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Dealing with Complexity: Infant Feeding Choices and Experiences for Mothers with Infants in Neonatal Intensive Care Units and Transitional Care Wards

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RESEARCH WITH PLYMOUTH UNIVERSITY



Dealing with Complexity:

Infant Feeding Choices and Experiences for Mothers with Infants in Neonatal Intensive Care Units and Transitional Care Wards

The study was commissioned by

NHS Plymouth Public Health



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The full report will be available at <http://pearl.plymouth.ac.uk>

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We are grateful to NHS Plymouth Public Health for funding this research.

Thanks also to all respondents who took part in the study.

EXECUTIVE SUMMARY

The central aim of the research on which this document reports was:

To explore the knowledge, perceptions and experiences of infant feeding of mothers with infants in neonatal intensive care units (NICU) and transitional care wards (TCW) and the support these mothers receive from healthcare professionals and significant others with the aim of contributing to further support of mothers, significant others and healthcare professionals in the future.

The objectives were:

1. To explore mothers' with infants in NICU knowledge and understanding of infant, feeding and how this influences feeding choices.
2. To gain an understanding of mothers experiences of infant feeding,
3. To investigate the challenges of infant feeding in NICU.
4. To explore the significance of their self-identity and perception as 'good' or 'not so good' mothers in relation to this choice.
5. To ascertain the support women receive from healthcare professionals and significant others.
6. To identify further research needs, develop service provision and inform practice and policy.

Background to the study is supported by a review of the clinical and sociologically relevant literature and brief detail on a previous related study (Stenhouse and Letherby 2013) which focused on the experience of mothers' whose pregnancies were complicated by diabetes.

A mixed method ethnographic approach was adopted:

- Observations in the NICU and TCW were undertaken (alongside interviewing) amounting to approximately six hours.
- One-to-one and dyad/group interviewing were undertaken with mothers and some of their partners.
- Questionnaires (consisting of 10 questions, some of which were open to allow more respondent input) were distributed to all healthcare professionals working

in NICU and TCW. An audit involving a systematic and independent examination of maternal and infant notes was undertaken at the same time as the primary data was collected.

DATA AND DISCUSSION

The Audit:

This section provides a snapshot of infant feeding and expression of breastmilk from a cohort of mothers and babies who had previously been cared for in NICU, TCW or both.

Appendix IV is a copy of a poster presented as part of the Medical Training Special Studies Unit.

Interview and Questionnaire Data:

This section reports on data collected from women, significant others and healthcare professionals and includes detailed reference to the significance of 'The Journey', the mixed experience of 'Skills and Support' and the experiences of 'Pleasure, Pressure and Propaganda'.

CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

Six summary points

1. Training for staff is mixed and this is linked to confidence in supporting women.
2. Women 'sensed' the lack of confidence of some staff and this caused anxiety i.e. if the combination of staff on a shift had little experience/knowledge.
3. Women recognised that certain occupation groups had more time and experience to support them i.e. nursery nurses on TCW, midwives on NICU.
4. The physical environment was an issue for respondents. For example:
 - a. TCW privacy, or not, when expressing and feeding.
 - b. In NICU screens used for expressing or feeding sometimes caused anxiety given that screens are also used when baby is poorly/undergoing a procedure.

5. In TCW, formula feed was linked to early discharge resulting in some experiencing subtle pressure to formula feed.
6. Community outreach team very supportive to some and women respondents felt they would have benefited from longer support.

Six recommendations

1. Training needs to be consistent for all grades of staff and a whole day annually is preferred by healthcare professional respondents.
2. Release from service essential to ensure training is undertaken and given the high priority it deserves.
3. Different coloured screens for expressing/feeding AND for procedures would be beneficial and reduce stress for mothers and significant others.
4. Active recruitment of peer supporters with experience of having a baby in NICU.
5. Ensure continued support from peer supporters when moving from breastfeeding to formula feeding.
6. More information related to equipment available in the community on discharge i.e. hospital grade breast pumps.

1. INTRODUCTION

The central aim of the research on which this document reports was:

To explore the knowledge, perceptions and experiences of infant feeding of mothers with infants in NICU and TCW and the support these mothers receive from healthcare professionals and significant others with the aim of contributing to further support of mothers, significant others and healthcare professionals in the future.

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1. To explore mothers' with infants in NICU knowledge and understanding of infant, feeding and how this influences feeding choices.
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5. To ascertain the support women receive from healthcare professionals and significant others.
6. To identify further research needs, develop service provision and inform practice and policy.

The rest of this report is divided into five main sections. In **Background and Context** we locate the study in relation to policy and academic concerns. In **Previous Study** we include a brief overview of findings from a previous (related) study conducted by members of the research team. In **Methods and Methodology** we outline what we did and how we did it. In **Data and Discussion** we report on the themes and issues arising from the data and in **Conclusions, Implications and Recommendations** we summarise the main findings of the research and outline some implications for practice and for further research.

2. BACKGROUND AND CONTEXT

The Baby-Friendly Hospital Initiative: a brief history

The Baby-Friendly Hospital Initiative (BFI) was launched by the United Nations Children' Fund (UNICEF) and the World Health Organization (WHO) in 1992 (WHO, UNICEF, 2009). The guidelines promoted by the initiative are outlined in the Ten Steps to Successful Breastfeeding (Ten Steps), initially published in a Joint WHO/UNICEF Statement Protecting, Promoting, and Supporting Breastfeeding: The Special Role of Maternity Services (1989). Implementation of these Ten Steps and adherence to them has been effective in increasing breastfeeding duration and exclusivity in the normal healthy term baby (Sinha et al, 2015).

In 2009, WHO/UNICEF published the *Baby Friendly Hospital Initiative: Revised, Updated, and Expanded for Integrated Care* which identified the need for expanding the guidelines originally developed for maternity units to include NICU (WHO, UNICEF, 2009). The document articulated the need for understanding this population and the unique challenges they face initiating and maintaining the breastfeeding relationship and offered guiding principles for all NICUs. The revised version of the BFI: includes specific adaptations to the BFI, with the expert group suggesting the addition of three 'Guiding Principles' to the Ten Steps to support the vulnerable population of mothers and infants in NICU (Nyqvist et al 2012). These include:

- The staff attitude to the mother must focus on the individual mother and her situation.
- The facility must provide family-centred care, supported by the environment.
- The health care system must ensure continuity of care, that is, continuity of pre-, peri- and post-natal care and post discharge care.

Further revisions to BFI were made in 2012 to include mothers who formula feed their babies and the principles of BFI were adapted to incorporate this inclusion (UNICEF, 2012). The principles state that all mothers, irrespective of how they feed their infants,

should be offered support and advice to help them appreciate the importance of closeness for mother/baby wellbeing; how to hold their baby for feeding and understanding of responsive feeding. Mothers who choose to breastfeed their babies should be instructed on how to hand express breastmilk and support from healthcare professionals; family and friends should be given in relation to the value of exclusive breastfeeding. Additional information should be given to enable a mother to know her baby is getting sufficient milk and how to access support services when she is at home. For mothers who formula feed their baby, instructions and information should be given on how to sterilise feeding equipment and make up formula feeds. Advice should be given regarding feeding baby 'first milks' and limits on the number of people who feed the baby.

Infant feeding in NICU and TCW

In the USA, as a result of the BFI programme in NICUs, breastfeeding initiation rate increased from 35% to 74%, the rate of 2-week-old infants receiving any breastmilk rose from 28% to 66%, and the proportion of infants receiving only breastmilk increased from 9% to 39% (Merewood et al 2003). In the UK, the implementation of the Baby-Friendly standards in maternity units has had a positive indirect effect on breastfeeding rates and exclusivity, and frequency in the use of mother's milk in NICU. There is evidence that breastmilk reduces mortality and short and long-term morbidity among premature and small babies born in the UK (Morley et al 2004; Schack-Nielsen and Michaelsen 2006). Yet breastfeeding rates in NICU and SCBU in the UK remain low (Renfrew et al 2009) which may be due to the high demands of care required by the neonate and the associated difficulty of NICU nurses to provide consistent breastfeeding support (Nelson 2007). In a study undertaken in Australia, nurses described NICU as a different world when compared to the maternity unit. They further describe certain challenges: including the infants' medical condition sometimes being a barrier to breastfeeding; the physical environment in NICU lacking privacy; a limited number of family rooms for rooming-in, which means mother-infant separation is common (Taylor et al 2011). In a study in the UK Wallace et al (2013) concluded that clear communication skills and good relationships between staff and parents were key to promoting a culture of breastfeeding in NICU. Consequently, increasing maternal self-confidence has been shown as an important predictor for breastfeeding duration (Weimer et al., 2006; Isler, 2007). Yet, the specialised knowledge needed to provide

support to parents and babies in NICU might not have been part of a nurse's education or their NICU and TCW training (Narramore 2007).

Having a baby in NICU or TCW is an uncertain time for a new mother. In a meta-synthesis of 14 qualitative research studies on mothers' experiences of having a preterm baby, published from 2000 onward, Aagaard and Hall (2008) outlined five metaphors that captured the mothers' experiences. These being: the mother–baby relationship; maternal development (a striving to be a 'real', 'normal' mother); the turbulent neonatal environment; maternal caregiving and role reclaiming strategies; and mother–nurse relationships (from continuously answering questions through chatting to sharing of knowledge). Furthermore, as Ross and Browne (2002) note infants born prematurely and/or those who have extended stays in NICU are at higher risk of developing feeding and nutritional problems than full-term, healthy newborns. The complexity of the pre-term infant's needs, the specific worries of their mothers and the nutritional concerns are all relevant to the proposed study.

The National Institute for Health and Care Excellence (NICE) Quality Standard Neonatal specialist care (2010) provides quality standards related to the care not only of the baby requiring specialist care but also for the families of these babies. The standards acknowledge that it is not only specialist physical care for the baby that is required but also psychological and social care for the baby and the family. In Quality statement (QS) 5, involvement of the parents in the care of their baby is actively encouraged and it specifies that parents should be involved in the planning and providing of care. The specific quality statement related to breastfeeding (QS6) specifies that mothers should be supported to initiate and continue breastfeeding and if necessary supported to express breastmilk.

Methods of expressing breastmilk

Breastmilk production, especially copious production of milk lactogenesis II, is delayed in mothers having a preterm birth (Hartmann et al 2006; Cregan et al 2000). Consequently, establishing and maintaining lactation can be more difficult than for mothers of healthy infants and research has shown that expressing breastmilk can be demanding and demoralising for a mother who has a baby in NICU (Redshaw et al 2006). There are two methods of expressing milk; manual hand expression and

mechanical expression via a breast pump (which can be single or double breast pumping).

Morton et al (2009) suggests a combination of hand and mechanical expression of milk. Jones et al (2001) compared sequential with simultaneous breast pumping on milk volume and energy yield and concluded that milk volume and fat yield within the expressed breastmilk was improved by immediate simultaneous pumping and breast massage post birth. Simultaneous pumping after a pre-term birth ensures that the mother's own expressed breastmilk is given when enteral feeding is being established.

The initial expression of colostrum by gentle manual hand expression is advocated (Geddes et al 2013; Ohyama et al 2010). However, Lussier et al 2015 compared hand expression with electric pump expression and found reduced milk volume at seven days in the group who hand expressed. They concluded that following the expression of colostrum mothers should be encouraged to use the electric pump. Meier et al (2016) undertook a comprehensive review of the literature related to individualizing which method and which pump should be used in relation to the mother infant characteristics.

