poor or insufficient advice. This is perhaps unsurprising because these conditions are minimally, and in some cases entirely unresearched in terms of breastfeeding outcome. There are two case reports of tracheostomy-dependent infants who were supported by speech and language therapists and a lactation consultant to achieve direct breastfeeding with some supplementation of fortified expressed milk and formula (Van Osch et al., 2022; Graham, 2022). There is some promising research beginning to be undertaken by speech and language therapists who are experts in assessing and managing dysphagia and other disorders of the airway. However, there is still a reliance on using videofluoroscopy to assess the efficacy of swallowing and the presence of aspiration despite this being an inappropriate intervention for a breastfed child because it involves imaging the child while they are bottle fed. Videofluoroscopy can only assess the safety of feeding from a bottle, which is an entirely different mechanism to breastfeeding. In a recent study most of the mothers of children with surgically acquired vocal cord palsy following surgery for congenital heart conditions had long-term feeding problems. They commented that more support from lactation consultants and speech and language therapists would have helped them to manage their child's feeding condition and reduce their stress levels (Pettigrew et al., 2022).

Frustratingly, there is still a predominance of using bottles, albeit in a responsive style - such as elevated side lying - with infants with complex conditions (Hunt and Olney, 2022). Although some studies comment on the improved clinical outcomes when using breastmilk

for critically unwell children, they rarely explore how to achieve direct breastfeeding whilst simultaneously noting that it is possible. One study discussed the positive initiative of using breastmilk for trophic feeds to prime the gut in critically unstable infants undergoing open heart surgery, many of whom had complications such as surgical chylothorax, vocal cord palsy and necrotising enterocolitis, but unfortunately it did not investigate direct breastfeeding (Shine et al., 2021). Referring to the mothers in the second study who had first-hand experience of a staff knowledge gap, there are no research studies exploring breastfeeding children with cancer besides two expert opinion papers that make a brief mention of the theoretical benefit of continuing to breastfeed (Wallis and Harper, 2007; Carney, 2013). There are also no studies that explore the practicalities or lived experience of breastfed children with complex bowel disease. Therefore, as identified in the systematic review, there is extremely limited research and much of the research we *do* have is focused on children with cardiac defects.

Another separate problem was the apparent lack of understanding of breastfeeding beyond the age of one year. Säilävaara (2021) found that mothers of toddlers were highly motivated to breastfeed but required long-term, ongoing support to do so. Further research has found that many women encounter prejudice and misinformation and consequently may conceal their 'extended' breastfeeding status (Thompson et al., 2020). Jackson and Hallam (2021) found that because support is often lacking, women frequently resort to finding support and information online from international sources. The children represented in the parent study were aged between two months and three years, with the mean age being 15 months. Indeed, only seven infants were under six months, thus many of the mothers in the study were well beyond the age of exclusive breastfeeding. Many of the mothers commented that breastfeeding beyond six months seemed to be frowned upon, seen as pointless, or strange. Several described staff staring, immediately stepping out of the room if they saw mothers breastfeeding or behaved in a way that made the mothers feel confused, angry or ashamed.

Professionals also had poor awareness of further resources. Indeed, the percentage of people aware of the Baby Friendly Initiative was lower (45.4%) than the percentage of people who claimed to be experienced at supporting breastfeeding (53.8%). This is important because firstly it suggests that they were perhaps not as experienced as they

initially claimed to be, and secondly, by not referring mothers to more appropriate sources of support if they were not able to help them, they were missing an opportunity to reduce their workload. Many mothers report that they would like services to be more joined up (Brown, 2016), and this has been found among mothers of medically complex children as well (Lewis and Kritzing, 2004; Pettigrew et al., 2022). However, this is poorly researched. Whilst there are many research studies highlighting the benefit of multidisciplinary team involvement to improve feeding outcomes with medically complex children with a variety of conditions including cancers, critical illness and severe feeding difficulty, these studies make no mention of lactation support (Rommel et al., 2003; Ladas et al., 2005; Mehta et al., 2010; Cornwell et al., 2010; Sharp et al., 2017). Therefore, while it is clear that multidisciplinary input would be beneficial there is almost no data on how this can be achieved in the breastfed paediatric population. This explains why many mothers felt that their care was fragmented when they were asking for input from various sources including peer support groups, friends, neighbouring infant feeding leads and other professionals. There were no examples of joined-up care in the parent study, and none of the mothers were referred to appropriate literature, websites or other sources of support.

6.1.3 RQ 3: What are the barriers to providing lactation support that meets the needs of families?

Mothers intending to breastfeed encounter barriers on numerous levels, from the macro societal level (Brown et al., 2011b; Brown, 2015; Azad et al., 2020; Tomori et al., 2022) to the individual barriers they encounter unique to their child's illness. Wider barriers such as a default formula culture, lack of public acceptance of breastfeeding, predatory formula industry marketing, difficulty breastfeeding in public, and lack of adequate training for healthcare staff are all widely reported in the literature and may have direct or indirect impacts on hospital, ward and individual levels (Perez-Escamilla et al., 2023; Rollins et al., 2023; Baker et al., 2023).

Anecdotally, many people assume that lack of time is the main barrier to providing lactation support to families; in fact, the most cited barrier by the professionals in Study 1 was lack of knowledge. Lack of time was only raised as an issue by 33.9% of the professionals surveyed.

Many of the mothers commented that the staff seemed busy, but this was not necessarily related to them not being able to provide support, rather it was an observation that was independent of the support they did or did not receive.

Professionals in the first study felt that the most common barrier for families was stress. Stress was commonly cited by the mothers in the second study, though they provided much more nuance in their descriptions of this. It was also notable that the stress they described was multifactorial, and sometimes iatrogenic. 31% of the professionals felt that mothers were scared to breastfeed their sick child, yet none of the parents raised this concern. Many of the mothers found their child's illness stressful and, in some cases, traumatic. They also found the breastfeeding difficulties that arose because of their child's illness stressful. Beyond the direct stress caused by illness, stress came from other ward-related barriers such as unwillingness to facilitate bedsharing, inaccurate or inappropriate advice, not being provided with food, enforced privacy, the challenges of expressing and finding breastpumps, juggling other children, partners and work, and hostility from staff.

The wider literature has previously identified some of these barriers, although not within the paediatric setting. For example, related to bedsharing, there have been some studies and policy documents exploring and trialling side-car cribs on postnatal wards (UNICEF, 2004; Ball et al., 2006; Ball and Klingaman, 2008; Tully and Ball, 2012; Drever-Smith et al., 2013). The studies find that side-car cribs are associated with more frequent breastfeeding and were not associated with increased adverse outcomes. However, Drever-Smith et al. (2013) noted that there were wide geographical disparities in acceptance of bedsharing in hospitals and indeed, much of the UK bedsharing research has been carried out in the North of England which may not be representative of the rest of the UK. The parent study recruited mothers who had attended 30 different hospitals around the UK and bedsharing was only facilitated in a minority of those units. A further problem is that all the research in a hospital setting has explored newborns and side-car cribs. Side car cribs are well-suited for newborns but an older infant or toddler would physically not be able to fit, which renders them an incomplete solution to the problem on paediatric wards. In reality, bedsharing is likely to be more practical due to the size of some of the children we might reasonably expect to be bedsharing while breastfeeding. The practice of bedsharing is correlated with

longer durations of breastfeeding (Ball et al., 2016), so it is not surprising that in the parent study, where the mean child age was 15 months, the mothers were mostly bedsharing.

A separate, but related issue, raised by mothers whose children had been admitted to cardiac or paediatric intensive care was the challenge of not being able to be resident overnight. A recent European survey of PICUs found that only 50% have rooming-in facilities (Nielsen et al., 2022). The mothers in the parent study universally found that not being with their child overnight was disruptive to their sleep, made expressing harder, and added to their stress. Interestingly, bedsharing was not mentioned by any of the healthcare professionals in the first study following the questions about perceived barriers. This may be because the professionals were not aware that this was a problem, or because of personal biases and held beliefs. Some professionals agreed that mothers not being able to stay with their child was a barrier, but this was not expanded upon in the free text boxes; so it is unclear whether they meant the mothers chose to return home and not remain resident on a general ward overnight with their children, or whether this barrier only related to parents of children in PICU.

There were many aspects of ward culture that were felt to be barriers, with most units represented in the survey having a score that suggested multiple areas could be improved. Whilst there were also examples of supportive interactions in terms of psychological care and interpersonal communication, a range of attitudes from hostile to ambivalent were noted. Some professionals articulated hostile beliefs in the free text boxes. This was not common on the professional survey; however, as previously noted, there may have been an over-representation of breastfeeding advocates. Bearing in mind that mothers in the second study had experienced 30 different hospitals, nearly half the participants in the second study reported obvious hostility. This was in the form of outrageous comments, telling mothers that breastfeeding was to blame for their child's current condition, comparing breastfeeding to risky behaviours such as smoking, shouting at them, or displaying obvious signs of antagonism towards breastfeeding. Many mothers sensed that breastfeeding was inconvenient to staff, and some staff specifically said that they did not feel breastfeeding was important and did not want breastfeeding to 'infiltrate' paediatrics. Several professionals displayed ambivalence, both evident in their scores about the importance of

breastfeeding as well as their comments. Most of the mothers identified ambivalence on the wards or units where they were treated and, almost universally, found this to be an unhelpful attitude. Many of the mothers speculated that the ambivalent attitudes they encountered were an effort by the staff to not put pressure on them to breastfeed, or produce breastmilk and yet, since all but three of the mothers at the time of their child's admission were well established with breastfeeding this was felt to be irrelevant - what they wanted was active encouragement and support. Indeed, they perceived the ambivalence as disinterest and lack of care, a finding supported in the literature (Odom et al., 2014). Whilst many mothers noted that the staff did not actively sabotage their efforts, they felt entirely unsupported which added to their stress and complex emotions. There is a clear need to deliver sensitive, individualised, parent and child-focused infant feeding support that focuses on parental feeding goals. If this was achieved, it is unlikely that this support would be interpreted as either pressurising, or ambivalent.

There were some environmental and resourcing barriers identified by professionals, such as lack of expressing rooms, inadequate supplies of pillows, inappropriate chairs and lack of designated paediatric unit breastpumps. Professionals also identified deficits in support to re-establish breastfeeding after procedures or interventions. When comparing this with the mothers' reported barriers, the mothers in the second study agreed with the professionals that lack of pillows, uncomfortable chairs and beds was an issue, which has been previously explored in the neonatal setting (Flacking and Dykes, 2013). Chairs in hospitals are often hard, have inflexible armrests and do not recline. These could be barriers for any breastfeeding dyad but are particularly problematic for mothers breastfeeding older children as their children's bodies do not comfortably fit in a cradle hold as a newborn would. Many mothers also agreed with the professionals that there was no designated expressing room or adequate milk storage facilities.

Additionally, most of the mothers reported not having enough food, although this was not brought up by the professionals. Lack of food, and the expense of buying food for caregivers is a widely reported issue in paediatrics (Siffleet et al., 2010; Coyne et al., 2011; Meert et al., 2013) and greatly adds to the stress of parents who are trying to balance being with their child, needing to leave their child to obtain food, and the financial burden this presents,

whilst also not being able to work. In the parent study most mothers were not provided with food, and this caused anger, stress, financial anxiety and discomfort. Two of the mothers commented on the difficulty of obtaining water and felt that they were acutely dehydrated leading to reduced milk output which resolved once they had rehydrated themselves. Most of the mothers of infants under six months reported being given food, though not always enough. In many cases there was confusion among the nursing staff about whether they were 'allowed' to feed mothers of infants older than six months, even when the children in question were not consuming anything other than breastmilk. Several of the older children with cancer and severe feeding difficulties were breastfeeding as frequently as a newborn; yet a widely held perception by staff was that their mothers did not qualify to receive food from the ward which meant that they either ate their child's discarded leftovers, or bought food from vending machines, or the hospital shop. One mother remarked that her diet was unhealthy and consisted mainly of potato crisps, chocolate and pastries for the duration of her child's two-week-long admission.

A major barrier for many mothers, as well as the reason for breastfeeding cessation for one mother, was the lack of available breastpumps on the paediatric ward. There were no examples of breastpumps being located on the paediatric ward or PICU, though for the mothers in CICU, there were pumps available. It is not clear why CICU appeared to be able to provide breastpumps and PICU was not but, from an experiential point of view, CICU is often more similar to NICU than PICU, possibly because children with cardiac anomalies are often diagnosed antenatally and their admission to CICU is therefore planned and takes place immediately after birth. It could also be related to the fact that, as previously mentioned, most of the research that does exist about medical complexity in the paediatric population relates to children with cardiac conditions. On the paediatric wards, staff sometimes tried to obtain a loaned pump from maternity or NICU, but this was rarely successful. There is an abundance of literature relating to breastpumps on NICU (Larkin et al., 2013; Lucas et al., 2014; Meier et al., 2016; Porta et al., 2021) but the issue of how to improve pumping recommendations, access to pumps, providing spare pump parts, and innovations to improve maternal experience of pumping seems not to have been considered in the paediatric population, despite paediatrics being a clinical environment which cares for children from the first week of life.

A further logistical barrier raised by the mothers who had more than one child was the difficulty of managing home and hospital life. The professionals identified that some mothers need to care for other children at home, and the mothers in the second study confirmed that they often had to make difficult choices about which child to stay with. This was compounded when children were tandem fed, which many healthcare professionals demonstrated poor understanding of despite the many reported reasons for it (O'Rourke and Spatz, 2019; Sinkiewicz-Darol et al., 2021). Mothers often faced difficult choices about whether to leave a younger, exclusively breastfed healthy child to care for their sick breastfed toddler or navigate complex rules about sibling visitation. Even when they were not tandem feeding, many mothers described being split up from their other children as painful. The needs of siblings of hospitalised children have been previously reported, with many identified negative outcomes such as anxiety, becoming withdrawn, or taking on more adult responsibilities (Niinomi and Fukui, 2022). The impact on mothers of being separated from their other child or children while one is resident on the paediatric ward is less well-researched, though some studies have found this to be one of the reported stressors (Hagstrom, 2017; Foster et al., 2019; Abela et al., 2020; Alzawad et al., 2022). Newer models of family integrated care (FIC) as opposed to family centred care (FCC) are being successfully adopted in many neonatal units and seem to have a much greater emphasis on keeping the whole family together (van den Hoogen and Ketelaar, 2022) but this has yet to be adopted in paediatrics. An obvious area for improvement would be the facility for siblings to stay overnight on the paediatric ward which would require some creative solutions around sleep locations.

6.1.4 RQ 4: What is the importance and meaning of breastfeeding when a child is sick or medically complex?

One of the most prevalent themes in the parent study was the importance of breastfeeding beyond its nutritional value. Breastfeeding was seen as an immunological buffer and a significant source of pain relief. Breastfeeding is well-known to provide effective pain relief during and after needlestick procedures and vaccination (Shah et al., 2015; Harrison et al., 2016), 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 postoperative pain. To date, there are no studies that have explored the efficacy of breastfeeding as pain relief for more invasive procedures and severe pain, but the mothers' lived experiences of breastfeeding providing such effective pain relief was a major motivating factor to continue despite the challenges. Breastfeeding is known to provide immunological support (Hanson et al., 2003; Riskin et al., 2012; Hassiotou and Hartmann, 2014; Hassiotou and Geddes, 2015; Moosavi et al., 2019) and for some of the mothers whose children 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. Whilst there are no human studies to validate these clinically significant observations, there was a recent, promising discovery that a specific oligosaccharide abundant in breastmilk, 2'-fucosyllactose (2'FL), is effective at preventing intestinal epithelial cell apoptosis in mice exposed to chemotherapy (Zhao et al., 2022). Whilst this requires further study and a human subject focus, it is a breakthrough because mucositis affects up to 100% of patients undergoing high dose chemotherapy and yet, anecdotally, many breastfed children do not appear to suffer with this painful and debilitating side effect.

