

AN EXPLORATION OF ONLINE SOCIAL SUPPORT GROUPS FOR BREASTFEEDING  
MOTHERS

by

Amanda Wagg

Canterbury Christ Church University

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### Thesis Summary

This thesis provides a portfolio of research that focuses on online social support groups for breastfeeding mothers. The aim of this thesis is to explore how and why online breastfeeding support group are being used, how breastfeeding mothers make sense of and interpret their experiences, and how they perceive the impact on their breastfeeding journey.

Acquiring new breastfeeding skills at the same time as being becoming a mother is stressful and experiencing stress may lead some mothers to seek support. Historically people would interact, communicate, and thus seek and receive support from their healthcare provider face-to-face. More recently, this can occur online due to the increasing availability of the internet, home computers, mobile phones, and tablet technologies that provide quick access to others. It is well documented that breastfeeding rates in the UK are some of the lowest in the world, but with professional and peer support a mother is more likely to continue to breastfeed her baby for longer. For these reasons, online support interventions are explored in four original pieces of research, an area of practice only now emerging in the literature.

This thesis first examines the use of computer mediated communication in providing patient support. A literature review suggests that online interventions could be both what patients want, and way of delivering support in resource tight environments. This has implications for a range of health support needs and professionals. Secondly, a content analysis documents and describes the posts made to an online breastfeeding support group in the United Kingdom. Mothers are using online groups in their thousands to seek information from people in similar situations and discuss a range of parenting and breastfeeding topics. Thirdly, through Interpretative Phenomenological Analysis, it is highlighted that the online groups have the potential to provide confidence, reassurance, and to normalise breastfeeding.

Online groups provide a sense of community that supports an internal vision of what breastfeeding is like for them. The fourth study presents a case study of one mother's use of online groups to obtain donor milk for her baby. This final piece of research highlights a tangible support type that was not highlighted in the previous studies, and all four studies highlight the complexities around online support, and infant feeding decisions.

Throughout this thesis the term support is critically explored, and the theory of social support and becoming a mother is drawn upon to underpin the research. This thesis offers a definition and model of online breastfeeding support to guide practitioners and further research. Infant feeding policies should include a compulsory social support assessment that incorporates online support, and policies should encourage professionals to have conversations around taboo and stigmatised topics. Those supporting breastfeeding mothers need to be aware of the benefits and risks of online support and be encouraged to promote online support to the mothers with whom they work.

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## Chapter One: Introducing the research

### **Introduction**

This thesis documents a four-year journey exploring online social support as an intervention to support breastfeeding mothers. It aims to provide a deeper understanding of the different facets of online breastfeeding support groups, for those working in roles supporting breastfeeding mothers. There is a need to explore conceptual understanding of complex issues such as online breastfeeding support and provide an evidence-base for those providing this in the 21<sup>st</sup> century. This research aims to have the practice of breastfeeding support at the heart of its design.

This introductory Chapter outlines the questions that were posed throughout the course of this research, demonstrating how the questions shaped the choices made. It provides a rationale and context within which the research took place, and the theoretical and philosophical positions that anchor this body of work. Within the following, four pieces of research are introduced in chronological order before a final Chapter draws together and concludes the finding of the research.

### **The Starting Point**

As a nurse of eighteen years, various professional roles have included; adult nursing in the acute and community setting, Specialist Community Public Health Nursing (SCPHN), the Infant Feeding lead within a primary NHS trust, an International Board Certified Lactation Consultant (IBCLC), a Senior Lecturer in nursing, University Course leader for SCPHN, and founder of a breastfeeding support charity. Infant Feeding has been a substantial part of these professional roles for over eight years, and there are altruistic intentions to ensure currency in practice and to add to the body of literature around breastfeeding support.

Continuous reflection on professional practice, supported using Driscoll's Model of

Reflection (2007), led to the development of all research questions posed within this thesis. Reflection in nursing practice is crucial to the role of the nurse, as it enables the facilitation of sense making and emotional expression, and highlights areas of practice that require further learning and development (Nursing Midwifery Council (NMC), 2019). Driscoll's model of reflection is just one of many models of reflection but quite simply provides a reflective framework that asks three simple question: What, so what, now what? The initial reflection, taken within the first few weeks of study is documented in Appendix A, and it is here that personal bias is noted; the belief that women should be able to make informed choice, that breastfeeding is the biological norm, that support should be offered to all women but should be culturally sensitive, and therefore geographically close, that family and social systems in which people live play an important role in the breastfeeding journey, and that as practitioners we should strive to do better and know more.

### **Breastfeeding in the UK**

This section explores breastfeeding as a public health concern, and provides discussion around the benefits to breastfeeding, the UK breastfeeding culture, and challenges faced by breastfeeding women accessing breastfeeding support. This section sets the background information as to why online breastfeeding support is worthy of exploration.

**The benefits to breastfeeding.** The World Health Organisation (WHO, 2011) recommend exclusive breastfeeding for around the first six months of life, and complementary feeding until the age of 2 years or beyond, because of the known benefits to mothers' babies and society. It has long been noted that many mothers that breastfeed benefit from a reduced risk of breast cancer (ElShamy, 2016) saving 20,000 deaths, in the UK, from breast cancer every year (Victora et al., 2016). Mothers may also benefit from greater bone density, reducing the risk of osteoporosis (Salari & Abdollahi, 2014) and a lower risk of ovarian cancer (Modungno, Goughnour, Wallack et al., 2019). The implications for children

include reduced prevalence of allergic disease (Kull, Almqvist, Lilja Pershagen, & Wickman, 2004), reduced childhood cancers (Martin, Gunnell, Owen & Smith, 2005) and a reduced chance of type 2 diabetes (Gunderson, Hurston, Dewey, Faith, Charvat-Aguliar, Khoury, Nguyen, Quesenberry, 2015).

For society, breastfeeding is a naturally renewable resource that requires no packaging, shipping, or disposal, thus benefiting the environment. It is estimated that an increase in breastfeeding rates would deliver significant cost savings to the NHS and to the local authorities (Adams, 2019). Reducing the incidence of just five illnesses protected by breastfeeding, is estimated to translate into cost savings for the NHS of at least £48 million and tens of thousands of fewer hospital admissions and primary physician visits (Public Health England & UNICEF, 2016). The evidence outlined in the breastfeeding Lancet series (Victora et al., 2016) leaves no doubt that the decision not to breastfeed has major, long term, negative effects on health, nutrition, the development of children and women's health, and society at large.

**Breastfeeding rates in the UK.** Despite the known benefits, the UK has one of the lowest breastfeeding continuation rates in the world (Victora et al., 2016), with initiation rates currently averaging 75% (NHS digital, 2019), and six-week prevalence rates averaging only 46% (Department of Health (DH), 2019). Statistically, the United Kingdom (UK) ranked 16th of 44 developed countries for children's health, and 10th for women's health in 2012 (Save the Children, 2012). Today, England is still behind other countries on many key health outcomes (Adams, 2019). For example, the infant mortality rate of reductions have stalled, breastfeeding and obesity rates are among the lowest in the Europe, childhood immunisation rates are falling, and health inequalities are increasingly seen across all indicators (Adams, 2019; Marmot, Allen, Boyce, Goldblatt, Morrison, 2020), emphasising a long-standing public health concern. Improvements in the UK are required to reach levels comparable with other

developed countries (WHO, 2010), and a need to scale up and monitor breastfeeding support interventions noted (Victora et al., 2016).

There are multiple reasons why breastfeeding rates are suboptimal and the literature notes that the world is still not a supportive and enabling environment for most women who want to breastfeed (Rollins et al., 2016). Rollins acknowledges that there may be physiological reasons why women may not breastfeed but notes that social and societal factors play the larger part.

**A bottle-feeding culture.** It is suggested that declining breastfeeding rates in the UK have largely contributed to a bottle-feeding culture (Scott & Mostyn, 2003; Relton, 2019), and that aggressive marketing of formula companies, undermine a woman's confidence in their ability to breastfeed (Sriraman & Kellams, 2016). Table 1 provides evidence of a bottle-feeding culture, through emphasising the need for charitable organisations and legislation that promotes, protects, and supports breastfeeding. However, many initiatives by both statutory and the voluntary sector to improve matters have not been sustained and do not continue today, and today's contemporary national policy around breastfeeding in the UK could be improved (Adams, 2019) in order to support breastfeeding women in UK culture today.

**Table 1**

*Evidence of an increasing bottle-feeding culture in the UK.*

Charitable organisations	Legislation
1967 National Childcare Trust (NCT) Breastfeeding promotion group and Teacher's Panel launched to support breastfeeding.	1993 Breastfeeding awareness week launched to promote breastfeeding
1979 Association of Breastfeeding Mothers (ABM) launched to support breastfeeding mothers.	1999 Breastfeeding Scotland website launched to support breastfeeding
1989 UK Breastfeeding Initiative launched to improve UK breastfeeding rates.	2003 WHO global strategy for Infant and Young child feeding to support, promote and protect breastfeeding

2001 National breastfeeding Line launched by NCT to support breastfeeding.

2005 Breastfeeding Scotland Act to support promote and protect breastfeeding

2005 Sure start Children Centres launched to provide support and interventions for children and families including breastfeeding and parenting support

2007 Growth charts published, based on the growth of breastfeeding babies

2008 NICE published guidance recommending NHS trusts implement a structured programme to encourage breastfeeding

2010 Equalities Act brought in to protect women in UK breastfeeding in public

2011 National Breastfeeding Awareness week ceased emphasising a lack of government investment

2014 WHO global Nutrition Target 2025 promotes breastfeeding

2014 Movement of SCPHN and public health over to local authority commissioning and a disinvestment in Health Visitor services primarily responsible for community breastfeeding support (Adams, 2019).

2018/19 Closure of Sure Start Children Centres that provided many face-to-face breastfeeding groups across the county

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**Disinvestment in breastfeeding support.** It is accepted in the literature that mothers that have professional support are more likely to initiate breastfeeding (Persad & Mensinger, 2008) and continue to breastfeed for longer (Taveras, Cara, Braveman, Jensvold, Escobar & Lieu, 2003; Hanafin, 2020). Breastfeeding support is widely recognised as the most accessible and cost-effective action to improve public health (Adams, 2019). However, a national survey of face to face breastfeeding support groups and peer support (Grant, McEwan & Tedstone, 2017), both within and between NHS Trust areas, found inequalities in support across the UK, and a disinvestment in breastfeeding services that led professionals unable to provide the care they wanted (Anstey et al., 2018). It is noted in the national survey that some areas lacked support groups altogether and some areas had no training or ongoing



management of peer support. Of the groups and services that were running, many were underfunded and therefore unable to provide weekly support interventions. Taveras et al. (2003) place professionals as being in an ideal place to provide positive support, problem solve, provide continued patient education. Professional support, provided by a midwife, health visitor, or lactation consultant for example, in geographical areas with little or no groups or peer support, is even more crucial (Grant et al., 2017).

**Additional challenges faced by women.** Research has shown that positive maternal emotional experiences are associated with better breastfeeding outcomes (Wouk, Tucker, Pence, Meltzer-Brody, Zvara, Grewen & Stuebe, 2019), and emotional support is often required for a variety of additional challenges. In the UK it is not uncommon for women to have infant feeding decisions framed in moral terms, for example breastfeeding is the best thing for the baby and thus the right thing to do. Some women may also struggle to manage perceived tensions between their breastfeeding needs, expectations, and the comfort of others (Leeming, Williamson, Lyttle and Johnson, 2013). To elaborate, when there is a perception that breastfeeding is ‘natural’ and therefore easy to do, if experiencing challenges, she may judge herself as a failure (Larsen, Hall & Aargaad, 2008). Research has shown that feelings of failure can be a barrier to attending face to face support groups (Hunt and Thomson, 2016). Lastly, mothers’ may also feel judged by others in society if they breastfeed in public or if they do not breastfeed at all (Thomson, Ebisch-Burton & Flacking, 2015). These feelings could all be reasons to seek support.

Similarly, for professionals providing support, the dilemma of promoting the benefits of breastfeeding whilst not undermining the maternal identity of women who formula-feed is noted in the literature (Trickey & Newburn, 2014). These challenges require complex support interventions (Thomson and Trickey, 2013), where women can ask questions (Rossman et al.,

2011) and speak freely about their experiences (Nankunda, Tumwine, Nankaborwa, & Tylleskar, 2010).

This section has highlighted that breastfeeding is a public health concern due to the numerous benefits to babies, mothers, and society, and highlights a variety of reasons why there needs to be investment in breastfeeding support interventions in the UK. This thesis holds the belief that support is essential for breastfeeding women, that women should have access to appropriate and timely support locally, nationally, socially, and politically, and thus explores online support as a support intervention. The following aims to provide clarity on the definition of breastfeeding support.

### **Defining breastfeeding support**

Defining key terms is fundamental to setting the scene of this thesis, and breastfeeding support is the focal point of this research. There is no clear definition of breastfeeding support in the literature, so support as a general term was explored. The origin of the word support is Middle English and means to ‘tolerate’. As a verb, the Oxford Dictionary of English (2015) defines support as something that bares weight, gives assistance, and holds up, or something that gives approval, comfort, or encouragement. Support could suggest the truth of, corroborate findings, or indicate that something is now sustainable, tolerable, or endurable. As a noun support could be an object that bares the weight of something, financial support, and/or material support. Overall, the definition is all-encompassing and without context can be vague as to the assistance given. A picture soon developed around the complexity of the term ‘breastfeeding support’ and will be discussed in the following section.

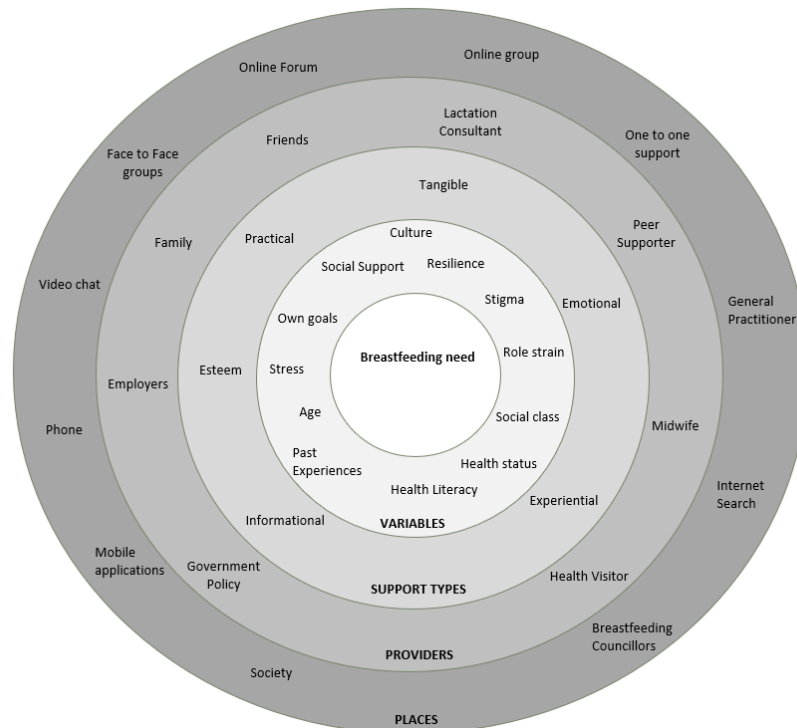
### **Breastfeeding support in practice**

The lack of definition led to consideration of when and how breastfeeding support is

delivered. The model proposed (see Figure 1) illustrates breastfeeding support in UK society today and focuses on the needs of the woman. The model recognises the multiple variables taken from the literature that affect a mothers breastfeeding behaviour. Factors such as maternal age (Forster, McLachlan & Lumley, 2006), socioeconomic status and culture (Kelly & Watt, 2005), health status and health literacy (Park, Rodgers & Stemmler, 2013), social support, and stigma around breastfeeding (Rempel, 2004; Newman & Williamson, 2018), past experiences (Glassman, McKearney, Saslaw & Sirta, 2014), knowledge (Augustin, Donovan, Lozano, Massucci & Wohlgemuth, 2014), role strain (Mercer, 2004), and breastfeeding attitudes (Rempel, 2004) all of which are important considerations determining if a person requires further support. The variables affecting the need for support are important to note as they go part way in explaining why some mothers require more support than others, and why some mothers require different support types at different times in their breastfeeding journey, and why they benefit from having different people to support them.

**Figure 1**

*A picture of breastfeeding support.*



The model also highlights the different types of support (House, 1981) available to breastfeeding mothers and informed by the social support literature. It is acknowledged that the mother may require different types of support at different points in her breastfeeding journey. This is followed by consideration of who might deliver such breastfeeding support, and then followed by the settings in which the support may occur. It is highlighted that breastfeeding support could be delivered by many people; Lactation Consultants, Peer supporters, Breastfeeding Councillors, Nurses, Midwives, Health Visitors, Physicians, Dieticians, Communities, and government policy makers, and in a variety of settings (Lactation Education Accreditation and Approval Review Committee, 2019). Those primarily responsible for breastfeeding support, also have different levels of training and practice experience, highlighted in Appendix B.

This model aims to demonstrate and summarise the complexities and layers to breastfeeding support before, more specifically, online breastfeeding support is discussed. The World Health Organisation (2010), Brown (2016) and UNICEF (2017) are amongst many that recognised a need to shift the emphasis from the individual's characteristics, and a mother's choice on whether or not to breastfeed her child, to the responsibility of wider societal, environmental and cultural determinants of health, to foster a supportive breastfeeding environment. Overall, support systems influence a mother's choice to breastfeed (Wade, Haining & Day, 2009), and those mothers who access support are more likely to initiate breastfeeding and breastfeed for longer (Balcazar, Trier & Cobas, 1995; Hanafin, 2020).

### **Online breastfeeding support**

Given the possibility of multiple breastfeeding needs, support types, providers, and locations, it is arguably not surprising that no single breastfeeding support intervention is able to meet all breastfeeding needs. In fact, the full range of interventions available is noted in the literature (Hoddinott, Seyara & Marais, 2011). Multicomponent interventions, with professional involvement, in the pre-natal and post-natal period, incorporating hospital and community settings are most beneficial (Kim, Park, Oh, Kim & Ahn, 2018). The question is how and why do women use online breastfeeding support, and what are the potential benefits of doing so?

Online support interventions are now emerging in the literature, especially since commencing this research in 2016 (Alianmoghaddam, Phibbs & Benn, 2018; Bridges, 2016; Regan & Brown, 2019; Robinson, Lauker, Davis, Hall & Anderson, 2019; Skelton, Evans, LaChenaye, Amsbary, Wingate & Talbott, 2018), and Facebook the most widely used social media platform. Historically people would interact, converse, communicate and thus seek support face to face, and the literature on breastfeeding support often focuses on the support

received in person or by telephone (Britton, McCormack, Renfrew, Wade & King, 2007).

Professionals supporting breastfeeding mothers have even called for the use of social media as a way of adapting to current trends (Audelo, 2014).

However, more recently support can occur online: data in 2018 shows mobile subscriptions per 100 inhabitants worldwide to be 104% and in the UK in 2019 117.55% (International Telecommunication Union, 2020). People do not simply make calls on mobile devices they search the internet. The Office of National Statistics (ONS, 2016) found that searching health related information to be one of the main reasons for internet use along with browsing the social media site Facebook. Facebook has the largest activity for people aged 16-44, thus child bearing age, adding to the emerging scholarly literature about what parents are doing while they use social media and technology, and how social media is supporting breastfeeding.

Studies exploring the use of different platforms are now emerging which talk about bringing people together, and this research adds to this growing body of literature. For example, Marcon, Bieber & Azad (2019) explored 4,089 images and 8,331 comments of content via Instagram. They noted how Instagram can create supportive networks that “normalise”, protect, promote and support breastfeeding broadly across large and diverse global online communities. Similarly, empirical research from online support forums (Lebron, George, Eckembrecher & Alvarez, 2019) is now emphasising the potential benefits of online social support for breastfeeding mothers.

Studies researching the use of Facebook are now showing how Facebook is a source of parenting information and support (Duggan, Lenhart, Lampe , & Ellison, 2015) and able to help mothers at different stages of parenting (Holtz, Smock & Reyes-Geastelum, 2015; Bartholomew, Schoppe-Sullivan, Glassman, 2012) and support breastfeeding mothers’

(Asiodu, Waters, Dailey, Lee & Lyndon, 2015; Niela-Vilen, Axelin & Melender, & Salantera, 2015; Regan and Brown, 2019; Robinson, Laukner, Davis, Hall and Anderson, 2019). However, studies that explore a mothers' experiences in online support setting is lacking in the literature (Robinson, Laukner, Davis, Hall & Anderson, 2019).

This thesis aims to explore a mother's experiences, but caution is taken to note that not all online experiences may be positive. When there is an expectation of support, and then a failure to receive support, the effects can be devastating. This is something noted in seminal work on social support (Harris, 1992). More currently online support could also expose the user to cyberbullying, online harassment and abusive online comments which can impact on mental health (Thurlow, Lengel & Tomic, 2007; Viner, Gireesh, Stiglic, Hudson, Goddings, Ward & Nicholls, 2019). The finding of this research in the context of emerging research will be discussed in the final chapter.

### **Theoretical Positions**

Whilst searching for useful frameworks in which to ground this research, social support theory, online social support theory, and the theory of 'Becoming A Mother' were three key areas of interest. These will all be explored in this introductory Chapter. Firstly, social support theory was a complex issue considered within many academic disciplines such as sociology, psychology, anthropology, computer science and communication science, with a collective conclusion that there is no clear definition. To date only one model addressing online social support groups from a nursing perspective was found, so acknowledgement is given to the seminal social support theories to understand this phenomenon.

**Social support.** Social support is an umbrella term for a variety of different pathways linking the involvement of social relationships to wellbeing (Cohen & Wills, 1985; Gubbins, Harrington & Hines, 2020). In the simplest sense social support theory describes when an

individual is faced with a stressor in their life, and the extent to which social support provides a buffering effect (Cooper et al., 1999; Steers, Chen, Neisler, Obasi, McNeill & Reitzel, 2019). Social support is cited in thousands of texts and the benefits are well documented for reducing mental health issues, reducing work related stress, increasing a person's resilience (House, 1981) and life expectancy (Ford, Ahluwalia & Galuska, 2000).

From Hupcey (1998) to Gubbins, Harrington and Hines (2020) it is emphasised that social support is a multifaceted concept that has been difficult to conceptualise, define and measure. Theorists have strived to define social support and as a result it has been conceptualised in multiple ways (Madge & Marmot, 1987; Harrington and Hines, 2020). Although the concept has been extensively studied, there is little agreement among theoreticians and researchers as to its theoretical and operational definition, as a result almost everything that infers a social interaction may be considered as social support. Consequently, researchers have consistently ignored the complexities of the concept and have measured the variables in a simplistic manner (Hupcey, 1998, p1232).

Social support has been researched in pregnancy and parenthood. A concept analysis by Williams, Barclay and Schmied (2004) found 30 definitions of social support and included prominent theorists (House, 1981; Hupcey, 1998; Leavy, 1983; Lin, Dena & Ensel, 1986; & Sarason et al., 1990), of which nine definitions related to pregnancy and parenthood. From these nine studies, three key themes were identified: reciprocity, accessibility, and reliability. All three themes were noted as key aspects of social support during pregnancy and parenthood. Whether this is true for online breastfeeding support groups remains to be seen. The following explores and organises the various elements of social support theories so that a clear theoretical aim can emerge.



Social support was first discussed as early as 1871 by Charles Darwin (1871/1952), who spoke of the benefits of support to the social animal. He proposed that those communities that included the greatest number of the most sympathetic members, would flourish best, and rear the greatest offspring (Darwin, 2008, p309). The 1970s saw a proliferation of definitions and theoretical discussions on the concept of social support, and many attempts were made to measure and influence social support. Seminal theories during this time explored how social environments influence health and health related behaviours and stressed the importance of the social context in which people live their lives (Gabbay, 1998). Such seminal theories are still relevant today. Through changing the environment in which people live it is possible to change an individual's health behaviour. Today this is most noted through government policy and the Social Determinants of Health (Dahlgren & Whitehead, 1991). These determinants of health highlight the relationship between work, travel, housing, friends, and neighbourhoods on health, and for this reason public health departments currently sit within the auspices of the local authority who commission, manage and design services around local public health agendas in a timely manner (KingFund, 2019).

Social networks were also considered within the 1970s literature. The larger and more diverse an individual's social network the more access he or she will have to functional relationships and the more potential benefits are likely to occur for health (Thoits, 1995). However, Madge and Marmot (1987) and Thoits (1995) speculate that it might be more beneficial to health and wellbeing to have only one functional relationship than to have a large social network of unsupportive acquaintances, thus emphasising the ambiguous nature of social support. Cooper, Arber, Fee and Gimm (1999) discuss how support from friends, family and health professionals can enhance physical health by encouraging health promotion and discouraging unhealthy related behaviour, also noted more recently by Moore (2018). Positive social support networks may encourage an individual to attempt to change his or her

health-related behaviour, but attempts can be harmed by negative social support e.g. friends smoking. Cooper et al. (1999) also discuss how health may be affected by the characteristics of the local community such as the support between neighbours, group affiliation and frequency of participation in community activities. How this translates and takes shape within the online breastfeeding social support environments is an aim of this study.

Stewart (1993) outlines several different theories that have impacted on the conceptualisation of social support theory in nursing. These include coping theory, social comparison theory, social exchange theory, attribution theory, social learning theory and social competence and the stress and coping paradigm. Common to all was the belief that social support facilitates coping, acting as a moderator of life stress either to daily hassles, acute periods of time, or across the life course. All theories emphasizing the need for an individual to be cared for as part of a group.

**Community level social support.** Many attempts in the literature have been made to measure social support at individual and community level. Social capital, social cohesion and social ties being just a few of those measures prominent within the literature. Social capital is defined as the features of social life such as networks, norms and social trust that facilitate coordination and cooperation for mutual benefit, and the social cohesion at community level (Putnam, 1995; Flores, Fuhr, Bayer et al., 2019). A social group with a high level of social capital is likely to be cohesive and to have well developed networks of communication and mutual support. The more people that work together the greater the social capital (Putnam, 1993; Flores, Fuhr, Bayer et al., 2019 ) because social capital is the resource of social access in the community, and the context in which people live their lives.

Social connectedness or social cohesion is generated by social network interaction. The social cohesion is the shared sense of identity and enables them to all work together for

the benefit of the whole community. The community being defined as a group of people with a collective identity, communities of great social resource and social capital. A socially cohesive groups tends to have a collective resource of trust, communication and feeling of belonging (Putnam, 1995). Social cohesion is the glue holding everything together (Kawachi, Kennedy & Locher, 1997 p2). The individuals within the groups Putnam (1995) describes as social resources, classified by informal, reciprocal, and altruistic support between individuals.

Relating this measure to the context within this thesis it could be argued that the lack of government funding, closure of Sure Start Children Centres and thus the closure of many breastfeeding support groups across the country, could equate to a lack of social capital for breastfeeding support. If, and how, online social support groups contribute or provide social capital or social cohesion is explored within this research.

**Individual level social support.** Social support at an individual level could refer to the companionship, practical information or esteem support which derive from a person's social network. Overall, support assumes a conversation or interaction between two people in which one person requires support and the other provides it. House (1981) names four main functional units, or differing types of support, that are often used to measure support: instrumental/ tangible, informational, emotional and esteem/ appraisal support. Many theorists attempted to label the types of support and attempted to differentiate the types of structure and functional aspects (House & Khan, 1985). This will now be discussed.

Emotional support refers to empowering and motivating people, complimenting, and encouraging them to follow the path that they have chosen to tread. Emotional support is delivered with empathy, love, trust, care and respectful of their choice. Emotional support could also include helping them cope with distress and provide a trusting relationship. The latter could involve a physical show of affection such as a hug, listening to a person's

problems or sharing life experiences. Secondly informational support requires suggesting or directing advice and this requires skills, knowledge, and the sharing of information whereas instrumental support, although resource limited, is being able to help someone with a task they find difficult. Additionally, instrumental support could relate to tangible assistance to address a problem and could be financial. Lastly, appraisal support could be the constructive feedback for the purpose of self-evaluation and social comparison.

However, these functions could be enacted or just perceived (Lazarus & Folkman, 1984). Enacted social support is defined as the things that people say or do to help on another cope with stressors, as opposed to perceived support being what they feel others would do. Additionally, Barrera, Sandler and Ramsay (1981) found that in some cases the more enacted support offered the greater the level of stress. However, not all enacted support was recognised as helpful (Goldsmith, 2004). Enacted support is seen to be influenced by the timing of the support offered, the source of the support and the type of support (Goldsmith, 2004).

The theory at individual level is much the same as community level in that the more opportunities to interact with others the greater the enacted and perceived support available, which will in turn have a beneficial effect on health (Cooper et al., 1999). The theory between enacted and perceived support notes that perceived support has a greater effect on mental health than enacted support (Dunkle, Schetter and Bennett, 1990; Pierce & Sarason, 2013). Interestingly, it is seen that married people tend to report higher levels of perceived social support, than unmarried people (Turner and Marino, 1994) as do women (Belle, 1987; Lee, 2005), who tend to have larger social networks than men. Belle found that women's network relationships tend to be intensive and thus perceived as more supportive. She also found that working women have more stress than men in general because they hold more social roles. Flaherty and Richan (1989) and more recently Lee (2005) suggest women are

more sensitive to their own needs and the needs of others for support therefore they are more likely to offer it.

Researchers have also found that the network size, degree of network participation (Thoits, 1982; Turner and Marino, 1994) and level of perceived support increase with socioeconomic status but decreases with age. The larger the social network the greater the access to a range of information (Cohen, 1988). Schwarzer and Leppin (1992) also point out that the giver of support could support in a negative or positive way and could even undermine attempts at behaviour change. Researchers' have written extensively about designing support interventions to encourage health promoting behaviours (Gottlieb, 1988), still considered today (Taylor, Mathers & Parry, 2019). It has been suggested that support can have a more positive effect on health and health behaviours especially in terms of stress when provided by people of the same age gender and ethnicity and socioeconomic background, or by people that have shared similar life experiences (House, 1981; Cohen & McKay, 1984).

There is, however, a cost to social support (Coyne & Downey, 1991; Rook, 1992). If a relationship is unsatisfactory in some way supporters may feel they are incapable of sorting things out themselves or support is an obligation or a duty (Thoits, 1995). To add to this, House and Khan (1985) and Vaux (1988) state that relational content, social network composition and social integration are key variables when considering social support.

Cohen and Wills (1985) state that in social support research, too little attention has been paid to personal meanings events and relationships have for individuals, also noted by others (Thoits, 1994; Madge & Marmot, 1997). This thesis aims to explore the personal meanings behind the use of online breastfeeding support groups. Given there can be problems with measuring social support, as experiences become hard to compare, and there is lack of definition in a multidimensional construct (Uchino Cacioppo & Kiecolt-Glaser, 1996). This

study is specific to the online support groups utilised by breastfeeding women during their breastfeeding journey. This is the focus of the content of the final Chapter of this thesis.

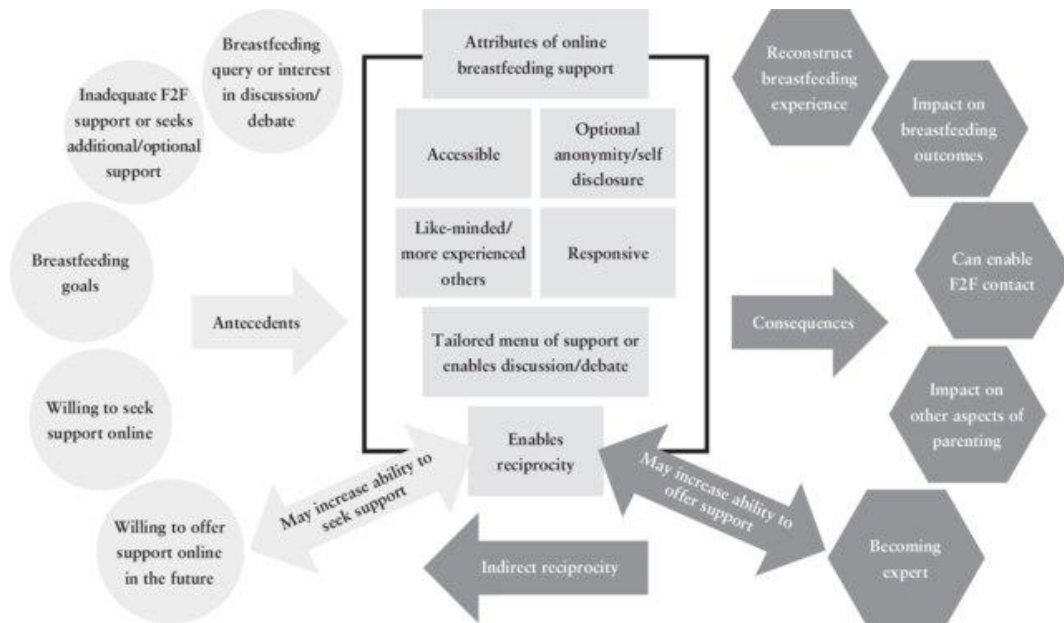
### **Online breastfeeding support theory**

Two models were found that support the work in this thesis: one specific to online breastfeeding support and another to online support from a nursing perspective. Herron, Sinclair, Kernohan and Stockdale (2015) offer a working model of online breastfeeding support (Figure 2) and the following definition: ‘a sustainable mother generated system based on indirect reciprocity, which offers easily accessible, highly responsive, tailored support from more experienced others in discrete online environments’. Their concept analysis, illustrated in Figure 2, helps to explore the concept of online support and ground, and support the research findings of this thesis.

Their model considers five antecedents and five consequences of online social support groups. The middle of the model acknowledges the attributes of the group, such as responsiveness and reciprocity of group members as well as the ease of access to likeminded others. Herron et al. emphasise the reciprocity of group members in the success and longevity of the group. The model is utilised in Chapter Six as a starting block in which to support further development of the concept of online breastfeeding support, thus adding to the body of literature on this topic.

**Figure 2**

*Concept analysis of online breastfeeding support (Herron, Sinclair, Kernohan & Stockdale, 2015).*



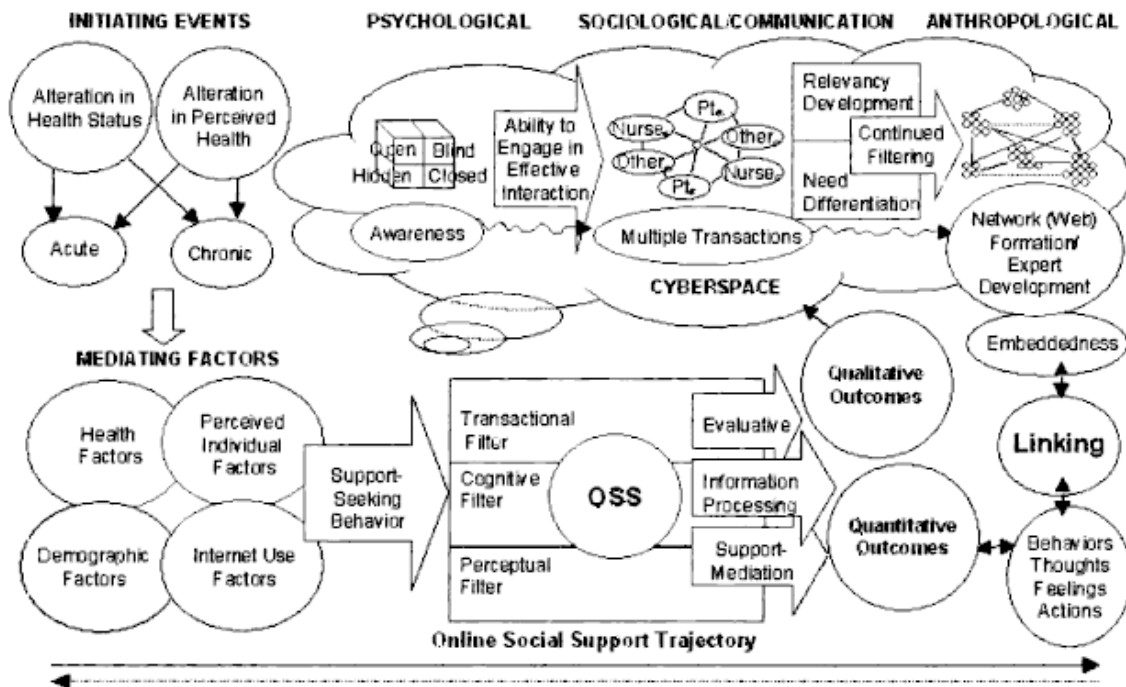
**Online social support theory.** Although not specific to breastfeeding support, a model of online social support theory, from a nursing perspective, proposed by LaCoursiere (2001) is used to assist the holistic conceptualization of online support. This model applies traditional quantitative and qualitative methods in a descriptive and integrated way, but with the addition of entries, meanings, and nuances of an online setting (LaCoursiere, 2001). The model proposes a definition of online social support as the cognitive, perceptual and transactional process of initiating, participating in and developing electronic interactions or means of electronic interactions to seek beneficial outcomes in health care status, perceived health, or psychological processing ability.

LaCoursiere (2001) proposed a model of online social support theory (Figure 3) to assist in further knowledge development relating to online social support and further refinement of the social support theory discussed in this Chapter. In this instance it offers a

starting point to further develop sub concepts relating to this virtual phenomenon from a theoretical nursing perspective.

**Figure 3**

*Online Social Support Theory (LaCoursiere, 2001)*



The model begins with initiating factors. It describes how patients seek online social support due to acute or chronic changes in health, considering the mediating factors unique to every person, such as demographic factors, perceived individual factors, health factors and internet use factors. As the person engages in online social support activity LaCoursiere describes three filters; perceptual, cognitive, and transactional, which describes how a person processed information and judges the meaning this information has for them. These three filters are unique to this model and they form the basis of their definition of online support. Each filter has certain properties; the perceptual filter acknowledges the feelings and emotional state of the individual seeking support, the cognitive filter looks at how the



individual processes information, and then the transactional filter represents and evaluates all the information received, and how it is evaluated for personal relevance.

The model then describes quantitative and qualitative outcomes. Quantitatively the patient develops their own personal meaning of online support. Such outcomes include health status, functional status, or quality of life. Perceived hope, empowerment, valuing support and psychosocial processing ability, such as decreased stress and anxiety and increased coping are all noted as quantitative outcomes. It is the qualitative approach that considers cyberspace, which is defined as a non-linear domain without spiritual or temporal attribute (Rogers, 1992). Cyberspace considers the psychological, sociological, and anthropological perspectives.

Psychologically, four areas of transactional discourse are considered based on the patient's own awareness. Johari's window (Luft & Ingham, 1955) is used to explore transactions between self and others and provides a model that explains how to engage in effective interactions with others and is often used as a success tool for forging teams and building relationships.

Secondly, from a sociologically perspective it is here that interactions are considered at group level. Two processes occur as individuals talk within communities; relevance development, whereby information that is relevant is utilised, and needs are differentiated, whereby the individual has a need and they are looking for information for that need. As these multiple transactions occur online, further refinement occurs again utilising the three filters. This information is then continually filtered through hundreds of possible online exchanges until the individual decides which transactions have a personal meaning.

The anthropological perspective considers the network formation as groups expand and information is shared across groups. Links are then made between new and old learning,

consciously and unconsciously, and the individual becomes an expert sharing the information between groups. LaCoursiere draws upon nursing learning theory (Benner, 1984) which describes how nurses learn new skills in a linear way, moving from novice through to advanced beginner, competent, proficient, and expert stages.

The Fourth stage of the model is called embeddedness. Borrowed from the work of Rogers (1983), LaCoursiere describes embeddedness as a stage in which the user continues to return to the groups and engage in online support. Embeddedness considers the adoption of the group as a good support intervention, where people believe in the power of online support and transmit this to others. Following this a synthesis of independent experiences begin to accumulate and the user experiences processes of change and adapts their behaviours. Overall, this model is useful in making sense of the findings from the following four distinct pieces of research and in organising the findings into one final Chapter; discussed in full to conclude this thesis.

**Chosen theoretical position.** As identified in this theoretical section, the theory of social support is difficult to conceptualise, define and measure. Through supervision and in the discussion, care was taken to ensure that the theory is not over simplified and that the complexities are not ignored. The literature has shown a proliferation of social support theory through the 1970s and 1980s, with only a couple of models identified relating specifically to online social support. For this reason, it is the model by House (1981) that is taken forward to guide this research. This framework although simplistic has been utilised by many models proceeding it, as discussed above, and does provide a clear explanation of social support.

However, the models of online social support will not be ignored. In the final chapter these will again be considered to further the literature on online social support theory, using the findings from this research. Areas of the online social support model will be considered

but it is not the aim of this research to do so. The aims of this research will be discussed in a following section, where the overarching research questions are outlined.

**The theory of ‘Becoming a Mother’.** Whilst the act of giving birth determines motherhood in the biological sense, emotionally and personally ‘becoming a mother’ takes time (Barclay, Everitt, Rogan, Schmied, Wyllie, 1997). The theory of ‘Becoming a Mother’ (BAM) is explored to provide a deeper understanding of why and when breastfeeding mothers’ require support. Understanding the deeper psychological experiences of women as they transition to the role of a mother is a key aspect underlying the theory to this thesis, as it provides further context. Although having a baby can be a pleasing and joyful experience for the parents in a family life cycle, it is also considered a difficult period since it brings along a change that requires a new role and responsibility (Taskan, 2007). Maternal role is a concept that has been well researched, and is still being researched today (Mercer, 1980; Shrestha, Adachi, Petrini & Shrestha, 2018). One reason being is that it is one of the main roles that many women assume in their life, which in turn, lays the foundation for neonatal development (Ruchella, & James, 1997).

BAM although a complex theory is described in four main stages, and the latest version of this theory is utilised. Ramona Mercer has been refining the theory over decades of study into maternal role attainment, now considered as the theory of BAM due to the progressive and changing nature of the model (Mercer, 1980, 1981, 1985, 1986, 2004). In pregnancy the mother is said to be making a commitment to the pregnancy, preparing for her role as mother, taking in all the information available to her. This progresses on to what was the formal stage of BAM but is now considered the stage whereby the mother becomes acquainted and attached to the infant. This occurs between two and six weeks postnatally, and behaviours include copying expert advice. The next stage describes how the mother is making her own judgements and moving towards the normal, prior to reaching her own

maternal identity, the fourth stage. Mercer states that the maternal identity is reached between four months and one year, however the last three stages are said to be highly variable (Mercer, 2004).

BAM is based on the premise that becoming a mother is individualised and influenced by maternal and infant variables. It is an ongoing process taking months or even years (Husmillo, 2013), with overlapping of the four stages (Ozkan & Polat, 2011). Several variables that occur after birth play a large role in this complex process, and these variables can affect the bond between a mother and her child (Husmillo, 2013). Breastfeeding is one of these variables and keeping babies close and exclusive breastfeeding are well-documented variable that affects maternal bonding in a positive way. Other variables that affect BAM include stress, social support, self-concept, mother-father relationship, role strain and health status (Mercer, 1981 1986; Oakley, 1992; Ozkan & Polat, 2011). Here Mercer notes the importance of social support and the impact on BAM as a maternal variable. Infant variables include temperament, appearance, and gratification in the maternal role is also noted.

BAM (Mercer, 2004) is said to be best applicable to a Nursing or Midwifery environment that directly interacts with the childbearing family, and is beneficial in the clinical setting (Noseff, 2014). The model is useful to professionals working with women throughout pregnancy and the postpartum period, emphasizing its place in this research within the underlying theory. However no one theory is able to capture the varied nuances of motherhood or what it means to become a mother; and the importance of subjective experience is emphasised (Bassin, Honey, & Kaplan, 1994; Laney, Hall, Anderson & Willingham, 2015).

BAM describes the transition to motherhood as a major developmental life event (Mercer, 2004). This transition requires restructuring goals, behaviours, and responsibilities

to achieve a new conception of self (Barba & Selder, 1995), and women must modify their understanding of themselves and who they are in relationship to other people (Steinberg, 2005). This new identity reflects the qualities, traits, attitudes, and achievements she finds desirable in motherhood, rejecting behaviours she judges as inappropriate for herself (Rubin, 1967).

Overall, BAM emphasises that social support, stress, and breastfeeding can play a large part in achieving the various stages of BAM, and maternal identity (Mercer, 2014; Ozkan & Polat, 2011). It is defined as a women's perceptions and feelings as a mother about the mother-infant relationship that forms after childbirth through physiological transition to motherhood and the process of adapting to maternal behaviours and maternal role attainment (Badr, 2005). It is noted that establishing a solid maternal identity will further enhance the women's psychosocial development, which ultimately increases her adaptive functioning (Mercer, 2004). Achieving BAM, and a maternal identity has been proven to be the most important aspect for influencing the mother/infant relationship (Mercer, 2004). More specific to breastfeeding one study showed how maternal role training programmes that include lactation support can reduce anxiety around infant care and increase maternal role attainment and identity formation (Fasanghari, Kordi & Asgharipour, 2019).

The role of the professional to support the mother not only with breastfeeding but with her maternal identity is pertinent theory underpinning this research. Mercers theory is applicable to everyday practice and assists healthcare providers in planning and delivering competent care to the mother and the child which promotes positive bonding for the mother and infant (Husmillo, 2013). The nurse works with the mother's support systems and builds on strengths to develop self-efficacy (Dawley & Beam, 2005).

**Thesis aim**

The aim of this thesis is to explore the phenomenon of online breastfeeding support, and to add to the theory and practice in this area. Breastfeeding support practice is changing and developing as we move through the 21<sup>st</sup> century, partly due to new technologies, and this thesis contains four pieces of research that explore this. The aim is to add depth to the literature around the potential benefits and risks associated with online social support groups for breastfeeding women. Objectives include answering questions such as; what online support interventions currently exist, how, when and why are they used to support breastfeeding women, what does it mean to the mother to have access to online support and what is the impact, if any, on their breastfeeding journey. This in turn led to questioning around what is breastfeeding support, what does support mean, what support is offered in practice and how could this be advertised so that women can navigate various interventions to meet their individual needs.

**Overarching research questions**

At the start of the research journey there were numerous research questions considered as noted above (see Appendix D), which in turn led to five overarching questions being set: how do women use Facebook for breastfeeding support; why do women use Facebook groups for breastfeeding support; what are the women's experiences of using Facebook groups for breastfeeding support; what is the perceived impact of online breastfeeding social support groups on the mothers breastfeeding journey; and what do the professionals, who support breastfeeding women, need to know about online social support groups? These five overarching questions guide the research in the following chapters.

**Guide to the Chapters**

This thesis has six separate Chapters: this present Chapter, four original pieces of research and a final reflective Chapter; each complete with their own reference list and

appendices. By design, this thesis provides four original pieces of research that align to create an integrated study of online breastfeeding support, combining practice, research, and implications for future practice. The four main pieces of research and the reflective final Chapter will now be outlined in detail.

Chapter Two contains a critical review of the literature. Undertaken in 2016-2017, and then published in the *International Journal of Nursing Studies* in 2018, this research broadly explores how computer mediated communication has been used to support patients in the healthcare setting. This provided a starting point and scoping exercise for the study to understand how, when, and why interventions may be useful, as well as identifying any potential risks.

Chapter Three was a small-scale research project undertaken in 2017, and published in 2019, and focuses on online social support groups. It was evident from the literature review that online support groups were a popular avenue of support. A search of the literature particularly for studies that had explored Facebook, showed a small but growing body of interest. Curiosity led to a site search of Facebook.com which indicated on average 42,000 Facebook groups titled breastfeeding support. This sparked a professional interest and way forward with this research.

This small-scale research project details a content analysis of one weeks' worth of posts captured from a UK based online breastfeeding support group. It aimed to document and describe the online group activity. It examined author variables such as time of post, numbers of like and number of pictures shared, as well as the themes of discussion and types of support requested. This study was a key aspect to understanding the online platform, terminology used and the extent to which the groups were being used. This Chapter is focused on the group, and not the individual, which subsequently led to more research

questions about the mother experiences. The process of beginning this primary research was also an opportunity to begin to develop and refine new skills as a researcher with guidance from the Vitae Researcher Development Framework (Vitae, 2011).

The large-scale research project, in Chapter Four, consists of an Interpretative Phenomenological Analysis, an in-depth qualitative analysis, exploring the complexities of online support. This large-scale project offered the opportunity to conceptualise, design and implement a research methodology to create new knowledge. The aim was to explore how breastfeeding mothers make sense of and interpret their experiences of online support groups and the perceived impact that this has on their breastfeeding journey.

The final piece of research in Chapter Five, adopts a case study approach. This piece of research studies one women's experiences of peer breastmilk sharing sites to produce a single case example of tangible online breastfeeding support. Previous research highlighted three functional units of online support: esteem, emotional and informational support, however tangible support had not been highlighted. This case study was chosen as a way of showing how online support groups could offer tangible support. This study was pertinent to fully understanding all aspects of online support. It was interesting to uncover one mothers motivation of using the site, as well as how she made sense of this experience and what it meant to her.

Finally, Chapter Six provides a reflective review that looks back on the learning from all four pieces of research before moving forward and transferring the findings into practice. This overarching element connects and synthesises all Chapters into a coherent piece of work, linking the new research, to the underpinning theory again, by way of a critically evaluated account. A model of online social support specific to breastfeeding mothers is proposed to inform future practice, policy, and research. It is here that the importance of the



research findings is demonstrated, and from a practical viewpoint for use by all those supporting breastfeeding mothers.

### **Philosophical Position**

A paradigm is a set of beliefs, shared by communities which regulate inquiry within a discipline providing lenses, frames, and processes through which investigation is accomplished (Weaver & Olson, 2006). The need to clarify the paradigms of nursing research is highlighted as one of the top ten issues facing the discipline (Weaver & Olson, 2006). It is for this reason, and for clarity, that the philosophical position will be discussed at this point.

Since the 1860s, with the introduction of nurse training, nursing has been acquiring theoretical knowledge for application to practice. The evolution of nursing as a profession necessitated the establishment of a scientific research base (Kerkevold, 2008) to increase disciplinary credibility. Theory deriving from post-positivist paradigm inquiry, whereby the approach relies on scientific experiments and statistics, has produced prescriptive theory, such as interventions for managing specific health threats (Gortner, 1993). Certainly, the research around the benefits of breastfeeding and composition of human milk required this positivist approach. However, the theory generated through the interpretative or constructivist paradigm inquiry, whereby research looks at meaning-making and practices, enables nurses to develop insights into unique individual responses within clinical situations that could improve the care of those involved (Van der Zalm & Bergum, 2000).

Critical realism is a series of philosophical positions on a range of matters including ontological causation, structure, persons, and forms of explanations. Critical realism was developed in the post-positivist social sciences offering researchers an alternative paradigm, and is the approach taken in this research. Baskah (1979) states that critical realism assumes that there is a reality, but that we are in the process of knowing, which mediates what it is

known. It is an approach concerned with ontology and seeks to explain and offer plausible explanations about the world. Like all philosophies critical realism is accompanied by a set of tenets that inform the research design, provided by Clark, Lissel & Davis (2008).

Firstly, critical realism believes that there is an independent reality that exists separate from our beliefs, and that culture is independent to the beliefs that individuals hold in their mind. It is for this reason that a bracketing interview was carried out at the start of the journey, as a reflexivity tool and undertaken yearly (see Appendix C for the initial bracketing interview). Bracketing is a method used in qualitative research to mitigate the potential deleterious effects of preconceptions that may taint the research process (Tufford & Newman, 2010). Bracketing encompasses the positing of thoughts and hypotheses (Starks & Trinidad, 2007); biases (Creswell & Miller, 2000); preconceptions (Glaser, 1992); presuppositions (Crotty, 1998); and assumptions (Charmaz, 2006). There is a lack of consensus over when this should occur; at the start (Ahern, 1999), or at the data analysis stage (Giorgi, 1998) so regular bracketing interviews were completed.

Secondly, to work within a critical realist approach, the importance of ontological reflexivity is emphasised, in which presuppositions about the social world are noted. Again, for this reason a reflexive journal was kept throughout the research. The journal extracts are provided within the following chapters to highlight the changes in decisions that were made along the way, the questions that were asked and the decisions that were made.

Subsequently, the journal was used during supervision sessions to help reflect on the data collection and interpretations made. These were used during learning set weeks, where updates on the work were presented to the research team. This was a time for collation of thoughts, presentation, and a protected space in which the research team would challenge ideas, beliefs, and thoughts. All are provided throughout to demonstrate research reflexivity

and the ability to evaluate one's self, reflect on biases, and preconceptions that may influence data collection or interpretation (Mruck & Breumer, 2003, p3).

Critical realism also informs the research design. Interviews were used in two out of the four pieces of research. Interviews are used to construct the experiences of individuals in a reflective way, to look at the critical decisions made by the group users (Archer, 2003). Critical reasoning also fits well to the single case study, which studies a unique event with one single case (Steinmetz, 1993; 2014).

Critical realists believe that it is possible to refine and improve knowledge about the real world over time, and to make claims about reality which are relatively justified, whilst still being historical, contingent and changing (Archer et al., 2016). This is a key tenet of any research looking at online environments that are every changing as new users and new technologies change the platforms that are used. Chapter Six provides a model of online breastfeeding support, so it is important taking a critical realist approach, that the model is placed in the context of the UK, with the belief that reality is complex, but not chaotic, and that it can be uniformly patterned, observable, uncontrolled and that trends happen (Clark, Lissel & Davis, 2009). For this reason, it is advised that if using the model in future practice or research, that practitioners and researchers refine and adapt the model as required, within a cultural context.

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## Appendix A, Initial reflection

Driscoll's model of reflection (2007) identifies three simple questions to guide reflective thinking: what, so what, now what? As reflection is a personal endeavour; this appendix will be written in the first person. To begin I will provide a description of my career and the origins of my curiosity around online breastfeeding support. I have been a registered Nurse for 20 years and an International Board-Certified Lactation Consultant (IBCLC) for over 5 years. When I began my research, I was working as a Specialist Community Public Health Nurse (SCPHN), within the Health Visiting Service in the UK and worked in a leadership role as an Infant Feeding Lead. I have since moved into Higher Education as a senior lecturer and course leader for SCPHN.

Previously as Infant Feeding Lead, and as a Health Visitor, I have been involved in breastfeeding support and spent over 15 years teaching families, colleagues and students about the skills and knowledge required for successful breastfeeding. How, when, and where breastfeeding support is offered has always been an interest of mine, with an altruistic approach to improve services. I believe that breastfeeding is biologically normal, but is not for everyone, and that as professionals we can always know more, and can should always strive to do better.

Currently I am the founder of a local breastfeeding support charity, and this question is still pertinent as I work one-to-one with mothers. Professionally, I undertake the training of peer supporters, and student midwives and child nurses. I believe it is important to not only ensure currency of information but to add to the body of literature. I also believe that women are not separate from the world in which they live, and that culture, society and family all have a really important role in the breastfeeding journey.

So what? I have reviewed the literature on many occasions around interventions that support breastfeeding and acknowledged that few had researched online breastfeeding support. From speaking with mothers, I knew online support was available to mothers and used regularly, so questions were contemplated such as what exists for breastfeeding mothers online, what are the potential benefits and concerns with this type of support, are there nurses that already offer this, how is this evaluated?

Driscoll's 'Now what' is now considered. I have chosen to undertake primary research myself, developing my research skills. This PhD in professional studies will provide me with an opportunity to develop a deeper understanding of the term 'support' and a deeper understanding of online support. This seemed the perfect choice to do this, as trying to get scholarly time at work, or encouragement in the healthcare setting to conduct primary research myself is lacking. Emotionally I am happy and exciting and ready to start this, anxious that I will not be clever enough to undertake research and have imposter syndrome, but that's how I have felt before and things worked out OK.




Appendix B, Breastfeeding Support Training

There are four main types of peer support training: International Board-Certified Lactation Consultant, Breastfeeding Counsellor, Peer Supporter, Baby Friendly training (IBCLC, 2020), refer to Figure B1.

Figure B1

Who's who in breastfeeding support and lactation in the UK (IBCLC, 2020).




