

**POWERLESS RESPONSIBILITY: WOMEN'S EXPERIENCES
OF CARING FOR THEIR LATE PRETERM BABY/BABIES**

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ABSTRACT

Powerless Responsibility: Women's experiences of caring for their late preterm baby/babies

This study explores the experiences of women who are caring for late preterm baby/babies (LPBs). These women's experiences are especially relevant to examine, as the number of babies born late preterm is rising. Traditionally mothers and their LPBs have been studied under the umbrella of the general preterm infant population, with all experiences extrapolated from within this group. Whilst there is a growing body of literature related to late preterm babies, the focus is on physiology and physical needs. There is minimal research exploring women's experiences of caring for a late preterm baby and their views largely unknown.

My aim was to privilege women's experiences, therefore a feminist approach to research was utilised. A feminist lens offered me an opportunity of understanding the world of women who care for LPBs, and what I learned from their experiences. To obtain in depth perspectives, individual qualitative interviews in two phases were carried out, with a purposefully selected sample of fourteen women who were caring for a baby or babies within the late preterm gestation in South West England. Template Analysis linked to Birth Territory Theory (BTT) was carried out to identify key issues and experiences of women.

The findings indicate women who become mothers' of late preterm babies have a complex journey. It is one which begins with separation, with babies being cared for in unfamiliar and highly technical environments where the perceived experts are healthcare professionals. Women's needs are side-lined in favour of their baby/babies, and they are required to mother with 'powerless responsibility'. Institutional and professional barriers to mothering/caring are numerous.

The study recommends organisations and healthcare professionals listen to women, hear their stories and use their experiences of mothering/caring to direct developments in practice. Professionals need to accept late preterm babies do not belong to an institution and to the professionals that work within it, but instead

recognise a mother's prime relationship is with her baby and thus work with women to facilitate autonomous mother-work.

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Abbreviations

| |
|---|
| Artificially rupturing a woman's membranes (ARM) |
| Assisted reproductive technology (ART) |
| Association for the Improvements in the Maternity Services (AIMS) |
| Birth Territory Theory (BTT) |
| Black and minority ethnic (BME) |
| Blood pressure (BP) |
| Body Mass Index (BMI) |
| Caesarean Section (CS) |
| Centre for Maternal and Child Enquiries (CMACE) |
| Care Quality Commission (CQC) |
| Cardiotocography (CTG) |
| Care Of the Next Infant (CONI) |
| Computer-assisted qualitative data analysis software package (CAQDAS) |
| Department of Health (DH) |
| Day Assessment Unit (DAU) |
| Disintegrative power (DP) |
| Edinburgh Postnatal Depression Scale (EPDS) |
| Emergency departments (ED) |
| Family centred care (FCC) |
| Friends and Family Test (FTT) |
| General anaesthetic (GA) |
| General Practitioners (GPs) |
| Grounded theory (GT) |
| Health Visitor (HV) |
| Induction of Labour (IOL) |
| Kangaroo care (KC) |

Labour wards (LW)

Late preterm baby/babies (LPBs)

Length of stay (LOS)

Local co-ordinator (LC)

Local neonatal unit (LNU)

Midwifery-led units (MLUs)

Naso-gastric tube (NGT)

National Audit Office (NAO)

National Childbirth Trust (NCT)

National Federation of Women's Institutes (NFWI)

National Health Service (NHS)

National Institute for Health and Care Excellence (NICE)

NHS Litigation Authority (NHS LA)

National Maternity Review (NMR)

National Perinatal Epidemiology (NPEU)

National Service Framework for Children, Young People and Maternity Services (NSF)

Neonatal intensive care unit (NICU)

Non-evidenced based (NEB)

Non-governmental organisations (NGO)

Nursing and Midwifery Council (NMC)

Office of National Statistics (ONS)

Operative delivery (OD)

Poppy Steering Group (PSG)

Postnatal ward (PNW)

Pre-labour rupture of membranes (PPROM)

Preterm labour (PTL)

Psychological Stress Measure (PSM)

Randomised controlled trials (RCT)

Respiratory Syncytial Virus (RSV)

Skin to skin (S2S)

Special care baby unit (SCBU)

State-Trait Anxiety Inventory (STAI-Y)

Sudden Infant Death (SID)

Supervisor of Midwives (SoM)

Template Analysis (TA)

Transitional units (TU)

United Kingdom (UK)

United States of America (USA)

World Health Organisation (WHO)

Wrapped holding (WH)

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INTRODUCTION TO THE RESEARCH

This study explores the experiences of women caring for late preterm baby/babies (LPBs). These women's experiences are especially relevant to examine as the number of babies born late preterm is rising. In addition, there is currently a dearth of research concerning the experiences of women who birth babies at the late preterm gestation. Late preterm babies are those who are born between 34^{0/7} and 36^{6/7} weeks gestation.

Women in preterm labour (PTL) face an unknown future, this includes uncertainty over whether their pregnancy continues to Term or whether they give birth early not knowing the extent or risk of complications their baby may experience. Women who become mothers of preterm babies have a complex journey, as for many; mothering begins within an environment which is unfamiliar and highly technical and where the perceived experts are healthcare professionals. The meaning of motherhood is a concept that requires further exploration and is discussed in more depth in Chapter 2, 2.1.2.

Whilst there has been a drive to identify service users' experiences in all areas of care, including maternity, this has tended to be achieved through the use of large scale quantitative surveys. These do not allow the in-depth experiences of women to be explored, and presuppose what matters in quality terms, rather than allowing women to determine this. In addition, they have not tended to separate out preterm birth experiences from more general maternity experiences. This leaves a significant gap in what is known about women's perspectives.