Breastfeeding was also important as a comfort and parenting tool, and many mothers felt that it facilitated them to be closer to their children and more intuitive to their needs. Some of the mothers noted that breastfeeding calmed *them* down, as well as their children, which is supported by other literature focused in the NICU and maternity settings which found that breastfeeding is important to increase maternal self-efficacy, as well as connection (Flacking et al., 2007; Ekstrom and Nissen, 2006; Murray et al., 2007; Moberg and Prime, 2013; Butler et al., 2014).

A commonly raised theme was that because breastfeeding was so important to mothers, both the difficulty and the lack of support for breastfeeding and responsive parenting increased the mothers' stress in a tangible way. There were numerous aspects of breastfeeding a sick child that led to psychological challenges. Psychological distress has previously been reported to have an adverse impact on milk supply (Nagel et al., 2022) and has been specifically studied in relation to depression (Dias and Figueiredo, 2015; Butler et al., 2021), anxiety (Fallon et al., 2016; Hoff et al., 2019), and psychosocial factors (De Jager

et al., 2013). In the parent study several of the mothers reported an immediate and discernible impact on their milk supply, and this was most pronounced when children suffered rapid deterioration or sudden onset of critical illness. There are two main proposed mechanisms for this observation including a hypothesis that acute stress may alter glucose metabolism and therefore interfere with insulin sensitivity which has been found to impair milk production (Nommsen-Rivers, 2016). Another theory is that cortisol production via the hypothalamus pituitary adrenal (HPA) axis inhibits the release of oxytocin leading to impaired milk ejection reflex, leading to a perception that the milk has 'dried up' - which is not physiologically plausible but certainly understandable from a clinical perspective - because many mothers find that their milk ejection reflex is impaired by stress. However, the connection between cortisol and oxytocin is less well-researched (Nagel et al., 2022).

There was a general lack of awareness of the importance of responsive parenting which had indirect impacts on breastfeeding and direct impacts on maternal stress. For example, many mothers had negative experiences with bedsharing not being facilitated, not being encouraged to hold their children, and skin-to-skin was not recommended or suggested. Many mothers felt profoundly angry that their effort and perseverance with breastfeeding was not recognised or valued, and the positive impact they felt it had on their children was often disregarded. The inter-relationship between breastfeeding and responsive parenting is one that should be part of healthcare professional training since the two behaviours have been shown to share many parenting characteristics (Gibbs et al., 2018).

What is clear is that breastfeeding is meaningful to mothers of sick children and can support their mental health. However, when they encounter challenges that they struggle to overcome, this can have a profoundly negative impact on their mental health. This is not a new observation having been noted in other research settings (Beck et al., 2011; De Jager et al., 2014; Kendall-Tackett, 2015; Azad et al., 2021; Brown and Shenker, 2022). The psychological needs of parents of sick children in paediatrics are well-known, but the impact on milk supply and breastfeeding has not been researched. Certainly, the professionals in Study 1 identified that stress was a major barrier to mothers being able to continue to breastfeed. There is a clearly identified need for more comprehensive psychological support

not only to optimise milk production, but equally to support maternal mental health and wellbeing.

6.1.5 RQ 5: What are the breastfeeding challenges of medically complex children in the paediatric setting?

In terms of the professionals' perceptions of the clinical challenges the most cited were enteral feeding, being fluid restricted or needing additional calories; but these challenges were perceived to be secondary to stress. On the other hand, the mothers placed greater emphasis on a wide range of clinical challenges, with breastfeeding challenges being the most cited theme in the study overall. The discrepancy in the range of issues between mothers and professionals may be due to professionals simply not knowing how to help, or not understanding the gaps in their own knowledge. In addition to the challenges identified by the professionals, the other difficulties for mothers were broadly split into four key areas of difficulty:

1. Needing support after surgery, intubation and intensive care
2. Difficulties directly related to the child's condition
3. Difficulties indirectly related to the child's condition
4. Breast and expressing difficulties

Needing support after surgery, intubation and intensive care

Firstly, many of the children who were more seriously unwell had specific breastfeeding challenges. The difficulties were related to re-establishing breastfeeding after intubation, enteral feeding and being nil by mouth following ventilation, sedation, or periods of receiving total parenteral nutrition (TPN) or trophic feeds. There were also separate challenges that were associated with surgical and medication complications, such as pain, vocal cord palsy, iatrogenic opiate withdrawal, loss of reflexes and tone, and feeding refusal.

Human milk may be particularly important for enteral rehabilitation after major bowel surgery or intestinal failure as it contains glutamine, epidermal growth factor, nucleotides, leukocytes and Secretory Immunoglobulin A (SIgA); these are hypothesised to support the

infant intestinal microbiome, increasing bowel recovery (Olieman and Kastelij, 2020), as well as reducing the length of hospital admission and length of time on TPN (Andorsky et al., 2001; Kohler et al., 2013). This is particularly relevant as increased time to transition from TPN to enteral feeding, unpleasant oral experiences - such as suctioning, intubation and frequent passing of nasogastric and orogastric tubes – and prolonged periods of being nil by mouth are all risk factors for oral aversion and disordered eating (Cernat et al., 2021).

Dysphagia following extubation is common but usually temporary. However, there is a lack of research exploring how to support more complex children to re-establish oral feeding following tracheostomy and major airway reconstruction surgery (Volsko et al., 2021). In one study, 85% of the children undergoing airway reconstruction who were orally fed prior to their surgery resumed oral feeding within eight days of the procedure; whilst the remaining were diagnosed with dysphagia and also respectively with oral aversion, aspiration, and faltering growth, requiring more intensive speech and language therapy, as well as long-term enteral feeding with nasogastric or percutaneous endoscopic gastrostomy (PEG) tubes (Smith et al., 2009). Aspiration has historically been thought to be an absolute contraindication to oral feeding for children with dysphagia, but a promising recent pilot study did not find aspiration with breastmilk to cause any pulmonary effects in 90% of the infants with clinically significant dysphagia. The other 10% were found to have a significant underlying cause such as a laryngeal cleft, or total intolerance of oral feeds and subsequently required a PEG (Hersh et al., 2022).

Re-establishing oral feeding after these invasive interventions is known to be highly variable and dependent on multiple factors including the duration of ventilation and more complex disease (Eggink et al., 2006). According to a recent systematic review, other factors that are thought to be associated with more difficulties establishing feeding are painful oral experiences, pre-existing feeding difficulties and underlying conditions (Morton et al., 2019). Unfortunately, this review, whilst intending to include data relating to PICU patients, mostly only reviewed NICU patients. The one paper that explored feeding rehabilitation in PICU patients was actually a study of children with cardiac conditions, many of whom were born prematurely (Kogon et al., 2007). One study in the NICU found that some of the challenges of re-establishing oral feeding can be mitigated somewhat by a program of positive facial

touch by parents (Indramohan et al., 2017). In general, however, there are more identified challenges than solutions reported in the literature.

One parent in the second study described a very distressing situation when her child suffered from opiate withdrawal. Sedating analgesia is a necessary intervention to reduce pain and suffering, as well as accidental endotracheal tube displacement. The medications usually chosen are opioids and benzodiazepines although different units may have different protocols. In general, the longer a child is exposed to these sedating analgesics the more likely they are to experience withdrawal. Symptoms of withdrawal include tachypnoea, nausea and vomiting, sweating, hypertonia and irritability (Ávila-Alzate et al., 2020). Withdrawal has been found to be under-reported and under-treated, and furthermore, unvalidated or inappropriate scales are sometimes used to measure withdrawal. Many approaches to weaning a child from sedating analgesics have been proposed (Sneyers et al., 2020); but clinically, parents should be better prepared for some of the possible behaviours that their opiate exposed child might exhibit after extubation. Preparation for the behaviour changes such as irritability, or very frequent feeding may reduce some of the stress experienced. This was demoralising for the mother in this study and made worse by nobody, including a nonclinical IBCLC, being able to provide adequate and sensitive support due to lack of knowledge.

Two of the children in the study had loss of tone and reflexes and these challenges were difficult to manage. Had skilled support to provide feeding assistance been available - such as using the Dancer hand technique (Wambach and Spencer, 2019), utilising breast compressions, upright feeding, a nipple shield to provide greater sensory-oral feedback (Currie et al., 2019), or providing gentle postural support (Thomas et al., 2016) - they may have had an easier breastfeeding experience.

Difficulties directly related to the child's condition

Secondly, there were difficulties that were directly related to the child's acute condition, rather than the effect of a surgical or critical care intervention. These included difficult latch due to respiratory compromise and painful latch caused by recurrent candida infection due to immunodeficiency (Öner et al., 2022). Respiratory compromise is known to adversely

affect feeding and many infants who present to emergency care are at risk for dehydration and malnutrition (Nazal and ve Etkinligi, 2019). There has been a lack of coherency regarding whether to withhold enteral feeds, or aggressively enterally feed during respiratory compromise in the paediatric critical care literature, which may add to the clinical decision-making confusion regarding feed volumes. The most recent literature is clear that CPAP and humidified high flow nasal cannula (HFNC) oxygen are not contraindications to oral feeding, and even when infants are tachypnoeic the feeds are well tolerated (Sochet et al., 2017). Moreover, early feeding alongside treatment of respiratory compromise reduces the length of PICU admission (Slain et al., 2017), therefore oral feeding should not usually be withheld. This does, however, mean that clinical staff may need to learn how to support feeding in infants and children with acute respiratory distress. Clinically these children tend to pull off the breast frequently, latch poorly, feed frequently and inefficiently, and tire quickly. While most of the literature relating to respiratory compromise and oral feeding discusses NG tube feeding and bottle feeding, breastfeeding causes less physiological instability and oxygen desaturation during feeding (Chen et al., 2000; Goldfield et al., 2006; Moral et al., 2010). Energy expenditure during breastfeeding is no different to bottle feeding – dispelling the myth that breastfeeding is ‘harder work’ or conversely, that bottle feeding is ‘easier’ (Berger et al., 2009).

Difficult, painful, or shallow attachment at the breast places mother-infant dyads at risk; not only is this unpleasant for the mother, but it is usually associated with poor milk transfer (Wambach and Spencer, 2019). The solution would be to correct the attachment using skills and strategies to optimise positioning. Although this is a simple problem to address, only 25% of the professionals surveyed felt they had lots of experience with this, thus it may be difficult for mothers to access effective support.

Another commonly reported challenge was infant fatigue due to critical illness and high calorie requirements which ultimately led to weight loss, or faltering growth because high resting energy requirements can lead to a deficit of adequate calories for growth (Lima et al., 2022). These problems are commonly researched in the cardiac population, since fatigue is a frequent cause of feeding disruption for these infants (Jones et al., 2021). One study found that post cardiac surgery the most common problems included fatigue, poor tone,

weakness, need for respiratory support and pain (Jones et al., 2022). Another study instigated a program involving speech and language therapists, occupational therapists, physiotherapists, nurses and lactation consultants to develop teaching to support nursing staff to identify when infants require altered feeding practices due to physiological instability. The documentation compliance was poor, limiting the interpretation of the work; but there was evidence that the teaching prompted some nurses to modify feeding to cue-based, paced feeding with pauses if an infant showed signs of compromise during standard gravity bottle feeding (Burch, 2022). A study of a cohort of infants with Down syndrome found that 57% of the children had clinically significant dysphagia and exhibited many signs of feeding stress including coughing, choking, and oxygen desaturation (Stanley et al., 2019). The authors noted that the usual treatment for these problems was often feed thickening, but they did not measure simple strategies such as changes in positioning or paced bottle feeding which are known to improve physiological stability (Shaker, 2017; Pados et al., 2017; Park et al., 2018).

While these studies relate to cardiac conditions, Down syndrome and preterm infants respectively, it may be possible to borrow techniques which are known to work in other populations. Petersen (2018), in her thesis exploring developmental care of infants with cardiac conditions, points out that the NICU and paediatric CICU populations are different and what works in one population may not necessarily work in the other. However, she also stresses that certain interventions that do not *add* risk could be trialled, including borrowing aspects of developmental care common in NICU, such as supportive positioning, cue-based feeding, skin-to-skin, and effective pain relief – which are all known to support neurodevelopmental outcomes (Altimier and Phillips, 2013).

Many mothers described patterns of very frequent feeding, and this was particularly marked among the children who had more complex needs, including the children with cancer, severe bowel disorder and severe sensory food disorders. In the case of one of the children with cancer, as well as both the children with sensory food disorders, they rejected *all* solid foods, leading to feeding behaviours that closely resembled a newborn pattern. Several of the other mothers described a temporary period of frequent feeding either prior to, during or after their child's acute illness which was often described as exhausting and consuming. A

few of the children with serious illness also had complications of fluid restriction with high calorie needs which essentially made exclusive breastfeeding impossible. A new classification of Paediatric Feeding Disorder (PFD) was proposed by Goday et al. (2019). They point out that feeding is a complex interaction of the central nervous system, as well as the musculoskeletal, oropharyngeal, cardiovascular and gastrointestinal systems, and craniofacial structures. A diagnosis of PFD was previously defined from a simple medical perspective, but the authors stress that PFD relates to feeding that is not age appropriate and is associated with medical, nutritional, feeding skill and psychosocial dysfunction. Therefore, it cannot be seen as a single discipline diagnosis since it involves multiple systems and has broad reaching implications for a child's physical, social, cognitive, neurological and emotional functioning, as well as parental well-being and stress. This is particularly pertinent for children with more complex conditions; indeed, all the mothers identified the complexity of their child's feeding challenges within the context of their medical condition, with one of their most common complaints being that there was usually not a multidisciplinary approach to addressing these complex problems.

Difficulties indirectly related to the child's condition

Thirdly, some of the children had challenges that were indirectly caused by their condition, or the treatment for their condition. These included children only feeding on one breast, usually due to having a portacath, PEG, stoma or wound on one side of their body and the child refusing to lie on that side. Unilateral breastfeeding is not unheard of, but the literature largely discusses this in relation to maternal factors such as unilateral mastectomy (Baslaim et al., 2011; Ko et al., 2013; Barco et al., 2015). This is notable as unilateral breastfeeding due to infant breast preference is a risk factor for early cessation of breastfeeding and may also be a risk factor for breast cancer in the unsuckled breast (Novrial et al., 2020). There is no literature available relating to breast preference due to medical devices or how to overcome this. In the second study, the mothers reporting unilateral breastfeeding were highly motivated to continue, which may not be true for other families, and so creative options such as using alternative positions, cushions, positioning aids and pillows could be explored to maintain bilateral breastfeeding if this is the mother's wish.

Other children experienced appetite changes due to steroids which resulted in very frequent feeding. While steroids are a common and necessary part of pharmacological management of many malignancies (Kim et al., 2022) as well as some respiratory conditions (Fernandes et al., 2019), their use is known to increase appetite (Sweeney et al., 2021). Conversely, some children suffered with nausea which often made them reject solid food, again leading to more frequent breastfeeding. Nausea and vomiting are very common side effects of cancer treatment (Ruggiero et al., 2018) and managing this is difficult, with many children suffering loss of appetite (McCulloch et al., 2018). However, the children in this study appeared to compensate for their rejection of food by very frequent breastfeeding.

Many mothers and children clearly struggled to manoeuvre around cannulas and devices and found breastfeeding more awkward because of this. On a related note, many mothers had to adopt creative positioning strategies due to their child's condition to support more effective or safe feeding. Support with positioning is a fundamental part of breastfeeding counselling, particularly with a sick infant (Theurich et al., 2020). Several mothers had to feed in a more upright position which is a common strategy to support infants with airway compromise, somnolence, and respiratory distress (Genna, 2016). One mother was not able to follow the given positioning instructions by the maternity infant feeding lead who was recommending a 'nose to nipple' position, because her child had a CPAP mask following extubation. Whilst this advice may work for many infants and mothers it was inappropriate for this mother, clearly demonstrating a lack of ability to be able to apply broader principles of good breastfeeding positioning to a more individually complex scenario.

Some of the mothers felt that their infants were irritable, or 'on alert' and that it was hard to help them relax enough to be able to feed effectively. This problem could have been managed by a focus on co-regulation (Somers et al., 2021; Verde-Cagiao et al., 2022), reducing parental stress, optimising close, responsive parenting and offering strategies that engage parasympathetic nervous system activation (Guan et al., 2014). Given that sick infants and mothers are at risk for dysregulation this should be a core part of family centred models of care (Doiron et al., 2022).