Some studies have shown that nurses working in NICU have a positive attitude to breastfeeding or feeding with breastmilk but their knowledge is varied Cricco-Lizza (2011). Other studies have shown that improving nurses' knowledge related to breastfeeding and breastmilk expression provides more supportive behaviour towards mothers and reduces the conflicting advice frequently quoted as a barrier to successful breastfeeding (Boucher et al 2011; Spatz et al 2011)

Environment for milk expression and breastfeeding

To facilitate milk production, the environment where milk expression or breast feeding is undertaken needs to be calm and relaxed. Research by Sisk et al (2006) has shown that maternal anxiety reduced milk production. This has been supported by the systematic review undertaken by Renfrew et al (2009) who advocate privacy with Nyqvist et al (2008) suggesting that a lack of privacy and a noisy and stressful environment causes anxiety for mothers. In Nyqvist et al's (2008) study all mothers expressed a need for privacy in a breast feeding expressing room and the use of curtains to facilitate this. The mothers also expressed a desire for the room to be quiet,

pleasantly decorated with no fluorescent lights. When establishing breastfeeding within NICU the mothers expressed strongly the need for privacy and quietness which was not often achieved due to the busy clinical environment. Peer support while expressing their breastmilk was discussed in this research and some mothers valued support from other mothers and found it therapeutic, while others found it disturbing and requested solitude while expressing milk.

Peer Support

Peer support is usually (but not always) a voluntary activity, which involves shared experiential knowledge of the health issue concerned, and shared personal characteristics (Dennis et al., 2002). Breastfeeding peer supporters are therefore mothers who have breastfed their own children, and have been shown to provide emotional assistance, appraisal assistance (providing feedback relating to breastfeeding) and information to other breastfeeding mothers (Dennis et al., 2002; Hopper and Skirton, 2016). Studies have shown that peer supporters are able to spend more time with new mothers, compared with maternity ward staff (Schmied et al., 2011; Hopper and Skirton, 2016); this supports the recommendation of providing peer support alongside professional support (Dyson et al., 2006; Renfrew et al., 2012b).

In research focusing on women who experienced extra-ordinary breastfeeding problems, Hegney et al. (2008) found that peer support was a likely contributing factor to the continuation of breastfeeding. Although the women in Hegney et al.'s (2008) research did not necessarily experience premature or sick babies, the presence of someone who could relate to their experience and knowing that they were not alone was shown to be an important factor in their breastfeeding success.

The availability and nature of breastfeeding support services is inconsistent across the UK (Renfrew et al, 2012a), with most peer supporters being community based, some based in maternity units, and support being either face-to-face or via telephone (Renfrew et al, 2012b). It is therefore difficult to compare the benefits of different models of peer support. Indeed Jolly et al. (2012a) found that peer support interventions were significantly more effective in low or middle-income countries compared with high-income countries, however the support offered in the UK was

less intensive than that studied in other countries. A randomised controlled trial of peer support service in the UK showed that community peer support within 24 to 48 hours of hospital discharge showed a no significant effect on breastfeeding rates. However, McAndrew et al. (2012) demonstrated that the steepest decline in breastfeeding rates in the UK occurred during the first week after birth, so early support, such as that provided whilst the mother is still in hospital, is essential.

Breastmilk expression protocols and guidelines

Clinical guidelines are well established and used thought the NHS and have been defined as an operational tool to assist in clinical decisions (Hope Suarez 2015). They recommend a course of action or procedure to be undertaken within a clinical situation. All clinical guidelines must be focused on the client/patient group or clinical condition to which they apply. Guidelines promote continuity and quality of care and offer a range of practices that can be adapted to meet the individual specific needs. There are a number of guidelines related to expressing and storing breastmilk, for example, Great Ormond Street (10 09 2014) and NHS Choices (20 03 2014). Local guidelines are incorporated within Trust Infant Feeding Policy Version 6:1 (08 07 2014) with minor amendments 09 2014 within section 9: Sustaining breastfeeding and/or lactation, even if mother and baby are separated.

Supporting breastfeeding

Lactogenesis occurs throughout pregnancy and post birth. This process includes preparation of breasts for the production of breastmilk, the manufacture and secretion of breastmilk (lactogenesis I) and post-birth following the delivery of the placenta and subsequent withdrawal of progesterone, the initiation and maintenance of the milk supply (lactogenesis II) (Neville et al 2001). For mothers of extremely premature infants there are particular difficulties in establishing lactogenesis I as the breasts may not have developed sufficiently, to reach secretory activation prior to delivery. Furthermore, the mammary epithelium may not be sufficiently prepared by the pregnancy hormones to produce milk efficiently and establish lactogenesis II.

The immediate post-birth care a mother and her neonate receive is important to establish feeding and assist breastfeeding. A strategy to promote mother and infant bonding that also contributes to successful early breastfeeding is skin to skin contact

(SSC) between mother and neonate. SSC has been defined as ‘the placing of the naked baby prone, head covered with a dry cap and a warm blanket across the back, on the mother’s bare chest at birth or soon afterward’ (Moore et al 2012). The benefits of SSC include the facilitation of milk production and supply, improving neonatal glucose levels by increasing blood glucose levels for up to 75 – 90 minutes post-birth (Durand et al., 1997), and successful early breastfeeding (Moore et al, 2016). The BFI advocate that all mothers should have SSC immediately post-birth for at least one hour or until after the first feed. However, the practice of SSC may be disrupted by factors such as mode of delivery.

Women with complicated pregnancies such as premature labour or pre-eclampsia have a higher incidence of operative deliveries with further evidence showing initiation and establishment of breastfeeding is reduced in women who give birth by cesarean section (CS) (Hauck 2011). It has also been found in general that CS can delay the first feed including breast and formula and this reduces the incidence of exclusive breastfeeding and increases the likelihood of supplementation of feeds with formula milk (Stevens et al 2014). A further factor that may disrupt SSC at birth is the separation of the mother-infant dyad. The separation of mother and neonate has been shown to delay and reduce the frequency of breastfeeding and increase the potential for supplementary feeding.

Supporting formula feeding

The most appropriate alternative to breastmilk is formula feeding. This modified cow milk is available in two forms: the sterile ready-to-feed liquid or the powdered infant formula that requires reconstitution and is not sterile. There has been much research undertaken related to formula feeding of infants which has focused on different aspects of this feeding method, for example the incidence of infant infection including gastro intestinal infection, inappropriate and incorrect preparation of infant formulae and over concentration of formula within the feeds (Peng 2011; Le Huërou-Luron 2010; Renfrew et al 2003; Ball and Wright 2010). Other research has been conducted to identify the reasons why mothers choose to formula feed. This has highlighted a range of factors that influence a mothers’ decision; including a lack of knowledge of breastfeeding, and if breastfeeding when difficulties arise, a lack of help and support from healthcare professionals to overcome these problems (Atchan et al 2011; Brown

et al 2011; Lakshman et al 2009). Other issues identified by Earle (2001) included partner involvement and approval of feeding method, with Lee and Furedi (2005) citing a mothers wish to return to work.

Many mothers say there is a lack of support when they have made the decision to formula feed their infants both during the ante-natal period and post-birth (Tarrant et al 2013). They further report limited and inadequate information from healthcare professionals (Chezem 2001; Basire 1997). Cairney et al (2006) found that mothers reported seeing midwives give more time to breastfeeding mothers than those who were formula feeding. They consequently felt unsupported. Overall, mothers reported that healthcare professionals gave some information, but limited support regarding formula feeding and most of the support and information they received was given via friends and family. Cairney and Barbour (2007) concluded that mothers felt healthcare professionals did not value formula feeding and therefore did not value them if they chose this feeding method.

Thinking sociologically about infant feeding

Midwives, nursery nurses and others give individualized care to mothers and their role is to support mothers in their infant feeding choices. However, the promotion of breastfeeding (alongside the general care and support of a woman through her pregnancy and birthing journey) is a key aspect of the midwife role with women/mothers being given information and advice related to the benefits of breastfeeding in the ante-natal period and post-birth (see above). A consideration of infant feeding from a wider sociological and feminist perspective and an exploration of empirical research on infant feeding suggests that a more complex analysis is needed of both the lived experience of breastfeeding and the promotion of it (Lee 2007, Knaak 2006, Beniot et al 2015).

Pregnancy and childbirth has an emotional impact on parents and on the midwives (and others) who support them. Additionally, part of the role of the healthcare professional is to provide emotional support to mothers and their families (Hunter 2004, Kirkham 2000, Mander 2001, Deery and Fisher 2015). In relation to breastfeeding, research indicates that mothers need emotional support alongside information and practical support (Bäckström et al 2010, Beniot et al 2015). Research suggests that

midwives (and we would add other healthcare professionals) need to reflect on their own views, feelings and experiences towards infant feeding as this influences the care they give (Ekström et al 2003). Battersby (2009: 107) argues that supporting breastfeeding is a ‘highly charged emotional experience’ for midwives whether they are mothers or not.

Studies show that mothers often feel unprepared for the realities of breastfeeding and there is a tension between the often idealised views of breastfeeding versus the more challenging reality, especially when difficulties arise. Women who feel that breastfeeding is important to their identity as a mother, who subsequently have problems in fulfilling this desire, express strong feelings of disappointment and guilt. Sadly some of the literature adds to the negative perception of these women e.g. ‘pain and discomfort may detract from mother’s care giving capacities and intentions’ (Kelleher 2006).

Such negative experiences pose a challenge to current BFI guidelines (2009, 2012) thus:

1. Ensure that all pregnant women are prepared for feeding and caring for their new baby,
2. Support all mothers and babies to initiate a close relationship and feeding soon after birth,
3. Enable mothers to get breastfeeding off to a good start,
4. Support mothers to make informed decisions regarding the introduction of food or fluids other than breastmilk,
5. Support parents to have a close and loving relationship with their baby.

Previous research and writing on infant feeding provides a complex and sometimes contradictory message. Whilst ‘breast is best’ reflects scientific evidence about maternal and infant health, this message also has ideological overtones (Murphy 1999, Lee 2007). Although mothers who breastfeed are seen to be ‘doing what is best’ for their baby(ies), at the same time they need to be careful not to transgress other norms and expectations. For example, they must maintain ‘their modesty’ and must stop feeding their child(ren) at the (often externally) defined appropriate time (Murphy 1999). This has implications for mother’s choices and experiences of breast and formula

feeding and mother's feelings of self-worth with reference to motherhood. If 'breast is best', formula is second best and by association mothers who successfully breastfeed are better mothers than those who do not. With this in mind, breastfeeding has been argued by some to be symbolic of both womanliness and good motherhood and representative of an era that 'demands' intensive mothering/parenting (Lee 2007, Furedi 2008). These feelings may be compounded when a baby is born small and/or sick and the mother may not be able to produce milk or the baby may not be able to feed at the breast.

Furthermore, social networks and societal influences effect all mother's infant feeding choices and for various reasons including the desire for paternal involvement in feeding, the belief that formula feeding is more convenient, the ability to quantify formula feeds, difficulty of managing paid work and breastfeeding and dislike of breastfeeding in public, all mitigate against breastfeeding as a positive choice (Earle 2000; Shaker et al 2004; McCann and Baydar 2007; Soltani et al 2008, Burns et al 2010).

3. PREVIOUS STUDY

In an earlier project, two members of the research team (Stenhouse and Letherby 2013) explored the experience of mothers with pregnancies complicated by diabetes. The focus in this project was on the support women did or did not receive and on the significance of familial support. Twelve women (plus four of their mothers, one father and three partners) were recruited by clinicians.

One issue that arose was that of infant feeding. Women living with diabetes may have co-morbidities or diabetes related complications which have the potential to influence their decision to breastfeed. It is of note that several women in our study commented upon the lack of information or support from healthcare professionals about the importance of breastfeeding their infants and post-birth, they received conflicting advice from practitioners especially if the infant had neonatal hypoglycaemia. The numbers in our study were small and all except one of our respondents were Caucasian (reflecting the demographics of the area), yet we suggest that this study highlights important issues that need to be addressed in clinical practice. For example,

the need for midwives and healthcare professionals caring for women with diabetes to consider:

- their own attitudes, values and opinions in relation to breastfeeding and
- the emotional wellbeing and positive self-identity of the women in their care (with specific reference to the implications of the ‘breast is best’ discourse both for women who want and do not want to breastfeed).