Lactation Consultants of Great Britain  
The professional voice of breastfeeding since 1994

**WHO'S WHO IN BREASTFEEDING SUPPORT & LACTATION IN THE UK**

	International Board Certified Lactation Consultant (IBCLC)	Breastfeeding Counsellor (BFC)	Peer Supporter	Baby Friendly (BF)
Also known as	Only IBCLC certified Lactation Consultants are listed on <a href="#">IBLCE Registry</a> . <a href="#">Role &amp; Impact of the IBCLC</a>	Breastfeeding Counsellor ( <a href="#">ABM, NCT</a> ) Breastfeeding Supporter ( <a href="#">BFN</a> ) La Leche League Leader ( <a href="#">LLLGB</a> )	Peer Counsellor, Mother Supporter, Helper, Breastfeeding Buddy etc.	BFI Baby Friendly accredited hospitals and communities listed <a href="#">here</a>
Accreditation	IBCLC the only internationally recognised professional breastfeeding qualification. Examining body <a href="#">IBLCE</a>	Awarded by each organisation, some have university accreditation	Awarded by each organisation, some have college accreditation	<a href="#">UNICEF Baby Friendly Initiative</a>
Who	Health professionals (HP) and accredited Breastfeeding Counsellors (BFC). For other routes see <a href="#">IBLCE pathways</a>	Experienced breastfeeding mothers	Usually women who have breastfed	Usually HPs and allied health workers, children's centre workers
Prerequisites	HPs and BFCs require advanced lactation education and extensive clinical experience to sit IBCLC exam	Breastfed own baby for at least 6-12 months	Ability and motivation to undertake voluntary role. Usually has breastfed own baby.	None
Clinical Hours Prerequisites	1000 hours supporting breastfeeding families in a supervised setting (post HP or BFC qualification)	None	None	None
Breastfeeding Education	Minimum of 90 hours post- HP or BFC qualification. <a href="#">Exam information</a>	Average 2 years part time	Average 16-36 hours	Ideally, about 18 hours over several days
Counselling Skills	HPs training varies, in depth training for BFCs	In depth	Basic communication and listening skills	Brief introduction to counselling skills
Standards of Practice	Professional Standards of Practice, Scope and Disciplinary Procedures	Individual organisation's policies and procedures	Supervising organisation's procedures	Baby Friendly accreditation audits
Recertification	5 yrl <a href="#">Recertification</a> following accredited continued education. Re sit exam after 10 years	Individual organisation's continued education requirements vary	Continuing education should be provided	Annual update (1-6 hours) by some employers. Regular BFI audits
Work	Employed in; hospital/community, Infant Feeding Lead, NICUs, training HPs/Peer Supporters, research and policy making. Private Practice; voluntary	Volunteer and paid roles; antenatal classes, breastfeeding support groups, Helplines etc. Breastfeeding counselling free to mothers.	Volunteers' expenses may be paid. Community, Children's Centres, breastfeeding drop-ins, hospitals. Services to mothers free.	Hospitals and Community NHS services, Children's Centres - free to mothers
Scope	Any breastfeeding issue including complex situations, high-risk babies, oral assessment etc, as well as common issues.	Support with common breastfeeding problems. Referral to further professional information as needed. Supervision within accrediting body.	Encourage and support basic breastfeeding issues under supervision. Refer complex issues to a specialist.	Health service & council staff work within the scope of their existing employment.

Compiled by LCGB – Revised Oct 2017

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## Appendix C, Initial Bracketing Interview

**Personal Bias**

I am a trained professional so am trained to provide the most up to date information to the women that I see. Reflecting on this I see myself to be in a role where women need to make informed choices. I need to make sure that all women have the right information in a timely manner.

When giving the information I am a middle aged, Caucasian female from a professional background in the UK. I appreciate that this is not the culture of all the other women that I see and that culturally we may do and think about all aspects of parenting and feeding a baby differently.

I often meet mothers in my role as a health visitor. Some people like their health visitor and some do not. We are not a statutory service; women can refuse to see me. I must build a trusting open honest relationship with the mother so am conscious not to judge. I also often meet mothers as a lactation consultant. Some people have heard of lactation consultants and some people have not. Here in the UK, there are not as many lactation consultants as there are in America and Australia for example. I must explain what I offer, and I run a face to face breastfeeding support group.

As a senior lecturer, I teach students the knowledge and skills around breastfeeding, from a range of disciplines (Health Visitors, child nurses, adult nurses, and managers). People see me as a breastfeeding advocate and champion and I guess I try to live up to this role, promoting and protecting breastfeeding.

**Personal experiences of breastfeeding:**

I grew up believing the motto *“breast is best”* from my mother and fed both my children for different lengths of time. I remember a midwife saying to me, after I had introduced formula with my first son, *“you may as well continue to formula feed him now, since you have already started”*. I remember feeling like I had failed, and I use this example in training saying, *“don’t be this health professional”*. I was a teenage parent with my first and fed much longer with my second, but I did feel that breastfeeding was easy. When training to be a UNICEF baby friendly trainer and doing my training to become a Lactation Consultant, I remember thinking *“if only I had known what I know now, back then”*.

I have been trained to be sceptical of formula milk. I have had training and know about the unethical marketing practices of formula milk. I do not feel as though formula milk is ‘evil’ or ‘bad’ in any way. I used it myself for my children. I do not feel like I preach about how good breastfeeding is, and I have always been mindful not to come across strongly one way.

With regards to breastfeeding support, it is something that I feel is my main role in the community. I am there if people choose to feed and struggle, and there to build a community and bring people together so they learn from each other. I do feel as though the act of breastfeeding is hidden in society and I do try and promote it within my local community, Our charity logo is colourful knitted breasts and not a breastfeeding mother and baby, because I don’t want to offend people. Maybe I should not be worried about offending when breastfeeding is in fact biological normal.

### **Personal experiences of online support**

I like technology and there are increasingly more and more breastfeeding apps available and online resources. I do feel now that there is lots of information, probably too much information. As a previous experience, googling symptoms myself when unwell it

caused me to be worried. I took no comfort in knowing more. It made me consider: how does a mum get an individualised plan? As breastfeeding services in the local areas were non-existent, I started a charity in the community, using all I had learnt in the NHS. More and more services are being closed and I feel mothers do not have quick access to information. I am aware that some are going online, which made me wonder what we could do. I then thought about the potential for bad practice and harm therefore the risks inherent in an unregulated and evolving clinical service.

## Appendix D, Research Questions

## Questions relating to the mother

- Why do breastfeeding mothers use online groups?
- What are the experiences of group use?
- Does using the group ever make them anxious?
- What do mothers gain from using the groups?
- What did they hoped they gained from using the group?
- How often did they use the online groups?
- Do they trust the information that they read?
- Why did they choose one group over another?
- Do they favour online groups over other types of support?
- What type of support where they hoping to get?
- What do women want professionals to know about online social support groups?

## Questions relating the group

- What is already known about online social support group use in general?
- How do women use the online breastfeeding support groups?
- What information does it cover?
- What types of support are requested?
- Quality if information?
- Does someone monitor the information?
- Are groups all the same?
- What are the differences between groups?
- What is discussed in the groups?
- Are they used all times of the day?
- What do professionals need to know about these groups?

Chapter Two: The use of computer mediated communication in providing patient support: A review of the research literature.

### Abstract

**Objectives:** The aim of this study is to explore how computer mediated communication has been used by a variety of healthcare professionals to support their patients and discuss the implication that this may have for future practice.

**Design:** A systematized review of the literature.

**Data sources:** A review of empirical studies within the literature was carried out in April 2016 in CINAHL, MEDLINE, ASSIA, BNI, Psychinfo, and Web of Science databases.

**Review methods:** The databases searched produced 2930 titles, of which 190 publications were considered relevant to the objectives. Titles and abstracts were then reviewed, and duplicates removed producing 67 publications. Exclusion and inclusion criteria were applied. The inclusion criteria were (1) interventions that facilitate two-way communication between any healthcare professional and their patients via a computer; (2) Interventions aimed at providing any type of support e.g. emotional, tangible, informational, or esteem support; (3) English language; (4) Primary empirical studies. Data quality was assessed, and thematic analysis applied.

**Results:** Thirty-one publications were included in this study. Intervention types included email (n=8), videoconferencing (n=7), online social support groups (n=9) and multifaceted interventions (n=7). Three themes emerged from the data including increasing access to healthcare, adding value to healthcare delivery, and improving patient outcomes. Twenty-five (81%) of the studies found that computer mediated communication could produce positive effects.

**Conclusions:** Computer mediated communication could be both what patients want and a way of delivering support to patients in a resource tight environment. This has implications for a range of health support needs and professionals including nurses, midwives, and allied healthcare professionals. Reviewing the lessons learnt will ensure future interventions are tailored to the support needs of the patients, carefully planned and mindful of the risks.

## **Introduction**

The NHS constitution (NHS, 2015) states that it is the responsibility of all staff to take every opportunity to encourage and support patients and colleagues to improve their own health and wellbeing. However, the definition of support is all-encompassing and without context can be vague as to the assistance required or given.

The Oxford dictionary of English (2015) defines support as something that bears all the weight, or holds up, gives assistance to, or something that gives approval, comfort or encouragement. Support can also suggest a truth of, corroborate findings, or indicate that something is now sustainable, tolerable, or endurable. As a noun, it could include financial support or something in favour of, encouraging or comforting.

Drawing theory from the social scientists, House (1981) best describes the concept of support as belonging to four types: emotional, informational, instrumental and esteem/appraisal support. Dykes, Hall, Burt and Edwards (2003) theory of network support develops House's definition further and incorporates 'network support' whereby help is provided to activate relationships with peers and significant others. Overall support assumes a conversation or interaction between two or more people in which one person requires support and another provides it. For this review, 'support' is defined using the work of House (1981) and Dykes et al. (2003).

### **Computer mediated communication in healthcare**

Historically people would interact, converse, communicate and thus seek and receive support from their healthcare provider face-to-face. More recently, this can occur via computer: at the end of 2011 there were 6 million mobile phone subscriptions corresponding to a global penetration of 86% with 2.3 billion internet users worldwide and 70% of households in developed countries having internet access (International Telecommunication



Union, 2012). Greater access to information on personal devices, smartphones and tablets is now more prevalent for patient's families and clinicians.

Social media or social networks are web 2.0 internet-based applications. This version of the internet came about in the 1990s and has allowed user generated content. Patients can therefore continuously organize and form their own groups and networks on social media, share observations and experiences, exchange emotional support, find recognition and understandings, and help other members (Mo & Coulson, 2014). Social media is described as 'no passing fad' with NHS Employers encouraged to take the lead in promoting and encouraging the use of social media in the NHS (NHS confederation, 2017).

Within this review computer mediated communication is used to define the use of computers, phones, or mobile devices to interact and share information, thoughts, and ideas with other users. This definition incorporates the use of any of the following platforms: social media through the development of Web 2.0, websites, social projects, blogs and micro blogs, Twitter, social networks, and virtual worlds.

### **Study aims**

This review aims to explore the fifth overarching research question: What do professionals, that support breastfeeding women, need to know about online support? Specifically, this review seeks to address the following questions: What types of interventions have already been used in healthcare, what literature currently exists on topic of online support, and how have such interventions been evaluated.

The aim of this review is to explore how computer mediated communication has been used as a tool for providing support to patients by a variety of healthcare professionals and further discuss the implications that this may have for supporting patient care in the future. It aims to stimulate thinking and analyse the benefits and concerns around the use of computer

mediated communication in the healthcare setting and meets a personal goal to develop the practice area.

### **Review process**

Search string development began with the identification of keywords, concepts, and phrases central to the phenomenon. These included words such as social media, internet, mobile applications, support, social support, practical support, emotional support, psychological support; patients service users, healthcare, health services (see Appendix A for search strings). These were then refined and a final search using six databases (CINAHL, MEDLINE, ASSIA, BNI, Psychinfo, and Web of Science) performed in April 2016 was conducted. Choosing the appropriate data bases to search is key to receiving the right information (Parahoo, 2006) so the databases were chosen for their relevance, notable quality, and extensiveness. Browning and Abrahams (2005) describe how the apparent convenience of computer searches is deceptive and potential publication bias is noted.

A final literature search, conducted in April 2016, produced 2930 citations and the titles and abstracts were manually and cursorily screened for eligibility and relevance. Articles were only included if they involved primary research, qualitative or quantitative, written in English, available in online journals, and examined the patients' experiences of computer mediated support interventions such as email, videoconferencing and other forms of support that offered means of two-way communication. This produced 190 publications.

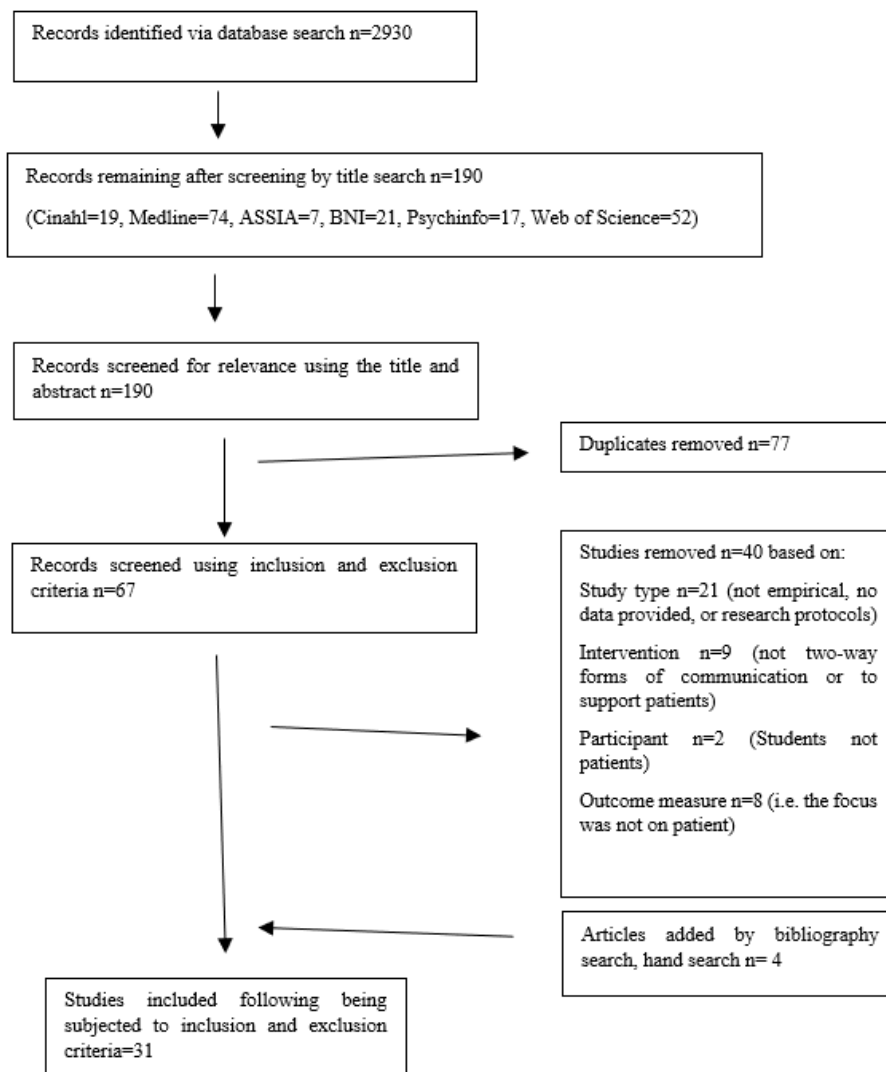
An abstract search of the 190 articles was then completed and duplicates removed leaving 77 publications. Studies excluded were those that analysed content of webpages, content of peer support forums, the general effects of social media, healthcare-seeking behaviours, user-generated content analysis, and recruitment of volunteers and study participants. These did not look at a two-way communication intervention, thus satisfying the

inclusion/exclusion criteria. No journal, study designs, or subject filters were placed on the search, however, conference proceedings and abstracts were not included. This stage produced 67 articles.

The full text studies (n=67) were then assessed for relevance using the inclusion and exclusion criteria. In total 31 articles were included for critique in the next stage of the review. Figure 1 summarizes the study selection process.

**Figure 1**

*Study selection process.*



**Article details**

Table 1 provides an overview of the thirty-one empirical research studies chosen for inclusion within this review. Study variables including author, title, field of study, taxonomy of intervention, clinical purpose, study design, and sample size were extracted. The Critical Appraisal Skills Programme (CASP) tools (CASP, 2013) were used to assess study quality. The benefits of using the CASP tools include the fact they are freely available online and specific to each method of research (Aveyard, 2014; Parahoo, 2006; Polit & Beck, 2005). These were chosen as they are readily available, tailored to each study design, and recommended by the Cochrane collaboration (Higgin & Green, 2009).

## RUNNING HEADER: EXPLORATION OF ONLINE BREASTFEEDING SUPPORT

**Table 1**

*Overview of the articles within the literature review.*

Authors	Title / year	Field/ location of study	Taxonomy of intervention	Clinical purpose	Study design	Sample
Barrera, Glasgow, McKay, Boles & Feil.	Do internet-based support interventions change perception of social support? An experimental trial of approaches for supporting diabetes self-management (2002)	Diabetes/ USA	Multifaceted: online social support, coach + information	Providing social support online	Randomised controlled trial	160 Diabetic patients
Bergmo, Kummervold, Gammon & Dahl.	Electronic patient provider communication: will it offset office visits and telephone consultations in primary care? (2005)	GP / Norway	Email	Could secure web-based messaging systems be an effective way of providing patient care?	Randomised controlled trial	6 GPs + 200 patients
Bjoernes, Laursen, Delmar, Cummings & Nohr.	A dialogue-based web application enhances personalized access to healthcare professionals- an intervention study (2012)	Cancer/ Denmark	Email	Explore patient experiences of online contacts with healthcare professionals	Survey	34 patients with cancer
Castillo, Wegener, Newell, Carlini, Bradford, Heins, Wysocki, Pollak, Teter & MacKenzie.	Improving outcomes at level 1 trauma centres: An early evaluation of the trauma survivors' network (2013)	Mental health/ USA	Multifaceted: online support, information, and a self-management program	Providing social support online	Randomised controlled trial	251 trauma survivors
Danbjørg, Wagner, Kristensen & Clemensen.	Intervention among new parents followed up by an interview study exploring their experiences of telemedicine after early postnatal discharge (2014)	Maternity/ Denmark	Email + information + automatic messages	Does the app provide a sense of security and self-efficiency?	Semi structured interview	Interviews with 27 mums and 11 dads

Ellis, Drew, Wakefield, Saikal, Punch & Cohn	Results of a nurse led intervention: connecting paediatric cancer patients from the hospital to the school using videoconferencing technologies (2013)	Paediatric oncology, UK	Videoconferencing	feasibility and perceived outcome of videoconferencing linking children to school	Semi structured interviews	8 parents, 3 patients (5-18), 5 teachers (n=16)
Friesen, Hormuth, Petersen & Babbitt	Using videoconferencing technology to provide breastfeeding support to low income women: Connecting hospital-based lactation consultants with clients receiving care at a community health centre (2015)	Breastfeeding/ USA	Videoconferencing	Feasibility of linking children with school	Interviews	35 post-partum mothers
Gallienne, Moore & Brennan	Alzheimer's caregivers psychosocial support via computer networks (1993)	Alzheimer's/ USA	Online social support + online information + self-management program	Look at the experiences of providing psychosocial support to caregivers of people with Alzheimer's disease.	Case study	3 adults
Gilmour, Campbell, Loane, Esmail, Griffiths, Roland, Parry, Corbett, Eedy, Gore, Matthews, Steel & Wootton.	Comparison of Tele-consultations and face to face consultations: preliminary results of a United Kingdom multicentre Tele-dermatology study (1998)	Dermatology/ UK	Videoconferencing	To compare face to face consultations with those performed from a distance using computer technology	Exploratory/ interview	155 patients
Glasgow, Boles, Mckay, Feil & Barrera.	The D-Net diabetes self-management program: long-term implementation, outcomes, and generalization results (2003)	Diabetes / USA	Online social support + online information + internet based self-management	D-net intervention evaluation	Randomised controlled trial	320 diabetic patients
Grimsbø, Finset & Ruland.	Left Hanging in the Air. Experiences of Living with Cancer as Expressed Through E-mail Communications with Oncology Nurses (2011)	Breast and prostate cancer/ Norway	Email + information + online social support.	Explore the use and content of emails between patient and nurse...snapshot of experience	Qualitative content analysis	276 messages between nurses and patients

Harris, Haneuse, Martin & Ralston.	Diabetes quality of care and outpatient utilization associated with electronic patient-provider messaging: a cross-sectional analysis (2009)	Diabetes / USA	Email	Utilisation of outpatient systems.	Cross sectional analysis	5274 messages between patients and health care providers
Houston, Cooper & Ford	Internet Support Groups for Depression: A 1-Year Prospective Cohort Study (2002)	Mental health/ USA, Canada, Australia, Europe	Online Social support	Describe characteristics of users of depression support group online and assess there were changes in depressive symptoms and social support.	1-year prospective cohort study: internet survey at base 6 months and one year	130 mostly women in their forties
Leiderman & Morefield.	Web Messaging: a new tool for patient-physician communication (2003)	Primary care / USA	Email	Improving communication between primary care provider and patient	Survey	238 patients
Lindberg, Ohrling & Christensson.	Midwives experiences using videoconferencing to support parents who were discharged early after childbirth (2007)	Midwifery/ Sweden	Videoconferencing	Increased support for parents	Mixed method study	7 post-partum mothers
Lopez, Ramirez, Valenzuela, Arguello, Saenz, Trujillo, Correal, Fajardo & Dominguez.	Sexual and Reproductive Health for Young Adults in Columbia: 'Teleconsultation' using mobile devices (2014)	sexual health/ Columbia	Email + information	Improving sexual health in young adults	Survey	58 patients
Lowitt, Keesler, Kauffman, Hooper, Siegael & Burnett	Tele-dermatology and in person examinations (1998)	Dermatology / USA	Videoconferencing	Could dermatology clinics be done from a distance	Interview	139 patients

Mackenzie, Terao, Bosarge, Henry, Klees, Morrison & Kossoff	E-mail management of the Modified Atkins Diet for adults with epilepsy is feasible and effective (2012)	Neurology/ USA	Email	Evaluate the feasibility, safety, and effectiveness of an email administered dietary therapy for refractory epilepsy in adults.	3-month cohort study	22 Adults
Oh & Lee	The effects of computer-mediated social support in online communities on patient empowerment and doctor-patient communication (2012)	Diabetes/ Korea	Online Social support	Test the mechanism through computer mediated social support influenced intention to talk to a Doctor. How a sense of empowerment acted as a mediator in this decision.	Internet survey	464 diabetic patients who currently use diabetes online communities
Pacaud, Kelley, Downey & Chiasson	Successful delivery of diabetes self-care education and follow up through e-health media (2012)	Diabetes / Canada	Email + online information + virtual appointments	Care and follow up for diabetic patients online	Randomised controlled trial/ longitudinal study	79 patients
Patten, Rock, Meis, Decker, Colligan, Pingreem Doenlas, Offord, Boberg & Gusftafson	Frequency and type of use of a home-based internet intervention for adolescent smoking cessation (2007)	Smoking cessation/ USA	Email + online social support + online information	Reducing smoking rates in adolescents	Content analysis	70 adolescents
Patten, Croghan, Meis, Decker, Pigree, Colligan, Dornelas, Offord, Boberg, Baumberger, Hurt & Gustafson.	Randomized clinical trial of an internet based versus brief office intervention for adolescent smoking cessation (2006)	Smoking cessation / USA	Email + online social support + online information	Reducing smoking rates in adolescents	Randomised controlled trial	139 adolescents



Petrovski, Zivkovic & Stratrova	Social Media and Diabetes: Can Facebook and Skype Improve Glucose Control in Patients with Type 1 Diabetes on Pump Therapy? One-Year Experience (2008)	Diabetes/ USA	Videoconferencing	Evaluate results from SM (FB and Skype) and care link software as tools to provide DM control	Randomise controlled trial	56 children and adolescents with type 1 diabetes aged 14-23.
Roter, Larson, Sands, Ford & Houston	Can E-Mail Messages Between Patients and Physicians Be Patient-Centred (2008)	GP /USA	Email	Explores the extent to which email messages patient and GP mimic tradition communication dynamics.	Content Analysis	8 volunteers from a larger study
Salonen, Kaunonen, Astedt-Kurki, Jarvenoa, Isoaho & Terkka.	Effectiveness of an internet-based intervention enhancing Finnish parents' parenting satisfaction and parenting self-efficacy during the post-partum period (2010)	Midwifery / Finland	Online social support + online information + access to a professional	Evaluate the effectiveness of an internet-based intervention to support mother s and father.	Quasi-experimental design with a non-equivalent control group	354 mothers
Shaw, Baker, Witherly, Hawkins, McTavish & Gustafson	How women with breast cancer learn using interactive cancer communication systems (2007)	Cancer / USA	Social support online + online information + personalised information	Which district services within CHESS contribute most to the effect	Randomised controlled trial	231 patients
Tjora, Tran & Faxvaag	Privacy vs. Usability: A Qualitative Exploration of Patients' Experiences with Secure Internet Communication with Their General Practitioner (2005)	GP/ Norway	Email	Experiences of people using medaxess	Semi structured interviews	15 patients
Turner, Robinson, Tian, Neustadt, Angelus, Russell, Mun, & Levine	Can Messages Make a Difference? The Association Between E-Mail Messages and Health Outcomes in Diabetes Patients (2013)	Diabetes/ USA	Email	Examine the impact of social support messages on patient health outcomes	Non-randomised prospective study	41 patients
Varsi, Gammon, Wibe & Ruland.	Patients reported reasons for non-use of an internet-based patient provider communication service: Qualitative study (2013)	Paediatric care/ Norway	Email + information + online social support.	Exploring non-use of Email	Interviews	22 patients

Weiss, Whieley, Treviranus, & Fels	Pebbles: A personal technology for meeting educational, social and emotional needs of hospitalised children (2001)	Paediatrics/ Canada	Videoconferencing	Improving educational social and emotional needs of children.	Case study	1 child
Yoo, Chi, Kwon, Yang, Cho, McLaughlin, Among, Shah & Gustafson.	Predictors of the change in the expression of emotional support within an online cancer support group: A longitudinal study (2013)	Cancer / USA	Online social support	Social support change over time	Thematic analysis	18064 messages between patients and a healthcare provider.

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### **Article findings**

From the thirty-one articles within this review the use of four main types of computer mediated communication interventions were noted: email (n=8), videoconferencing (n=7), computer mediated social support groups (n=9) and multifaceted interventions (n=7). The definition of email is a message distributed by electronic means from one computer user to one or more recipients via a network. Videoconferencing is the use of a live, two-way video link between two people in different geographical areas using a computer that provides sound and vision. Computer mediated social support groups link numerous people, with common conditions/illness/diseases via a computer platform such as Facebook or a forum. The multifaceted interventions noted (n=7) looked primarily at an email intervention that also incorporated a package of tools such as email and online social support and/or email and written information.

These interventions covered a range of healthcare fields including primary care (n=5), dermatology (n= 2), diabetes (n=7), sexual health (n=1), epilepsy (n=1), smoking cessation (n=1), paediatrics (n=3), post-partum care (n=4), mental health (n=3) and cancer (n=4). They also covered a variety of geographical areas including the United States of America (USA), UK, Norway, Denmark, Korea, Finland, Australia, Europe, Sweden, Columbia, and Canada.

Both positive and negative outcomes were associated with such interventions but overall, eighty-one percent (25/31) of studies found that computer mediated forms of communication could produce positive effects when used to provide patient support. Largely the findings supported the belief that computer mediated communication could be used to support patients in the healthcare setting.

Inductive thematic analysis was applied guided by Aveyard (2014). This entailed reading and re-reading the data, as Aveyard (2014, p112) states you cannot begin to compare

studies until you have a good understanding of the content. Following this process three main themes emerged from the data. Thematic analysis involved pinpointing, examining, and recording patterns (or "themes") that emerged when reading and re-reading the data. It was evident that the aims of the interventions were to improve or provide access to health professionals, provide a more valuable service, and support better patient support.

Firstly, the interventions were trying to increase, encourage, and/or provide ways in which patients and healthcare providers could communicate with each other. This theme incorporated discussion around the ease of use, reasons for use, and patient demographics.

Secondly, the interventions were trying to provide a valuable service. Measures of value included quality measures, patient satisfaction levels, an increase in patient health outcome, and ability to complete the task. Cost saving and reduction in waste were also important. Practice environments that experienced high service demands and worked within limited resources held service value in high regard. Value for money was important but equally important were interventions that provided worth, importance, and usefulness.

Lastly, the interventions aimed to provide many types of support to patients for example informational, esteem, tangible and emotional support. Intrapersonal patient outcomes such as reduced anxiety, increasing confidence and self-efficiency were common outcomes within the literature. The following analyses the three themes common throughout the literature within each of the four intervention types.

### **Email interventions (n=8)**

In total, there were eight articles relating to email interventions all of which occurred in a community setting but covered four fields of practice, primary care (n=4) and patients living with diabetes (n=2), cancer (n=1) or epilepsy (n=1).

**Ability to access health professional.** Email was offered as a way of increasing access to healthcare professionals and meeting informational needs of patients in three

studies. Firstly, Cervenka, et al. (2012) delivered a health education program, sending on average six informational emails around diet. Their 3-month prospective cohort study, in the United States, looked at the feasibility, safety and effectiveness of an email administered modified Atkinson diet. They concluded this to be a useful method of communicating health programmes with patients.

Secondly, Bjoernes et al. (2012) aimed to meet the information needs of patients with prostate cancer via an email intervention. They found that the asynchronous nature of email meant that patients did not feel like they were disturbing anyone, that they had time to formulate questions calmly and liked the flexibility of the tool as a means of accessing healthcare at any time and that email increased communication between patients and primary care providers.

Thirdly Roter et al. (2008) showed that most of the physician communication was to accomplish information tasks, with three quarters of emails containing medical information and 10% around lifestyle topics like self-care, and one third of the physician's messages included a question. In fact, it was seen in Norway (Bergmo et al., 2005) that email could offset telephone consultations, but not office visits and that email was used for rescheduling office calls, non-urgent healthcare issues, test results or health questions. Repeat prescriptions, sick note renewal, requests for referrals also made up the lower percentages of reasons for email use.

Many outcomes were seen within the literature: Tjora et al. (2005) found that patients thought email provided easier access to primary care yet at the same time found logging into secure emailing systems awkward compared to ordinary email. Unlike Bergmo et al. (2005), who found that email intervention, did not increase access to the GP. Concerning systems, patients self-assessed security risk and preferred ordinary email. Overall, many studies supported the fact that emails from patients were not time consuming for doctors nor were

they overused (Bergmo et al., 2005; Cervenka et al., 2005; Tjora et al., 2005), however low uptake of email in general were noted at the time (Bergmo et al., 2005; Liederman & Morefield, 2003;). A quality improvement article written by a paediatrician in the UK more recently reported similar findings from an email audit conducted (Cohn, 2014).

**Value of the intervention.** Quality, satisfaction, and ability to complete a task were outcomes indicative of the value of an intervention. When assessing the quality of email intervention Harris et al. (2009) were one of three articles looking at how email could benefit diabetic patients and better glycaemic control was found. They hypothesised that email is associated with increased care quality and reduced outpatient use, however direct causation was not possible through this cross-sectional analysis.

Harris et al. (2009) added to the literature when discussing the possibility that email alone, without even using it, adds to a ‘feeling of security’. Typical verbs used within this study were ‘valuable, practical and useful and the quality felt was rated ‘good’. The literature was built upon by Turner et al. (2013), who looked at enacted social support email messages. They found enacted emotional support messages improved patient health outcomes in diabetes; this was also mirrored by Petrovski et al. (2015). Oppositely though Turner et al. (2013) state the actual message itself is important and that although email may provide a ‘sense of security’ (Harris et al. 2009) it is not just the system technology and interaction itself that produces effect, but it is content that is also important.

Concerning satisfaction, Liederman et al. (2002) asked whether email meets patient demand for online interaction. Half of the participants’ claimed email was much better than the phone and just over half of GP’s felt satisfied using email. Despite some satisfaction seen within this survey doctors in the Bjoerne et al.’s study (2012) state that it is vital for online contact to be twenty-four / seven to be of any value, adding another element to the findings.

**Support provided by the intervention.** Email intervention was found to be useful in simple and complex medical cases. Some concerns raised within the studies were that emails could make healthcare more task focused limiting the ability to have a positive effect on the relationship and rapport. Tjora et al. (2005) nevertheless found email beneficial in complex health problems with feelings of empowerment through the ability to maintain control over one's situation (Bjoernes et al., 2012). Roter et al. (2008) added to this literature when coding the content of email communication. In this instance emotional tone and rapport was evident and patients were found to speak more in email than face-to-face.

### **In summary**

Email intervention could increase access to healthcare and more specifically the asynchronous nature of text provides time to write and formulate a question/response meeting the unmet informational needs, which provides a sense of security. Positively enacted social support emails in three diabetic studies found an increased control in their blood sugar levels. Moving forward from the literature this could be applicable to other areas of practice. Furthermore, engaging with patients and encouraging use would need consideration, due to a noted underuse, as well as consideration for a twenty-four-hour email service.

### **Video conferencing (n=7)**

From the seven articles that focused on videoconferencing four fields of practice were identified including paediatrics (n=2), post-partum care (n=2), dermatology (n=2) and diabetes care (n=1).

**Ability to access health professionals.** The use of videoconferencing in the literature connected people in two ways, either providing patients at home with access to skilled professionals that are hospital based, or through connecting patients in hospital with the outside world.

Two studies that leave a positive impression of videoconferencing are Lindberg et al. (2007) and Friesen et al. (2015). In Indiana videoconferencing increased access between hospital-based lactation consultants and low-income rural families (Friesen et al., 2015). In Sweden videoconferencing linked families to hospital-based midwives to provide routine contacts (Lindberg et al., 2007). They found videoconferencing provided patients with access to a skilled professional and that services could reach a wider client base, increasing some patients' access to support (Friesen et al., 2015). Friesen et al. (2015) found videoconferencing easy to implement, more specifically it was quick to establish a connection, easy to handle and make an assessment.

More discouragingly, Gilmour et al. (1998), Lowitt et al. (1998), and then Lindberg et al. (2007) found they had poor picture and sound quality and problems controlling the camera. Despite the talk of current advances in technology, Weiss et al. (2001) and Ellis et al. (2013) raised issues relating to technology and technical issues encountered when using the equipment. Additionally, the need for training, resources and funding for staff is identified and any technical difficulties seen as disruptive in both.

**Value of the intervention.** Two studies, both conducted in 1998 that highlighted the value of videoconferencing were those of Lowitt et al. in the United States and Gilmour et al. in the United Kingdom. They both found that via a videoconferencing intervention dermatologist could successfully diagnose and treat skin conditions through viewing the necessary anatomical areas via videoconferencing. There was a greater confidence in diagnosing in face-to-face (98%) than by video (85%), but an 85% confidence was still relatively high. Reassuringly there was a high level of agreement with diagnosis (identical in 89% of cases) and management plans were correct in 72% of cases. Both studies were well designed and reported. Interestingly, videoconferencing is now becoming developed in the



UK with the invention of [www.pushdoctor.co.uk](http://www.pushdoctor.co.uk) and the value of such interventions will undoubtedly be explored and evaluated as these technologies develop further.

Professionals felt satisfied making assessments and when having contact with families (Lindberg et al. 2007) however, Lowitt et al. (1998) found no difference in patient satisfaction, unless it meant saving on travel and patients reportedly preferred face-to-face interventions. Gilmour et al. (1998) found patients to be positive about videoconferencing and found it was a valuable experience. Lowitt et al. (1998) did add to this by specifically stating that satisfaction is higher in younger generations who are more likely to accept the technology (Gilmour et al. 1998).

**Support provided by the intervention.** Rich data were gathered from two videoconferencing interventions in the paediatric settings. Weiss et al. (2001) and Ellis et al. (2013) both recognised that whilst a child is in hospital, they could become isolated from their peers and hospitalisation can be at the detriment of school attainment. The two studies collectively included four participants' in total providing in depth rich data. Both studies reported noticeable changes in behaviour such as increased concentration, greater academic progress, and increased frequency of response. Ellis et al. (2013) found that an ability to maintain relationships between peers and teachers in this instance providing a feeling of normalcy and distraction from illness reducing social isolation, increased mood and academic ability, two things also noted by Weiss et al. (2001). Compared to the telephone contact, videoconferencing can assist a deeper engagement and presence (Lindberg et al., 2007). This reduced anxiety around attending hospital and increased a mother's confidence around the birth of her baby (Friesen et al., 2015).

On a more negative note, videoconferencing was seen to require facilitation. The teachers often found themselves managing concerns raised over the child's physical

appearance, and parents were left as the go-between between the school and hospital (Ellis et al., 2013). In some cases, (18%) the camera made participants' feel uncomfortable or embarrassed (17%) (Gilmour et al., 1998).

### **In summary**

Videoconferencing has positive and negative aspects. On a positive note, videoconferencing could provide healthcare services to a wider community and link the outside world to the hospital-based patient. Patients found they were satisfied when it saved them time on travel and when they were of a younger generation. Caution is required as the technology itself may cause technical difficulty, which in turn increases workload. Videoconferencing can also cause a patient to feel uncomfortable and it was noted that, although patients had positive experiences, they did prefer face-to-face care.

### **Computer mediated social support groups (n=9)**

Computer mediated social support groups were seen to be used by patients that have diabetes (n=3), cancer (n=2), mental health issues (n=3) and in post-partum care (n=1). Three articles looked solely at online social support as a standalone intervention (Yoo et al., 2013; Oh et al., 2011 and Houston et al., 2002) and the remaining six articles talked of a combination of online social support and electronic information giving. Unlike the multi-faceted interventions, the focus of the studies was around computer mediated social support.

**Ability to access health professional.** These groups were found to be easy to access via many platforms including Facebook or webpages by many different groups of people. Any user has a choice to simply read posts written by others, dubbed as 'lurkers' or choose to add their own content if they wish, therefore dubbed as 'approachers' (Yoo et al., 2013). Yoo et al. further describes how 'approachers' would typically post around the middle of the

intervention whereas ‘lurkers’ would use avoidance coping strategies and comment at the end of the intervention highlighting different types of users.

Similarly, to the other interventions’ anonymity was again advantageous relieving anxiety and embarrassment around questions asked. Emotional support specifically was a key factor in computer mediated social support groups and a factor that predicts engagement (Yoo et al., 2013). Regarding engagement, Glasgow et al. (2003) found that engagement was greater when the ‘digital divide’ was minimal, meaning that older generation may have limited use or access to computers. Yoo et al. (2013) added that those more comfortable with computers used them more and that cessation in use occurred at around a year, indicating that interventions may have a ‘ceiling effect’, a time when they are no longer useful. Characteristically the older and more alone the person (Yoo et al., 2013), and the lower social support and close tangible support (Houston et al., 2002) the more patients engaged in online support. Like email intervention, twenty-four-hour access was felt to be an important aspect (Oh & Lee, 2012).

**Value of the intervention.** These groups were not always found to be of great value to the patient. Glasgow et al. (2003) implemented three interventions groups (access to online information, access to a tailored self-management support via an online coach, access to online social support). Overall results were uniform across all three interventions; however, the patterns of change did favour the usage of the computer mediated social support and the self-management conditions. Secondly, Shaw et al. (2007) trialled another three-point system for patients with cancer that addressed how patients learn. Unlike the positive finding of Cervenka et al. (2012), when implementing the email Atkins diet, their study only partially supported the hypothesis that information availability and interactive services were associated with higher health information competence and only partially supports their second hypothesis that interactive services may supplement and extend learning (Shaw et al., 2007).

In this instance, the use of computer mediated social support groups did not contribute to an enhanced learning outcome. Additionally, in this study the 'ask the expert' service was not related to perceived information competence (Shaw et al., 2007) whereas Cervenka et al. (2012) felt it viable through a series of emails to deliver health education materials.

Looking specifically at types of support offered through this intervention Yoo et al. (2013), despite adding to the literature around 'lurkers' and 'approachers', found that the combination of personal coach and computer mediated communication did not result in the greater emotional support being received. Statistically though, this intervention proved slightly more beneficial than the information and control conditions. Dissimilarly, Oh and Lee (2012) saw that the need was greater for informational support, followed by a need for emotional support and then esteem support.

Satisfaction was also an indicator of value. Salonen et al. (2011) set out to test the hypothesis that parents that have access to web information, computer mediated social support, and email access with a professional would have increased satisfaction and parenting self-efficacy during the post-partum period. This was not found, and no significant difference seen between group users and group non-users in parent satisfaction.

Similarly, Castillo et al. (2013) offered a package of social support, a self-management program, and electronic information for people who had suffered traumatic injuries aimed at increasing self-efficacy and patient activation with the key outcomes being to improve physical and mental health and reducing anxiety. Satisfaction was high in this study with 86% saying they would recommend the support group to a friend. Although the effects did not differ significantly between groups with respect to self-efficiency, a significant difference in rates of depression was found between treatment groups. This highlights the

potential benefit for online social support in patients with depression, something highlighted by Houston et al. (2002).

Encouragingly, Houston et al. (2002) looked at a prospective cohort study of 103 computer mediated social support group users with chronic depression and social isolation. They assessed the interactions of the computer mediated groups for depression and face-to-face depression care. Ninety-five percent of participants agreed that chatting in the online groups helped their symptoms and one-third preferred social media to face-to-face counselling. They also stated that healthcare providers knew they supplemented face-to-face sessions with the online group and that this encouraged them to ask questions. This was echoed in a study by Oh and Lee (2012) reinforcing this information. Relating this back to previous findings, receiving emotional support, having low levels of close social support, and being comfortable using a computer could have lent to these high numbers finding benefit in this intervention, thus perhaps defining the type of person that might be suited to computer mediated social support.

**Support provided by the intervention.** Empowerment, perceived support, and psychosocial support were achieved via computer mediated social support. Oh and Lee (2012) looked specifically at online support and empowerment in their observational study. Their snapshot, showing the effects of support groups over time, found that online activity positivity relates to perceived support (the more the participant used computer mediated social support the more supported they felt), the greater the perceived support the more they felt empowered and the more they felt empowered the more they spoke with the doctor.

Barrera et al. (2002) and Glasgow et al. (2003) both conducted randomised controlled trials, offering information, access to a personal coach, computer mediated social support or a combination of the latter, over a period of ten months (Glasgow et al., 2003) or three months

(Barrera et al., 2002). Both saw participants' receiving online support as the only condition that had increased perceived social support. Participants' however were novice internet users and the results may have been greater in patients who were familiar and happy using the computer as already discussed. To add to this further Oh and Lee (2012) found that the duration of group membership, frequency of visits to the group and time spent in the community all positively related to a whether a patient felt, or did not feel, supported by the group. Furthermore, posting to an online support groups facilitates an identity within the group leading to more expression over time and an increase in emotional support received (Yoo et al., 2013).

As far back as 1993, Gallienne et al. offered access to a computer mediated social support and an email intervention to caregivers of relatives with Alzheimer's disease and was well received. In this instance, psychosocial support, defined as meeting the informational/ instrumental and emotional/ spiritual support needs of a person, had a positive effect. The study itself however only referenced three interactions from the forty-seven people that had access to the site, making generalisation of the findings difficult, however Houston et al. (2002) mirror these finding strengthening the argument. They also highlighted that training for practitioners was required.

### **In Summary**

Computer mediated social support groups have produced an array of positive and neutral outcomes. The groups are easily accessible, easy to use and the patient may 'lurk' reading the posts of others or 'approach' the group and write their own posts. 'Lurking' on its own can provide much needed perceived support, however it was seen that the more a person engages and posts on the group the greater the perception of support. Again, a degree of anonymity provided comfort and that availability twenty-four hours a day was perceived as

supportive. With regards to patient outcomes, the ability to enhance learning, supplement learning or gain information competence was not found. No improvement in self-efficacy amongst new parents or trauma patients was seen.

### **Multi-faceted interventions (n=7)**

The fields of study included sexual health (n=1), cancer care (n=1), smoking cessation (n=1), post-partum care (n=1), primary care (n=1) and diabetes care (n=1).

**Ability to access healthcare professional.** Two studies implemented mobile apps to support patients. Mobile apps can be accessed by anyone via an app store making accessibility easy. For smartphone users in Columbia, Lopez et al. (2014) devised a mobile application ‘app’ that provided information around sexual and reproductive health for young adults and offered asynchronous chats with a doctor as required. Similarly, Danbjorg et al. (2015) detailed an ‘app’ available to postnatal women for 7 days following hospital discharge aiming to meet unmet information needs. Information, pre-empted automatic messages, and online chat were available. Parents in this instance liked that they could search information rather than having to resort to asking, that it was asynchronous and therefore they had time to construct questions. Parents also felt it offered an acceptable way to seek help after early discharge and felt that they did not hesitate to contact nurses as opposed to telephone contact, all of which increased access to healthcare.

**Value of the intervention.** The value of the mobile app interventions mentioned above was eclectic. On one hand well over half (74.6%) of users in the Lopez et al. study (2014) thought that in person sexual health advice was ineffective and half of the 48 participants’ thought the virtual method was ineffective. The tool itself did not influence sexual practices. Despite this half of the users felt that it could provide reassurance and that having access to the app was felt important by 92.3% of users and rated overall as ‘good’. Participants’ also enjoyed interactive links that they could watch in their own time and that

they could send pictures and receive long useful answers (Danbjorg et al., 2015) adding value to the intervention.

Positively, 'Webchoice' is another example of a multifaceted intervention program that offers a package containing email contact with a professional, computer mediated communication, online information, and a self-management program (Grimsbo et al., 2011). The aim was to meet unmet care needs of patients with cancer and look at outcome measures on a patient's symptoms, distress, self-efficiency, quality of life, social support, and depression. This study identified that patients often felt as though they were 'left hanging' between appointments and this intervention provided reassurance and information. Interestingly patients used the online patient nurse communication as a place for venting; writing of experiences and frustrations with the healthcare system and the nurses would respond and listen, responding to them personally (Grimsbo et al., 2011).

Rather than looking at the use of interventions Varsi et al. (2013) performed the first study in this review into the non-use of an intervention. They found that the information was simply available elsewhere, that patients did not have worries about security or about bothering people and did not know what they did not know so were happy and had no concerns. Computer mediated communication was not an alternative to other forms of health information and people's preference was for written or spoken forms of communication.

Elaborating further, Patten et al. (2006) and Patten et al. (2007) provide a two-sided story. Patten et al. (2006) offered smoking cessation to adolescents in the United States via an adapted 'Webchoice' program that they called CHESS aimed at 'stomping out smoking'. This intervention proved to be ineffective with no participant being abstinent from smoking at week four. They found engagement was hard and after just three weeks less than one third accessed the site. This was raised earlier by Yoo et al. (2013) demonstrating that each intervention has a possible 'ceiling effect'. They found that when people felt they would no



longer benefit then they promptly ceased use and again a ‘ceiling’ to use was noted. The difference between this study and Grimsbo et al. (2011) was that the information was not tailored to the participant. This could have been the result of a comparison being made between this and a face-to-face consultation which did provide tailored information. Patten et al. (2007) then looked at this study but more directly at the frequency and type of use of the different components of CHES. They found that females were more likely to utilize this intervention, with the interactive part being the most used. To add to this further the computer mediated social support group was the most used part of the intervention and the ‘ask a professional’ and discussion board used least of all.

Lastly, a randomised controlled trial carried out in Canada (2012), which supported people with diabetes (Pacaud et al., 2012), offered synchronous and asynchronous communication via email, online information, and online social support. By looking directly at diabetic control of blood sugar levels, they found the intervention to have little impact on blood glucose control. However, there were statistically significant correlations between the website users and improved knowledge, self-care, and self-efficacy.

**Support provided by the intervention.** As noted above providing health information via an app is one way of providing timely information that can provide a feeling of control support and reassurance (Danbjorg et al., 2015). Caution is required to ensure the messages do not cause anxiety (Varsi et al., 2013). A concern around online education is that when people know more, they could worry more, and what they do not know cannot cause worry. Ethically the application should aim to do no harm. The intervention provided the feeling of having a ‘lifeline’, being in control with a sense of security and Independence (Danbjorg et al., 2015). Danbjorg et al. (2015) talks of achieving mastery through experience, which strengthens parental self-efficiency.

**In Summary**

Comparing multifaceted intervention was problematic due to the variations between interventions; however, common themes did emerge from the data. Optimistically, people again liked the asynchronous aspects that allowed them to write their story. They liked to share pictures and messages. Many of the interventions provided a sense of security and reassurance despite the interventions proving ineffective for example in smoking cessation and in the post-partum care. Increased self-efficacy was not evident and engagement was difficult. In one study into non-use of the intervention, it was clear that people either did not feel they needed to use the intervention, or they had access to information and support elsewhere and tailored information is required.

**Discussion**

The aim of this study was to explore how computer mediated communication has been used in the healthcare setting to support patients and discuss the implication that this may have for future practice. What was found was that healthcare is changing and that new ways of delivering care were much needed. Historically people sought healthcare advice or information face to face. Nowadays the increased availability of various forms of computers and other devices such as phones, tablets, and laptops meaning greater access to advice and information. Consumerism, control of healthcare costs, increasing demand on healthcare and shorter stays in hospital has also led to scattered interventions and less personalised care. All the above has led to a redefining of the relationship between healthcare provider and patient.

This systematized review provided details of 31 empirical studies that use a range of computer mediated support interventions including Email, videoconferencing, online social support groups, and multifaceted interventions. These show a positive effect overall on a patient's access to services, the value of the healthcare offered and health outcomes. Linking

this back to the thesis aims, only one article was found relating directly to the use of computer mediated communication in breastfeeding support (Friesen et al., 2015), highlighting a need for more research in this area.

The research is leading us to believe that computer technology could be both what patients want and a way of delivering healthcare to meet the patients' needs. The uniqueness of computer mediated communication has led to a steady increase in the popularity of computer mediated social support groups (White & Dorman, 2001) for example, and there are many similarities between the interventions that will be discussed further.

Email and computer mediated social support groups are both text-based and written asynchronously with or without anonymity. The patients have time to tell their story, at their own speed and think about what they are writing from the comfort of their own home. A degree of anonymity is advantageous in all intervention types so is a leading point to note moving forward especially if new interventions do not allow for this.

There are also similarities between videoconferencing and social media. Videoconferencing is now possible through many social media platforms and users can send pictures to share and enhance written word or perform 'live-chats'. It is worth noting that even until recently concerns around quality of image and sound were seen. The literature highlights that younger generations are more comfortable with this form of technology, which is promising as breastfeeding mothers, women of child bearing age, do fit this demographic. For this reason computer mediated communication interventions may also be beneficial for specific groups of breastfeeding mothers known to have lower rates of breastfeeding for example teenage mothers (Wambach et al., 2011), mothers with lower literacy (Rahman et al., 2012), or mother of lower socio-economic status (Fatunde et al., 2017).

These interventions could provide an alternative to written text in a form that is easily accessible to them. Video, like computer mediated social support, has the advantage of connecting people from around the world boasting no travel costs and at very little expense. Findings suggest patients were satisfied with video interventions when it saved them time on travel. It is plausible that a breastfeeding assessment could be completed in this way, given the positive results found in Tele-dermatology to view and observe the patient in some detail. Noted in the literature was concern that video interventions can cause anxiety, unease or embarrassment and a realisation that although video was welcomed patients did prefer face-to-face contact. This again highlights a need for more research in this area.

Similarly, the multifaceted approaches, using other elements of email and computer mediated social support groups, shared advantages. Social media was beneficial, like email and the multifaceted interventions, in meeting unmet informational needs and the esteem needs of parents. The benefits of these interventions are seen within the tailored information response and not seen in general information giving. Patients did like to search information alone, watching and re-watching useful videos. This has implications for practice when posting breastfeeding information that was not prompted for and sharing links and videos that were not requested. Oppositely, the multifaceted apps were used to foster a sense of empowerment and mastery around their situation helping to build confidence and reduce anxiety thus being considered as valuable but with careful consideration.

Such considerations include practitioners being mindful that their tool is easy to use, and that training and supervision is provided. Interventions must be assessed carefully to prevent waste of resources or cause harm. The literature has shown how information giving alone can prove ineffective and automatic messages can raise anxieties. The professional must think about whether the informational part of the intervention could be achieved more easily elsewhere, whether patients would prefer to seek information elsewhere and whether

the best information is provided. Computer mediated communication is demonstrated as being able to provide timely, appropriate, and efficient care to families. However, training, and additional resources are required and although computer mediated communication offers a more flexible approach it is noted that the most effective interventions are available twenty-four-seven.

Additionally, it must be noted that in many studies uptake of the interventions was low and that a 'ceiling' of use observed. When the patient deemed the intervention no longer helpful, they disengaged. If implementing a computer mediated support intervention, a plan for promoting usage would be beneficial and thought put into how the intervention will be promoted and encouraged to prevent low uptake.

Only two of the 31 articles looked at non-use of an available intervention. It was noted that in many cases people either thought they did not need support or information or had access to support and information elsewhere. The implication of this for practice is that the benefits of any interventions moving forward need to be stated and clear so that the patients know what is on offer and what they are likely to achieve from it.

Moving forward research conducted in this area would benefit from careful consideration of the types of support on offer and the desired outcome. Matching specific support types, such as emotional support, tangible support, esteem support (House, 1981), to specific outcomes, such as self-efficacy or confidence for example, would add further clarity to the benefits of any intervention. From this review other outcomes have been explored and should be considered such as self-efficacy, empowerment, and levels of perceived social support. The need to define the different types of support using a social science model and applying these as outcome measures to provide depth to the research that is currently lacking when moving forward.

**Study Limitations**

The limitations of this systematized review are that all the interventions were quite unique and different in structure, practice area and participants', making comparability difficult. The review also excluded articles that were not written in English or that were not available via the online databases.

**Conclusion**

This review has highlighted some key thinking points for nurses, midwives and allied health professionals who are, or may be thinking about developing, using, or advising patients' use of computer mediated forms of communication interventions in order to better support their patients. Computer mediated communication is timely, accessible and an exciting prospect too many nurses in the current resource tight environment. Reviewing the lessons learnt from previous support interventions will ensure that such interventions are tailored to the specific needs of the patients, well thought out, carefully planned and limit potential risks.

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## Appendix A, Search String Development

Initial search string run through CINAHL (accessed on 25.3.16) Producing 313 citations is detailed in Table A1.

**Table A1***Initial search string*

String	Search string
1	"social media" OR internet OR "mobile applications"
2	support* OR "Social support" OR "Practical support" OR "emotional support" OR "psychological support"
3	Patients OR "service user" OR clients
4	"Healthcare" OR "secondary care" OR "Health services" OR "primary care"

As the focus of the study was to look at communication it was then decided that the term 'communication' needed to be added within string number one to ensure all citations were gathered, as detailed in Table A2.

**Table A2***Second search string*

String	Search string
1	"electronic communication" OR "social media"
2	support* OR "Social support" OR "Practical support" OR "emotional support" OR "psychological support"
3	Patients OR "service user" OR clients
4	"Healthcare" OR "secondary care" OR "Health services" OR "primary care"

Using the strings, noted above, these search terms were then run through CINAHL, OVID, MEDLINE, ASSIA, and Web of Science, and the resulting number of articles recorded (Table A3).

**Table A3***Data base searches*

String	1	2	3	4	1+2	1+4	1+2+3	1+2+3+4
Cinahl	1,033	50,459	148,219	45,488	74	56	19	4
Ovid (Medline,BMJ)	3595	10998	11467	8675	1508	598	303	117
Assia	515	89869	112635	1078	228	62	80	32
Web of science	37243	8,185,783	16,753,637	1,183,816	3,057	9,454	512	147

After discussion with the university librarian, some further changes were made to the search strings to ensure maximum results through the operators (Table A4).

**Table A4***Third search strings*

String	Search string
1	("electronic communication" OR "social media" OR "computer mediated communication" OR "social networking" OR "online communication")
2	Support
3	Patients OR "service user" OR clients
4	("healthcare" OR "secondary care" OR "health services" OR "primary care" OR "health care" OR physicians OR nurses OR doctors)

Running the search strings from Table A4 through the previous search engines and Assia, BNI, Psychinfo, produced the final results, as seen in Table A5.