Breast and expressing difficulties

Finally, there were several problems that were specifically related to the impact on mother's breast health and expressing, and several professionals specifically identified that expressing was a challenge that they witnessed mothers encountering. Several of the mothers struggled with triple feeding, describing it as exhausting and unsustainable. Triple feeding is the term used when mothers are breastfeeding, expressing, as well as feeding their child with expressed milk, infant formula or donor milk by bottle. There is little high-quality research on this topic, but many clinical papers and case reports have identified triple feeding as tiring and time consuming (Lucas et al., 2014; Briere et al., 2015; Noble et al., 2018; McCue and Stulberger, 2019; Elder et al., 2022). Many of the mothers also experienced breast pathology, ranging from mastitis, delayed or absent milk ejection reflex, engorgement and blebs, to an infected nipple fissure that was hard to treat. Mastitis and engorgement are both inflammatory mediated conditions that are associated with milk stasis, poor positioning and infrequent or ineffective milk removal (Mitchell and Johnson, 2022; Mitchell et al., 2022). Blebs are poorly researched, but some research suggests they may follow a deeper plugged duct and may also be associated with hyperlactation (Mitchell and Johnson, 2020), though this was not the case with the mother in this study whose bleb had no clear aetiology. Nipple fissure is a more unusual condition that in this case was caused by a poorly fitting pump flange, which is unfortunately a common mechanism of this type of trauma (Higgins, 2022). The lack of provision for women with variable anatomy could reflect the general low levels of awareness of the nuances of breastfeeding. Given that nipple size varies between women, different sized flanges are an entirely appropriate resource to have in stock on a paediatric ward to prevent this type of iatrogenic injury.

For all the mothers in this study who had breast and nipple problems, this resulted from an underlying failure to appropriately manage breastfeeding. The professional survey found that only 18.4% of the professionals had lots of experience managing breastfeeding challenges, such as mastitis. This may be because they did not feel that managing an adult's condition was part of their role, but it is more likely to be due to lack of training. All the mothers in this study had conditions that could have been either prevented or managed more appropriately and would have improved outcomes for the children in several of the instances by increasing milk removal.

There were also many problems with expressing, from lack of provision of pumps, to lack of knowledge of how the pumps worked. Many of the mothers had to work out how to use the pump on their own and two mothers were unable to use the pump at all due to lack of clear instruction. Beyond these practical issues, many mothers found pumping to be an unsatisfactory experience. In the first study 40% of the sample reported that they had lots of experience supporting mothers to express, but only 29.1% reported that they had lots of experience helping mothers to protect or increase their milk supply. This discrepancy may suggest that while professionals feel confident to simply provide mothers with a breastpump; the nuances of how to use the pump effectively and how to support lactation with a pump was actually a more advanced skill.

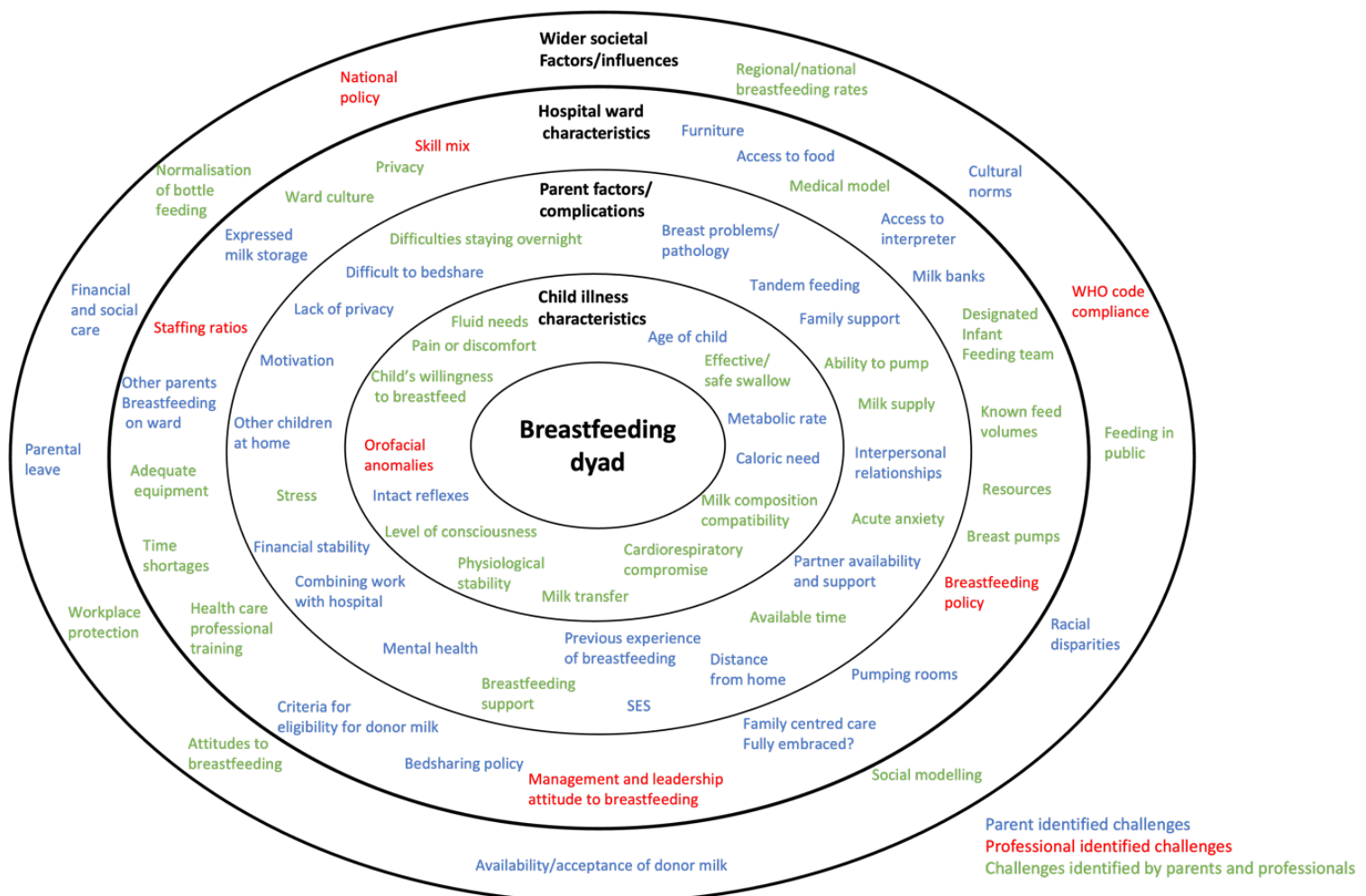
6.2 Considering the findings in light of the theoretical model: Ecological systems theory

The two studies were designed to explore the challenges of medically complex breastfed children in paediatrics, using Bronfenbrenner's (1979) ecological systems model. The challenges affecting the medically complex breastfeeding dyad were acknowledged to be likely at all levels of the child's ecological system (see Figure 12). The study findings have been broadly mapped onto the ecological systems theory model in previous chapters, but as previously alluded to, many of the challenges were articulated by both parents *and* professionals, and spanned more than one layer of the ecosystem. Triangulation of the data within this chapter has therefore included not only consideration for whether there was concurrence or discrepancy between parents and professionals, but has also used the ecological model to situate the challenges in context.

Figure 12 therefore uses ecological systems theory to populate a new model that specifically considers the challenges of breastfeeding sick children from the perspective of both health care professionals and parents. It identifies numerous issues, positioning them at the relevant sphere of the ecological model, and categorises whether the challenges were articulated by parents, professionals, or collectively by both, using colour codes. The model illustrates the complexity of the challenges of breastfeeding medically complex children. One of the striking aspects of this topic is that parent and professional-identified barriers sometimes match, and sometimes look very different. This may be due to the fact that

parents are not always aware of the complex and difficult issues entrenched within NHS systems and undergraduate training, as well as the wider hospital culture. Equally, professionals may be blind to the real challenges faced by parents because they have not received suitable training, and the systems to support breastfeeding are not established in paediatrics.

Figure 12: Ecological systems theory approach to breastfeeding medically complex children (Adapted from Bronfenbrenner, 1979; Davison and Birch, 2001).



The first study mostly started on the outer concentric 'circles' of the model, exploring the exosystem and macrosystem. The second study sought to understand the factors at the individual and familial level. However, triangulation occurred by asking professionals about their perceptions of the challenges within the micro and mesosystem, and the mothers

commented on factors relating to the exosystem and macrosystem, with many overlapping and similar themes at all levels.

At the microsystem, the mothers cited many factors unique to their child's challenges; many of these factors had occurred to the professionals observing them, though not always ascribing the challenges in the same order of magnitude as the mothers. At the mesosystem, mothers were clear about the impacts of illness and complexity on their families and other children, and many spoke about interactions with wider family members. At the exosystem level, many challenges relating to the ward and hospital environment have been uncovered, with much concordance between mothers and professionals. Finally, at the macrosystem level, issues such as policies, financial support, training at undergraduate level and the wider issue of the lack of acceptance of the normalcy of breastfeeding have been cited by both mothers and professionals. The ecological systems model provided a framework in which to consider the challenges both independently but also allowed the relationships between the challenges in different levels to be explored.

The model could also be used to identify who should be responsible for actioning certain identified challenges. Some challenges are beyond the scope of an individual ward to address – such as factors relating to policies, training and societal attitudes. However, other challenges might be effectively addressed at hospital level – such as the provision of expressing rooms and designated fridges. Certain units might need a stronger focus on training that aims to equip professionals to support infants and children with certain clinical conditions. The model also points to the inter-related nature of paediatric breastfeeding challenges within the ecosystem. While microsystem-level clinical challenges for an individual breastfeeding dyad might appear to be best addressed with a solution for that mother-child pair, the reality is that the solution should be embedded at the macrosystem layer, with training that is fit for purpose, policies that are standardised, and a wider acceptance and positive attitude towards breastfeeding sick children that filters into the culture. In a similar vein, improvements and investments at the macrosystem layer will inevitably trickle down to changes that are made at the individual ward (exosystem) layer, and thus improve care for families at the mesosystem and microsystem layers.

6.3 Reflexive considerations during the studies

As previously mentioned in Chapter 3, reflexivity was an important part of this study and various strategies were used throughout both the survey and the qualitative study to ensure that personal motivations and experiences did not bias the findings. Reflexivity is a vital part of research analysis, in order to enable the researcher to appreciate the role their perspective has in the research (Braun and Clarke, 2022). Reflexivity requires a researcher to engage with critical self-reflection in order to be more consciously aware of what biases they hold (Cypress, 2017). This awareness, if actively engaged with, can reduce the biases and assumptions that the researcher might otherwise bring to the study.

While part of this research included reflexive thematic analysis, it was part of a larger overall mixed methods study, and therefore, to some extent, my position and influence as a researcher had to be managed in different ways. Yardley and Bishop (2015) point out that at a practical level, pragmatism is simply about choosing the most appropriate research design for the research question, but at a philosophical level, pragmatism views qualitative and quantitative methods as distinct and yet compatible. Yet this presents certain challenges – namely that during reflexive thematic analysis, my position and experience as a clinician and researcher was not a flaw but a strength, and yet during the design and analysis of the survey, bias created by my personal views had to be managed in a meaningful way.

In addition, I recognised that both studies could be personally difficult for me to conduct – firstly because as a health professional, it is hard to accept that my fellow colleagues might have failings that are important to acknowledge. Equally, as a health professional, I am well-aware of some of the shortcomings of training provision and it might have been hard to recognise the genuine skills and knowledge of other professionals when I am fully aware that training is patchy and not paediatric-specific. Secondly, as a parent of a sick child, I could easily have over-identified with certain parents, or become distressed when interviewing parents of children who had similar challenges or experiences to me. Reflexivity was therefore an active process of engaging with my biases as well as my personal feelings, in order to produce data that meaningfully answered the research questions.

For these reasons during development of the studies and analysis, strategies used included:

- Having a multidisciplinary clinical supervision group where difficult experiences could be debriefed and evaluated for significance.
- The maintenance of a personal reflective diary which was used as a catharsis. This diary allowed me to collect my thoughts and assumptions as I conducted the studies and began the analysis, enabling me to separate my personal feelings around the issues, my growth as a researcher, and the empirical data that I was trying to gather.
- Management of potentially difficult situations. One specific scenario that I anticipated was interviewing parents of children with leukaemia. I realised that it would be easy for me to project my own experiences, or insert my own assumptions. For this reason I considered whether it was fundamentally a good idea to interview parents of children with this condition. I decided to include a child with leukaemia because firstly it is the most prevalent form of childhood cancer, secondly childhood cancer and breastfeeding are unresearched, and it felt appropriate to include the condition, and thirdly because I had numerous parents of children with leukaemia apply to take part. To ignore all these parents felt disingenuous. Having made this decision thoughtfully, I put several protective mechanisms in place. I chose to interview the mother of a boy, rather than a girl, and he had a different form of leukaemia to my own daughter. I also chose a child who had a nasogastric tube because this was a different experience to my own – my daughter never needed nasogastric tube feeding. I arranged the interview on a day when I had no other commitments, and booked it for the morning so that if I needed time to debrief, I could do that. Finally, I arranged to be able to talk through the interview and potential triggers with my clinical supervision group.
- Separation of personal feelings and experiences through writing a book primarily focused on these more personal aspects to avoid them creeping into the thesis. The research raised several new thoughts and ideas and while they were meaningful and important, they were not all relevant to the research study. Writing a book concurrently allowed me a place and a process to validate important ideas, while not including them in the research.

- Regular academic supervision and early checking of analysis to ensure that the process of analysis accurately reflected the research studies.

Though it is impossible to remove personal motivations, these protective processes allowed separation of personal experience and views from the identified themes developed from the data.

6.4 Summary of findings

In summary, mothers of medically complex children frequently encounter additional barriers and challenges in their breastfeeding journey. The training of paediatric healthcare professionals' lags behind other clinical areas that also support breastfeeding mother-infant dyads. Mothers in the second study, especially those with more severely unwell or complex children, did not have such good experiences when their healthcare professional was not lactation trained, or their lactation professional was not clinically trained. There is a clear gap in both clinical and lactation training in terms of paediatric-specific challenges and solutions which leads to increased stress for mothers and may partly explain the additional difficulties experienced by families of medically complex children. Addressing this clinical knowledge gap may improve experiences and reduce iatrogenic breastfeeding cessation in this vulnerable and under-researched group. The final chapter will discuss the clinical implications of these findings, make recommendations for practice change, and suggest future research directions.

Chapter 7

Conclusion

The previous chapter summarised and discussed the findings from the two research studies, and highlighted areas of congruence and contradiction between the mothers and professionals. This chapter will draw on the findings to make clinical recommendations, suggest areas for future research, as well as acknowledge the limitations of this research.

7.1 Clinical implications from the findings

The two studies have identified numerous health professional gaps in knowledge, as well as specific breastfeeding challenges for mothers of medically complex children. The overarching summary is that medical complexity can present additional breastfeeding challenges and overcoming these challenges is not something that is adequately addressed by currently available training. Considering the identified challenges within the theoretical framework of the ecological systems model (Bronfenbrenner, 1979), there are multiple layers of clinical implication which address the barriers at several levels. The findings have led to four recommendations for practice change and improvement and are discussed in more detail below.

7.1.1 Organisational guidelines and policy

At a national level there are certain guidelines and human resourcing changes that should be developed:

1. Clear and nuanced guidelines around bedsharing
2. Adoption of paediatric specific BFI standards based on identified challenges
3. Funding for paediatric infant feeding leads in hospital
4. Clearer guidelines around family integrated care in paediatrics including sibling visitation
5. Paediatric-specific breastfeeding assessment process adopted in paediatrics

Bedsharing was one of the most common challenges cited by mothers, and the link between breastfeeding and bedsharing, particularly in longer-term breastfeeding, is clear. Whilst this is a complex issue to address, the inconsistencies revealed in the parent study demonstrated just how disparate the guidelines around bedsharing are. This needs to be urgently addressed to create clarity for families, and nuances due to infant condition and individual circumstances made clearer.