Furthermore, the management of the mother’s diabetes and the consequential effect this may have on the neonate is important, but should not be the sole focus of care. Overall, the data suggests that for women with pre-existing diabetes, infant feeding is particularly complex, not least because babies are often born compromised and may need to be admitted to NICU. If this complexity is not acknowledged by those who support mothers in this situation, additional distress is likely. Our research suggested that midwives and other healthcare professionals need training to better understand the information and support pregnant women and new mothers (including those with pre-existing diabetes) may need from them in terms of infant feeding choices and experiences. We also argued that further research focusing on mothers’ knowledge of infant feeding and how this influences their initial feeding choices is required. Midwives’ and other healthcare professionals’ knowledge of infant feeding in relation to the infant of a mother with diabetes is essential to provide pregnant women living with diabetes with the information to make informed choices. It is important that women get this support, and it is imperative, as BFI (2009, 2012) insists that all women are supported in their infant feeding experiences irrespective of their infant feeding choices. If not, as our study indicates, women’s emotional wellbeing will likely be negatively affected, as will their positive sense of self.

4. METHODS AND METHODOLOGY

For the research on which this report is based, nurses/midwives’ nursery nurses and all medical staff with clinical responsibility for caring for infants in NICU and TCW require relevant knowledge of infant feeding in relation to the neonate in NICU and TCW. As such the research focussed on:

- i) the type of information relevant to mothers with infants in NICU and TCW necessary to help them make informed infant feeding choices,
- ii) the emotional and practical support mothers with neonates in NICU and TCW require from healthcare professionals and others in their feeding choices,
- iii) the information relevant to partners/mothers and other significant others needed to help them support their partner/daughter/friend in their feeding choices and experiences,
- iv) the relationship between feeding choices, intentions and experiences and the ways in which these may relate to mothers perceived self-worth in relation to their understanding of ‘good’ or ‘not so good’ mothering practices,
- v) the related training needs for healthcare professionals.

A mixed method ethnographic approach was deemed most beneficial in this case. The use of ethnographic research in the study of healthcare situations has been well established (e.g. Savage 2000, Dykes and Flacking 2015). Such an approach utilises mixed method triangulation in order to examine respondents’ experiences. It allows ‘everyday’ practices to be observed and enables researchers to both highlight ‘best practice’ and also identify areas for improvement. In the study reported here, observations in the NICU and TCW were undertaken (alongside interviewing) amounting to approximately six hours. One-to-one and dyad/group interviewing were undertaken with mothers and some of their partners, which enabled the exploration of issues in greater depth than would be possible with larger groups. The semi-structured format enabled a flexible agenda with respondents able to influence the direction of the research and focus on issues of importance to them (Stanley and Wise 1983, Koch and Kralik 2001). Questionnaires (consisting of 10 questions, some of which were open to allow more respondent input) were distributed to all healthcare professionals working in NICU and TCW. Data was collected related to grade of the healthcare professional length of service and length of service in the specialised areas of NICU and/or TCW. Following construction of the questionnaire, the relevance and appropriateness for this specific group of healthcare professionals was assessed. Content validity was evaluated by an expert panel which consisted of the Clinical Director of NICU/TCW, Senior Sister NICU and Practice Educator NICU/TCW. The questionnaire was amended in response to the clinical experts’ suggestions.

(Appendix I QUESTIONNAIRE). An audit involving a systematic and independent examination of maternal and infant notes was undertaken at the same time as the primary data was collected.

The study utilised a purposive sample of healthcare professionals working within NICU and TCW and mothers who had or had had an infant in NICU or TCW at the time of the data collection or previously and included a mixture of qualitative and quantitative methods. Our mixed method approach enabled ‘thick description’ (Geertz, 1973) through the active engagement of the researcher(s) in the research setting. This enabled comparison between information given by healthcare professionals with perceptions of information received by mothers (Miller and Brewer 2003, Letherby 2009) and between what is said with what is done (Koch and Kralik, 2001; Stanley and Wise 1983). The audit was designed and conducted to produce information to inform delivery of best care. The questionnaire enabled healthcare professionals to give their ‘honest’ opinions anonymously and the interview format encouraged mothers and their supporting others to ‘tell it how it is for them’ (Koch and Kralik, 2001; Stanley and Wise 1983; Barbour, 2008).

Interviews were digitally-recorded and transcribed verbatim with on-going analysis grounded in the experience of respondents and our aim was to be faithful to respondents’ accounts (Strauss and Corbin 1990). All members of the research team read the transcriptions independently. From these readings it was clear that data saturation had been achieved. Each research team member identified themes and topics and these were discussed and debated until consensus was achieved. Similarly, questionnaires were collated for demographic characteristics and the free text for analysis like that of the interviews. Although our findings may not be generalisable to the experience of all individuals and areas it is likely that the experiences reflected here will have meaning for others in similar situations (Clyde Mitchell 1983).

Ethics and ethical issues

The study was approved by the NHS Heath Service Authority Cornwall and Devon Research Ethics Committee Number REC 15/SW/0308. Additionally, the study addressed NICE Quality Standard Neonatal specialist care (2010) Quality Standard 5 as it sought the parental (and professional) views and experiences of the specialist

neonatal care and services and Quality Standard 8 which states that parents should be encouraged to participate in applicable research studies. (For Participant Information Leaflets see Appendix II).

The Audit

The audit was conducted by Grace Nichols a Medical Student studying with Plymouth University.

A comparison of infant feeding methods between two clinical areas TCW and NICU over the period January 2014 to October 2015.

The aim of the audit was to explore the effect of demographic and situational factors on breastfeeding initiation rates in babies that are admitted to NICU and TCW. Additionally, breastfeeding rates at delivery and discharge were calculated.

The maternal and neonatal hospital notes were requested for 50 NICU and 100 TCW patients, reflecting the 1:2 admission ratio ($n = 150$). However, a NICU/TCW ‘patient’ essentially constitutes both infant and mother, giving a total of $n = 300$.

Some of the demographic data was extracted from the hospital electronic database supplemented with information from maternal and neonatal notes.

Information extracted for database, maternal and infant notes included:

- Admission: TCW or NICU
- Gestation at birth
- Mode of delivery
- Single or multiple birth
- Mother's age at delivery
- Mother's ethnicity
- Mother's marital status
- Index of multiple deprivation decile
- Parity
- History of prematurity

- Breastfed previous babies
- Intention to breastfeed
- Time before milk was expressed
- Mode of feeding at delivery
- Mother-infant separation
- Duration of stay
- Breastfeeding at discharge

Due to time constraints and availability of patient notes, demographic data of 49 mothers was extracted from the hospital database and included in the analysis of the variables: admission to NICU; TCW gestation at birth; birth number; mothers age at delivery, index of multiple deprivation (derived from post codes), Department for Communities and Local Government (2015).

Inclusion criteria

Babies were born in Derriford Hospital

Babies were admitted to NICU/TCW within the first 12 hours of life

Babies survived until discharge from NICU or TCW

Additionally:

Feeding at discharge must have been recorded

Babies must have been discharged home and not transferred to another hospital or discharged into foster care.

Exclusion criteria

Babies who were born at home or transferred from another hospital

Babies who were born with congenital anomalies or life limiting conditions

Babies who went home being partially tube fed.

The Interviews

Interviews took place in NICU and TCW or at respondent's homes. Eight interviews took place in the community, four in NICU and six in TCW. Interviews lasted between 15 minutes and 90 minutes. There was a total of 23 mother/significant other

respondents, 13 women (single interviews) and five partners (dyad interviews). (For further details on respondents demographics and feeding choices see Appendix III. Respondents were accessed via healthcare professionals following discussion of the project at staff meetings and one-to-one discussions on site.

The inclusion and exclusion criteria were as follows:

Inclusion criteria

Mother who had an infant being cared for in NICU or TCW

Mother who have had an infant cared for in NICU and/or TCW or previously.

Exclusion criteria:

Mothers with limited conversational English.

The Questionnaires

All healthcare professionals working in NICU and TCW were asked to complete the questionnaires. This was distributed by the Ward Clerk, a member of the research team or the lead clinicians on duty in NICU and TCW, 100 questionnaires were distributed. Respondents were accessed following discussion of the project at staff meetings and one-to-one discussions on site.

A total of 59 healthcare professionals completed a questionnaire. Thus:

40 healthcare professionals between Grade 4-8

10 doctors F1 – consultant

7 unclassified

2 bank staff

Dilemmas in the field

Issues of emotional involvement, management and work are an aspect of research relationships. ‘Emotion work’ includes regulating and managing the feelings of others and oneself in order to conform to dominant expectations in a given situation (Frith and Kitzinger 1998, drawing on Hochschild 1983[2003]). This is likely to be particularly the case in research about issues, such as infant feeding, which may be distressing. Clearly, displays of emotion can be difficult for both researchers and the

researched and in research. But emotion **is** integral to methodological processes not least because emotion is part of everyone's life and emotional expression within the research process is often data in itself (e.g. Hochschild ([1983] 2003), Young and Lee 1997, Lee-Treweek and Lingokle 2000, Gray 2008). With this in mind, it is important not to over-passify respondents by always defining them as vulnerable for the power dynamics in the respondent/researcher relationship is subject to shift, change and negotiation is subject to shift, change and negotiation (Cotterill 1992, Letherby, 2003, 2013). Sometimes parents became upset in interviews but, although we asked if they would like to, no respondents wished for the interview to stop.

Despite recent improvements – both within research and in attitudes more generally - reproductive and parenting experience are still sometimes viewed as ‘women’s business’ which denies the significance of men in discussions of infant feeding and reproduction more generally and confirms traditional gendered expectations of women (Earle and Letherby 2003, Davidson and Letherby 2013). With this in mind we were keen to include fathers whenever they were available and wanted to be included.

The methods were designed to give respondents as much control as possible over the direction of the research although we are aware that as researchers, the ultimate control over the data remains with us (e.g. Letherby 2003).

5. DATA AND DISCUSSION

THE AUDIT

RESULTS

Admission: NICU n = 14; TCW n = 35

Gestation at Birth ranged from 24.6 to 41.6 weeks

Birth Number: Single n = 46; Multiple Birth n = 3

Mother's Age at Delivery ranged from 18 – 50 years

Index of Multiple Deprivation (IMD) Decile calculated vis post code of home address:

IMD 1 n = 12); 2 (n = 12); 3 (n = 4); 4 (n = 7); 5 (n = 1); 6 (n = 5); 7 (n = 4); 8 (n = 3); 9 (n = 1);

Duration of stay range 3 – 112 days (NICU or TCW not specified).

The characteristics of mother's ethnicity and marital status were poorly documented and therefore not included in the analysis.

The remaining audit data was not collected on only 19 mother infant dyads due to time constraints and the availability of maternal and neonatal notes.

Parity; history of prematurity; breastfed previously; intention to breastfeed, time before breastmilk expressed, method of feeding at delivery, mother-infant separation; duration of stay, and breastfeeding at discharge.

Breastfed previously; n = 6 did not breast feed n = 1 data was not recoded on n = 12
Intention to breastfeed; n = 16; intention to formula feed n = 3

Time before breastmilk expressed within 1 hr of birth n = 6; within 2hrs of birth n = 4
no information recorded in notes n = 10

Method of feeding at delivery breastfeeding of feeding with breastmilk n = 13;
formula milk n = 6

Mother and infant separation n = 4; not separated n = 6; not recorded; n = 9

Breastfeeding at discharge n = 9; not breastfeeding at discharge n = 10

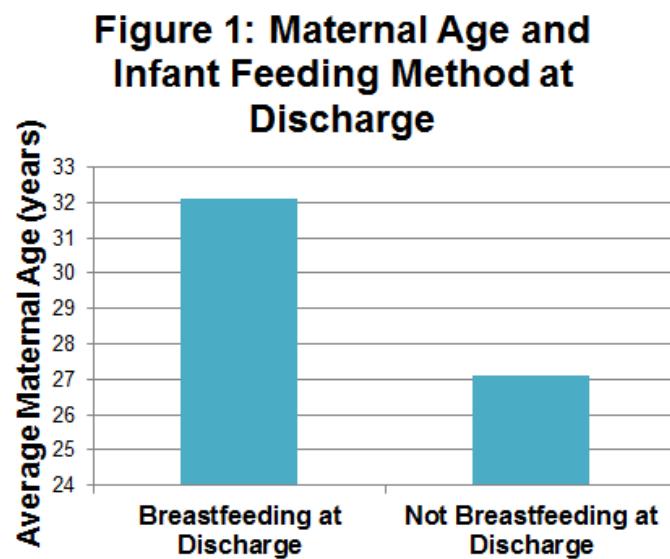
Based on the data available the breastfeeding rates in NICU and TCW were at delivery and at discharge (n = 18).