**Table A5***Second recorded data base search*

	String 1	String 2	String 3	String 4	String 1+3	String 1+2	String 1+4	String 1+2+3	String 1+2+4	String 1+2+3 +4
Cinahl	368595	183678	576299	689203	942723	494	1236	91	105	51
Medline	5476	7977163	4133650	967635	854	2527	1218	455	555	255
Assia	974	720678	92385	109763	112	191	236	27	62	15
BNI	680	24398	79076	133307	205	162	434	65	97	47
Psychinfo	14570	373937	594310	210126	976	2503	948	235	254	115
Web of Science	65473	7818317	13113130	3123702	1975	9965	5065	541	778	306

## Chapter Three: Online social support group use by breastfeeding mothers: A Content Analysis

### Abstract

**Background:** Breastfeeding is a public health priority and lack of breastfeeding support a contributing factor to the low initiation and continuation rates in the UK. Online social support groups are being increasingly utilised by breastfeeding mothers and research into this phenomenon is only now emerging.

**Aim:** To document and describe the posts made within an online breastfeeding support group.

**Method:** The posts made to an online breastfeeding social support group between 1st -7th November 2016 were recorded using an unobtrusive non-participant design, and subject to systematic message content analysis. Themes relating to topics of discussion were deduced from the data and concepts of social support used to analyse the data.

**Results:** The group received 501 posts over the week ( $m=72$ , range 20-93 a day) and was accessed 24 hours a day. Eighty-two percent of posts received comments ( $m=12$ , range 0-415,  $SD=24$ ) and 93% received likes ( $m=11$ , range=0-641,  $SD 42$ ). The group was used from pregnancy and until the child was over two years old. The majority of infants discussed were aged 6 weeks to 6 months. Informational support was the greatest reason for use (65%), followed by esteem support (18%) and emotional support (10%). Thirteen topics of conversations were identified.

**Conclusion:** Mothers are using online social support groups in their thousands to seek information from people in similar situations. Not only do they pose questions, but they discuss a range of parenting and breastfeeding topics in an environment that aims to support and facilitate responses. The impact of this support avenue within the wider context of

professional, family, and offline support warrants further investigation through a qualitative approach.

## Introduction

Globally, breastfeeding has long been regarded as a public health priority due to the benefits for mothers and babies (UNICEF, 2017b; WHO, 1981). In the United Kingdom (UK) exclusive breastfeeding rates are some of the lowest in the world, with 24% of mothers exclusively breastfeeding at 6 weeks and only 1% at six months (Infant Feeding Survey, 2010). Positively, the implementation of the UNICEF baby friendly initiative into national and local policy has coincided with an increase in breastfeeding rates to 55% at six weeks (rising from 48% in 2005) and 34% at six months (rising from 25% in 2005) (Health and Social Care Information Centre, 2012). Such initiatives are based on a large body of evidence around breastfeeding support, promotion, and protection.

Despite current government policy around Infant Feeding (Department of Health (DH), 2009; Public Health England, 2013; Public Health England & UNICEF, 2017a; UNICEF, 2017b), breastfeeding rates remain low and lack of support is noted as a contributing factor (Victora, Bahl, Barros, Franca, Horton, Krusevec, Murch, Snakar, Walker & Rollins, 2016). Breastfeeding support is also impacted by the closure of Sure Start Children Centres, which provided breastfeeding support groups across England, and infant feeding lead roles across NHS services in England, which provide a focus on infant nutrition in policy and practice, due to restrictions in government spending (UNICEF, 2017a). The conversation around breastfeeding rates is now moving away from the emphasis on a mothers choices and acknowledging the public health imperative for which government, policy makers, communities and families all share responsibility (UNICEF, 2017b). Professional breastfeeding support, noted in the policies above, place emphasis on a biomedical model of professional training and support. This leaves peer support falling mainly to the voluntary and charity sectors such as the Association of Breastfeeding Mothers, Le Leche League or smaller local charities. However, mothers are increasing forming their own peer led groups online.

These online social support groups are increasingly being utilised as a way of sharing and interacting with others with similar experiences, irrespective of geographical location.

A site search of [www.Facebook.com](http://www.Facebook.com) (see Appendix A for site search results) showed on average 60,000 breastfeeding support groups available in a given month (average taken from 5 consecutive months July-November 2016), with one group boasting 20,000 members and approximately 177 posts a day. To help explain this phenomenon, the Office of National Statistics (ONS, 2016) shows that the internet usage of adults doubled between 2006-2016, searching for health related information was one of the top five reasons for use, and the largest internet activity for people aged 16-44 was browsing Facebook. This increasing availability of the internet, home computers, mobile phones and tablet technologies means quick easy access to others in similar situations.

Online breastfeeding support is only now emerging within the literature (Alianmoghaddam, Phibbs & Benn, 2018; Bridges, 2016; Brockwel, Benzies & Hayden, 2017; Jin, Phua & Lee, 2015; Victora et al., 2016), and for that reason is still not present in systematic reviews looking at interventions to support breastfeeding. A review of the literature into the use of computer mediated communication in patient support (Wagg, Callanan & Hassett, 2017; Chapter 2) identified many professionals beginning to use online social support groups to support their patients. This includes diabetes care (Glasgow et al., 2003), post-partum care (Salonen et al., 2011), oncology (Shaw et al., 2007) and mental health (Castillo et al., 2013). The aim of this research is to explore the use of online, peer led, social support groups by breastfeeding mothers. To achieve this, the theory around social support is explored.

## **Background to social support theory**

Social support is a term that describes a variety of different pathways linking the involvements of social relationships to wellbeing (Cohen & McCay, 1984), and is well documented as being able to reduce mental health issues, work related stress, and increasing a person's resilience (Antonucci, 1986; Antonucci & Jackson, 1990; House, 1981; House & Khan, 1985). The most basic of the social support models describes how when a person is faced with a stressor they turn to their social networks and close relational partners with whom they talk about their problems and are offered emotional, informational, instrumental and esteem support (House, 1981). Berkman and Glass (2000) stated that seminal theories have provided richness, understanding and a rigorous attempt to define the critical domains of social support, that are still used today.

Group support, however, occurs within a context. A collective context can help individuals coordinate actions and meaning all within communal norms. Social network theories, from Hymes (1972) through to Parks (2007), describe how groups share the same language, which is used to accomplish social purposes. For example, we tolerate different kinds of support from different people in different settings and a degree of reciprocity is part of the communal rules.

Despite the potential benefits to online social support groups, these groups may not be supportive to all that use them. Harris (1992) added that when expectations of support from others may be strong, the failure to receive support can be devastating. When advertising a group as supportive caution is required, as those that do not find support through the group may be disappointed. Additionally, online use may expose the user to cyberbullying, online harassment and abusive online comments (Thurlow, Lengel & Tomic, 2007). The negative aspects to group use require further investigation (Barlett & Chamberlin, 2017), however this is not the focus of this study.

## **Study aims**

During clinical practice, when auditing mother's experiences of breastfeeding support, it was evident that many mothers were turning to online support groups, intervention also noted in the literature review in Chapter Two. This created a professional curiosity and when realising the amount of breastfeeding support groups on Facebook alone, it was decided that this was worthy of further research. To explore the overarching research questions: 'how do women use Facebook for breastfeeding support', this study specifically aims to describe and document the use of an online breastfeeding support groups to provide an insight into the group activity. This research seeks to answer specific questions such as: when do mothers use online groups, are the groups utilised day and night, where are the mothers from, and how old are their children?

The second overarching research question asked: Why do women use Facebook groups for breastfeeding support? This research aims to provide a greater understanding of the support needs of breastfeeding mothers by exploring the types of support requested and common discourses discussed. More specifically the research questions were: What do mothers talk about in the groups, what type of support do they seek, do the groups provide an avenue in which the mother can tell her story or simply ask quick questions, is it useful in the early weeks of breastfeeding or used for longer periods of time?

The fifth overarching research question asked: What do the professionals, who support breastfeeding women, need to know about online social support? It is the intent of this exploration to provide those supporting breastfeeding mothers with an insight into this phenomenon for further consideration in practice.

## Method

### Design and data collection

Online support groups, that support breastfeeding mothers, already exist in large quantities on many social media platforms. By way of illustration, on Facebook.com data is readily and freely available for viewing and sits within the public domain. For this reason, the study assumes an ontological approach that the phenomenon already exists and is measurable to some degree. The research questions sit within the positivist paradigm and includes variables such as the frequency of posts. Verbatim text is also explored, categorised, and then quantified. Due to the research question being to describe and document the online group and given the philosophical position the research lends itself well to a content analysis.

Content analysis as a way of establishing categories and system linkage between the categories (Silverman, 2013). The benefits of content analysis could be applied to all kinds of written text, pictures, videos, and the manifest content of text e.g. the countable composites of the text and substantive features. In this instance it was chosen to explore the types and number of themes identified in the text (Silverman, 2013). The frequent ideas in text offer uncontained interpretation based solely on the assumption that frequency means something (Krippendorff & Bock, 2009). Krippendorff and Bock (2009) also state that content analysis is appropriate for the dynamic communication environment of the web, however care must be given to not oversimplify and overgeneralise.

A large, UK based, online breastfeeding support group, through Facebook.com was chosen for data collection. The group was chosen for its freely available information, active engagement levels, lack of affiliation to any medical professionals, and because it was peer led. The page boasted more than 8000 members, was moderated by volunteer breastfeeding



mothers who agreed to the study being undertaken and had a strong set of group rules stating the need for all members to ensure a supportive community.

Data was collected between the 1st and 7th November 2016 and all posts made within this time was collected as a unit of data and included for analysis. Data were collected unobtrusively using a non-participant design to maintain ecological validity and to avoid damaging the community by raising suspicion and disrupting the dynamic within the group (Hewson, Vogel & Laurent, 2016).

### **Ethics**

Internet text-based communication has opened a whole new field for ethnographic investigation of textual data, including chat rooms and email correspondence (Silverman, 2013). University ethical approval was obtained, and care was taken to anonymise the data by removing all names and applying unit numbers to the posts. Care was taken so that no data could be traced back to the original source, as although information is freely available the online members retain an expectation of privacy.

Methodologically, care is given to disclose the findings in full and to not misinterpret the data. Positively harvesting data online can produce rich linguistic data, from a diverse sample and responses are non-biased and straight from the source. Data collection such as this is increasingly becoming popular, acceptable, and justifiable through online platforms (Hewson et al., 2016).

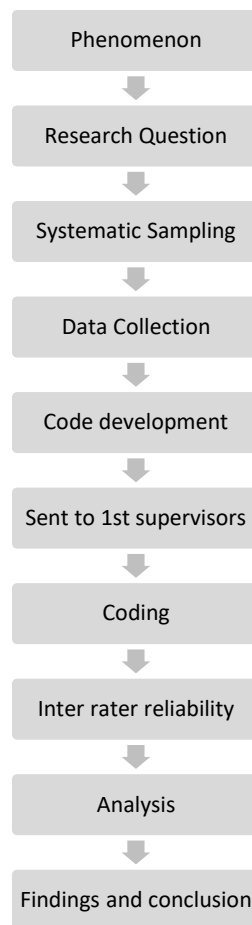
### **Data Analysis**

The data collected was subject to systematic message content analysis (Figure 1) and used as a research design and method of analysis. Firstly, a single coder collated the presence or absence of variables within each unit of data including date, time, location, word count, infant's age, presence of visual content (videos, poems, inspirational quotes, and pictures),

and presence of a shared link, to provide an overview of how the page is used. This was all recorded in an excel spreadsheet and unit numbers assigned to each post, a sample of the data spread sheet can be seen in Appendix B. Secondly, to explore the support needs of the mothers, social support theory was utilised, guided by House (1981).

### Figure 1

*Systematic message content analysis.*



House (1981) categorised four social support types; emotional, informational, tangible and esteem support, and the framework continues to be used in recent literature (Grassley, 2010). For each unit of data, a support code was applied, and to provide rigour an ‘other’ box was added to allow for any other emerging elements to be captured (Breakwell et al., 2006) (see Appendix B, data spreadsheet). The support definitions and examples from the data are

contained within the code book which is detailed in Appendix C. Rose, Spinks, Canhoto (2015) state a code book provides classification rules and definitions and examples, used by the coder, when assigning codes to the data, and ensures that systematic and replicable coding of the data. Each category is exhaustive and mutually exclusive.

Prior to coding, a coding form and the code book were sent to the research supervisor who piloted a selection of units (n=51) to ensure rigour of definition and usability of the code book. Differences in application/ interpretation of terms were discussed between researchers' before commencing full data analysis, as recommended by Neuendorf (2017). In this instance over 10% (n=51) of the data was rated by a second rater and interrater reliability was 96%. The coding scheme was then finalised, and coding began on all 501 units of data. Lastly, deductive thematic analysis was applied to deduce from reading and rereading the data, any common topics discussed. Each discussion point was assigned an arbitrary code so that the frequency could be observed, and an 'other' box was included so that all the data was captured. The theme descriptors and examples can be seen in Appendix D.

## **Findings**

### **Page activity**

Over the seven days, 501 self-authored posts were uploaded to the breastfeeding support group with an average of 72 posts a day (range=20-93 posts a day). When choosing a UK titled page, there is an assumption that the users are from the UK. In fact, only thirty two percent of the 501 posts contained a location (n=162), and a wide spread of people across the UK were noted. There were two mothers identified that posted from outside of the UK from Spain and the United States of America. The largest geographical area represented was London, however this location was only noted in 14 of the 501 posts. Looking at the age of the children being discussed, 284 of the 501 posts (56.69%) provided an age, 217 did not

(43.31%), and 12 women stated they were pregnant. The average age of the child being discussed was 35 weeks old (range= 0-156 weeks). The age categories were grouped together in line with the UK breastfeeding data collection; 0-6 weeks, 7-26 weeks, 27-52 weeks, 1-2 years and then 2 and over. When grouped by frequency most infants discussed (n=105/284) were within the 7-26-week category, accounting for 37% of posts.

With regards to page activity it was clear that posts were made throughout the day and night (range=2-44 posts an hour) with a trend line showing an increase in frequency throughout the day and the highest frequency of posts at eight pm. To elaborate the text, twenty five percent (n=127) of posts contained a picture or video whereas 74.6% (n=374) did not. All pictures or videos shared were of mother's breastfeeding their infants. These posts were often used to pose questions to the group for instance "*Why is he doing this? [Video of an infant feeding at the breast]*" (#47), "*my lg [little girl] is struggling so much... any advice [video of infant feeding at the breast]*" (#45). Some posts attached a picture and stated, "*pic for attention]*" (#118).

In respect to the page activity the following question was asked 'do mothers ask quick questions or do they write long posts in which they tell a story'? To begin to answer this question the word count was explored and was variable (range= 0-440 words, m=55, SD=46.49). Sixty-six percent (n=331) of posts were long posts and forty percent (n=170) were short posts. A short post is defined as 140 characters (28 words) or less, similar to the characters allowed within a standard text message, and a large post was 141 characters (29 or greater words). The ratio of word count to character count was agreed from the analysis of 10 random posts (m=4.9). The largest post contained 440 words and was a request for information regarding re-establishing milk supply. In contrast, there were fourteen posts that contained no words, instead only a picture or link to an online resource was shared.

Alternatively looking at the reaction to the posts, the 'comments' and 'likes' to each post

were quantified. Eighty three percent of posts received comments (n=415) and 93% received 'likes' (n=466). An average of 12 comments (range=0-415, SD=24), and 11 likes (range=0-641, SD=42) were observed. The post with the greatest amount of comments (n=415) was one asking for group opinion relating to breastfeeding school aged children (#162), of which the comments were pro-breastfeeding. The post with the greatest number of likes (n=641) was a mother who shared professional breastfeeding pictures (#462). However, 86/501 posts (17.2%) received no comments and 35/501 (7%) of posts received no likes or comments.

### **Support type requested**

Analysis showed that 65.3% (n=330) of posts were for informational support, 18.2% (n=92) were relating to esteem support, 10.1% (n=51) for emotional support. Five percent of posts (n=25) were added to the 'other category' and only 2.7% of posts requested tangible support (n=7) with requests for administration assistance to add group members making the majority of these posts.

Typical informational posts included questions such as *"does anyone own the \* breast pump, is it any good or worth the money?"* (#2), or *"where can I buy an amber anklet from please"* (#26). The posts often stated, *"Quick question!"* (#35), *"ladies I need your help"* (#37) *"Hi I have a question"* (#38). Additionally, mothers were seen to post questions whilst waiting for specialist advice, an example being *"I've contacted an IBCLC waiting for a reply therefore I am wondering..."* (#50) or whilst in hospital *"any advice. Had my baby just before lunch... he has no idea how to latch. The midwives have recommended..."* (#159). They also use the site to ask medical questions e.g. *"Can I take these [Picture of high strength effervescence vitamin C tablets] it just says contact a doctor or pharmacist"* (#239), in which instance other's shared their experiences and directed her to a reputable source of information, in this instance the 'Breastfeeding Network' website. Esteem support posts were often easily identifiable, for instance *"no advice guys, just purely moral support"*

(#332). Thirty-three posts referred to how proud the mother was of her breastfeeding journey and nine posts referenced a social media trend which involved awarding mothers at different stages of breastfeeding. Appreciation was also expressed “*thank you ladies. I did \* as advise*” (#449), and “*thank you all you lovely ladies for your daily posts that help me get through tough times*” (#438). The greatest frequency of pictures was found within the esteem support posts (n=56), closely followed by the informational posts (n=51) and a statistical significance observed (Chi square= 62).

Thirdly, emotional support posts were seen and highlighted in the following; “*I think I’m at breaking point*” (#344), “*feeling miserable*” (#362), “*want to cry*” (#356), “*please tell me it’s normal to have days when you feel like this (crying emoji)*” (#377). One mother referred to her feelings as ‘a mother’s guilt’ (#376) and others stated, “*I’m feeling completely overwhelmed... just want to talk to someone*” (#362). The reason for the emotional post was clearly documented in all cases and included being upset by family members or professionals. One mother who wrote “*OK so I’m left feeling... awful [concerning poor weight gain in her infant]*” (#364) after a health visitor had recommended a human milk substitute and illustrated their text with three angry emoji’s (#247). Several other types of posts were also seen (n=25), such as posts that shared personal experiences aimed at normalising breastfeeding and the everyday challenges of breastfeeding, seen through a post explaining obscure places or in seemingly unusual positions. Some of which were intended to be humorous illustrated through laughing emoji’s or emotional through the sharing of poetry or memes (pictures videos or text, typically humorous that are copied and spread across the internet).

### **Topics of discussion**

Thirteen main topics of discussion were deduced from the data and included, in descending order with posts not relating to breastfeeding being the largest group (n=66).

Following this were posts relating to the mothers' health (n=63), effective feeding (n=60), the breastfeeding journey (n=53), expressing milk (n=49), the infants' health (n=40), breastfeeding at night (n=38), introducing solid foods (n=19), medications in human milk (n=16), breastfeeding whilst out and about (n=15), human milk substitutes (n=5), and group administration (n=6). And an 'other' category (topic 13) was added and contained 45 posts to ensure all topics of discussion were captured. These topics will be discussed below in more detail.

Topic one highlighted the non-breastfeeding related posts and discussed topics such as advent calendars, amber anklets for teething, visiting a dentist, and pregnancy. Secondly, the mother's health category covered posts regarding pain in the breast and/or the nipple. Effective breastfeeding (topic three) saw the sharing of pictures, videos, links, or videos to pose questions such as *"why is my baby doing this [Video of infant crying and fussing at the breast]"* (#47). Others asked questions such as *"my little boy is \*weeks old, he hasn't been latching quite right and it is making me sore"* (#147). Posts around babies' stools, weight gain, the use of dummies/pacifiers, and feeding patterns were all common here. The majority of posts that discussed the mothers' breastfeeding journey (topic four) fell under the category of esteem support and talked of how happy and proud they were to have reached a milestone, such as *"so proud of us both"* (#472), *"so proud to be sporting golden boobs [with reference to the social media awards]"* (#493). Words of reassurance were also posted *"YOU CAN DO THIS"* (#412) along with appraisals of their journey such as *"I really never expected to go this long"* (#267)

Topic five was categorised as expressing milk. Posts relating to expressing milk included breast pumps recommendations, reusing expressed milk, how to feed expressed milk, expressing milk when returning to work, and questions around how much expressed milk to feed the infant. Emotional posts were seen within this topic for example *"I feel like*

*I'm going mad!! or "Pumping is such a struggle but I need some expressed"* (#333) as well as posts of excitement *"Excited to make... breast milk ice lollies (clapping emoji)"* (#463). Infant health (n=45) was highlighted within the data and included *"Sticky, stringy slightly lumpy mustard coloured stool... can this be normal"?*(#10), *"On average how many wet nappies do you change in a day?"* (#15) and medical conditions such as cow's milk protein allergy, reflux and remedies for conjunctivitis were also seen. Whereas the posts regarding breastfeeding at night typically included sleeping positions, bed sharing, co-sleeping, as well as humorous posts about being unable to move because the baby will wake. Introducing solid foods was discussed in 19 posts. Direct questions such as *"When did you all start weaning?"* (#36) were seen, as well as emotional posts around introducing solids foods before the recommended age of six months *"sorry... but I needed to get that off my chest [Nine angry emoji]"* (#365). This post criticised another's choice to introduce solid foods before the recommended age of 6 months and generated 49 comments. This is one example of how the group may not be entirely supportive. Conflicts and online judgemental comments made by group members are not within the remit of this research, however such posts do warrant further investigation.

Topic nine saw mother's requests for informational support around medications in human milk. Seen were posts relating to hay fever medication, relieving sinus pain, contraception, treating dehydration, cold remedies and even how safe it was to breastfeed whilst taking strong prescription pain killers. People again shared their experiences and directed others to reputable websites for further information. Whereas, topic 10 included discussion and celebration around breastfeeding whilst out and about included *"I just did it- just nursed in public place"* (#481), another post read *"I breastfed on \*... my biggest audience to date"* (#465).



The last two identified groups were administrative tasks and human milk substitutes. A small percentage of posts were requests for the group administrators to add other members and another small group was around human milk substitutes. One post was a mother's reflection upon something that she had seen and disagreed with that made her feel angry "*she made her formula bottle with water from the tap (angry face emoji)*" (#441), implying that the mother had endangered her baby. This also provides another case where group members may be critical of each other. Other posts were seen relating to the sale of milk substitutes and posed questions related to the laws around the sale of breastmilk substitutes. Lastly, the 'other category' were breastfeeding related posts that failed to fall into one of the other categories already described (n=47). These posts included worries about letting the family look after their breastfed child, articles they had read in magazines, comments about others, including "*Why are people so uneducated about breastfeeding [5x crying emoji]*" (#331). Only one post was seen where a mother requested information about her local area for example "*anyone know of a good BF [Breastfeeding] groups in \**" (#247).

## **Discussion**

### **A need for support**

Social relationships and activities are arguably one of the most important areas of life (Bowling, 1995, Bowling & Windsor, 2001). When a woman is pregnant, births her infant, and chooses to breastfeed, her body experiences significant changes. These changes will arguably be a stressful life event, and the entire process of childbearing has long been conceptualised as a period of change, anxiety, and adaptation where the woman is not in control of her body (Borders et al., 2013; Hanford, 1968; Hobfoll, 1986; Levy & McGee, 1975; Leifer, 1977), hence she will seek support. At times there may be intimate encounters with professionals, as well as possible discomfort if breastfeeding challenges arise. Likewise, there may be feelings of pleasure and happiness due to a release of oxytocin (Bartz et al.,

2010). These online communities provide an environment for women to interact, share experiences and support each other through the possible positive and negative aspects of breastfeeding. Moreover, it has been noted that individuals identify and socialise with others who are like themselves (Neal, 2013).

This study draws awareness to the fact that many breastfeeding mothers are participating in online communities, such as those on Facebook, to support their breastfeeding journey. There is an assumption that a group titled 'breastfeeding support' does provide support. This study, through documenting and describing the use of the group goes part way in looking for evidence of this.

### **Page activity**

It is seen through this study that social media does provide an avenue in which to request support, at any time of the day, with no geographical boundaries. This study saw that, despite the group being titled as a breastfeeding support group, the largest topic group related to posts that were non-breastfeeding related. Previous studies have found benefit in online groups due to fact that they are available 24 hours a day (Lee, 2010). The literature states that simply having access to such groups could provide a sense of self-identity which could provide a feeling of worth and external validation (Yoo, Chih, Kwon, Yang, Cho, McLaughlin & Gustafson, 2013). This study saw mothers thanking each other for the informational support they were receiving (#449, #438). Additionally, mothers can tell their story, share pictures and videos, links, poems, inspiration words, questions, and thoughts with their peers. Previous studies have shown that clinical decisions around complex skin conditions and soft tissue injury can be effectively made through videoconferencing and photographs (Gilmour, Campbell, Loane, Esmail, Griffiths, Roland & Wooton, 1998; Lowitt, Kessler, Kauffman, Hopper, Siegel & Burnett, 1998; Vandepol, Jones, Fleeger, De Vries & Burns, 2013). With digital photography available on even the basic models of smartphones,

sharing videos and pictures could be both feasible and effective in supporting breastfeeding online.

A strong set of group rules, identifying the communal norms and social identity for the group is seen. Positively these rules focused on the promotion, protection and support of breastfeeding, which happens to be in line with the strategic and national breastfeeding aims such as those by the Department of Health (2009), Public Health England (2013), and the Public Health England and UNICEF (2016). This community, and its group rules, provides a space for likeminded mothers to come together the following comment illustrates *this “I just wondered about people’s opinion on here as I’m sure they are extremely different, I can’t really post on my profile” (#483)*. For this mother, the breastfeeding support group was somewhere she could write something that she would not put on her own Facebook page.

Although not the remit of this study, judgemental posts were seen within the data around early weaning and preparing a bottle, despite the presence of strong group rules. More research is required to look at the impact of these, as well as the group and individual’s management of such comments.

### **Support needs of mothers**

This study found that most posts were to seek informational support. In recent studies, Facebook has been found to be a useful way to share breastfeeding information amongst women (Jin, Phua & Lee, 2015; Tomfohrde & Reinke, 2016). Whereas older studies have found that the giving of emotional support and expressing feelings has been the biggest reasons for using breastfeeding forums (Cowle, Hill & Robinson, 2011). This study saw esteem support closely followed requests for informational support. This category of support contained the greatest number of pictures and topics of discussion included the mother’s breastfeeding journey and breastfeeding accomplishments. Overall emotional support

accounted for only 10% of posts with a smaller percentage of requests for tangible support identified. Most of this category was for administrative group assistance.

Additionally, this study found that the largest category, for the child's age at time of posting, was between seven weeks and six months of age. In practice this coincides with a gap in routine health services, a time when the health visiting services offers no routine service and the midwifery service is no longer involved. Although causation cannot be implied there is a correlation seen.

Lastly, this study found that the group also provides a platform in which to normalise breastfeeding. Leahy-Warren, Creedon, O'Mahony, and Mulcahy (2017) found that facilitating a sense of normalcy for breastfeeding women at individual, community and societal levels was essential in promoting breastfeeding. The online support group provides a platform in which to achieve this.

### **Study limitations**

The aim of this study was to document and describe the use of an online breastfeeding support group however this study does not look at the quality of the information being provided, or the effects of receiving support online. This study does not examine the mother's satisfaction with the support offered, or the negative effects attributed to its use. As a method, content analysis can be applied to the dynamic communication environment of the web if care is taken not to oversimplify, and generalizability is questioned (Krippendorf & Bock, 2009). Current findings indicate that mothers use the page, for the most part, to request information. In some post's questions were short and clear, however, a mother may post a question to bolster her self-esteem indirectly. For example, a mother may already know the answer to the question but would like the reassurance from the group that she has made the right decision, affecting the results.

The positive and negative impact of such an intervention is also not explored, and further research into the perceived value of online groups would add to this area of study. There is always a wider context, each woman will have differing levels of tangible support, varying levels of support from friends and family or the environment in which they live, all of which will impact the choices that they make around infant feeding. Many factors such as socio-economic status, age, and education level are already known to influence feeding choices (Glassman et al., 2014). The impact that online community has overall and in relation to all these other factors, when faced with stressful events, is unknown and again warrants further investigation.

### **Conclusion**

Breastfeeding is a public health priority and cuts to government spending, the closure of community breastfeeding support groups and pressures on the health service is leading practitioners, and mothers themselves, to find new, innovative, and cost-effective ways to provide and receive breastfeeding mothers. This research drew on the social support theory to explore the use of online breastfeeding support groups. Online support groups are being actively used by women as peer led interventions to support their breastfeeding journey, and research into this area is growing. Understanding how the groups are being used and the support needs of mothers will enhance understanding of the supportive capacity of online peer-led platforms. This research has shown how one breastfeeding social support group has provided a medium by which to request informational, esteem support, and emotional support and to pose questions to their peers on a range of breastfeeding and non-breastfeeding related questions any time of the day and night. Positively, the online social support group creates a community of likeminded people, regardless of geographical boundaries, that share not only questions but celebrate accomplishments within an environment of mutual acceptance.

Overall, most posts were made by mothers seeking informational support relating to their child, typically aged between six weeks and six months old. Previous research has provided evidence of the usefulness of Facebook for sharing breastfeeding information, whereas previous research emphasised emotional support as a driver of use. Further qualitative research is needed to explore the positive and negative experiences of mothers that use these groups and to further explore the impact that such groups have on their breastfeeding journey in relations to other avenues of support.

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## Appendix A, Site search of Facebook.com

A site search was carried out by using the following search string through google.com in 2016: site: facebook.com + “breastfeeding support” + “groups” and detailed in Table A1.

**Table A1**

*Site search of Facebook, per month, in 2016*

Month	Results
June	49,100
July	63,400
August	73,100
September	71,100
October	63,100

One closed Facebook group titled “Breastfeeding yummy mummies” had 20,000 members and had 177 posts on the 29.10.16. Another titled “UK breastfeeding and parenting support” had 17,100 members and 79 posts on 29.10.16.



Appendix B, Data spreadsheet extract

A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R
Unit number	Day 1-7	Post No. per day	Time of post	Location	No. of likes	No. of comments	Word count	picture present	link shared	Support code	Post is BF related	Age in weeks	Post topic code	Post content	interrater reliability	Supervisors comments	my comments
1																	
2	1	1	06:18:00	worthing	0	0	96	0	0	1 and 2	1	0.99	4	I feel lousy...paracetamol is not helping. I had the implant two weeks ago and 2 days ago I felt so itchy everywhere esp the implant area. Dr tho it was allergic to something. The tablet he gave me has made it much worse. My throat is sore and difficult to swallow. Think I have a cold or something coming which is annoying. Is there anything extra stronger I could take as I'm going away Monday for 5 days so really need to feel better. Cetirizine has made it much worse. I'm bling as well.	1 and 2	No comment	not clear cut like 13 and couldn't use comments as there were no comments to clarify the situation so placed as both.
3	2	1	07:51:00	0	0	1	16	0	0	1	1	0.99	5	Does anyone own the medela freestyle breastpump, is it any good or worth the money ?	1.00	No comment	no comment
4	3	1	08:01:00	0	0	4	25	0	0	1	1	0.99	6	I'm going to Dusseldorf in a few days; I'm not one for public feeding if I can help it but is it acceptable to feed anywhere?	X	No comment	no comment
5	4	1	06:53:00	newquay	1	22	125	0	0	1	0	52.00	2		X	No comment	no comment
5	5	1	08:47:00	0	0	2	33	0	0	1	1	0.99	5	I've just expressed milk for lg's breakfast cereal. I'm Okay to use the same bottle over the next couple of days right? She's not drinking from the bottle I'm just pouring it on.	X	No comment	no comment
7	6	1	09:15:00	newcastle under lyme	0	5	9	1	0	1	0	0.99	8	Am I correct in thinking that this is not allowed? (pic of reduced formula)	X	No comment	no comment
3	7	1	09:06:00	0	1	9	60	0	0	1	0	28.00	7	Is it ok for my 6.5 month old to sleep on her front? She's not done this before, but she's having a nap on the bed (we share with a side car cot as well) and she's got onto her front, her nose is clear and she can breath but I'm just worrying a little! Should I move her?	X	No comment	no comment
3	8	1	09:09:00	0	0	4	17	0	0	1	1	0.99	13	Any know of real life help in - n Marston Green in Birmingham, really near to the airport?	X	No comment	asking a Q about tangible assistance. It is clear that not everyone is happy to post so online support is not for everyone. Clear request for info though so 1 otherwise breastpump request to buy would be tabgible as well.
0	9	1	11:14:00	0	0	2	90	0	0	1	1	70.00	7	*private post for a member*	X	No comment	no comment
1	10	1	09:56:00	0	1	6	37	0	0	1	1	14.00	2	Can I ask your advice ladies?...sticky, stringy, slightly lumpy mustard coloured stool off my 14 week old daughter. Can this be normal? She is fine in herself just feeding a lot more lately. Thank you!!!	1.00	No comment	no comment
2	11	1	10:38:00	stansted mountfitchet	0	12	24	0	0	1	0	0.99	11	I've brought an advent calender that you fill yourself...any ideas an little pressies for my nearly one year old? Not chocolates or sweetsies (Pic of a sweet)	3.00	No comment	agree to disagree

## Appendix C, Code book

Code	Name	Description	Examples on when to use	When not to use
1	Information support	The giving, sharing and/or request for information/ knowledge.	<p>The sharing of a story and then a direct request for further information e.g. <i>“How long should a new-born baby go between feeds”</i> (#263) <i>“Any advice on...”</i> (#264). <i>“Please help...”</i> (#276).</p> <p>Direct questions without the sharing of a story e.g. <i>“Are hand pumps any good or is it worth investing in an electric pump”</i> (#269).</p> <p>A post that shares a link, picture, or information, with or without discussion and/or question.</p>	<p>The criteria for use are not met.</p> <p>When a question is not posed.</p> <p>When the post does not offer information.</p> <p>When the post relays a statement with no question.</p> <p>When the criteria for emotional, esteem appraisal support is met.</p>
2	Emotional support	Emotions are a subjective psychological phenomenon in which someone expresses a strong feeling derived from one’s circumstances, mood, or relationship with others. It may be anger, fear, disgust, surprise, happiness, anxiety, depression, empathy, frustration, gratitude, remorse, stress, horror. Emotional support posts either contain or request support with such emotions.	<p>There is a direct request for emotional support, reassurance, or motivation to deal with a stressor. Example: <i>“Just looking for a bit a reassurance really”</i> (#338), <i>“HELP!!!”</i> (#61)</p> <p>A post that states a strong feeling or emotional state for example anger, panic, and upset. Example: <i>“An article in.... magazine made me so angry”</i> (#331), <i>“Really panicking”</i> (#343)</p> <p>A post disclosing a situation in which they are struggling, distressed, tearful, crying, lacking motivation, vulnerable, sensitive, happy, and expressing humour. Example: <i>“I’m exhausted three crying emoji”</i> (#341), <i>“Don’t really know what I’m asking but tired and frustrated”</i> (#342).</p>	<p>The criteria for use are not met</p> <p>When there is a clear question being asked requesting information</p> <p>When the criteria for esteem appraisal is met.</p>
3	Esteem/ appraisal support	The definition of esteem is to admire and respect someone. In sociology and psychology self-esteem reflects a person’s overall subjective emotional evaluation of his or her own worth. Esteem	An appraisal/ reflection upon their own situation. <i>“When baba stops mid feed, and gives these big smiles [picture shared]”</i> (#404), <i>“Today I am officially nursing a one year old..... thank you ladies for educating me”</i> (#410)	<p>The criteria for use are not met.</p> <p>When there is clear request for emotional support.</p>

		support posts contain either a reflection upon a mother's own situation or that of others, is a post in which she judges herself or can be an attitude towards herself.	Someone shares a link that they appraise and pass comment on " <i>it makes me a bit annoyed that breasts are so sexualised in the Western culture we live in</i> " (#406). Post offers encouragement to others or offers information that allows others to appraise their situation or offers gratitude. Example: " <i>is it just me that cringes when they see early weaning posts</i> " (#408), " <i>YOU CAN DO THIS</i> " (#412).	If the post is telling someone out right how to feel, think or what to do and there is no appraisal of the situation. When a question for information is posted.
4	Tangible/ instrumental support	Instrumental support could relate to a tangible assistance to address a problem and could be financial. Concrete direct way to assist others	A direct request for someone to do something for someone in a hands-on way. Examples would be to do someone's shopping if they are recovering post birth or driving to someone to an appointment if post caesarean section they could not drive yet. The nature of online support implies a lack of tangible assistance due to a lack of geographical boundaries however some posts directed at the admin team are seen. i.e. " <i>Hi, please can an admin add me to the off-topic group please? I have an off-topic question. TIA x</i> " (#78) " <i>Can someone from admin plz inbox me? Tia.</i> " X (#302).	If someone is asking for information about something tangible like buying a breast pump or where to find a face to face group. This would be recorded as informational support as would a request for tangible support "Any know of real-life help in ***" (Post 8)
5	Other types of post	Other refers to a post made by a breastfeeding mother that is neither a request for information, esteem, emotional or tangible support.	Post uses humour to normalise breastfeeding " <i>Where's the ... bottle? NOT IN THIS HOUSE</i> " [Picture of a child's toy that breastfeeds] (#424) or a shared link showing a picture of a breastfeeding Barbie doll (#425).  Post to another person e.g. " <i>to the lady at * .....it warmed my heart seeing you feeding ..... I hope you enjoyed your day xxx</i> " (#435)	When the criteria for tangible. Esteem, emotional or informational support is met.

## Appendix D, Themes descriptors

Code	Theme within the post	Theme description	Examples (as written to Facebook)
1	Effective feeding	Posts that relate to the attachment and positioning of baby at the breast, recognising effective feeding, and babies breast feeding behaviours.	<i>"My little bot is 10 weejs old, for the past 2-3 days he hasn't been latching quite right and it's making me sore and causing pain within my breasts...."</i> (#147)
2	Babies health	Posts that relate to the health of the baby i.e. colic, illness, allergies, and recognising poor health through stool colour and types. Also included are talk of preventative healthcare such as vaccinations.	<i>"Can I ask your advice ladies?...sticky, stringy, slightly lumpy mustard coloured stool off my 14 week old daughter. Can this be normal? She is fine in herself just feeding a lot more lately. Thank you xx"</i> (#10)
3	Mothers health	Posts that relate to the health of the mother i.e. breast or nipple issues, mastitis, poor milk supply, and general health whilst breastfeeding. Also included are practical aspects such as posts around breast pads and bras as well as the lactational amenorrhea method.	<i>"Hey, I've noticed I have a milk blister, It's not painful at all. How do I get rid of it? Thanks (Smiley emoji) x"</i> (#20)
4	Medications in breast milk	Posts that relate to any types of medicines (prescribed or over the counter, illegal or legal) and their possible transfer into the breast milk.	<i>"Help meeeee. Is there anyhting I can do or take to releive blocked sinus pain apart from paracetamol while bf? Heat? Cold? Any pressure point tricks? My head feels like its gonna explode (sad emoji)"</i> (#61)
5	Expressing milk	Posts that relate to the expressing of breast milk (By electric or manual pump or by hand). This also includes the storage of expressed milk, freezing, refrigerating, or thawing of expressed milk. Also included is the bottle, cup finger or syringe feeding of expressed milk and breast milk donations.	<i>"Does anyone own the medela freestyle breastpum, is it any good or worth the money?"</i> (#2)
6	Feeding out and about	Posts that relate to breastfeeding out and about, in pubic and in front of other people.	<i>"I'm going to Dusseldorf in a fewdays; I'm not one for public feeding if I can help it but is it acceptable to feed anywhere?"</i> (#3)
7	Breastfeeding at night	Posts that relate to breastfeeding at night, feeding behaviours at night, ways of managing night-time feeds, cluster feeds and managing to safe sleep or co sleep whilst breastfeeding.	<i>"Can I have some advice please. My little man is 9 1/2 months. ON solids and boobie. At bedtime... he's a nightmare. He feeds off both sides...and tehn cries for ages. Last night I fought with his from seven 7'oclock to</i>

			<i>10.30 until he fell asleep. Been the same tonight. He's been fed off both sides AND 2 1.2oz of my stash and still carrying on. Advice please? (sad emoji)" (#73)</i>
8	Formula milk	Posts that relate to the use of formula milk, the advertising, sale, constitution, or preparation of formula milk. Also included are posts relating to 'top ups' of formula milk.	<i>"Does this class as illegal?? Cleared to 20p a carton of Sma ready to use from birth milk? (pic of formula on a supermarket shelf)" (#16)</i>
9	Weaning and breastfeeding	Posts that relate to continued breastfeeding whilst introducing solid foods (weaning). This could include discussion around baby-led weaning or spoon feeding and feeding at different ages. Also included are the types and varieties of weaning foods on the market or suitable first foods.	<i>"Really paniking...my 6 month old has just started solids (and taken to them very well), hasn't fed from me since 6am! He's had breakfast and lunch and a bit of water but I'm really worried, he's never gone this long, not even overnight!" (#343)</i>
10	Breastfeeding journey	Posts that relate to a mother and child's breastfeeding journey. Achievements, issues and resolutions and emotional aspects of their breastfeeding journey.	<i>"Totally forgot we've now got silver boobs with diamond nipples as of Tuesday! So happy we are still going at 11 months (pic of mother and baby smiling)" (#383)</i>
11	Not breastfeeding related	Posts that are not related to breastfeeding and discuss other topics with no mention or correlation to breast feeding.	<i>"Where can I buy a amber anklet from please x" (#26)</i>  <i>"NBFR...random question, but does anyone know if you can get footmuffs for buggies that are larger in size? LO is nearly 2, but his is a little snug length wise when he's got shoes on. TIA". (#52)</i>
12	Group admin	Posts that relate to tangible support for a group administrator to add another member wishing to join the group.	<i>"Hi, please can an admin add me to the off topic group please? I have an off topic question. TIA x" (#78)</i>
13	Other	Posts that relate to breastfeeding but do not relate to any of the other themes.	<i>"Any know of real life help in - n Marston Green in Birmingham, really near to the airport?" (#8)</i>  <i>"Mortified (Shy emoji) signed for a parcel with my boob out, he kindly looked away !!! I was so embarrassed (cry emoji, laugh emoji)". (#495)</i>

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Chapter Four: “*Can we talk about other ideas*”? An interpretative phenomenological analysis into online breastfeeding support groups.

Abstract

**Background:** The transition to motherhood is a vulnerable time in a woman’s life and she requires proactive psychosocial support, and the literature supports that women who are practically and emotionally supported have higher rates of breastfeeding. In the UK, where breastfeeding rates are some of the lowest in the world, supporting mothers with breastfeeding is a priority. It is noted that breastfeeding mothers may seek support online, yet the experiences of women seeking support from online social support groups is largely unreported.

**Aim:** To explore how breastfeeding mothers make sense of and interpret their experiences of online social support groups and explore the perceived impact that this has on their breastfeeding journey.

**Method:** Ten unique narratives, from breastfeeding mothers who actively use online breastfeeding social support groups on Facebook.com, were collected through in-depth semi-structured telephone interviews. The narratives were then analysed using Interpretative Phenomenological Analysis.

**Results:** Four superordinate themes were identified along with subordinate themes. The online breastfeeding support groups supported an internal vision of what breastfeeding is like. The mothers all had a vision about how they saw themselves as a mother, and as a breastfeeding mother, and when faced with times of stress the groups supported them in regaining control. This was achieved through the building of a community that shared knowledge and experiences and subsequently the groups provided confidence, reassurance,

and normalised breastfeeding, affirming their parenting choices. The groups also sparked reciprocity and an activist approach to supporting breastfeeding in society.

Conclusion: This study provides an insight into the views of breastfeeding mothers regarding online breastfeeding social support groups, demonstrating the complexities surrounding breastfeeding choices. The group offered access to similar, like-minded others, in their thousands, with no geographical boundaries, and with ease of access. Services may benefit from penetrating their systems with volunteer led online social support groups to help build supportive breastfeeding communities, acknowledging that it is everyone's responsibility to build a community, supportive of breastfeeding, on and offline.

## Introduction

Human beings have always lived in communities and social relationships and activities are arguably one of the most important areas of life (Bowling & Windsor, 2001). Societal changes such as industrialisation, urbanisation, and capitalism all lead to a change in societal structures and settings, and technological developments such as the internet provide a way for people to communicate, meet others and form communities online (Preece, Maloney-Krichmar & Abras, 2003). These online communities have been found to be environments where support, empathy, and friendship develop (Rheingold, 2000).

The uniqueness of computer-mediated communication has led to a steady increase in the popularity of computer mediated social support groups (White & Dorman, 2001). Chapter Two shows how online support groups can be utilized to empower diabetic patients to self-manage their condition (Oh & Lee, 2012), support patients with depression (Houston, Cooper & Ford, 2002), and support patients following a diagnosis of Cancer (Yoo et al., 2013). To date there is little reference to either the advantages or disadvantages of online support group use as a mechanism to support breastfeeding mothers.

Breastfeeding has long been a public health priority due to the benefits for mothers' babies and society (UNICEF, 2017; WHO, 1981). Despite the known benefits, the UK has the some of the lowest breastfeeding continuation rates in the world. A recent Lancet series on breastfeeding (Victora et al., 2016) highlighted a need to scale up and monitor breastfeeding promotion interventions aimed at supporting breastfeeding mothers. In part this could be due to the transition to motherhood being a vulnerable time in a woman's life requiring proactive psychosocial support (Teefflen, Nieuwenhuijze & Korstjens, 2011). The literature suggests that women who are supported practically and emotionally have higher rates of breastfeeding (Brown, Raynor, & Lee, 2011).



There is a large variety of online forums/message boards around breastfeeding, for example the 'What to expect breastfeeding' forum offers a discussion board with an excess of 88,000 members and 137,000 posts (accessed on 15.03.2018). Facebook could be viewed as an unlikely place for breastfeeding support as historically Facebook has received a lot of media attention for banning breastfeeding pictures and those that posted them (Wortham, 2009). The national and international attention that this issue received in over 25 languages encouraged Facebook to change their photo policy in 2012. Now, pictures of babies nursing at the breast are allowed, however anything they consider nudity will be removed from the site if reported (Facebook, 2019).

Previously in Chapter Three it was highlighted that there were 64,000 breastfeeding groups on Facebook alone. In 2019 this figure remained high at 53,000. Facebook, as noted by the Office of National Statistics (2016) had the largest internet activity for people aged 16-44, thus of child bearing age, so exploring this phenomenon would add to the scarce scholarly literature about what parents are doing while they use social media and technology (Tomfohrde & Reinke, 2016), and the effectiveness, or not, of the internet in supporting breastfeeding (Giglia & Binns, 2014). A large, UK based survey (BabyCentre, 2011), also revealed a 45% increase in internet usage after becoming a mother and increasing engagement in social media and use of mobile phone technology. It is imperative that health promoters understand how families use the various resources available to them, the nature of these resources, and the relationship they have with subjective infant feeding behaviours (Newby, Brodribb, Ware, & Davies, 2015).

### **Study aims**

The previous chapter explored the use of online breastfeeding support groups but did not explore the experiences of women directly. This research aims to do this and address the overarching research questions: what are the women's experiences of using Facebook groups

for breastfeeding support, and what is the perceived impact of online social support groups use on the mothers breastfeeding journey? It aims to answer questions such as: how and when do women use the online social support groups, how do they describe the groups, what were their experiences of the groups, what are the perceived benefits and risks of using the groups, did they make changes to their decisions as a consequence of using the groups? To address these questions Interpretative Phenomenological Analysis (IPA) was chosen as the research methodology.

Finlay (2009a) describes three types of IPA question; one that would explore the 'life world' of a breastfeeding mothers use of online support, one that explore the general structure or essence of the use of online support groups for breastfeeding mothers, and one that explores the stories breastfeeding mothers tell of their online support group use. Underlying all of these is to what extent online social support groups describe the experiences in general. The focus of this research was to explore the stories that breastfeeding mothers tell of their online social support group use.

This research sets out to gain a fresh, rich, complex description of a mother's experiences using an online social support group (Finlay, 2009a). Secondly it aims to capture and explore the meanings that breastfeeding mothers assign to online social support groups (Smith & Osborn, 2015), including the experiences, thoughts, reactions, emotions, and conflicts (Wagstaff et al, 2014). Thirdly it aims to capture the perceived impact that the breastfeeding social support group had on any breastfeeding decisions and to understand and interpret the experiences through asking those best suited to provide them (Reid, Flower, & Larking, 2005). Overall, this study aims to tell a story and focus on the meaning of experiences over any kind of measurement (Holloway & Bilney, 2011).

As mentioned above, the previous research explored in Chapter Three, allowed for one week of Facebook posts to be analysed, however there was an obvious omission of

subjective experience to this approach. For this reason, IPA was chosen as a method of narrative collection through to analysis, to provide an alternative perspective and develop this thesis further.

Exploring a mother's experience of online groups, using IPA, provides a deeper understanding (Clarke, 2009), and allows for the potential of online support as a viable support intervention to be explored. This research also adds to the literature within the academic and professional community (Smith, Flowers, & Larkin, 2009) and the knowledge base around innovative breastfeeding support interventions. The aim is to present a new perspective to understanding the popularity of such groups and the support needs of breastfeeding women.

### **Interpretative Phenomenological Analysis (IPA)**

IPA offers an inductive approach concerned with personal accounts of experiences rather than finding causal exploration for events (Smith & Osborn, 2015), and allows a mother to tell her story (Halling, 2009), which is similar to working in the practice setting delivering individualised patient-centred care. IPA is often used in health research to gain service user perspectives, and frequently used in nursing research (Pairman & McAra-Couper, 2010).

IPA explores personal meaning attached to the descriptions of the lived experiences, grounding the impact and nuances in the socio-cultural aspects of their stories. This is pertinent in breastfeeding support which similarly has multiple socio-cultural determinants (Smith, Hausman & Labbock, 2012). IPA's epistemological roots are in phenomenology, hermeneutics, and the method is ideographic (Smith, Flowers, & Larkin, 2009). Each of these three disciplines will now be explored, and the terminology will be taken from Smith, Flowers, and Larkin (2009), to better understand and embrace the IPA methodology. The influential philosophers in the field of IPA will also be explored, and integrated with the underpinning theory, so that the experience of mothers can be explored.

## **Phenomenology**

Smith (2006) states that phenomenology is a wide-ranging examination of how human experience is shaped by structures, cognition, and perception, to self-consciousness, physical attentiveness, and affection responses. Phenomenology offers individuals the opportunity to be witnessed and gives voice to what they are going through, giving the participant and researcher time to make sense of the experience (Finlay, 2011). Engagement with phenomenological approaches help to inform and drive the research processes (Finlay, 2011).

In phenomenology the external event is less important than the phenomenological inquiry as it exists outside of the person's physical being. Phenomenology asks the researcher to connect directly and immediately with the world as it is experienced and not as they believe it to be (Langbridge, 2007). Given this, this study will allow a deeper understanding of social support networks than previously researched within Chapter Three, attempting to be open and meet the phenomenon in a more open way (Wagstaff et al., 2014).

Phenomenology aims to clarify taken-for-granted human situations and events that are known in everyday life but typically go unnoticed or unquestioned (Seamon, 2000). This fits in well with the research question as online support is a phenomenon, characterised by interpersonal relationships with others unseen or unknown (LaCoursiere, 2001), and is currently occurring and under researched. It offers individuals the opportunity to be witnessed and gives voice to what they are going through, giving the participant and researcher time to make sense of the experience (Finlay, 2011).

The German philosophers, Husserl and Heidegger greatly influenced IPA. Husserl focused on the 'life world' of an individual and regards experiences as a source of knowledge (Dowling, 2007). He argues 'essence' can be understood by revising an immediate conscious experience of it (Clarke, 2009a). The essence is not a social construct, intellectual or

otherwise but a general meaning structure of a phenomena (Halling, 2010). IPA grew from Husserlian traditions but moved away from the descriptive concerns. Whereas, Heidegger explores making sense of something, understanding, determining, and looking after something (Clarke, 2011), all familiar questions within this research.

Additionally, Heidegger talks of many disparate categories; authentic/inauthentic, speech/talk, fear, anxiety, openness or 'theyness', and 'Dasein' which translates to 'being there' (Clark, 2011). Heidegger states that to be human is to be embedded and immersed in the physical and literal tangible day to day world (Steiner, 1978) and ontologically the world is here now and around us. Heidegger's work is often explored when looking at having to do something, producing something, looking after something, giving up something, making use of something, accomplishing, interrogating, understanding, and determining (Heidegger, 2011). This research attempts to make sense of online support resonating with the work of Heidegger and his theories of 'what it means to be' and the assumption that human beings are immersed and open to the surrounding world (Heidegger, 2010).

'Dasein' implies that our very nature is to be there, always somewhere, always located and always amidst and involved with meaningful context (Larkin, Watts and Clifton, 2006). He describes this in two ways: authentic and inauthentic. Humans are seen as having choices in the world and these possibilities make each person unique. When acting on our own decisions we are classed as authentic. When we adopt the standards and beliefs and prejudices of society and do not differ from the masses we are described as inauthentic and not true to ourselves. The work of Heidegger informs the research method for this study. A rationale for the use of interviews as a research tool in this study is founded in the belief that 'Dasein' is grounded in language, and being in the world expresses oneself in the discourse and cognition as to what is being communicated (Steiner, 1978).

Heidegger talks of a person finding their true self, which can be related to seminal theories of 'becoming a mother' (BAM) (Mercer, 1981). Simply, BAM describes a mother's journey in finding a maternal identity in which she is in harmony with her child. The theory of BAM describes an anticipatory stage before pregnancy whereby the mother wants to know all the information necessary to raising her child. This theory then describes how a mother transitions into the formal stage post-delivery whereby she imitates the experts and follows the advice given to her. This can be likened to Heidegger 'theyness' in that people work as a 'they' by listening and trying to implement the evidence base and best advice. This stage is then followed by the informal stage in which she may struggle to follow all the advice given to her and finds her own way of parenting, again linking to Heidegger's concept of 'falling away' and becoming aware of the loss of self and then striving to return to the authentic being. Heidegger states that these stages, just like BAM are an essential prerequisite towards the possession of self and the struggle towards true 'Dasein' (Steiner, 1978).

**Lived experience and sense making.** Van Manen (2017) talks of lived experience as the vividness and descriptive detail provided through narrative accounts, and not just emotional reactions. The lived experience is described as meaningful yet superficial until we ask the question 'what is the lived experience like'? Examples are the data of phenomenological research, and experiential data that require study, investigation, probing, reflection, analysis, and interrogation (Agamben, 1993). These epistemological bases to IPA again inform the research method and probing investigation is required (van Manen, 2017).

French philosopher Maurice Merleau-Ponty was greatly influenced by Husserl and Heidegger and believed that our bodies are fundamental to our relationship with the world (Merleau-Ponty & Smith, 1962). John-Paul Satre, a French philosopher also explored existentialism and phenomenology (Satre, 2003). Both works resonated with this research

around breastfeeding due to the embodied nature of babies feeding from the breast which influenced the research design.

Merleau-Ponty states that we can only view another person if we understand ourselves as separate from them (Merleau-Monty & Smith, 1962). For this reason, journaling, and reflexivity, as discussed in Chapter One, were practiced from the start of the research.

Merleau-Ponty (1962) states that because we can only imagine what it is like for someone else, we never really know. Merleau-Ponty assists in the understanding of proximity between the researcher and the participants. Likewise, for Satre 'being in the world' recognises interactions with the world and the development of the self-consciousness. From Satre's stance of 'nothingness' reflexive thoughts must be as attentive to what has not taken place as opposed to what has (Satre, 2003).

### **Hermeneutics**

The second branch to IPA is hermeneutics. Hermeneutics sits within the interpretivist paradigm and is concurrent with nursing philosophy (Clarke, 2009a). It is the theory of interpretation influenced by Fredrich, Schleiermacher, Heidegger, and Gadamer whose theories underpin IPA (Larkin, Watts & Clifton, 2006). The emphasis of IPA is on the interpretation and not the description (Eatough & Smith, 2008), therefore IPA provides a framework for developing deep insight into unique experiences (Finlay, 2009b) through a double hermeneutic, whereby the participant interprets their own experience (meaning making) and the researcher interprets the participants' narrative (sense making) (Smith & Osborn, 2015). This allows for interpretation on how the online presence fits in and around everyday life, what role this plays, and the effect on health and wellbeing, all within the social and political climate.