The BFI-UK are currently proposing to pilot their standards for use in paediatric settings which is positive. But these need to reflect the identified clinical needs of breastfeeding a medically complex child. Alongside more basic, mainstream training the curriculum developed for paediatric staff should enable clinicians to either manage the challenges experienced by families of sick breastfed children, or identify opportunities to work in a multi-disciplinary way. Closely related to this recommendation is the obvious need for a fully funded paediatric infant feeding lead and team. Borrowing staff from other (often under-resourced) departments is not sustainable and delays access to timely intervention and support. Non-paediatric feeding support has also often been found to be insufficient to address a problem that would not be within the usual scope of experience of a maternity or neonatal infant feeding lead.

Clearer guidelines are required to clarify the situation when a mother is tandem feeding two children, including one admitted to a paediatric ward. Whilst this is sometimes facilitated this is by no means standard, which means that this gold standard care is a postcode lottery. There is also a need to develop or utilise a more appropriate breastfeeding assessment process that better meets the needs of sick breastfed children, and train staff in all paediatric areas to use it as part of their overall clinical assessment. A method that utilises a 'body systems' approach would be more clinically appropriate and has not been previously suggested or adopted. Rather than attempt to use an assessment that might only work for specific conditions, ages of children, or stages of lactation, this approach would account for the specific adaptations required with specific body system dysfunction, to focus breastfeeding intervention on targeting strategies to overcome that particular dysfunction.

7.1.2 Equipment, resources and policy change

Secondly, at a policy, funding and wider hospital level, there are many changes that could improve support for families of breastfed medically complex children:

1. A breastfeeding policy to be part of the orientation to paediatric clinical environments
2. Immediate investment in equipment such as breast pumps
3. Designated expressing facilities including private spaces and adequate milk storage provision
4. Unrestricted provision of food to resident parents on the ward
5. Access to donor human milk for certain children when supplementation is required

Addressing these wider systemic barriers would lead to more consistent care for families. Approximately half of the professionals knew where the breastfeeding policy was, and it was only accessible to families in 10% of the units represented by the survey. A breastfeeding policy is important to clearly articulate that breastfeeding is welcomed, and what families can do if they require more support. There needs to be an immediate investment to ensure that adequate numbers of designated paediatric department breastpumps are available which would reduce some of the barriers. This would also require sufficient fridges and additional resources such as expressing rooms, or the option of private spaces if this was required by a mother. There was also widespread apparent confusion around the issue of feeding mothers on the ward. A simple guideline to create a consistent decision to feed the primary caregiver would remove the frustrating questions about whether a mother is breastfeeding and would more easily enable mothers (or fathers) to be resident with their child while hospitalised which is an important part of responsive parenting. Finally, access to donor human milk would reduce some of the negative mental health outcomes for mothers when they are unable to express milk due to acute trauma or high stress.

7.1.3 Training for clinical staff

1. Clear resources made available to paediatric clinical staff so that they can refer to appropriate sources of support
2. Mandatory basic breastfeeding training for all clinical paediatric staff as part of undergraduate training
3. Communication training to support individual feeding decisions
4. Advanced paediatric breastfeeding training for those who work directly with families

The skill gaps identified by the professional survey included many basic breastfeeding skills as well as some more complex skills. The parent study in general found that while most of the mothers were negatively affected by staff lack of knowledge, it was the children with more complex medical needs who had the most difficulty. This suggests that children with more complex problems are disproportionately affected. The study by Heilbronner et al. (2017) did not find an association between severity of illness and risk of breastfeeding cessation. However, in Study 2 the mothers of children who were chronically or more seriously unwell *did* experience more breastfeeding challenges, as well as more unusual and complex difficulties. This study may have found greater disruption to breastfeeding with more severe illness due to the greater breadth of illnesses represented, as opposed to the Heilbronner study which only explored bronchiolitis.

Because it is not always possible to tell which professionals will require more specialist skills, one practical option could be to incorporate basic breastfeeding training at undergraduate level for all clinical healthcare students. Those who later work in paediatrics could then access training that more fully meets the needs of the heterogenous paediatric population. Alongside this training, communication skills training to support staff to facilitate individual feeding decisions should be part of mandatory paediatric infant feeding training.

To illustrate the clinical skill gaps in a meaningful way, Table 34 shows the challenges raised across the two studies and identifies whether the training is currently covered in basic 1–3-day breastfeeding training, more extensive training, or whether it is a gap in training.

Table 34: Breastfeeding challenges identified in Studies 1 and 2, and training coverage

Covered in currently available basic training	Covered in more extensive training	Not currently covered
Benefits of breastfeeding	Basic training elements covered in greater depth	Practical, hands-on clinical skills training
Non-nutritive sucking and skin-to-skin	Supported feeding, i.e., elevated side-lying, breast compression	Breastfeeding assessment specific to sick children
Initiating breastfeeding	Some techniques for hypotonic children, i.e., Dancer hand technique	Supporting feeding in children on non-invasive ventilation, i.e., CPAP, HFNC and oxygen therapy
Supporting effective positioning and attachment	Positioning techniques for sleepy/weak infants	Supporting children with tracheostomy
Breastfeeding challenges such as mastitis	Developmental challenges, i.e., distractibility	Supporting children with nasogastric and PEG feeds alongside breastfeeding
Recognising active feeding	Specific techniques with expressing to maximise milk output	Children with airway challenges and dysphagia
Identifying adequate intake	Communication skills with bereaved parents	Feeding children with serious, chronic illness
Conducting a BFI breastfeeding assessment	Tandem feeding	Supporting children with critical illness
Responsive bottle feeding	Supporting breastfeeding strikes	Supporting safe return to oral feeds post extubation/NBM/TPN/enteral feeding
Close relationships and attachment	Use of tools and devices to support preterm and hypotonic infants	Tandem feeding while one child is acutely unwell
Safer sleep		Psychological needs of families of sick children, and impact on milk supply
Basics of expressing		Iatrogenic withdrawal and impact on breastfeeding
		Positioning challenges with wounds, stomas, lines and devices

		Complex fluid challenges, i.e., large fluid losses, fluid restriction, hyperhydration, high calorie need
		Feeding rehabilitation for oral aversion
		How to effectively utilise the skills of the multidisciplinary team

7.1.4 Training for nonclinical or non-paediatric staff

Finally, a parallel issue for several mothers was that while nonclinical and non-paediatric lactation professionals had excellent general lactation knowledge and counselling skills, they were not always able to provide care that was appropriately nuanced for a sick child. One plausible solution would be to provide specific add-on training for these professionals:

1. Bridging training to enable lactation advocates unfamiliar with the specific breastfeeding challenges seen in paediatrics to adapt their care
2. Adaptation of the breastfeeding skills and knowledge survey to repeat with both nonclinical lactation advocates and non-paediatric advocates

Professionals in Study 1 felt they could refer to the infant feeding lead from the neonatal or maternity departments if they could not help a particular family. However, without exception, when this strategy was utilised in the parent study, it was found to be unhelpful. The strategies suggested by the neonatal or maternity infant feeding teams did not meet the unique needs of the children and left the mothers feeling frustrated. Equally, when mothers with more complex challenges approached an experienced but nonclinical lactation advocate, they again encountered skill gaps. Sometimes the support from a non-paediatric lactation advocate, such as a midwife, will be sufficient to meet the needs of a breastfeeding mother and infant dyad in paediatrics. This is more likely if the child is admitted with a condition familiar to the midwife – such as jaundice. Equally, a neonatal infant feeding supporter is likely to be able to support challenges such as respiratory compromise in a younger infant. Whilst there are some areas of overlapping challenges across clinical areas, there are multiple conditions and ages of children that would be unfamiliar to both

maternity and neonatal staff. Therefore, the children admitted with serious health challenges, especially those who are older, are the least likely to be able to access timely, experienced support as standard. Further surveys could identify the specific training needs of both nonclinical and non-paediatric staff to ensure their skill gaps are also adequately addressed.

Many mothers, when they did not find the solution to their challenge among the staff on the paediatric ward, went to great lengths to curate their own bespoke package of support from various sources. However, this was associated with increased mental load, as well as services that were not joined-up because nobody had oversight of all the facets of the situation. Ensuring that families can access timely, individualised, compassionate support that is appropriate for the needs of their sick child and unique breastfeeding challenges in all likelihood means a combination of investment in equipment, policies and training, alongside greater utilisation of multi-disciplinary team working.

7.2 Limitations of the thesis

The two studies were both unique in terms of their populations of exploration and depth of content and provide a useful addition to the body of lactation knowledge. However, in common with all research (Connelly, 2013), this thesis has many limitations which are important to acknowledge with transparency to enable appropriate conclusions to be drawn by those seeking to build on this work, as well as effect change in paediatrics (Ioannidis, 2007).

The first limitation is the lack of previous topic-specific research. The lack of knowledge in paediatric lactation fundamentally limits the scope of research because it is not possible to know about unknown areas. Therefore, the research questions as well as the design of the two studies - which were influenced by the findings of the systematic review - may be incomplete or erroneous in some way that future research will illuminate. The findings of the systematic review included seven themes which were explored in more detail during the subsequent research. However, as acknowledged in chapter two, much of the previous research was dated, focused on single conditions and younger infants, had a narrow range

of conditions, and geographical bias towards North America. While these limitations were accounted for, they may have adversely influenced the generated themes and thus the two studies in this thesis.

Secondly, the recruitment of both studies was via an online advert. With the first study, this was a pragmatic choice to recruit a large sample with good geographical representation. The second study was initially designed as an in-person study, but this was impractical due to the covid pandemic and difficulties accessing clinical departments. However, the advantages of changing the recruitment strategy were that a much more geographically varied sample was achieved, and the sample could be purposively selected from the initial potential participants to achieve more ethnic diversity. With both studies, however, online recruitment is known to have potential bias (Ball, 2019) though the data collection instruments were designed with the CHERRIES checklist in mind (Eysenbach, 2004). One of the benefits of online surveys is that busy practitioners can complete them at a time which suits them (Callegaro et al., 2015); however, it is hard to prevent more invested professionals from being over-represented in the survey. Thus, the sample of healthcare professionals in the first study may not represent a true picture of UK paediatric breastfeeding skills and attitudes. It would be interesting to recruit a much larger sample which may have identified additional barriers, hostility, strengths and skills that are yet unknown. The health professionals, while generally invested, had a low representation of those with additional breastfeeding qualifications particularly at breastfeeding counsellor and IBCLC level. This may be a true reflection of the skill mix in paediatrics, or it could be due to an under powered sample and self-selection bias (Ross and Bibler Zaidi, 2019). Furthermore, the study did not explore the skills and knowledge of nonclinical lactation supporters, because to do so would have introduced further variables and complexity which would not have been within the scope of this PhD candidacy. Nevertheless, given that the mothers in the second study made several comments about the mixed experiences they had with nonclinical lactation professionals, this would be interesting to explore further.

Thirdly, in terms of the validity of data collection in Study 1, there were no appropriate valid data collection tools because this study was unique in its focus on multidisciplinary professionals working in paediatrics, and it was not measuring a pre and post-test

intervention. The survey therefore could have been improved to gather higher quality data, expand on areas such as attitudes to responsive parenting, or ask more specific questions about skills. The skills questions could also have attempted to quantify level of skill more accurately. However, the survey was designed with the aim of not being intimidating or putting participants off. Asking questions that were too specific could have led to social desirability bias and therefore the questions, whilst potentially limiting the results, were designed to reduce participant discomfort (Krumpal, 2013).

Fourthly, considering the design of the research, the overall methodology was an explanatory sequential mixed methods approach. This was because it was felt that having a clearer idea of the skills and attitudes of a large sample of healthcare professionals was helpful to establish the general state of paediatric breastfeeding provision prior to interviewing mothers. Had an exploratory sequential design been adopted, in which qualitative methods are used to design the quantitative instrument, the resulting data might have looked very different (Cresswell, 2014). However, not only was it felt that basing a national survey of healthcare professionals on the experiences of just thirty mothers may have been inappropriate, but this design is also more difficult. As a novice researcher, this may have been too complex to achieve with good results.

Fifthly, in terms of the generalisability of these findings, both studies may have recruited those who were more invested in this topic, and by definition, this may limit the generalisability of the findings (Price and Murnan, 2004). This was an anticipated limitation, and the questions on the health professional survey were designed accordingly, collecting data about the unit culture and organisational structures as well as personal experience and skill. In terms of the parent study, the shift to online recruitment presented an opportunity to reduce this limitation by recruiting a large sample which enabled greater variety of participant demographics. Nevertheless, these limitations are acknowledged, and future studies recruiting larger samples may overcome this problem more successfully.

Finally, the discussion may be compromised due to lack of experience of the researcher, and a failure to comprehend or conduct more subtle analysis of the data. Furthermore, researcher bias may have led to flawed assumptions or research aims which would have

jeopardised the validity of the findings. Throughout the studies several approaches have been utilised to attempt to overcome this, including extensive researcher reflexivity, piloting the studies, and seeking advice from more experienced researchers at multiple stages (Sheppard, 2004; Bolton, 2010; Denscombe, 2017).

Despite the limitations of this thesis it provides an important addition to the existing knowledge of lactation by identifying a significant gap in the literature, leading to novel findings relating to the needs of breastfed medically complex children and their families. The identification of the gap in skills and knowledge could provide opportunities to develop targeted training that meets some of the identified needs of families.

7.3 Future research directions

As identified previously, there were many limitations of this thesis, partly related to the lack of quality research in this area, which could be addressed with further studies and larger samples. There are three main suggested areas of future research – firstly related to training, secondly related to the clinical impact of breastfeeding and thirdly, related to the wider impacts of improvements in care on maternal mental health and family functioning.

In terms of training, it would be helpful to know how mandatory undergraduate healthcare professional breastfeeding training affects breastfeeding competence. This could be achieved by instigating a multi-disciplinary designed curriculum incorporating clinical practical skills testing stations which are common among many healthcare professional training curricula. Skills could be assessed by conducting pre and post-test scoring. There could also be a scoping exercise based on the identified skill gaps, and led by a multi-disciplinary panel, to establish which topics should be included in post-registration breastfeeding training for clinicians. This nuanced training could then be delivered to health professionals in paediatrics and similar pre and post-test scores collected, to be run in conjunction with auditing the impact this has on family experiences and breastfeeding outcomes. This multi-disciplinary approach is also likely to improve inter-professional working and collaboration as well as lead to better outcomes for families (Pettigrew et al., 2022). A similar exercise could be conducted to establish what bridging training nonclinical

lactation advocates require to equip them to work safely with medically complex breastfed children. Another option would be to pilot an approach that includes nonclinical lactation advocates and paediatric clinicians working together to ensure adequate lactation support as well as maintaining appropriate scope of practice. Related to this proposal is the suggestion to adopt a body systems approach to assessing and managing breastfeeding challenges. This approach would lead to more individualised and specific care that accurately addresses the identified needs. Developing this approach would require multi-disciplinary input and potentially the involvement of innovation and technology to create tools and resources to improve efficiency and accuracy.

The second area of future research priority is related to the clinical impacts of more infants and children maintaining breastfeeding, or breastmilk consumption during illness and medical complexity. It is reasonable to hypothesise that breastfeeding would reduce the severity of disease, iatrogenic infection and length of hospital stay, but the extent to which this is true in this population is unknown. This is important, as it would provide clinical justification for the widespread adoption of Baby Friendly standards in paediatrics. On a related but more specific topic, it would also be relevant to know to what extent breastfeeding provides effective pain relief during procedures and for post-surgical pain. At present there is clinical justification for offering mothers the option of breastfeeding during or immediately post immunisation or heel stick, but there are no studies exploring the efficacy of breastfeeding as pain relief for more invasive procedures or significant pain. This is important missing information and would potentially provide further evidence of the impact of continuing to breastfeed through hospitalisation, medical intervention and illness. There is also no research exploring skin-to-skin as a comfort and pain-relief tool. Whilst there is plentiful evidence that skin-to-skin is beneficial for neurodevelopment and physiological stability in preterm neonates, the medically complex and critically unwell paediatric population may also benefit from this being a standard recommendation on paediatric wards and PICU. The implications for safety, acceptability to parents, and impacts on infants are all important unresearched aspects of family centred care.