DISCUSSION

There are many benefits to using clinical databases and patients' notes to collect data but there are also limitations. Errors can occur at every stage of data collection, recording, and entry onto the databases and the maternal neonatal notes. These issues need to be considered when discussing the results from this small audit (Hersh et al 2013; de Lusignan and van Weel 2006).

From the data available 88.9% of the cohort (mothers) intended to breastfeed ($n = 16$). Of these, 81.3% breastfed at delivery ($n = 13$), and 56.3% were still breastfeeding at discharge ($n = 9$).

Figure 1 illustrates the 5-year difference in the average age of mothers that continued to breastfeed at discharge (32.1 years) compared to those that did not (27.1 years).



In this small audit, the data shows that breastfeeding rates in NICU and TCW were 72.2% at delivery and 50% at discharge. The breastfeeding rate in this cohort is marginally below the national and Plymouth averages. However these results are exclusive to NICU and TCW, where having a vulnerable infant necessitating a prolonged hospital stay with research showing that this affects breastfeeding initiation and continuation rates (NHS England 2015).

BFI and published research (Acuña-Muga et al 2014; Sisk et al 2010; Hill et al 2001) advocate that breastmilk expression, when a mother and neonate are separated, should occur within one hour; however, these results indicate that this measure is poorly documented. Of the nine documented occurrences, only six were within the specified time frame. This would suggest that healthcare professionals are not actively engaging with this process or if so, not documenting the time and initiation of

breastmilk expression. There was inconstant documentation of how this milk was expressed; hand or mechanical expression. Mother/infant separation was also poorly documented which is regrettable given that such separation is known to influence initiation and continuation of breastfeeding (Scheeren et al 2012; Nyqvist, and Ewald 1999). Two cases highlighted how length of stay influences feeding method at discharge. Both mothers initially intended to breastfeed and did so at delivery, however after 93 and 94 day neonatal admissions respectively, both mother/infant dyads were not breastfeeding at discharge. These findings are supported by Maastrup et al (2014); and Åkerström et al (2007). Complementary qualitative data would be useful in identifying factors that influenced these changes in feeding method.

The limited size of the cohort reduces the robustness of the results and limits their ability to be generalised to a wider population. A larger sample size is required to confirm the associations that have been made in this audit. The clinical audit presented in this report can be of value as it highlights the need for more accurate documentation and attention to detailing in particular times of initiation of milk expression. In the systematic review undertaken by Johnson et al (2000), it was concluded that the healthcare professionals perceived the benefits of audit as improving the communication among healthcare professionals working within the speciality and other professional groups. Furthermore; the audit improved patient care, increased job satisfaction and better administration including more accurate documentation of many variables that had been examined within the audit. Ultimately the quality of healthcare and its delivery was improved as a result of the audit process (Govender et al 2012; Berk et al 2003).

Figure 2 demonstrates that mothers who breastfed at discharge were of a lower socioeconomic status (Median Index of Multiple Deprivation [IMD] Rank = 2) than mothers who continued breastfeeding (Median IMD Rank = 6).

Figure 2: Index of Multiple Deprivation (IMD) Rank and Infant Feeding Method at Discharge

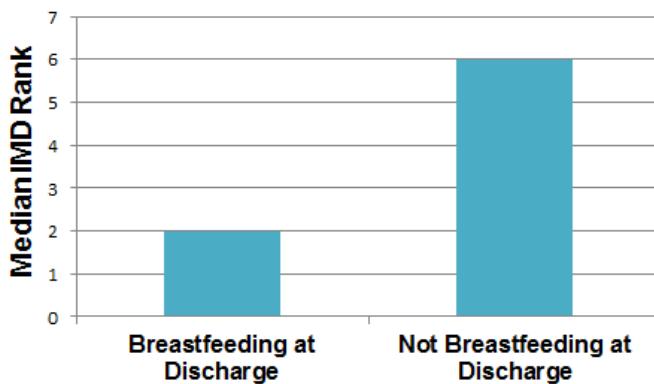
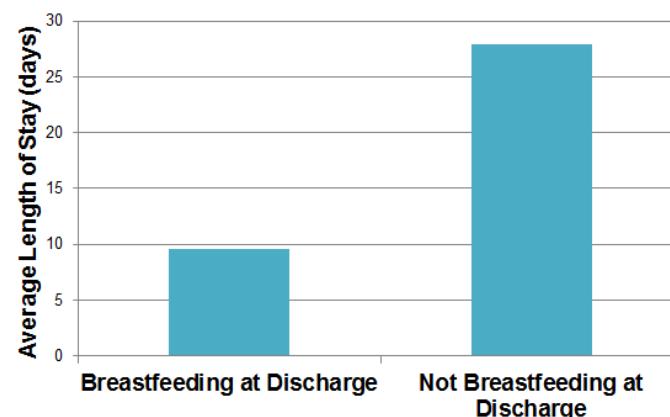


Figure 3 shows how mothers who did not breastfeed at discharge had a longer average NICU/TCW stay (27.9 days) compared to those who breastfed (9.6 days)

Figure 3: Length of Stay and Infant Feeding Method at Discharge



Appendix IV is a copy of a poster presented as part of the Medical Training Special Studies Unit.

THE INTERVIEW and QUESTIONNAIRE DATA

THE JOURNEY

In this section, we include data that highlights the significance of the ‘journey’ – from antenatal experiences through to NICU/TCW and beyond - from the perspective of all involved. The ‘journey’ here includes reference to the physical ill/health journey

(mother and baby) and embodied experience, which includes reference to the infant feeding experience.

Mother respondents felt that antenatal classes could be started earlier in the pregnancy, especially if risk factors had been identified that may result in a premature birth as this would help to ensure that all mothers and fathers were well prepared. This was particularly significant in terms of infant feeding choices:

I didn't get to any [antenatal classes] because I was early. I told them I was probably gonna be early and could they book me on to an earlier one and they didn't and they were due to start probably around the day I had him, I think it was about 6 weeks before my due date, so I didn't get to any, so I think that they should be between 12 and 20 weeks rather than 30 and 40, it just seems ridiculous that they leave it that late... I did wanna go to the breast feeding one and I didn't get to that one either, so maybe even do the breast feeding one earlier if they're gonna keep it to this between 30 and 40 weeks coz that's the one that you need isn't it I think. [Lisa]

There was a bit of a delay in, you know I hadn't been to any antenatal classes, so I didn't know how when your milk comes in and the types of, I'd learnt a bit at University when I was doing my dietetic degree about the type of milk it is at the start and how it forms and develops, but at that time, I wasn't aware of what was gonna happen with his feeding or when I could start. [Sally]

Those that did attend the classes reported that they were helpful, but they still felt unprepared:

Lois: We had the Great Expectations antenatal classes, the 6 sessions at the local children's centre and the community midwives are always there if we need them.

Interviewer: Do you think that prepared you?

Lois: not even close. Not through any fault of their own, it's just a huge thing, there's no way that you can be taught how to deal with things that you don't know are gonna happen. I was hoping for, like I said, a lovely home birth, calm, as drug free as possible, idyllic, with plinky plonky music and you know, I ended up in here completely stoned out of my mind with numb legs and being cut from one end to the other, you can't be prepared for that because you don't know what's gonna happen, it's one of those things that they can give you information, but I don't think you can be prepared for it.

With reference to the physical ill/health journey of mother and baby several respondents spoke of traumatic experiences. Discussion here included reference to the birth experience and afterwards. Mothers reported feeling anxious and vulnerable, overwhelmed, tired and isolated. Thus, feelings of loss of control were common:

It was horrific, I had a really long labour that went from one extreme to the other of no dilation, getting sent home because I thought my waters had broken... and I was told they hadn't, but I'm pretty sure they had because when they did start trickling more on the Sunday, it was the exact same liquid, exact same thing and then I got sent home because I wasn't ready to stay or anything and then I went home and within 40 minutes, I was rushed back in an ambulance and then it was all the pain relief and then I got dilated up to 9 cm and then nothing happened so I had to have a C-Section anyway and then I had blood loss and then the placenta was dodgy and now we're here and I'm infected and he's infected [Kitrina].

. . . I was in intensive care for two days and then in the high dependency labour ward for two days before I'd even met him and when I got moved to transitional care, then I saw him for the first time... I was in the bed next to him and he had all different wires in his head... Luckily he's pulled through it all and he seems to be a little fighter like me. . . [Pippa]

. . . the first day she's born, she's taken away, so nothing really sinks in, but the next day, you start hearing them say 'she's got a syndrome and she's not

'tolerating her milk' and then you have some other person coming in 'well her eyes are too wide apart and her head's a funny shape' and you know, you start looking at your baby like she's an alien and it's hard to bond... I think we both broke down so much, I couldn't quite get on top of my emotions... [Sally]

These problems can make the initiation of breast feeding difficult as healthcare professionals of all grades recognised:

The biggest challenge on NICU is promoting early and continuous expressing by mothers of very sick or extremely premature infants. Often the mothers themselves are quite ill and parents are focused on how critically ill their baby is and whether they will survive the next few hours... It is hard to be promoting the long-term benefits of breast feeding in this situation. [R48 F2]

When mum poorly from delivery and baby on NICU. [R5 G5]

When a baby was ill, distress increased:

The most negative part was the fact that he was being tube fed to start with without my breast milk and just the whole, I'm used to tubes in like, you know I deal with tubes every day at work in adults, but in children, it's so different. X did all the feeding through the tube, because I just didn't want to touch it, because it wasn't how it should have been, I didn't want him fed through a tube, I was supposed to be breast feeding him, so yeah, that was the hardest part. [Phoebe]

At that time, the only thing I can do to help her was to express milk, that was the only way I could be useful in that situation.you don't get to do any of the caring, you don't get to change a nappy, coz it's all done every six hours and they weigh this and they do that and I knew that, so I wanted to get involved in her, so that I had some kind of bond with her as I said, the first 72 hours I wasn't creating a bond at all for my self-protection really emotionally... one of the NICU nurses overnight who was, 'I've got cares at midnight, so

come and join me' and I was like, well, I'm awake anyway, so yeah I'll come.
[Felicity]

Some mothers' had trouble expressing milk:

It was not good at first, it really wasn't, I sort of kept going with it, but I never really had the supply I did with my term babies, it never came in that well, but we got there in the end. It was a long...when they say 'don't cry over spilt milk', some mother who has never expressed has obviously said that. [Bella]

I was so ill like for two days that I couldn't do nothing, so I couldn't express or anything, because I was too ill to do anything and then by day three when I tried to express, it was becoming hard. The first time we had hand express, didn't get on very well with that, so then they let me use a pump, got on a bit better, but then as the days are going by, my milk was just getting less and less. [Ella]

Healthcare professionals are aware of these issues:

Majority of babies are preterm, mothers often struggle with expressing and getting high volumes of milk – I think this can lead to feelings of inadequacy and it's the one thing nurses cannot do. Preterm babies often require more milk than mothers provide so formula is often introduced. Term babies are often pushed towards formula so we can get baby off drip. Expressing facilities are not brilliant, small room etc. Many staff unhappy to cup feed so baby remains tube fed or get given a bottle. [R08 G5]