Hermeneutics again influence the research design. To capture a person's interpretation interviews were used and seen as an appropriate method. Interviews produce

shared stories that give testament to past events and experiences (Crowther, Ironside, Spence, & Smythe, 2017) and reveal new ways of being, thinking, and acting in the world that sheds light on what is known but covered over or forgotten. Hermeneutic analysis requires the researcher to delve into the data, awaiting glimpses of the phenomenon and crafting rich and meaningful stories (Crowther, Ironside, Spence, & Smythe, 2017).

### **Idiographic**

The third element to IPA involves the idiographic standpoint and provides a strong emphasis on the narrative element (Finlay, 2009b). This element looks at the exact nature of an experience, particularly attending to the specific context and temporal frame and not a focus of direct attention to reliability, validity, and generalised finding (Eatough & Smith, 2008). This element again shapes the research design, lending itself to a small sample size that is homogenous (Clarke, 2009a). The emphasis is on a strong ideographic, narrative element (Finlay, 2009a), in this instance around why the mother chose to look online, how they felt before during and after, and how they made sense of it (Pringle, Drummond, McLafferty & Hendry, 2011). However, there is some tension in IPA reported (Wagstaff et al., 2014) between the idiographic focus and development of general themes, so providing transparent narrative accounts to each theme is essential (Smith, Flower & Larkin, 2009).

### **Justification for the research design**

There are many advantages and benefits to IPA research. IPA provides a complete and in-depth picture of the wholeness and uniqueness of the individual (Malim, Birch & Wadeley, 1992). It firmly anchors direct quotes from individuals to illustrate themes (Smith, Flowers & Larkin, 2009), and provides an analytical commentary leading to useful insight with wider implications. The idiographic nature of IPA facilitates insight into the individual's journey and the essential overarching themes that may impact on practice. It also offers a



framework, accessible guidance, and procedural base for novice researchers' (Smith & Osborn, 2015).

Conversly, there can be disadvantages to using IPA as a research design. Idiographic studies are potentially subjective and impressionistic (Malim, Birch & Wadeley, 1992) and variables are hard to establish (Smith, Flowers & Larkin, 2009). Braun and Clark (2006) argue thematic analysis is a method in its own right and that IPA is constrained by its theoretical roots; however, the roots can add depth. For researchers undertaking IPA it is nonprescriptive and adaptable (Smith, Flowers & Larkin, 2009), and frequently used in nursing research (Benner, 1994).

Overall, IPA is deemed a useful methodological tool for discovering meanings constructed from complex experiences where little is known (Reid, Flowers & Larkin, 2005). There is criticism is criticism of nurses claiming to use Husserl's phenomenological approach without fully understanding the approach and paying 'lip service' to the idea (Paley, 1997). This research aims to adopt the approach openly, and the work of philosophers fully explored as a prerequisite to using IPA.

### **Method Description**

The following details the methods used within this research. This section details the decisions made around the participants, interviews, narrative interpretations, ensuring quality research, reflexivity, and data storage. This section aims to provide a transparent and open approach to the data collection.

#### **Participants**

Ten participants were recruited via an advertisement posted on an online breastfeeding support group on [www.Facebook.com](http://www.Facebook.com) (see Appendix A for research advertisement). Participants' emailed their interest to the primary researcher who then followed up with an email containing participant information, consent form and an overview

of the interview schedule (see Appendix B for participant information sheets). If the participant was happy to continue, then an interview was arranged at a mutually convenient time and informed that the interview would last about an hour.

A purposive sample of ten participants were selected from over 40 emails received. The first ten to have satisfied the inclusion criteria (see below) and that were accessible for interview were included within this study. The adequate size for the ideographic nature of IPA is discussed in the literature (Brocki & Wearden, 2006; Smith & Osborn, 2015), and four-to-ten participants are recommended for professional doctorates (Hefferon & Rodrigues, 2011) although many researchers are known to be indecisive around participant size (Wagstaff et al., 2014).

**Inclusion criteria.** Only those with experience of the phenomena can take part in the study (Todres & Holloway, 2004) to capture a homogenous sample required for IPA (Smith & Osborn, 2015). Only mothers from the United Kingdom, that were currently breastfeeding their infant and have done so for at least four weeks were accepted. They were required to have been actively using a UK breastfeeding online support group, at least weekly and birthed a full-term healthy baby with no medical complications post birth. The groups themselves have their own criteria and ground rules around promoting a 'pro-breastfeeding' environment and the mothers that join the group adhere to these communal rules.

**Exclusion criteria.** Mothers not included were those that did not meet the inclusion criteria above, whose babies required additional support after birth e.g. with babies who were born prematurely, or those that had a history of breast surgery, as these can all affect milk supply that require additional support.

**Briefing and debriefing of participants.** On the day of the interview the primary researcher ensured the consent form had been received and then telephoned the participant at the pre-arranged time. Appendix C details the screening, pre-interview briefing, and post

interview debriefing schedules. Additionally, preliminary draft findings of the research were later presented to participants' in the first instance to provide open and honest disclosure of the research. These were sent via email unless the mother had opted out of receiving this, although no participant declined this offer.

**Introducing the participants.** Each of the 10 participants came with their own stories to tell, their own experiences of online support to share, and were all from different parts of the UK. Despite being geographically dispersed they had online social support group use in common, which was the phenomenon under examination. Details relating to the background of the participants' and their pseudonym name, to protect confidentiality, are detailed in Table 1.

**Table 1**

*Participant demographic information*

Name	Demographic information
Carole	Carole is a mother to four girls aged fourteen years, eleven years and a set of twins aged four and a half months. She is married, born in the UK and resides in the North of England. She works as an advisory teacher and is educated to master's level. She has accessed several Facebook support groups and regularly uses an online breastfeeding support group for parents of twins or triplets, which boasts around 3000 members.
Teresa	Teresa is 23 years old and has a ten-month-old son who she exclusively breastfeeds. She is a stay at home mum, white- British, and lives with her partner. She was at university studying counselling. She accesses several Facebook groups and regularly uses one of the smaller national groups with around 300 members. She does not attend face to face support but does have good family and professional support.
Tracey	Tracey is a mother of 15-month-old twins. She is married and has a master's degree in accounting. She considers herself to be white British and lives in the north of England. The group she uses most often is the breastfeeding twins and triplets UK group.
Chloe	Chloe is a mother of six-month-old twins. She lives in Cornwall, is white-British and uses the breastfeeding twins and triplets' group. She lives with her partner and works as a nursery Nurse.
Anne	Anne lives in north east coast of England and is breastfeeding her nine-month-old. She is a teacher trained at post grad level. She uses the Cows milk protein allergy (CMPA) group. Local breast buddies' group and a national group that supports mothers undertaking a total elimination diet.

- Jane Jane is a Paediatrician, and currently breastfeeding a nine-month-old in the south of England. She is married, white British and frequently uses a Physicians mums' group to support breastfeeding. There are thousands of members and is a UK wide group.
- Val Val has two children aged three years and a son who is fifteen months. She lives in the North East of the UK and works as an advanced nurse practitioner. She regularly uses a local online group called human milk buddies' group.
- Emma Emma has two children aged three years and one year and is currently breastfeeding her youngest. She classes herself as white-British and lives in the southern east part of the UK. She frequently uses the breastfeeding older babies and beyond online group.
- Gail Gail is a thirty-year-old mother to her son whom she hasn't finished breastfeeding at the age of three. She frequently uses online groups and works as an administrator of an online group. She is white-British and lives in the north east region of the UK and cohabiting with her partner. She regularly uses a small local online breastfeeding support group.
- Lauren Lauren is a twenty-five-year-old mothers in the East of England. She has one daughter aged nine months and works as a medical representative. A co-worker introduced her to social media in pregnancy and she just uses the one locally based yet online social support group.
- 

## Interviews

This section describes the choices made around the use of interviews and the development of the interview schedule, detailed in Appendix C. A qualitative approach was taken using semi structured questionnaires, constructed of eight main questions and five prompting questions. Overall, ten narratives were completed, and audio recorded, and all included in this study. The interview schedule was designed as a way of getting a better understanding of reality, working with the assumption that there is a historically occurring reality out there, adopting a critical realist approach (Wengraf, 2001).

The interview schedule was prepared in advance to ensure it was dynamic, flexible, and ethnically orientated (Fielding & Thomas, 2001; Walker, 2007). To ensure all elements of a good story exist (Hay & White, 2005) the interview started with questions that help to develop rapport and a caring and empowering dialogue by way of a general question; *“so tell me a little bit about your breastfeeding journey so far”* was used to start. The mother was then asked to *“describe the online support group in general, how would you describe and*

*define it to someone that was thinking of joining the group*". This stage adopted deliberate naiveté, asking for a definition (Kvale & Brickman, 2009). The questions then including what happened, how they behaved, evidence and witness to what happened, providing meaningful levels of reflection to the participant and the researcher (Holloway & Biley, 2011). Overall, each interview was built upon the last with a flexible structure (Kvale, 2007) and aimed not to resemble a checklist (Roulston, 2010).

The interview schedule was used as a framework, an open format, to get closer to the participants experiences and guide deeper exploration (Smith & Osborn, 2015). Participants were asked to talk through their experiences, good and bad, to develop layers of meaning (Todres, 2007) and to enrich the data (van Manen, 1990). Before concluding, the participants were asked *"Overall how would you describe the impact of using the group on your breastfeeding journey"* and conclude by asking if there was anything they felt was missing.

Wengraf (2001) talks of how the research interview is not designed to help empower or change the informant at all, the interview is used to know about the discourse, objective referents, and subjectivity. This discourse was intended to elicit a narrative account and around a breastfeeding mothers' lived experience of online breastfeeding support. Semi structured interviews have long been designed to ascertain responses from persons regarding situations or phenomenon that they have experienced (Merton & Kendall, 1946). Participants are free to respond to open ended questions and researchers can probe responses. Prompts to scaffold interactions to avoid mistaken assumption and provide greater depth (Arthur et al, 2012; Kvale, 2008; Wimpenny & Gass, 2000), such as *"can you give me an example of ...?", "You said... walk me through what that was like for you"*, were used. This flexible framework provides an opportunity to explore the topic whilst remaining responsive to the participant (Bartholomew, Henderson & Marcia, 2000). To deepen discussion, within this loose structure, 'why' questions were used to produce a more focused answer 'what' questions

were used to invite more feeling and creative reflections towards understanding (Yoshida, 2010). German philosopher Hans-Georg Gadamer believes nothing exists without language and conversations in what he calls a fusion of horizons, blended of present interpretations and interpreters' preconceptions (Gadamer, 1989) as "*One does not write primarily for being understood, one writes for having understood being*" (Derrida & Ferraris, 2011, p30).

Differing interview formats have been considered for IPA studies; in-depth interviews (Smith, Flowers & Larkin, 2009), loosely structured interviews (Smith, 2007), and unstructured interviews (Brocki & Wearden, 2006). Smith and Osborn (2015) promote semi structured as an exemplary method of IPA research, as do Smith and Eatough (2006) and van Manen (1990). Open ended interview questions maintain a careful balance between being guided and being led, starting with broad general questions so the participants' can see the parameters of the study and not impose their understanding on the participant (Smith, Flowers, & Larkin, 2009).

Interviews are set apart from other data collection tools because of the researcher/participant relationship (Wimpenny & Gass, 2000), and the dual role of the interview to capture the meaning and narrative of the experience (van Manen, 1990) and providing a window to their stories (Rabionet, 2011). Kvale (2006) discussed the importance of developing rapport and a caring and empowering dialogue. For this reason, the opening question asked participants to talk about their breastfeeding journey so far, to explore the nuances, expressions, and spontaneous thoughts (Smith, Flowers & Larkin, 2009).

**Telephone interviews.** Shuy (2001) argues that face to face interviews are beneficial as the presence of the interviewer provides a structure and communication that is optimised using visual aids. This is beneficial as the researcher can see confusion, offer breaks and emotional support. However, this may inhibit the response to sensitive questions and the interviewer may affect the interview and inhibit a truthful response. Exclusive auditory

communication also means that the any barriers are removed about the interviewer's appearance (McIntosh & Morse, 2015). The literature notes both positive and negative aspects to telephone interviews.

It is seen that telephone interviews can be shorter than interviews in person (Irvine, Drew and Sainsbury, 2012; de Leeuw, 2008; Vandermate, 2004). However, they provide access to hard to reach people and are less costly in terms of time and labour therefore more effective (McIntosh & Morse, 2015). A small scale, exploratory, study by Irvine, Drew and Sainsbury (2012) explored face-to-face interviews versus telephone interviews. They found that in telephone interviews the researcher contributed a less often in the dialogue and telephone interviews did not lead to increased difficulties in substantive understanding, which may be due to the phone interviewer requesting clarification more frequently. Due to online support being commonplace for the mother, coupled with the fact that the internet allows for a wide geographical location of potential participants, telephone interviews were used.

To aid the interview, simple notes were jotted down during the interview. These notes included interesting areas that required clarification, but rather than interrupting the participant flow of narrative, were saved until they paused and collected their thoughts. A perceived advantage of telephone interviews noted by Chapple (1999), Irvine et al. (2012), Stephens (2007), Sweet (2002) and was the ability to take notes unobserved by the interviewee thus reducing distraction and disruption of the interview process.

### **Narrative interpretation**

The audio recorded narratives were transcribed and then analysed using the seven-step approach described by Smith, Flowers, and Larkin, (2009) (see Table 2).

**Table 2**

*Adapted from Interpretative Phenomenological Analysis (Smith, Flower & Larkin, 2009).*

Step	Title	Description
1	Reading and re-reading	Immersing oneself in the original data
2	Initial noting's	Free association and exploring semantic content
3	Developing emergent themes	Focus on chunks of transcript and analysis of notes made into themes
4	Searching for connections across emergent themes	Abstracting and integrating themes
5	Moving to the next case	Try to bracket previous themes and keep open-minded in order to do justice to the individuality of each new case
6	Looking for patterns across cases	Finding patterns of shared higher qualities across cases, noting idiosyncratic instances
7	Taking interpretations to deeper levels.	Deepening the analysis by utilizing metaphors and temporal referents, and by importing other theories as a lens through which to view the analysis

This involved reading and re reading the transcripts, making initial notes, developing emergent themes, or meaning units (Giorgi, 1989), and searching for connections across the emergent themes before moving to the next case. Patterns across all cases were then explored and a deeper level of interpretation was undertaken. Various papers have been published describing these analytical steps (Flowers, Smith, Sherran & Beail, 1997; Osbourne & Smith, 1998; Smith, Osborn & Jarman, 1999; Willig, 2001), with the consensus being on a flexible and varied route through this process.

Larkin, Watts, and Clifton (2006) state that the researchers must approach the data with two aims in mind. Firstly, to understand the world and what it is like, recognising the complexity which produces a coherent first-person account, and a psychologically informed description staying close to the participants' view. Secondly an interpretation that places the initial description in a wider social context and perhaps a theoretical context. This allows the researcher to think about what it means to the participant. A detailed account of the research method is now discussed, indicating the choices made and rationale.



**Step One.** Preparing for the analysis involved transcribing the recordings into a word document, with wide margins, numbered lines and double spacing in a landscape profile. Each participant was given a pseudonym, as were locations, children's names, and exact names of groups. Transcribing data into an electronic format allowed for reading and re-reading of the data which is noted as step one by Smith, Flower and Larkins (2009).

**Step Two.** Once the transcript was written it was printed in paper format with a large box on the right and left of the transcript. It was also printed one sided to allow for reflection and thoughts to be captured. The transcript at this point was sent to the main supervisor and comments and reflections on interview technique were discussed, as above in the post interview reflection. An example of transcript is included in Appendix D.

The audio recording was played, and the initial noting's were then added one category at a time. Initial noting's consisted of descriptive, linguistic, and conceptual comments and added to the right-hand side margin and each in a different colour. These were then typed up again whilst listening to the original recordings to ensure the noting's stayed close to the narrative. A table introducing each participant was written, can be seen in Table 1. Table 1 marks the first impressions and demographic data, untouched by time. This was used as an aide memoire for when moving forward.

**Step Three.** The interpretations, of the mothers' experiences were then summarized in a patient story. This began the double hermeneutic stage to IPA. The initial noting's were summarized and considered in narrative form to aid the development of emergent themes. Carole's story is provided in Appendix E to demonstrate this stage.

**Step Four.** At this stage the two main aims highlighted by Larkin, Watts and Clifton (2006) were considered; describing the participant's world and then applying the wider social, cultural and even theoretical context to the participants world. Overall, the

participant's stories invite the reader to listen to and call upon their own thinking (Smyth, Ironside, Sims, Swenson, & Spence, 2008). This approach opens interpretation rather than closing it. To achieve this the main themes were collated and grouped into sub themes. This was then sent to the main supervisor as a completed transcript for independent analysis. The subthemes were then discussed at length during supervision to ensure rigour in breadth and depth of analysis and methodological competence (Yardley, 2000).

**Step Five.** To stay true to the idiographic nature of IPA each story/ narrative was considered before moving to the next narrative. Each transcript was given time and attention and not considered against the other. Themes were written for each person to catch the essence of what was discovered. Each narrative is a testimony of truth valid today but may not be valid tomorrow (Derrida & Ferraris, 2011), because how we are listened to will influence the 'how' and 'what' of telling (Fiumura, 1990).

**Step Six.** The themes were then collated and presented in many forms to summarize and clarify the patterns across the cases. Appendix F illustrates how patterns were gathered across cases. Supervision was sought to discuss these themes and findings. The following section details the superordinate and subordinate theme and the interpretations taken to a deeper level.

**Step Seven.** Taking interpretations to deeper levels. The narratives obtained from the participants provide in depth accounts of ten women's breastfeeding journeys and seeks to understand how these women interpret their experiences of online social support groups.

### **Ensuring research quality**

To supplement the interpretation process, a journal was kept alongside the analysis as a tool for learning and reflexivity (Finlay, 2011; Vicary, Young & Hicks, 2016). Extracts from the journal included in Appendix G, written in the first person, with the aim of demonstrating reflexivity throughout the research process. The journal provides an open and

honest account about the interpretations made in an aim to separate these from the participant's experiences. Unlike Husserl, Heidegger states that you cannot separate yourself from features of everyday life (Larkin, Watts & Clifton, 2006) so a journal challenges reflexivity and separates these from the participant's descriptions. It would produce bias if the researcher did not pay regard to self-awareness through reflective contemplation (Larkin, Watts & Clifton, 2006).

Additionally, this is separate from 'bracketing' or setting one's beliefs aside. Reflexivity embraces the belief that pre-understanding, pre-preconceptions and experiences run as a cycle. This too indicates the temporality of the human experience. Self-reflection constitutes an important step of the research process, paying attention to what happens before, during and after the interview (Colaizzi, 1973; Smith & Osborn, 2015). Reflections written during the research process were used during supervision to discuss processes and challenges (Wagstaff et al, 2014), and allow moments of discovery and to pause and reflect (Halling, 2010).

Within the works of Merleau-Ponty, reflexivity is noted as a key aspect in IPA. Finlay (2011) states that constant reflexive appraisal allows recognition of the researchers' influence in the analysis, encouraging overt participation in the process of interpretation. It was for this reason that pre interview and post interview reflections were written (see Appendix H for pre and post interview reflections). The reflections were guided by Chadwick, Bahr, and Albrecht (1984) who posed six questions to help guide reflection following the first interview. These are still used today (McIntosh & Morse, 2015), and considered to ensure the quality of the study. The questions included; whether all necessary questions were included, any elicited responses, use of appropriate language, review any possible double meanings, the order of the questions, and whether the interview guide motivated the respondent.

Field notes were also made and are detailed in Appendix I. Wolfinger (2002) discusses the importance of field notes and paying attention to what is being noticed, and the choices made as to what we pay attention to. Reflexive experiences from the field notes are included using four categories to guide reflexivity; observations of the world, theoretical reflections, methodological reflection and critique of the research process and analytical reflection of the questions raised. These notes were completed during the analysis process and provide open and transparent accounts of the process, theme development and crucial questions raised. Smith et al. (2009) add that if the research account is rich and transparent enough, and sufficiently related to current literature, the reader should be able to assess and evaluate transferability.

Ensuring quality is one of Descombe's (2010) ten golden rules of research. To ensure the quality of this study the work of Yardley (2000) and Smith (2010) will be drawn upon. Yardley (2000) offers 4 broad principles to IPA through an open-ended and flexible approach and Smith (2010) produced a guide 'what makes a good IPA'. Both provide a more tailored approach to quality assurance than tools designed generically for qualitative research.

Other quality tools include more general models such as Mays and Pope (2000) or Rolfe (2006). Mays and Pope (2000) look at quality in qualitative research and specifically validity and relevance. Rolfe (2006) talks of validity, trustworthiness, and rigour as quality within qualitative research and most specifically within nursing research. Rolfe explores the lack of consensus in criteria and questions the appropriateness of trying to find one. Elliott, Fischer, and Rennie (1999) also produced guidelines for publication of qualitative research in psychology and related fields.

This study chose to utilise the work of Yardley (2000) and Smith (2010), who provide a quality framework noted to benefit the IPA research process and epistemology (Yardley, 2000). IPA requires interpretation, thoughtful analysis, and empathetic exploration of a topic.

A quality assessment tool needs to offer the same approach (Yardley, 2000) and explore sensitivity to context, commitment and rigour, transparency and coherence, impact, and importance. Smith's (2010) evaluation guide states that IPA research needs to provide; a clear focus, strong data, rigor, space to elaborate each theme, be interpretive and not descriptive, point to convergence and divergence, and be carefully written.

Quality assessment tools will support the flexible, double hermeneutic approach (Smith, Flowers & Larkin, 2009) that allows the researcher to become entwined in the narratives provided (Finlay, 2011). When this occurs instances of the lived experience get transformed through in-depth analysis, into textual description of the essence of the phenomena, moving the experience to a general insight (Finlay, 2011). Finlay (2011) goes onto describe how the research breaks free of the original narratives and focus on the phenomenon and intuit implicit meanings exploring dynamic reflexively.

These quality assurance tools were used from the start to prevent issues arising, for example producing large numbers of descriptive subordinate themes, or large numbers of short descriptive quotes, leaving a quote to itself with no interpretation, or making generalisations (Hefferon & Rodriguez, 2011).

Lastly, Smith Flowers and Larkin (2009) make no recommendations about computer software and emphasise that manual coding can help to develop an intimacy that might not be achieved otherwise (Clarke, 2009a). Although large amounts of narratives have been managed through automatic coding programmes (Langbridge, 2007), this research stays true to the intimacy delve into the stories and lived experiences within print and utilises written text. Smith and Osborn (2003) state this is useful when recoding, reorganising themes when referring to original transcripts.

### **Management of information**

University ethical approval was sought and granted for this study. In line with university regulations all information collected was kept strictly confidential and anonymised from interview collection and a pseudonym assigned to respect the autonomy of the participant. Only the researcher had access to personal details e.g. full name and email address and a signed copy of the consent form was kept by the research team. Care was taken to anonymise narratives prior to any publication. The difference between confidentiality and anonymity was fully explained to the participant, because although participants' may not be identifiable to the public they may be to their peers (Sandelowski, 1994). This was discussed in the participant information sheet and in the pre interview briefing.

The narratives were stored on a memory stick that was password protected/ encrypted and stored in a locked draw. Data is stored for five years as per University guidance and not shared with any third parties. Only authorised persons such as the researchers', regulatory authorities, and research and development audits (for monitoring of quality of the research) will have access to narratives and the analysis. After the five-year period, all data will be destroyed and disposed of securely. Any participant information such as email was stored confidentially and in a separate location to the reported data and in the same manner as above.

### **Findings**

Although the journey of each women is unique, themes emerged from the data reflecting their understanding of online breastfeeding support group use. The ten narratives present a picture of how support is used to maintain their own internal vision of what breastfeeding could be like for them. In this instance, it is seen that breastfeeding issues caused them to 'fall away' from this vision, to challenge their strength of character and their sense of identity. Bodily experiences, judgements from peers and from others, feelings of guilt, isolation and

loneliness were dissolved, and mothers felt empowered using the online breastfeeding support groups.

The following explores the group as a resource to information, it explores how the mothers embraced reciprocal relationships, felt empowered and reassured and for some even developed an activist role. Additionally, it illustrates how women use the group to affirm their choices, bolster their self-esteem to achieve the vision. A time and place for different types of support are described within the narrative however, the positive nature of experiential learning offered through the online support group was found to have had a profound impact on their breastfeeding journey, leading to longevity of breastfeeding. These findings are all explored within the following themes and summarized in Table 3. Illustrative quotations are included in the text.

**Table 3**

*Superordinate and subordinate themes*

Superordinate themes	Subordinate themes
Supporting an internal vision of what breastfeeding is like.	A vision. Falling away. Regaining control.
Providing a sense of community.	A tribe of like-minded people. Support to find the right information. Finding the right community online.
Different types of support at different times.	Types of support. Temporal moments in time for support.
The impact of the online social support group.	Confidence. Reassurance. Normalising. Reciprocity. Activism.

**Theme One:** Supporting an internal vision of what breastfeeding is like: *“I felt it was the one thing that I just should be doing, and the one thing I want to do, so I didn’t want to lose that bond with him”* (Teresa).

The first Superordinate theme describes the mothers’ thoughts and beliefs around breastfeeding; her vision of what she wanted to achieve, a vision of what it could be like for her. The online group was interpreted as something that helped her achieve her vision. All the mothers interviewed provided survivor stories, in that they had overcome a variety of breastfeeding challenges and were still breastfeeding at the time of the interview.

The group was perceived as a tool that helped them to gain control over their situation, to move closer to their vision of what they wanted, and not fall away from it. The following subordinate themes: a vision of breastfeeding, a bodily experience, and falling away and regaining control of that vision will be discussed in depth using examples from the mother’s narratives to ensure transparency (Yardley, 2000).

**A Vision:** *“I was like well I’m going to breastfeed and there’s no option”* (Emma). All mothers were invited to talk about and reflect on their breastfeeding journey so far. All talked about their physical and emotional beliefs surrounding breastfeeding and what they wanted to achieve from breastfeeding their child.

Emma decided in pregnancy, by researching feeding methods she decided that she wanted to breastfeed: *“I was like well I’m going to breastfeed her there’s no option, I’m just going to breastfeed”*. By saying no option Emma was talking of the benefits of breastfeeding and felt the evidence supporting breastfeeding was so strong that breastfeeding was what she needed to do. Emma was determined to breastfeed and continue to breastfeed her toddler through the belief that her baby needs her for food but also *“breast supporting”*:



*She needs this, she needs me, the thought of telling her [no], I mean she feeds a lot in the day and gives my breasts a little kiss in the morning [ ], she doesn't need them because she's hungry, well she does sometimes, but she's not, my breasts aren't just a food source for her they're a comfort [ ], it's lovely having that connection that I know is there for her and I love providing for her and knowing that.*

Anne had always wanted to breastfeed and grew up in an environment where breastfeeding was encouraged by both professionals and her family:

*I think it [breastfeeding] had been a decision ever since [childhood], it's not really a decision if you know what I mean it's always been like If I had a child I will breastfeed. I know the whole thing at the moment is 'fed is best', but fed is desired, but breast is still best. For me it was never really an option, and there's so much crap in formula, there is no way I was going to put that into my child.*

Interpreting Anne's story, not only has Anne grown up in a family culture believing that breastfeeding was best for her baby but also that formula was not. She refers to a social media campaign known as the 'fed is best' campaign which rivals the 'breast is best campaign'.

Teresa took a similar view to Anne in that she believed breastfeeding was best for her baby, however due to mental ill health herself she interpreted breastfeeding as a protective factor for her:

*Breastfeeding is such a lovely bond and I never wanted to give it up and I was scared that I would get post-natal depression if I gave it up, and I know that sounds ridiculous I know that sounds like an exaggeration but I had regular depression, prenatal depression and I was really worried I was going to get post-natal depression.*

To add context to Teresa's narrative, she grew up in a family environment that encouraged breastfeeding especially from her mother:

*She was a real support system, I was really glad she did help me and I'm glad I reached out for support [ ], if I stopped breastfeeding, I felt it was the one that I just, the one thing I should be doing and the one thing I want to so and didn't want to lose that bond with him.*

Teresa had a clear vision of breastfeeding based on her family culture and strong emotions that breastfeeding would help her and protect her own health and support a bond with her baby. Lauren, however, was more ambivalent in her vision from the start:

*I'll give it a really good shot and I'd like to do it. I really wanted to do it and I didn't want to bottle feed. On the other hand, I didn't really put the line down that I was going to and I kind of initially thought let's get six months.*

Lauren feels undecided in her almost contradictory account, and from her vision takes a pragmatic approach.

Another example is provided by Tracey. Tracey had a vision of breastfeeding that was supported by seeing people feeding in person and online. Although she had access to the online group in pregnancy and was culturally exposed to breastfeeding, she was surprised that her reality of breastfeeding was that it was harder than she had thought. Tracey states "*I don't know how people parent without boobs*". Interestingly this also intertwines parentings styles with breastfeeding preferences as she becomes a mother.

**Falling away:** "*Oh my god why do I feel like I'm failing*" (Carole). This subordinate theme illustrates the range of issues that challenge a mother's vision of breastfeeding. Emma was determined to breastfeed and her vision was strong, but when her baby wasn't gaining weight, and formula was recommended by a professional she felt as though the vision that

she had was not achievable Emma discussed feeling: *“completely lost because if an expert is telling you to give formula, I came to the realisation that if my baby was hungry I would have given her formula”*. Emma is seen here to trust the advice of professionals. She is seen falling away from her vision and having to reevaluate her beliefs and vision due to her situation. This realisation caused a cognitive dissonance, a state where thoughts and beliefs were challenged causing an emotional time: *“I literally cried for the 45-minute drive home”*.

Gail describes how her baby had a restricted frenulum causing poor attachment at the breast and subsequent pain of the nipples, well documented in the literature (Wambach and Riordan, 2016). This impacted her breastfeeding journey both physically and emotionally, demonstrating a need for support at this time of falling away from what Heidegger refers to as the authentic self, or in this instance it added a barrier between accomplishing her vision:

*Every day I nearly threw in the towel and every day I was going to buy formula and everyday I'd say one more feed, just one more feed and we're still having one more feed... I was literally crying all the time to anybody that would listen.*

Carole also shared an experience where she had posted to the group saying, *“oh my god why do I feel like I'm failing”*. This emotional post came after a night of *“constantly breastfeeding”* that ended in bed sharing. Carole reflected on how the dangers of bed sharing *“were rammed down my throat”* so held the belief that it was the wrong to bed share with her infant. Carole made this choice out of self-preservation at an exhausting and emotional time, yet it led to feelings of *“guilt and self-torture that was doing something wrong”*. Bed sharing is discouraged by professionals due to safety concerns, unless done safely. Carole, like Emma above, had forged their vision from professional advice with negative repercussions.

Chloe describes how she felt: *“I just lost the plot. I was too scared to go back to this lady [A professional who told her to give her baby formula milk] in case she told me to give*

*him bottles so I looked elsewhere*". Chloe describes how she felt physically tired and emotional and as though she was failing as a mother if she gave bottles leading her to "*cry her eyes out*". At this vulnerable time she questioned if she "*could go on*" and was uncertain of her own abilities which led her to feel defeated: "*I didn't know if I could carry on and I really wanted to make it work and things were going wrong and I felt defeated*".

Part of the narratives around falling away, described the bodily experience. All mothers described the physical and bodily experiences of breastfeeding, of babies feeding at the breast and experiences of feeling pain or discomfort. Pregnancy, childbirth, and breastfeeding all involve a bodily experience and the following will illuminate this.

Anne simply describes times of "*tiredness and exhaustion*" whereas Val speaks of her experiences of pain with her first child:

*I felt under a lot of pressure to breastfeed despite the pain. In fact, if someone would have said shut up and get on with it, it is painful for a few weeks, but when you get into it its fine, I would have probably carried on. I remember just sat there crying and thinking I don't want to do this it's too painful [] I found it so painful couldn't get to grips with the pain.*

Breastfeeding was something Anne had always wanted to do. For Anne, the bodily experience of pain and discomfort challenges that vision. Anne explains: "*I suppose everyone tells you it's difficult. I don't think I realised just how painful it would be at the beginning... I found it harder than I thought I would*". Anne however reflects today and states "*it's almost crazy that it was so painful because it doesn't hurt at all anymore*".

Pain was also a dominant factor in Carole's discussion. Carole was given a breast pump in hospital and it was at this time that she first turned to online support for help managing this pain:

*They gave me an ancient breast pump; it wasn't the best, but it was really powerful. But oh my god it left my nipples in tatters. I lasted about two days of this and one of the nurses came in to find me crying and in agony because honestly it gave me selective turrets every time, it was horrible, it was a bit painful to say the least [ ] the wards are fantastic but they are busy aren't they, and they don't always have the time, and they don't always have the equipment.*

Tracey talks of specific times in her journey where she needed support. In the early days of being in hospital she describes not being “*with it*” and “*not feeling strong because everything's emotional, it was genuine emotion. I ended up having crazy thoughts. I just felt guilty. I was feeling horrendous*”. Tracey had a vision that she wanted to achieve, and this was a time where she needed support to continue. Falling away from her vision of breastfeeding and having to use a breast pump meant that she now felt “*it was a really big regret for me*”. She described the breast pump as a “*horrible machine. It's not pleasant and it's not breastfeeding*”. These times in her journey that she described as “*big leaps*” were often experienced as changes within her physical body and felt as though she was moving further from her vision of breastfeeding that she held.

**Regaining control:** “*I just wanted to make it work*” (Chloe). Gaining control describes how the mothers utilised the group as a tool to achieve their vision, to prevent, or overcome challenges and gain personal control over their situation. Each mother's story was unique and individual to them however the overarching theme of taking control was evident in all. In theory the second stage of becoming a mother (Mercer, 2000) is indeed to find their own way of doing things.

We have seen how mothers such as Carole and Emma follow the advice given to them by professionals and their vision of breastfeeding is based on this evidence-based advice.

However, when faced with challenges and embarking on finding their own way, feelings of guilt and feeling deflated were reduced or alleviated. This is illustrated in the following.

Val describes pain in her nipples whilst breastfeeding motivating her to seek online support in the hope of gaining control:

*I used the group [] I wouldn't actually post the question; I would just do the search to find the answer. No doubt at all I would find the answer. I relied on it really. It was completely invaluable.*

To help Val stay in control she states: *"I'm more of a silent um member, I just look at it, I just look at what they're talking about each day"*. The online social support group in Val's case is still a valuable resource in maintaining control and describes how having access to other experiences provided answers to her questions.

Emma presents as a strong determined woman and there is evidence of being well informed throughout her narrative. When struggling with milk supply she had learnt about how milk production works and: *"actually after that realisation [of being told by a professional to give her baby formula] I just put her on [the breast] all the time and just nonstop fed, and of course I built up my supply"*. There is confidence in her saying *"and of course"*, showing how she is mastering the skill of breastfeeding and making her own choices. Emma was able regain control of her own situation through education and consider all her options. She moved against the advice of the professional and found her own way to making her vision of breastfeeding a reality.

Similarly, Tracey regained control through reading information and learning from the experiences of others in the group. Tracey talks of a time when she went to see a professional face to face however it turned to tears and frustration when she could not replicate practical information when arriving home: *"I did end up crying for the rest of the evening after the*

*comments that she gave me, she told me how to latch properly and I just couldn't do anything what she did and what she told me".* In this moment Tracey turned to the group to regain control and states *"I was not disappointed"*. Tracey describes the files of information that she found and read, that when she was feeding, she was reading and learning more information that built her ability to control her situation:

*It takes a lot of confidence to ignore people [professional advice] and be like that [finding her own way], If I'd have had an easy journey then I wouldn't have read all those articles that I have done at three o'clock in the morning. All that extra knowledge that I've built up. It's made my experience stronger.*

It is within this narrative that the mother's journey is apparent. The group is not simply a tool to gain information it's a tool to build confidence and resilience and progress as a mother through the stages of becoming a mother.

Chloe was originally told that she would not be able to breastfeed so when she realised, she could it was even more important to her: *"I felt defensive of it at the start because I was worried it was going to fail"*. Struggling with breastfeeding after gaining this vision made Chloe feel *"gutted"* and she describes how she felt she *"was going to lose something"*, lose her a *"glimmer of hope"* and *"a vision of successful breastfeeding"*. Chloe refers to overcoming challenges as *"making it out the other side [ ] I just wanted to make it work and once I had an idea on how I could do it, and I had support saying that I could, I just kept going and it worked [ ] I was so surprised by my own reaction"*. The strength that Chloe found even surprised herself but the words of encouragement from others online supported her vision and progressed her journey.

Teresa was a young mother supported by her own mother, which she appreciated. However, Teresa found value in the group as it supported her finding her own way *"I just*

*wanted it to be me and my baby and not me my mum and my baby, so posting meant it was just me and my baby but my phone as well*". The group was another way for her to transition into motherhood. This transition is evidenced in the following narrative where she reflects on a conversation with her mother about her mother's own breastfeeding experiences "*I told her not to beat herself up over stuff like that she made a decision at the time and got to feed me for 12 months so that's still really good*". In this short narrative Teresa shows how she has moved from the mothered to the mother, gaining control of her situation, emphasising the importance of the group in supporting development of the mothering role.

Anne's story focused around gaining control and becoming an expert, with this she describes annoyance and frustration and she believed that professional had "*poor advice and lack of education*" around breastfeeding a baby with allergies. Anne states:

*It was frustrating at times seeing advice people had been given by their so called medical professionals, um and when I knew I was right... it was frustrating seeing how uneducated a lot of GPs [general practitioners] are in terms of breastfeeding and particularly allergies and breastfeeding.*

Falling away from what she felt she knew, along with spoken feelings of exhaustion and frustration, contributed to her finding out the information and becoming her own expert. The group to Anne was more than a way to glean information it was a way to become the expert in a world where she felt the "*so called experts*" were not meeting her expectations.

Lauren was different in that she did not have episodes where she felt she was falling away from her vision instead she maintained her beliefs through the group preparing herself for all eventualities. Lauren provided a story of gaining control of her vision to prevent falling away:



*Because I was reading, I noticed it [a redness of the breast]. I thought OK I know what this is and dealt with it. You need the information really before you start because you're exhausted after 3-4 days of doing it. I had a nice 'preloading', so I already knew what I was getting in for. I knew I should be expecting this and that and go from there, I think.*

Similarly, Jane perceived all the potential challenges she might face and acted even before they arose, demonstrating her control of the situation. She harvested colostrum in the early days just in case it was required post birth and tried elimination diets in case her baby had an allergy however both were not required in the end. Jane, as a doctor herself, took a medical viewpoint to her breastfeeding and stayed in control from the start by surrounding herself with other breastfeeding professionals in an online group. She managed risk and found her own way of doing things leading to proud feelings that her baby was exclusively breastfed. Jane admits that as a professional she usually saw breastfeeding complications, so her actions were self-justifiable, and the online group provided a way of staying in control. Jane states that she took *"a realistic view to breastfeeding. Whether we would exclusively breastfeed or whether we would top up or whatever works as fed is best is my kind of mentality"*.

### **Theme summary**

The degree to which each participant is represented under each sub-ordinate theme is detailed in Appendix J. Within this theme all mothers' stories were present within this super-ordinate theme. We saw how these ten mothers have a vision of what they wanted their breastfeeding journey to look like for them and when issues arose how they were forced to re-evaluate their situation as they became a mother. This emotional and embodied time saw how these mothers used the online group, not simply as a source of information but to regain or

maintain control and achieve their goals. How exactly this might occur, and the impact variable will be considered in more detail within the next theme.

**Theme two:** Providing a sense of community: *“that community feel”* (Lauren).

This second superordinate theme focuses more on the group itself and discusses how the online group provided a sense of community, and the people within the group described as a tribe, likeminded people and a supportive network that celebrates breastfeeding. The following notes the key factors that make up this online community including the people within the group, the experiences of those people, the support to find the right information and how the mothers chose to interact and engage in the online groups. On many occasions the participants’ referred to the ‘we’ as opposed to saying ‘I’, emphasising a feeling of community, all of which will be elaborated in the following, using narratives to explore this further.

**A tribe of likeminded people:** *“the experiential is also valid because a lot of these things are much more about how it feels”* (Lauren). When first using the group, Emma explains: *“I think I went to find, my friend keeps referring to it as her tribe, I think I went to try and find my tribe”*. Emma was searching for people that were like her, that were breast feeding a toddler and said she found:

*Thousands of us that do it, and I know them, and I can talk to them, and say this is my problem or is anyone else doing this. I know there will be hundreds of women and replies saying ‘yes I do that’ and it’s so nice to be able to say it’s not just me and it makes it a little bit more normal for them as well. Like it’s normalising for them too.*

Emma talks of being part of a group and part of creating a community, not just for her but for others, referring to the group as *“support in numbers”*. Like Emma, Gail also talks of her tribe. Gail frequented the group originally because she was experiencing pain and discomfort

whilst feeding and was looking for information and solutions. It was also a place to vent frustration with people that understand her issues and explains:

*It makes me feel better because sometimes I have an issue that I can't speak to others about, sometimes being able to talk to a stranger about an issue. I can go to them, it's like they're my tribe, and they understand my issues. It's good we call it our tribe, it's good to have those people around you. There's that many people that someone would have the same experience, and someone will know a good way to cheer you up.*

Carole also describes the group as “a support network of likeminded people”, Carole discusses:

*Finding likeminded people that have a likeminded approach for example a parenting point of view feels like you've got a, well it's a support network basically that you've got out there. Yes the people are invisible and they are faceless and you don't know them but because they are in the same situation particularly for something like breastfeeding which is very, and mothering in generally is hard in the early days, it's very emotive and do you do very much rely on the group of people because people in your everyday life don't really get it because they're not the ones doing it.*

Chloe also describes the breastfeeding group as a supportive group that is friendly, responsive, and non-judgemental and easy to access. Chloe does not describe individuals but describes a safe community: “it's nice to have the, well not friends, but the community again”. Chloe placed a lot of emphasis on the community aspect of the group and talked of the group being a tool for getting rapid advice, 24 hours a day. With this rapid advice for Chloe came reassurance and feelings of joy:

*When you're nine o'clock at night and your baby's struggling to latch and you're in pain and you're both tired and they are not getting fed, and you're panicking and you*

*can't wait a couple of days to see someone, you get the answers then and your baby's fed and everyone's happy.*

Teresa also talks of finding likeminded people which directly affects which group she participates in: *"I don't have anything in common really with them [mothers on a general group that bottle feed] so I don't use it anymore"*. Teresa would avoid the groups that may tell her something that she didn't want to hear *"oh give him a bottle, just give him a bottle and that is just one thing that I never wanted to hear"* classing these as non-likeminded people.

Jane describes community as a place with commonality, familiarities, and similarity to others. Jane had joined many groups but the place where she feels most comfort is the one where she feels people are similar to her and in this instance this is a professional based group *"I think you feel a bit of solidarity with your medical colleagues"*. Here Jane emphasizes that solidarity and felt sense of community through her language: *"you feel"* rather than *"I"*.

Anne also considers the group as a supportive network, rather than friends: *"not friends, but you see the same names and the same people, it becomes a supportive network"*. A friend is defined as someone attached by feelings and emotions. Anne does not feel that this is the case through the group, it is more a collective of individuals, posting questions to the group and not to individuals. Likewise, Val states: *"I just felt I had somewhere to go if I had an issue. I just logged on"*. Val has a strong sense of self, who she is and what she wants, and describes herself as a *"determined"* person. Val states:

*I feel more of a connection with the people on the group because you can see what they are asking, what they are nervous about, their thoughts. I see people on the group every day that I can completely relate to.*

The group is also a place to celebrate and encourage feeding: “*I click ‘like’ to lots of things I like, so when a lot of posts are like ‘so I got to six months’ or ‘I got to one month or I got to 23 months’ its happy and encouraging*”. Chloe also said that when faced with “*developments and all the problems*” she was provided with “*solutions and kind words*” from the community which encouraged use.

Lauren reflected on why she liked the online group as opposed to an antenatal class she had attended that was delivered by the midwives: “*it’s all about that sort of experience, it’s very hard to replicate that community feel*”. The community feel within the online group was of appeal to Lauren as opposed to “*someone sort of sitting there and giving you information*”. Lauren believes that it is the experiences of the people within the group that are of value to her. When seeking professional support, she likes the professionals to have also had their own experiences. She felt professional “*follow the party line and not individualised care*”. The party line that Lauren alludes to was described as a professional approach characterised as only giving evidence-based facts and information. It is the experiential learning of other people that Lauren feels “*echoes the normal as the experiential is also valid because a lot of these things are much more about how things feel and less about the processes and biological things that are happening*”. Lauren along with others described the group offering a broad collection of variables and experiences that she feels are “*written very honestly*”. The honest experiences of mothers are valued highly by the mothers interviewed.

Lauren, like many of the mothers, chose to co-sleep with her baby at night. Lauren talks of being encouraged through the experiences of mothers to co-sleep and found the group normalised her gut feeling that this would be best for her. In this instance she was affirming her feelings and beliefs and the people within the group were supporting her to find her own way. Lauren talks of falling away and “*being close to breaking point making sure that she*

*was moved back into her cot*". This falling away was accompanied by feeling of guilt and the group provided details way to minimise risk and Lauren was reassured by others.

Similarly, to Lauren, Teresa also feels that mothers are more honest about their experiences of parenting within the group, than in her local community. Lauren states:

*A lot of personal friends anyway I think like to mask that they're the perfect parent and their child never cries and they've never had an issue [ ] in the group however a lot of people confess that they've left their child in front of the TV for 5 hours and they've had five cups of coffee cos they don't want to brush their hair and stuff like that. There's no shame in not putting your makeup on and leaving your house but you can feel quite judged if you go and see all these mums that have got it so together and you don't.*

These bodily experiences that Teresa is mentioning are outward projections of what Teresa believes a mum that *"has got it so together"* is like. These things are removed in an online platforms and Teresa values the honesty to reassure herself and normalise her experiences. For this reason, Teresa explains how she connected to the people within the group: *"I feel I have better friends in the online community than the actual friends I have in real life. I just found it much easier to make a connection with them"*. Interpreting this narrative, the connection with the group, due to shared commonalities leads to perceived strong friendships. Friendships that due to the perceived openness and honesty of others provides a sense of connection that has not been received in face to face encounters.

Ultimately finding this community of likeminded people meant that the mothers felt less alone. The mothers spoke of being surprised by the support they found through Facebook *"if I hadn't got this group on Facebook there would be no one to ask. You don't stop needing support"* (Emma). In Emma's situation her child had grown too old to access the baby group

in her local community and home support no longer existed due to funding cuts causing Emma to feel isolated: *“The group provided a real source of comfort because I know that there are others like me”*. Emma did seek support face to face and ‘feeling less alone’ was a theme within this interaction, highlighting the value in having others around her: *“The lady said I have no idea but I’ll go and look into it for you. That was really important having someone say I don’t know but I’ll find out for you was really important”*.

Similarly, other mothers felt value in having others at hand: *“I guess it’s like having thousands of friends in your phone”* (Jane). *“I didn’t know you could find anything like this in Facebook. I thought it was just friends and businesses. I didn’t think of things like support groups but It’s amazing”* (Chloe). *“So, to be able to have support on my phone and be in my bedroom it was brilliant. Lots of people are in the same situation made me feel less alone”* (Tracey).

**Support to find the right information:** *“If it doesn’t feel like it’s the right thing to do can we talk about other ideas?”* (Emma). The information the group provides was mentioned by all, and the knowledge shared was the reason for engaging in the community. Subsequently the lack of information felt by all participants at times was noted, and the lack of knowledge of others was also described. All mothers reflected deeply on why this knowledge was important and is discussed in the following.

Seeking knowledge was the main reason Chloe chose to use the online group. Gaining her own knowledge to achieve her vision was important to Chloe as she did not have a person in her life that was knowledgeable about breastfeeding:

*When I had a problem, I didn’t know where to go and ask for advice [] I have learnt more things about breastfeeding from the page than anywhere. [] It gives me something to do, something to try or just lets me know it’s normal and just wait it*

*out... I've still got loads to learn, it's amazing but I've still got loads to learn. I can work out for myself on what's caused the problem and how I can get around it.*

Val describes that within the first day of joining the group how she had gained copious amounts of information: *"I got clued up because the questions were coming all the time about sore nipples, blisters cracks, pain, and latch. I couldn't believe how much information that I didn't have before"*. Val reflects on how she was motivated to *"feed for longer with her second and see how it goes"*. Val purposely went on a voyage to seek as much information as possible stating that with her first: *"I just hadn't done my research"*. The online group this time around filled her knowledge gap.

Anne talks of actually *"using the group"* and used the group for fast access to information and information that she did and didn't need. Anne had a clear sense of identity as a breastfeeding mother but use the group for information *"in the future I can use that. I was learning things that I don't know I needed to learn"*. Anne is scaffolding her learning through this online environment, a term used in pedagogy whereby a person systematically builds upon experiences and knowledge as they learn a new skill (Vygotsky, 1978). She is building her knowledge everyday by reading the information shared. Reading information shared helped her to pre-empt potential issues, unlike the face group whereby her questions were answered. When first joining the group, she thought that there was a lot of information but became familiar with the content:

*Wow that's a lot of information but it's the same stuff over and over and you get your head around it and it's like you become more of an expert quicker and quicker. All the information has been put into files and files within Facebook group and all the files are research that has already been done for you and all the reading and collated.*



Emma also places value in knowing all her options. When meeting professionals she describes how some professionals only share the safest advice something she called “*very, very NHS choices*” which she describes as the politically correct version that lack all the options:

*Sometimes we've clashed a few times because she's telling me the right thing to do and I've said that doesn't feel like it's the right thing to do can we talk about other ideas, and she's said oh you need to do this.*

Emma values access to all information and finds her own way of doing things. Tracey also valued the information and described how the group also reduced her feelings of isolation. Interestingly a different approach is taken by Chloe who states she does not choose the most popular answer but the “*one that feels right at the time*” when finding her own way.

Anne describes temporal experiences of anxiety, frustration and worry, and a need for information “*I don't think if I dropped out of all the groups early on that it would have stopped me from breastfeeding*”. Anne was a determined breast feeder and had numerous avenues of support from local groups and family. Anne reflects that face to face support holds great value to her however believes that online support would be almost as good as the face to face support. She used the group in the early days “*it keeps you awake whilst breastfeeding*”. For Anne it normalised and reassured her through the learning of information. Nowadays the group is used less “*I just don't have time to be scrolling now and I can't just sit in my phone scrolling I'm running around after her*”.

Carole also considers the group compared to the face to face group and the language used by Carole during the interview is interesting. Carole describes the online groups as fantastic, however describes the face to face group as “*a little support group downtown*” and “*really nice but*”. Interestingly she describes the face to face group as “*just peers, just*

*mums*”, Carole feels that her peers in the online group are somehow better due to the literature and evidence base being shared.

Along with the felt need for their own information, many felt that professionals also needed to increase their knowledge to support them. Chloe was frustrated with professional advice: *“I think I know more than most professionals from going to that page. It would be nice if doctors, midwives, and health visitors had a bit more training on it [breastfeeding]”*. Tracey was also surprised when her own friend that was medically trained gave advice that she felt was not correct. At the time Tracey felt: *“as if it was me versus everyone at the time that it was just me and the Facebook group versus everyone else”*. Through a deeper level of reflection Emma feels that the emotional support that accompanies the information is pertinent to understanding the impact of the group, thus the support to find the right information is important. Emma reflects:

*I think it's not about having the information available to you through the groups, I think it's knowing other people are going through it too and other people think it's worth keeping going. Even if they've done it and gone through it there still saying you know what you can keep going and try different things but just keep going because this is important to you then this makes a massive change to know how you feel, your emotional level.*

Lastly the quality of the information was discussed. Both Tracey and Val believe the online group to be: *“A really well-informed group and the advice, um it is of the quality I would be getting from a lactation consultant”* (Val). Tracey talks of quality belonging to reputable sources such as government information and lactation consultants. This narrative provides a look at the quality of the information. Tracey also adds that larger groups provided more anecdotal information thus not as high quality. Bigger groups also have *“more formula*

*bashing*” and feels they are too big to control. This introduces the next themes and discussion around the importance of finding the right community, a community that feels safe.

**Finding the right online community:** *“A safe space, free from judgement”* (Jane).

Many of the women interviewed wanted the online groups they used to feel like a safe space, and the group administrators were seen to have a contributing role in making the group feel safe. They talked of finding the right group for them, a group where they felt safe to be themselves and post questions around their needs, free from judgement. The size and locality of the group were also discussed on numerous occasions making this a key sub-ordinate theme within the community. Tracey felt that the administrators were gate keepers to accessing the group, essential for the monitoring of inflammatory comments, as well as the givers of evidence base for discussions and prevention of poor-quality information being shared. Poor quality information attributed to *“someone’s opinion really [ ] weeding out the old wife’s tales”* (Tracey), and *“you don’t have to sift through loads of rubbish... I’ve never seen [on the breastfeeding group] disparaging posts, and that’s very bizarre because it is an online environment”* (Lauren). Many of the mothers talk of this safe space, that meets their needs and was right for them.

Carole also concedes that when the administrators share the evidence around breastfeeding, they add value to the groups:

*I would say I think the breastfeeding one in particular, is the one I engage with the most anyway, there admins are brilliant they jumping particularly with um fantastic advice pointing you in the direction of articles and research and things like that and putting links on for things that you can go and look up and stuff like that.*

Gail states that the administrators for each group vary, and this affects her online behaviours and use of certain online groups. She describes how some topics are allowed in certain groups

and not others, learning what she can and cannot post within them. Gail states there are additional off-topic groups to ensure that the breastfeeding support groups stay as purely breastfeeding support. Finding the right online group for her was important and Gail states “*groups can be very argumentative*”. Gail discusses childhood immunisations as one of the topics known to produce conflict within discussion: “*yea oh God yea. I know it’s not breastfeeding related but even a mention of vaccinations can cause World War Three*”. Gail says for this reason some topics of discussion such as vaccinations have been banned from the groups by the administrators. Gail controls her online world and states:

*I try not to get involved in that case because it makes me quite anxious arguing with them. I don’t like it. I have to be careful with the things I write sometimes I have to read it a few times to check that it doesn’t sound like I’m being sarcastic or argumentative or anything. I just want to be, I try, and I just want to make positive comments. I don’t want to make anyone else’s day horrible.*

Here we see that the mothers search for the right group for them and talk of wanting an online space in which they feel safe, yet this may not be possible. Gail demonstrates how she herself takes responsibility for the group being a safe space. Chloe also shares that groups can be confrontational and judgemental conversations can be “*nasty*”. These judgemental conversations Chloe feels are not breastfeeding related but based on parenting styles. Chloe also highlighted sleep as a controversial topic along with immunisations and tries to avoid talking about these topics. Like Gail, Carole shares accountability for making this a safe group: “*I am very cautious about offending anybody [ ] I ask gently have you tried this kind of thing but um I don’t need to worry but I always try and be supportive*” (Carole). Carole is mindful and does not see this as an anonymous space in which she is free to say anything. She is cautious not to “*wade in, jump in and say that... you have to step back and say hang on a minute, [ ] there are people that aren’t like that*”.