Qualitative research exposes these experiences in much more detail with the bulk concentrating mainly on preterm babies born in categories known as 'very preterm' (<32 weeks gestation) and 'extremely preterm' (<28 weeks gestation). However a focus that is becoming increasingly important are babies who are born late preterm as this group accounts for the largest percentage within the spectrum of prematurity (80%) with their numbers rapidly rising (Cheong and Doyle 2012). Many North American papers publishing on preterm birth rates have one common factor: the rise of preterm births during the past twenty or more years is due to a

rise in late preterm births (Davidoff et al. 2006; March of Dimes 2006; Engle et al. 2007; Rojas 2007; Santos et al. 2008; Kramer 2009; Martin et al. 2009; Cheong and Doyle 2012; Shapiro-Mendoza and Lackritz 2012; Barfield and Lee 2014).

In the United Kingdom (UK) the picture is not clear as to whether the moderate to late preterm gestation range (between 32 and 36 weeks gestation) has increased, as nationally, data on gestational age is not regularly available as it is not routinely recorded at the registration of live births (Tucker and McGuire 2004; Moser et al. 2007; Dattani et al. 2012). However a recent publication reporting on gestation-specific infant mortality for 2010 in England and Wales revealed seven percent of all live births were preterm with the majority of births (5.9%) occurring within the moderate to late preterm range (Office for National Statistics 2013). Whether these statistics represent a rising trend is not known as preterm statistics in the UK do not make a distinction between babies classed as late and moderate preterm (Office for National Statistics 2013). The true number of late preterm births therefore is hidden, as they are not identifiable as a separate subset of the preterm range (Jensen 2011).

Whilst there is a growing body of literature related to LPBs, this tends to focus on the physiological and physical needs of babies born at this gestation. There is minimal research concerning women's experiences of LPBs, therefore their views of caring for this sub-group of preterm baby is largely unknown. The literature suggests the needs of these babies are unique, however there is no consensus in which environment they should be cared for. Furthermore, both parents and healthcare professionals appear to underestimate their care needs and treat these babies as 'near normal' (Khashu et al. 2009) to the baby's detriment (Pados 2007; Ramachandrappa and Lucky 2009; Wright et al. 2012). The emphasis in the literature is, however, almost always on the baby. Many publications are scientifically 'late preterm centric' with parents hardly mentioned or falling into a category of 'What Parents of Near Term Infants Need to Know', or exhorting healthcare professionals to be the advocate for LPBs, all of which point to health professionals leading the way towards knowledge production.

The obvious question was 'where is the woman?' Women appear in the literature but only as 'problems' to be managed so reasonable outcomes can be achieved for the unborn/born baby. We do not know about the human experience for the mother, the meaning of a late preterm baby to her and we do not know anything about the context or the individual circumstances of women and their families. This struck me particularly when I critiqued the two neonatal surveys 'Parents experiences of neonatal care' (Howell and Graham 2011; Burger 2015) which, despite parents being involved in the design, formulation and refinement of questions, remains largely a traditional positivist method for surveying the views of large cohorts of parents. Narrative feedback from the 2015 survey is available but only to individual trusts involved within the survey. The neonatal surveys, whilst entirely appropriate and necessary, have a major flaw in my view, as experiences of mothers and fathers are combined when reporting on findings and women appear to experience neonatal care differently to fathers. The majority of respondents were women, in what appears to be traditional relationships. It is not discernible within the survey as to whether any of the women participants were in same sex relationships.

As my aim was to privilege women's experiences, a feminist approach to research was utilised since my interests in exploring women's voices was based on feminist values. A feminist lens offered me an opportunity of understanding the world of women who care for LPBs, and what I learned from these women's experiences (Brooks 2007). Throughout my thesis it is acknowledged that diversity in relationships is important although the focus was on women regardless of their status. The aim of this study was to give voice to the mothers as 'producers of knowledge' (Jackson and Mannix 2004).

Therefore this research was developed with the following aims:

Main research question:

- What are the experiences of women who are caring for a late preterm baby?

Secondary research questions:

- What are the early postnatal experiences (i.e. first few days after birth) of women who are caring for their late preterm baby (LPB) by considering some of the following issues:
 - To document the current situation in relation to care on the postnatal ward or special care baby unit
 - To document the current situation regarding the discharge process
- What are the later postnatal experiences (i.e. 5-6 weeks after birth) of women who are caring for their LPB's by considering some of the following issues:
 - To identify what support was available in the community and who provided this support
 - What are the needs of these women especially if discharged home early (less than 24 hours post birth).

To obtain in-depth perspectives, individual interviews were used in two phases, with a purposefully selected sample of fourteen women who were caring for a baby or babies within the late preterm gestation. Template analysis (TA) linked to Birth Territory Theory (BTT) was carried out to identify key issues and experiences of women. In addition, adopting a feminist lens enabled me to examine issues of power and dominance evident within environments where women were required to care for their late preterm babies (Fahy and Parrat 2006). Approaching the data from this perspective reversed "the hierarchy traditional in medically dominated maternity settings, privileging the experiences of women" over doctors, midwives and neonatal nurses (Jenkinson, Kruske and Kildea 2017).