Thirdly, in terms of the impacts on families, the two studies have uncovered many impacts of breastfeeding sick children on maternal mental health and emotional wellbeing as well as

practical, logistical and financial strains. There is a need to more extensively research the impacts of breastfeeding on parental self-esteem, self-efficacy, and stress, as well as the wider implications of profound shock and trauma on breastfeeding within this population. In paediatrics, illness can present suddenly, and mothers may be attempting to continue to breastfeed directly. Previous research has focused on the effects of trauma on pumping in the neonatal unit, but not direct breastfeeding on PICU (Johns et al., 2013; Bower et al., 2017; Bujold et al., 2018). It would also be useful to explore in more depth which interventions and strategies mothers find supportive to enable them to meet their personal feeding goals during both acute, as well as chronic, serious and critical illness; and whether there is a difference in which interventions are perceived to be effective and supportive depending on whether the illness is short or longer-lasting, self-limiting or more serious.

Additionally, many mothers struggled with their milk supply during acute stress and trauma and many of the children were supplemented with formula for various reasons. The provision of screened donor milk is currently prioritised for preterm neonates due to the robust research supporting its use to prevent necrotising enterocolitis and optimised neurodevelopmental outcomes (Quigley et al., 2019). However, there may be a compelling clinical rationale for the use of donor human milk in the paediatric population that has not yet been identified. We already know that the use of donor human milk can lead to significant improvements in maternal and paternal mental health (Brown and Shenker, 2022). A larger study exploring the acceptability of donor human milk, as well as identifying who would most benefit from this intervention, would also be a compelling piece of research.

Finally, the lactation needs of mothers whose children have been diagnosed with a palliative condition, or who are receiving end-of-life care are minimally researched. Much of the research comes from NICU settings and refers to very preterm neonates or a foetal diagnosis of incompatibility with life (Kennedy et al., 2017; Warr, 2019; Marc-Aurele, 2020). There may be additional complexities after an illness of longer duration, or when a child is older, and lack of anticipatory guidance about how to manage lactation after a child has died can increase the complexity of grief for mothers (Cole, 2012; Marc-Aurele, 2020). Children who die in the paediatric setting are a heterogenous group, and therefore the

management of end-of-life lactation will differ depending on the age of the child, the exclusivity of breastfeeding, the duration and nature of illness and many other factors. Future research should attempt to sensitively identify which strategies are supportive and compassionate towards mothers and families when a child has a life-limiting condition or their care focus shifts from active treatment to palliative support, and they attempt to make decisions about end-of-life lactation.

7.4 Conclusion

This thesis was designed to identify the needs and challenges of breastfed medically complex infants and children in the paediatric setting. The systematic review revealed the paucity of data in this clinical environment, and two related studies were designed. The first study set out to establish the skills, knowledge, experience and attitudes of paediatric healthcare professionals as well as the ward culture. The second study explored the experiences, challenges and held views of mothers breastfeeding their medically complex child.

The studies identified widespread gaps in clinical knowledge and skills that were significantly correlated with less breastfeeding training. The mothers of more chronically or severely unwell children generally had more challenges and were more likely to encounter difficulties that are not addressed in currently available training. The studies collectively point to the need for recognition of the unique clinical lactation needs of the paediatric population, and investment at national, policy, hospital and ward levels to reduce the skill gaps with nuanced training in order to improve experiences and outcomes for breastfed children and their families.

Appendix 1: Children's Nursing: Field specific competencies (2014)

The following competencies could be perceived to have direct or indirect relevance to breastfeeding:

- 1.1 Children's nurses must be able to recognize and respond to the essential needs of all people who come into their care including babies, pregnant and postnatal women, adults, people with mental health problems, people with physical disabilities, people with learning disabilities, and people with long-term problems such as cognitive impairment.
- 5.1 Children's nurses must include health promotion and illness and injury prevention in their nursing practice. They must promote early intervention to address the links between early life adversity and adult ill-health, and the risks to the current and future physical, mental, emotional and sexual health of children and young people.
- MM35,7 Awareness of approaches to managing symptoms, including relaxation, distraction and lifestyle advice.
- CCC2,14 Actively helps people to identify and use their strengths to achieve their goals and aspirations.
- OAC9,3 Understands the concept of public health, and the benefits of healthy lifestyles and the potential risks involved with various lifestyles or behaviours, for example substance misuse, smoking, obesity.
- NFM31,4 Administers enteral feeds safely and maintains equipment in accordance with local policy.
- NFM31,5 Safely maintains and uses nasogastric, PEG and other feeding devices
- NFM27,7 Supports people to make appropriate choices and changes to eating patterns, taking account of dietary preferences, religious and cultural requirements, treatments and special diets needed for health reasons.

Appendix 2: Systematic review study characteristics

Article	Country	Pub year	Objective	Design	Main findings	Sample	N	Potential confounding factors?	Variables controlled for/commented on?
Banta-Wright et al.	US/ Canada	2015	Describe meaning and purpose of BF to mothers	Qualitative descriptive	Diagnosis required a re-commitment to BF, including learning about child's condition. BF was meaningful, maintaining closeness and connection, but required some adaptation – being flexible about how much/little BF, as well as maintaining lactation. Mothers required support. Mostly this came from peers. Most cited a lack of clear written info. LCs helped but had to be found. Final theme was that although BF infants with PKU was hard work, it was worth it. BF gave them a way to see their infants as normal.	Mothers of babies with PKU	10	Socio economic status, intention to breastfeed, education status, previous breastfeeding experience, prior knowledge of PKU, support from partner, support from health care professionals, information about PKU, NICU/PICU admission, gestational age, availability of breast pump, distance from hospital or access to regular domiciliary nursing for blood tests, BFI-accredited hospital, parental mental health condition.	Socio-economic status, partner availability, education status, previous children with PKU.
Barbas et al.	USA	2004	Describe BF outcomes among mother-infant pairs in a CHD context	Retrospective survey	Breastfeeding provided mothers with an opportunity to feel more involved in their infant's care, as well as higher sense of self-efficacy. Making a 'difficult experience bearable'.	Mothers of babies with CHD	68	Socio economic status, intention to breastfeed, education status, previous breastfeeding experience, antenatal breastfeeding education, access to	Maternal age, level of education, marital status, number of children, classification of CHD, prenatal preparation for CHD, availability of specialist

					Many mothers found nursing and medical staff unsupportive – the importance of breastmilk was not acknowledged by many, and many of the staff were felt to imply that formula was better, and less ‘icky’. There were some notable exceptions from supportive staff members. The most common positive comment was about the availability of pumps.			specialist breastfeeding support, NICU/PICU admission, gestational age, breast pumps, support from health care professionals, infant calorie need/growth rate, BFI-accredited hospital, parental mental health condition.	breastfeeding support.
Barros da Silva et al.	Portugal	2019	Explore experiences of mothers breastfeeding children with Down syndrome	Qualitative, semi-structured interview	Mothers expressed dissatisfaction with health care practitioners regarding their support and knowledge of breastfeeding children with Down syndrome. Mothers persevered due to their commitment to breastfeeding, and despite a lack of support and the challenges of feeding babies with low tone, sucking problems or cardiac anomalies.	Mothers of children with Down’s syndrome	10	Socio economic status, education status, intention to breastfeed, previous breastfeeding experience, antenatal education, prenatal diagnosis of Down syndrome, comorbidities (such as CHD), support from health professionals, infant stability, NICU/PICU admission, gestational age, availability of psychological support, BFI-accredited hospital, parental mental health condition.	Confounding variables not commented on.

Duhn and Burke	Canada	1998	What are the key issues experienced by mothers feeding their babies with CHD	Qualitative interviews using a grounded theory approach (unpublished)	There was a theme of acknowledging that the feeding and mothering process was different. This involved grief and shock. Mothers described the hard work of feeding, and incorporating this into everyday life was difficult, stressful, time-consuming and anxiety-provoking. Mothers began to develop feelings of control after reframing their experience, persisting with feeding even though it was hard, and choosing to remain positive. There were recurring experiences of loss, fear of their baby dying and an emotional battle between feeling close through feeding yet needing to create a protective distance due to a feeling of threatened survival. All mothers stopped breastfeeding within 4-6 weeks, and though some continued to pump, nobody resumed breastfeeding after initially stopping.	Mothers of infants with CHD	7	Socio economic status, education status, previous breastfeeding experience, BFI-accredited hospital, parental mental health condition.	
Heilbronner	France	2017	Evaluate breastfeeding disruption	Cross sectional study	43% of mothers stated that hospitalisation modified their breastfeeding	Breastfeeding mothers of children	84	Child age, prior difficulty with breastfeeding, social	Age of child, length of stay, severity of illness, length of

			during hospital admission for bronchiolitis		experience. Several either stopped, switched to partial breastfeeding or reduced breastfeeding. Lack of support by health care staff as well as medical advice was the most cited reason for this.	hospitalised with bronchiolitis		support, socio-economic status, intention to breastfeed, PICU admission, ventilation, respiratory support, tube feeding, whether parent was able to be resident overnight, nursing ratios, level of nursing knowledge in breastfeeding, problems with recall, availability of breast pump, BFI-accredited hospital, parental mental health condition.	PICU stay, length of ventilation, nutritional support, growth rate prior to hospitalisation. Socio economic status only available for 54/84 patients.
Lambert and Watters	Canada	1998	Share insights about the experiences of mothers of CHD infants	Descriptive survey	Some parallels noted between maternal reported benefits of breastfeeding a sick child with those reported by mothers of preterm infants. Most of the mothers were not encouraged to breastfeed, and many health care professionals expressed inaccurate views of breastfeeding in the context of physiological instability. There were also barriers put up by health care professionals due to concerns over the difficulty	Mothers of children with CHD	12	Socio economic status, education status, intention to breastfeed, previous breastfeeding experience, degree of infant stability, NICU/PICU/CICU admission, gestational age, antenatal education, prenatal diagnosis of CHD, peer support, availability of specialised lactation support, support from health care staff, BFI-accredited hospital,	Maternal age, education status, nature of cardiac anomaly, personal breastfeeding goals, whether information provided by medical professionals was broadly positive, negative or absent.

					with measuring volumes when babies are breastfed.			parental mental health condition.	
Lewis and Kritzinger	South Africa	2004	Describe the experiences of feeding children with Down syndrome	Descriptive survey	There were several feeding challenges due to low tone, heart defects, infant exhaustion, problems with sucking and safe swallowing. Mothers experienced a range of emotions, such as shock, concern, stress, disappointment and frustration. Mothers identified that they required support, choices and skilled guidance from professionals, as well as peer support to achieve their feeding goals. They also valued encouragement to continue breastfeeding.	Mothers of children with Down syndrome	20	Socio economic status, education status, intention to breastfeed, previous breastfeeding experience, comorbid condition, prenatal diagnosis of Down syndrome, NICU/PICU admission, gestational age, nutritional/feeding support, BFI-accredited hospital, parental mental health condition.	Maternal age, but not level of education, partner status, or antenatal education. Many infant variables accounted for. Apart from NICU/PICU admission – though questions were asked about whether baby was ventilated.
Madhoun et al.	USA	2019	To examine trends in breast milk provision and characterise barriers and supports to maintaining breastfeeding or breastmilk feeding.	Online retrospective cross-sectional study of mothers of babies with cleft lip/palate	Breastfeeding duration was dependent on cleft type. CL only babies were more successful at breastfeeding. Many mothers in the study pumped, and pumping duration was not affected by cleft type. Lactation consultants were the most common source of support but were not 'required' members of the cleft team. Feeding duration	Mothers of babies with Cleft lip/palate	150 (69 BF)	Socio economic status, education status, previous breastfeeding experience, intention to breastfeed, partner support, lactation support, medical professional support, access to breast pump, NICU/PICU admission, cleft lip and/or palate, comorbidities, BFI-accredited hospital,	Socio economic status, maternal age, marital status, education status, intention to breastfeed, age of infant, cleft type, comorbidities, maternal depression, NICU admission.

					was also improved by peer support. Many mothers described anxiety and/or depression.			parental mental health condition.	
Moe et al.	USA/ Canada	1998	Determine what support is useful in establishing and maintaining lactation in infants with Rubenstein-Taybi syndrome	Retrospective survey	Even with very little support, babies with RTS demonstrated ability to be able to breastfeed successfully. However, mothers reported that many health professionals were discouraging, and there were not enough lactation consultants to support them with specialist feeding techniques to facilitate effective feeding. Support more often came from booklets, family members and their prior experience of breastfeeding another child. The research suggests ways in which the techniques described in this study may be of help to babies with other conditions that involve low tone – such as Down syndrome.	Mothers of children with Rubenstein-Taybi syndrome	194	Socio economic status, education status, intention to breastfeed, previous breastfeeding experience, NICU/PICU admission, comorbidities, lactation and health care professional support, BFI-accredited hospital, parental mental health condition.	No data on socio-economic variables, parental age, partner status, prenatal preparation. Data was provided about breastfeeding duration, reasons for cessation, quality and prevalence of support provided, and by whom.
Rendon Macias et al.	Mexico	2002	Determine frequency of breastfeeding, and identify factors associated with	Descriptive cohort study	Infants with congenital malformations are less likely to BF. Mothers cited many reasons, including medical advice, separation, and	Mothers of babies with congenital anomalies	120	Socio economic status, education status, previous breastfeeding experience, BFI-accredited hospital, intention to	No data relating to socio-economic status, partner status, education level, provided.

			initiation and cessation among mothers of children with congenital anomalies		infant disease – especially GI disease.			breastfeed, infant condition, comorbidities, NICU/PICU admission, breast pump availability, parental mental health condition.	Data about parental age, employment, intention to breastfeed, antenatal education, initial infant feeding pattern, and infant condition is provided. No breast pumps available at this facility, and no rooming in facilities – though parents are permitted to stay (unclear how this is facilitated). Unclear differentiation between exclusively and partially breastfed infants when calculating duration of breastfeeding.
Ryan et al.	UK	2013	Explore the experience of breastfeeding a baby with chronic illness or disability	Narrative interviews	Chronic illness or disability causes disruption to the breastfeeding relationship. In this study, mothers' sense of self efficacy was closely tied to their ability to breastfeed, and thus was an important part of emotional adjustment to chronic illness or disability.	Mothers of children with Downs, Cleft and CHD	5	Socio economic status, education status, previous breastfeeding experience, intention to breastfeed, infant condition, NICU/PICU admission, comorbidities, BFI-accredited hospital, parental mental health condition.	Parental age, marital status, employment status, ethnicity was collected. Data about infant illness or disability was also provided.

Appendix 3: CASP checklists

CASP Checklist: Qualitative research (2018)

All available here: <https://casp-uk.net/casp-tools-checklists/>

CASP Criteria	Met the criteria? Yes, No, Can't tell
Q1: Was there a clear statement of the aims of the research?	
Q2: Is a qualitative methodology appropriate?	
Q3: Was the research design appropriate to the aims of the research?	
Q4: Was the recruitment strategy appropriate to the aims of the research?	
Q5: Was the data collected in a way that addressed the research issue?	
Q6: Has the relationship between researcher and participants been adequately addressed?	
Q7: Have ethical issues been considered?	
Q8: Was the data analysis sufficiently rigorous?	
Q9: Is there a clear statement of findings?	
Q10: How valuable is the research?	

CASP checklist: Cohort studies (2018)

CASP criteria	Met the criteria? Yes, No, Can't tell
Q1: Did the study address a clearly focused issue?	
Q2: Was the sample recruited in an acceptable way?	
Q3: Was the exposure accurately measured to minimise bias?	
Q3a: Was the outcome accurately measured to minimise bias?	
Q4a: Have the authors identified all important confounding factors?	

Q4b: Have the authors taken account of confounding factors in their design and analysis?	
Q5: Was the follow up of subjects complete enough?	
Q5b: Was the follow up of subjects long enough?	
Q6: What are the results of this study?	
Q7: How precise are the results?	
Q7a: Do you believe the results?	
Q8: Can the results be applied to other populations?	
Q9: Do the results of this study fit with other available evidence?	
Q10: What are the implications of this study for practice?	