The size of the group is also raised, when navigating multiple online groups. Lauren considers the size of the group and location to be important. Her online group is locally run and for this reason there seems a shorter geographical distance between the group members. Lauren believes this makes people more mindful about what they say. Lauren feels that with in the national groups it is easier to write more harmful comments. Gail also perceives the larger group as having more conflict and the administrators are a fundamental aspect to building a friendly online community:

*The larger groups can be catty and there can be a lot of name calling at times, if the admins don't see it in time there can be a big sort of bitchy site which is not nice but you're in a forum with women it bound to happen [laughs].*

Gail sees the smaller local groups, as opposed to the national groups, as add-ons to the local face to face groups. Gail finds the smaller groups less “*catty and bitchy*” than the larger national groups. This was also noted in Laurens narrative. Gail holds strong to the evidence base as she pursues a professional role in breastfeeding support now herself. She states that she loses faith, even in her own profession, when they do not follow the evidence base “*I had to just walk away, I can't even get into this it will irritate me*”. For Gail, an evidence base is important to her. There appears to be an appreciation for evidence-based information with all mothers, but the experiences of others and what the mother feels to be right is also important. Finding a group which provides the right mix of these is key to feeling belonging in that group. Gail for example feels particularly happy in her more local online group that offers a lot of evidence-based information, probably as it is attached to her local NHS.

Carole talks of people with strong critical opinions as “*keyboard warriors*”. Carole finds a community with “*likeminded people and approaches that give encouraging words*”. Carole describes a trial and error approach to finding a group with likeminded members, big

or small and demonstrates the control she has of her own online environment: *“I don’t post in the twins one as that’s where people get more heated”*.

### **Theme summary**

All mothers are represented in this second superordinate theme, and again detailed in Appendix J. In the first superordinate themes we saw how mothers often fell away from an internal vision of what they wanted, and to some degree, with the assistance of online support groups, were able to regain control of their situation and continue breastfeeding. This superordinate theme looked more specifically at the groups themselves providing an insight into how they were able to support the mother.

It was here that we saw how the online groups provided a sense of community and access to other breastfeeding mothers, likened to a tribe of likeminded people. It was noted however that it was pivotal to them to find an online group that not only provides information but one that supports them emotionally whilst doing so. The mothers interviewed highlighted how they had to find the right online community for them, and find where they fitted in, where they felt the safest and free from judgement and any conflict, which were two negative aspects of the group. More local groups, linked to NHS health services and served a local community were perhaps smaller in numbers, but contained fewer ‘keyboard warriors’ than the larger national groups.

**Theme three:** Different types of support at different times: *“You don’t bother professionals with something you can solve in a different way”* (Emma).

As noted within previous themes all mothers experienced times when they had breastfeeding concerns and would often select support from a variety of community, face to face, telephone, professional, peer, online and family support to help them. Support is an ambiguous term and the mothers were asked what support meant to them. This third

superordinate theme describes how they define online support and the thought processes around where they would seek support and why, making sense of the different types of support available to them. The mothers talked of an internal criteria or triage system that justified their choice of support avenue at different times in their breastfeeding journey.

**Types of support:** *“It’s all about that sort of experience”* (Lauren). Lauren described support in three distinct areas emotional, technical, and experiential. The emotional support she felt was words of encouragement and feels *“I received most of this type of support from my family”*. Emma also defines support as ‘well wishes’, or words of encouragement from others. The technical support she feels comes from professional involvement and used *“when something’s not going right what do I do”*? The experiential support is the primary reason for using the online group. When discussing professionals, she felt professionals *“towed the party line and were going to stick to it and there is no deviation or explanation”*. The deviation from the party line was achieved through the group and learning from the experiences of others. Reflecting upon these feelings Lauren said: *“I think the do this and don’t do this kind of stops people from wanting to go forward if they feel they can’t do more things”*. Using online groups provided multiple possibilities.

Val also values the experiential learning and values this highly: *“I have to say it’s the only thing that has kept me breastfeeding so long”*. Even when working with health professionals it was the experiences of that professionals that she values highly: *“I was talking to someone that knew what they were talking about because she’d fed her son”*. Teresa also values personal experience, listening and connecting with people that are also breastfeeding.

Interestingly, Gail evaluates how she perceives the different types of online groups and values the evidence based informational support. Gail describes the groups that she

perceives as good as the groups that relay NHS guidance and conversely describes the groups as poor if there is no evidence base and offers more anecdotal personal accounts with little research being shared. The groups she perceived as poor caused her to feel disheartened:

*It makes me feel disheartened because I think we're trying our best to give out information [in her local group] the department of health and world health organisation have put millions of pounds into but someone's more inclined to listen to personal stories. I'm not saying it isn't valid, of course it is, everyone's experiences are valid but when you're giving the final word on a mums that need support we should we should really be giving, if we're true breastfeeding supporters we should be giving information for her to make a choice at the end of it.*

**Temporal moments in time for support.** *“To seek out the support of a professional I think you have to be really struggling”* (Jane). Within the following the mothers reflect on when and where they received different types of support. They reflect on a time in their journey when they most needed support, the places that they sought support, and the types of support they felt they required.

There were precise moments in time where the mothers felt as though they had achieved their vision and times when they had concerns. Teresa describes how up and until four months into her breastfeeding journey she was struggling: *“It was a journey of me really struggling until then, a journey of me really suffering”*. At the fourth month stage Teresa attributed this change to a change in attitude: *“I think I started to accept that some babies do really find it hard to um settle”*. Teresa, at this time, was also finding her own way of doing things, making her own choices.

Similarly, Emma describes building her confidence over time leading to the point where breastfeeding was no longer a conscious cognitive process and is more of an



unconscious “*habit*”. For Emma this was around nine weeks post-partum and remembers thinking “*Oh gosh I can do this, we’ve done it [ ] before this I was still concentrating on every feed, probably I didn’t stop concentrating on every feed for like 3 months*”. Up to this point Emma describes an “*accumulation of good experiences and good words of encouragement that all kind of build upon each other*”. Emma talks of how the group bolstered her determination and built her resilience.

Despite vocalising precise moments in time there were flexible perceptions of competence. Carole talks of personal moments where she felt as though there was a cycle of novice to expert and then novice again. Carole repeatedly referred to a loss of confidence and returning to a novice state. Carole reflected on the early weeks as being the hardest and feeling unprepared: “*it took a good few weeks to get on properly, properly attached. [ ] The first three or four weeks were the most difficult [ ] I felt unprepared for twins*”.

Jane, as a medical professional, took a medical approach to seeking support. She applied an internal triage system in her mind about who to seek support from. Jane was first introduced to the online group around three months, by a friend, but in the early days felt that professional support was best if she was struggling: “*to seek out the support of a professional I think I have to be really struggling*”. Professionals included General Practitioners, Midwives, Health Visitors. She felt as though they were there for emergencies. The online group however included her peers, where she felt she could ask more trivial questions:

*The online group was for minor things, day to day things that you think aren’t necessarily a problem but you’ll be wondering about something or baby’s doing something different whilst they’re feeding or something you wouldn’t like to bother a professional about.*

Jane also used [www.Google.com](http://www.Google.com) to search for information and used walk in groups, reflecting:

*You don't bother professionals with something you can solve in a different way. I know how overwhelmed everybody is and if I had a genuine issue that I couldn't solve without seeing someone face to face then I would access that but if there's another way to solve a minor issue that's not an emergency or doesn't necessarily need the healthcare professional then I'll do it I guess and another thing I won't feel like I'm wasting anyone's time.*

Jane is seen here prioritising services as she perhaps would, working in the NHS. The rapid and reassuring posts reinforced Jane that her triage system was the right approach. Jane felt “*there is absolutely no substitute for face to face review because you can't do that kind of assessment and give that kind of advice without watching a feed*”. Face to face support for Jane was reserved for issues such as attachment. Jane also considered the emotional aspect of leaving her house to obtain support as she said it was a daunting experience to leave the house and required courage to meet new people.

Emma believes that support is required in two distinct stages, in the early days of support and then support to continue breastfeeding:

*There are two different types: establishing it, the connection and then continuation. They are two different things, I think. This makes sense because were always talking about women still breastfeeding at X amount of weeks that don't know how to continue, and they don't have the support to continue.*

Emma feels that there is a need for face to face support at stage One where she is learning a new skill: “*support is generally someone in person, I think in person is invaluable, until you've got a bit more confidence*”. Emma feels it is crucial to have someone watch and read

her body language and support practically in the moment through individualised one to one care. The second time and place for support Emma describes the second stage as the continuation of breastfeeding and less personal it's the *"reassurance from others that it's OK and normal reassurance that it will get better, reassurance that you're not on your own"*.

The group supported Teresa at a time when she had *"severe baby blues and I just blamed everything on breastfeeding, and I knew it was just giving birth to a child"*. Teresa talks a time when she *"was posting two to three times a day. I did have a lot of problems and I remember that I posted constantly"*. Doing so made Teresa feel less alone and provided emotional support for her:

*It made me feel less alone and thinking oh God it's not just me that is going through this and feeling awful for I feel like I'm torturing my own child trying to breastfeed him [ ] clearly I'm doing something wrong and I'm not good enough.*

Teresa feels the network of support from professionals, family and online *"all combined really helped me. If I'd have just had one support system, then I might not be feeling as good as I am now"*.

Often online and face to face support were compared. Carole, when talking about professional support refers to a biomedical model of breastfeeding such as checking the latch and the checking the position and attachment of the baby at the breast. When in hospital, with access to professional support Carole was still using the online group for advice, which she describes as fantastic: *"advice that they gave there in terms of how to move from the little bottles was fantastic"*. Carole also saw an International Board-Certified Lactation Consultant (IBCLC) to check her baby's attachment and feels that professionals are there to provide tangible and practical support. However, she felt a distinct lack of time was provided by the hospital staff led her to look online for more information.

If choosing between online and face to face support Gail felt online support was better: *“online because it’s easier, I think it is easier to access but I think you get better support face to face”*. Gail felt that face to face support allows for interaction and observation which adds value however online support provides *“a network of breastfeeding mums that are still feeding at two o’clock on the morning and somebody’s there”*. However, the face to face group helped her find what she believes are lifelong friends. A friendship based on reciprocity whereby she helped others and others helped her.

Some mothers experienced a degree of social anxiety meeting new people, and for this reason preferred online support. Overall, the online support suited Lauren because it reduced small social anxieties, she felt meeting people face to face: *“personally I never went locally because I could find them a bit awkward”*. Lauren states she finds social venues quite difficult to enter and with the online group she did not have to worry about the initial social interaction.

Chloe also felt that the online platform has made it easier for her to learn the social experiences of others from a distance: *“it means that I can ask questions and find out about other experiences without having to do the face to face and small talk bit”*. Teresa also states, *“the online community I feel I’ve got so much support from the online community than I did face to face, it was more comfortable, well it was for me anyway, very uncomfortable for me to go to a breastfeeding group”*. Teresa experienced self-doubt and compared herself to others and when attending group: *“I just remember sitting in the corner crying it was awful”* she felt as though she was being judged, The online group provided a safe space free of these experiences and where she was no longer alone.

Teresa also felt the ease of access as a positive aspect of the group. The ease of meeting other people reduced that feeling of being alone and reduced her social anxieties:

*Everyone nowadays has a smart phone so if you're breastfeeding you can be on your smartphone and asking is this normal is this normal whilst it's happening, and you can get a quick response. It does feel as though you constantly have support, even if I post at two o'clock in the morning. In a way I didn't have to leave the house, I didn't have to get dressed, I didn't have to smile whilst I was struggling.*

For Teresa it was more than ease of access to others it was the anonymity that the group provided and the anxiety of social interactions that were alleviated from this online medium: *“it made me uncomfortable when I had people face to face asking me about and trying to support me”*.

### **Theme Summary**

This third superordinate theme looked at how the mothers defined and utilised online support in relation to other support avenues at different times in their breastfeeding journey. All mothers were represented within this theme (see Appendix J). Overall mothers characterised the online social support groups as offering emotional, technical, informational, and experiential support. There was value in the experiences of others who shared within the groups. Despite access to evidence-based information the mothers felt that the experiences of others provided more options for them when faced with a concern. Interesting the second subordinate theme emphasised an ongoing need for support. The mothers disclosed how the group build self-confidence but that they moved in a cycle of novice to expert and then back to feeling like a novice again at times. The early weeks were highlighted as the hardest time requiring all types of support, and they ranked their support needs as either major or minor problems and would seek different avenues of support for each. More minor problems requiring emotional support were passed to the online group. Major problems such as attaching baby to the breast were technical issues and required more professional support and face to face. Overall, there is a need for many avenues of support, at different times in the

breastfeeding journey. A clear understanding of the support needed helped mothers to decide on the avenue taken. A place for online support within the list of support interventions is warranted, and the outcomes of this support is discussed in the following theme.

**Theme four:** The impact of the online social support group. Potential impact: “*massively, massively reassuring*” (Carole).

During the interviews, the mothers were asked: “*overall how would you describe the impact of the group on your breastfeeding journey*”? This question invited them to provide examples and reflect more deeply on the impact of their experiences: “*Did the group cause you to feel differently about breastfeeding and when did this happen*”. Five main sub themes emerged, three of which related to the individual and two related to the more social aspects of the group. The three sub themes that emerged that related to the individual discussed how online support group use increased their confidence, provided reassurance, and normalised their experiences. A further two subthemes emerged that related more to being part of an online community and included reciprocity and activism. These subthemes will now be discussed.

**Confidence.** Firstly, confidence was a reoccurring theme within the narrative.

Emma’s talked about the confidence she has gained from using the online group:

*It’s kind of given me the confidence to say that this is what’s working for me and I’m not going to change and I don’t care what people say which is a strange side effect, but quite a useful one.*

Emma states that her “*tribe*” has provided “*other people’s opinion and other approaches... which are absolutely amazing and has given me ideas that I never thought, have never occurred to me. So, the confidence to question*”. Val also describes how the confidence she gained was through the information that the group provided: “*no this is normal he’s trying to*

*regulate my supply; this is the full fat cream*". Val talked of the confidence being needed and how she felt it was able to *"protect from the pressure, I'd of succumbed to the pressure"*.

Many felt their confidence grow through the group knowledge:

*A lot from having the knowledge and because I've gone through it myself I can say I tried this and it worked and just having extra support online and in person because everyone's a bit more supportive not that everyone's got used to it and just time.*

(Chloe).

Having the group in the background was constantly reassuring (Lauren).

*Knowing that there are other mums out there doing the same was really useful, and things like just knowing, being able to ask, it reassures you that you're heading in the right direction* (Anne).

*It's just fascinating, I wouldn't have been breastfeeding if it wasn't for the group*  
(Tracey).

Tracey attributes a growth in confidence as the main reason for successful breastfeeding.

**Reassurance.** Anne mentions reassurance here, another sub theme identified. Carole also states that the group was reassuring: *"massively, massively reassuring"* and a *"lifeline"*. A temporary struggle for Jane was overcome through the reassurance from the online group. Jane describes a time when she was returning to work and her baby would not take her milk from the bottle. She had sought professional support and asked her Health Visitor and was told *"some babies never take a bottle"*. This angered Jane as it was not constructive advice, and family advice was not considered credible:

*My mother's generation have probably forgotten quite a bit and probably very different then. I think it's great to get up to date information from people that are*

*actually and currently breastfeeding and who are peers and not necessarily professionals. [ ] yea reassurance that it had happened to other people and they had found a way and you know coming away with multiple things to try as opposed to just like oh you've got one of those babies that won't take a bottle.*

Jane places value in the experiential learning of others and their words of encouragement:

*Reassurance that it will be OK. I think that I can accept that a little more easily from a peer. A professional might have some knowledge but hasn't necessarily had that experience themselves.*

Jane also felt that in a large national group such as this that reassurance is easily sought due to the high numbers of users: *"the odds of finding someone with the same specific situation that shared experience that you would like to know more about is high"*. Whereas Anne found the group reassuring *"it makes you feel a little bit more like, a little bit less concerned about doing it, because you know there was another couple of mums doing the same"*. Anne belonged to a smaller more local based Facebook group and was reassured that mothers in her local area were feeding around her. Anne enjoyed her local online group *"it makes you feel a little bit more like, a little bit less concerned about doing it [Feeding in the local areas]"*.

Chloe found reassurance from the fact that the other mothers within the community were well informed and had experience. The sense of community felt by Chloe was reassuring because she did not feel alone *"oh my God me too"*. She talks of how she felt less isolated because around here *"no one likes to talk about it [breastfeeding] it seems a bit taboo"*. This leads nicely into the next sub theme and feeling less alone.

Reassurance was also gained, through the group interaction, affirming the mothers' choices, as she found other with views that resonated with her own. Anne believed there are



many benefits to breastfeeding, so when told by a dietician *that “it wasn’t nutritious enough and that I needed to stop”* she sought information from the groups to affirm her own view point: *“I wanted to go armed with actual facts and literature that I could point her in the direction of that she was wrong, so I asked the group and in literally minutes”*. Anne had access in the online group to the information that she needed and was able to learn what was ‘normal’: *“things like cluster feeding! I don’t know why we weren’t told that at the breastfeeding course”*

Lauren felt the main reason she used the group initially was for affirmation, feeling as though her choices were the right choices. Lauren found the group particularly useful when breastfeeding an older baby. Lauren describes feeling awkward feeding after the age of two and feels the group normalised this for her *“I definitely don’t think I’d of managed that if I’d of not been in the group”*. Lauren is expecting her second baby and is using the group now to remind herself now of some of those early challenges that she might encounter.

Emma and Chloe also found the group affirming:

*It was amazing, it was like my instinct to carry on was the right one. I would have carried on regardless, but it feels like I could carry on and carry on and know it’s OK. I felt I was the only one fighting this tide of ‘you shouldn’t be feeding a 2-3-year-old’. Yea so that’s amazing (Emma).*

Chloe has a clear sense of self and idea on how she wanted to parent her children. She was careful not to pass judgement on others but looked to the group to affirm her beliefs. All mothers found the groups that they liked affirmed their beliefs, consequently with other likeminded people they felt a reduction in confrontation and negativity.

**Normalising.** The group was beneficial in making the mothers experiences appear the norm, especially when breastfeeding an older baby, feeding in public and child behaviours.

There are many times when the mothers felt judged by others, and within all the narratives, the mothers feel that society is not conducive to breastfeeding and that formula feeding is the norm:

*So, I think in this day and age because we have that generation gap, I do think that this was the only way to get support that you need at that time. I think my mum would have told me all this. Yea if my girls go through all this, I want to be that support for them to be able to tell them little bits here and there that you need to know along your journey (Tracey).*

Many mothers valued the information and celebration of feeding as important aspects of the group, especially in normalising breastfeeding. These were all key aspects of the group use and perceived gaps in knowledge and culture:

*I like seeing that there's lots of people saying ah I went and fed for the first time in public and I've fed somewhere unusual or I've managed to hit six months... I like seeing that I like the facts that people are celebrating feeding and that breastfeeding should be more normalised than it currently is (Anne).*

*It was the only thing that normalised it in my head. There were pictures on their everyday and that's the only thing that normalised it for me. Normalising breastfeeding was a main reason for using the group because it's not the norm, even though it should be, it's not the norm" (Emma).*

*I was trying to find out if it was normal, I didn't know what normal was. I just assumed they'd have breastfed like 3 times a day and like three meals a day. [] I grew up with my mother telling me it was beautiful and to do it. [] I feel like I'm part of something, like part of a community and it's nice, it's a nice feeling. You mainly see*

*bottle feeding out. I think it should be normalised so that people feel confident to feed in public” (Teresa).*

*It’s normalised later feeding well for me being on these groups and people are still feeding at 18 months to 2 years (Jane).*

Jane talked of not being exposed to longer term breastfeeding in society, so the group has provided that experience. The group has also changed the mother’s attitudes around feeding the older child, providing a broader view:

*Once I saw a baby that was 18 months or so or 2 or older and, in my mind, saying oh still breastfeeding that’s strange because that the way society shapes our beliefs. But since on this group my baby’s 10 months old and we’re not going to stop any time soon you know and I’m of the opinion now that we’ll stop when its right for the both of us to stop you know. I feel more empowered to feed whenever and wherever and for as long as we want to do it (Jane).*

*The thing I find most reassuring now is that people, the women on the group they, there’s people that post pictures of themselves everyday feeding. There’s just pictures on their everyday and that’s the only thing that normalises it for me. Apart from the women on the website I only knew one other girl that was breastfeeding. The group normalises feeding an older baby (Val).*

*How I see the breastfeeding has changed over time. It is more real now, and it has broadened my view of it. That view of being an ‘earth mother’ has changed to (Lauren).*

The mothers’ narratives often explored the stereotypes, judgements and stigmas around breastfeeding, and highlights that the online groups helped to change these

judgements through normalising breastfeeding. The judgements that the mothers have faced also goes some way in understanding behaviours and highlights the appeal of online support.

Lauren offers her own previous assumptions around breastfeeding mothers, prior to having her own child, and based on the culture in which she grew up. Lauren saw herself as “*not very earth motherish*”. To elaborate she described an earth mother as “*holistic, wishy washy and not scientific based*”. She feels that an ‘Earth Mother’ is a persona associated with breastfeeding mothers, and especially linked this to mothers that breastfeed toddlers and co-sleep. She has a clear identity of herself as a professional woman, logical thinking and organised thus “*not very earth motherish*”. Lauren challenged her own stereotyping around breastfeeding mothers once she became one herself, and through meeting others in the online groups.

Prior to Val’s breastfeeding journey breastfeeding had held a negative stereotype:

*Oh, yea there is in my head [a stereotype] before I started that mums who breastfed for too long had many attachment issues of their own, yea I definitely thought that. I would have been disgusted if I’d thought 15 months ago, I would have still been feeding him but now its fine. Its’s OK. The group is completely responsible for that change in my attitude. If I was to have another baby I would not, not consider breastfeeding. I’d feel like I was denying them something amazing.*

This view demonstrated negative stereotyping towards breastfeeding that, through her own experiences rather than culture, she challenged.

Secondly Chloe describes a felt stigma around breastfeeding mums being seen as preachers: “*preachers, you must breastfeed, or your child will suffer*”. She herself when joining the group thought “*oh my God breastfeeding mums*”. She believed that breastfeeding mothers were activists and opposed to formula feeding. Chloe, despite feeding herself,

thought others would feel the same as she did. When speaking with others she was *“terrified of talking about it or telling people that I breastfed. I’m quite paranoid anyways, but um it just makes me feel anxious”*, this is contrast to being at home and *“feeling happy and relaxed at home breastfeeding her babies”*. Chloe reflects and feels *“this is the perception of breastfeeding mums”* but questioned *“or maybe I’ve just met the wrong people. But you’ve got to be careful who you talk to it’s like a landmine”*. This stigma stops Chloe being her authentic self *“I am very proud of the fact that I breastfeed especially because I didn’t think I could and doing it with twins, but it feels like I’m not allowed to be proud of it”*. Chloe shows to some degree how she feels repressed as a breastfeeding mother by stating *“I’m not allowed to be proud”*, as if society forbids her to outwardly celebrate her achievements of successful breastfeeding. The online group allows her to do this, its normalised breastfeeding.

Teresa discusses normalising breastfeeding to reduce judgements. The judgements that she had heard, and explains how she tried to support others in the online group to not be judgemental, and to support each other:

*Some people can be like if you don’t breastfeed then you’re a horrible woman, and that’s not support, and you know don’t judge. It can be quite intimidating to come across people going like it’s disgusting to give formula. I’ve always thought look its support not judge, be nice not nasty. [] Someone to be fighting your corner and someone’s got your back, someone to be like it’s OK you can do this you’ve got this.*

Similarly, Emma and Val talked of being judged by others for feeding an older baby *“I find it really strange. It’s like we should be ashamed partly because they’re breasts and we’re doing it for our own good and partly because of our child”* (Emma). *“People were appalled I was still feeding a toddler, give him a bottle, give him a bottle, that what I got all*

*the time from everybody neighbours, family even my mum*” (Val). The online group supported the view that feeding an older baby was normal.

Val describes how the judgements of others changed her behaviour and even caused her to disengage from friends: *“I’ve gone through quite a lot emotional struggle really about how long, um how long it’s acceptable to feed for”*. At points when describing her friends speaking negatively of breastfeeding, she whispers *“then I thought God that could be me”*. There was a need there not to be judged that affected her behaviour in such a way that Val actually distanced herself from close friends whom she thought might judge her *“I really haven’t spoken to \* for a while because I’d worry if she would say Oh are you still breastfeeding”*.

Val also received negative comments about breastfeeding from friends and family and acquaintances receiving comments such as *“oh just give him a bottle”*, even from her mother. These were not judgments seen within the groups as the groups normalised breastfeeding. When discussing returning to work Val talks of hiding from society *“a few weeks back into work and I though actually I can manage this people don’t actually have to know I’m still feeding because I don’t have to feed him in public anymore, nobody asks so nobody knows”*. Val however was proud of her breastfeeding and by breastfeeding stated *“I was sticking two fingers up at the product [formula milk] and the product placement and like being told their milk is more superior to mine, I felt like I was sticking two fingers up at the establishment really, fly high for breastfeeding so you know what I mean. I was pleased she breastfed”*. For Val the group provided a space where breastfeeding is normal.

The narratives show that judgements are passed, and that these judgements affect the behaviour of those they are directed towards. It is also seen how the mothers themselves have

challenged their own judgments. In both cases the online support groups can provide a space free of judgement, and the mothers actively try to reduce judgement in the groups they use.

**Reciprocity:** *“If there’s anything I can give back then I’d love to” (Tracey).* This subordinate theme discusses the community of reciprocity felt within the group, and that reciprocity creates a lasting community. For most mothers, receiving online support has led them to want to reciprocate and give back some of the knowledge and experiences they have had, which further builds the community. This is described in the following:

*A reciprocating situation [] there’s always people on their asking questions but then further down the line you’re the one that can answer questions (Carole).*

*You are talking to someone who’s taken the time to reply to your post that you have put on there, having empathy from another person who is also going to understand you. A shared empathy of being in similar situations (Jane).*

Most of the mothers now use the group to help others, just as they were helped: *“I’m a frequenter commenter, I comment a lot and try to pinpoint to resources”.* Emma values the fact that she and others have access to: *“informed, unbiased advisory sources”.* Emma states she will continue to use the group indefinitely so that she can help others to make their own choice: *“So far for me my role is definitely I’ve got information and I really needed that and I really needed that when I was starting out so maybe I can do that for someone else”.* Emma talks of not knowing important information and feeling that through the community of reciprocity she could help others so that they do not have the same troubles as she did:

*I regret how I fed my daughter because I fed her on a three-hourly schedule. I think she suffered because she had to wait, and I think I deprived her of the nutrients and antibodies that she could have had and maybe it’s encouraged me to feed her as long*

*as she needs. Why did no one tell me that, why didn't the breastfeeding people tell me that.*

For Emma, her milk supply reduced due to infrequent feeding and Emma gives back so that others are not as uninformed as she was. Similarly, Tracey Chloe and Jane all enjoy supporting others. Tracey said:

*I think of how much it gave me, and If I could help someone who has a question and it's not for me wanting to help now but if there's anything I can give back I'd love to and that makes me feel nice for doing it.*

Tracey enjoys the breastfeeding support group but also joined another online breastfeeding support group relating to feeding older children. Tracey believes that feeding older babies group provides her with experiences from others like hers and still receives that normalisation and experiential learning from people going through the same thing as her. She can support and continues to feel supported. Chloe's experiences and knowledge and growth into her role of breastfeeding mother has led her to want to give back and become a peer supporter and help others. Chloe states *"I think I'm more pro breastfeeding than I was. Before it was take it or leave it, but now I know more about it"*. The group had empowered Chloe and encouraged her to give back and share her learnt knowledge. Jane explains how previously she would have *"lurked around"* however she has *"started to become the advice giver"*.

Teresa describes the group as:

*Vital if you're struggling and even if you're not struggling you can put 'I've had a wonderful breastfeeding experience'. From the get-go you can offer advice and how it works for you and stuff so I think it's just really helpful for anyone whether you help or can give help.*



Teresa appreciated the community reciprocity and celebration of breastfeeding: *“and people praising you when you get to certain months and being able to praise others”*.

Alternatively, Anne described a time when she no longer reciprocated within the group. As part of the group Anne was also part of giving back information to other people and enjoyed an environment that celebrates breastfeeding. Reciprocity was felt by Anne who states that a few months after being in the group stated:

*I’ve done my bit and I came off [of one particular group]. You can get pulled into responding to people a lot and it sounds a bit harsh but I’m not helping those people so much anymore, but it got to the point where I was on there a lot responding to people. But it wasn’t positive.*

Anne demonstrated an ability to control her online environment and when she felt there was an imbalance towards the negative aspects of the group then she withdraws and focused on the groups which were positive. For Anne it is was important that she was happy: *“well it makes you feel good doesn’t it, it makes you feel happy and pleased to see there’s lots of people breastfeeding, and you’re doing the right thing for your baby”*.

Similarly, the reciprocity seen by Val was a group effort. Val does not post on many occasions to the group however states she occasionally comments if it is something, she is going through herself. She reflected on her decision and stated, *“this appears selfish”*, however Val knows that if she does not someone else will as there is a shared responsibility within the shared community.

Gail also wanted to help people but at times felt obligated to help other: *“you could be my worst enemy and if you come to me with breastfeeding issues, I will help you”*. Gail’s motivation for supporting the community is both egoistic and altruistic. On one hand she is developing her career and on the other hand believes it is in her nature and why she became a

nurse. She reflected on her love of problem solving and hate of seeing people suffer. Gail also stated that *“I feel worried that if I need something in the future then people might not comment and help me because they think I tried to talk to you last time and you didn’t respond”*.

**Activism.** *“I’ve gone from being a breastfeeding mum to a lactavist” (Gail).*

Activism refers to the mothers campaigning for social change and the term ‘lactavist’ dubbed as a play on words for an activist supporting lactation, a term commonly used on social media with no known source. When asked what the impact was of the group on Gail’s breastfeeding journey she laughed: *“I’ve gone from being a breastfeeding mum to a lactavist. They [the group] fuelled this fire that’s inside of me”*. Gail described how she did not feel that the fire had always been there and that the group is responsible for this and was proud to be considered a lactavist. Gail had previously completed a science-based degree and was interested in immunology.

Additionally, Gail belonged to a variety of different groups, each she perceives differently through a perception of the different attributes. Gail described a ‘secret group’ that she was invited to join: *“a secret group for really hard-core breast feeders. If you’re assumed to be a lactavist, if you’re really passionate about breastfeeding you get invited into”*. Gail describes the hard-core breast feeder as someone who fights for the rights of women in society. Gail was happy to be associated with the group because of her commitment and belief in breastfeeding and said, *“I think I annoy people, [people with whom she works with supporting breastfeeding] because I am so proactive. I wouldn’t want anyone to feel put out by my passion. I’m not trying to show off”*. This is a brief glance of the negative side to Gail’s strong commitment and belief in breastfeeding which could go part way in explaining the stereotype described by Chloe, all be it unintentional, by Gail.

Similarly, Emma talked of women's rights and feels passionately about women making informed choices: *"I become very passionate about women's rights and informed choice. I'd like women to have information on these humanity-based choices"*. Tracey also discussed women helping women and empowering each other: *"women need to come together and support themselves, and utilising Facebook in a completely different way, and men wouldn't use it, they don't need the same support, I don't think you'll get this in a male group"*. Tracey feels that breastfeeding is unique and that women should empower other women. In fact, Chloe stated *"if something comes up and I wanted some advice, I wanted to try baby wearing and a baby sling, so I found a sling twins group. I look on Facebook now instead of googling"*.

### **Theme summary**

All the mothers are represented in this fourth superordinate theme (see Appendix J), which discusses the potential impact of using an online social support group. The mother's stories talk of a growth in confidence in their breastfeeding journey, and how the group reassured them, affirmed their choices, and normalised breastfeeding for them. This normalisation often came with changes in their own judgement of breastfeeding mothers and highlighted the judgement of others. Linking back to previous themes the groups are certainly spaces of likeminded people that once supported then continue to support others. These reciprocal behaviours help to build online communities, reflecting upon the point made at beginning where we are now seeing hundreds of Facebook support groups. This theme highlighted that some women became involved in their new role as a breastfeeding mother, supporter to others, and now activist. This theme highlights not only changes at an individual level but as a social level, building online communities that help fill a gap between their vision and reality. Overall, women supporting women is viewed as a unique aspect of the

group, and many wanted to bring about social change so that breastfeeding was talked about and celebrated more. The group provided a place to do this.

### **Discussion**

There is now a growing amount of literature into the potential of online support groups as a breastfeeding support intervention (Alianmoghammad, Phibbs & Benn, 2018; Bridges 2016; Jin, Phua, & Lee, 2015; Tomfohrde & Reinke, 2016), and this is one of the first IPA studies, undertaken in the UK, that provides an in-depth exploration of the use of online breastfeeding support groups. Four themes were identified from the research: two discussing the needs of the mother both individually and socially, one emphasising the types of support and support needs and one on the impact of the group.

Ten women spoke openly about the phenomenon and provided rich data into why and how they used online breastfeeding support groups, and the impact of the groups on their breastfeeding journey. This research shows that online social support groups provide emotional support alongside the sharing of information and experiences. The groups were used to affirm the mother's choices, grow confidence and provide reassurance, findings consistent with past research, strengthening the evidence in this area (Bridges, 2016; Brown, 2019; Hanning & Day, 2009; Schmied, Beake, Sheehan, McCourt & Dykes, 2011; & Wade, 2009).

The literature highlights the importance of immediate and early breastfeeding support (Darmstadt et al., 2005). Health related information (Informational support) was noted as the main reason for accessing social support groups in some studies (Coulson, 2005; Oh and Lee 2012; & Yoo et al. 2013), and emotional support highlighted in others (Baum, 2004; Cowie, Hegney, Fallon, & O'Brian, 2008; Hill & Robinson, 2011; & Hoddingnott, Chalmers & Pill, 2006). This study adds to this body of literature by suggesting that there are better outcomes

for mothers when receiving both together, hence support groups may be more beneficial than a simple online search for information.

There were mixed messages around the balance between experiential support and evidence-based informational support, and the decision to change behaviour based on the information from either type of support was largely dependent on the issue faced. This research highlights that experiential learning is a factor that draws mothers to these groups, as is the evidenced-based support. Some studies have shown how although women were drawn to online chatrooms by the peer experience, they were less willing to trust the advice they found in such locations (Newby, Brodribb, Ware & Davies, 2015; & Silence, Hardy & Briggs, 2013).

The experiential learning from others was seen through the discussion around Co-sleeping, defined as an adult and baby sleeping together on any surface (Blair & Ball, 2004), and was discussed by most mothers as something that supported their breastfeeding journey, and something that was normalised in the group. Herron, Sinclair, Kernohan & Stockdale (2015) states that online social support groups can normalise any type of behaviours amongst members.

Co-sleeping is classed as a risk-taking behaviour because of its link with Sudden Infant Death Syndrome (SID). The risk of SIDS to any baby is 1 in 3180 children (ONS, 2016), and from the 700,000 babies born in the UK each year (ONS, 2016), 350,000 babies have co-slept with an adult before the age of three months (Blair & Ball, 2004). In 2016, 219 babies died from SID (Vennemann et al., 2009) and half of these were co-sleeping with an adult (Blair et al., 2009). The mothers in the online groups often disclosed how they co-slept with their baby after seeking support from others online. They were aware of the risks and learnt of ways to practically manage their night-time breastfeeds, often not disclosing their behaviours to professionals through fear of judgment.

The groups themselves were internally audited by the user based on the evidence being used. Newby (2015) discussed how the online forums may be characterised by a low level of professional and evidence-based knowledge, but this study showed the women and groups sharing reputable sources, collating files, so that the women could navigate through. Although peer support was highly valued, there is a risk that the information is inaccurate, especially in unmoderated environments (White & Dorman, 2001).

Managing night-time breastfeeds is just one example of a breastfeeding issue discussed within the group. These mothers' stories highlight a need for support at different times throughout their breastfeeding journey. They talk of feeling like a novice when an issue arises and then developing into an expert. They describe a cycle of continually learning, often returning to feeling like a novice again, when another issue arises. Herron et al. (2015) talked of mothers gaining knowledge from online support until she becomes an expert, however a more cyclical model is suggested within this research.

The theory of 'Becoming a Mother' (BAM) (Mercer, 1981) is a pertinent theoretical link as the breastfeeding mother is learning new skills and developing a new role and identity as a mother. BAM describes how, over time, the mother develops a maternal identity and finds her own way of mothering her child, an important influence on the mother/ infant relationship. This research demonstrated how support was not a linear process, something that was received and not needed again. At times mothers felt confident, but then faced new challenges and again needed support. It is noted that those struggling with transitional states may benefit from the opportunity to discuss it with another (Harrison, Neufeld & Kushner, 1995). The online groups were seen to support the development of this maternal identity through the availability of information, factual and experiential. Following the birth of the baby, Mercer describes a period of time when the mother follows the information learnt during pregnancy, but then after 6 weeks the mother moves towards a new 'normal to her',

characterised by the mother finding her own way of doing things. This is a time where confidence is needed, and the mother's choices need affirming to reach maternal identity (Mercer, 2004). Use of such a theory in the design of breastfeeding services would strengthen the theoretical element of interventions.

The mothers often frequented many groups until they found their 'tribe'. The importance of a sense of community is also found in existing literature (Holtz, Smock, & Reyes-Gastelum, 2015), with peer support known to play a vital role in breastfeeding support (Gill, Reifsnider & Lucke, 2007; Hegney et al., 2008; & Hoddinott, Chalmers & Pill, 2006), as individuals are seen to identify through social comparison, and relate with persons like themselves (Tajfel & Turner, 1985). Women are increasingly isolated in postmodern society (Drentea & Moren-Cross, 2005), with a loss of informal support and in the interactions surrounding motherhood that they would have traditionally shared (Litt, 2000). The changes in society are noted in the introduction and provide a rationale for this research.

This research goes part way in exploring and making sense of what the mothers wanted from the online community and how mother navigated the social support options available to them. The mothers talked of frequenting many groups until they found the one that felt right for them. Often the term 'we' was used instead of 'I' when the mothers were relating their stories. This research highlighted many more groups than originally anticipated.

There were breastfeeding support groups and groups titled as such, but also breastfeeding groups for older children, new mothers, mothers with twins, children with allergies, parents who are doctors, and groups for those deemed as 'lactivists' (activist in lactation). Groups were also national, or more local and linked with face to face groups, contain a few, hundreds, or thousands of members. One outcome drawn from this research was how some mothers became breastfeeding activists, committed to improving support for other, who even have their own invitation-only groups. Jin et al. (2015) found that larger

groups were more visible and had more active members and therefore were of greater interest and appeared more credible.

This research goes part way in illustrating that an important aspect of the group use was that the group felt like a safe space, characterised by a place with likeminded people, that celebrated and openly discussed breastfeeding. This was often compared to today's society where legislation, such as The Equalities Act (Gov.uk, 2010) needed to be enacted so that women are legally supported to feed in public. However, the groups were not always deemed safe, sometimes containing conflicting opinions, judgements, and enforced rules by others.

Reciprocity between members was seen in most cases. Online groups are noted as being dependent on the willingness of members to share information with others (Jin, Phua & Lee, 2015). In the cases where the mother did not actively engage in reciprocating support there was a belief that the other members would. Reciprocity and connectedness of the community is found in other studies to be held in high regard (Bridges, 2016). Previous research has shown how groups enable widespread collaboration and interactivity with users playing a role simultaneously as both receiver and provider of information (Bennett & Glasgow, 2009). This research highlighted a move from novice, and being supported, to expert and being the supporter, a journey that led to reciprocity.

Discussion around the social ties associated with social support provide an interesting literary link for this research. This research showed Carole describing the group members as 'faceless and invisible', a weak social tie categorised by a lack of relational closeness to an individual (Aldelman, Parks & Albrecht, 1987). Holtz et al., (2015) described weak social support ties between group members, which were made through common connections, and seen in this instance. However, there was a strong tie to the group, and Carole's narrative demonstrates this. Carole described how reassuring the group was and how it was her 'safety net'. Strong ties are associated with increased wellbeing, whereas weak ties are associated with



poor social support (Wright, Raus, & Banas, 2010), however in this instance this was not the case. More recently, in the literature it is noted that there is an ability of non-close relational partners to provide social support regardless of network structure, particularly online (Walther & Boyd, 2002). Further research into the social support ties in these online communities would further expand this area. O'Connor and Madge (2004) found that the weaker ties and anonymity of the internet make it easier for mothers to ignore offered advice that does not fit with their own ideas, as well as speak candidly to others.

### **Study limitations**

IPA is not widely used to explore breastfeeding support, although it is utilised in nursing practice because it also offers lengthy analysis of the lived experiences. This study does not aim to produce generalisable findings (Eatough & Smith, 2008), it aims to provide possible interpretations of the phenomenon. It shares the experiences of mothers using the online support groups to explain how the groups may be effective in supporting breastfeeding mothers. Taking a critical realist approach, it does identify patterns and trends in the data but acknowledges that different cultures may hold different beliefs and that these beliefs may change over time.

A criticism of qualitative research is that it can be journalistic, so this study aims to minimise this through noting the context in which the study occurs (Morse, 2006). Researchers' must write a story and analyse in a way that is open to alternative explanations (Holloway & Biley, 2011), and with elements of realism, truth, authenticity and authority but also use some techniques of fiction to make the report interesting and clearer for the reader (Caulley, 2008).

Thirdly, as a Health Visitor, Nurse, and lactation consultant there will undoubtedly already be many experiences of breastfeeding support that could bias the interpretations made (Sherman, 2015). To limit this a reflective journal was completed throughout the study to

note thoughts and interpretations as they occurred. This was utilised during supervision and the interpretation stages to help highlight any potential bias and to provide opportunity to challenge this. Appendix K presents an example of reflexivity using a framework by Sherman (2015). Through noting's and supervision, it was hoped that cognitive and confirmation bias particularly could be minimised. Cognitive bias addressed the mental models that may have already formed as a practitioner, which may influence reactions and interpretations to a situation (Sherman, 2015). In fact, it was noted that the model chosen was borrowed from the nursing literature itself. Confirmation bias, whereby current opinions are favoured and those that challenge a view are rejected, was also challenged (Sherman, 2015, Brown, 2019).

### **Conclusion**

This study has explored the experiences of women using online breastfeeding support groups and explored the mothers understanding as to why and how the groups have been used. All ten mothers provided individualised personal account of using the groups and what it meant to them. All mothers alluded to the informational, emotional, and experiential support it offered, whilst they were 'Becoming a Mother'. Support that bolstered their confidence, provided reassurance, affirmed their choices, and normalised breastfeeding so that they did not feel alone in their breastfeeding journey. One statement "*Can we talk about other ideas*" resonates with the overall results of this research. Mothers held a vision of what they wanted breastfeeding to be like for them, and when faced with problems large or small they wanted options so that they could find their own way of doing things, and a main step within the theory of becoming a mother.

This study did not aim to generalize the online experiences as merely labels of support types, but rather understand the complexities of breastfeeding today and to add to the body of literature that considers breastfeeding interventions, their effectiveness, and movement with technological developments. It is noted within the introduction that thousands of mothers are

already using online social support groups to support their breastfeeding. Understanding why and how these groups are used is key to understanding the needs of women when designing services. Computer mediated forms of communication could be viewed positively, however such interventions are not without risk, but these mothers voiced their need to learn from others, and to belong to a community of like-minded people that in society undervalues breastfeeding.

In summary, the literature around online breastfeeding support interventions is only now developing, and online interventions should be carefully considered so that they are designed effectively and with minimal risk. These mothers talked of wanting to hear from other mothers like themselves, and these groups should be promoted as a way of supporting the women's needs. No one intervention type will suit all mother's needs, at all times, in their breastfeeding journey, and so multiple interventions are required, but should be clearly identified. Given also that support can be offered at many different levels it is everyone responsibility to build a community, supportive of breastfeeding, online and offline.

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Appendix A, Research Advertisement

**ARE YOU A BREASTFEEDING MOTHER IN THE UK THAT USES AN ONLINE BREASTFEEDING SUPPORT GROUP?**

WOULD YOU BE WILLING TO TAKE PART IN A RESEARCH STUDY THAT AIMS TO EXPLORE MOTHERS EXPERIENCES OF ONLINE BREASTFEEDING SUPPORT GROUPS?

**WHAT WOULD I NEED TO DO?**

IF YOU AGREE TO TAKE PART, THEN A CONVENIENT TIME WILL BE ARRANGED TO DISCUSS YOUR EXPERIENCES VIA A TELEPHONE INTERVIEW. YOU WILL BE ASKED A FEW QUESTIONS WHICH SHOULD TAKE NO LONGER THAN ONE HOUR.

**BACKGROUND INFORMATION:**

THE UK HAS SOME OF THE LOWEST BREASTFEEDING CONTINUATION RATES IN THE WORLD SO I AM INTERESTED IN LEARNING ABOUT YOUR EXPERIENCES OF ONLINE BREASTFEEDING SUPPORT AND IF THESE HAD AN IMPACT ON YOUR BREASTFEEDING JOURNEY. THIS RESEARCH INFORMS MY PRACTICE AS A LACTATION CONSULTANT AND FORMS PART OF MY PHD STUDIES AT CANTERBURY CHRIST CHURCH UNIVERSITY.

**INFORMATION:**

To find out more detailed information about the study and to take part please contact me:  
**Mandy Wagg.**  
email:  
**m.wagg524@canterbury.ac.uk**

Appendix B, Participant Information Sheet/ Consent form

**Research Project title**

How breastfeeding mothers interpret their experiences and perceive the impact of online social support groups.

**Invitation**

Hello. My name is Mandy Wagg. I work as a lactation consultant supporting women with breastfeeding and founded a charity that does just that ([www.lactationmotivation.com](http://www.lactationmotivation.com)). I am also undertaking a PhD in Professional Practice at Canterbury Christ Church University with a specific interest in online breastfeeding support. My supervisors are Alex Hassett and Margie Callanan, and they are supporting me through my research.

I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being undertaken and what it would involve for you. Please take time to read the following information carefully and discuss it with others as you wish. Please email me directly if there is anything that is not clear or if you like more information. Thank you for taking the time to decide whether or not you wish to take part.

**What is the purpose of the study?**

The purpose of this research is to gain a detailed account of your experiences using online support groups aimed at supporting your breastfeeding journey. I am interested to know how you have found and felt whilst using the group and your reasons for using it. Your insight and views will help provide a snapshot of the group activity and how it may be used by breastfeeding mothers and potentially influence their breastfeeding journey.

**Why have I been invited?**

Mothers that are at least weekly users of a least one online breastfeeding support groups are invited to join this study as your views are of particular importance to me. You must however have been using the group for at least 4 weeks, had no previous breast surgery, and birthed a full-time healthy baby that required no medical intervention following birth.

**Do I have to take part?**

It is completely up to you to decide to join the study. Even if you agree to take part, you are free to withdraw at any time, without giving a reason. If you agree you will be asked to sign a consent form and you will get to keep a copy of the consent form along with this information sheet.

**What will happen to me if I take part/ what will I be asked to do?**

If you are interested, then we can arrange a mutually convenient time to conduct an interview over the telephone. I will ask you a series of open-ended questions about how you have used the group and how you felt interacting within the group. You will be given the interview questions in advance, at least the day before, to have a look at. There are no right or wrong answers your perceptions and experiences are what I am trying to explore. The interview should take no longer than one hour.

**Expenses and payments**

There should be no cost to yourself for completing this interview, other than your time. The researcher will contact you so that you do not incur any charges.

**What are the possible disadvantages and risks of taking part in this research?**

Participating in the research is not expected to cause you any disadvantages or discomfort.

**What are the possible benefits of taking part in this research?**

Whilst there are no immediate benefits for you participating in this project, it is hoped that this study will have a beneficial impact in supporting other breastfeeding mothers, and go some way in understanding what is required and thus what we can do as professionals in the future.

**What if there is a problem?**

If you have any complaints about this project in the first instance you should contact myself, Mandy Wagg at: [m.wagg524@canterbury.ac.uk](mailto:m.wagg524@canterbury.ac.uk) so that I can address your concerns. If you feel the complaint has not been handled to your satisfaction, then please follow the complaints section below.

**Will information from or about me from taking part in the study be kept confidential?**



All information that is collected in this study will be kept strictly confidential. Anonymised quotes will be used in the final write up. However, you will not be identified or identifiable in any reports or publications. Any data stored online will be password protected and any paper or electric copies will be stored as anonymised data and in a locked draw within the university. All data is stored for five years as per University guidance and will not be shared with any third parties. Only authorised persons such as the researchers', regulatory authorities and Research and development audits (for monitoring of quality of the research) will have access to data. After the five-year period, all data will be destroyed and disposed of securely.

**What will happen if I don't want to carry on with the study?**

If you have completed the research and then decided, you wish to withdraw all data will be extracted and no longer used.

**Complaints**

If you remain unhappy and feel I have not addressed your concerns and wish to complain formally, you can do this by contacting Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology Email: paul.camic@canterbury.ac.uk,

**What will happen to the results of the research study?**

As a participant you will have access to the preliminary findings in draft upon completion. Following this I am intending on publishing the results. To clarify you will not be identified in any report/publication. Anonymised quotes may be present in published reports.

**Who is organising and funding the research?**

I am organising and funding this research as part of my PhD at Canterbury Christ Church University.

**Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the Salomons Ethics Panel, Salomons Centre for Applied Psychology, Canterbury Christ Church University.

**Further information and contact details**

1. General and specific information about research or whether to participate is available from Mandy Wagg

Email: [m.wagg524@canterbury.ac.uk](mailto:m.wagg524@canterbury.ac.uk) , Tel: 07472663365 24-hours a day leaving a message for me containing your name and contact number so that I can get back to you. .

2. If you have specific information about this research project that is not answerable by Mandy Wagg then information is available from [alex.hassett@canterbury.ac.uk](mailto:alex.hassett@canterbury.ac.uk)

4. If you are unhappy with the study then please contact [Paul.camic@canterbury.ac.uk](mailto:Paul.camic@canterbury.ac.uk)

Centre Name: Canterbury Christ Church University

Study Number:

Patient Identification Number for this study:

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**CONSENT FORM**

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Title of Project: **How breastfeeding mothers interpret their experiences and perceive the impact of online social support groups.**

Name of Researcher: **Amanda Wagg**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated [15.03.80] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.
  
3. I agree to part in the study and for the interview to be audio recorded.
  
4. I understand that relevant sections of the answers I give may be looked at by Amanda's supervisors; Alex Hassett and Margie Callanan. I give permission for these individuals to have access to the data.
  
5. I agree for anonymised quotes to be used within the write up of the study and publication as long as the information is fully anonymised.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Please return this form electronically to the following email: [m.wagg524@canterbury.ac.uk](mailto:m.wagg524@canterbury.ac.uk) prior to the interview.

## Participant Information: Interview Schedule

Question: How do breastfeeding mothers interpret their experiences and perceive the impact of online social support groups: An Interpretative Phenomenological Analysis.

Setting the scene	So, tell me a little bit about your breastfeeding journey so far, in general -How old is your child, how long have you breastfed
Defining	How would you describe the online social support group in general, how would you describe or define it to someone that was thinking of joining the group?
Developing discussion	Could you talk me through your experience of online social support groups from joining the group to today in as much detail as you can
Describing meaning	From what you have told me: What is the most positive element of the group? What are the challenges? Was the group what you expected?
Providing examples	Overall, how would you describe the impact of using the group on your breastfeeding journey? Are there specific examples that you would like to tell me about? Did you make any changes to your breastfeeding decisions that were a consequence of using the group? Did the group cause you to feel differently about breastfeeding? And when did this happen? What do other people think of you using the group?
Looking forward	In what way has using the group influenced your future breastfeeding looking forward? Will you continue to use the group? When do you think you will discontinue use of the group?
Concluding	Is there anything we have missed in our conversation that you feel is important to tell me about the group
Prompts	You mentioned that...could you tell me what that was like for you? Can you give me an example of...? You said.... Can you describe that in more detail for me? How was.... different to you? You said.... Walk me through what that was like for you?

Appendix C, Participant Information Sheets

Screening question, pre interview briefing, post interview briefing as provided to the participant.

Participant Screening Questions:

Strictly confidential

All participants' will be asked the following questions to screen for inclusion and exclusion criteria of the study.

Was verbal consent obtained from the potential participant before asking the questions below?

Yes/No

1. Is the participant a breastfeeding mother?
2. Has the participant been using a breastfeeding online social support group for longer than 4 weeks?
3. Do they feel comfortable discussing their personal experiences of using online breastfeeding support?
4. Did they deliver a full-term healthy baby that required no additional medical complications at birth?
5. Has the mother ever had any breast surgery or health concerns that could affect her ability to breastfeed her baby?

### **Aims of investigation**

- To explore how breastfeeding mothers ‘make sense of’ and interpret their experiences of online social support group and to explore the perceived impact on their breastfeeding journey.
- Gain a fresh, rich, complex description of a mother’s experiences using online social support groups.
- Capture and explore the meanings that breastfeeding mothers assign to online social support groups, including the experiences, thoughts, reactions, emotions, and conflicts.
- Capture the perceived impact that the online breastfeeding support group has on any breastfeeding decisions made.
- To understand and interpret these experiences through asking those best suited to provide them.

### **Procedure of interview:**

- The interview will last for approximately one hour.
- The interview will be tape-recorded.
- All participants’ will be asked similar questions during the interview.
- The questions will act as a guide for the interview.
- The aim is to hear your experience.

### **During the interview:**

- If at any time you wish to stop the interview you may do so without giving a reason.
- You are in no way obliged to answer the questions provided by the researcher.

### **Confidentiality:**

- Your participation in this project will remain confidential as explained in the participant information sheet.
- Your personal details will only be known to the researcher.
- Anonymised quotes will be used in the final write up however you will not be identified or identifiable in reports of publications.
- Your personal details and tape recordings will be separated and held in a secure filing cabinet at the researchers’ premises. All data will be encoded, and password protected
- If you disclose information during the interview which leads to sufficient concern regarding your own or others safety, it may be necessary to notify a relevant third party without formal consent. If appropriate, before this occurred, the researcher would

inform the project supervisor to discuss the concern, unless a delay would result in a significant risk to health, well-being, or life.

**Provision after interview:**

- Following the interview, you will be given further opportunities to ask questions regarding the project and any concerns you may have. If the researcher is unable to provide you with the correct answers for your questions, she will endeavour to provide you with appropriate source of professional advice.
- You will be provided with a list of support services you may be interested in contacting if you feel you may wish to talk about your experience further.

**Questions**

- You are free to ask the researcher or the research supervisor any further questions you may have about this research study.

**Interview Schedule:****Demographic questions**

Age, geographic location, age of child, occupation, highest level of education obtained, Ethnicity, marital status, name of online social support groups used, Name of the group used most frequently, number of group members in that group.

**Question.** How do breastfeeding mothers interpret their experiences and perceive the impact of online social support groups: An Interpretative Phenomenological Analysis.

Developing rapport and a caring and empowering dialogue (Kvale, 2006)	So, tell me a little bit about your breastfeeding journey so far, in general  -How old is your child, how long have you breastfed
Definition and deliberate naiveté (Kvale and Brickmann, 2009).  Employing a neutral and non-committal approach (Denscombe, 2010).	How would you describe the online social support group in general, how would you describe or define it to someone that was thinking of joining the group?
Developing an open format (Smith and Osborn, 2015).	Could you talk me through your experience of online social support groups from joining the group to today in as much detail as you can
Providing narrative material intended to enrich the conceptualisation of the phenomena (van Manen, 1990). Building layers of	From what you have told me:  What is the most positive element of the group?  What are the challenges?  Was the group what you expected?



<p>meaning and asking more (Todres, 2007).</p>	
<p>Consequences of the experience. Ask for specific examples to evidence what they know (Hay and White, 2005).</p>	<p>Overall, how would you describe the impact of using the group on your breastfeeding journey?</p> <p>Are there specific examples that you would like to tell me about?</p> <p>Did you make any changes to your breastfeeding decisions that were a consequence of using the group?</p> <p>Did the group cause you to feel differently about breastfeeding? And when did this happen?</p> <p>What do other people think of you using the group?</p>
<p>Meaning of the experience (van Manen, 1990).</p>	<p>In what way has using the group influenced your future breastfeeding looking forward?</p> <p>Will you continue to use the group? When do you think you will discontinue use of the group?</p>
<p>Concluding</p>	<p>Is there anything we have missed in our conversation that you feel is important to tell me about the group</p>
<p>Prompts to scaffold interactions individually and flexibly to avoid mistaken assumption and provide greater depth (Wimpenny and Gass, 2000; Kvale, 2008; Arthur et al. 2012).</p>	<p>You mentioned that...could you tell me what that was like for you?</p> <p>Can you give me an example of...?</p> <p>You said.... Can you describe that in more detail for me?</p> <p>How was.... different to you?</p> <p>You said.... Walk me through what that was like for you?</p>

## **Debriefing Schedule**

### **Recap on purpose of study:**

- To explore how breastfeeding mothers ‘make sense of’ and interpret their experiences of online social support group and to explore the perceived impact on their breastfeeding journey.
- Gain a fresh, rich, complex description of a mother’s experiences using online social support groups.
- Capture and explore the meanings that breastfeeding mothers assign to online social support groups, including the experiences, thoughts, reactions, emotions and conflicts.
- Capture the perceived impact that the online breastfeeding support group has on any breastfeeding decisions made.
- To understand and interpret these experiences through asking those best suited to provide them.