This thesis commences with an introductory chapter which outlines my research study. It is then followed by a chapter which seeks to explore women's experiences of maternity services. It is divided into two sections. Section one provides an overview of national patient surveys whilst section two explores what is known about women's experiences of maternity care in general. It then critiques overall experiences by examining elements of maternity experience that are considered

important for women: choice, continuity and involvement in care. Chapter 2 is centred on women and preterm babies. It includes a mini review of the literature to determine whether any surveys have specifically examined women's maternity services experiences from a preterm perspective. The findings from the literature review explore women's experiences of preterm labour from two perspectives: at home and as an inpatient in hospital. The chapter concludes by examining parents experiences of neonatal care by exploring two national surveys (Howell and Graham 2011; Burger 2015). Chapter 3 provides insight into late preterm birth by considering definitions, rates of late preterm birth, potential factors contributing to the rise in late preterm births and problems associated with being born at this gestation. It is followed by Chapter 4 which is a further literature review to determine whether research has been undertaken exploring women's views of caring for their LPBs. The findings from the literature review are explored within three main activities: breastfeeding, kangaroo care (KC) and psychological/emotional issues.

Chapter 5 considers feminism and its' application to my research including research methods and methodology. My positioning both from a personal and professional perspective is explored within this chapter. The findings and discussion chapters follow (6&7) and the thesis concludes by identifying original contributions, recommendations for practice and suggestions for further research. Included in this final chapter (8) is a section on reflexivity which explores my learning throughout the research process. My study has enabled women to identify their experiences of caring for a late preterm baby and they may benefit from knowing that their experiences were similar but in other instances different.

CHAPTER 1 WOMEN'S EXPERIENCES OF MATERNITY SERVICES

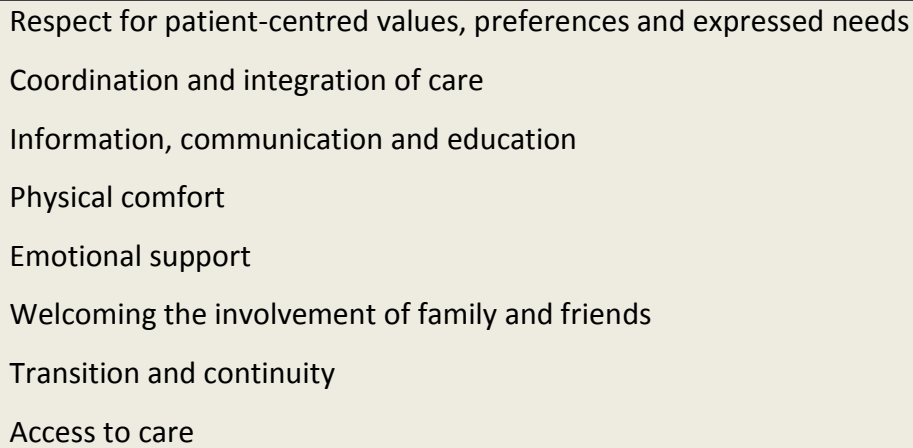
Introduction

This chapter seeks to explore women's experiences of maternity services. It is divided into two sections: section one provides an overview of National Health Service (NHS) patient experience surveys, and section two explores women's experiences of maternity care by examining large scale maternity services surveys. Women's overall maternity experiences are then critiqued by examining choice, continuity of care and women's involvement in care. The chapter concludes by highlighting the many factors that impact on the quality of women's maternity experience, including the institution where the majority of United Kingdom (UK) births occur.

1.1 OVERVIEW OF PATIENT EXPERIENCES SURVEYS

The NHS provides care for more than one million UK residents every day (de Silva 2013) and ensuring that user experience informs the delivery and quality of healthcare, remains an important priority for the NHS and the government of the day (NHS Confederation 2010; Blunt 2014). A core component of high quality care revolves around the patient experience, with evidence indicating organisations who place a priority on providing an excellent quality experience for patients have better outcomes, especially in areas such as mortality and patient safety (NHS Confederation 2010).

Key drivers which have placed a priority on listening, collecting and acting on patient experience include the Darzi Review of the NHS and the NHS Constitution (Department of Health (DH) 2008), mandated by the Health and Social Care Act 2012 (DH 2012). These lawfully require healthcare commissioners and providers to enhance the quality of healthcare by focusing on improving the patient experience (DH 2011a). The DH (2011a) has defined eight core concepts which are critical to a good patient experience:

The diagram consists of a light beige rectangular box with a thin black border. Inside the box, eight text items are listed vertically, separated by line breaks. The items are: 'Respect for patient-centred values, preferences and expressed needs', 'Coordination and integration of care', 'Information, communication and education', 'Physical comfort', 'Emotional support', 'Welcoming the involvement of family and friends', 'Transition and continuity', and 'Access to care'.

Respect for patient-centred values, preferences and expressed needs
Coordination and integration of care
Information, communication and education
Physical comfort
Emotional support
Welcoming the involvement of family and friends
Transition and continuity
Access to care

Figure 1-1: NHS Experience Framework

Patient experience therefore, can encompass both an experience of care and feedback about those experiences (satisfaction) (Ahmed et al 2014) and strategies for improving experiences when patients are sick and unwell within institutions that are under pressure to maximise efficiencies have become especially relevant (Goodrick and Cornwell 2008). Studies have demonstrated that anxiety, fear and poor communication (a core concept of the NHS Experience Framework) between patients and healthcare professionals delays recovery, including impacting on emotional well-being (Cole-King and Harding 2001; Rosenblatt and Myers 2016; Shaohai 2017).