Some mothers had so much milk, they didn't know what to do with it. Many of these mothers said they would have liked to have donated their milk, but this didn't seem to be an option, was not well known about or mentioned:

. . . when I stopped feeding her, we had so much milk at the NICU, they started putting it in the freezers and we've got two freezers out the back, one of the freezers was full of milk and the NICU were saying 'we've got so much

of your milk, can you please come and take some home' and there was no way I was gonna bin it . . . There's a Facebook page called 'Human Milk for Human babies' and it's mums contacting mums and there was one mum that had triplets and she just couldn't supply enough for all three, so I met her at the hospital a couple of times and she had like several bottles and then there was a mum that contacted me from Cornwall, she had a little boy, who was born with a cleft lip and he was born by surrogate . . . [Sally]

They weren't giving her the full amount that I was expressing either. She wasn't taking everything that I was expressing because they were limiting what she had, so a lot of what I was producing was frozen because there was so much of it. I would have donated it, I asked them about donation schemes and they couldn't tell me anything, so I asked a friend of mine who does the upfront peer support groups at the children centre, she directed me to a couple of websites, but when I looked into it, they said that they screen so much that by the time they get to the person that wants to use them, it's probably less effective than formula. It would be nice if at the hospital, there could be a donation scheme where maybe the first lot is screened and then subsequent batches can be used. . . . Nobody was able to give me any of that information [about donating milk] in the hospital [NICU and TCW]... I asked a few people and they couldn't tell me anything. [Helen]

Some mother respondents spoke of their breast feeding success:

The first time I was able to put him to breast it had reached what would have been 32 weeks gestation, it was a bit of a battle, but when he latched on, I could have celebrated. [Bella]

I think it was about 6 days, so it wasn't very long, but she took to breast feeding really quickly and I think we did, as soon as she came out, they were like breast feed her completely, so she didn't have a bottle at any point, so even when I was starting to wean her, she wouldn't have a bottle, she was not interested in bottles at all. [Helen]

One mother explained her expressing experience with her baby still in hospital:

I didn't feel it at all helpful with them saying to me you can just come back and forth, you know just keep coming into the hospital every time you need to pump because that does not work. It's all well and good if you haven't got any other children because my husband could have taken me in each time I needed to pump, we would have said ok this is what he needs so that's what we'll do, but with another child, that is just not going to work... Massively added to the stress. I did feedback and I did ask them to come back to me on it because I don't think it is appropriate, sending women home who are wanting to breast feed, whilst other women who aren't breast feeding are allowed to stay in, why is that? Sending them home with no facility for pumping. [Laura]

SKILLS AND SUPPORT: a mixed experience

Here we focus on the confidence of mothers and fathers and the (mixed) skill set of professionals. Reference is given to the continuum of care OR not mothers receive both in hospital and in the community.

Almost all healthcare professionals felt that BFI training should be available to all. Respondents were about equally divided between considering the training to be VERY or FAIRLY useful. Criticisms were specifically related to 'lack of attention to formula feeding' and/or 'lack of attention to NICU/TCW'.

Several healthcare professionals added comments on what more they felt was needed in terms of training:

Very little on preterm feeding on training day, everything focussed on trouble shooting Breast feeding rather than expressing . . .[R08 G5]

We do not give sufficient information/advice to bottle fed babies or train staff with the appropriate information. [R57 G8]

More advice on how to handle Breast feeding with a mother who had inverted nipples. [R37 G5]

It was clear from the data that many mothers felt unprepared and reliant on professional support:

It worries me slightly not knowing how much he's gonna be getting on me especially with the tube, coz I'm gonna have to top it up and I'm not sure how I'm gonna know that but I'm sure they'll... [Lisa]

I just assumed that it was something that would happen naturally, you put them there and they did what they had to do, but it doesn't work like that. . . I just went with the flow really, I just went with what they told me [NICU]... I think you need to put yourself in their hands and assume that they're doing what needs to be done. [Phoebe]

Although sometimes mothers felt that their past experience was not taken into account:

I said I think I'm alright, because I've done this before, I didn't need someone to explain to me oh this is what you need to do, I just needed to find my little way with him. I did ask her about the tube and what do I do and she said just ignore it and pretend it's not there. She was just a little bit overbearing really and maybe she was trying to encourage me, but I found it quite off putting.
[Laura]

Doctors were generally very complimentary about the skills of nurses and midwives with respect to infant feeding but insecure about own knowledge. The following was typical:

I think midwives and nursery nurses and NICU nurses do well in discussing feeding and breast feeding for new mums. [F48 F2]

Many parents stated that NICU were fantastic in their care, but with reference to the care from TCW there was a mixed reaction.

NICU were amazing, I thought NICU were exceptionally good, they were very good at coming down to our level at explaining and I think they were very good when they saw fear in our faces, saying 'it doesn't sound as bad as it is', they were absolutely amazing. TCW was a mixture of some really amazing staff and some staff who really seemed quite frustrated with some of us mums being upset. I had one healthcare assistant tell me there was people far worse off than me, which was not a positive experience... there were some who were so kind and so lovely and you feel even when they were busy they were making time for you, but there were some who were clearly just stressed and frustrated that we were asking questions. [Natalie]

It's not joined up between NICU and TCW. NICU will encourage and encourage and encourage you to breast feed, particularly for the prem babies, because they can't uptake the formula, so then its donor milk and donor milk is really expensive and actually what's better for your baby is your milk, coz it's your antibodies, so they will encourage and encourage, but I think they think that the TCW people are giving support and having been in the situation, I know it's very difficult to then go and ask for support, because if you don't know what support you're asking for, if you're a new mum, what do you do?.... It takes someone to sit down with each new mum and say what are you wanting to do, if you're wanting to express, then this is what you need to do and we need to come up with a plan, coz it's all a bit haphazard. [Laura]

Yet again healthcare professionals were aware of these issues:

Mums made to feel they are not producing enough milk – not explained to them that preterms have a higher calorie requirement than term babies. Lack of confidence in staff to support them – many staff direct mums to transitional care ward for support. [R08 G5]

Most mums on NICU for a long period struggle to move to Breast feeding due to ‘not knowing how much they are taking’. Some are concerned as we use dummies for non-nutritive sucking to make the connection between sucking and full stomach – permission is obtained but they all question nipple, teat confusion. [R11 G6]

Many healthcare professionals cite ‘time’ or lack of it, amongst the key concerns for them:

The challenges are time and we need a breast feeding link nurse, who can spend quality time with mothers when they start to breast feed. On the neonatal unit we have a lot of staff who will spend time with mothers but when the mothers get transferred to TCW they don’t leave enough staff to be able to give quality time. [R54 G7]

The amount of time you are able to spare/give new mums has an impact on what information is retained. Also the fact that they may be exhausted, stressed or on high dose pain killers impacts the information retained. Dependant on workload and the visiting time to NICU by parents, time span can be varied – ward rounder – parent asked to leave or delay feeding. [R55 G6]

Many parents spoke positively of the support/encouragement they received from healthcare professionals:

... it depends on the nurses really, like the nurse last night, she came in, she was really good, she said ‘at the time we give her the Cow and Gate milk, put her on the breast, if she gets association with the smell of you, rub the colostrum maybe on her lips, she gets a little bit of the taste and associates the warmth and comfortable feeling of being fed with you’ and I thought ‘yeah, it’s more of a connection then’. [Daphne]

There was a lot of support, it was really good, a lot of encouragement, even though I'd bring a little pot into the unit and there was only a tiny bit of milk,

they'd be like 'brilliant, that's really good' and that made all the difference I think. [Bella]

With regard to interaction with the staff, fantastic, I got loads of support and he was good at performing for witnesses, you know, he'll latch on beautifully and maybe with a bit of guidance with his head position and things, he latches on great, he feeds well, but then in the privacy in your home, when you've not got that person stood in front of you guiding you, you don't always necessarily realise that you're missing out on something or he's not perhaps latching as well as you think he is. [Lois]

The midwives, the HCAs, the nursery nurses, the staff nurses, paediatricians, everybody has been utterly fantastic, it is an incredibly supportive atmosphere... it's not like they're just chucking you in the deep end, they'll sit down and say 'if he's not latching on try it from this angle, try raising his head up a little', just trying to make sure that it's the best for him and best for the mum, which is wonderful, it kind of relaxes...I was quite tense, so having that little support was very relaxing, made it a bit easier. [Paul]

I think it was really useful, it was what I needed, the right people were there at the right time to encourage you to do it at the right time and make sure coz everybody was saying you need to start doing it straight away, so that things don't dry up... [Hayley]

I can't fault anything. If everybody had the experience that I had, you guys are doing a great job, I can't fault any of the support, I felt really, really well supported [Brigit]

However, there were other mothers who felt they did not have the support/encouragement from the healthcare professionals that they needed:

No, not really, it was just assumed that they'd want to try get some milk from me, which I didn't question because that's what I wanted to do anyway, but no one had asked me [breast or bottle]. ...I don't remember much being

explained to me in there, I think that's the worst thing about TCW, it's what everyone is saying. Coz they do it all the time, nothing was particularly explained, none of it was, quite scary... they don't explain things, but I think its coz they're understaffed to be honest, they looked stressed a lot of the time.

[Natalie]

I started using the breast pump, but I wasn't really sure how to use it and I wasn't using it correctly I was told, I was doing it for too long. I was never informed to do 15 minutes a time, on each breast, so I suppose that's when I started thinking right I'll just give up then. I always agreed that they would get bottle fed anyway by formula and stuff, so I wasn't asked about breast feeding the twins until maybe a week or so later, coz the midwife at the time didn't realise at the time that I wanted to start giving them breast milk, to try and help them along. It was on the documents that I was gonna bottle feed, so they just didn't bother asking if I'd changed my mind, so it was me that had to go up to them and say can I have a pump to start expressing. [Ruby]

... they've got one peer support person, I only saw one, I think it's on the board in the family room that there's two or three, but I saw one person in TCW... I was very lucky that I was able to breast feed without a problem, but as I said there were some ladies in there that were desperate to breast feed and couldn't and were having to combine and one was quite happy with that and the other one was really beating herself up that she couldn't and just wouldn't take to it and I'm not sure what support she was getting, but she did get herself in a pickle a couple of times and I was comforting, but probably wasn't the best person to as I wasn't having the same problem, so I think she could possibly done with more support. [Helen]

And others spoke of a mixed level of support:

I think for a like a day or two, I was supposed to be trying, but nobody actually showed me what to do, so I was gently putting him and was like yeah he's not feeding yet and then, I think like after a couple of days, one of the old school midwives came in, she said ' right I'm very old school, do you mind me

manhandling you?' I was like no whatever to get us home basically. So she just grabbed x, grabbed me and after a day and a half we were doing it on our own and then he pulled the tube out overnight and they were happy with suckling and feeding well... Well, she got the job done. . . . I shall always be thankful for her doing that. . . I just needed to be told that and shown really, that was the most positive part really. [Phoebe]

I remember when my son was on NICU, I didn't want to be taking the nurses away from looking after my baby, I needed him well, I didn't want to be wasting their time showing me how to pump and express. I needed them to be concentrating on him. There were women on TCW that I could ask for help, but because I didn't have a baby on TCW, they didn't come to me, the breast feeding women didn't really come to me, to see how I was doing with the expressing, they were just, there's a discrepancy, I don't feel they've got it sorted between NICU and TCW... [Laura]

Some felt confident to ask for help if they needed it:

No-one came back really to check on how I was doing, but then I'm big enough to go and ask for help if I need it really so I wasn't too worried about that . . . [Lisa]

Whilst others found it more difficult to ask for help:

I just don't feel like I wanna rock the boat too much and make a bit of a nuisance of myself really, that's what I was saying weren't it. . . . I don't want to be a burden to anybody, I just feel like I don't want to keep asking, I feel like... [Daphne]

Continuity of care was also an issue. Some spoke positively about this:

They [Outreach] come every two days to check baby, make sure see what sort of amounts he's feeding... He'll also be sent up to our local health centre and the health visitor and things like that, not that they really bothered about X

being tube or anything, it was more normal health visitor and stuff, but the outreach team have got a bit bigger, there used to only be 3 of them, now there's 5, and they offer 7 day support whereas before it was only five day support, so and they are always available at the end of the phone. [Pippa]

Again time appeared heavily in healthcare professionals accounts:

Time and staffing, although this is mainly an issue on the postnatal wards.
[R20 Grade not stated]

Time constraints – if the unit is busy not enough time to sit with breast feeding mums. [R32 G5]

Time barriers – over TCW you can have lots of mums feeding at the same time and needing help / knowledge TCW and NICU babies have different needs. [R33 G5]

Sadly there is not enough staff in the community to support breast feeding which I am sure is why we have such a low breast feeding rate. [R35 G6]

Several respondents spoke/wrote of mixed messages and mixed levels of support. Their frustration was obvious:

Daphne: It's just I suppose until someone else gives you that advice you don't realise that you haven't been having it. When she came, I thought 'oh that was really good, it was really helpful' and then I thought 'why didn't know one else tell me that?', I suppose that then gets you thinking don't it and everybody comes in telling you different things and...