### **Review of interview:**

- You will be asked how you found the interview.
- You will be asked if you would have preferred anything to be done differently.
- You will be asked if there are any recommendations for the researcher to aid improvement of the investigation.

### **Unresolved issues:**

- The researcher will ask you if you feel that any issues have been raised during the interview which may have concerned you.
- It is the researcher’s duty to ensure any questions you ask are answered sufficiently. This may involve directing you towards the correct professional resources.

### **Future concerns and contact with researcher:**

- If you have any concerns or further questions about this research, please do not hesitate to contact myself or my project supervisor.
- My supervisor and I will be available for contact up to six months after participation for any issues relating to the research project.

Appendix D, Example Transcript

SUBTHEMES		COMMENTS
	<p>1 Interview with Carole 25.5.18. Demographic information:</p> <p>2 Age of children= 4.5 month old twins,</p> <p>3 Age of mother= 45 years old,</p> <p>4 Place of residence= Staffordshire,</p> <p>5 Occupation= Advisory Teacher,</p> <p>6 Highest level of education obtained= MSc,</p> <p>7 Ethnicity= White British,</p> <p>8 Marital Status= Married,</p> <p>9 Group most frequently used= Breastfeeding twins and triplets UK,</p> <p>10 Number of group members= 3000 members.</p>	<p>KEY:</p> <p>Exploratory comments</p> <p>Linguistic comments</p> <p>Contextual comments</p>
	<p>11 Pre-interview checklist completed but not included for analysis.</p> <p>12 Interviewer: I So tell me a little bit about your breastfeeding journey so far.</p>	<p>Introduces her early experiences</p> <p>Breathless and talking really fast.</p>
Reflection on the past experience	<p>13 Carole: Well I breastfed my elder two and that was totally straight forward they are 14 and 11 so that was a good while ago obviously and there wasn't any online support available back then</p>	<p>All words emphasizing trying lots of approaches to feeding, no definitive answer.</p>
Reflection on the past	<p>15 Interviewer: A Hmm, no</p>	<p>'I never had any trouble' Reflection on previous experiences</p>
Unique situation with twins	<p>16 Carole: In the same way there was back then. I never had any trouble and I found it straight forward, umm having twins is a whole different ball game and within a day [sigh] of when they were born because one was in an incubator I was trying to express colostrum for her which was a bit difficult to get going. The other one was so tiny that she couldn't latch. So again</p>	<p>'Twins is a whole different ball game and within a day' Twins are seen as a unique situation to Carole that was troublesome from day one. She sought support online on day two whilst still in Hospital. But why when she has professional support?</p>
Early breastfeeding challenges	<p>18 we were sort of expressing and trying to give it to her with a bottle, and messing around, and it took us a good few weeks to get on properly, properly latched</p>	
Acceptance of online support	<p>20</p> <p>21 Interviewer: Yea</p> <p>22 Carole: and umm it was probably about day two that someone I know that is having twins pointed me in the direction of this umm forum support group on Facebook</p> <p>23</p>	<p>'umm forum support group on Facebook' Not sure what to call it.</p>

## Appendix E, Carole's story

**Carole's story.** The following aims to focus a light on Carole's lived experience of online breastfeeding support groups. The following details a crafted phenomenological story of her contemporaneous experiences (Crowther et al. 2017) of the today. Derrida and Ferraris (2011) argues that this account is a testimony of the truth today and may not be important tomorrow. It has been long stated that the mood and context and how we are listened to, all influence the 'how' and 'what' of telling (Fiumara, 1990). This account provides 'a' version of the truth but her version of the truth. Here Carole provides close observations of her lived experience of online breastfeeding support as well as a bird's eye view.

**Context and Temporality. The online support journey.** The following gathers a sense of what has happened in Carole's breastfeeding journey so far and provides context to her life world through her narrative. As she begins by reflecting on previous breastfeeding experiences described as "*totally straightforward*" and breastfeeding her older children seemed almost intuitive to her. She has a self-awareness that "*I knew it was going to be harder with twins, but I hadn't given it much thought*". There was a degree of reflection that she had breastfed successfully before and was confident in this skill. Carole begins her story by talking of the early weeks of breastfeeding being the most difficult "*it took a good few weeks to get on properly, properly attached*" and reflection that the "*first three or four weeks were the most difficult*". Carole describes a loss of competence returning to the novice learner. It was in this time that Carole accessed the online support group. Halfway through the interview she casts her mind back to the beginning and states she "*felt underprepared*" for twins.

Carole's understanding of the hospital setting was insightful. She accessed professional support in the hospital as well as the online group on day Two. She talks about a

lack of time provided by the hospital staff and acknowledges the context of staff shortages and poorly resourced hospital wards, with old equipment, saying sadly “*and they don’t always have the time*” and more bluntly “*they don’t always have the equipment*”. Carole talks of “*crying in agony*” due to a “*horrible*” experience with a breast pump that “*she literally just handed me the breast pump and went go on get on with it*”. Philosophers Monty-Ponty and Satre both talk of our bodies being fundamental to our relationship with the world. This emotional experience was certainly something that Carole wanted to quickly tell me about early in her narrative. Embodiment is a key feature in breastfeeding support due to the very nature of breastfeeding and the baby physically attaching to the mother’s breast.

This cycle of competence to novice repeats as Carole describes a dance almost of once feeling competence in her ability to breastfeed her children and then the feeling of desperation and torturing herself and then through group reassurance feeling competent again. The group was then perceived as a lifeline and an important part in regaining that competence. The stressors described by Carole were the early feeds when the twins were young and bed sharing. These were the moments of returning to a novice and using the group to scaffold new behaviours.

Beyond the belief that she is a competent breast feeder Carole describes taking part in a publicity campaign and her competent moves from the individual change to wanting to make a social change by encouraging others to breastfeed in public.

**Sociality/ “*a time and place for support*”/ “*finding the right space*”.** When talking about the professional support Carole refers to a more biomedical model of breastfeeding, one of “*checking the latch and checking the position and attachment of the baby at the breast*”. On day Two when accessing the online group from her hospital bed she was seeking advice and states that the “*advice that they gave there in terms of how to move from the little*

*bottles.... was fantastic*". Despite the perceived lack of time nurses appeared to have in the hospital she describes the nurses in the Special Care Baby Unit (SCBU) as "very good" and appreciated that although she herself was fit for discharge they had let her stay to establish breastfeeding. Carole also talks of having access to a 'lactation specialist' in her local community who she can call to have 'someone look at her latch and stuff like that' emphasising a tangible approach to support.

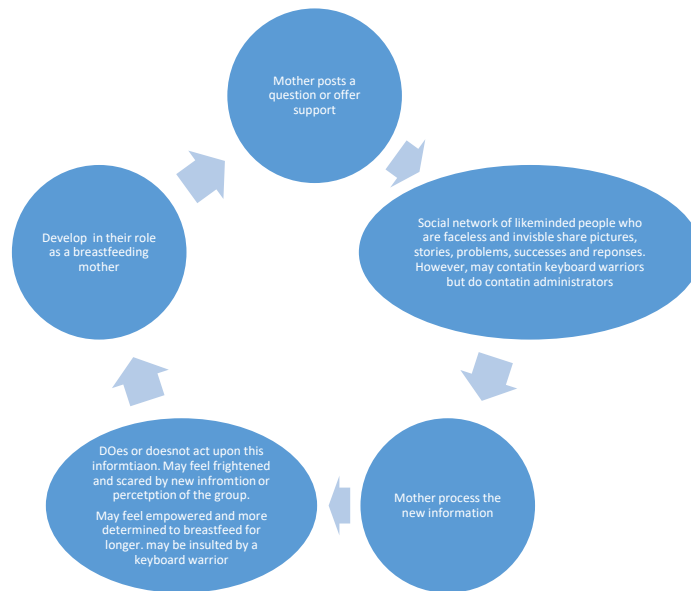
Face-to-face support was also described but in a much more neutral way. Almost as an after thought Carole said, "I go to a little support group down in town". A sense of minimalizing the impact of the group was felt by the use of words such as "little" and "it's really nice, but" and then referring quickly back to the online group as "fantastic". Interestingly she says the group is run by "just mums" and "just peers" however the online group is also peer led. Through the narrative many times Carole refers to the group administrators, "Similar I would say [long pause] I think the breastfeeding one in particular, is the one that I engage with the most anyway, their admins are brilliant and jump in regularly with um fantastic advice and pointing you in the direction of articles and research and things like that and putting links on for things that you can go and look up and stuff like that um".

When talking of the online group she often talks of the information that she has access to now that she didn't have with her previous children, all because of the group. She begins to challenge the idea that she was ever an expert with her previous children knowing what she does now. Carole shares an example of wanting to buy a breastfeeding pillow to support her physically but also support her journey so that she can "manage them both comfortably" and "because it saves a lot of time" because "if I feed one then the other I would be permanently feeding".

So how does she view herself and the relationship with other people in the group?

Carole describes the group as a “*support network*” of “*likeminded people*”. She describes the group members as “*faceless*” and “*invisible*” but because they are all in the same situation as each other they “*get it*”. This is further emphasised when discussing the support from her husband and family. Carole states that they “*don’t necessarily get it, even though they are close to you...and are supporting your breastfeeding journey they don’t really get all of it because they are not in it and even for my husband he’s very supportive of it but he’s not doing it is he*”. Carole provides repetition and speaks fast when trying to explain this point and emphasises this further by saying “*he can’t understand the emotions that go with it, sometimes the guilt is something goes wrong that women in this situation really get*”. Carole often talks as one of the groups, moving away from singular of ‘I’ and into the plural when describing group presence, emphasising that community in which she participates. The sense of female empowerment is stated towards the end of the interview however also noted when speaking about her trust and that “*women in that situation really get*”.

Figure E1 illustrates the cyclical nature of support. Carole talks of needing support and regaining her confidence to the point where she is confident to support others through a “*reciprocating situation, because there’s always people on their asking questions but then further down the line you’re the one that can answer questions*”.

**Figure E1***Cyclical nature of support*

The group represents a safe space where people are kind and polite. It is almost a reflective support mirror where Carole feels understood and acknowledged but a space which resonates with her own views, confirming her own values and ideas. The administrators were important to Carole and she likened them to the ‘police’. Conversely Carole talks of ‘keyboard warriors’ who are critical and argumentative and subsequently causing conflict in a group.

**Selfhood (personal part of the breastfeeding journey).** Carole has a strong sense of self, and the mother which she wants to be, evidenced in the dialogue *“they don’t agree with me and the way I want my family to be”*. She talks of using groups that she feels are supportive in which she interrupts as a community of *“thoughtful people”* that *“give encouraging words”*, *“people say I hear ya”* and include *“likeminded people and approaches”*. Carole talks of unjoining groups that include *“keyboard warriors”* those with strong opinions, that are *“critical”* and where *“approaches don’t fit to my own values”*. She describes a trial and error approach to group choice based on these factors. In groups that



display the desired behaviours Carole describes them as “*absolutely invaluable*” and finds their posts “*fascinating*”.

Carole’s clear sense of self, applies to her breastfeeding and parenting style and affects her group engagements and the perceived availability of support “*I don’t post in the twins one [online twin group that is not about breastfeeding] as that’s where people get more heated*”. Interestingly Carole often refers to the group being beneficial for her specific situation and the “*twin thing being niche*” however she did not join this particular group.

Heidegger talks about an authentic presence, Carole demonstrates this through her self-awareness, by emphasising “*I am very cautious about offending anybody*” and wanting to “*ask gently have you tried this kind of thing but um I don’t need to worry but I always try and be supportive*”. The strong sense of community described by Carole means that within that “*proper community*” she is mindful to be supportive and not offend others, indicated by her use of plural language again, that she values her role within the group. She describes how instead of “*wading in*”, or “*Jumping in and say that...you have to step back and say hang on a minute*” recognising that “*there are people that aren’t like that*”.

Carole shows capacity to mentally visualise herself in that situation and not respond. She has an awareness of how she comes across and doesn’t treat this as an anonymous space, filtering her contributions demonstrating appropriate online behaviours. Although she is aware of how she is she does describe others as faceless implying some anonymity. Carole openly talks of her determination to breastfeed regardless of group support saying, “*it’s just made me more determined than ever that I can do it and will do it*”. At the same time, she talks of the group being “*massively, massively reassuring*” and a “*lifeline*” that she will continue to use as a “*safety net*”. This ambivalence demonstrates her need for agency and control over her situation. In fact, Carole exercises this control over the groups that she joins

and unjoins and chooses how she interacts with them e.g. *“I jump in when I need them”*. She wants to be clear the group aids her and that her determination is key.

**Mood.** Mood as a subject of analysis that examines how someone’s mood can affect them within the world. Carole shared an experience of posting a message to the group saying, *“Oh my god, why do I feel like I’m failing”*. This emotional low mood and resulting post came after *“a patch of feeding all night”* which resulted in bed sharing with the twins. Carole reflected on a time with her previous children where the dangers of bed sharing *“were rammed down her throat”*. This behaviour led to feelings of guilt and self-torture at the thought of doing something wrong. Her emotional state was relieved by *“loads of responses and people sending photographs of their bed sharing set ups if you like and advice on bed sharing safely”*. This experience shared just one possible reason why Carole repeatedly states the group is *“reassuring, massively, massively, reassuring”*. The sheer act of *“other people sharing successes has made me feel well I can do that”* and causes her to *“stop worrying about everything”*.

Philosophically, Carole experienced a time, discussed by Heidegger, of ‘falling away’ before achieving ‘Dasein’ known as the experience of being, or human, being. Carole had made decisions that did not fit with her current picture of reality which caused her to feel as though she was failing, and she was then striving to return to her authentic self. When looking at BAM, a mother is seen to learn all the information, try to follow this information before she finds her own way of doing things and reaches expert level. The role attainment model however does not fully allow for the continuous learning of information seen here in Carole’s Story or consider Carole’s anticipation of further possible learning.

The themes that emerged from Carole’s narrative were collated and grouped in a Table (Table E1), and this was also completed for all interviews prior to following stages.

**Table E1***Theme refinement from Carole's narrative.*

Individual themes	Grouping of themes
Self-aware Realistic vision Feeling unprepared Sense of identity Sense of agency Mood Feelings of failing Feelings of guilt Feelings of relief Falling away	Taking control
A unique learning space Likeminded people Network Faceless invisible members Connections with similar others Safe space Sense of community Awareness of choices Community feel Determination Reassurance Lifeline Affirming	Community
Activist Giving back Judgement	Society
Early challenges Bodily experience Objects- pump Cycle of novice to expert Time and place for support Finding the right support Trial and error approach	Journey

Appendix F, Patterns Across Cases

Carole:	Teresa:	Tracey:	Chloe:	Anne:	Jane:	Val:	Emma:	Gail:	Lauren:
Journey/ context/ Temporality	journey	Embedded in time	Gaining knowledge	Access to information	The medical approach	Receiving information/ bodily experience	The determined feeder	Early challenges	an easy journey
Time and place/ Finding the right place	Community	Community	Amazing support in a surprising place	Temporality	Triage system	Silent group member	journey	The lactivist	Preloading on experiential learning
Selfhood	Selfhood/ ID/ agency	Sense of control	Taking control	Celebrating/ likeminded people	Common experiences shared	Protection from society	Knowing all options	Good bad and secret groups	The online journey
Mood / failing away	Tribe	Generation gap	Group dynamics and judgement	The adamant feeder	Society that doesn't value breastfeeding	Normalising/ sense of agency	tribe	Supported becomes the supporter	
		Supported becomes the supporter		Feeling like the professional	Filling the gap	Change in attitude			
				The local online group		New truth/ personal growth/ breastfeeding journey			

(Key: Green: the journey, Blue: society, Orange: Agency and self, Yellow: Group impact).

## Appendix G, IPA Diary Extracts

Location within the text	Examples of journal entry
Study Aims	How do I get a deeper level of thought, I need a better sense of how online social support groups are experienced by breastfeeding mothers, in the context of their daily lives and not in the context of service delivery that I was embedded in. How do I change my thinking? What if I am looking at this all wrong?
IPA	In lactation care people bring their stories, their journeys of their breastfeeding experiences, and dreams of what they want to achieve in the hope that the supporter can interpret their stories and provide the support they need to continue.
Phenomenology	A bodily experience of breastfeeding may initiate a stress response, causing the breastfeeding mother to engage in online social support engagement. This process is complex and requires a methodological approach that can explore this. I feel phenomenology is well suited here.
Heidegger	I am interested to know the individuals voice within this community and the interrelationships amongst different aspects of the group and individual thought.
Lived experience and sense making	<p>Reflecting on the first interview made I reconsider what I knew about sense making and lived experience. I started reading around sense making and found an article on lived experience by van Manen (2017) upon which to reflect. Although not academic I wanted to make sense and best learn through audio visual methods that I could pause reflect and think.</p> <p>This made me think of my own life experiences. My first supervisor asked me to follow the fed is best campaign [the fed is best campaign is a movement that believes breastfeeding is not always best for the baby and counters the breast is best campaign], to make sure that I see the other side to my arguments. I must push aside the habitual ways I perceive this topic, and the medical approach that I work in to fully understand the mother perspective.</p>
Idiographic not nomothetic	I am sitting watching TV, relaxed my body is warm and calm and breathing is slow. I don't hear anything around me as I am engrossed 100% int the drama of the TV show and in my own little world. As my children bound in, they changed my perception and I start to understand what 'had been' and 'what is now'. The change for me isn't either a good or bad experience it is just a change. I thought to myself this is idiographic this is what I was reading about. I am surrounded and connected by a world of objects and relationships and all in relation to external phenomena.
Rejection of ideas	This is not only an intellectual project it is about me growing and seeing things differently. I am fascinated with phenomenology and the multiple layers of human existence that I know surround the topic of breastfeeding. I was descriptive at first, and that was ok, but I need to focus on the deeper meanings and discover the extra ordinary. I spent many months looking into Q methodology. I was thinking of looking at the avenues of support for mothers and was thinking of exploring which one they felt supported them the most and why. Reflecting on what would made a difference to me in practice I took a step back, started from the beginning. What are people's experiences and what do they mean is more important to understand and inadvertently shed light on other questions too.
Interviews	<p>I worry that I have never conducted an interview for research purposes so I must weigh up all the options. I guess I do interview students nurses in my job as a lecturer and I do adopt consultancy models when working with breastfeeding mothers in practice. I need to spend some time really looking at the interview schedule to make sure that I have done all the prior planning I can.</p> <p>The first interview conducted with Carole was the shortest and I was worried that this was because telephone interviews were found to be shorter in length. This</p>

however was not the case for subsequent interviews and could be attributed to my inexperience and lack of probing and initialising a deeper understanding from the participant. This was certainly my feedback from my first supervisor.

Reflexivity and the reflexive journal

I have spent the past 4 months reading around reflexivity and phenomenology, so that I can approach my IPA with the correct attitude (Halling, 2012), moving away from my medical approach in nursing that is undoubtedly embedded in my thought processes. Published literature is seen as authoritative and my tendency is to fall back on that. Previously I was consumed with looking for a definition of support and I had previously written a working definition of breastfeeding support based from the literature. So instead I contemplated what my own experience of support were and connecting on a personal basis rather than just a theoretical one. I questioned the bracketing exercise I had previously done and considered how my thoughts have changed over the past few years of study. Relating this to IPA, IPA is more about adopting a special open phenomenological attitude and setting aside judgements and frameworks. I feel I have opened up to new ideas and to accept that I may have been looking at things through only one lens.

Ensuring research quality

I like Smiths discussion on making sense of nuances. It got me thinking ‘why do people go online and not ring a helpline? Or do they do both? What led to the use and the impact on the group on how they see themselves?’

Carole’s Journey: Sociality

I had not really thought of the perceived roles assigned to different types of support avenues before. In my own practice I was somewhat naively thinking we were offering a full package of tangible, emotional and peer support to name a few. But upon reflection regardless of my offer people might just see me as the ‘latch lady’. Am I the latch ‘lady’?

I assumed Carole’s life to be busy having 4 children, because I know I am busy with just having 2, and the older two are similar ages to mine. When Carole began the interview, she talked fast, and I felt as though I was along as a passive traveller to the journey she was describing. Her story had a brief pause when her daughter made a noise. At this time, I was gifted a glimpse of her current world and said to me “*it’s OK I can do things one handed because she had to*”. I did appreciate Carole’s time for taking part in this interview and thought to myself, why? Why would Carole spend an hour talking to me when she is clearly a busy mother? This could be part answered by her “*passion for it [breastfeeding]*” that she has developed over her lifetime.

Carole’s story: step 4 searching for connections

I feel scared to add this structure to the narrative and have so many themes, too many to list alphabetically as I tried to do this. I listened to audio again with my paper copy in hand and found myself summarising the descriptive comments, linking these to the spoken words and other comments added. After looking at single sentences and words I found myself zooming out again looking at chunks of data again. I found myself clustering these into three main areas and writing my thinking down as I went along. This experience is reassured after reading Wagstaff et al. (2014), that others experienced the same trials and tribulations.

Carole’s Journey: Step 5

Having completed all the interviews and reading them back, I have forgotten what I didn’t know when I started. I have already begun to change my thinking in my mind theories and questions are raising so I am jotting these down, so I do not forget them.

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## Appendix H, Pre and post Interview reflections

Participants name	Pre interview reflection
Carole	Completed my first interview this morning as planned. I felt nervous actually and procrastinated tidying my workspace, making sure I had all my paperwork that I had submitted to ethics and my schedule with all my notes on. I prepared the house as if I was planning to go out. I not only tidied I fed and watered the dogs and shut them away so that they didn't bark, went to the bathroom myself, I prepared my family asking for peace and quiet and rang my husband quickly to ensure my voice recorder was working. I feared the technology breaking down and losing my data. When everything felt ready, I had to tell me self to 'just get on with it' and be prepared to learn from this experience. So, I dialled the number after arranging my external environment and wondered if Carole would be doing the same.
Teresa	I was conscious to use more probing questions, so I had my interview schedule. I had some reworded areas and different ways of saying stuff all written down on my sheet and added the probing questions around the main questions rather than just in the bottom. My in-review schedule now has speech bubbles all over the front and a picture of a mum sitting in a room with her baby and computer to help me picture what is this like for her.
Tracey	I was conscious to use more probing questions. So, I had my interview schedule and I reworded some areas and different ways of saying stuff all written down on my sheet and added probing questions around the main questions rather than just in the bottom. My interview schedule now has speech bubbles all over the front of it and a picture of a mum sitting with her baby and computer to help me picture what this is like for her.
Chloe	I felt previous interviews went well. Everyone has been chatty and the interview itself seems to flow nicely. The reservations that I had about telephone interviews for example they are quicker and harder to build rapport, has not been felt so far. I am feeling positive about my work. As always, I prepared my space shut myself away from the family and distractions and committed as much time as is needed to hear Chloe's story.
Anne	Going into the interview I was feeling confident. Again, I prepared the room grabbed by interview schedule and made sure my recorder was on. It was late near teatime so my mum said she would cook tea. She has been a great support whilst doing these interviews helping divert problems and dog noises etc. whilst recording.
Jane	Feeling positive about progressing with my interviews. I am loving hearing people's stories. Jane said she found my advertisement on a doctor's group. I have not heard of doctors' groups before so am interested in what have to say. Anne rang me whilst I was going to physio, so I was a little late ringing her back. I hope her baby does not wake early and cut short the interview.
Val	Val had phoned me out of the blue as we had exchanged numbers one evening. She felt free and wanted to talk so had just called me. I made myself free, grabbed my interview schedule and locked myself in my bedroom.

Emma Today is a hot afternoon. Its middle of the day and I am pleased she was able to speak to me. I had set myself a deadline of before my holiday now to complete the final few interviews.

Gail Gail called early one evening on her way home from work. She thought the drive home would provide less interruptions for the interview and I really appreciated her time. She is obviously out working and managing a family so to spare me time was an honour. Gail was hard to pinpoint a time with. Email response was slow, and I did not think I'd get to interview her, so I was surprised. She also thought I would not want to speak with her because her baby was older. But she had moved from breastfeeding mother to supporter and to group administrator, so I was interested to hear her journey, and how she came about these different roles within the group.

Lauren Lauren called me one morning after getting her little one off to sleep. I had travelled to work today with my interview schedule in the hope that she would get a chance to call me. I prepared the soundproof pod at work so that I would not be overheard, and my manager was happy for me to nip off for an hour to complete it. I appreciate her time. This was the last interview, so I was hoping it was good.

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Participant name	Post interview reflections
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Carole	<p>The interview itself lasted 40 minutes and felt quick. It felt great to have started, I was excited, and I ran through to my mum and said, 'I did it'. Then I sat to complete my field notes. I sat in my office and now worried it was not long enough. I worried if I had enough depth to my data. I was grateful for Carole's time, pleased that she felt so free to chat with me and that there were no moments of uncomfortable silence, or hesitation on my behalf. I felt like a passive traveller looking in on this experience that she spoke of and now worried that I had not been active enough in exploring her personal meaning to the events she described. I decided to focus on the questions asked and to think about the responses they elicited. I made a plan to type the notes, listening and writing every word that had been spoken and to ask for supervision on the questions firstly before moving onto the analysis as this was important for the rest of the study. 6 questions to guide reflection following the first interview (Chadwick, Bahr and Albrecht (1984):</p>
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1. Has the researcher included all the necessary question? Yes, but he questions on how to define support could have been probed further.
2. Do the questions elicit the types of responses that were anticipated? Yes
3. Is the language meaningful to respondents? Carole did not ask for any clarification on anything
4. Are there any other problems with the questions? When asked about the impact Carole gave an outcome. This needs to be more about what influenced her decision. I need more about what influences decisions, the how and why. The challenges of using the group were also a little muddled with the challenges of breastfeeding so this needs to be clearer.
5. Logical order? Yes
6. Does the interview guide motivate the respondent? Yes, she was talkative, and one question flowed to the next.

Teresa	<p>The interview this time lasted 1 hour and 1 minutes. I felt a lot more relaxed this time and because I had my questions all written on the interview schedule, I felt more focused. The conversation flowed nicely. She was friendly and chatty and there were no uncomfortable</p>
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silences. Again, I was just let her talk like last time around her feelings and experiences but asked for clarification more and definition. Some things I went back to redress just to clarify. She started with lots of description just like last time and the initial question is working well in easing in and getting Teresa thinking, as we talked, she said at one point. *“Wow that is weird you kind of forget all the problems that you had”*. This showed me that she was thinking more about how she used the group and why and that I was gaining more information on her understanding of the impact of the group from this. Teresa really did share her experiences and discussed in depth her support and own mental health issues that she faced. I could not help but think why this lady did who has anxieties want to contact me to talk about her experiences. This led me to thinking that there was some motive for talking with me, some therapy almost in talking about her experiences.

- Tracey Tracey was chatty. The room was quiet, and she had given herself time to talk with me. She was educated and reflective and in control of her situation. It was lovely speaking with her, and it felt as though she really thought about her answers.
- Chloe Chloe was quiet, and she got going and reflected nicely on her experiences. She was anxious socially and so the group suited her shy personality. It allowed her a glimpse into the world of others without the small talk and social interactions that caused her to feel anxious. This is something she needed in a culture that was not supportive.
- Anne Anne is a strong and determined women that had lots of support locally and online and though herself to be *“lucky”* for this. She grew up with a breastfeeding culture and therefore the group had little impact on her journey however she did find it useful.
- Jane The field notes looking at the participants’ world, methodology and theoretic reflections etc. really helps to pull out the themes. I learnt a lot from Jane about social class and breastfeeding support online. I had heard from other interviews that doctors are blamed for not knowing enough and had never thought about how it might feel to be a doctor and access this group. Or had I thought that doctors might have their own group. Jane worked as a paediatrician yet has no formal training in breastfeeding. Her support needs are not unlike anyone else’s. Because Jane normally sees the down sides when babies are unwell because they are not breastfeeding well or struggling because they are unwell that they might need more support. Jane took a biomedical approach to breastfeeding that was not necessary. She is a logical practical thinker when it came to her own breastfeeding issues and even used a medical triage approach to who she would ask for help. This was interesting.
- Val First impressions were that why if she is a nurse is, she not helping others like I do. I judged her on my own standards, but our situations are different. Upon analysis I understood her more. We were similar but her picture of society was different to mine.
- Emma Emma gave me a glimpse into her life. I learnt about her holidays, her support, her troubling issues, and her character as a person. I also got a glimpse of how she was parenting. Emma liked all options and it left me wondering how we talk to mothers about breastfeeding. We stick to that biomedical model and leave out options that might help the mother because we deem them risky management tools.
- Gail My first impression was that I’ve got a lot in common with Gail. Gail wants to be an IBCLC and is about to start training as a midwife and support women like I do. Gail focused on the groups and talked of the conflict she sees in the groups. She talks of being responsible for creating a safe space, free from conflict. I too had concerns about this.
- Lauren Lauren spoke quickly, and I struggled to keep up with her and make probing questions at the right time. Reading and re-reading the data she was reflective and explained why she thought things and I just hope I got enough. She talked a lot about experiential learning which was interesting.
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## Appendix I, IPA Field Notes

Category	Carole	Teresa	Tracey	Chloe	Anne	Jane	Val	Emma	Gail	Lauren
Observations of their world	Carole has given me her full attention. When her father arrived, she prioritised my call. She had prepared her world just as I had.	Teresa has given me her full attention. She was in her son's bedroom and rocking on a rocking chair that she says she never uses because her son sleeps with her. Her partner is looking after her little boy although she does not stop thinking of him at one point, she thinks she hears him crying but he was fine. Her mothering radar was always listening out for him.	Tracey's environment was quiet and not interrupted. Her life is controlled and educated and thoughtful. She has a great ability to reflect and logically deduce the best options for her.	Chloe gave me her time. It was quiet and not rushed. I had her full attention and she really wanted to talk and share her experiences with me.	Anne gave me her time uninterrupted and even when her mother rang, she hung up. She was chatty and reflective	Jane is a doctor and surrounds herself online with other physicians. She has medical approach to her breastfeeding journey even though she didn't have to.	Val describes a society that does not support breastfeeding. Today she was sat at home with her husband and children feeding her little one and her daughter was being put to bed by dad. She gave me her time and attention.	Emma lives with her husband and two children. She talks throughout the interview about her journey with her eldest with whom she still feeds. Her younger son is hardly mentioned as Emma uses the groups to support her feeding her eldest. She is an experienced breast feeder now.	Gail's busy and gave me time driving home from work. She even arrived home and sat in her car talking to me so that she would not be disturbed (for 30 mins) and her husband came out to check on her. I felt honoured that she valued this and gave me her time.	Lauren was the last participant and again gave me her undivided attention and interruption free. She loved the group so that she could learn from other people's experiences.

Theoretical reflections -with the research question in mind	Carole struggled unexpectedly with breastfeeding. Her previous experiences of breastfeeding had lured her into a false sense of security which meant she had to seek support from many avenues. She developed her skills through advice and information sought online. The online community has eased her journey and provided reassurance of which she now gives back.	Teresa was a novice to breastfeeding. This was her first baby and she expected breastfeeding to be easy and had always been told it was a beautiful thing. It was not until baby was 4 months when she describes breastfeeding as going well and describes " <i>a journey of me really struggling</i> " until then. Teresa had support from mental health services, Health Visitor, Midwife, online groups, and her mother appears influential and important to her support network. The group to Teresa was a community in which she could affirm and explore her choices as well as give back. A protective group where she never felt judged and that never said that formula was required. This is something she never wanted to hear as breastfeeding was something she	Tracey talked of the generation gap and lack of support was something that Tracey felt. She sought advice online to fulfil that generation gap. She felt the support was easy to access at any time of the day and gave her confidence. She was self-aware and had a strong sense of identity.	Chloe wanted to tell me about her struggles with breastfeeding and lack of support she faced. She wanted to show how much knowledge she had now and spoke of how she was proud of her accomplishments. The group provided a space to share her accomplishments in an offline culture that she felt she couldn't. The group was a tool to build her confidence and made of knowledge and kind words and shared experiences.	Anne is a determined breast feeder and lives in a culture where breastfeeding is normal and was adamant that she was going to do it. There were times of need in her journey and she used the group to learn information and celebrate breastfeeding. She valued one to one support and the group and little impact other than change her vision of breastfeeding longer than one year. She talks of the group as a network of mums who praise and share experience at a time of need.	Jane introduced me to social class and breastfeeding. An angle I hadn't seen before and offered a different perspective. Jane had an internal triage system in her thought processes that match a medical model in the NHS which was interesting.	Val describes an environment that is pro bottle feeding. She describes feeling guilty for not feeding her first baby for long enough and the pain that caused her to end her journey. The group she describes as invaluable and supporting her physically to prevent sore nipples and emotionally as well.	I got an insight into what Emma was like. How she parented and how she thought about breastfeeding support. Emma describes searching for and finding her tribe.	I got a good insight into Gail the lactivist and the group conflict that can occur. Gail comprehensively described how she saw the different group and how she felt about them. She valued her local group	Lauren talked of and values experiential learning. She felt professionals were too restrictive in their advice and learnt more from the experiences of others.
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should and wanted to do to keep a bond with her baby and something she feared losing.

Methodological reflections-my critique of the research process

Carole gave me close and personal observations through stories, as well as a bird's eye view of her lived experiences. Deeper descriptions connecting thoughts feelings and actions is required moving forward.

This second interview explored more about how certain parts of her journey felt and what meaning she assigned to them. I felt as though I really got to know Teresa and how supporting others was important to her. I could see the value that personal experience has for her. She valued bothered with experience over knowledge and valued her own struggles as important when giving back to others. Her speech slowed and her thoughtfulness deepened as the interview progressed. When asked at the end if she had any questions for me she asked, 'how long have you breastfed'. She said this bluntly and quickly again emphasising that

Using reflective models from nursing worked well here the What? So what? Now what? Approach was successful in gaining a deeper understanding.

The questions started with short answers, but she did become chattier and more comfortable and spoke more about how she was feeling. She became reflective and was able to identify what she did and didn't get in her breastfeeding journey.

Anne was reflective and connected her past experiences to her knowledge now. The questions had a nice order to them, and we kept scheduling applying prompts at key times for deeper understanding .

The interview schedule provided Jane with an opportunity to provide a personal account of how and why she used the groups.

Val was reflective. She looked back at various stages of her journey and applied the information that she had now. The longer the interview went on the more reflective she became.

Emma gave an honest thoughtful account of why and how she used online groups. I am trying to maintain the same interview for all and feel my schedule has become easier over time.

*"oh gosh now you're asking... I don't know I never really thought about that before to be honest with you"*  
Comments like this showed that the interview schedule as sufficient in seeking deeper levels of understanding.

She talked quickly I hope I captured enough emotion and feeling in her interview. Reading it back she was good at explaining herself and her thought processes.

personal experience that she values.

Analytical questions	Does the current model of role attainment allow for that continuous learning of knowledge and the anticipation of the need for more information?	Do Online Social Support Group speed up role attainment around breastfeeding? Role attainment is complex and does this variable effect role attainment. Is there a therapy for these mothers speaking to me?	Filling the generation gap/ How big is it now? Is it likely to get better? Can the group fill it?	Does sharing accomplishments increase perseverance and motivation to continue? What are the parenting styles associated with breastfeeding?	Breastfeeding role attainment! Is there one? Is the journey so up and down that one minute you're OK and then next you have an issue? Do people ever feel like they have cracked it? Are the personal connection that people are missing damaging?	How many other groups am I unaware of?	You can just 'lurk' and take from the group because the community will respond.	Finding a tribe. Finding a place to belong when society does not provide that. How do we support all option within the constraints of the NHS policies and procedures on discussing best practice?	Do all women's groups have the potential to be "catty" with sarcastic or cutting comments? Do women expect this?	How do strong ties and weak ties in social support, work in an online environment? Strong ties are associated with increased wellbeing. This current study shows weak ties between people but increased wellbeing through strong ties with the community.
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## Appendix J, Participant Representation per Theme

Super ordinate theme	Subordinate themes	Participants
	A vision	Anne, Emma Lauren, Teresa, Tracey
Supporting an internal vision	A bodily experience	Anne, Carole, Tracey, Val,
	Falling away	Chloe, Emma, Gail, Tracey, Val,
	Gaining control or finding your own way	Anne, Chloe, Emma, Jane, Lauren, Teresa, Tracey, Val.
Super ordinate theme	Subordinate themes	Participants
	The people within the group	Anne, Carole, Chloe, Emma, Gail, Jane, Lauren, Teresa, Val.
Providing a sense of community	The knowledge	Anne, Carole, Chloe, Emma, Tracey, Val.
	An easily accessed safe space	Carole, Chloe, Gail., Jane, Lauren, Tracey.
Super ordinate theme	Subordinate themes	Participants
	A time and place for support	Carole, Emma, Gail, Jane, Lauren, Teresa, Val.
Temporal moments of need met through online support	A positive impact on the breastfeeding journey	Anne, Carole, Chloe, Emma, Jane, Lauren, Teresa, Tracey, Val.

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Super ordinate theme	Subordinate themes	Participants
Filling the gap between the vision and today's society	Judgement	Chloe, Emma, Lauren, Teresa, Val.
	Activism	Carole, Chloe, Emma, Gail, Tracey.
	Reciprocity	Anne, Carole, Chloe, Emma, Gail, Jane, Tracey, Teresa, Val

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## Appendix K, Reflexivity

Appendix K provides an example of reflexivity, in the aim of reducing potential bias and was written mid-way through the large-scale research project (Sherman, 2015).

1. What am I not considering in this situation?

I am not speaking to people that have used the groups and now no longer use them or did not find them supportive in anyway. I had not considered that there was a huge diversity in groups, this had become apparent. I was not looking for reasons why these groups were not supportive, more trying to understand why they are, and when.

2. What do those with opposing viewpoints believe and how do others view online support?

I asked my husband who uses forums to ask questions about fixing computers. He goes in with the belief that other people, like him can help. However, he also does not trust everything he is told so when something is suggested he investigates the suggestion before making his mind whether to follow that piece of advice. He is cautious of the advice for others and is sceptical of anything online.

There will inevitably be mothers who have used an online group and did not find it supportive in any way. It would be unrealistic to believe that all mothers enjoy the groups, trust online information, or even go online for support. Any conclusions must acknowledge this.

3. Is it possible I am wrong in my thinking?

I am trying to open minded looking for answers, rather than making any predictions on what will be discovered. I have been doing some reading around confirmation bias and how the mind works. I am trying to challenge myself to think differently and to keep an open mind.



Actually, I am really enjoying hearing the stories of mothers around online support. I have currently undertaken four interviews and they have similar but different stories. Supervision also helps challenge the interpretations being made, and a reflexive diary continues.

4. Have things changed and am I unaware of new evidence?

The research question led me to this point, I have already changed my thinking around how to research this question, changing from a Q-methodological study to an IPA study. To keep aware of new evidence I have been continually searching the literature around support particularly through Facebook and around breastfeeding.

5. How is my own life story affecting how I think about the situation?

This was noted in Chapter One, Appendix a via bracketing interview.

6. Could a reluctance to change be affecting my viewpoint?

I do not consider myself reluctant to change. Working in the NHS there is a culture of continuous change and innovation and it is instilled into practice. Of course, change is inevitable however change is also unsettling. I have tried to remain impartial and really look for ways to change and develop future practice.

7. Do I feel threatened when presented with new information?

Yes I can, I think everyone can. My first reaction may be to try and discount information, however through noting conflicts these can be discussed in supervision and talked through with another.

8. If I came to this situation without experience would I make the same decisions?

Yes, I think so purely because I did not come to this research with any experience of online breastfeeding support. I have an electric car and I have used electric care forum, as they discussed using electric chargers which was useful information to me. I never shared personal

information or disclosed my location online, cautious not to share this with others. I have noted that I personally am sceptical of being my authentic self-online and can not assume that the mothers using the online groups are the same.

9. How would I react if I found out my thinking on a key issue was totally wrong?

I feel that this research adds to the body of literature on the topic. Regardless of the outcome, whether online support is beneficial or not then this information helps inform the next steps in policy and practice. This research never aimed to find a definitive answer. Taking a critical realist approach, this is just one perspective based within a context.

Chapter Five: *“It’s more than just milk its mental health”*: A case of online milk sharing.

### Abstract

*Aim:* To produce a single case example of an online tangible breastfeeding support group use, demonstrated through one mother’s experiences of seeking peer to peer breastmilk online.

*Background:* Milk sharing is not a new concept and occurs today via regulated human milk banks and unregulated online peer to peer milk sharing groups. Exploring and understanding how, and why, mothers use these peers to peer milk sharing groups, is a vehicle to understanding how breastfeeding mothers can be tangibly supported online. It is also important in understanding how best to support them and adds to the body of literature around peer milk sharing, from a recipient’s perspective, and online social support group use. The role of these tangible online social support groups plays in providing tangible support, and in buffering potential stressors, such a low milk production is explored in this piece of research.

*Method:* This is a qualitative, exploratory study observing the attitudes, thoughts, and feelings of one mother who is seeking human breastmilk for her child through online groups. A single key case was identified, and the participant was asked to capture dates, thoughts and feelings as she searched for milk online. After two months the mother was interviewed via telephone. The method allowed for the capturing of data from the contemplation stage through to seeking and using donor milk. Online page activity from [www.humanmilk4humanbabies.facebook.com](http://www.humanmilk4humanbabies.facebook.com) was captured for the week following the interview. The results were presented in a chronological and linear analytical approach adopting pattern matching.

*Results:* ‘Abbi’ is a mother who has Polycystic Ovary Syndrome and subsequent low milk supply, for which she sought donor breastmilk online to supplement her own supply. Abbi

describes how online support groups not only introduced her to donor milk sharing but facilitated this, which not only helped her baby but supported her own mental health. This case provides an example of how online groups can provide tangible support but illustrates the complexities around breastfeeding support, and the diversity in online groups. Abbi talks of the need to build a trusting relationship with her donor, due to the lack of regulation, and the positive impact it had for her and ‘Lucas’, her baby.

*Conclusion:* Considering milk sharing groups simply as tangible online support ignores the complexities around Abbi’s decision to use donor breastmilk. Peer milk sharing online is an option for mothers, but it is surrounded by stigma amongst other mothers, professionals, and even within pro breastfeeding support groups. This case study goes some way in demonstrating the value of this online social movement in supporting breastfeeding mothers, and the role the internet plays in providing a community of tangible online breastfeeding support.

*Keywords:* online breastfeeding support, breastmilk sharing, peer-to-peer milk sharing.

## Introduction

Breastfeeding is a public health priority because of the known benefits for mothers, babies, and society (UNICEF, 2016; WHO, 2003), and the Infant feeding survey of 2010 showed that the United Kingdom (UK) has some of the lowest rates in the world (Health and Social Care Information Centre, 2012). This emphasizes a need to scale up and monitor breastfeeding interventions aimed at supporting breastfeeding mothers (Victora et al., 2016). Milk banks and peer-to-peer sharing of breastmilk online are both interventions that support women to provide breastmilk for their babies in a tangible way.

Women wanting to help other women is not a new concept. A mother might support another by, and using a simple definition of support, providing assistance (The Oxford Dictionary of English, 2015). Utilising the social support theory, which looks at a variety of different pathways linking the involvement of social relationships to wellbeing (Cohen, 1988), a mother sharing breastmilk with another is seen to offer tangible support (House, 1981).

Tangible support, in the literature, is also often referred to as instrumental or practical support, but for clarity this functional unit of social support is, from here on in, called tangible support as described by House (1981), a term still used within the literature today (Berkman & Glass, 2000). Tangible support is often used as a simple measure of social support, and sits alongside emotional, esteem and informational support, which have all featured highly in this thesis so far and defined in Table 1. Online support in the previous Chapters, has seen how informational, esteem and emotional support are obtained through online social support groups aimed at breastfeeding mothers. At most, tangible support was seen through posts asking for information about local face to face groups or asking the

administrators to add others to the group. This raises the question, how do online milk sharing sites, that offer tangible support, support the breastfeeding mother?

**Table 1**

*Functional units of social support (House, 1981)*

Name	Description
Information support	The giving, sharing and/or request for information/ knowledge.
Emotional support	Emotions are a subjective psychological phenomenon in which someone expresses a strong feeling derived from one's circumstances, mood, or relationship with others. It may be anger, fear, disgust, surprise, happiness, anxiety, depression, empathy, frustration, gratitude, remorse, stress, horror. Emotional support posts either contain or request support with such emotions.
Esteem/ appraisal support	The definition of esteem is to admire and respect someone. In sociology and psychology self-esteem reflects a person's overall subjective emotional evaluation of his or her own worth. Esteem support posts contain either a reflection upon a mother's own situation or that of others, is a post in which she judges herself or can be an attitude towards herself.
Tangible/ instrumental support	Instrumental support could relate to a tangible assistance to address a problem and could be financial. Concrete direct way to assist others

As a concept, the term support is ambiguous and needs to be based in context. Social support researchers have consistently ignored the complexities of the concept and have measured the variables in a simplistic manner (Hupcey, 1998, p1232). This study aims to provide a context in which to explore this online social support platform.

### **The history of milk sharing**

A brief history of breastmilk sharing is provided to add historical context to this ancient practice. Breastmilk sharing is not a new concept. In 18<sup>th</sup> century Britain 'Wet nursing' as a paid profession, was a popular appointment by wealthy families, and lower-class women could earn more than their husbands who were generally employed as labourers. In Victorian Britain, many wet nurses worked in the homes of wealthy women, often at the

detriment of their own children as they could not always feed both (Fildes, 1986). Wet nursing became much less popular in late 19<sup>th</sup> century for a number of possible reasons; the introduction of modified cow' milk formula, journalists publishing articles about the high mortality rates of infants who were wet nursed, the alleged spreading of disease by wet nurses, and reports of wet nurses abandoning their own children (Fildes, 1986). It could be argued that this was the start of the stigma surrounding milk sharing in the UK today.

Wet nursing is not unique to the UK and has existed in cultures around the world for centuries. Mentioned in the Old Testament, writings from ancient Egypt, Greek mythology, and ancient Roman texts, show that wet nursing has been practiced by many cultures to ensure the survival of the child (Bradley, 1986; Wolf, 2004). O'Reilly (2010) explored wet nursing and motherhood, highlighting that 18<sup>th</sup> century France saw approximately 90% of infants being wet nursed. Such practices were regulated by the Bureau of Wet Nurses in 1769, who supported the regulation of wet nurse salaries to improve the wet nurses' homes and thus the infants living conditions and thus reduce mortality rates. In Europe, wet nursing reportedly continued throughout World War 1 (Fisher, 1921). In the United States, it was commonplace for enslaved black women to wet nurse the white children with whom they lived (O'Reilly, 2010). The historical relationship between wet nursing and slavery may also contribute to the stigma surrounding wet nursing practice.

It has been seen that children were often sent away to wet nurses, often living in lower social status households and thus poorer living conditions, which increased their risk of dying from an infectious disease as well as from malnutrition. Some however, were nurses in their own home, with the wet nurse hired as more of an employee. In many cultures, especially in the UK, wet nurses often took on more roles in childcare other than simply nursing, developing a relationship with the child and family. This is seen in contemporary Vietnamese family structure, where 'wet nurse' translates to mother, and in Islam where 'milk kinship' is

practiced in many Arab countries, whereby the child would have a second family to support them, and breastfeed them if harm came to the biological parents (Soraya, 1980).

This case study aims to explore milk sharing practices online in the UK, however in western cultures, where this case study is undertaken it is important to note the social discomfort around milk sharing, recognised within the literature (Tomori, Palmquist & Dowling, 2016). In developing countries wet nursing is still prevalent, and socially accepted. However, in the UK there is cause for concern, controversy and suspicious around the transmission of infection (Hausman, 2006), the donors' lifestyle habits (Golden, 2001), and lack of regulation (Akre, Gribble & Monchin, 2011). Human milk, in its unpasteurised, raw, state, could pose many risks similar to any other food stuffs such and virus transmission including cytomegalovirus, Hepatitis B and C, Human Immunodeficiency Virus, Human T-cell Lymphotropic Virus type 1 and 2 and the bacterium *Treponema Pallidum* subspecies pallidum that causes Syphilis (Keim et al., 2014; Vogel, 2009).

UK milk banks emerged around 1985 as non-profit organisations to offer pasteurised milk to those wanting to use donor milk. In the UK today there are 18 regulated human milk banks, mostly sited in NHS hospitals, all affiliated with the Associations of Milk Banks (2019), and all adhere to the National Institute for Health and Care Excellence (NICE) Guidance for Milk Banking: service information (NICE, 2010). However, it is estimated that over 130,000 mothers participate in online milk-sharing networks (Perrin, Tigchelaar, Goodell, Allen, & Fogleman, 2014), and in a study by Gribble (2014) it was highlighted that tens of thousands of milk sharing exchanges worldwide are facilitated through websites annually. Keim et al. (2014) found that milk sharing was considered by 25% of women. In fact, the WHO (2003) declared that for women or infants with health issues where infants cannot, or should not, be fed directly at the breast then expressed milk from an infant's own



mother is advised. If this is not possible then donor human milk should be offered before a modified cow's milk.

'Human milk for human babies' written 'Humanmilk4humanbabies' (HM4HB) is an online breastmilk sharing site, on Facebook.com, that runs in almost 30 countries. It links women that have breastmilk to donate with women that would like to receive it, with no monetary gain. These milk sharing sites appear to offer tangible support facilitated through an online platform; an avenue not yet explored in the thesis so far. They appear to offer little emotional and esteem support, just tangible support through informational posts purely related to milk sharing. When exploring online support for breastfeeding mothers it was important not to discount a tangible support option.

HM4HB operates outside of the regulated milk banks offering tangible support to breastfeeding mothers, with the donor appearing to have purely altruistic reasons to help women with an insufficient milk supply. The donor has often expressed milk for later use but for several reasons does not go onto to use it, nor want to see it wasted (Gribble, 2014). Although there are few medical reasons why a mother might struggle with her supply (Wambach & Riordan, 2016 p385), certain hormonal imbalances such as Poly Cystic Ovary Syndrome may inhibit lactation (Hoover et al., 2002). This would mean that, despite lactation support, a mother may have a reduced supply (Wambach & Riordan, 2016).

### **Becoming a mother**

Underpinning this research is the theory of 'Becoming A Mother' (BAM) (Mercer, 1986), which describes the psychological processes involved in becoming a mother. BAM describes the transition to motherhood as a major developmental life event (Mercer, 2004), that requires the restructuring of goals, behaviours, and responsibilities to achieve a new conception of self (Barba & Selder, 1995). This new identity reflects the qualities, traits,

attitudes, and achievements she finds desirable in motherhood, rejecting behaviours she judges as inappropriate for herself (Rubin, 1967).

BAM, although a complex theory, is described in four main stages: making a commitment, formal, informal, and maternal identity. To begin with the mother makes a commitment to her pregnancy and takes on the advice of professionals as she begins this journey. The mother is seen to then attempt to follow the advice of professionals, known as the 'Formal Stage', before transitioning to the informal stage in which she finds her own way of doing things. The final stage is where the mother is comfortable in her decision and journey and reaches maternal identity.

There are many variables along the way that would prevent or prolong the period of achieving maternal identity. Wanting to breastfeed and not being able could delay a mother from reaching maternal identity (Husmillo, 2013). The role of these tangible online social support groups plays in providing tangible support, and in buffering potential stressors, such as a low milk production is explored in this piece of research.

### **Study aims**

Previous chapters have explored that use of online social support groups and highlighted how mothers use the groups to seek informational, emotional and esteem support. Only occasionally were tangible support options discussed. In chapter three for example 65% of posts related to informational support, 18% to esteem support and 10% emotional support. In chapter four it was emphasised that the groups can provide a community of reciprocity that builds confidence and provides reassurance. However, it is acknowledged that online social support groups exist that provide tangible support, in this instance through online milk sharing.

To continue to explore the overarching researching questions around how and why mothers use online support, and the perceived impact of this support, this chapter explores a mothers experiences of using tangible online milk sharing sites. This research seeks to answer questions such as: why would a women use this tangible support options, what are the women's experiences of using this support option, how do women make sense of their experiences using these milk sharing sites.

To address these specific questions the aim of this study is to produce a single case example of an online tangible breastfeeding support group, demonstrated through one mother's experiences of seeking peer to peer breastmilk online. Care is taken to not have too many objectives, a common pitfall in case study design (Flyvberg, 2006), so it is the sole aim of this study to explore how and why the online support group was used; and how this tangible support might potentially buffer potential breastfeeding stressors. This research aims to add to the body of literature on online support groups, and further explore how to best support breastfeeding mothers through online platforms.

## **Method**

### **A Case study approach**

Case study is a systematic enquiry into an event or set of related events, which aims to describe and explain a phenomenon of interest (Bromley, 1991), in this instance online breastfeeding support groups. A case study approach considers how and why questions, without manipulation of behaviour and within the context in which it occurs (Yin, 2018). A story board (Yin, 2018) was constructed to capture research ideas and to plan the case study (see Appendix A for the case study story board). Similarly, a case study approach begins with a case; a phenomenon of some sort occurring within a bounded context, with attention paid to the analysis of this phenomenon (Miles & Huberman, 1994). Thomas (2016) claims that the

quality of a case study is determined by the line of inquiry, thus this is planned and made clear from the start.

Given the importance of context to the case study, attention was paid to the mother's whole ecological system. Appendix B highlights Bronfenbrenner's ecological systems theory (Bronfenbrenner & Morris, 1998), which was considered as this model emphasises how the individuals behaviours occurs within a context of others' activities, such as family, work, school, community, cultural, linguist, legal and physical environments. This wider lens will be adopted throughout the research process to widely examine this phenomenon and consider the cultural elements pertinent to case study, without losing the focus on the mother's experiences but to deepen the interpretation.

There are many ways in which to research a case, and case study methodology is a creative alternative to traditional approaches to description, emphasising the mothers' perspective as being central to the process (Zucker, 2001). Cresswell (2003), Stake (1995) and Yin (2003) all talk of binding a case through time, place, activity, definition and context, all areas explored below when determining the case.

### **Determining the type of case study**

Merriam (1988), Stake (1995), Bassey (1999), de Vaus (2001), and Yin (2009) all define and categorise types of case study in slightly differing ways. Across all approaches Thomas (2016) highlights that the importance throughout is the consideration for the case, purpose, approach, and process of the case design (Table 2). To ensure quality these are clearly stated before the study begins to provide openness and transparency (Mays & Pope, 2000).

**Table 2**

*Elements chosen within for the design of this case study. (Thomas, 2016, p114)*

Subject	Purpose	Approach	Process	Process detail
Outlier case	Intrinsic	Test theory	<b>Single</b>	Nested
<b>Key case</b>	Instrumental	Build theory	Multiple	Parallel
Local Case	Evaluative	Draw a picture		Sequential
	<b>Exploratory</b>	<b>Descriptive</b>		Retrospective
	Explanatory	<b>Interpretative</b>		Snapshot
				<b>Diachronic</b>

In this instance, and to best answer the research questions a key case was chosen. The mother selected for the study was what Yin (2003) describes as a key case, characterised as someone that is a good example, in this instance a breastfeeding mother that is actively seeking donor breastmilk online. The key case is not an outlier or a local case (Yin, 2003).

The purpose of the study, as highlighted in the aim, was to explore this phenomenon. Through an exploratory design, exploration of a phenomenon that has no clear single set of outcomes is possible (Yin, 2003). Given all experiences are assumed individual and subjective then the exploratory design will facilitate the understanding of the woman’s story, where outcomes are not predicted.