Patient surveys used by the NHS are typically described as ‘satisfaction surveys’ which appears to be an inaccurate description (Goodrick and Cornwell 2008) since ‘satisfaction’ as a concept seems broad and imprecise (Coulter et al. 2009). For example, does it refer to information gathered after patients have experienced an episode(s) of care (what happened to them) or could experience be utilised to illustrate events that occurred and the degree to which people’s needs are met, while satisfaction could be associated how people feel about those events (de Silva 2013). A recent literature review appears to confirm this ambiguity. Al-AQBri and Al-Balushi (2014) explored patient satisfaction surveys as a tool towards quality improvement and discovered there was no consensus on how to define the concept of satisfaction. This is illustrated quite vividly by research undertaken by Fitzpatrick and Hopkins (1983), which sought to explore patients’ experiences whilst attending a neurological outpatient clinic. Although the study appears dated, its’ analysis

revealed that whilst several positive and negative comments were voiced by the participants about many aspects of their consultations with the neurologist, they were rarely communicated in terms of satisfaction or dissatisfaction, findings which appear contemporary. This highlights the weakness of undertaking 'surveys' since they "force patients to generalise in order to rate their own experience" and limiting responses to 'always', 'sometimes', 'no/don't know', 'yes', definitely 'yes to some extent' and so on (Goodrick and Cornwell 2008, p.17), requires patients' to reflect on their experience 'as a whole' and prioritise what should be reported. Despite the criticisms and limitations of satisfaction surveys, they have a role to play (such as tracking of trends and comparing results between different hospitals) in conjunction with other tools which can capture the 'person' in the patient and which brings the experience alive (van Teijlingen et al. 2003; Goodrick and Cornwell 2008).

Understanding a patient's experience in hospital is therefore complex, which explains why many NHS hospitals utilise a range of sources to identify and improve the experiences of users, such as patient stories, surveys, complaints/compliments, and Friends and Family Test (FTT) to name but a few (Goodrick and Cornwell 2008; de Silva 2013). None of these methods are ideal, as each particular methodology has its own advantages and disadvantages, and a 'one size fits all' approach to gathering and interpreting information regarding the patient experience will not suit the many varied contexts in which NHS healthcare is provided (de Silva 2013). Thus, it is almost impossible to generalise about patient experiences of care as many influences impact on individual experiences, such as organisational, human and political factors and analysis of evidence and interventions which shape and improve experience remain undeveloped (Goodrick and Cornwell 2008; de Silva 2013).

1.1.1 National patient surveys

The most common form of capturing patient experience of healthcare within the NHS is through the use of national surveys (Black and Jenkinson 2009). Organisations such as the Care Quality Commission (CQC) (the independent

regulator of health and social care in England) are responsible for laying down the survey methodology and for the questions it wants answering, although hospitals are free to add any of their own (Goodrick and Cornwell 2008). For example, in preparation for an amended 2015 survey of women's experiences of maternity care, the CQC consulted with key stakeholders (NHS England, DH, and the National Perinatal Epidemiology Unit (NPEU) concerning the scope of the survey and policy priorities (Graham et al. 2016). It is not clear whether women had any input into the redesign of the questionnaire which was based on previous surveys, to determine whether it reflected their priorities (Richards and Coulter 2007), although it appears a sample of women who had given birth within the previous year were used to 'cognitively' test it (Graham et al. 2016).

Generally, patient experience surveys ask patients who recently underwent an episode of care from the NHS to recollect and describe their encounter with the service (Richards and Coulter 2007). Patients are therefore randomly selected and sent a postal questionnaire to complete (Richards and Coulter 2007; Goodrick and Cornwell 2008). Common limitations of questionnaire surveys revolve around its administration, data entry and expertise around statistical packages for analysis, but when considering users of healthcare services, surveys are not suitable for those with low literacy levels, patients with language barriers (De Silva 2013), cognitive limitations and mental illness (Gayet-Ageron et al. 2011). These patients' views would not be represented when results are interpreted and their experiences would be unacknowledged or unknown when contemplating service improvement (Gayet-Ageron et al. 2011). Additionally, response rates vary, ranging from between 38% and 75% (Sheldon et al. 2007; Goodrick and Cornwell 2008) which calls into question selection bias and validity of results (Gayet-Ageron et al. 2011). However, despite the recognised drawbacks, survey findings reveal, on the whole, that most patients as users of NHS services are positive about their care in hospital and of the NHS as a whole (Goodrick and Cornwell 2008). As positive as these results are, they need to be "interpreted cautiously" (Goodrick and Cornwell 2008, p.11), for example, when questioned on particular aspects of their treatment and the

specificity around processes of care, the same patients reported problems (Goodrick and Cornwell 2008).

As the NHS is committed to empowering patients to take more control over their own care and treatment (NHS England 2016) it is worth considering whether survey findings over recent years reflect a more patient-focused NHS. A report compiled by Richards and Coulter (2007) examined data from an accumulation of 26 national patient surveys undertaken in England between 2002 and 2007, in which nearly one and a half million NHS patients reported on their experiences of care. The year-on-year results enabled Richards and Coulter (2007) to examine whether the NHS has become more 'patient centred'. In addition, the researchers wished to gauge whether government's goal of a patient-centred service was within sight.

The original patient experience surveys measured actual experience; including dimensions of care considered most important by patients see Figure 1-2. If all of the patient identified dimensions are working well, then care can be said to be "truly patient-centred" (Richards and Coulter 2007, p.9). Re-examination of survey data from a range of services provided by the NHS such as primary and secondary care revealed that, whilst NHS care has improved significantly in many key areas, with most patients being thankful for the care they received, the NHS as a whole "is still far from patient-centred" (Richards and Coulter 2007, p.2). An earlier review by Coulter (2005), which explored trends in patient experiences of the NHS, revealed similar findings, which suggests that in two years, patient centred care had improved, albeit slowly, although the overall governmental goal had not been achieved (Richards and Coulter 2007).