Checklist for Cross sectional study adapted from CASP (2018) Cohort study

CASP criteria	Met the criteria? (Yes, Can't tell, No)
Q1: Did the study address a clearly focused issue?	
Q2: Was the sample recruited in an acceptable way?	
Q3: Was the outcome accurately measured to minimise bias?	
Q4a: Have the authors identified all important confounding factors?	
Q4b: Have the authors taken account of confounding factors in their design and analysis?	
Q5: Was the follow up of subjects complete enough?	
Q6: What are the results of this study?	
Q7: Do you believe the results?	
Q8: Can the results be applied to other populations?	
Q9: Do the results of this study fit with other available evidence?	
Q10: What are the implications of this study for practice?	

Appendix 4: Participant information sheets

4.1 Health professional survey

What is the purpose of the research?

We know that the Baby Friendly Initiative standards have successfully increased the initiation rates of breastfeeding in the maternity, neonatal and community settings. Breastfeeding training and support are provided to all staff caring for families of young infants and children. However, at present, these standards do not cover the paediatric setting, leaving many staff under-supported and under-resourced when it comes to providing support and information to families. The aim of this questionnaire is to find out what training and experience professionals working in paediatrics have, and how confident they feel in supporting families on their ward or department with a range of breastfeeding issues. It is open to any professional working in paediatrics and caring directly for children.

Who is carrying out the research?

The data is being collected by Lyndsey Hookway in the Department of Public Health, Policy and Social Sciences at Swansea University, and supervised by Professor Amy Brown. The research has been approved by the Research Ethics Committee, College of Human and Health Sciences, Swansea University.

What happens if I agree to take part?

If you would like to take part, you will be invited to complete a questionnaire about your experiences of supporting families with breastfeeding their sick or medically complex infants and children in the paediatric setting.

The questionnaire will take around 10-15 minutes of your time. There are no right or wrong answers. We want to hear your open and honest experiences on this topic. If there are any questions you do not wish to answer you can skip them and carry on with the rest of the questionnaire.

Are there any risks associated with taking part?

There are no significant risks associated with participation. If, as a result of taking part, you have any questions or concerns about your wellbeing, we will encourage you to contact your ward manager, or GP who can provide you with further information and support. If you have any questions specifically about your own breastfeeding experience, you can contact the National Breastfeeding Helpline on 0300 100 0212 any day of the year between 9:30 and 9:30pm or any of the other breastfeeding organisations and further details can be found at the end of the questionnaire.

Data Protection and Confidentiality

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. Your data will only be viewed by the researcher/research team. All electronic data will be stored as an encrypted file on a password-protected computer file on a private laptop.

What will happen to the information I provide?

An analysis of the information will form part of the report at the end of the study and may be presented to interested parties and published in scientific journals and related media. The analysis will be used as part of a PhD thesis and may inform future policy development. All information presented in any reports or publications will be anonymous and unidentifiable.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not want to.

However, please note that the data collected for this study will be made anonymous. Thus, it will not be possible to identify and remove your data at a later date once you have completed the questionnaire.

Data Protection Privacy Notice

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data and can be contacted at the Vice Chancellors Office.

Your personal data will be processed for the purposes outlined in this information sheet.

Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you.

The legal basis that we will rely on to process your personal data is necessary for the performance of a task carried out in the public interest. This public interest justification is approved by the College of Human and Health Sciences Research Ethics Committee, Swansea University.

The legal basis that we will rely on to process special categories of data is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

How long will your information be held?

Data will be preserved and accessible for a minimum of 10 years after completion of the research. Records from studies with major health, clinical, social, environmental or heritage importance, novel intervention, or studies which are on-going or controversial should be retained for at least 20 years after completion of the study. It may be appropriate to keep such study data permanently within the university, a national collection, or as required by the funder's data policy.

What are your rights?

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

Any requests or objections should be made in writing to the University Data Protection Officer: -

University Compliance Officer (FOI/DP)
Vice-Chancellor's Office
Swansea University
Singleton Park
Swansea
SA2 8PP
Email: dataprotection@swansea.ac.uk

How to make a complaint

If you are unhappy with the way in which your personal data has been processed, you may in the first instance contact the University Data Protection Officer using the contact details above. If you remain dissatisfied, then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at:

Information Commissioner's Office,
Wycliffe House,
Water Lane,
Wilmslow,
Cheshire,
SK9 5AF
www.ico.org.uk

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact Lyndsey Hookway at [REDACTED]

If you would like to take part in the questionnaire, please read through the following statements:

- I have read and understood the information above.
- I am over 18 years of age.

- I live and work in the UK
- I am currently working within paediatrics (not neonatal unit)
- I consent to taking part in this study.

If you can answer yes to all the above answers then click next to progress to the next page, otherwise thank you for your time.

4.2: Parent interview study

The Breastfeeding Sick Children in Hospital Study

Thank you for considering taking part in this study of parents who have breastfed their sick or medically complex child in the paediatric setting (paediatric ward, paediatric intensive care, paediatric high dependency unit, paediatric specialist ward or cardiac intensive care unit)

PLEASE NOTE: While we recognize the significance of a neonatal unit admission for families, this is a survey for those whose children have been cared for in PAEDIATRICS only.

What is the purpose of the research?

We know that the Baby Friendly Initiative standards have successfully increased the initiation rates of breastfeeding in the maternity, neonatal and community settings. Breastfeeding support is provided to all families of young infants and children within maternity, neonatal and community services. However, at present, these services do not cover the paediatric setting as standard, leaving many families under-supported in the paediatric ward.

The aim of this research is to understand the experiences of parents continuing to breastfeed or provide breastmilk to their medically complex child while they are inpatients in the paediatric ward or PICU.

Objectives

The objectives of this study are:

- To understand parents' motivation to breastfeed their medically complex child
- To explore how child illness impacts parent's decisions to breastfeed
- To consider what factors facilitate ongoing breastfeeding

- To identify the challenges and setbacks that parents encounter while trying to breastfeed or maintain their milk supply
- To understand what interventions parents find supportive in their breastfeeding journey
- To learn what additional support parents feel they need or would benefit from
- To better appreciate the ways in which illness and the hospital environment make achieving breastfeeding goals different or more difficult

Who is carrying out the research?

The data is being collected by Lyndsey Hookway in the Department of Public Health, Policy and Social Sciences at Swansea University as part of her PhD. The project is being supervised by Professor Amy Brown. The research has been approved by the Research Ethics Committee, College of Human and Health Sciences, Swansea University.

Who is eligible to take part in the study?

If you would like to be considered for the interview, please read through the following statements.

- I have read and understood the information above.
- I am the breastfeeding parent of a child who has received UK based paediatric hospital care.
- I am a parent aged 16 years or over, and understand the purpose, risks and benefits of taking part in this study.
- I speak English.
- I am the parent of a child hospitalised for at least one night in the paediatric ward or PICU within the last 6 months.
- My child (of any age) is currently breastfeeding partially or exclusively, or I am expressing my milk.
- I am a parent who stopped breastfeeding during my child's hospital admission within the last 6 months.

- I am attempting to relactate or induce lactation for my child, after a period of formula feeding.

If you can answer yes to all the above answers and still wish to proceed then please continue reading, otherwise thank you for your time

What happens if I agree to take part?

If you would like to take part, you will be invited to complete a short initial questionnaire which will ask some basic questions about you and your child. These questions will be used to ensure that the parents selected for interview are a wide and diverse sample.

The questionnaire will take around 5-10 minutes of your time. Of the completed questionnaires, a sample of 20-30 parents will be invited to take part in an interview.

If selected, and if you consent to take part, the interview will take place via video or phone call, at a time that is convenient to you.

The interview will last approximately an hour, and you will be able to see some examples of the questions that you may be asked in advance. You do not have to give any information you are not comfortable with sharing.

Your name and your child's name will not be published, nor will the hospital you were cared for be named.

As a token of appreciation for your time, you will be sent a £20 gift voucher after the interview has taken place.

Are there any risks associated with taking part?

There are no significant risks associated with participation. If, as a result of taking part, you have any questions or concerns about your child's care, we will encourage you to contact the ward manager, or PALS. If you have any questions specifically about your own breastfeeding experience, you can contact the National Breastfeeding Helpline on 0300 100 0212 any day of the year between 9:30 and 9:30pm. Every participant will also be provided with some resources to help them find support.

Data Protection and Confidentiality

Your data will be processed in accordance with the Data Protection Act 2018 and the General Data Protection Regulation 2016 (GDPR). All information collected about you will be kept strictly confidential. Your data will only be viewed by the researcher/research team. All electronic data will be stored as an encrypted file on a password-protected computer file on a private laptop.

What will happen to the information I provide?

An analysis of the information will form part of the report at the end of the study and may be presented to interested parties and published in scientific journals and related media. The analysis will be used as part of a PhD thesis and may inform future policy development. All information presented in any reports or publications will be anonymous and unidentifiable.

Is participation voluntary and what if I wish to later withdraw?

Your participation is entirely voluntary – you do not have to participate if you do not want to.

Data Protection Privacy Notice

The data controller for this project will be Swansea University. The University Data Protection Officer provides oversight of university activities involving the processing of personal data and can be contacted at the Vice Chancellors Office.

Your personal data will be processed for the purposes outlined in this information sheet. Standard ethical procedures will involve you providing your consent to participate in this study by completing the consent form that has been provided to you.

The legal basis that we will rely on to process your personal data is necessary for the performance of a task carried out in the public interest. This public interest justification is approved by the College of Human and Health Sciences Research Ethics Committee, Swansea University.

The legal basis that we will rely on to process special categories of data is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

How long will your information be held?

Data will be preserved and accessible for a minimum of 10 years after completion of the research. Records from studies with major health, clinical, social, environmental or heritage importance, novel intervention, or studies which are on-going or controversial should be retained for at least 20 years after completion of the study. It may be appropriate to keep such study data permanently within the university, a national collection, or as required by the funder's data policy.

What are your rights?

You have a right to access your personal information, to object to the processing of your personal information, to rectify, to erase, to restrict and to port your personal information. Please visit the University Data Protection webpages for further information in relation to your rights.

Any requests or objections should be made in writing to the University Data Protection Officer: -

University Compliance Officer (FOI/DP)
Vice-Chancellor's Office
Swansea University
Singleton Park
Swansea
SA2 8PP
Email: dataprotection@swansea.ac.uk

How to make a complaint

If you are unhappy with the way in which your personal data has been processed, you may in the first instance contact the University Data Protection Officer using the contact details above. If you remain dissatisfied, then you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be contacted at:

Information Commissioner's Office,
Wycliffe House,
Water Lane,
Wilmslow,

Cheshire,
SK9 5AF
www.ico.org.uk

What if I have other questions?

If you have further questions about this study, please do not hesitate to contact Lyndsey Hookway at [REDACTED]

If you feel you meet the criteria for eligibility to this study, and wish to proceed, then please click to continue to the next page.

Appendix 5: Health care professional survey questions

Section 1: About your clinical experience and where you work

1.1 What is your ethnicity?

White/ White British	White/ White Irish	Gypsy/ Traveller	Asian or Asian British: Bangladeshi	Asian or Asian British: Indian	Asian or Asian British: Pakistani
Asian or Asian British: Chinese	Asian or Asian British: Other	Black or Black British	Mixed or multiple	Other	Prefer not to say

1.2 What is your gender?

- Female
- Male
- Trans *male
- Trans *female
- Gender non-binary
- Self-defined (please state)
- Prefer not to say

1.3 What is your profession? (Choose one)

- Paediatric nurse
- Health care assistant working in paediatrics
- Paediatrician (consultant)
- Paediatrician (clinical fellow)
- Paediatrician (ST 1-6)
- Physiotherapist
- Occupational therapist
- Speech and language therapist
- Dietitian

- Other

1.4 How long have you been qualified? (Choose one)

- Less than 2 years
- 2-5 years
- 5-10 years
- 10-15 years
- 15+ years

1.5 Do you work in a specialist (tertiary) paediatric referral centre, or a local hospital?

(Choose one)

- Specialist centre
- Local hospital

1.6 Which region best describes where you work?

- England – North
- England – South
- England – East
- England – South West
- England – Central
- England – London
- Wales
- Scotland
- Northern Ireland
- Ireland

1.7 Within your hospital, what kind of environment(s) do you work in? (Allow more than one)

- General paediatric medical/surgical ward
- Ambulatory care/rapid assessment unit
- Emergency department
- PICU
- Cardiac intensive care unit
- Children's outpatients
- Theatre/recovery

- Other

1.8 Do you regularly care for infants and children under the age of 2 (choose one)

- Every shift
- Nearly every shift
- Hardly ever
- Not at all

Section 2: How you feel about supporting families of breastfed infants and children

2.1 How much would you agree with this statement: "I have a lot of experience supporting breastfeeding"? (Choose one)

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

2.2 Where does your breastfeeding information largely come from? (Allow more than one)

- My undergraduate training
- Additional courses provided by my NHS employer
- Private courses or training I have funded myself
- My personal breastfeeding experience
- A colleague on the ward
- Websites
- I don't feel like I have any specific information

2.3 Do you have any experience supporting families with any of the following issues: (allow more than one)

- Providing encouragement to breastfeed
- Positioning, improving latch to help with nipple pain
- Identifying poor milk transfer
- Identifying adequate milk intake

- Supporting common breastfeeding parental challenges, such as mastitis, blocked ducts
- Supporting parents to express their milk
- Helping parents who need to be able to protect or increase their milk supply
- Re-starting breastfeeding, or inducing lactation
- Supporting infants with higher calorie need
- Supporting infants with low tone or sleepiness
- Supporting infants with anatomical challenges such as oro-facial anomalies
- Supporting infants to return to breastfeeding after tube feeding
- Providing information to families about the non-nutritive benefits of breastfeeding

Section 3: Your experience and training within infant feeding

3.1 Do you have any kind of additional responsibility specifically related to infant feeding on your ward? (Choose one)

- Yes (please specify)
- No

3.2 Do you have any of the following breastfeeding credentials? (Allow more than one)

- IBCLC
- Breastfeeding counsellor
- Peer supporter
- Something else
- None of the above

3.3 Have you attended any of the following training: (allow more than one)

- IBCLC preparation courses
- Online lactation training courses providing 50-90 hours of training
- Peer support training
- UNICEF 2-day breastfeeding training
- UNICEF eLearning for paediatric nurses
- Other training

3.4 During the course of an average week, how often do you provide clinical care to a breastfed child? (Choose one)

- Every shift
- Most shifts
- Rarely
- Never

3.5 On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise (choose one)

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

3.6 When you remember your initial training, how much education did you receive in relation to breastfeeding? (Choose one)

- We had a whole day of training
- We had 1-2 hours of basic training
- It was assumed we would learn on the job
- I can't remember having any information about breastfeeding
- Other

3.7 Thinking back to the training you have received (not including any personal experience), to what extent do you agree that your training equipped you to be able to support breastfeeding families on the ward? (Choose one)

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Section 4: Post-registration training and continuing professional development

4.1 Thinking about the training you have received *after* qualifying, is breastfeeding training something that you have been provided with? (Choose one)

- Yes, it is mandatory
- It is offered, but not mandatory
- No, it is not provided

4.2 Is there someone on the ward or department where you work who has been identified as someone with additional infant feeding/breastfeeding expertise? (Choose one)

- Yes
- No
- I'm not sure

4.3 I feel that breastfeeding training is something I need or could benefit from (choose one)

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

4.4 In paediatrics, you need different skills and tools to be able to adequately support breastfeeding to continue, compared with people supporting healthy infants and children (choose one)

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

4.5 Have you ever asked for breastfeeding training from your ward manager? (Choose one)

- Yes, and I have received it
- Yes, and I wasn't given any
- No, I've not asked

4.6 If you have not asked for breastfeeding training, could you explain your reasons for this?

4.7 In your opinion, what would help you to be better able to support breastfeeding families on the ward or department where you work? (Allow more than one)

- A breastfeeding policy
- Better undergraduate training
- Specific breastfeeding training that relates to the care of sick children
- Leaflets and handouts available to give to parents on the ward
- A designated paediatric infant feeding team
- Something else?
- I'm not sure

4.8 I believe that breastfeeding is important for children, whether they are unwell or healthy

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

4.9 I believe that supporting parents to reach their breastfeeding goals is an important part of my job

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Section 5: Barriers to providing breastfeeding support on the ward/department

5.1 On an average shift, in my ward/department there is enough support for families who are trying to breastfeed

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree

- Strongly disagree

5.2 Knowing how busy and stressful it can be on the ward, what do you think are the main barriers to professionals being able to support breastfeeding? (Allow more than one)

- Pressure from health care professionals to stop breastfeeding
- Lack of knowledge of how to help
- The need to be able to measure fluid balance
- Infant instability affecting their ability to effectively feed
- Adaptations required to breastfeed due to the child's condition
- Critical care takes precedence
- We don't have the time to support breastfeeding
- Something else?