The process adopted in this research was a single diachronic study to observe changes in attitudes, beliefs and meaning over time. According to Yin (2018) this would be a type 1, holistic, single-case study. A descriptive and interpretative approach was then taken to the data provided. The descriptive approach concentrates on the describing the different aspects of the phenomenon, whilst the interpretative approach explores how the phenomena unfold over time (Miles & Gilbert, 2005). This allows for the researcher to describe the mothers accounts at the same time as learning more about what is happening and why (Thomas, 2016).

Another way to guide case study research is with propositions. Propositions are created by researchers in advance, they are a set of decision-making concepts or behaviours that the researcher proposes are typical for the given case (Woodside, 2010). This exploratory study, like many exploratory studies does not have sufficient knowledge on which to base any propositions so the exploration is based on the purpose and aims of the study (Zucker, 2001). However, there is an assumption that this is a tangible form of social support, and that this support could support BAM. On the surface, by merely viewing the group, this is a site in which milk is exchanged from person to person, however any other types, measures and understandings about the group are unknown.

### **Participant**

Abbi was one of ten mothers that responded to an advertisement which was placed in the HM4HB Facebook group, posted in May 2019 (see Appendix C for the participant advertisement). It asked for breastfeeding mothers to come forward if they were considering seeking donor breastmilk online. Professional colleagues, who work as lactation consultants, had also been asked to share the advertisement on their Facebook pages, to find a participant. The participants were then sent a participant information sheet, which is detailed in Appendix D, and consent form which presented in Appendix E. Following this the details of the study were discussed, and they were subject to the inclusion and exclusion criteria.

**Inclusion criteria.** Only those that had experienced the phenomena could take part (Todres & Holloway, 2004), therefore it was decided that the participant must be a mother who is currently seeking donor breast milk through an online peer led milk-sharing network in the UK. The groups themselves have their own criteria and ground rules around promoting a ‘pro-breastfeeding’ environment and the mothers that join the group adhere to these communal rules. They had to be at the contemplation stage as a recipient, so that the mother’s thoughts over time could be seen. They must have also sought lactation support

from a professional to support their own breastfeeding, so that the safety concerns were minimised, and the study was not limited to first time mothers. This phenomenon is not felt to be unique to first time mothers in anyway and there may be some interesting meaning around donor milk if the mother has other children.

**Exclusion criteria.** The exclusion criteria included any mother that did not satisfy the inclusion criteria. People seeking breastmilk for themselves, for example adults with chronic illness, bodybuilding, or fetishes that were not seeking breastmilk for infant feeding purposes were also excluded.

All ten mothers, that came forward, were eligible to take part in the study and presented a purposive single case worthy of exploration. Abbi was selected as the chosen participant based on convenience. Abbi was the first mother that was forthcoming, in that contact was prompt, she was easily contactable and willing to undertake this study over a period of months. This was a consideration as attrition was a concern and raised in the literature (Silverman, 2000). Following an email from the participant, a telephone call was requested. Conversations were had with the participant to build a professional relationship and rapport (Nursing Midwifery Council, 2019), and so that she understood that her story was the primary focus of the study, and research aims.

### **Data Collection**

Data collection for case study can come from several places including documents, archives, records, interviews, direct observations or physical artefacts (Yin, 2018). The hallmark of case study research is the use of multiple sources (Baxter & Jack, 2008), as it enhances credibility (Yin, 2003). This piece of research asked the mother to record her thoughts as she used the tangible online groups searching for donor milk over a two month period. A telephone interview was then conducted and the page activity on the HM4HB group was recorded.

**Recording of thoughts as the mother searched for donor milk.** To begin, Abbi was asked to keep a log of her thoughts, attitudes, and feelings around seeking online donor milk through the group. She was asked to complete this for 2 months (eight weeks, over the months of June and July 2019) and then a telephone interview was scheduled for late July 2019. This aimed to capture the contemplative stage at that specific time (Stake, 1995), and to accurately describe a most comprehensive description of the case (Zucker, 2001). This log provides an unobtrusive, real time capture of thoughts, to limit response bias or inaccuracies in recall bias (McGregor, 2006).

There were concerns that some things may be deliberately withheld, may be incomplete, or that it is difficult to write at emotional times (McGregor, 2006). However, the recording of thoughts does provide multiple measures of the same phenomena, which is a major strength of case study (Yin, 2018). Logging thoughts as they are experienced also helps to prevent the tainting of data through experience, tracking experience over time (Zucker, 2001).

Abbi regularly engaged in online support groups aimed at breastfeeding women, she regularly posted to friends in an online private group, and on the pages of the online social support groups. These posts were provided and included in this study as a log of her thoughts, feelings, and activities during this time. These entries were saved as screen shots and sent to the primary researcher after the interview had taken place and was instigated by Abbi. Her idea redesigned the traditional approach suggested by the primary researcher, which was to keep a diary, and deemed appropriate due to the purpose of this research was to look at support online, and online platform usage.

**Interview with recipient.** The main body of data is taken from a telephone interview. The interview schedule (see Appendix F for the interview schedule) consisted of open



questions that focused on the research question (Zucker, 2001). Interviews were chosen as they explore the how and why of key events and the insights reflect the participant's relativist perspectives (Yin, 2018). Yin explains how interviews can be useful in providing explanations as well as personal views such as attitudes, perspectives, and meanings.

The rationale for telephone interviews was that the chosen online group covers the whole of the UK, the participant could in theory be hundreds of miles away making face to face interviews problematic regarding time, travel, and funding. Telephone interviews are also easily arranged at any time of the day or night and the mother was therefore offered flexibility to suit her and her family's needs. Children are also unpredictable in their sleep, feeding and comforting needs and the telephone interview would offer a flexible approach to the mother. In the literature, telephone interviews are shown to provide access to hard to reach people and are less costly in terms of time and labour therefore more effective (McIntosh & Morse, 2015). They also offer the researcher the ability to take notes unobserved reducing distraction and disruption (Irvine et al., 2013).

**Facebook group activity.** Zucker (2001) highlights that the context of the case includes other persons and sources of information independent of the case. For this reason, over a one week period, at the time of the interview in July 2019, the group activity was recorded from [www.humanmilk4humanbabies.Facebook.com](http://www.humanmilk4humanbabies.Facebook.com). This is a publicly visible page and access is unrestricted. Page activity such as the number of posts made, content of the posts and subsequent comments were recorded in order to provide a context to the study and relate this to this mother's journey, but not to take away from the spoken word of the mother. The aim was to add another element to this case study, to further understand how the group is used and the part played in the mother's journey. This strengthens the case study by providing an opportunity to use many sources of evidence (Yin, 2018).

### **Analysis and write up**

As the case study provides one single case, the analysis of the findings focuses on the mother's experiences and does not aim to generalise any of the findings (Stake, 1995). It focuses on the narrative description and the interpretative using Bronfenbrenner ecological systems model, to ensure context is captured. Method and analysis occurred simultaneously, moving between the literature, field notes to the interview narratives, and then back to the literature (Zucker, 2001). Pattern matching was adopted within the analysis to develop this case description (Yin, 2018). Pattern matching is noted as one of the most desirable techniques because it allows for connections within the data to be explored and noted (Yin, 2018). In this instance data from the notes made by the mother prior to interview were matched to the narratives from the interviews to strengthen the case analysis.

Yin suggested six types of report when writing up a case study: linear-analytic, comparative, chronological, theory building, sequenced and un-sequenced. A combination of linear-analytic and chronological structures was used to write up this study. A linear analytic approach is often referred to a standard research report sequence for journal articles and dissertations (Yin, 2018), characterised by the analysis presented in a linear, logical order and therefore complements the chronological approach to presenting data. A linear-analytic structure is a standard approach for research reports starting with the research problem, literature review, methods, findings and conclusions, and the chronological structure also aids understanding and meaning-making of events over time. The aim of the research, to explore the phenomenon, did not lend itself to a theory building approach or comparative approach of reporting for example.

Abbi was given an opportunity to read the transcribed interview to make sure that she was happy with her account and that no mistakes had been made, through a process of member checking (Yin, 2018). A second follow up phone call was arranged to discuss any

discrepancies or alterations required, providing an opportunity for deeper reflection and to ensure they have been accurately recorded and therefore credible (Sandelowski, 1993; Stake, 2006). Whether or not to show participants their data before or after interpretation is not without challenge (Koch & Harrington, 1998), as it is not necessary for participants to recognise themselves (Houghton et al., 2013). In this instance member checking occurred after the transcript was written and after interpretation to ensure that the themes identified were pertinent to the mother, increasing credibility.

### **Ethics**

Full ethical approval was granted through the University Ethics Panel. More particularly this research adopts a 'thick disguise'. This is the most common method of dealing with confidentiality in case reports and often considered alongside informed consent (Gabbard, 2000). During this process, the details are changed to add disguise, however without being misleading to the purpose and reality of the findings, or the reader (Gabbard, 2000). Informed consent is ensured, and the motives of the researcher are openly discussed along with the rights of the participant to withdraw at any point up to publication (Gabbard, 2000).

It was anticipated that this may be an emotional and sensitive topic for the mother as 'A mother's guilt' is documented in the literature (Sutherland, 2010). The mother's emotional wellbeing was paramount throughout the study. The mother was informed that she could stop at any point throughout the interview and withdraw at any time. Support avenues such as her local Health Visitor, GP or national breastfeeding helplines were prepared, and all documented in the participant information sheet for discussion. The mother was provided with reassurance, if needed during the interview, with no judgement made around her choices, with the aim to provide a clear and accurate account of her experiences in mind.

As a nurse researcher there is a duty of care and responsibility as outlined by the Nursing and Midwifery Council (2019) to ensure that there is no harm to the participant or the child. There is an implicit duty of care to ensure that the mother is fully informed and indeed makes informed decisions. Any areas of discussion that the nurse researcher deemed unsafe were raised at the end of the interview.

### **Quality assurance**

Sample, reliability, and validity are all key terms imported into research methodology looking for accuracy of data collection (Thomas, 2016), that simply do not apply to case study methodology. Thomas (2016) utilises the work of Hammersley (2005) who provides indicators for use in case studies, that focus on the quality of the case study that relate to conception, construction and conduct of the study (Thomas, 2016). Hammersley's criteria were considered throughout the research process from contemplation to analysis through to write up (see Appendix G for Hammersley's criteria). Maintaining a journal of thoughts during the process and data collection also ensured that the case study was interpreted inductively (Denzin & Lincoln, 2013). Denzin and Lincoln (2013) state that the investigators of the constructive paradigm are orientated to the production and reconstructed understanding of the social world. For this reason, traditional criteria of internal and external validity are replaced with terms such as trustworthiness and authenticity (Zucker, 2001).

### **Findings**

Abbi is a 29-year-old mother of three sons; Logan aged nine, Harry aged six and Lucas aged four months. Abbi lives in the East of England with her husband and children and is of British nationality. She has an NVQ in childcare and currently volunteers with the National Childbirth Trust providing mother support groups.

In 2004, Abbi was found to have ovarian cysts and later diagnosed with polycystic ovary syndrome (PCOS). In 2009, after her first child, Logan was born PCOS affected Abbie's ability to breastfeed, affecting her ability to produce sufficient breastmilk and maintain an adequate milk supply. This case study was undertaken whilst Abbi was breastfeeding Lucas, and shares Abbi's attempts to breastfeed Lucas and to go on to obtain breastmilk through online milk sharing sites, to supplement her supply. In chronological order it explores the meaning behind seeking donor milk and using online milk sharing sites, whilst reflects on experiences with her first two children.

### **The journey so far**

At the start of the interview Abbi openly discusses her expectations around breastfeeding when becoming a mother for the first time:

*For as long as I can remember I've wanted to breastfeed and it's been the one thing I wanted to do as a mum was breastfeed, when I couldn't do that, it I suppose it's a very natural, it's meant to be one of the most natural things in the world just to feed your baby that's what breasts are for and when I can't do that it felt like it was my fault like my body had failed him. Um I did find that quite hard to deal with... it was just something I wanted to do, I don't know why I have no idea, it's just something I wanted to do and expected to do... so I didn't expect it to be as hard or even not produce milk to be able to feed my baby that was just a bit of a shock, that I didn't have any milk. Yea I wasn't expecting that.*

Abbi breastfed her eldest for two days before switching to formula. She described a lack of milk and a lack of support around breastfeeding at that time. With her second child she again felt as though she had a limited milk supply but did feel more supported with her breastfeeding. Abbi openly discussed the impact that this had on her mental health and feels

that it was a large contributing factor to the Post-Natal Depression (PND) she experienced with Logan and Harry. These were feelings that this time Abbi was keen to avoid and motivated her during pregnancy with Lucas to take a different approach.

**A need for milk:** *“It’s not just milk it’s mental health”.*

When pregnant with Lucas, Abbi felt determined to try to breastfeed, as she wasn’t planning to have more children in the future, she felt as though this was her last attempt to fulfil her desire to breastfeed. This determination led to certain behaviours in order to make this into a reality. Even when pregnant she was looking for people, and surrounded herself with breastfeeding mothers that could help her visualise and achieve her goal to breastfeed Lucas:

*So, I knew who to speak to when I needed help and I think that was a big help knowing where to go when I was struggling and needed support. I knew where to go for support.*

Abbi also joined online breastfeeding support groups for support and information in the hope of breastfeeding and thus reducing the reoccurrence of PND this time around:

A big part of it [PND] was not being able to breastfeed because one of the things that I wanted to do was breastfeed and because I couldn’t I felt I failed them, so yea I was more determined his time as it was my last chance to breastfeed.

Since Lucas’ birth Abbi has been breastfeeding him, however this has been a turbulent time. The messages Abbi shared between her and a friend show just how difficult this time was:

*Spent the day in hospital after Lucas lost weight again. He is down to 3320g. More than 11% loss. Got to keep feeding him every two hours, then express straight after then give*

*him expressed milk... I'm finding it very hard to do more...I'm tired and emotional not sure if there is any point in going to bed tonight, will probably sleep on the sofa... by the time Lucas has fed, I've pumped, expressed milk and I've washed the pump up and sterilized it will be time to start feeding Lucas again. I really hope this works quickly as I can't see how I can keep this up long term... I can't physically pump anymore.*

Abbi soon realised that her PCOS was affecting her milk supply. Her reaction was to seek both professional help and support from the peers to try and maximise her milk supply. In the interview Abbi said:

*So, we have pumped, to start with I was pumping every two hours as well as feeding every two hours, um yea, and I have used fenugreek and I've had medications.*

In an early message posted to an online support group, at the time when she began taking prolactin enhancers in tablet form, (known to increase breastmilk supply), Abbi felt a moment of joy when Lucas had gained weight, she wrote:

*Basically, they like them to put on 35g per day, so 100g in 4 days, so the fact he put on 155g in 4 days is epic. That was with 2-3 formula top ups of between 1-3 oz per day. Now going to max of two formula top ups per day and this is while he was feeding so managed to pump 60mls!!! Most yet! I also started taking Fenugreek and Domperidone yesterday so hoping that helps my supply”*

Abbi describes how she pumped her milk regularly to increase supply, she took fenugreek, a herb known for its prolactin enhancing properties, and took a two-week course of Domperidone, also a prolactin enhancer. This was prescribed off-licence by her primary care physician as a Galactagogue known to increase milk supply (Breastfeeding Network, 2014). Abbi worked with an International Board-Certified Lactation Consultant (IBCLC) and after a few weeks started on Metformin, which replaced the Domperidone prescription. Top ups of

expressed milk were given to Lucas and a supplementary nursing system was also one of her final attempts to increasing her milk supply. It is seen in this post that Abbi used the online groups to share the joy of her successes within a community of breastfeeding mothers who would understand her efforts.

At around four weeks old, Lucas was not gaining weight. In messages to friends Abbi wrote:

*Lucas has lost more weight. Paed [Paediatric] registrars want him re-weighing in 48 hours. Midwife has recommended that I express every other feed but top up if he is unsettled. Basically, it's my low supply that's causing the issues, so I'm feeling a little fragile/ guilty but won't be giving up feeding.*

Abbi's sadness, yet determination, can be heard here when she says, "but I won't be giving up feeding". This led Abbi to ask many groups for advice online, in the interview she said:

*Yea it's a big decision [seeking donor milk], he was low weight gain because of my low supply, and we were having Midwife and Health Visitor visiting every two days and we were having admissions because of low weight gain. They were trying to convince us that formula was the way forward and although he went on formula for about a week he still didn't put any weight on, he just became constipated from it, and it was almost out of desperation that I needed to do something, just to help. It was almost out of desperation that I put that post up thinking no one going to help us, but I have to try something this is not working for us and I need to do something, so I did.*

The desperation that Abbi talks about in her interview was seen in messages that she had posted online: "What can I do to increase my low supply? Lucas has lost more weight". This was a difficult time for Abbi "um I started to worry that I wasn't good enough and I could



*feel them doubts and failure creeping back and I thought I don't want this, and I decided to do something".*

At 4 weeks old Lucas was supplemented with infant formula. Abbi believes that as a direct consequence of this Lucas became constipated and unsettled and Abbi describes feeling desperate as she began viewing the infant formula negatively. Abbi talks of how she did not like the effects of infant formula on her baby, or the impact of not feeding her child on exclusively herself her mental health.

It was at this time that a close friend offered her some of her own frozen expressed breastmilk and she accepted. She began looking more into donor breastmilk as an option for Lucas, something she had not considered previously. This avenue of support Abbi feels was due to her own internal issues as opposed to pressure from professionals or others to breastfeed stating *"it's not just milk it's mental health"*. Abbi felt breastfeeding could be promoted more. Abbi talks of her own internal issues that caused her to search for donor milk online.

Following a need for support, Abbi went online. She talks of the benefits of online support groups in general, in providing options and ideas from others, support not available in offline communities. The value of the online groups in providing access at all times of the day, to encouraging words and information was noted. There was a felt need to find milk, and a real tangible need.

*Um I've posted in the middle of the night asking something really silly, but checking like am I doing this right, should I keep going, should I stop, is he getting enough milk um unfortunately in this case I wasn't, but I was signposted to places that helped and it showed me how it helped me see that he's getting enough milk... and I posted on the group about milk donation.. just loads of different things... I don't feel like there is*

*pressure to breastfeed... it was my own guilt and my own feelings it wasn't because of what somebody else had said. It was my own issues that made me feel guilty.*

From previous children Abbi already had an online group of friends. They had originally met in a parenting group; however, the group implemented an increasing amount of group rules, so a select number of mothers started their own group, a group of likeminded people:

*Most of the group breastfed to term [Breastfeeding until the child no longer asks for breastmilk], cloth nappy and use baby carriers and are known as alternative/ gentle parents. I love the group for its honesty and help. They all tell me straight if I need to get a grip or if I should be doing something differently but are also the most supportive strangers I have ever met.*

It was interesting to hear how easily these online groups form, and continue over several years, yet Abbi still referred to them as strangers due to the fact that they had never met in person. She had strong ties to this group of mothers however interestingly was selective in who she talked about milk sharing to:

*I also glossed over using donor milk especially from HM4HB as one particular lady expressed her disgust at it previously so I decided that was not the place to ask for advice about it [donor milk] which is a shame as I think other members would have been awesome at signposting me sooner.*

Abbi showed a sense of agency in her online support behaviours, she knew where to go and where not to go for support around donor milk. Abbi shared some messages between her close friends who were long time breast feeders stating, *"I messaged them as I knew they would be supportive and caring"*. Abbi liked to share her successes with her online groups and received many words of encouragement in reply. Typically the small weight gains that Lucas achieved were points of celebration for Abbi and she shared these with the group *"60g*

*weight gain!!!, 155g weight gain in 4 days!!!!, I am loving our breastfeeding so want to continue, I am so proud of this one whole week!!!”.*

### **Finding a donor**

When Lucas was around four weeks old Abbi discussed milk donation within an online breastfeeding support group. She discussed how some sites were not supportive of these discussions and had a blanket ban about talking about milk donation, leaving her feeling judged:

*Some of the other groups that I am on have a blanket ban on it not being talked about at all. I was told because it was unregulated, even when I said about it from the milk banks, they had a blanket ban and say no we don't talk about, we don't have milk donated in our group.. I left that group quite quickly because no I didn't understand that at all... I found that very judgemental and I did leave. If that has been the only group that I was on I would have found that very difficult to carry on breastfeeding because I didn't have the support there... it's a shame that they took that view. I could stay in the group I just couldn't talk about; I wasn't allowed to talk about donor milk on there. It made me feel judged and it did make me feel like a failure that I was having to use donor milk to help my baby... um it's still breastmilk and yea I did I took deep breaths and thought right well that's how they feel get rid of the group and I don't need them sort of people in my life I can go to my other group and say help me and that's what they did, they then did help.*

Abbi showed her sense of agency and control over her online behaviours. She demonstrated her ability to know how, where and where not to seek support, “*so I looked into it and researched it*”, using the information from peers and from professionals to meet both hers and her baby's needs. Abbi valued the science provided by professionals but values the

experiences of others when the science did not work for her. Abbi discussed making an informed choice and her thought processes before using donor milk facilitated by an online milk sharing site. She weighed up the risks, was aware of the risks of peer shared milk, and developed her own internal criteria before using peer led donor breastmilk.

After searching Abbi found the HM4HB page, a peer to peer human breastmilk sharing site stating, “*Once I’d found the right channels it was easy to access*”. This social media group linked Abbi to similar minded people that she had not met before. Via the site, and when Lucas was 5 weeks old, she successfully found a breastmilk donor.

This tangible online support elicited many feelings for Abbi. On one hand Abbi described feeling joy:

*Just amazed, just... I was amazed that people do that for other people, amazed about it but also gutted that I didn’t know about it for my other children because it would have made such a difference to how I felt after. Because I was diagnosed with post-natal depression I think it would have really helped me feel not as low as I did in those times, because I would have still given them breastmilk which to me is preference over formula.*

Abbi also experienced feeling ‘saved’:

*Oh goodness someone has helped us, we haven’t got to use that formula, he won’t get belly ache any longer because he was really struggling with constipation and I was like this formula isn’t working and he can have breastmilk, I can keep breastfeeding him. Um, it saved my sanity and my mental health, yea I was overjoyed completely overjoyed, overwhelmed, overwhelmed by somebody else’s kindness, and it means my baby is healthy and thriving and happy.*

Such positive feelings also brought with them some apprehensive, as she was nervous about taking milk from a stranger:

*I was very unsure, not unsure about it, just really, I don't know apprehensive about it I suppose about somebody else's breastmilk, but I thought it was better than what we were going through now... but at the time I was a bit apprehensive about it to start with, quite nervous about accepting somebody else's breastmilk I suppose I worried that I didn't really know, wasn't sure if I really knew the person. Um, but I made sure I looked into who was donating and actually met them before accepting the milk.*

*When I started thinking about it, it was more of ugh I was apprehensive but also very much a last resort, but now I'm very positive and I've told people about it, and promote it when I can.*

Here we can see a change in Abbi's thinking, from once nervous emotions to a confidence in what she is doing.

### **Group Activity**

At the time of interview the human milk for human babies' site had 22,281 followers on their UK page. To provide context the group was created on Facebook on 28.2.11 and year on year the group attracts around 2000 new followers to its pages. On 20.12.17 the page had 18,000 members and then by the 7.9.18 had 20,000, hitting 21,000 members on 21.1.19 and then 22,000 by March.

During the week of the interview (July 2019) there were 55 posts to the page. Just twelve of the post were from donee's, like Abbi, requesting milk, which were then reposted by administrators 11 additional times. The page also had 16 mothers come forward offering donor milk, which administrators shared 16 additional times to increase visibility of the posts.

#milk to share, #freezerstash, #milkto share, #donormilk were all common social media tags added to increase visibility to these posts.

On the site, the posts from donors were typically short detailing amounts and location of donor milk, for example *“I have 40oz of dairy free milk pumped on Friday in...”*, or *“70oz to donate in [area name]. Pumped from December up to March. Looking for a happy home”*. Most posts also contained a picture. These posts are easy to read, and it is easy to identify which would be appropriate in terms of location.

**Meeting the donor:** *“Trust not regulation”*.

When Lucas was about three months old Abbi met Lauren, a milk donor through the HM4HB site:

*She posted on a local group um saying she had some and I was tagged in the post by several different people and I messaged her we messaged each other for a little while as we talked.*

Abbi describes talking with Lauren, asking open questions, and building a relationship with her. She discussed lifestyle habits such as alcohol use, smoking, diet, and medications until she felt comforted and reassured:

*We talked before and she was very open about everything that she had been through um how many children she had and the whole background which made me feel happier about doing, about accepting the milk. I suppose if somebody wasn't very open or preferred not to discuss certain areas that I did ask about, like smoking and drinking. Because those things would put me off because I don't do those things, or if they were on lots of medications, I think at the start that would have put me off.*

Abbi discussed her reasoning:

*[The decision to use donor milk] It was based on they wouldn't feed their own baby with that milk if it could harm them, so why would they give it to my baby... I suppose it helps my trust that other people know her, um that she's local because Lucas doesn't like being in the car. I prefer someone who's friendly, um and I can speak to them freely and they can speak to me freely. I think if someone was abrupt or not very open or I don't feel that I wouldn't then trust them if that makes sense... it a relationship definitely, that mother is feeding my baby basically and I feel that relationship, and friendly relationship yes.*

Abbi did obtain donor breastmilk from a lady that she did not feel she made a personal connection with. Despite collecting the breastmilk, she did not feel that she wanted to use it. Abbi described how she and Lauren had friends in common and frequented the same group which made her feel at ease about this donation.

Abbi also sought support from a milk bank. In the early days Abbi was unaware that she could get milk from the milk banks, writing to a friend:

*I'm using donor milk from a local friend but running low so will probably need to use formula again soon bit it made him horribly constipated before. We have started the process of applying to the milk bank, but I doubt I will get funding or accepted as we are low on the order of need.*

Abbi received two batches of milk via the milk bank which was delivered straight to her house. She believes that “breastmilk is precious and shouldn't be wasted” and because the milk bank donate to the hospitals she was happy to also receive milk from peers because it would meant there was plenty of milk to go around:

*I definitely feel that even when I had Lucas and even when I had Harry there was only mention of NICU having to have the milk, and it wasn't available anywhere else and*

*even when I had Lucas this time, there was still a thought that it was only really available to NICU's and poorly babies un and it was hard to access which although I had to find the right channels, once I had found those channels it was easy to access. Once you're in a breastfeeding group it is very easy to find out about it.*

Through the online support groups Abbi has been able to find a regular donor Now that she has a regular donor, she feels she doesn't have to use this form of tangible support at the moment.

*I use the local online group the most, and the donor milk one I suppose it's the HM4HB group I was using a lot but I've got a regular donor now so I'm not having to use it. Well one lady she had four moths supply in her freezer and what she can pump in a month is just under what Lucas needs in a month, so I'm not having to use it.*

**Impact of the online milk sharing group on breast feeding journey:** *"it's not just babies' wellbeing it's mums' wellbeing".*

Abbi used the milk sharing site and an online breastfeeding support group to support her journey. Both contributed differently to her journey and this case provided valuable insight into how different groups can support in different ways, and the diversity in groups. Overall, Abbi feels social media has made breastfeeding support and particularly donor milk more accessible:

*I suppose it's, it is social media that has made it more, more like, accessible to me, I thought in our area it was just for NICU [Neonatal Intensive Care Unit] and new babies... because it's there all the time, someone to encourage to say keep going you're doing well, which in the middle of the night is vital.*

She found vital support for her breastfeeding journey through the online support groups:



*The online groups have been a life saver in the middle of the night yea yea it is it really is mental health and it is just a lifesaving support group. It probably doesn't sound like it, but it really does help with the worry and concerns and just the loneliness in the middle of the night when you are struggling. It's there. You don't have to post something you just have to read through what other people have written and make sure like you're not alone you're fine carry on going, un, yea it has the breastfeeding group has made a big difference and impact in my life to keep going to where we are now and hopefully keep as long as we can.*

The main reason given was the access to esteem support and words of encouragement throughout the day and the night that have kept Abbi's motivation high and supported the longevity of feeding. Due to Abbi's previous history with unsuccessful breastfeeding the group has been vital to her:

*The online group is there all the time. There is always someone there to answer your question, or if you're having a rough night there's always someone there to go keep going, don't stop just make sure you're happy and baby's happy...in the middle of the night it's vital.*

The informational support and access to both professionals and peers was also indispensable to Abbi:

*I looked into it and researched it and I asked several groups about it and um and yea there were lots of people that were willing to help and then I was signposted to other people on other groups and organisations that so it as professional channels as opposed to my friends... another benefit of the online group is loads of people have loads of different tips and they can tell you about donor milks and what can happen.*

Abbi described how the Human milk 4 Human Babies site links her with donors that “*have had bits and bobs of what people can donate*”. Due to Abbi’s own fluctuating supply she has relied on these bits and bobs from peers and the milk bank, using formula as a last resort. She talks of fluctuations and growth spurts and the uncertainty of this process. One message in the early days, to her online group, read “*My supply seems to have dipped again so I am waiting to hear from the milk bank about the next delivery as none left from them*”. The impact of this for Abbi meant that she set short-term and long-term breastfeeding goals. Abbi’s long-term goal is for Lucas to self-wean from the breast, but she talks of having enough human milk to support Lucas until he is eight months old. Abbi adds that if something were to happen now, she feels she would know that she has done her best and would not have the troubles with depression that she has previous had because of this:

*It means the absolute world to me, and saved my sanity and my mental health...I’m now feeling like if something happened this week and we had to stop I feel like I have given it my best shot and it wouldn’t affect me as much as not feeding. I don’t feel like a failure... The online groups have provided professional and peer support and feels as though all the groups are about being there, experience, knowing how it affects you and being there.*

Abbi believes that both groups could certainly help other mothers going through the same thing as her:

*Now I’m very positive and I’ve told other people about it and I’ve told them to look into it and I promote it as and when I can it’s the most amazing things to do and it helps so much. It’s not just baby’s wellbeing it’s for the mum’s wellbeing., my mental health has been so much better this time.*

## Future

Abbi wanted to share her story to encourage others to seek support online to meet their breastfeeding goals. She wanted to share the difference that she feels it has made to her and for her son Lucas. She feels that donor milk needs promoting, and an awareness needs to be raised about this so that other mothers can make informed choices:

*I didn't realise there were people who were willing to do it and I could access it through a milk bank... professionals need to talk about it and provide leaflets and information... I think it's such a small areas of Facebook and social media that know about it and only a small amount of breastfeeding mums that know about it as well but it seems to be getting more popular as its being promoted and made awareness of, but I think it depends on, it's sort of quite blurry because not all women can feed, can pump and express their milk to do it. It is only what is available. Um so it is there but a very small select people can donate their milk.*

Here Abbi shows the power of social media in linking this small group of women with other donors and donee's.

Abbi also wanted to share her story to encourage professionals to talk to mothers about all available options and to be aware of the milk sharing sites saying, *"I do think more professionals should be aware of milk banks and they should promote them or they should have information to hand just like they would have information to handout about another other medical, because it is a medical need as much as, my baby needs feeding"*. Abbi felt as though her health visitor didn't want to talk about milk sharing or the use of milk sharing sites stating *"she was definitely scared as a professional to talk about it, it felt she would have preferred not to talk about it at all"*. This has implications for future practice as she felt she would have benefited from talking about this with a professional, or even an awareness

week, *“it needs promoting we need an awareness week. We need to get this subject out there and who other people that its possible and it does help and it’s more than just food...we need social media for things like this”*.

### **Discussion**

This is amongst the first studies to provide an in-depth exploration of a mother seeking donor breastmilk online. Abbi’s case goes part way in exploring how and why the phenomenon of tangible online social support groups could support the breastfeeding mother. The HM4HB site, during the week of the interview, saw twelve mothers, like Abbi, searching for donor milk. The group provides clear posts from people wanting to receive donor breastmilk and people wanting to donate, in the hope that the two will link up and exchange can occur. Although tangible support is evident through how the group works, it was the deeper cognitive processes, highlighted within this study, that were enlightening.

Abbi described how Polycystic Ovary Syndrome reduced her milk supply, something noted in the literature (Marasco, Marmet & Shell, 2000; & Vanky et al., 2008), and how not breastfeeding significantly contributed to her depression. Research has shown that experiences of lactation insufficiency can be extremely difficult, isolating and cause a ‘breastfeeding grief’ that often goes unnoticed (Brown, 2019; Tomori, Palmquist & Dowling, 2016). This is a time when mothers need all types of support (Wambach & Spencer, 2020, p761). The research also offers a discussion around how the group provided hope, along with options and ideas. The ability of social support to support a person’s mental health, reduce stress and increase a person’s resilience is well noted (Antonucci, 1986; Antonucci and Jackson, 1990; House, 1981; House & Khan, 1985), and unique to this study is the contribution of tangible online milk sharing social support groups in supporting breastfeeding mothers.

There were several points worthy of discussion, and one area that echoed through the research was the stigma around milk sharing. Despite being a historical practice, still widely practiced today in developing countries, the stigma around milk sharing in the UK is noted in this study through the lack of discussion offered to Abbi around the use of donor milk by the professionals involved in her care, the fact the online breastfeeding groups that support breastfeeding banned such conversations, and from Abbi herself who chose who not to disclose her milk sharing with, through fear of being judged.

Stigma around milk sharing amongst health care professionals leads many women to do so in secret. Professionals fear saying the wrong thing, losing their jobs and losing face in communities are some reasons why such stigma exists (Tomori, Palmquist and Dowling, 2016). This research notes Abbi's impression that the professional did not want to talk to her about this topic. Health professional who actively involve themselves in an informal exchange of milk can raise both ethical and liability questions (Wambach and Riordan, 2016), which has implications for future practice. This research has highlighted a source of information online that mothers could be signposted too, however open, and honest discussions should be had between the professional and mothers. Abbi felt that if she had had conversations with professionals then it may have made a real difference to her breastfeeding journey, and felt social media was a platform to raise awareness. Similarly, in the Wambach and Riordan (2016) study it was found that women feared talking to professionals through fear of stigma or even being referred to child protective services.

The Nursing and Midwifery Council (NMC, 2019) state that the Nurses and Midwives must treat people as individuals, recognising diversity and individual choice, listen to people and respond to their preferences and concerns in a way that encourages people to share decisions that contribute to health. Wambach and Riordan (2016) continue by noting that lactation supporters should provide information to enable the mother to make her own

choices, and discussion around donor milk should be no different. This group offered a space free from stigma, but Abbi was still left to make such decisions without the support of health professionals.

The professional's advice given to Abbi is also worthy of discussion, as the thesis aims to inform professional practice, and highlights a possible educational need. Poor supply, and Lucas' subsequent slow weight gain, meant that professionals advised Abbi to introduce some infant formula milk after feeds, which she did. Formula milks are often used unquestioned, expected and a convenient alternative to a mother's own milk (Tomori, Palmquist & Dowling, 2016). Professionals in the UK follow the National Institute of Clinical Excellence (NICE) guidance on the recognition and management of faltering growth in children (NICE, 2017), and the NICE guidance warns that whilst supplementary feeding with formula may increase weight gain in the breastfed baby with faltering growth, it often results in cessation of breastfeeding. As Abbi experienced no donor milk was offered in or outside of the hospital setting, despite it being available through regulated milk banks. Doing so may have meant that Abbi did not need to seek donor milk through the online groups.

Another area worthy of discussion is the trusting relationship that Abbi built with the donor, through the group. Unique to this type of support offered through the group were the one-to-one discussions, rather than support, which was aimed at the whole community, as seen in Chapter Four. Compared to other breastfeeding support groups, where the mother posts the community and receives multiple responses, this groups linked one mother to another, and a relationship was formed. This relationship needed to make Abbi feel comfortable and reassured around receiving donor milk. In this instance, as seen in the literature it was the quality of the interaction as opposed to the frequency (Oh, Ozkaya & Larose, 2014). Similarly, the mothers do meet in person, to exchange milk, as opposed to the other friends that Abbi had made online.

Linking the discussion to the underpinning theory, the online social support groups facilitated Abbi in her journey to becoming and Mother (BAM) described by Mercer (2004). Abbi describes a time in which she was vulnerable, with feelings of desperation and guilt, and the online groups were described as a 'life saver'. Abbi was trying to find her own way of parenting, breastfeeding, and providing breastmilk for Lucas. She felt as though breastfeeding would build her resilience against PND. Abbi is describing the informal stages of BAM and both her breastfeeding struggles and depression could hinder her transition in the mother she wanted to be, her maternal identity (Husmillo, 2013). Abbi demonstrated a sense of agency navigating through different types of online support groups, engaging with those where she felt supported to meet her goals. Although HM4HB simply links donors with donee's, psychologically it provided hope, and allowed Abbi to feel as though she was doing her best. This was coupled with the reassurance and esteem support from other online groups which bolstered and protected her mental health. Abbi stated her PND would have been worse if it was not for the group, through the many options that the group provides.

Overall, on one side, breastmilk is idealised, however on the other, milk sharing can provoke stigma and thought to be dangerous. Health professionals may avoid conversations that conflict with guidelines; however, this causes people to search online and hide their practices, preventing opportunities for discussion and honest conversation to ameliorate risk. Health professionals must help explore options, making sure they have the information and advice that is evidence based.

### **Study limitations**

There are limitations to any study; and although a rigorous and transparent approach was taken to this research, there are inevitable limitations. Case study approach has often been criticised for lacking scientific rigour and providing little basis for generalisation (Yin, 2009). Case study is also dependant on the wider political and social environment. These

results present one case, one example of tangible online breastfeeding support offered through the milk sharing site, and these results are not generalisable. Alternative explanations around the use of these groups are possible.

This case may neglect other factors unknown to the researcher (Howcroft and Trauth, 2005). The researcher may have influenced the finding in some way given the close relationship and rapport necessary in case study approach (Yin, 2009). However, case study could strengthen or weaken a current argument (Crowe, Cresswell, Robertson, Huby, Avery, Sheikh, 2011), and does support theoretical development.

### **Conclusion**

This is a case of one mother's journey to provide breastmilk for her child, facilitated through online peer to peer milk sharing sites. Recognising negative feelings and to prevent occurrence of mental ill health, Abbi sought online support and came across donor milk sharing online. The sites, although when found were easy to use, and offered tangible support, there was much deeper psychological meanings and realities expressed including guilt, mental ill health, and necessity. This was not simply tangible support, and Abbi dealt with the decision making around donor milk on her own. Labelling the group as tangible support ignores the complexities around milk sharing.

For Abbi she felt she needed to build a trusting relationship with the donor first. At the beginning, the feeling of joy and feeling 'saved' were also coupled with anxiety around the potential risks that she was fully aware of. When these relationships with the donors were forged Abbi found the process to "*mean the absolute world to her*" and she wanted to share her story with others to promote online social support for breastfeeding women. Abbi talks positively of the HM4HB site and the positive impact that this tangible support had on her breastfeeding journey and her mental health.



Abbi's journey is supported by the theory of BAM and is a good example of how online social support can support an individual's journey. Variables such as mental ill health and failure to breastfeed can prolong achievement of maternal identity, which can affect the mother-infant bond. The HM4HB site, although tangible in nature, links donors with donee's and fulfils a much greater need than simply providing breastmilk. Abbi states "*it's more than just milk it's mental health*".

More awareness of the availability of donor milk and peer to peer sharing online is required. Looking at the online environment there are thousands of mothers that are doing the same, having to navigate the online environments with varying levels of professional support to aid their decision making. Professionals working with new mothers and babies must ensure they have the evidence and skills to have these conversations so that they can best support the mothers and infants that they work with. Abbi is just one example of a well-educated, well informed mother that chose an unconventional way to feed her baby. As nurses, midwives and health visitors we should have the courage to engage in difficult conversations that reduce any perceived stigma, at the same time as providing evidence based and reliable information so that mothers can make informed choices, maintain their own autonomy and make their own decisions.

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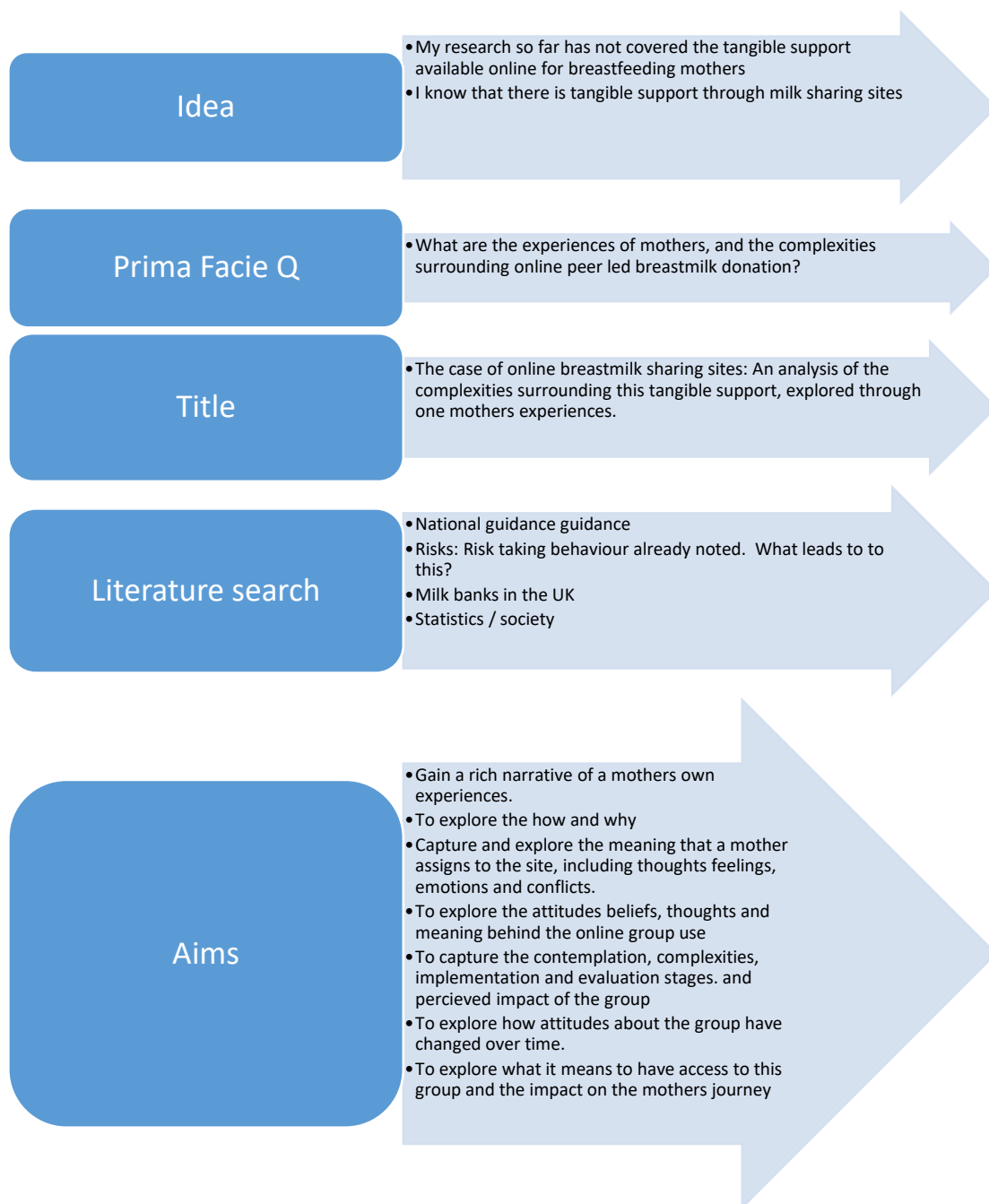
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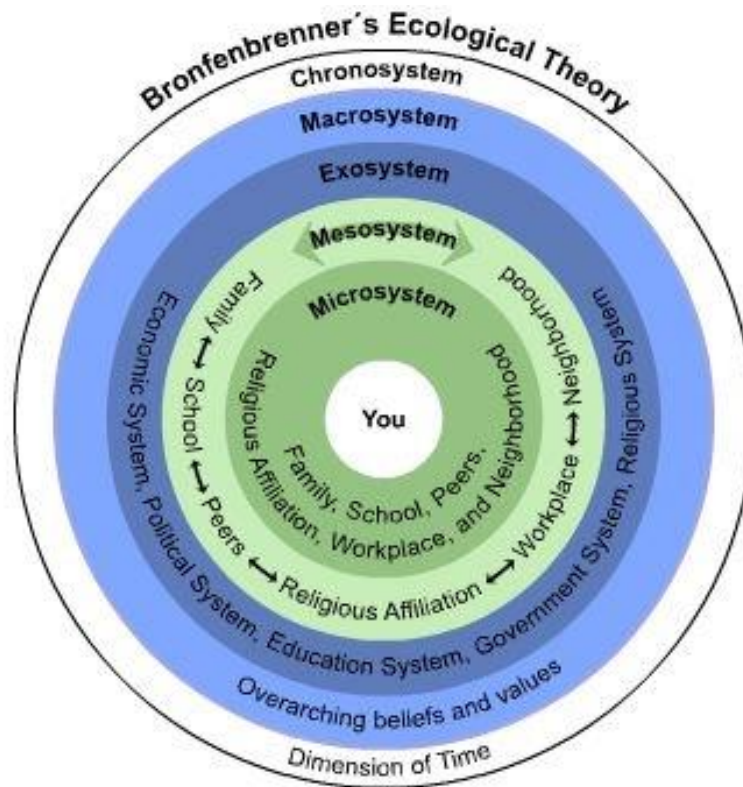
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Appendix A, Case Study Story Board



Appendix B, Bronfenbrenner's ecological systems theory



## Appendix C, Participant Advertisement

**ARE YOU A MOTHER IN THE UK THAT IS  
LOOKING FOR DONOR BREASTMILK ONLINE?**

HI MY NAMES MANDY AND I AM CONDUCTING RESEARCH INTO ONLINE BREASTFEEDING SUPPORT. I AM LOOKING FOR A MOTHER THAT IS WILLING TO DISCUSS HER EXPERIENCES OF ONLINE DONOR MILK SHARING. MY AIM IS TO EXPLORE HOW AND WHY ONLINE GROUPS COULD OFFER PRACTICAL ASSISTANCE TO MOTHERS. THERE ARE NO RIGHT OR WRONG ANSWERS, NO JUDGEMENT, I WOULD JUST LIKE TO HEAR YOUR STORY.

**WHAT WOULD I NEED TO DO?**

IF YOU AGREE TO TAKE PART, THEN YOU WILL BE ASKED TO KEEP A DIARY OF YOUR EARLY THOUGHTS AND EXPERIENCES SEARCHING FOR DONOR MILK. YOU WOULD BE ASKED TO JOT DOWN NOTES ABOUT HOW, WHEN, AND WHY YOU DECIDED TO USE AN ONLINE GROUP TO SOURCE DONOR BREASTMILK.

FOLLOWING THIS AT A CONVENIENT TIME I WOULD LIKE TO ARRANGE A TELEPHONE INTERVIEW TO DISCUSS IN PERSON YOUR EXPERIENCES. YOU WILL BE ASKED A FEW QUESTIONS WHICH SHOULD TAKE NO LONGER THAN ONE HOUR.

**BACKGROUND INFORMATION:**

AS A LACTATION CONSULTANT I SUPPORT WOMEN WITH BREASTFEEDING EVERY SINGLE WEEK AND A SMALL PERCENTAGE OF THESE WOMEN DONATE AND RECEIVE DONOR BREASTMILK VIA THE INTERNET. AS PART OF MY PHD STUDIES, AT CANTERBURY CHRIST CHURCH UNIVERSITY, I WOULD LIKE TO EXPLORE THIS PRACTICAL AND TANGIBLE SUPPORT AVENUE TO BETTER JUDGE THE BENEFIT/ OR NOT OF ONLINE BRASFEEDING SUPPORT.

**INFORMATION:**

**To find out more  
detailed information  
about the study  
please contact me:  
Mandy Wagg by  
email:  
m.wagg524@  
canterbury.ac.uk**

## Appendix D, Participant Information Sheet

### **Research Project title**

The case of online breastmilk sharing sites: An analysis of the complexities surrounding this tangible support, explored through one mothers' experience.

### **Invitation**

Hello. My name is Mandy Wagg. I work as a lactation consultant supporting women with breastfeeding and founded a charity that does just that ([www.lactationmotivation.com](http://www.lactationmotivation.com)). I am also undertaking a PhD in Professional Practice at Canterbury Christ Church University with a specific interest in online breastfeeding support. My supervisors are Alex Hassett and Margie Callanan, and they are supporting me through my research.

I would like to invite you to take part in a research study. Before you decide, it is important that you understand why the research is being undertaken and what it would involve for you. Please take time to read the following information carefully and discuss it with others as you wish. Please email me directly if there is anything that is not clear or if you like more information. Thank you for taking the time to decide whether or not you wish to take part.

### **What is the purpose of the study?**

The purpose of this research is to gain a detailed account of your experiences using peer to peer milk sharing networks/ groups. I am interested to know how you have found and felt whilst using the group and your reasons for using it. Your insight and views will help provide a snapshot of the group activity and how it may be used by breastfeeding mothers to potentially influence your breastfeeding journey.

### **Why have I been invited?**

Mothers that are searching for breastmilk donors online are invited to join this study as these views are of particular importance to me. You must however have been using the group for at least 4 weeks, had no previous breast surgery, and birthed a full-time healthy baby that required no medical intervention following birth.

### **Do I have to take part?**

It is completely up to you to decide to join the study. Even if you agree to take part, you are free to withdraw at any time, without giving a reason. If you agree you will be asked to sign a consent form and you will get to keep a copy of the consent form along with this information sheet.

### **What will happen to me if I take part/ what will I be asked to do?**

If you are interested, then we can arrange a mutually convenient time to conduct an interview over the telephone in about two months' time. Before this interview you will be asked to keep a diary whilst searching for online milk. I am particularly interested in dates, events, feelings thoughts and emotions during this time. I will ask you a series of open-ended questions about how you have used the group and how you felt interacting within the group. You will be given the interview questions in advance, at least the day before, to have a look at. There are no right or wrong answers your perceptions and experiences are what I am trying to explore. The interview should take no longer than one hour.

**Expenses and payments**

There should be no cost to yourself for completing this interview, other than your time. The researcher will contact you so that you do not incur any charges.

**What are the possible disadvantages and risks of taking part in this research?**

Participating in the research is not expected to cause you any disadvantages or discomfort.

**What are the possible benefits of taking part in this research?**

Whilst there are no immediate benefits for you participating in this project, it is hoped that this study will have a beneficial impact in supporting other breastfeeding mothers, and go some way in understanding what is required and thus what we can do as professionals in the future.

**What if there is a problem?**

If you have any complaints about this project in the first instance you should contact myself, Mandy Wagg at: [m.wagg524@canterbury.ac.uk](mailto:m.wagg524@canterbury.ac.uk) so that I can address your concerns. If you feel the complaint has not been handled to your satisfaction, then please follow the complaints section below.

**Will information from or about me from taking part in the study be kept confidential?**

All information that is collected in this study will be kept strictly confidential. Anonymised quotes will be used in the final write up. However, you will not be identified or identifiable in any reports or publications. I will aim to disguise any identifiable information.

Any data stored online will be password protected and any paper or electric copies will be stored as anonymised data and in a locked draw within the university. All data is stored for five years as per University guidance and will not be shared with any third parties. Only authorised persons such as the researchers, regulatory authorities and Research and development audits (for monitoring of quality of the research) will have access to data. After the five-year period all data will be destroyed and disposed of securely.

**What will happen if I don't want to carry on with the study?**

If you have completed the research and then decided, you wish to withdraw all data will be extracted and no longer used.

**Complaints**

If you remain unhappy and feel I have not addressed your concerns and wish to complain formally, you can do this by contacting Professor Paul Camic, Research Director, Salomons Centre for Applied Psychology Email: paul.camic@canterbury.ac.uk,

**What will happen to the results of the research study?**

As a participant you will have access to the preliminary findings in draft upon completion. Following this I am intending on publishing the results. To clarify you will not be identified in any report/publication. Anonymised quotes may be present in published reports.

**Who is organising and funding the research?**

I am organising and funding this research as part of my PhD at Canterbury Christ Church University.

**Who has reviewed the study?**

This study has been reviewed and given favourable opinion by the Salomons Ethics Panel, Salomons Centre for Applied Psychology, Canterbury Christ Church University.

**Further information and contact details**

1. General and specific information about research or whether to participate is available from Mandy Wagg  
Email: m.wagg524@canterbury.ac.uk , Tel: 07472663365 24-hours a day leaving a message for me containing your name and contact number so that I can get back to you. .
2. If you have specific information about this research project that is not answerable by Mandy Wagg then information is available from alex.hassett@canterbury.ac.uk
3. If you are unhappy with the study then please contact Paul.camic@canterbury.ac.uk



Appendix E, Participant consent form

Centre Name: Canterbury Christ Church University

Study Number:

Patient Identification Number for this study:

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**CONSENT FORM**

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Title of Project: **The case of online milk sharing networks: An analysis of the complexities surrounding this tangible support, explored through one mothers' experiences.**

Name of Researcher: **Amanda Wagg**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated [26.03.19] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
  
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.
  
3. I agree to part in the study and for the interview to be audio recorded.
  
4. I understand that relevant sections of the answers I give may be looked at by Amanda's supervisors; Alex Hassett and Margie Callanan. I give permission for these individuals to have access to the data.
  
5. I agree for anonymised quotes to be used within the write up of the study and publication as long as the information is fully anonymised.

\_\_\_\_\_

Name of Participant
Date
Signature

Please return this form electronically to the following email: [m.wagg524@canterbury.ac.uk](mailto:m.wagg524@canterbury.ac.uk) prior to the interview.

## Appendix F, Interview schedule

Questioning category	Question asked
Setting the scene	So, tell me a little bit about your breastfeeding journey at the start? -How old is your child, how long have you breastfed.
Defining	How would you describe the online milk sharing community? How would you describe or define it to someone that was thinking of obtaining milk?
Developing discussion	Could you tell me about the breastmilk sharing sites that you used? How do they work? Do you feel as though they are supportive? Can you describe the support you get from them?
Developing understanding	Can you tell me about when you first started considering obtaining donor milk? Those early thought when I asked you to keep a diary?
Describing meaning	How do you feel now about the groups? What do you like most about the groups? What do you like least about the groups? Is that different to how you feeling previously about the groups? What do the groups mean to you?
Providing examples	Overall, how would you describe the impact of using the group on your journey? Are there specific examples that you would like to tell me about? Did you make any changes to your breastfeeding decisions that were a consequence of using the group? Did the group cause you to feel differently about breastfeeding? And when did this happen? What do other people think of you seeking out donor milk?
Looking forward	Did you have expectations about the group? Did the group meet your expectations? Will you continue to use the group? When do you think you will discontinue to use of the group? Where will you go from here? Would you recommend the group to others?
Concluding	Is there anything we have missed in our conversation that you feel is important to tell me about the group?
Prompts	You mentioned that...could you tell me what that was like for you? Can you give me an example of...? You said.... Can you describe that in more detail for me? How was.... different to you? You said.... Walk me through what that was like for you?

## Appendix G, Reflexivity in the research process

Utilising the framework from Hammersley (2005).

Criteria	Questions	Answers
The clarity of writing	Is there consistency in the use of terms?  Are definitions provided where necessary? Are sentences well-constructed?	The introduction provides clear definitions of key terms and provides context and history.
The problem or questions being addressed	Is this clearly outlined?  Is sufficient rationale provided for its significance?	It was hard to focus on the online groups use when the narrative provided around milk sharing was so interesting. I had to keep bringing it back to the online group use and how and why this advantageous to the mother. A clear focus on the tangible element was reviewed and made clearer throughout the study.
The methods used	To what degree, and in what respect, was each of the methods chosen (as regards selection of cases for study, data collection and data analysis) likely to be an effective one?	The case was chosen for convenience, a single case that is well defined using a variety of theorists. I have put lots of thought into the design of the case and how to explore online support. Diaries were chosen but the mother herself didn't keep a journal, but her journey was well documented online through forums and chat with other groups online. This emphasised further how mothers use online platforms.
The account of the research process and the researcher	Is there sufficient, and not too much information about the research process?  Is there sufficient and not too much information about the researcher?	Transparency and rigour were the key components of this study. I worked really hard on exploring all options for choices made and justifying these. Every chosen decision and the interview schedule were chosen and described in depth.
The formulation of the main claims	Are the main claims made clear?	This piece is a descriptive piece but does emphasise that although the group may appear to offer tangible

support, the actual act of milk sharing means much more to this mother.