- Fast access to reliable health advice
- Effective treatment delivered by trusted professionals
- Involvement in decisions and respect for preferences
- Clear, comprehensive information and support for self –care
- Attention to physical and environmental needs
- Emotional support, empathy and respect
- Involvement of, and support for family and carers
- Continuity of care and smooth transitions

(Richards and Coulter 2007)

Figure 1-2 Eight dimensions of care patients consider most important

There were significant improvements in waiting times to access specialist help (secondary care) although access to General Practitioners (GPs) had become more difficult, a downward trend that has continued (Richards and Coulter 2007; Stupples 2015). Primary care professionals (psychiatrists, community psychiatric nurses and primary care nurses) retain the confidence and trust of patients, but these values have not extended into secondary care. Confidence and trust in hospital nurses has decreased, with surveys demonstrating quite markedly that availability of nurses to help patients has deteriorated, with nearly half of all patients reporting not enough nurses to meet their needs around care and provision of information (Richards and Coulter 2007). Whilst this could be related to staff shortages, the authors speculate it is more likely nurses are preoccupied with tasks that take them away from direct patient care. In their opinion, as a quality indicator of 'patient experience', task orientated nursing staff do not augur well for a more patient-centred hospital service (Richards and Coulter 2007).

Encouragingly, the interpersonal skills of healthcare professionals ranging across primary and secondary care were positive with upward of 80% of patients reporting they were 'always' treated in a respectful and dignified manner, reflecting an increasing trend in survey findings between 2002 and 2005 (Richards and Coulter 2007). NHS institutions might feel comforted that the overwhelming percentage of patients (80%) 'always' felt they had been treated with dignity and respect, however, considered from an alternative position 80% equates to one in five patients who are not 'always' treated in a dignified and respectful manner, statistics which imply many patients are not at the receiving end of compassionate care (Wood et al. 2015).

All major political parties over recent years have unanimously agreed the NHS should support patient involvement in their care and treatment, as shared decision making between patients and healthcare professionals leads to a more satisfying experience, resulting in patients who are "more likely to choose treatments based on their values and preferences rather than those of their clinician" (Wood, Collins

and Taylor 2015, p.9). The review by Richards and Coulter (2007) and that of Coulter (2005) illustrates NHS clinicians within primary and secondary care continue to apply paternalistic attitudes when approaching care with patients, which in their opinion, demonstrates the NHS is still not moving in the direction of increased patient-centred care.

Whilst these reports were published around ten years ago, a contemporary review by Wood and colleagues (2015) exploring whether the NHS provides person-centred care during 'this parliament' has revealed comparable results. In a 2013 patient survey, over half of patients (56%) reported being involved in decisions about their care and treatment as much as they wanted, which suggests an improvement. Conversely however, the report also revealed more than four in 10 in-patients stated they wanted more involvement in decisions about their care and treatment (Wood et al. 2015), indicating in my view, there is still some way to go towards patient-centred care. A recent perspective by McCrae (2013, p.1125) argues that patient-centred care continues to be "hindered by paternalism and collective organisation" and unless organisations acknowledge the underlying tension that exists between evidence-based practice (objective knowledge) and person-centred care, neither patient nor healthcare practitioner will ever truly feel valued (McCrae 2013). On a positive note, the review by Wood, Collins and Taylor (2015) highlighted the majority of participants who responded to a survey on GP services, rated their GP or nurse as good or very good at involving them in decisions, which suggests relationships within community settings are more 'person-centred' (McCrae 2013).

Other elements noted by Richards and Coulter (2007) which impacted on patient experience related to the environment of care. Many patients complained about noisy wards (patients and staff) and cramped conditions. Others were unhappy at having to share a room/bay and toilet facilities with members of the opposite sex. A research study conducted for the DH by Ipsos/Mori (2007) in which 2,000 members of the public were interviewed on their perceptions of privacy and dignity in hospitals, revealed 65% of people found mixed-sex accommodation as

unacceptable, citing a lack of privacy as their main concern. In addition women, more than men, were concerned with safety and dignity issues. It appears women over the age of 65 were singled out, because in this age group, more women appeared to live alone (divorced/separated/widowed) and were therefore no longer used to living with a member of the opposite sex (Ipsos/Mori 2007). Words such as 'disturbing', 'grossly uncomfortable', 'found it hard' were used by the women when describing mixed-sex accommodation (Ipsos/Mori 2007). The survey does not reveal whether any of the women 'singled out' were living with other women or indeed were in same sex relationships.

The foundation of 'women only' wards in hospital should be provided, not just on the basis that women over a certain age find it 'gross' sharing with men, but because healthcare providers should be mindful that many women, regardless of age, may have experienced male violence (domestic or sexual abuse) and would be just as appalled at having to share with men not known to them. Eliminating mixed sex accommodation has been government priority since 1997 and the present government has pledged to eradicate it completely (DH 2011b). Recent evidence reveals many NHS-funded providers of healthcare hospital sleeping accommodation in England, continue to breach the Mixed-Sex Accommodation (MSA) guidance (occurrences of unjustified mixing) (Government Statistical Service, 2016).