5.3 What do you think are the main barriers for families who are trying to breastfeed their sick or medically complex child? (Allow more than one)

- Needing to tube feed
- Stress
- Lack of privacy
- Cannot find a breast pump
- Unable to stay with their child
- Need to look after other children
- They feel scared to breastfeed their sick child
- They don't get enough support
- They are advised not to breastfeed
- Something else

5.4 Have you heard of any of these resources? (Allow more than one)

- Breastfeeding network
- La Leche League
- Kellymom
- Lactmed
- Baby friendly initiative
- Hospital infant feeding network
- Drugs in breastfeeding factsheets

- Academy of breastfeeding medicine
- Breastfeeding the Brave support group

5.5 Thinking about the general attitude towards breastfeeding in your ward or department, how strongly would you agree with the following statements: (choose one for each statement)	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
Our unit values breastfeeding for the nutritional, immunological and psychological impacts it has. Supporting families to meet their breastfeeding goals is something we try to do.					
The staff on our unit are adequately trained and are able to support most breastfeeding challenges.					
Breastfeeding families generally have a good experience on our unit.					
The multi-disciplinary team all work together to try to find solutions that enable breastfeeding to continue alongside clinical care.					
Our unit is a good example of how to support and protect breastfeeding in challenging circumstances.					
I am one of just a few people who advocate for breastfeeding.					

Section 6: The organisational structures relating to breastfeeding:

6.1 Do you know who the infant feeding lead is? (Choose one)

- Yes
- No
- I'm not sure

6.2 Do you know of any helplines you could refer families to? (Choose one)

- Yes

- No
- I'm not sure

6.3 Are you aware of any websites or resources you could share with families or colleagues?

(Choose one)

- Yes
- No
- I'm not sure

6.4 Do you know where the breastfeeding policy is? (Choose one)

- Yes
- No
- I'm not sure

6.5 Was the breastfeeding policy part of your orientation to the ward or unit where you work? (Choose one)

- Yes
- No
- I can't remember

6.6 Is the breastfeeding policy somewhere that is accessible to families wishing to read it?

(Choose one)

- Yes
- No
- I'm not sure

Thank you, this is the end of the questionnaire. Thank you for your time, your responses are very much appreciated.

If as a result of taking part you have any questions or concerns about your wellbeing, we encourage you to contact your midwife, health visitor, or GP who can provide you with further information and support. If you have questions about the support or training provision in your department, you can ask your manager.

If you have any questions about your own personal feeding experience, you can also contact one of the breastfeeding organisations:

- National Breastfeeding Helpline 0300 100 0212.
- Association of Breastfeeding Mothers 0300 330 5453.
- La Leche League 0345 120 2918.
- National Childbirth Trust (NCT) 0300 330 0700.
- The Breastfeeding Network Supporter line in Bengali and Sylheti: 0300 456 2421.

Appendix 6: Interview prompt guide

This interview prompt is available for you as a potential participant to view before you consent to the interview. During our interview, I will be led by you, and anything you feel that is important to mention, but I may ask questions such as:

Demographic information (this will be anonymized)
Parent age
Child's age
Previous children
Marital status
Previous breastfeeding experience
Ethnicity
Disability
Distance from hospital to home
Employment status
Educational level
Any BF education (antenatal class etc)
Type of birth
Regular contact with any form of BF support now?

During the interview, we will cover three main areas – your child’s condition, your infant feeding journey, and the hospital environment.

1. Your child’s condition
<p>Can you tell me a bit about your child’s condition?</p> <ul style="list-style-type: none"> • When was your child diagnosed? • Is it acute/chronic?
<p>How often are you in hospital for your child’s condition?</p>
<p>How has your child’s illness affected their feeding?</p> <ul style="list-style-type: none"> • Do they feed more/less? • What does breastfeeding mean to you and your child? • How does their condition impact feeding? • Has your child’s condition made it harder/different to continue feeding?
<p>How do you feel about feeding your child since they have been unwell?</p>

2. Your infant feeding story
<p>How is your child currently being fed?</p> <ul style="list-style-type: none"> • Breastfeeding • Bottles (of what) • Tubes • Supplements • Fortifier • Solids
<p>When your child was born, did you have a particular feeding goal in mind?</p> <ul style="list-style-type: none"> • Did you want to feed for a particular length of time? • Did you make any decisions about exclusive or partial breastfeeding?
<p>Do you think your breastfeeding goals have changed since your child has been unwell?</p> <ul style="list-style-type: none"> • Have you had to adapt your goals? • Have you been forced to change your feeding goals in a way you didn’t want to? • Has the importance of breastfeeding changed for you since your child has had their condition?
<p>Can you tell me about your breastfeeding journey before and through illness?</p> <ul style="list-style-type: none"> • What was it like before they became ill? • Did their feeding behaviour change when they became unwell? • How is illness or hospitalisation changing the way they feed at the moment? • How do you feel about your current feeding situation?

3. The hospital experience

Have you needed any support for breastfeeding or providing human milk while your child has been in hospital?

- Have you needed help with positioning, milk supply, breastfeeding problems?
- Has your child refused to feed or found it difficult? In what way?
- Have you needed equipment such as pumps?

How have the staff been when you have needed help?

- Have you felt supported?
- How have the staff reacted?
- Sleeping arrangements?
- Did anyone suggest skin-to-skin?
- Does there seem to be a culture of protecting breastfeeding?
- Do you feel like breastfeeding is valued?
- Have you had enough emotional support?
- Have you been provided with practical support? (Food, drinks, privacy)

Do you feel like the staff have enough breastfeeding knowledge to be able to help you?

- Were they able to answer any questions you have had?
- Have you been given any websites, leaflets, helplines, or specific information to help you continue to breastfeed?

Have any strategies been particularly helpful or supportive to you during this time in hospital?

Is there anything that has happened that has been less helpful or supportive?

How do you find breastfeeding or pumping on the ward?

Do you feel supported to breastfeed or express here?

Do you have enough facilities, like breast pumps, expressing rooms and fridges?

Is there support and advice available to help you if you have questions about milk supply?

Do you feel like it's easy to breastfeed on the ward? Do you have enough privacy?

Is there anything else you would like to share with me about your experience of feeding and caring for your child on the ward?

Appendix 7: Parent interview study screening questions

1. What is your ethnicity?

White/ White British	White/ White Irish	Gypsy/ Traveller	Asian or Asian British: Bangladeshi	Asian or Asian British: Indian	Asian or Asian British: Pakistani
Asian or Asian British: Chinese	Asian or Asian British: Other	Black or Black British	Mixed or multiple	Other	Prefer not to say

2. Do you identify as:

- a. Male
- b. Female
- c. Trans female
- d. Trans male
- e. Gender nonbinary
- f. Prefer not to say
- g. Other

3. Are you the parent of a child who has received **UK based** paediatric hospital care?

- a. Yes
- b. No

4. Are you aged 16 or over, meet the eligibility criteria and able to consent to be interviewed?

- a. Yes
- b. No

5. What is your postcode?

6. How would you describe your marital status?

- a. Single
- b. Living with partner
- c. Married
- d. Separated/divorced
- e. Widowed

7. What is your highest educational attainment?

- a. High school/secondary school education

- b. NVQ/Apprenticeship
 - c. Bachelor's degree
 - d. Master's degree or higher
8. Do you consider yourself to have a disability?
- a. Yes
 - b. No
9. Has your child ever been admitted to the neonatal unit?
- a. Yes
 - b. No
10. What hospital(s) have you been admitted to with your child?
11. What condition(s) was your child hospitalised with?
12. What is the longest length of hospitalisation you have experienced with your child?
- a. 1-3 nights
 - b. 3-7 nights
 - c. 7-14 nights
 - d. 14+ nights
13. How recently was your child hospitalised for at least one night in the paediatric ward or PICU?
- a. We are currently in hospital
 - b. We were discharged less than 2 weeks ago
 - c. We were discharged 2-4 weeks ago
 - d. We were discharged 1-3 months ago
 - e. We were discharged more than 3 months ago
14. How is your child currently feeding?
- a. I am exclusively breastfeeding
 - b. I am partially breastfeeding (including solids, formula, or specialised feeds)
 - c. I am expressing my milk
 - d. I am not currently breastfeeding
15. If you are not currently breastfeeding or expressing, which of the following best describes your situation
- a. I was breastfeeding, but stopped within the last 3 months due to my child's condition/hospitalisation/on medical advice
 - b. I am not currently breastfeeding but am actively trying to re-lactate or induce lactation
 - c. I have never breastfed and have no plans to

16. Would you like to be considered for the study, which will involve an interview lasting approximately 45-60 minutes?
 - a. Yes
 - b. No
17. If selected for interview, how would you like to be contacted?
 - a. Telephone
 - b. Email
18. Please leave your contact details in this box, so that a member of the research team can get in touch to arrange the interview

Thank you for taking the time to complete this screening questionnaire. A member of the research team will contact you by March 31st if you have been selected to take part.

Appendix 8: Examples of quantitative analysis

How long have you been qualified within your role? * What is your profession? - Selected Choice Crosstabulation

		What is your profession? - Selected Choice				Total
		Paediatric nurse	Health Care Assistant working in paediatrics	Paediatrician	Allied health professional based in paediatrics	
How long have you been qualified within your role?	Less than 2 years	14	2	9	2	27
	2-5 years	37	4	22	4	67
	5-10 years	55	1	42	9	107
	10-15 years	50	1	17	16	84
	15+ years	89	4	11	18	122
Total		245	12	101	49	407

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	43.927 ^a	12	<.001
Likelihood Ratio	46.153	12	<.001
Linear-by-Linear Association	3.261	1	.071
N of Valid Cases	407		

a. 6 cells (30.0%) have expected count less than 5. The minimum expected count is .80.

Univariate Analysis of Variance

I believe that breastfeeding is important for children - whether they are unwell or healthy

Between-Subjects Factors

	Value	Label	N
What is your profession? - Selected Choice	1	Paediatric nurse	214
	2	Health Care Assistant working in paediatrics	9
	3	Paediatrician	90
	4	Allied health professional based in paediatrics	39

Tests of Between-Subjects Effects

Dependent Variable: I believe breastfeeding is important for children - whether unwell or healthy

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	6.634 ^a	4	1.386	5.119	<.001
Intercept	38.777	1	38.777	143.217	<.001
Qualified_years	.583	1	.583	2.152	.143
Profession	4.548	3	1.516	5.554	<.001
Error	93.953	347	.271		
Total	647.000	352			
Corrected Total	99.497	351			

a. R Squared = .056 (Adjusted R Squared = .045)

Univariate Analysis of Variance

I believe that supporting parents to achieve their personal breastfeeding goals is an important part of my job

Between-Subjects Factors

		Value Label	N
What is your profession? - Selected Choice	1	Paediatric nurse	215
	2	Health Care Assistant working in paediatrics	9
	3	Paediatrician	90
	4	Allied health professional based in paediatrics	39

Tests of Between-Subjects Effects

Dependent Variable: I believe that supporting parents to achieve their personal breastfeeding goals is an important part of my job

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	.928 ^a	4	.232	.510	.728
Intercept	2154.309	1	2154.309	4738.779	<.001
Qualified_years	.062	1	.062	.137	.712
Profession	.849	3	.283	.622	.601
Error	158.205	348	.455		
Total	24946.000	353			
Corrected Total	159.133	352			

a. R Squared = .006 (Adjusted R Squared = -.006)

Crosstabs

When you remember your initial vocational training (nursing/medicine etc), how much education did you receive in relation to breast/chest feeding? - Selected Choice * What is your profession? - Selected Choice

		What is your profession? - Selected Choice				Total
		Paediatric nurse	HCA working in paediatrics	Paediatrician	AHP based in paediatrics	
When you remember your initial vocational training (nursing/medicine etc), how much education did you receive in relation to breast/chest feeding? - Selected Choice	We had a whole day or more	8	0	3	1	12
	We had 1-2 hours of basic training	61	2	24	8	95
	It was assumed we would learn on the job	33	0	12	4	49
	I can't remember having any information about breastfeeding	117	4	51	24	196
	Other (please specify)	8	2	3	4	17
Total		227	8	93	41	369

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	13.797 ^a	12	.314
Likelihood Ratio	11.005	12	.528
Linear-by-Linear Association	1.940	1	.164
N of Valid Cases	369		

a. 9 cells (45.0%) have expected count less than 5. The minimum expected count is .26.

When you remember your initial vocational training (nursing/medicine etc), how much education did you receive in relation to breast/chest feeding? - Selected Choice * How long have you been qualified within your role?

Crosstab

		How long have you been qualified within your role?					Total
		Less than 2 years	2-5 years	5-10 years	10-15 years	15+ years	
When you remember your initial vocational training (nursing/medicine etc), how much education did you receive in relation to breast/chest feeding? - Selected Choice	We had a whole day or more	1	1	2	2	6	12
	We had 1-2 hours of basic training	5	20	29	19	21	94
	It was assumed we would learn on the job	5	10	10	13	11	49
	I can't remember having any information about breastfeeding	11	26	56	40	63	196
	Other (please specify)	1	5	3	2	6	17
Total		23	62	100	76	107	368

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	15.072 ^a	16	.519
Likelihood Ratio	15.326	16	.501
Linear-by-Linear Association	.968	1	.325
N of Valid Cases	368		

a. 11 cells (44.0%) have expected count less than 5. The minimum expected count is .75.

Crosstabs

Do you have any of the following breastfeeding credentials? - Selected Choice IBCLC * What is your profession? - Selected Choice Crosstabulation

		Paediatric nurse	HCA working in paediatrics	Paediatrician	AHP based in paediatrics	Total
Do you have any of the following	IBCLC	3	0	0	4	7
breastfeeding credentials? -	2	11	0	6	3	20
Selected Choice IBCLC	3	34	1	6	6	47
	4	197	11	91	36	335
Total		245	12	103	49	409

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	20.603 ^a	9	.015
Likelihood Ratio	18.008	9	.035
Linear-by-Linear Association	.746	1	.388
N of Valid Cases	409		

a. 7 cells (43.8%) have expected count less than 5. The minimum expected count is .21.

Case Processing Summary

	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Do you have any of the following breastfeeding credentials? - Selected Choice IBCLC *	407	99.5%	2	0.5%	409	100.0%
How long have you been qualified within your role?						

Do you have any of the following breastfeeding credentials? - Selected Choice IBCLC * How long have you been qualified within your role? Crosstabulation

Count

		How long have you been qualified within your role?					Total
		Less than 2 years	2-5 years	5-10 years	10-15 years	15+ years	
Do you have any of the following	IBCLC	0	0	1	2	4	7
breastfeeding credentials? -	2	1	2	6	4	6	19
Selected Choice IBCLC	3	2	9	9	9	18	47
	4	24	56	91	69	94	334
Total		27	67	107	84	122	407

Chi-Square Tests

	Value	df	Asymptotic Significance (2- sided)
Pearson Chi-Square	6.993 ^a	12	.858
Likelihood Ratio	9.351	12	.673
Linear-by-Linear Association	4.113	1	.043
N of Valid Cases	407		

a. 10 cells (50.0%) have expected count less than 5. The minimum expected count is .46.