Are the relations between the claims and evidence made clear?

This is emphasised in the abstract discussion and conclusion.

Is the nature of each claim (as description, explanation, theory, and evaluation) indicated?

This offers one explanation, and this is noted in the limitations.

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## Chapter Six: Online breastfeeding support: A reflective review

### **Overview**

The overall aim of this research was to explore online support for breastfeeding mothers and explore how new technologies are being used to provide breastfeeding support in the 21<sup>st</sup> century. This Chapter represents the cumulative stages of the research journey, revealing new knowledge and exploring and reforming existing knowledge in the context of online breastfeeding support. Throughout this process deeper definitions and understanding has been sought and a model of breastfeeding support, and online breastfeeding support is offered. Through the linking of theory and practice, recommendations for future practice and policy are made, and the research limitations are considered.

### **Revisiting the research questions**

At the start of this research journey five very broad and overarching research questions were set: how do women use Facebook for breastfeeding support; why do women use Facebook groups for breastfeeding support; what are the women's experiences of using Facebook groups for breastfeeding support; and what is the perceived impact of online breastfeeding social support groups on the mothers breastfeeding journey and what do the professionals, who support breastfeeding women, need to know about online social support groups? These broad questions were then addressed through four separate pieces of research, each with more specific research questions. In the following, these questions are revisited and addressed in light of the research undertaken.

### **How and why do women use Facebook for breastfeeding support?**

How and why do women use Facebook for breastfeeding support, were two of the first overarching questions of interest and addressed in all four pieces of research. The literature review in Chapter One highlighted a growing amount of online social support

groups relating to a range of healthcare topics, which sparked an interest and exploration into whether the groups were used to support breastfeeding. In fact, a Facebook search revealed tens of thousands of online social support groups.

These two overarching questions then led to further questions such as: when do mothers use online social support groups, are they utilised day and night, how old are the children discussed, what are the topics of discussion, what are the support needs of mothers, do they write long posts that tell a story or short answerable questions? The content analysis, in Chapter Three, appeared a logical starting point in which to explore these questions. The aim of the content analysis was to simply describe and document the use of the online social support groups by recording all group activity over a one-week period.

This research demonstrated that breastfeeding women were able to use online social support groups to meet others with similar experiences to them. Not only were they able to pose questions, but they were able to discuss a range of parenting and breastfeeding topics in an environment that supports and facilitates responses. The theory of social support by House (1981) was used to identify that informational support was the greatest reason for use, followed by esteem and emotional support.

The case study research, in Chapter Five was also devised to address these research questions, but specifically looked at tangible online support. Chapters two, three and four emphasized that women sought information, esteem, and emotional support. However, tangible support types, noted in the social support literature had not discussed. It was evident that such support was available online, through tangible milk sharing sites, and it was felt that this needed to be highlighted. Chapter Five explored the experiences of one mother using the 'Human Milk for Human Babies' group, and the perceived impact this had on her breastfeeding journey. Unlike the other groups, emotional and esteem support were not a

main reason for use and interactions were limited to tangible geographical locations and the quantity of milk being donated or requested.

Although a very tangible milk exchange, the psychological aspects added a layer of complexity. In this chapter Abbi described a stigma around milk sharing, judgement and fear, and a lack of professional support. She described how this led to her developing her own risk assessment based on trust. Importantly this research showed a complexity to using just four rudimentary support types; that simply labelling tangible support as a reason for group use undermines the decisions around the act of milk sharing itself, and highlights again a need for emotional support whilst breastfeeding.

**What are the women's' experiences of using Facebook groups for breastfeeding support and what is the perceived impact of online social support group use on the mothers' breastfeeding journey?**

As the research journey progressed; following the literature review and the content analysis, it was evident that the women's' experiences of Facebook could only really be answered by asking mothers, with experience of using the group, directly about their experiences. More specific research questions were asked such as: why do you use the groups, what are your experiences of using the groups, what are the perceived benefits and risks to using Facebook groups, where there changes made as a consequence of using the groups, and what was the impact of using the group? These questions were all addressed in Chapters Four and Five.

It was in this research that the mother's' visions and breastfeeding goals were revealed. The mothers interviewed talked of finding new ways of managing breastfeeding challenges through discussions from others with similar experiences. They talked of regaining control, feeling empowered, reassured and more confident in their decisions, and all through a

community of likeminded people. The experiences of using online groups normalised breastfeeding, affirmed their parenting choices, and provided a community online that was not present for them in the communities in which they lived. Chapter Five also highlighted that not only did Abbi's child benefit physically from her online activity but that she herself benefited mentally.

### **What do professionals that support breastfeeding women need to know about online social support?**

**Implications for policy.** Nurses, midwives, health visitors, lactation consultants and others supporting breastfeeding mothers require clear policies and procedures to ensure the workplace complies with UK law and local regulations. Policy removes any uncertainty in a range of situations and protects professionals and the public from harm. In National policy, in the United Kingdom (UK) the Department of Health measures a range of indicators under a Public Health Outcomes Framework for England (Gov.UK, 2016). Health improvement is one domain in which there is a specific indicator monitoring breastfeeding, requiring local authorities to prioritise breastfeeding support locally and to increase breastfeeding initiation and prevalence (UNICEF, 2020).

Additionally, each health care provider in England adopts their own policy for the protection, promotion, and support for breastfeeding, so guidance to support policy development is vital. In the UK, International Board-Certified Lactation Consultant's (IBCLC) do work in NHS Trusts but many also work in the private or the third sector. In addition, it is part of the role of the IBCLC to facilitate the development of policies that protect, promote and support breastfeeding (International Board of Lactation Consultant Examiners, (IBCLE), 2018).



Currently in the UK, August 2020, and indeed across the world, the Covid-19 virus is spreading, rapidly decimating the number of face-to-face contacts available to mothers from a range of breastfeeding supporters, professionals, or peers. A UK report looking at the impact on lockdown on families and children, commissioned by Best Beginnings, Home-Start UK, and the Parent-Infant Foundation, highlights clear inequalities in the breastfeeding support received by new parents during lockdown, emphasising how lockdown has left families struggling to cope (Saunders & Hogg, 2020). Of the 5000 mothers surveyed just 1 in 10 parents, of under twos, had seen a health visitor face-to-face, over half were breastfeeding but over half of those using formula had not planned to do so, and just over a quarter of those breastfeeding felt they had not receive the support they required.

The pandemic has certainly led to a steep incline in interest for telehealth; defined as the delivery of health care services, where patients and providers are separated by distance (WHO, 2016). In response the IBCLE (2020a) issued a telehealth and social media advisory update regarding online use for breastfeeding support, as many people seek to find new ways in which to support women online. Other healthcare providers will also now be reviewing policies, based on evidence-based practice around online interventions. Research such as this could therefor contribute to local and national policy.

Currently, online webinars are plentiful, joining up large organisations whose aims are to consider Infant Feeding in emergency situations. The publication relating to Chapter Three was used in one such webinar on the 6<sup>th</sup> April 2020 that looked at ‘Protecting promoting and supporting Infant and Young child feeding during the Covid-19 Pandemic’. Hosted in Geneva, Switzerland, it was attended by representatives from Save The Children, Safely-Fed Canada, John Hopkins University, IFE Core group and the Technical Rapid Response Team. Participants were considering ways to support breastfeeding mothers through the Covid-19 pandemic. Currently the finding of this thesis is pertinent to infant

feeding policies in emergency situations, however these online support interventions could possibly become more routine activities after the pandemic. Recommendations for future practice policies, that guide those working with breastfeeding mothers will now be considered and are summarised in Table 1.

**Table 1**

*Summary of the recommendations for policy*

Number	Recommendation for future policy
1	All Infant Feeding Policies should include a compulsory social support assessment at each visit that include online support.
2	All Infant Feeding Policies should promote, protect, and support professionals to have discussions around taboo and stigmatised topics.
3	All Infant Feeding Policies should promote online support but recognise and teach about the complexities surrounding online breastfeeding support.

Firstly, given the emphasis on the benefits of social support throughout the literature and throughout this thesis, it is recommended that all Infant Feeding Policies promote a social assessment of the mother at the initial contact. Policy in the UK, for the protection and safeguarding of children (HM Government, 2018) provides all practitioners working with children with a complete assessment tool (see Appendix A for the Safeguarding Pyramid). This tool looks at parenting capacity, the child's developmental needs and the family and environmental factors. As part of this, looking specifically at the family and environmental factors, the professional is asked to consider the family history and functioning, the wider family and the family's social integration and community resources. This safeguarding assessment could be easily implemented for all mothers as a framework, and online social support groups included when discussing community resources. Online groups should be discussed as a support option, but not as an alternative to face to face support (Alianmaghaddam, Phibbs & Benn, 2018).

Secondly, Infant Feeding Policies should protect, promote, and support professionals to have open and honest discussion around all breastfeeding support options and topics, even taboo topics clouded in stigma, to better support mothers. It was highlighted in Chapter Five that mothers may well be risk assessing situations and making important decisions on their own. The Nursing and Midwifery Council (NMC, 2019) code of conduct clearly states that nurses and midwives should listen to people and respond to their preferences and concerns. That nurses and midwives should encourage and empower people to share decisions about their treatment and care, recognising diversity and individual choice (NMC, 2019). Similarly, the IBCLE Scope of Practice (2018) highlights a need to provide support and encouragement to successfully meet breastfeeding goals, whilst building a supportive relationship with clients.

Thirdly, policy should acknowledge online support avenues and promote the potential these have for social capital through paid roles. Online support groups should be considered in order to develop practice interventions, but the complexities of online breastfeeding support, and online environments must be acknowledged in any infant feeding policies and taught through training packages, to provide a balanced view of online support.

Internationally, breastfeeding peer support interventions have been shown to have significant effects in low- or middle-income countries (Jolly, Ingram, Khan, Deeks, Freemantle & MacArthur, 2012) and valued by most mothers regardless of location (Tomson, Crossland & Dykes, 2012; Ingram, Thomson, Johnson, Clarke, Tricky et al., 2020). In the introduction it was noted that in the UK there are a range of both paid and voluntary peer support programmes, but that inequities in the distribution of groups across the UK exist (Dennis, Hodnett, Gallop, & Chalmers, 2002; Scheid, Beake, Sheehan, McCourt & Dykes, 2009). Disinvestment in breastfeeding services was noted and an increase in breastfeeding services offered through charitable organisations seen. This raises questions around potential

‘free labour’ and questions why breastfeeding is being viewed as charitable. In fact, it could be argued that women’s work is rooted in gender-specific presumptions: women are caregivers, nurturers and service providers, and that women’s work is undefined, thankless, unpaid, and undervalued in our society (Barooah, 2017). Women that offer their time freely to support other breastfeeding mothers yet receive no monetary reward is in part emphasizing that breastfeeding is undervalued in society. Policy makers should consider paid roles for evidenced based interventions such as peer support, online and offline, and women should be adequately remunerated.

As highlighted above, professionals must be clear on the advantages, disadvantages, and the potential consideration of using online support options within practice. In this instance Table 2 outlines the considerations based on the findings of this thesis and current policy (IBCLE, 2020). Policy should be clear that any professional wanting to undertake online support should be familiar with the working of the platform prior to implementing this as an intervention, so that it can be closely monitored (IBCLE, 2020), and those supporting groups are not “free labour”.

**Table 2**

*Considerations of online support group use*

Advantages	Disadvantages	Considerations
Ease of Access	Unable to perform an examination of the breast	Offer to talk in a closed rather than open forum
Increases the longevity of breastfeeding	Unable to perform an examination of the Infants oral anatomy	Obtain consent, maximise privacy and confidentiality in an online forum
Normalises breastfeeding	Inability to observe attachment and position at the breast in person	Maintaining adequate medical records
Provides timely Support	Users must be familiar with the platform before use	Communicate with other healthcare providers as appropriate.

Provides a mother with alternative options, ideas and choices	Training may be required on how to fully use the platform in order to be able to moderate online content	<p>Working geographically and culturally close.</p> <p>Appreciate the GDPR, HIPAA compliance, to ensure online communication is private, secure and protected. Even deleted electronic information can still be retrieved.</p> <p>Consider how online information be monitored to ensure it is accurate and appropriate, so not to erode public trust</p> <p>Consider professional boundaries</p> <p>Consider how the online support group is to be evaluated.</p> <p>Refrain from recording or taping a mother or child, unless written consent is provided by herself and on behalf of the child.</p> <p>Consider if the interaction online is responsive and appropriate.</p>
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**Implications for practice.** Throughout this thesis consideration has been given to the recommendations for future practice, and the implications of using the internet for breastfeeding support. It was shown from the literature review at the start of this research journey that online support could be both what people want, and what they need. There are attributes to online support groups such as anonymity, accessibility, reciprocity, finding likeminded people, and enabling timely discussions, that make online platforms appealing. However, caution is required and recommendations for practice are made. These are summarised in Table 3.

**Table 3**

*Summary of the recommendations for future practice.*

Number	Recommendation for future practice
1	Address the emotional state of the mother, prior to delivering health promotion, through active listening and motivational interviewing.
2	Provide evidence-based information on all breastfeeding related topics, even those clouded in stigma
3	Complete a social support assessment for all mothers.
4	Consider the use of online social support groups to complement face to face support.

Firstly, a mother must be given time to tell her story, share her concerns and aspirations for her breastfeeding journey, prior to the delivery of health promotion messages. This research highlights a need for women to be heard and discuss their story and hear other people's advice and ideas. Public health messages that try to elicit an emotional response are often used in mass media messages as an effective means of changing public health attitudes, intentions, and behaviours (Dunlop, Wakefield & Kashima, 2008). However, breastfeeding is already an emotional time for mothers, and these biological states fluctuate and change thoughts, feelings, and behavioural responses. This, coupled with having to learn the required breastfeeding skills, is a stressful time for new mothers and noted extensively in this thesis.

It is therefore recommended that those supporting breastfeeding mothers firstly address the emotional needs of the woman before delivering any public health messages. It is seen that many mothers have a breastfeeding goal, and when breastfeeding difficulties arise, they could need several different types of support, from several different people to regain control of their situation. These goals should be recognised and heard through meaningful conversations (Haigh & Hardy, 2011, Wanzer, Booth-Butterfield & Gruber, 2009, UNICEF, 2020) taking a motivational interviewing approach (Rollnick, Miller, & Butler, 2008), an approach whereby the supporter would use a guided interview style, exploring a mothers strengths and aspirations to discover and evoke her own motivations for change (Rollnick et al., 2008).

Historically a series of 'listening visits', ostensibly a version of non-directive counselling were often carried out by health visitors and are considered an effective intervention in the management of mild-to-moderate depression (Morgan, 2017), however in a resource tight environment such visits have been reduced and replaced with short scattered

interventions (Adams, 2019). With the considerations in Table 2 in mind, the health professional may consider the use of Internet discussion boards, online groups, or even email, all noted in Chapter Two, as a way to digitally facilitate asynchronous user-generated content, in which mothers could tell their story, and have their stories heard. Likewise, the benefit to mobile applications aimed at providing information to breastfeeding mothers must be considered. Mobile applications that provide information alone would not provide the emotional support so clearly needed by mothers, further research into such applications is required.

Secondly, whilst fostering active listening and motivational interviewing noted above, health professionals must also provide evidenced-based information, in an open and honest way, around all topics relating to breastfeeding including those clouded in stigma. It is a responsibility of all professionals to seek and be aware of all infant feeding options, for example milk sharing, and be able to talk about the advantages and disadvantages in a non-judgemental way. Signposting mothers to online forums and groups should be promoted but then the mother should feel free to come back to the professional and be supported to make an informed decision. It is suggested in this research that all support is best delivered alongside emotional support.

Thirdly, all health professionals supporting breastfeeding women should complete a social support assessment, as discussed above. Building this assessment into the routine conversations being had with women, as a further routine, and promote online social support groups as a resource and social capital would as this thesis has shown support the mother's journey. Health professionals should also encourage mothers to find a group in which they feel comfortable and the other members of the group are like them in their ideas and parenting styles. This research raised awareness of the many different types of group e.g. groups for feeding older babies, groups for doctors, groups that were more evidenced based

than experiential and vice versa. Mothers talked of finding one in which other members were likeminded. Additionally, there could be unease expressed by the mother, as she may come across 'fake' information, which is known to circulate on social media (Brown, 2019, Waszak, Kasprzycka-Wasak & Kunaek, 2018). Providing opportunities by the health professional to discuss what is being read is an important part of this practice recommendation.

Additionally, Online support groups are a viable adjunct for health professionals wanting to support a local population, as a supplementary way of providing evidenced based information instead of, or as well as, the face to face group support. This should however be supported through policy as highlighted in the previous section, and all considerations clearly addressed. Online groups could provide a platform to share and discuss "*fake news*" and to reinforce or counteract such messages with evidence-based information. The health practitioner must ensure that the limitations of the group, such as the inability to perform a complete assessment are clearly identified and stated on the platform. They should also ensure any messages requesting support are dealt with privately, and wherever possible a face to face contact offered. This will ensure the mother feels comfortable to provide a detailed history of how they are feeling. Health staff workloads are also a consideration in setting up an online support group as moderation and monitoring of the group is required if linked with a healthcare provider to ensure non-maleficence.

Lastly, this process has strongly suggested a variation in the time, place and person delivering the support. It was suggested that professionals are best suited to helping during the early hours and days, and especially for when there are major concerns that are more clinically based such as allergy, ankyloglossia in the infant, pain or discomfort. Although it was clear from the research that the experiences of others are highly valued, more research is needed to examine when health professional are most needed and why. The views of the



women in the Thesis, although forensically examined, are not statistically significant enough to claim such recommendations. To further identify where healthcare resources should be spent service-user feedback and consultation on all breastfeeding interventions is required and will need to be based on a thorough assessment of all local support avenues, thus will fluctuate from area to area.

### **Theoretical framework development**

#### **Defining ‘breastfeeding support’**

In the introduction the term ‘support’ is described as all-encompassing and without context, with no clear definition of breastfeeding support given in the literature. In fact, breastfeeding support is often the title of books (Brown & Jones, 2019) or Chapters within books (Campbell, Lauwers, Mannel & Spencer, 2019), with no clear definition offered to those in a supporting role. Williams, Barclay and Schmeid (2004) state that any form of social support should be defined contextually for it to be relevant and qualitative, and for this reason a definition is proposed within this final Chapter.

Following extensive utilisation, throughout this thesis, of social support theory and the theory of ‘becoming a mother’, the following definition of breastfeeding support is offered for clarity: the, perceived or actual, practical, informational, esteem, or emotional support provided by another to meet a breastfeeding need, that bolsters knowledge and skill, confidence and/or reassurance, and normalises breastfeeding as the mother transitions into her new role.

This definition utilises the functional support types (House, 1981) used throughout this research, as they are comprehensive and easily understood. Despite being criticised as simplistic (Berkman & Glass, 2000), they help to frame and elaborate the term support. The definition also notes the outcomes noted within the interviews with mothers, and backed by

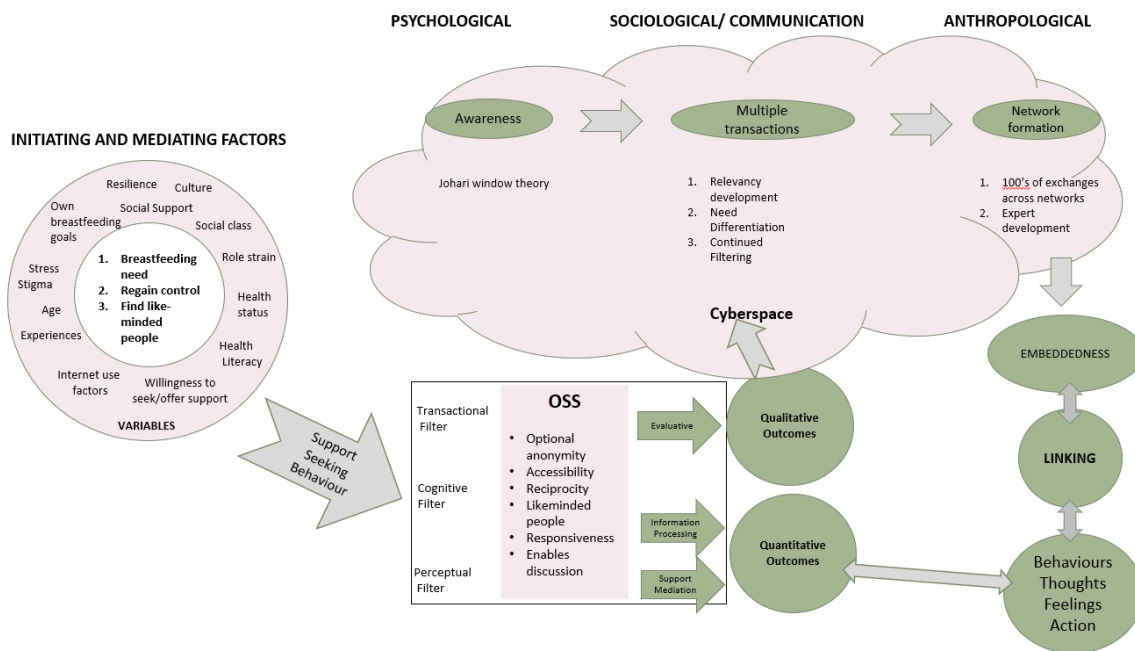
the literature, such as informational support (Yoo, Chih, Kwon, Yang, Cho, McLaughlin, & Gustafson, 2013), reassurance and confidence (Bridges, 2016, Schmied, Beake, Sheehan, McCourt & Dykes., 2011), and the normalisation of breastfeeding (Alianmoghaddam, Phibbs & Benn, 2018). Finally, this definition allows for the fact that the support needs of a woman change, as she transitions to a new role, by crediting seminal theories around becoming a mother (Mercer, 2004).

### **A model of ‘online breastfeeding support groups**

Both models of online support groups proposed within the introductory Chapter will now be considered, as the concept of online breastfeeding support is refined in light of new knowledge. Within this section, the online social support group model by LaCoursiere (2001) is used as a building block for new information specific to online breastfeeding support groups, and a revised model proposed (see Figure 1). The work by Herron, Sinclair, Kernohan and Stockdale (2015) is incorporated into this model, as are the findings of this thesis, and both are used to discount or affirm the various stages of the model. This model will now be discussed.

**Figure 1**

*A model of online breastfeeding support groups*



**Initiating factors.** Common throughout both models, the literature, and this research is the consideration of factors that lead to online social support group use. The theory of becoming a Mother (BAM) (Mercer, 2004) is used to emphasise that pregnancy and early motherhood is a time when mothers need to adapt to a new role and acquire new skills. A support need at some time appears almost inevitable, particularly when women are faced with the realities of motherhood in juxtaposition with their ideas of motherhood (Laney, Hall, Anderson & Willingham, 2015). For this reason, and in the introductory Chapter, a breastfeeding need was at the centre of the breastfeeding model.

LaCoursiere’s model (2011) suggests that there are perceived or actual changes in health status that could be acute or chronic with many mediating factors. Whereas Herron et al. (2015) provide a view that is more breastfeeding specific, suggesting that a breastfeeding query or interest in discussion/ debate, or a breastfeeding goal, are the reasons why

breastfeeding mothers use online social support groups. For this reason, LaCoursiere's initiative factors are removed, and a breastfeeding need is added, along with an additional initiating factors suggested by Herron, which will now be discussed.

Firstly, and added to the model in Figure 1 is the need to find like-minded people. It can confidently be said that there is a felt need to be involved in a community that discusses breastfeeding. Doing so helps to a mother to receive additional and optional support, another of Herron's antecedents. This was emphasised within the content analysis, which saw women engage in online support groups to share their successes and celebrate breastfeeding. Similarly, the mothers in the IPA study also talked of finding a 'tribe' and community of like-minded people in which they felt they belonged and could discuss their breastfeeding. Additionally, the case study demonstrated how a tangible support need brought together women who believed and facilitated in online milk sharing, likeminded people that were often stigmatised by others. The findings from these three pieces of research warrant the need to find like-minded others to be included in the model and its initiating factors.

A clear need to learn from likeminded others was seen. Herron et al. (2015) suggests that inadequate face to face support or the need for additional support leads to the use of online social support groups, either way a need is seen. This research indicates that it may not simply be that face to face support was inadequate, although this may be the case, but that women appreciated, and wanted to learn of the experiences of others. It is seen within the findings of Chapters Three and Four, that women were searching for alternative answers from women with similar experiences. It is seen that there is an increase in mothers being isolated in postmodern society (Drentea & Moren-Cross, 2005). Women returning to work early reduces the number of women and children within communities supporting each other, meaning information is not as readily accessible (Arendell, 2000). Additionally, it is noted that new mothers experience changes in lifestyle, stresses when parenting, and mental

tiredness (Gibson & Hanson, 2018), and often take comfort in knowing others are experiencing similar experiences (House, 1981, Cohen & McKay, 1984).

Secondly, regaining control was added to the model in Figure 1, as a reason for using online social support groups. Herron et al. (2015) noted that an antecedent of using an online breastfeeding support group use was having a breastfeeding goal. However, Chapter Four noted that, not only was it clear that the mothers had set themselves a breastfeeding goal to achieve, but that for many they felt they were unable achieve this. It is well noted in this research and the literature that when mothers do not reach their ideal, they often feel guilty and blame themselves for their shortcomings (Arendell, 1999; Phanco, 2003). The use of online social support groups provided them with other ideas and possibilities, to support them regaining control of their situation. As an example, Abbi's determination to provide breastmilk to her infant led her to using online tangible milk sharing sites to regain control of her goal. It is for these reasons that this third initiating factor was added; regaining control.

**Mediating Factors.** LaCoursiere's model (2011) highlights the mediating factors that influence online group use. More specific to breastfeeding support and noted in Chapter One is the factors known to affect breastfeeding success, taken from the literature. These are brought forward into Figure 1. Additional to these, and noted in both models, were two additional considerations specific to online support groups use; the willingness to seek and offer support (Herron et al., 2015) and internet use factors (LaCoursiere, 2001).

Firstly, not all women are willing to seek support online. The research in this thesis looked specifically at women that were willing, and did use online support, to explore how online support was used. What was seen in the literature was that mothers could choose to approach the group, by asking questions and writing posts, or choose to 'lurk' in the group and simply read the posts of others (Yoo, et al. 2013). Those that tended to lurk did not

always want to then offer support, and Chapter Four saw mothers that did and did not reciprocate support to others. The literature also describes a downstream reciprocity, described as one individual helping another with the aim of obtaining help in the future, and an upstream reciprocity, where by an individual who received help reciprocate that support to others later on (Nowak & Roch, 2007). Studies have shown that half of those mothers that sought help returned within the year to help others (Nowak & Roch, 2007, Wasko & Faraj, 2000), thus supports the longevity and success of the online support group. The finding of this thesis corroborates the literature and highlights these variations in group use.

Secondly is the addition of Internet use factors (LaCoursiere, 2011) which includes historical use of the internet searching for health-related information, comfort using online technologies, patterns of internet use, and behaviours seeking support both online and offline. Despite the content analysis highlighting many mothers using online groups and active page activity, it was seen that mothers were often invited to the groups or just happened upon them. Online behaviours and searching often led to their discovery, with most mothers interviewed wishing they had known about them sooner. These internet use factors are important to note, especially when considering promoting such groups to all mothers.

**The Process of online support: Attributes of online groups.** The centre of the model proposed by Herron et al. (2015) suggests attributes associated to online social support groups, these attributes highlight the features of the online support environment. Attributes such as accessibility, optional anonymity, likeminded people, responsiveness, and discussion that enables tailored support were among the attributes proposed by Herron et al, (2015) and not noted in the original model by LaCoursiere (2011). These attributes are noted in the findings of this thesis so included in Figure 1 to provide a thorough picture of online social support group use and is now discussed.

The ability for online groups to provide ease of access to support was noted in Chapter Two, and even provide groups when there were no groups. Online groups were also deemed useful in linking professionals with a larger geographical area and provide more timely support. Certainly, all attributes noted were appreciated by the mothers interviewed in Chapter Four. Also, the responsiveness of group members, noted in Chapters Three and Four, highlights that this feature complements that ease of access to all functions of support. Chapter Four however did highlight, that although ease of access was an advantage to group use, Facebook was not an obvious place for breastfeeding support.

Anonymity was another attribute included within the model and emphasises that mothers interact with others online that they do not know in person. The advantage of anonymity was highlighted in Chapter Two and captured in Chapter Four where mothers described other group members as 'faceless'. Anonymity however in this model concurs with the findings of Herron et al (2015), in that anonymity is optional. In tangible online groups such as the milk sharing groups an open and honest relationship is described and seen between donors' and recipients. Such milk transactions are based on trust, where complete anonymity would be a disadvantage. The fact that women can share parts, or all their stories with others, is something discussed later when psychological perspectives are considered. Responsiveness was another attribute included within the model, and in part already discussed. The groups themselves would not be possible if support were not reciprocated between members. The content analysis evidenced the user generated comments between members which offered a reciprocal environment. Chapter Four again added depth to this discussion. From the women interviewed it was clear that not all women wanted to reciprocate support to others, but many did, some even taking up training in breastfeeding management through charity organisations or provided support through health care providers. Many mothers said if they felt they had something to offer then they would, but the sense of

community provided them with the reassurance that if they did not reply then someone else would. The discussions and responsiveness from likeminded people mentioned by Herron et al. (2015) as attributes can confidently be assured throughout all parts of this research thesis.

### **The Process of online support: Perceptual, Cognitive, and Transactional filters.**

The three filters proposed by LaCoursiere (2011) help to explain and understand how mothers think and come to decisions facilitated by online activity, without merely considering the attributes of support that make using the groups appealing. This was an important aspect of online group use that was explored in the Chapters Four and Five. This model provides a framework for what was seen, and the three filters will now be discussed, within the context of breastfeeding support.

Firstly, it is acknowledged in the introduction that breastfeeding and parenting is a stressful and emotional time. Emotive posts were documented in Chapter Three and acknowledged as one of the reasons for group use. This was again seen within Chapter Five, where Abbi's emotional state was seen a driver to using online tangible support groups. The emotions expressed in Chapter Four, as mothers describe losing control of their vision and their breastfeeding goals, included anxiety and sadness which led them to feel hopeless and as though they were failing. Also noted in the literature is that behaviours are strongly driven by emotions and that emotions can override logic (Brader, 2006). Brader also states that support is often about hearts and minds and not facts. This perceptual filter is certainly a fundamental part of any model looking at online social support groups for breastfeeding mothers.

Interestingly, the users use the groups for breastfeeding mothers' differently from their own Facebook profiles. Publicly making one's emotional needs known on Facebook is likely to be interpreted as too much information, overly emotional, or needy (McLaughlin &



Vitak, 2012). Many researchers have found that Facebook profile posts are limited to requests for information or tangible support (Ellison, Gray, Lampe & Fiore, 2014; Jung, Gray, Lampe & Ellison, 2013; Vitak & Ellison, 2013), however this model of online support group focuses on emotions and emotional support has been shown to be in high need. This research shows the power of online social support groups in delivering emotional support.

The cognitive filter which looks at the processing of information, is another pertinent part of the breastfeeding support model, that is supported through this research. The case study, in Chapter Five, illustrated that acknowledging simple social support functions, such as tangible, informational, esteem, or emotional support, was too simplistic. For example, the case study emphasised that the online group did not just provide tangible support, through the receiving of milk, but bolstered the mother's mental health. Similarly, the IPA study overall showed a level of sense making that again far exceeds the depth provided through categorisation of support functions. With greater understanding of a mother's sense making, comes greater understanding of the value of such interventions. The importance of this model, and specifically this filter in future research into support interventions is pertinent.

Thirdly, the transactional filter represents an evaluation of all the information received and how it is evaluated for personal relevancy. Chapter Three emphasised the activity within one group, and the amount of information available on a range of topics. It can confidently be said that mothers approach the groups with questions or went looking for discussions around issues that were pertinent to them. It is noted that not all information was relevant to all mothers at all time, but the IPA study showed that mothers would see repetition of information and remember information in case they too, later on, experienced the same thing. The narratives highlighted that mothers knew how to deal with issues if they arose because they had seen discussion previously. This indicates that the transactions not relevant at the time can still be supportive, just later in the mother's journey

The case study research is a good example of transactional filtering. The case study described how Abbi experienced multiple transactions online from peers who agreed, supported, and disagreed with her decision. Abbi herself was aware of the potential risks associated with peer milk donations but felt strongly that this would support not only her baby but her mental health. This processing of opinions, stigma, personal health, and beliefs were all processed at a deep psychological level. Such a step in using online support should be included in any model.

**Quantitative outcomes.** The literature review, in Chapter Two, noted that online social support groups could support people to manage their diabetes, reduce weight, feel in control of their situation, relieve anxiety, and empower self-care. In fact, many outcomes were measured in this thesis, through unique interventions, that made comparison hard. This research adds to the body of research around the quantitative outcomes of online breastfeeding support, known to be lacking from the initial review of the literature. Longer-term breastfeeding, feeling part of a community of support of likeminded others, reassurance, normalisation of breastfeeding and confidence were noted. Additionally, a reduction in stress, anxiety and increased coping suggested by LaCoursiere (2011) was also noted.

The model by Heron et al., (2015) noted ‘breastfeeding outcomes’ as an impact of online support. Online groups were a way of enabling face-to-face contact with professionals, especially for more complicated breastfeeding issues such as an infant oral assessment, infection in either mother or infant, milk intolerance, or breast pain. It was illustrated, during the IPA study, that mothers talked of when they would use online or face to face support, highlighting a difference between minor and major breastfeeding problems. They discussed how they triaged or decided who to seek support from and said that they would seek support face to face for major breastfeeding problems like those noted above.

Interestingly the content analysis however saw few mentions of tangible support being recommended and mothers writing messages to the group whilst still in hospital, where they had access to health professionals. This again emphasises and concludes that the value of online support is in both the shared experiences and evidence-based information, and the felt value in professional face to face support. This has implications for future practice discussed later on.

**Qualitative outcomes: Psychological perspective.** Johari's window (Luft & Ingham, 1955) appears pertinent to online support groups, where mothers are seen to build trusting relationships within the groups and with individuals using the groups. Johari's window explores what people ask others and tell others about themselves. Previously addressed was the fact that online communication is seen as beneficial due to the anonymity it provides. People may speak more openly online, voice their concerns, feelings, and opinions without fear of personal repercussion when there is anonymity online. Facebook specifically has also been associated with egoistic and boastful posts (Seidman, 2014), however the level of honesty and openness amongst likeminded people has been captured in this research. This is not to say that people tell others everything about themselves, just that the egoistic posts seen on Facebook typically are not seen on the online breastfeeding support groups. In fact, the IPA study highlighted that people shared more within their groups than they did on their own Facebook profile.

These findings are now being seen in the literature. Authentic presence was highlighted as the most valued type of breastfeeding support, and incorporated the group being available, empathetic, providing affirmations, and sharing experiences on a range of topics (Herron, Sinclair, Kernoham, & Stockdale, 2015). Chapters Three, Four, and Five concluded that a range of topics were discussed in these online groups, and that parenting choices also featured highly. Mothers were seen to frequent many groups until they found the

one in which they felt their style of parenting and beliefs matched those of other users.

Herron's model notes that a consequence of online group use for breastfeeding mothers was the impact on other aspects of parenting, and this is also seen in current literature (Nolan, Hendricks, Williams & Ferguson, 2018). It appears from the research that how much a mother posts to the group, and tells other members about themselves, is dependent on the particular group they are in.

Johari's window is often used as a tool to support the building of relationships and teams based on trust (Luft & Ingham, 1955; O'Brien, 2019). It is seen clearly in Chapter Five, the extent to which one mother valued building an open and honest relationship with the breastmilk donor in the absence of regulation. Likewise, she describes receiving donor milk and then choosing not to use the milk because of the absence of trust, making awareness of this step as an important part of the model in Figure 1. Trust was also seen as an outcome of this open honest authentic online presence in Chapter Four. Women openly discussed how they trusted the experiential advice of other women because they were in similar situations to themselves, even when this advice seemingly appears to contradict evidence-based advice e.g. bedsharing and co-sleeping.

Additionally, this model appears to cover all types of users. The 'lurkers' described previously (Yoo et al., 2013), noted in the literature review, and Chapter Four can also be placed with Johari's model. In one section of the model there is a 'hidden window' in which the mother keeps information to herself, that is hidden from others and equally she does not ask questions of the group. Overall, all mothers have a place within this model, and it is within this model that trust is built, and networks and communities are formed. It is within these communities that shared membership occurs which in turn creates a higher level of trust amongst the members in relation to the advice and information provided (Barkshy &

Messing, 2015). This leads into the sociological perspective of the model which occurs as multiple interactions occur.

**Qualitative outcomes: Sociological perspective.** It is here that the interactions are considered at group level and two processes occur as individuals talk across the communities; relevance development and need differentiation. During relevance development the individual is said to determine which transactions do and do not have personal meaning. They may find new meanings that were not apparent in the beginning and meanings that were important that are now not. In many of the IPA narratives mothers stated that they learnt something new, found information from others either experiential or evidence based which they used to support their breastfeeding journey. Mothers often went looking for answers when traditional evidence-based approaches had not provided the outcomes that they desired.

During the content analysis we saw thirteen different topics of discussion were noted, between thousands of members, in active posts throughout the 24-hour period. The mothers found benefit in the online support because they were able to expand their choices and options through hearing from many others. Through need differentiation we see that the mother moves from primary to secondary need and discovers information that furthers her original need. During this time, she engages in further cognitive, perceptual, and transactional filtering. This is similar to one of the consequences of group use provided by Herron et al. (2015) where they discuss mothers reconstructing breastfeeding experiences.

**Qualitative outcomes: An anthropological perspective, network formation.**

Evident in this research is the realisation that there are thousands of breastfeeding support groups on Facebook alone, with great diversity. This was a fact not entirely evident at the start of this research but only emerged when the content analysis was completed. These include large national groups or more local groups, groups specific to age of the child,

profession, or breastfeeding issues. These groups varied in professional involvement, evidence-based information sharing or sharing of stories and experiences. The differences in parenting style was also highlighted and some groups were renowned for being judgemental, opinionated, and even confrontational. This research highlighted the importance of this perspective and that mothers in groups where they feel accepted and safe and do not frequent groups where they do not. Subsequently the multiple transactions in one group create a community, a community with social capital. This information then spreads across into another group and greater networks are formed.

Expert development is highlighted in the models provided by LaCoursiere (2011) and Herron et al. (2015), and significant to any model of online breastfeeding support, sitting within this sociological perspective. What this research adds is the possibility that a mother does not simply become an expert in a linear movement. Findings of the IPA study showed how a linear movement from novice to expert was replaced by a cyclical one in which the mother was always learning and refining her breastfeeding skills. At one moment she may feel like an expert, but at other times, when another, or different, breastfeeding issue/complication arises she again feels like a novice. The different issues and the stages of breastfeeding produce time relevant issues for example from early attachment at the breast to toddlers biting the nipple during longer term breastfeeding. It is here that the process of becoming a mother over time is apparent, utilising the theoretical work of Mercer (2004).

**Embeddedness.** The IPA study showed that mothers chose a group in which they feel safe to be themselves and where they were surrounded by like-minded others. When finding such a group they become embedded within the group, engaging with others even when breastfeeding is going well for them. They also showed how they chose to leave groups, and did not become embedded in groups, when they felt uncomfortable or unsupported because people had different views to them.

All participants said they would recommend the groups to others. In fact, all participants came forward for interview as advocates of the groups they use, wanting to talk about the benefits of the group. For this reason, it is important to also note a limitation of this study, failing to capture women's views who do not use groups. Additionally, embeddedness considers individuals taking ownership of the group. This was seen in the IPA as mothers become admins of the group, and by many then taking activist roles promoting breastfeeding in the communities in which they live as well as online, for example one mother took part in social media photos to normalise breastfeeding and some joined groups specific for 'lactivists'.

**Linking.** This final stage helps to conclude the model in Figure 1. It occurs just prior to the development of behaviours, thoughts, feelings, and actions that represent a synthesis of skills and knowledge, within what La Coursiere (2015) describes as a web of knowledge. New learning is added to old learning and results in social support outcomes. The women interviewed for the IPA and the participant mother in the case study all demonstrated this synthesis of experiences at interview, as they relayed and discussed their experiences and thoughts. Their 'web of knowledge' explored in the narratives acknowledges this stage but also the nuances, experiences, and depth to online social support. It was during this stage the women synthesised information and negotiated the informal stage of BAM whilst striving for maternal identity.

### **Definition of online breastfeeding support**

From the model, and research involved in this thesis, the following definition of online breastfeeding support is offered: the perceptual, cognitive and transactional process of initiating and participating in user-generated electronic interactions that provide tangible, emotional, informational and esteem support, and bolsters a mothers breastfeeding knowledge, confidence and self-esteem, normalising breastfeeding as she becomes a mother.

This definition and model are then available for further research, and for those supporting breastfeeding mothers, to consider and build upon.

### **Limitations of the research**

There are a few limitations to the research within this thesis. The research conducted is based on interviews with women who are English and live in the United Kingdom.

Lactation care is specific to culture so these results may not be applicable to other cultures.

Care is required if considering changes to policy or professional practice, as generalisations should not be drawn from this research.

All women interviewed were white, British women. Although a homogenous sample was required for the IPA, future research would benefit from looking at the experiences of women from Black, Asian, and Minority Ethnic (BAME) communities as there may be differences in how people from different cultures use online social support groups. It is noted that much research is conducted without a diverse range of participants, particularly in the UK for a number of reasons; the research topic does not appeal to all people, or they do not feel valued, or they do not feel included or feel judged (Zuberi, 2008). The Infant Feeding Survey of 2010 (NHS, 2012) for example required a weighted analysis because ethnicity questions were not asked in Northern Ireland due to the small population of BAME groups in Northern Ireland. In fact, the increase in incidence of breastfeeding between 2005 and 2010 primarily came from white mothers, as non-white mothers already had high levels of breastfeeding. Although the literature concurs that this limitation is not uncommon it is important to note as a limitation of this research.

Secondly, whilst reviewing the literature it was clear that online interventions at the time were under researched, and because of this it was decided to look more generally at how online support had been implemented across healthcare. To date there are emerging studies



around social media applications being used for, and by breastfeeding women, and much more attention needs to be given to the subject. Although not included in the literature review, continuous reviews of the literature have been undertaken through those four years of study and these studies are now included in the discussion within this final chapter.

Thirdly, the content analysis looks at the activity within one popular, national, UK based support group. At the time this appeared to be the logical group to explore, based on its popularity, and page activity. However, during the IPA study, which purposively looked at the group activity in more detail, it became apparent that there were in fact many other groups available that varied in different ways; experiential or evidenced based, local or national, ones for older children ones for younger children etc. Although the content analysis is useful in showing how the groups are used, there are clear variations between the groups. Topics of discussion for example would differ between the groups used by mothers whose children are below six months of age and those aged over one year of age. Although the content analysis provides a scope and exploration, further research into the variety of groups content is required.

This thesis explores how online groups could support breastfeeding mothers, and why they may be deemed supportive. This research fails to explore in depth any negative aspects of the group use, that is seen in policy and the literature. More in-depth analysis into the occurrence and sense making around the negative aspects raised in the literature review and interviews is required to fully understand the possible disadvantages of online group use.

The IPA study itself aimed to explore mothers' experiences of online support group use. The mothers that came forward for interview were quick to respond to the advertisement and wanted their story heard. The women interviewed, and as the model suggests, had all embedded online group use into their routines and wanted to share their experiences with

others. This limits the findings as there were no women included who had used online groups and did not find them useful, or mothers who have never used online groups at all.

Additionally, social media platforms change frequently based on the members within the community, and therefore experiences when using the groups will change regularly. Groups that once were described as populated with likeminded mothers may soon be populated with unlike minded people several weeks or months later. The tangible milk sharing group may have donations available in a mother's areas one week and not the following week. These research conclusions will only provide one snapshot of online support, other variations are yet to be researched.

Lastly, the model proposed in this final chapter is subject to change and development. As the body of literature grows around online breastfeeding support then elements are inevitably going to be open to interpretation. The theories themselves that guide this model could be broadened or refined, and the model itself would require personalising to other health conditions for it to be applicable outside the confines of the breastfeeding support.

### **Reflecting on the research process**

Four years ago, whilst working in practice, online breastfeeding groups were beginning to be discussed by mothers. During practice audits of breastfeeding support, mothers would speak fondly of the groups that they were frequenting. At the time it was simply acknowledged that these groups existed, but it was only during this research journey that online support was really considered in depth, and only really during the Covid-19 outbreak that this type of support came under the spotlight, despite the potential benefits to mothers on a daily basis before the pandemic. Today many women that visit face-to-face support groups have accessed online groups too.

This thesis allowed for a systematic inquiry and critical understanding of online breastfeeding support and breastfeeding support in general, all completed in accordance with academic regulations and University Ethics Committee. This thesis attempts to provide an advanced level of independent reasoning aligned to the achievement of four pieces of research, which has generated new knowledge.

Through reflection and critical examination of professional activity clear aims and research questions, around online support, were generated. Although this section completes the thesis many questions remain. Through combined theoretical and professional practice new viewpoints and a model of online breastfeeding support has been proposed, leading the formulation of new literature, and to date two publications. Chapter Two was accepted for publication in 2018 (Wagg, Hassett & Callanan, 2018) and Chapter Three in 2019 (Wagg, Hassett & Callanan, 2019). The literature review was also presented at the Lactation Consultants of Great Britain as a poster presentation in 2018 (see Appendix B poster presentation) and research has been presented at University conferences. Further publications will come following the submission of this Thesis, and this is the beginning of more insightful knowledge and a participatory relationship between practice and theory.

Moving forward, using the term support flippantly should be discouraged by all professionals supporting breastfeeding mothers. Being specific about what is offered could aid those seeking support to navigate a range of services quickly and easily. Professionally the emphasis on the benefits and availability of social support networks, and the impact this has on health and wellbeing, and specifically for breastfeeding women, should be well considered in practice, policy and in the training of others. This exploration has changed professional practice supporting mothers, has changed the curriculum for student education and will hopefully inform the Policy that guides practice for others. This research process, and research journey has considered the fact that potentially there are many terms that are

used in healthcare that are not fully explored and understood. One major strength of this thesis is the contribution to the exceedingly sparse literature base around online breastfeeding support, online social support group theory and the contribution to e-health literature in general.

### **Future research**

Further refinement of the proposed model is required, especially as new information and research becomes apparent on the topic of online support for breastfeeding mothers. The model would benefit from further exploration into the individual components to strengthen credibility, for example further detail would be advantageous around the cognitive filter. In this research it was clear that mothers sought information to reduce anxiety (Maslow, 1963), however people may avoid information that contradicts with their views at the time and rejects ideas that do not agree with their world view (Rogers, 1983), a behaviour evident in health information behaviour (Case et al., 2005). It was also seen that not all mothers wanted, needed, or used all the information available to them online, something also noted in the literature (Narayan, Case & Edwards, 2011). Narayan et al., (2011) make a valid point, worthy of exploration in that many mothers may not want to be exposed to some types of information. Whether or not the information is deemed beneficial should be explored further.

Secondly there appears to be an urgent need to explore the quality of the literature on social media sites and the misinformation regarding breastfeeding advice, circulating on Facebook and other sites. The impact of this misinformation should also be considered. For example, an inaccurate image of breast anatomy was circulating on Facebook, and although inaccurate it did spread awareness of breastfeeding and breast anatomy which generated interesting discussion.

Thirdly this research also touches on the level of trust that mothers have regarding evidence-based information. Many mothers were turning to the experiences of others, even whilst in the hospital setting. Health Visitor and midwife advice was being shared for others to comment on, and the level of trust in advice was questioned at times. This warrants further exploration into current opinion but also how professionals are building trusting relationships with mothers especially when they are wanting to discuss stigmatised topics.

Lastly given the current worldwide pandemic of Covid-19, more and more professionals are consulting with women online. Further research is required to look specifically at video conferencing for breastfeeding support. This was something included in the literature review but not the focus of subsequent inquiry. Currently many consultations are occurring online, and currently it appears to be an ideal opportunity to evaluate these online interventions to contribute further to literature around online support. To conclude, this research could have implications for a range of support needs, from a range of professionals.

### **Thesis Conclusion**

Healthcare is changing; historically, people sought support face-to-face, but the increasing availability of the internet, mobile devices, and tablets is shaping human communication. Consumerism, control of healthcare costs, and the increasing demands on healthcare care systems, are some of the reasons why healthcare professionals are searching for new, innovative, and cost-effective ways to provide patient support. This research explored online social support groups for breastfeeding mothers and concludes that the use of computer mediated communication could be both what people want and a way of delivering healthcare to meet the support needs of patients. Key thinking points for practitioners who are or may be thinking of using online interventions to support breastfeeding mothers are offered, but this research also has wider implications for other healthcare fields.

From this research a definition of online breastfeeding support is offered. This encompasses the seminal theories of social support and becoming a mother that underpin this research. Noted in the model are layers of complexity to online interventions. Such layers include the initiating and mediating reasons for online groups use, the attributes of online group use, the processing and filtering of information, and the qualitative and quantitative outcomes of online social support group use.

This thesis highlights a range of online breastfeeding support groups that already exist in their thousands, showing how they are actively and successfully led by women, for women, with or without, professional involvement. The potential for these groups to deliver accessible, timely support, available twenty-four hours a day, with no geographical boundaries, on a range of breastfeeding and non-breastfeeding related topics has been reasonably concluded. Mothers can actively engage in the groups, or simply read the posts of others to request or gain informational, esteem, emotional or tangible support. This research highlights the experiential, emotional and informational support offered as the main reasons for group use.

This thesis suggests that online groups have the potential to buffer the stressors experienced by some mothers, and have the potential to bolster self-esteem, confidence, affirm parenting choices, provide reassurance and normalise breastfeeding through the sharing of experiences and celebratory posts. This research shows a need for some mothers to learn from others and belong to a community of like-minded others that value breastfeeding, in a society where it is felt that breastfeeding is undervalued.

Practitioners supporting breastfeeding mothers should be made aware of online support groups and their potential benefits. They should be encouraged, through policy, to raise awareness of the potential benefits to groups use and have conversations around taboo

or stigmatised areas of infant feeding so that mothers can make informed decisions. Those considering the implementation of online group interventions should immerse themselves in the chosen online environment to understand how they work but do so with caution. Further research into the negative aspects of using such groups is advised.

It is recommended through this research that a social support assessment be carried out with all mothers and that social support networks, on and offline, be explored and discussed. Mothers should be made aware of the depth and breadth of groups and be advised to frequent many groups to find one she feels has similar, like-minded others. Lastly the mothers should be encouraged to discuss information that they find in the groups with professionals so that misinformation can be corrected.

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Appendix A, Safeguarding Pyramid

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Appendix B Poster presentation



**The pros and cons of providing support online: considerations for those supporting breastfeeding mothers.**

Amanda Wagg MSc, IBCLC, RGN, SCPHN

PHD candidate at Canterbury Christ Church University and Lecturer in Nursing at Anglia Ruskin University

**Background**

Breastfeeding has long been a public health priority due to the plentiful benefits that it provides both mothers, babies and society. Despite the known benefits, the United Kingdom has some of the lowest breastfeeding continuation rates in the world (Victoria et al., 2018), and lack of support noted as a contributing factor (Victoria et al., 2018).

**Computer mediated communication in healthcare.**

Historically people would seek and receive support from their healthcare provider face-to-face. More recently, this can occur via computer. At the end of 2011 there were 6 million mobile phone subscriptions corresponding to a global penetration of 88% with 2.3 billion internet users worldwide and 70% of households in developed countries having internet access (ITU, 2012) and a greater access to information via personal devices such as smartphones and tablets.


Social media has allowed user generated content. Patients can continuously organize and form their own groups and networks on social media, share observations and experiences, exchange emotional support, find recognition and understandings, and help other members (Mo & Coulson, 2014).

**Method**

A review of the literature was conducted in April 2016. Search strings such as social media, internet, mobile applications, support, social support, practical support, emotional support, psychological support, patients service users, healthcare, health services were searched through six databases (CINAHL, MEDLINE, ASSIA, BNI, Psychinfo, and Web of Science). 2930 citations were found. Articles were included if they involved primary research, written in English, available in online journals, and examined the patients' experiences of computer mediated support interventions such as email, videoconferencing and other forms of support that offered means of two-way communication. Studies were excluded if they did not look at a two-way communication intervention, such as content analysis, effects of social media, health seeking behaviour for example. In total 31 articles were critiqued and included in this study.

**Multi-faceted interventions**

Comparing multifaceted intervention was problematic due to the variations between interventions; however, common themes did emerge from the data. Optimistically, people again liked the asynchronous aspects that allowed them to write their story. They liked to share pictures and messages. Many of the interventions provided a sense of security and reassurance despite the interventions proving ineffective for example in smoking cessation and in the post-partum care. Increased self-efficacy was not evident and engagement was seen as difficult. In one study into non-use of the intervention, it was clear that people either did not feel they needed to use the intervention or they had access to information and support elsewhere and tailored information is required.



**Online social support groups**

Computer mediated social support groups have produced positive and neutral outcomes. The groups are easily accessible, easy to use and the patient may 'lurk' reading the posts of others or 'approach' the group and write their own posts. 'Lurking' on its own can provide much needed perceived support, however it was seen that the more a person engages and posts on the group the greater the perception of support. Again, a degree of anonymity provided comfort and that availability twenty-four hours a day was perceived as supportive. With regards to patient outcomes, the ability to enhance learning, supplement learning or gain information competence was not found. No improvement in self-efficacy amongst new parents or trauma patients was seen and a 'ceiling to use' noted.


**Email**

Email intervention could increase access to healthcare and more specifically the asynchronous nature of text provides time to write and formulate a question/response meeting the unmet informational needs, which provides a sense of security. Positively, enacted social support emails in three diabetic studies found an increased control in their blood sugar levels. Furthermore, engaging with patients and encouraging use would need consideration, due to a noted underuse, as well as consideration for a twenty-four hour email service.

**Videoconferencing**


Videoconferencing has positive and negative aspects. On a positive note, videoconferencing could provide healthcare services to a wider community and link the outside world to the hospital based patient. Patients found they were satisfied when it saved them time on travel and when they were of a younger generations. Caution is required as the technology itself may cause technical difficulty (even today), which in turn increases workload. Videoconferencing can also cause a patient to feel uncomfortable, uneasy, embarrassed and anxious, and it was noted that, although patients had positive experiences, they did prefer face-to-face care.

**Discussion**



Historically, people sought healthcare advice face to face. However, control of healthcare costs, increased demand, and shorter stays in hospital has led to scattered interventions and less personalised care. Computer technology could be both what patients want and a way of delivering healthcare to meet the patients' needs. The points to consider are that anonymity is advantageous in all intervention types, and demographically, breastfeeding mothers are in the category of those most likely to engage with these interventions. It is plausible that a breastfeeding assessment could be completed via videoconferencing given its success in two studies undertaken with dermatologists. Thirdly, interventions are beneficial in meeting the unmet informational needs and the esteem needs of parents. Information however needed to be tailored to the individual and they found benefit in watching and re-watching videos appropriate to them. Caution is needed to ensure that tools are easy to use and that training and supervision is provided, to prevent waste of resource or harm. The literature has shown how information giving alone can prove ineffective and automatic messages can raise anxieties. This could be particularly true for breastfeeding due to the sheer quantity of breastfeeding support information already available online.

**Conclusions**



This review has highlighted some key thinking points for nurses, midwives and allied health professionals who are, or may be thinking about developing, using, or advising patients' use of computer mediated forms of communication interventions in order to better support their patients. Computer mediated communication is timely, accessible and an exciting prospect too many nurses in the current resources tight environment. Reviewing the lessons learnt from previous support interventions will ensure that such interventions are tailored to the specific needs of the patients, well thought out, carefully planned and limit potential risks, and the threat of low uptake.

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