In summary, despite most patients reporting their care as 'excellent' and 'patient satisfaction' with all levels of NHS care at a high, there are significant shortcomings in reaching the government vision of total patient-centred care. Many men and women are still cared for in mixed-sex wards, which do not offer privacy and dignity to either sex (Ipsos/Mori 2007), and in some situations safety may be an issue. Wards are noisy (see Filly et al. 2015), and patients report on average less than five hours sleep per night (Norton et al. 2015). Patient information needs are not always met, and nurses appear to be engaged in activities which are not focused on patients (McCrae 2013). Time pressures impact on healthcare professionals' ability to provide good care, but most of all; patients are still not wholly involved with their care and treatment (Wood, Collins and Taylor 2015). Paternalistic approaches

to care remain evident (Richards and Coulter 2007; McCrae 2013) with patients continuing to indicate through contemporary surveys that they are not involved in decisions as much as they would want (Wood, Collins and Taylor 2015). The “doctor/nurse knows best” culture appears to be “alive and kicking” (Richards and Coulter 2007, p.27). When patient needs around safe effective care, which includes clear information and communication around treatment that promotes respect and dignity are not met, potentially, patients can lose trust in healthcare professionals caring for them, which may impact on their recovery both in the short term and longer (Richards and Coulter 2007; McCrae 2013).

Finally, policy makers and providers of NHS healthcare services in the main, seem committed to listening and acting upon the views and the feelings of patients (Ahmed et al. 2014) despite the “multi-dimensional nature of satisfaction” (Redshaw 2008, p.73) and the intricate associations between expectations, preferences and satisfaction (van Teijlingen et al. 2003). The literature however, appears to concur that multiple approaches to capturing patients’ own experiences of their care has a greater potential in stimulating healthcare providers to improve quality (van Teijlingen et al. 2003; de Silva 2013; Ahmed et al. 2014) rather than just promoting the status quo (van Teijlingen et al. 2003).

1.2 OVERVIEW OF WOMEN’S EXPERIENCES OF MATERNITY SERVICES

Introduction

The previous section clearly highlighted that the NHS, as a provider of care, still has some way to go before total patient-centred care is achieved. The following section will explore women’s experiences of NHS maternity services, because although women of all ages are users of the NHS and its many services, only pregnant women access maternity services. It is unique, in that it supports women who are experiencing a normal physiological process (pregnancy) (Committee of Public Accounts 2014), since most remain well throughout their pregnancy and childbearing experience (van Teijlingen 2015). Therefore it is worth considering whether women’s experiences of maternity services surveys in England

demonstrate similar outcomes to general patient experiences (Goodrick and Cornwell 2008).

I will begin by providing an overview of the context in which women experience maternity care, following which, I will explore large scale surveys undertaken by the various governmental agencies such as the Health Commission (now known as the CQC), and the NPEU, a research unit based at the University of Oxford which receives funding from a variety of sources such as the Department of Health Policy Research programme and other agencies. In addition, I will also examine smaller studies such as those undertaken by the National Federation of Women's Institutes (NFWI), the National Childbirth Trust (NCT) (postnatal experiences) and the Dignity survey, which specifically surveyed women's experiences of dignity during childbirth. These surveys explore distinct aspects of maternity services and provide different perspectives, although there are some overlaps and they are carried out at different times. Thus, comparing findings from across these surveys may provide a more detailed overview of women's experiences than each individual survey would. By the end of the chapter you will have an understanding of women's experiences of maternity services and the many factors impacting on experience.

1.2.1 Context of maternity care

Women who access maternity services when pregnant will receive most of their care from midwives, with very little input from doctors, or as and when it is needed. The majority of midwives in the UK work within the NHS, a "complex, hierarchically structured organisation" (Pollard 2011, p.613) where they are required, as NHS employees, to adhere to policies/guidelines/protocols devised, dictated and underpinned by medical and/or management values and beliefs, as opposed to midwifery philosophies of care (Parry 2008; Pollard 2011). The essence of maternity care is situated between two distinct philosophies of care, each with its own "group of caregivers" (Pollard 2011, p.612). The social 'female' model of childbirth where pregnancy is a normal physiological life event (most pregnant women require little or no medical intervention until proven otherwise), is mainly subscribed to by midwives (MacKenzie Bryers and Van Teljingen 2010) and the other more dominant

ideology, the medical, scientific and 'male' model of childbirth, which only sees pregnancy and birth as normal retrospectively, has overwhelmingly been adopted by medicine and medical men (MacKenzie Bryers and Van Teljingen 2010, Pollard 2011).

The medicalization of pregnancy and childbirth (despite the appropriation of midwifery by medical men for centuries – See Cahill (2000) for a full appreciation of its historical roots) and the industrialisation of maternity care which only really took hold after the advent of the NHS, when services for women, which were located within the community and provided mostly by autonomous midwives (and GPs) was moved into hospital (Allison 1996; Kirkham 1999; Schiller 2015). The basis for this whole scale move (previously many women had homebirths) was predicated on the Peel Report (DH and Social Security 1970), which advocated 100% hospital births (Davis 2013). Despite objections citing a lack of evidence supporting hospitals as the “best and safest place for babies to be born” (Allison 1996; Cahill 2001, p.334; Davis 2013), the majority of women in England were required to give birth in consultant-led units (97%), and continue to do so, with a home birth rate at around 2.3% (Office for National Statistics 2015). The Birthplace in England Study (Redshaw et al. 2011) and more recently the publication by Dodwell (2013) produced on behalf of the Royal College of Midwives, appears to suggest that around 12,000 women plan to birth their babies in midwife-led units which equates to less than 2% of women in England birthing within these institutions. Moving from an environment where they were relatively self-directed, midwives were now required to provide midwifery care in hierarchical hospitals where their practice was under constant surveillance through “statutory supervision and hierarchical management” (Kirkham 1999, p.733).