Correlations

		Do you have any of the following breastfeeding credentials? - Selected Choice IBCLC	On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise Strongly agree	How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?
Do you have any of the following breastfeeding credentials? - Selected Choice IBCLC	Pearson Correlation	1	.322**	.376**
	Sig. (2-tailed)		<.001	<.001
	N	409	373	371
On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise Strongly agree	Pearson Correlation	.322**	1	.768**
	Sig. (2-tailed)	<.001		<.001
	N	373	371	370
How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?	Pearson Correlation	.376**	.768**	1
	Sig. (2-tailed)	<.001	<.001	
	N	371	370	380

** . Correlation is significant at the 0.01 level (2-tailed).

General Linear Model

Between-Subjects Factors

		Value Label	N
What is your profession? - Selected Choice	1	Paediatric nurse	226
	2	Health Care Assistant working in paediatrics	9
	3	Paediatrician	93
	4	Allied health professional based in paediatrics	41

Multivariate Tests^a

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.483	169.597 ^b	2.000	363.000	<.001
	Wilks' Lambda	.517	169.597 ^b	2.000	363.000	<.001
	Hotelling's Trace	.934	169.597 ^b	2.000	363.000	<.001
	Roy's Largest Root	.934	169.597 ^b	2.000	363.000	<.001
Qualified_years	Pillai's Trace	.042	8.038 ^b	2.000	363.000	<.001
	Wilks' Lambda	.958	8.038 ^b	2.000	363.000	<.001
	Hotelling's Trace	.044	8.038 ^b	2.000	363.000	<.001
	Roy's Largest Root	.044	8.038 ^b	2.000	363.000	<.001
Profession	Pillai's Trace	.039	2.389	6.000	728.000	.027
	Wilks' Lambda	.962	2.393 ^b	6.000	726.000	.027
	Hotelling's Trace	.040	2.396	6.000	724.000	.027
	Roy's Largest Root	.033	3.964 ^c	3.000	364.000	.008

a. Design: Intercept + Qualified_years + Profession

b. Exact statistic

c. The statistic is an upper bound on F that yields a lower bound on the significance level.

Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise Strongly agree	15.476 ^a	4	3.869	3.592	.007
	How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?	28.315 ^b	4	7.079	5.852	<.001

Intercept	On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise Strongly agree	334.678	1	334.678	310.688	<.001
	How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?	349.235	1	349.235	288.700	<.001
Qualified_years	On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise Strongly agree	10.468	1	10.468	9.718	.002
	How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?	19.495	1	19.495	16.116	<.001
Profession	On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise Strongly agree	3.561	3	1.187	.981	.551
	How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?	5.020	3	1.673	1.554	.200
Error	On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise Strongly agree	392.106	36	1.077		
	How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?	440.325	36	1.210		
Total	On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise Strongly agree	2926.000	36			
	How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?	2961.000	36			
Corrected Total	On an average shift, I feel confident about being able to answer any questions about breastfeeding that arise Strongly agree	407.583	36			
	How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?	468.640	36			

a. R Squared = .038 (Adjusted R Squared = .027)

b. R Squared = .060 (Adjusted R Squared = .050)

Univariate Analysis of Variance

On an average shift in my ward/department, there is enough support for families who are trying to breastfeed

Between-Subjects Factors

		Value Label	N
What is your profession? - Selected Choice	1	Paediatric nurse	208
	2	Health Care Assistant working in paediatrics	6
	3	Paediatrician	90
	4	Allied health professional based in paediatrics	38

Tests of Between-Subjects Effects

Dependent Variable: On an average shift in my ward/department, there is enough support for families who are trying to breastfeed

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	12.290 ^a	4	3.072	3.012	.019
Intercept	2880.762	1	2880.762	2824.522	<.001
Qualified_years	1.360	1	1.360	1.334	.249
Profession	9.186	3	3.062	3.002	.017
Error	343.710	337	1.020		
Total	36874.000	342			
Corrected Total	356.000	341			

a. R Squared = .035 (Adjusted R Squared = .023)

Univariate Analysis of Variance

Between-Subjects Factors

		Value Label	N
Do you have any of the following	1	IBCLC	8
breastfeeding credentials? -	2	2	19
Selected Choice IBCLC	3	3	46
	4	4	295

Tests of Between-Subjects Effects

Dependent Variable: skill

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	2547.918 ^a	3	849.306	24.730	<.001
Intercept	62841.707	1	62841.707	1706.452	<.001
Highest_qualification	2547.918	3	849.306	23.063	<.001
Error	13367.815	364	36.826		
Total	236330.000	368			
Corrected Total	15915.733	367			

a. R Squared = .160 (Adjusted R Squared = .153)

Univariate Analysis of Variance

Perceived skill

Between-Subjects Factors

		Value Label	N
What is your profession? - Selected Choice	1	Paediatric nurse	224
	2	Health Care Assistant working in paediatrics	9
	3	Paediatrician	92
	4	Allied health professional based in paediatrics	39
	5	Other professional (please specify)	3

Tests of Between-Subjects Effects

Dependent Variable: skill

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	382.078 ^a	4	95.520	2.226	.066
Intercept	29296.645	1	29296.645	682.736	<.001
Profession	382.078	4	95.520	2.226	.066
Error	15533.655	362	42.911		
Total	236330.000	367			
Corrected Total	15915.733	366			

a. R Squared = .024 (Adjusted R Squared = .013)

Nonparametric Correlations

		Correlations	
		skill	How long have you been qualified within your role?
Spearman's rho	skill	Correlation Coefficient	1.000
		Sig. (2-tailed)	.
		N	367
	How long have you been qualified within your role?	Correlation Coefficient	.128*
		Sig. (2-tailed)	.014
		N	366

*. Correlation is significant at the 0.05 level (2-tailed).

Correlations

		skill	How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?
skill	Pearson Correlation	1	-.676**
	Sig. (2-tailed)		<.001

	N	386	386
How much would you say you agree with the statement: "I have a lot of experience supporting breastfeeding"?	Pearson Correlation	-.676**	1
	Sig. (2-tailed)	<.001	
	N	386	388

** . Correlation is significant at the 0.01 level (2-tailed).

Univariate Analysis of Variance

Perceived skill

Between-Subjects Factors

	Value	Label	N
UG training grouped into 3 groups	1.00	A day or more	12
	2.00	A few hours	89
	3.00	None	238

Tests of Between-Subjects Effects

Dependent Variable: skill

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	35.513 ^a	2	17.756	.295	.744
Intercept	57096.262	1	57096.262	1312.222	<.001
UGTRAIN	35.513	2	17.756	.408	.665

Error	14619.744	354	43.511		
Total	219244.000	357			
Corrected Total	14655.257	356			

a. R Squared = .002 (Adjusted R Squared = -.004)

Univariate Analysis of Variance

Perceived skill

Between-Subjects Factors

		Value Label	N
Do you have any additional responsibility related to infant feeding on your ward/department? - Selected Choice	1	Yes (please specify)	63
	2	No	283

Tests of Between-Subjects Effects

Dependent Variable: skill

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	2257.076 ^a	1	2257.076	59.870	<.001
Intercept	147186.463	1	147186.463	3904.221	<.001
Additional_responsibility	2257.076	1	2257.076	59.870	<.001
Error	12968.565	344	37.699		
Total	224926.000	346			
Corrected Total	15225.642	345			

a. R Squared = .148 (Adjusted R Squared = .146)

General Linear Model

Between-Subjects Factors

		Value Label	N
What is your profession? - Selected Choice	1	Paediatric nurse	245
	2	Health Care Assistant working in paediatrics	12
	3	Paediatrician	103
	4	Allied health professional based in paediatrics	45

Multivariate Tests^a

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.392	128.705 ^b	2.000	400.000	<.001
	Wilks' Lambda	.608	128.705 ^b	2.000	400.000	<.001
	Hotelling's Trace	.644	128.705 ^b	2.000	400.000	<.001
	Roy's Largest Root	.644	128.705 ^b	2.000	400.000	<.001
Profession	Pillai's Trace	.056	3.877	6.000	802.000	<.001
	Wilks' Lambda	.944	3.881 ^b	6.000	800.000	<.001
	Hotelling's Trace	.058	3.886	6.000	798.000	<.001
	Roy's Largest Root	.044	5.904 ^c	3.000	401.000	<.001

a. Design: Intercept + Profession

b. Exact statistic

c. The statistic is an upper bound on F that yields a lower bound on the significance level.

Tests of Between-Subjects Effects

Source	Dependent Variable	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	Prof_barriers	44.930 ^a	3	14.977	4.634	.003
	Parentbarriers	126.502 ^b	3	42.167	5.776	<.001
Intercept	Prof_barriers	632.900	1	632.900	195.818	<.001
	Parentbarriers	1753.812	1	1753.812	240.232	<.001
Profession	Prof_barriers	44.930	3	14.977	4.634	.003
	Parentbarriers	126.502	3	42.167	5.776	<.001
Error	Prof_barriers	1296.068	401	3.232		
	Parentbarriers	2927.498	401	7.300		
Total	Prof_barriers	4084.000	405			
	Parentbarriers	9899.000	405			
Corrected Total	Prof_barriers	1340.998	404			
	Parentbarriers	3054.000	404			

a. R Squared = .034 (Adjusted R Squared = .026)

b. R Squared = .041 (Adjusted R Squared = .034)

Univariate Analysis of Variance

Ward culture

Between-Subjects Factors

		Value Label	N
What is your profession? - Selected Choice	1	Paediatric nurse	207
	2	Health Care Assistant working in paediatrics	6
	3	Paediatrician	89
	4	Allied health professional based in paediatrics	35

Tests of Between-Subjects Effects

Dependent Variable: Culture

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	47.590 ^a	3	15.863	.788	.507
Intercept	22217.968	1	22217.968	1089.803	<.001
Profession	47.590	3	15.863	.788	.507
Error	6788.921	333	20.387		
Total	99760.000	337			
Corrected Total	6836.510	336			

a. R Squared = .007 (Adjusted R Squared = -.002)

Correlations

		Correlations		
		Culture	Prof_barriers	Parentbarriers
Culture	Pearson Correlation	1	.277**	.250**
	Sig. (2-tailed)		<.001	<.001
	N	339	339	339
Prof_barriers	Pearson Correlation	.277**	1	.720**
	Sig. (2-tailed)	<.001		<.001
	N	339	409	409
Parentbarriers	Pearson Correlation	.250**	.720**	1
	Sig. (2-tailed)	<.001	<.001	
	N	339	409	409

** . Correlation is significant at the 0.01 level (2-tailed).

Crosstabs

	Case Processing Summary					
	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Do you know of any breastfeeding helplines you could refer families to?	339	82.9%	70	17.1%	409	100.0%
* What is your profession? - Selected Choice						

Do you know of any breastfeeding helplines you could refer families to? * What is your profession? - Selected Choice Crosstabulation
Count

		What is your profession? - Selected Choice				Total
		Paediatric nurse	Health Care Assistant working in paediatrics	Paediatrician	Allied health professional based in paediatrics	
Do you know of any breastfeeding helplines you could refer families to?	Yes	107	3	55	28	193
	No	68	2	26	3	99
	i'm not sure	33	1	8	5	47
Total		208	6	89	36	339

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	12.702 ^a	6	.048
Likelihood Ratio	14.735	6	.022
Linear-by-Linear Association	6.764	1	.009
N of Valid Cases	339		

a. 4 cells (33.3%) have expected count less than 5. The minimum expected count is .83.

Crosstabs

Case Processing Summary

	Valid		Cases Missing		Total	
	N	Percent	N	Percent	N	Percent
Do you know of any breastfeeding helplines you could refer families to? * How long have you been qualified within your role?	341	83.4%	68	16.6%	409	100.0%

Do you know of any breastfeeding helplines you could refer families to? * How long have you been qualified within your role?

Crosstabulation

		How long have you been qualified within your role?					Total
		Less than 2 years	2-5 years	5-10 years	10-15 years	15+ years	
Do you know of any breastfeeding helplines you could refer families to?	Yes	8	32	54	49	50	193
	No	10	15	28	18	29	100
	i'm not sure	2	10	10	8	18	48
Total		20	57	92	75	97	341

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	9.759 ^a	8	.242
Likelihood Ratio	9.355	8	.313
Linear-by-Linear Association	.017	1	.897
N of Valid Cases	341		

a. 1 cells (6.7%) have expected count less than 5. The minimum expected count is 2.82.

Crosstabs

Case Processing Summary

	Valid		Cases Missing		Total	
	N	Percent	N	Percent	N	Percent
Do you know where the breastfeeding policy is? *	341	83.4%	68	16.6%	409	100.0%
What is your profession? - Selected Choice						

Do you know where the breastfeeding policy is? * What is your profession? - Selected Choice Crosstabulation

		What is your profession? - Selected Choice				Total
		Paediatric nurse	HCA working in paediatrics	Paediatrician	AHP based in paediatrics	
Do you know where the breastfeeding policy is?	Yes	124	2	33	22	181
	No	55	3	42	9	109
	I'm not sure	29	1	14	7	51
Total		208	6	89	38	341

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	16.384 ^a	6	.012
Likelihood Ratio	16.707	6	.010
Linear-by-Linear Association	3.683	1	.055
N of Valid Cases	341		

a. 3 cells (25.0%) have expected count less than 5. The minimum expected count is .90.

Crosstabs

Case Processing Summary

	Valid		Cases Missing		Total	
	N	Percent	N	Percent	N	Percent
Do you know who the infant feeding lead is? * How long have you been qualified within your role?	341	83.4%	68	16.6%	409	100.0%

Do you know who the infant feeding lead is? * How long have you been qualified within your role? Crosstabulation

Count

		How long have you been qualified within your role?					Total
		Less than 2 years	2-5 years	5-10 years	10-15 years	15+ years	
Do you know who the infant feeding lead is?	Yes	6	22	47	33	46	154
	No	11	16	30	24	24	105
	There isn't one for paediatrics	2	10	7	9	16	44
	I'm not sure	1	9	8	9	11	38
Total		20	57	92	75	97	341

Chi-Square Tests

	Value	df	Asymptotic Significance (2- sided)
Pearson Chi-Square	14.067 ^a	12	.296
Likelihood Ratio	13.834	12	.311
Linear-by-Linear Association	.090	1	.765
N of Valid Cases	341		

a. 2 cells (10.0%) have expected count less than 5. The minimum expected count is 2.23.

Crosstabs

Case Processing Summary

	Valid		Cases Missing		Total	
	N	Percent	N	Percent	N	Percent
Do you know where the breastfeeding policy is? * How long have you been qualified within your role?	341	83.4%	68	16.6%	409	100.0%

Chi-Square Tests

	Value	df	Asymptotic Significance (2- sided)
Pearson Chi-Square	4.837 ^a	8	.775
Likelihood Ratio	4.990	8	.759
Linear-by-Linear Association	.827	1	.363
N of Valid Cases	340		

a. 1 cells (6.7%) have expected count less than 5. The minimum expected count is 2.06.

Do you know where the breastfeeding policy is? * How long have you been qualified within your role? Crosstabulation

Count

		How long have you been qualified within your role?					Total
		Less than 2 years	2-5 years	5-10 years	10-15 years	15+ years	
Do you know where the breastfeeding policy is?	Yes	8	19	44	45	65	181
	No	9	24	34	18	24	109
	I'm not sure	3	14	14	12	8	51
Total		20	57	92	75	97	341

Chi-Square Tests

	Value	df	Asymptotic Significance (2-sided)
Pearson Chi-Square	22.713 ^a	8	.004
Likelihood Ratio	23.080	8	.003
Linear-by-Linear Association	16.023	1	<.001
N of Valid Cases	341		

a. 1 cells (6.7%) have expected count less than 5. The minimum expected count is 2.99.

Crosstabs

Case Processing Summary

	Valid		Missing		Total	
	N	Percent	N	Percent	N	Percent
Is the breastfeeding policy somewhere that is accessible to families wishing to read it? * How long have you been qualified within your role?	340	83.1%	69	16.9%	409	100.0%

Is the breastfeeding policy somewhere accessible to families? * How long have you been qualified within your role? Crosstabulation

		How long have you been qualified within your role?					Total
		Less than 2 years	2-5 years	5-10 years	10-15 years	15+ years	
Is the breastfeeding policy somewhere that is accessible to families wishing to read it?	Yes	1	8	8	7	11	35
	No	10	19	42	33	47	151
	I'm not sure	9	29	42	35	39	154
Total		20	56	92	75	97	340

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