Charles: Its feeling a bit lost innit really...

Daphne: They don't really tell you [how long the stay in hospital will be], I don't feel like I know what's going on, the feed goes up each time as well, but they haven't explained that...

After yet another reference to time R38 [G6] wrote of the problem of prior expectations and the mixed message parents receive from formal and informal supporters:

Preconceived ideas re B/F and how easy! It is / Input from relations – advice differing from HCP. / Differing advice from HCP

Some mothers felt infantilised in their relationships with health professionals:

There was a machine where you could warm the milk up, but we weren't allowed to use it, because it was too expensive 'don't touch that', it was like being a naughty school child, rather than being like, 'it's an expensive machine, we're just going to show you how to use it, here you go', one or two were eventually like, 'we'll show you', but some were 'we're way to busy anyway, we have not got time to be showing you that machine and you're not stupid, you're adults, you know what you're doing, you can press a button', but no some of them, so that was, no that was not nice... I've had a few people saying to me, 'oh my husband was allowed to stay a few nights' and other people have said 'mine was kicked straight out', so real conflicting kind of things going on depending on what staff were working. . . . if they caught them on the bed, you'd get told off, it is like being a naughty school child. [Natalie]

Equipment was an issue for some:

. . . I learnt how to manually express then and I preferred that over the stupid little hand pumps you get, they're hideous. [Sally]

. . . there wasn't a bed ready for me on TCW and they wanted to put me into a room rather than in a bay, so then I went up to Argyle and while I was there, there was no mention whatsoever of expressing or anything at all, nothing... I just felt I was in there hands and they told me what to do. I was still on morphine at that point, so I just wasn't with it. With hindsight, I wish I had said 'can we do some more expressing', but actually it didn't hinder my breast feeding journey. . . . The next day I said 'can I go on the pump please', they

said 'we don't like to get you on the pump this early'... , I was useless at hand expressing... I had to fight though to get a second pumping kit. [Laura]

There were also mixed reactions to the experience of the breastmilk expressing room:

It was nice [the expressing room], really nice, coz you've the radio and you've got the curtains and it's very laid back and there's magazines there, not that you can look at a magazine while you're holding two pumps, but it's nice, I think I got more out of the hints and tips from talking with the other mums and some of the other mums had been there for months you know and you have some of the mums that are coming in and out that have had their babies so early that their milk's just not coming in, it's so frustrating for them when you're coming out with lots of bottles, you kind of feel guilty, trying to hide them on the counter, please stick it in the fridge. [Sally]

Sitting in that room (breast expressing room], I don't like that room, the little dark room with no light, listening to somebody next door to you, I had some quite funny conversations with people that I couldn't see because they were behind the curtain and we'd both be sat in there pumping away. [Felicity]

PLEASURE, PRESSURE, PROPOGANDER

Here we report on data regarding the value of breast feeding as it is perceived AND experienced. Also included is reference to the feelings of guilt that mothers and their partners sometimes feel either when deciding not to breastfeed or when things did not go as they planned. There is reference here to the support mothers and their partners did or did not receive (this time informally).

Mothers spoke of breast as 'best':

I knew it was best, I knew it was better for her ... [Lois]

I just wanted really what was best... I decided before I had X that I wanted to breast feed to give him the best start and because of him being so small and

we weren't expecting to have a baby that was premature, so it was very unexpected I just wanted him to get as much goodness as he could from me and just have that bond with him... [Sophie]

When you get pregnant, you get all the leaflets; I knew that breast feeding was the best thing for them. For me, it was something I felt I really wanted to do and a lot of women don't want to do it and there's this real stigma about getting your boobs out in public and feeding your baby, but a lot of women are standing up and saying 'oh actually this is the right thing to do'. Some women can't breast feed and I get that, however, you feed baby... [Bella]

Healthcare professionals were well aware of some of the barriers and challenges to successful breastfeeding:

Parents want to know that their baby is getting the best feed. However, it is very stressful in NICU and this can have an effect on mothers' milk production, and if this is the case they should not be made to feel that they have failed. They want their baby to grow and get better and go home. They want help and advice on how and what to feed. [R54 G7]

Different advice for professionals found confusing / Wanting to do the best for their babies / Coping with newborn and establishing feeding is a challenging time and can seem endless. [R45 Grade not stated]

I think that if the baby is progressing well and has an optimistic prognosis, parents are concerned to give the baby a good start in life and will often consider breast feeding even if they hadn't originally intended to. However, previous experience with other children can have a strange impact and if breast feeding was not a success they may be very much against it. [R48 F2]

Some mothers said that breastfeeding was the most convenient option for them:

I guess coz my mum did and just coz its natural and I know it sounds horrible, but it's cheap, it's free, it's what they need. At night, you have to make the milk

up, but if you're breast feeding, straight on to you and back to sleep. I feel it was the right thing. [Natalie]

I always knew that I wanted to breast feed, so that was the 100% plan. I have sought of got a bit of a health background; I'm a dietitian, so I obviously know about the benefits of breast feeding. It was the ease of it rather than making up bottles and formulas, finding a formula that the like, you know it seems like the most natural thing to do really. [Phoebe]

It's cheaper, it's better for baby, it's better for mum and it's there for a reason, it's what they're meant to have and I always said if I can do it, then I would and I did and I was determined to do it. Me and my sister are both very blessed I think, we inherited good genes to produce; there was oodles and oodles of milk. [Helen]

Although sometimes a certain amount of perseverance was required:

I'm disorganised, I knew I wouldn't be able to cope with bottle feeding and sterilising. My natural place is not in the kitchen, keeping things clean, I don't do that very well, so I just breast fed him and it was a nightmare for the first three months, everyone was saying just give up and bottle feed him and I was like 'no, I know that bottle feeding won't work for us, I need to be able to do something I can do on the hoof' and I like doing it, even though it hurt like hell, my nipples split and it was a bit of a nightmare, but we got there in the end. Also when you do see it work, it's lovely, it's just such a nice bond that you have with your child and I wanted that. [Felicity]

He's really interested, but I think he's just a little bit too small to be able to do it off me at the moment. He's doing fine with a bottle so before he does the bottle, I normally do some skin to skin contact with him just to keep him interested in going to the breast which he is interested in, but he seems to be doing better with having the bottle at the moment, but when I get home with him, I'm gonna do more work with him with the breast feeding. [Sophie]

Initially, started straight with breast feeding and he seemed to latch on amazing then he now, I don't think I'm producing enough for him to be satisfied so they've been topping him up on the little bottles that, this, in a little bottle, but only a small amount, but I'm gonna try and persist with breast feeding, and only have that, I bought that for him, so he can participate if I'm wherever. [Kitrina]

Others were willing to try, but were prepared for it not to be successful:

I won't be too disappointed you know if it doesn't work out express feeding, my Mum's said she's tried with both me and my sister and it never worked and a lot of people try and fail don't they, but I feel if I just give it the best shot, at least I can say I've tried my best and you know, it didn't work. [Daphne]

Others spoke of their decision to formula feed:

He was just not feeding enough and so we were trying to keep him on the breast for as long as possible supplementing now with formula because he's still hungry afterwards and he's not latching on properly and he's not taking as much as he should. We'd rather fill him up with formula and make sure he was supplemented with that rather than...[Paul]

I don't know, just a personal choice. My niece and my nephew were both formula fed. [Ellie]

Some felt no pressure to do otherwise:

The midwives kind of said it would be better you know for the colostrum and everything like that and I do understand that, but I think you deserve a choice and I'm gonna to be buying the formula so it's my choice and I stuck to that all the way through and to be fair they were pretty good, I never had the breast council or whatever they call it. No they didn't try with us and it all worked really well and I haven't looked back.... I know exactly that he's getting all the right nutrients and everything is done scientifically and professionally and I

know that he is gonna to be full when he's finished whereas my other friend had the baby she went to breast and just the baby was always screaming because it was always hungry, he wasn't getting enough... [Pippa]

Others did:

Out there by the ward there's those pictures of breast feeding, like its posters, even when my sister came to visit last week she went to get a drink of water and she'd seen the posters and she said I hate that, the pressure of breast feeding, coz obviously some people can't breast feed and people don't want to and it just makes you feel more pressured, the fact that they have posters just outside the unit. Definitely adds more pressure that they have posters and then you get staff telling you, I think they shouldn't pressure people, it should be whatever the parent wants to do. [Ellie]

There is such pressure about it that if you're not doing it or you have to supplement with a formula, it's almost like failing across the board, you let your child down, it's quite a lot of pressure, especially for new parents, you're second guessing everything you're doing anyway, that kind of additional pressure is not really helpful I don't think. The midwives and nurses have all been fantastic.... I think because there's so much visual literature for it, I mean if you look up there, the sign says 'I wish I'd done it for longer and I wish I'd done this and I understand the benefits more now' and obviously the whole thing about breast is best, I get that, it's obviously the natural choice for the child, but I think you get that pressure put on you that if you're not doing it, you've somehow failed. [Paul]

I don't think it's necessarily the healthcare professionals. I haven't come across that at all. In fact I've come across the opposite. It's other women out there, other mums, other breast feeding mums putting pressure on other mums and making them feel guilty. There's the whole natural birth/caesarean birth. 'Did you have pain relief?' Actually, there are no medals for this, you do what's right for you and you do what's right for your baby. What was right for me and my daughter was an epidural and ventouse and it was also right for

me to breast feed, its right for me to have a pushchair, it's not right for me to be carrying in a sling. You do what works and if it works, then that's fine. I do think it is other women more than professionals that give the hard line. [Laura]

Many healthcare professionals referred to pressure mothers and their partners feel and the impact of this. For example:

BFI can cause a great deal of angst and anxiety to those who for whatever reason cannot BF. [R39 G6]

BFI zealots can make parents feel bad about themselves and failures. Harm parent/infant relationships. [R23 Consultant]

. . . feeling that formula feeding is breast feeding failure. [R14 G4]

I do think too much pressure is put on mothers postnatally to breastfeed and they feel very guilty when they are unable to. [R20 ST4]

Sometimes this has consequences for relationships between professionals and mothers (and their partners):

Some people feel pressured to breastfeed when they don't want to and feel afraid to admit this to professionals. This is a waste of everybody's time and resources, when these are already so scarce. [R47 G not recorded]

Some non breastfeeding mothers spoke of the distress and/or guilt they felt:

It wasn't until she got round to the lesser dependant unit and she was off all the monitors and everything that they said ok, let's try, but she's got a cleft pallet, so she just couldn't suck, which broke my heart, really broke my heart, because you know you've gone through so much, I think when you're in the NICU, the only thing you can do for your child is to express and so there's that pressure and you see, that's all anybody talks about... [Sally]

I was worried for them because they were tiny and obviously I felt guilty, why didn't my body hold on for a couple more weeks, my body let me down, that's exactly what was going on in my head, but hey, I was at risk. [Brigit]

So I tried for a couple of days, got to day 3 or 4 when all my hormones kicked in, I just got so upset with it all and it was mainly over night that they were trying to help me with it and I was too tired, I couldn't concentrate on what they were saying, they were trying to put her on me as well and she wouldn't latch at all and in the end I got so upset that my husband had to say 'she's gonna have to stop and she's going to have to be formula fed' ... [Lisa]

Others felt strongly that they had not been put under pressure by health professionals:

On regards to the feeding though, I have friends and they tell me a different story. They tell me they've been put under pressure by the midwife to breast feed, I have never been put on that spot, I question is it really the poor midwives fault or is it the person's weak personality, sorry, is it the personality that feels I'm being put under pressure, maybe just like I felt by family and friends, but to me the midwife was helping me, so I didn't associate of being put under pressure by the midwife, the nurses and midwives they helped me. In actual fact, I wanted that, I seeked (sic) for their help as well as them helping me. They were great; I've never felt under pressure by the midwives to have to breast feed. ...