With the move into NHS hospitals came the inevitable, further medicalization of birth including domination of medical expertise over midwifery knowledge (Murphy-Lawless 2006; Kirkham 2010a; Davis 2012). Concurrently, there was a shift of power away from women who, whilst they birthed at home in spaces that were created and belonged to them and where midwives as professional visitors respected those spaces, now women were visitors in medical territory (Kitzinger

2005). Midwifery practice became defined and limited by obstetrics (Cahill 2001), a profession which viewed birth as dangerous and a process to be controlled and kept under surveillance (Pollard 2011; Cahill 2001). Pregnant women were thus required to negotiate their experiences in a “medicalised and fetocentric ideological context” (Parry 2006, p.459), which included submitting to on-going monitoring and intervention provided by midwives following policies/guidelines/protocols devised in the main by the medical fraternity (Parry 2006).

Oakely’s (1984) seminal book ‘The Captured Womb’, perfectly illustrates how pregnancy (defined as antenatal care) became separated as a social event involving mostly women, into one that became a ‘technical subject’ under the jurisdiction of expert authority (medical domain). A woman’s ability to make decisions for herself was removed, and women, in the hands of medical authority and its technology, become docile bodies and their babies a product of the doctor, the midwife and the institution (Davis-Floyd 1990, Pylypa 1998). Davis’s research (2013) which explored women’s experiences of childbirth during the second half of the 20th century, described how some women became resentful because their care was dictated to by hospital policies and practices rather than on their individual needs, which remains relevant when considering contemporary practice.

Women who gave birth in hospital prior to the Peel Report were already experiencing impersonal and conveyor-belt care (Newson and Newson 1963). In Davis’s (2013) research, one woman’s experience is highlighted where she described “waiting in rows in trolleys along corridors before being taken into the delivery room” and was “one in a sort of sausage machine” (Davis 2013). Walsh (2006, p.1332) has argued that conveyor-belt care, utilised by the motor industry to produce cars efficiently has parallels with care received by women in typical NHS obstetric-led units. Within these institutions labouring women are processed “through stages using a mechanistic model; both have a timescale for completion of product and both have a highly sophisticated regulatory framework”. It is a paradigm of care which does not, to borrow a phrase from Tricia Anderson, facilitate midwives “to drink tea intelligently” by trusting physiology and enabling women to labour and birth in ‘woman time’ (Walsh 2004, p.430; Stewart 2010).

Midwives are instead, required to measure and ensure women are labouring within a time frame, regulated by “clock time” (Stewart 2010, p.281). A ‘male and public’ approach to time ensures the efficient processing of women through labour wards (LW), in contrast to a more “female’ approach, which enables women to birth according to the ‘laws of nature” (Stewart 2010, p.281). Shorter labours therefore, allow for more births to be managed in the “one space” (Walsh 2006, p.1332).

In response to the medicalization of childbirth, pressure groups such as the National Childbirth Trust (NCT), and the Association for Improvements in the Maternity Services (AIMS) began to campaign for less medical interventions and for women to receive better care in hospital (Davis 2013). A major impact of these campaigns led to a reduction of unacceptable procedures such as pubic shaving at birth, routine episiotomy and an over-reliance of electronic fetal monitoring (Beech and Phipps 2004). In response, although somewhat belatedly (Davis 2013) to the growing consumer and professional demand (McIntosh and Hunter 2014) for women focused maternity services, and to counteract the biomedical model of pregnancy and childbirth, key government documents such as ‘Changing Childbirth’ (DH 1993) began to advocate choice and control for pregnant women. It was an influential report which had the support of all political parties, and had listened to and incorporated views of women, including suggestions of an earlier report (Winterton Report) (DH 1992), and was broadly welcomed by women, midwives and doctors (House of Commons Health Committee 2013).

Choice in maternity services therefore appears to provide women with an opportunity for a greater quality of experience, and “improved emotional outcomes in recognition that pregnancy and childbirth are both physical and psychological experiences” (Jomeen 2012, p.60). However, the inherent flaw in the choice recommendation, is pregnancy and childbirth is still viewed by many as a “medical event” and “service provision is therefore driven by the dictates of the medical model of care” with essentially women only able to choose options that are made available to them (Lowdon 2012). Key themes from a study undertaken by Jomeen (2007) revealed choices for women were inequitable, and were constrained by the healthcare professionals they came into contact with. The default position remains

a hospital birth for many women, from which they have to opt out of, although recent advice from National Institute for Health and Care Excellence (NICE) (2014) recommends low-risk multiparous women as 'particularly suitable' to give birth at home or in a midwifery-led unit, whereas for first time mothers, birth in a midwifery-led unit is 'particularly suitable' (Birthplace in England Collaborative Group, 2011). Midwives are asked to inform women there is a small increase in the risk of an adverse outcome for the baby if they are considering a homebirth. Whilst the guidelines appear supportive, some women, in particular, primiparous women and others who fall outside the bracket of low-risk would still need to convince authorities to achieve what they wanted.

A leading UK consultant in fetal medicine publicly posted a message on the MIDIRS website where he first berated NICE for recommending home birth as safe for first time mothers and then patronised women by declaring they risked "dead, damaged or handicapped babies" if they chose homebirth (Beattie 2014). His paternalism and obvious distrust in women's bodies is evident when he makes the following statement "it is impossible to classify someone as low risk using conventional antenatal care based on feeling and measuring a bump". He adds "and all 'low-risk' women who are considering a homebirth should have a scan at 36 weeks to ensure their baby is also 'low risk' and therefore ready for a normal birth", a biomedical approach which suggest only technology can confirm 'normality'. Pregnant women accessing this public website would be frightened by Beattie's emotive language which may deter them from seeking a homebirth and reducing their choices.