Yes, the first time they didn't latch on, but when they latched on it was with the help of the midwife and they picked up and I felt that suction, it was almost painful, but not painful to the point of oh my god I can't do this, but it was quite emotional actually, it was lovely and I wish I had put up with it and carried on, but I don't have regret, I wish I was better in my head... Yeah, I'm a naturally very strong willed woman, but it's amazing how you get bashed with this experience, even the strongest woman will become a little weaker with an experience like that. [Brigit]

For some mothers the decision to stop breastfeeding was/is pragmatic:

The main barriers/challenge is the gestational age of baby as prem babies may take weeks to breastfeed, which is very daunting and not expected.

Parents 'grieve' the normal term baby that they expected to take home after 24/48 hours in hospital. Many parents change to bottle feeding a lot of the time using [unclear] in an attempt to get home earlier. [R14 G4]

However, this is not always an easy option:

I found it exhausting once I got home, I ended up having to do the night feed, then express afterwards and just giving him a bottle of milk, then expressing, he was so little, he was only sleeping like for an hour and a half, so by the time I'd expressed and fed him and got myself back into bed, he was getting back up again and I just hit a wall with it. . . Yeah, it did feel like that, I was desperate to come home, that's why I stopped trying to breast feed because they were adamant on you have to give 50% down him orally for him to be able to go back and by that point I was climbing the walls, I wanted to go home with him, so I said fine, if I can't establish the Breast feeding then he'll have to go on to a bottle because I can't do it. [Natalie]

Mothers sometimes see bottle feeding as a quicker way to get home, however as outreach, we give mums the confidence to breast feed at home. [R58 G5]

Some mother respondents spoke about the 'informal' support they received:

... in the beginning I got most of my support from the Facebook page. . . I had to look online for breast feeding support groups and it was mostly American interest and even going to the booby babies group, they had nothing for anybody pumping. There's a huge gap here. . . The breast feeding support helpline were amazing, because they have volunteers 24/7 and they're mums that are qualified in giving hints and tips, they gave me a lot of information.

[Sally]

He's [husband] not pushy in the slightest, but he said 'this time just give it a go, seeing as you're in here on your own, chilled out, just give it a, you know, a good go' and that's exactly what I wanted to do and yeah he knows me very well... [Lisa]

My Mum was quite supportive with breast feeding, she said she's attempted with the both of us, she had a bit of a failure and didn't, but she said 'don't worry if it all fails', she didn't put any pressure on me. [Daphne]

They've said 'it's your baby, you can do what you want.' [Ellie]

I had more support from female mum friends of mine, practical useful advice from female mum friends of mine. [Lois]

But some occasions this was lacking:

My husband didn't like it really, but he accepted it, he wanted me to breast feed both of them, but didn't like it. Selfish reasons, if I can put it that way without being any more crude. I think that's all it was. He's no good with babies anyway. He did say it wasn't natural and I said there is nothing more natural; suck it up and get over it. [Helen]

AND FINALLY . . .

Overall, it was clear from the data that mixed messages, mixed levels of support, lack of resources can all impact on infant feeding choices and experiences and on mothers' confidence and wellbeing more generally:

I don't think it matters how well informed staff are re Breast feeding /formula – if the manpower is not available then Breast feeding will fail. Early discharge from hospital (before mum's milk has come in), lack of support in the community . . . conflicting advice from well-meaning friends, relatives and even some staff. Unrealistic expectations of what Breast feeding involves. . . . Interesting comment on Women's Hour the other day about a German lady

living in the UK – she assumed she would breastfeed (coming from a culture in Germany where Breast feeding rates are high) but was expecting her first baby while she was in the UK and was exposed to lots of attitudes of ‘what if you fail?’/the concept of failing to breastfeed, which had never occurred to her. These had a profound impact on her confidence and self-esteem which she had to really work through. [R47 G non recorded]

6. CONCLUSIONS, IMPLICATIONS AND RECOMMENDATIONS

Six summary points

1. Training for staff is mixed and this is linked to confidence in supporting women.
2. Women ‘sensed’ the lack of confidence of some staff and this caused anxiety i.e. if the combination of staff on a shift had little experience/knowledge.
3. Women recognised that certain occupation groups had more time and experience to support them i.e. nursery nurses on TCW midwives on NICU
4. The physical environment was an issue for respondents. For example:
 - a. TCW privacy, or not, when expressing and feeding.
 - b. In NICU screens used for expressing or feeding sometimes caused anxiety given that screens are also used when baby is poorly/undergoing a procedure.
5. In TCW formula feed was linked to early discharge resulting in some experiencing subtle pressure to formula feed.
6. Community outreach team very supportive to some and women respondents felt they would have benefited from longer support.

Six recommendations

1. Training needs to be consistent for all grades of staff and a whole day annually is preferred by healthcare professional respondents.
2. Release from service essential to ensure training is undertaken and given the high priority it deserves.
3. Different coloured screens for expressing/feeding AND for procedures would be beneficial and reduce stress for mothers and significant others.

4. Active recruitment of peer supporters with experience of having a baby in NICU.
5. Ensure continued support from peer supporters when moving from breastfeeding to formula feeding.
6. More information related to equipment available in the community on discharge i.e. hospital grade breast pumps.

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Appendix I

Dealing with Complexity: Infant Feeding Choices and Experiences for Mothers with Infants in Neonatal Intensive Care Units and Transitional Care Wards

Questionnaire for Healthcare Professionals (4 pages in total) PLEASE RETURN TO RECEPTION BY 27TH JANUARY 2016

With reference to the WHO Unicef UK Baby Friendly Initiative (BFI) how confident do you feel with reference to the following?:

	Very confident	Fairly confident	Not very confident	Unconfident
General advice for all mothers				
Advice for mothers who breastfeed				
Advice for mothers who formula feed				
Specific advice for mothers with babies in NICU				

Specific advice for mothers with babies in TCW				
--	--	--	--	--

Did you receive BFI training? YES NO Don't Remember

If YES when and how much (e.g. days/hours)?

Who would you ask for help in this area if you needed it?

What is your opinion of the value of BFI training given to healthcare professionals (HCPs)?:

	Very Useful	Fairly Useful	Not very Useful	Not worth doing
General advice for all mothers				
Advice for mothers who breastfeed				
Advice for mothers who formula feed				
Specific advice for mothers with babies in NICU				
Specific advice for mothers with babies in TCW				

Please add comments if you would like to:

Do you think BFI training SHOULD be mandatory?

	YES	NO	COMMENTS
For all grades			
For midwives only			
For midwives and doctors only			
For midwives and nursery nurses only			
For midwives and health care assistants only			
Any OTHER combination			

Please write as little or as much as you like on the following:

Overall views on the barriers, challenges and facilitators (for mothers, babies and healthcare professionals) on the implementation and practice of BFI:

What do you think are the main concerns for mothers and fathers in relation to infant feeding?

Any other issues especially relevant to the support of mothers' (and fathers') infant feeding choices and experiences:

Anything else you would like to add:

Your grade:

Length of overall service:

Time in NICU/TCW:

Many thanks

Liz, Gayle and Heather

Appendix II

Researchers:

Professor Gayle Letherby
School of Health Professions

Dr Elizabeth Stenhouse
School of Nursing and Midwifery

Faculty of Health and Human Sciences
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Tel: (01752) 586703
Mobile To be confirmed

gletherby@plymouth.ac.uk
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Clinical Contact
Mrs Nicky Phillips
Matron,
Maternity Unit, Level 4
Plymouth Hospitals NHS Trust

The normal NHS complaints mechanism is available to if you wish to complain about any aspect of the way you have been approached or treated during the course of this study.

Formal complaints may be addressed to:
Professor Graham Sewell
Associate Dean of Research
Faculty of Health and Human Sciences
Plymouth University, Plymouth, PL4 8AA.
Tel: 01752 588800



Dealing with Complexity: Infant Feeding Choices and Experiences for Mothers with Infants in Neonatal Intensive Care Units and Transitional Care Wards

Ethnographic Observations:

Healthcare Professionals

Information Sheet

We would like to invite you to take part in a study exploring infant feeding when the baby has been cared for in Neonatal Intensive Care Unit (NICU) or on the Transitional Care Ward (TCW).

The study will take place between October and December 2015.

Researchers from Plymouth University are carrying out this study which is funded by NHS Plymouth Public Health.

The study has several purposes:

To gain an understanding of the mothers experiences of infant feeding

To investigate the challenges of infant feeding in NICU and TCW

Below are some questions often people ask about research and our answers.

If you have any other questions or concerns, please don't hesitate to contact one of the project team, listed on the back of this leaflet.

1. Who has given ethics approval for the study?

The NHS Ethics Committee for South West Cornwall and Plymouth has reviewed the study and given ethical approval (number to be inserted following approval)

2. Why may I be invited to take part?

You are a healthcare professional working on NICU or TCW. Your participation is entirely voluntary, but we hope you can help us by taking part.

3. What would be involved in taking part?

As part of the project we would like to observe a range of staff in their daily work, to help us understand better your interaction with mothers their baby's and families. The observation arrangements would be agreed with you in advance and would involve one of our research team unobtrusively watching you at work. With your permission she would make notes about what she is seeing. If you do decide to take participate then we would contact you and agree a time for this observation.

4. What if I change my mind?

It is your right at any time to ask the researcher to leave to discontinue your participation. Should you choose to discontinue your participation, you do not have to give an explanation.

5. Will taking part benefit me?

We hope the findings of our research will contribute to a better understanding of infant feeding and therefore improve care provided to mothers. We will present the findings to all staff within the trust.

6. Are there any disadvantages in taking part?

You may feel uncomfortable having an observer watching aspects of your work. We do not expect anyone to suffer any harm or injury as a result of participating in this study.

7. Will what I say be confidential?

Yes, all information collected related to you and the mother/baby you are caring for will be anonymised and kept strictly confidential. Any notes we make will be given a code number to ensure they are not traceable to any individual. All notes will be stored securely and only accessible by the research team.

Researchers:

Professor Gayle Letherby
School of Health Professions

Dr Elizabeth Stenhouse
School of Nursing and Midwifery

Faculty of Health and Human Sciences
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**Dealing with Complexity:
Infant Feeding Choices**

Ethnographic Observations:

Mothers Information Sheet

Below are some questions often people ask about research and our answers.

If you have any other questions or concerns, please don't hesitate to contact one of the project team, listed on the back of this leaflet.

1. Who has given ethics approval for the study?

The NHS Ethics Committee for South West Cornwall and Plymouth has reviewed the study and given ethical approval (number to be inserted following approval)

2. Why may I be invited to take part?

You are the mother of a baby cared for on NICU or TCW. Your participation is entirely voluntary, but we hope you can help us by taking part.

3. What would be involved in taking part?

As part of the research we would like to observe a range of staff in their daily work, to help us understand better issues related to infant feeding.

This work involves observing the staff caring for you and your baby. This will mean giving one of our researchers' permission to observe your babies care. She will not ask you or the staff any questions but with your permission she would make notes of what happens. It is your right to ask her to leave, to stop taking notes, or to ask her to explain the study further.

4. What if I have any concerns?

If you think of questions about the study or feel anxious please feel free to contact the research team using the contact details on this leaflet. We will also give you contact details of the local support group Plymouth Precious Poppets.

5. What if I change my mind?

It is your right at any time to ask the researcher to leave to stop your participation. Should you choose to discontinue your participation, you do not have to give an explanation. The care for you and your baby will not be affected.

6. Will taking part benefit me?

Perhaps not directly but we hope the findings will lead to a better understanding of the information given related to infant feeding and therefore help future mothers and babies.

7. Are there any disadvantages in taking part?

It may be uncomfortable having someone watching the staff caring for your baby however we do not expect anyone to suffer any harm or injury as a result of participating in this study.

8. Will what I say be confidential?

Yes, all information collected related to your baby you are caring for will be anonymised and kept strictly confidential.

Researchers:

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School of Health Professions

Dr Elizabeth Stenhouse
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**Dealing with Complexity:
Infant Feeding Choices**

Mothers Interviews

We would like to invite you to take part in a study exploring infant feeding when the baby has been cared for in Neonatal Intensive Care Unit (NICU) or on the Transitional Care Ward (TCW).

The study will take place between October and December 2015.

Researchers from Plymouth University are carrying out this study which is funded by NHS Plymouth Public Health.

The purpose of this study is to gain a better understanding of issues related to infant feeding when the baby is or has been cared for in the Neonatal Intensive Care Unit (NICU) or Transitional Care Ward (TCW)

We would therefore like to hear your views on the issues important to you related to infant feeding.

Below are some questions often people ask about research and our answers.

If you have any other questions or concerns, please don't hesitate to contact one of the project team, listed on the back of this leaflet.

1. Who has given ethics approval for the study?

The NHS Ethics Committee for South West Cornwall and Plymouth has reviewed the study and given ethical approval (number to be inserted following approval)

2. Why have I been chosen to take part?

As you are a mother who is or has had a baby cared for in NNICU or TCW within the last 12 months we would like to talk to you about your experiences of infant feeding.

3. What would be involved in taking part?

We would like to invite you to take part in a confidential interview. The interview will address the issues previously mentioned but will be flexible to allow you to talk about the issues important to you.

The interview will take about 30mins or more if you would like at a time and place convenient to you and with your permission will be recorded. If you wish you can have a family member or friend with you.

4. What if I change my mind?

You can withdraw from the study at any time without giving an explanation and this will not affect your or your babies care if still in hospital.

5. Will taking part benefit me?

Perhaps not directly but we hope the findings of our research will contribute to a better understanding of infant feeding and therefore help future mothers and babies.

6. What if I have any concerns?

If you think of questions about the study or feel anxious please feel free to contact the research team using the contact details on this leaflet. We will also give you contact details of the local support group Plymouth Precious Poppets.

7. Are there any disadvantages in taking part?

We recognise that helping us with the study will take up a little of your time. We will do our best to minimise any inconvenience to you by ensuring that you take part at a place that suits you best.

We do not expect anyone to suffer any harm or injury as a result of participating in this study.

8. Will what I say be confidential?

Yes, nothing you say will be revealed to hospital staff or to anyone outside the research team in a way that could identify you. The recordings of the interviews will be stored securely and be made accessible only to the research team. The tapes will be destroyed at the end of the study.

With your permission we will inform you GP and Health Visitor of your involvement in this study.

9. How and where will the results be published?

We plan to publish the results in academic and professional journals and at conferences.

Appendix III

Mothers Name (anonymised)	Baby's name (anonymised)	Baby's Date of Birth	Mode of Delivery	Baby reason for admission	Gestation at birth	Initial feeding method	Interview Venue
Bella	Jack	03/01/2013	Emergency CS	Extreme prematurity	29/52	Expressed breast milk	Community
Felicity	Amanda	26/02/2015	Vaginal Birth	Postnatal collapse	38+1/52	Expressed breast milk	Community
Helen	Amy	24/08/2014	Emergency CS	prematurity	31+5/52	Expressed breast milk	Community
Brigit	Abigail and Rowena	13/06/2015	Vaginal and Forceps	Thermal care and blood glucose monitoring	33+6/52	Formula	Community
Ellie	Adele	16/01/2016	Elective CS	Low birth weight and prematurity	31+2/52	Expressed breast milk and formula	NICU
Laura	Angus	19/12/2013	Emergency CS	Maternal placental abruption	39+1/52	Expressed breast milk	Community
Lisa and Pete	Aaron	17/01/2016	Vaginal Birth	Prematurity and respiratory distress	34+1/52	Expressed breast milk and formula	TCW
Daphne and Charles	Poppy	20/01/2016	Vaginal Birth	Prematurity and blood glucose monitoring	35/52	Formula	TCW
Lois and Paul	Graham	15/1/2016	Ventouse	Low birth weight Raised Bilirubin	37+2/52	Breast feeding	TCW
Kitrina	River	18/01/2016	Emergency CS	Suspected sepsis	41/52	Breast feeding	TCW
Pippa and Mark	Zack	07/01/2016	Emergency CS	Prematurity	32+4/52	Formula	TCW
Sophie	Ben	04/01/2016	Vaginal birth	Prematurity	33+4/52	Formula	TCW
Sally	Charlotte	17/06/2014	Emergency CS	Respiratory distress	36+5/52	Expressed breast milk	Community
Natalie	Jago	29/06/2014	Emergency CS	Infection risk	35+5/52	Expressed breast milk and formula	Community

Phoebe and Callum	Danny	23/04/2 013	Vaginal birth	Prematurity	33+2/52	Expressed breast milk and formula	Community
Ruby	Fiona and Trudi	10/01/2 016	Emergen cy CS	Prematurity, respiratory distress and blood glucose monitoring	32/52	Expressed breast milk	NICU
Hayley	Joel	21/06/2 016	Emergen cy CS	Extreme prematurity and respiratory distress	29+2/52	Expressed breast milk	NICU
Vivienne and Stu	Keith	25/01/2 016	Vaginal birth	Respiratory distress	37+2/52	Expressed breast milk and formula	NICU

Appendix IV

The Ones That Need It The Most: Factors Influencing Breastfeeding Initiation in the Neonatal Intensive Care Unit (NICU) and the Transitional Care Ward (TCW)

Student ID: 10437586

PLYMOUTH
UNIVERSITY
PENINSULA
SCHOOLS OF MEDICINE & DENTISTRY

Background

The average breastfeeding initiation rate for mothers in England is 73.8%.¹ In Plymouth Hospitals NHS Trust, a rate of 74.9% is being achieved.¹

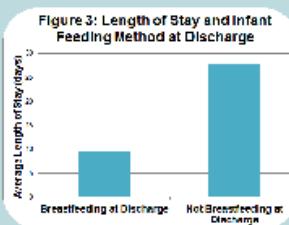
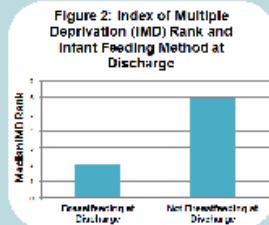
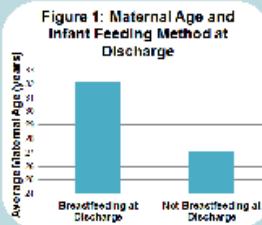
Consideration of factors that may influence breastfeeding initiation is required and data exclusive to the NICU and TCW centres at Derriford Hospital may identify areas for improvement in clinical care.

Aim

To explore the effect of demographic and situational factors on breastfeeding initiation rates in NICU and TCW. Additionally, to estimate breastfeeding rates at delivery and discharge for Derriford Hospital's NICU and TCW.

Results

- The breastfeeding rates in NICU and TCW were 72.2% at delivery and 50% at discharge ($n = 18$).
- 88.9% of the cohort (mothers) intended to breastfeed ($n = 16$). Of these, 81.3% breastfed at delivery ($n = 13$), and 56.3% were still breastfeeding at discharge ($n = 9$).
- Figure 1 illustrates the 5 year difference in the average age of mothers that continued to breastfeed at discharge (32.1 years) compared to those that did not (27.1 years).
- Figure 2 demonstrates that mothers who breastfed at discharge were of a lower socioeconomic status (Median Index of Multiple Deprivation [IMD] Rank = 2) than mothers who continued breastfeeding (Median IMD Rank = 6).²
- Figure 3 shows how mothers who did not breastfeed at discharge had a longer average NICU/TCW stay (27.9 days) compared to those who breastfed (9.6 days).



Method

Notes were requested for 50 NICU and 100 TCW patients, reflecting the 1:2 admission ratio ($n = 150$). However, a NICU/TCW 'patient' essentially constitutes both infant and mother, so $n = 300$.

Data related to maternal factors, delivery, admission and feeding intention/method were extracted and analysed.

Due to time constraints and availability of patient notes, 18 mothers were included in the analysis.

Discussion

The breastfeeding rate in this cohort is marginally below the national and Plymouth averages, however these results are exclusive to NICU and TCW, where the nature of having a vulnerable infant necessitating a prolonged hospital stay is known to affect breastfeeding initiation.³

This audit has identified demographic (mother's age and socioeconomic status) and situational (length of stay) variables that may affect the sustainment of breastfeeding. A review of the facilities available and the education provided to mothers could increase the percentage of mothers who continue breastfeeding until discharge.

Two cases highlighted how length of stay affects feeding method at discharge. Both mothers initially intended to breastfeed and did so at delivery, however after 93 and 94 day neonatal admissions respectively, were not breastfeeding at discharge. Complementary qualitative data would be useful in identifying factors that influenced these changes in feeding method.

The limited size of the cohort reduces the robustness of these results and limits their ability to be generalised to a wider population. A larger sample size is required to confirm the associations that have been made in this audit.

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Appendix V

NB: written during analysis so does not completely relate to analysis above.

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**Dealing with Complexity: Infant Feeding Choices and Experiences for Mothers
with Infants in Neonatal Intensive Care Units and Transitional Care Wards**

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Background

In 2009, WHO/UNICEF published BFI: revised, updated, and expanded for integrated care, which identified the need for the guidelines to include NICU and articulated the need for understanding this population, the unique challenges they face initiating and maintaining the breastfeeding relationship, offering guiding principles for all NICUs.

Aim

To explore the knowledge, perceptions and experiences of infant feeding of women with infants in NICU and TCW.

Objectives

1. To explore mothers' knowledge and understanding of infant feeding
2. To gain an understanding of mothers experiences of infant feeding
3. To investigate the challenges of infant feeding in NICU and TCW

Methods

Data was collected via in-depth qualitative interviews with 23 women/significant other 13 women (single interviews): five partners (dyad interviews): eight interviews conducted in the community: four in NICU: six in TCW. Interviews were digitally recorded, transcribed verbatim. Analysis undertaken by sub-groups of the research team, ongoing, grounded in the experience of respondents and examined for key similarities and differences

Findings

Three main and three subthemes were identified:

THE JOURNEY

- the pregnancy/post-birth timeline
- the physical ill/health journey (mother and baby)
- the embodied experience relating to the journey

SKILLS/SUPPORT/SPACES

- the skill set (professionals) AND the experience/confidence of mothers and fathers
- continuum of care OR not
- support (formal and informal)

PRESSURE, PROPOGANDER and PLEASURE

- value OR not of BFI
- guilt (for all 'the non-discriminatory nature of guilt')
- the embodied experience i.e. skin-to-skin sensuality, sexuality, 'my body has let me down'.

Conclusions

Mothers expressed infant feeding support varied among midwives and healthcare professionals with conflicting and unsupportive advice and practices affecting infant feeding choices and experiences.

Application to Practice

Mothers experience exceptional challenges with infant feeding when the infant is in NICU and TCW. Midwives and healthcare professionals need consistent training to ensure appropriate support is given to mothers, their babies and significant others.