The paradigms in which women experience maternity services have therefore, a dualism about them, on the one hand choice, continuity and involvement of care promoted by many significant documents (DH 1993, 2004, 2007) and on the other, a tightly controlled maternity service, where care is task orientated, disjointed and highly regulated (Kirkham 2011; The Association of Radical Midwives 2013). It is worth noting women who chose to birth at home or in a midwife led unit may undergo different experiences. Recently published research clearly identifies benefits for women who choose to birth in a freestanding midwifery-led as opposed to an obstetric unit. In the first study by Macfarlane et al. (2014a) which

was part of a project linked to the Birthplace in England (Birthplace in England Collaborative Group (2011), women from an inner city area who chose the freestanding midwifery-led unit had positive experiences. Midwives provided continuity of care and women were treated with dignity and respect. The second report highlighted that women experienced lower rates of intervention and were offered more choices and information (Macfarlane et al. 2014b). Significant differences were therefore noted between women's experiences in a midwifery-led unit compared to obstetric units, which suggests midwives in midwifery-led units are empowered to work more autonomously and practice compassionate woman-centred maternity care (McCrae 2013).

It therefore appears that overall, midwives within centralised maternity services are more constrained in their practice and unable to provide care to the best of their ability (Kirkham 2011). The heart of midwifery is embodied around creating meaningful relationships with women, these soft 'womanly' largely invisible caring values are difficult to measure and quantify and are therefore overshadowed by actions and interventions which are easier to evaluate within surveys (Kirkham 2007).

1.2.2 What is known about women's experiences of maternity care in general?

Seeking women's views of their recent experience with maternity care remains a priority (Redshaw and Heikkila 2010; Blunt 2014), as maternity services have changed since the first survey was carried out in 1995 by the National Audit Office and change is ongoing (Redshaw et al. 2007; Fowler and Patterson 2013;). Large scale surveys of women's experiences of maternity services have therefore regularly been undertaken in England by the Healthcare Commission (Commission for Healthcare Audit and Inspection 2007), now known as the CQC (2013; 2015) and the NPEU (Redshaw et al. 2006; Redshaw and Heikkila 2010; Redshaw and Henderson 2015). Information obtained from these large maternity surveys has provided women, governments of the day and commissioners of services with 'evidence' of current practice and points of comparison for the future (Redshaw and Heikkila 2010; Redshaw and Henderson 2015).

Following the 1995 survey, the next national maternity survey was undertaken in 2006 by Redshaw et al. (2007), partly in response to the publication of the National Service Framework for Children, Young People and Maternity Services (NSF), a major document setting service developments that would enable the universal needs of children and pregnant women to be met (DH 2004; Lachman and Vickers 2004). The aim of the 2006 survey was to provide a benchmark of practice as it was and to establish a baseline for the on-going measurement of change as the NSF was implemented (Redshaw et al. 2007). In addition, the findings from the survey would inform policy in maternity care, validate the principles of the NSF and provide benchmarks for local audits of women's views and experiences in individual trusts (Redshaw et al. 2007). Since then two further surveys have taken place, in 2010 and 2014 (Redshaw and Heikkila 2010 and Redshaw and Henderson 2015).

All three surveys utilised comparable methods, in that women were randomly selected (probability sampling) by the Office of National Statistics (ONS) from birth registration records to enable direct comparison and asked to complete a postal survey. Although exclusion criteria remained consistent (women whose babies had died and mothers less than sixteen years of age) (Fowler and Patterson 2013), women with preterm babies were not excluded. The surveys were paper-based, although the 2014 version offered an online questionnaire, of which, only 8% of women chose to complete (Redshaw and Henderson 2015).

The latest NPEU survey (Redshaw and Henderson 2015) displays a decline in response rates (47%) from the previous two surveys (63% and 54% respectively) (Redshaw et al. 2007; Redshaw and Heikkila 2010) with the authors acknowledging the 2014 survey findings may not be generalizable to the wider population. Ahmed et al. (2014) suggest where surveys have followed high standards in their methodology which the NPEU clearly have, then responses between 35-40% are regarded as "acceptable for the purpose of routine healthcare monitoring" (Ahmed et al. 2014, p.237). Demographic information gathered across all three maternity services surveys suggests the women's characteristics are similar, in that the majority were white, aged between 30 and 34 years of age, were married and came from London and the South East. The next highest area of respondents came from

the North West. Whilst there was a similar response rate from black and minority ethnic (BME) groups across the surveys (between 0.5 % Chinese and other and 10.0% Asian) it must be queried as to whether results from the NPEU surveys are representative of women from a BME background, since views of 'white' middle-class women do not represent perspectives of women of colour (Sheldon et al. 2007). Evidence from research undertaken with people from the BME population suggests they have different expectations of care (Ahmed et al. 2014).

The NPEU surveys indicated that, despite evidence of limited continuity, choice of birth place not available to all, not 'always' being involved in care or being listened to, not receiving pain relief as requested, and an increased rate of operative births, the majority of women were satisfied, rating their care as 'excellent' or 'very good', with the possible exception of postnatal care. First-time mothers were more dissatisfied with their postnatal care than multiparous women, a finding supported by a qualitative study which explored women's experiences on a hospital postnatal ward (PNW) (Beake et al. 2010). Women described their information needs not being met, ward routines did not reflect their needs and they received inconsistent and conflicting advice on breastfeeding (Beake et al. 2010). Postnatal care is an aspect of maternity services that has consistently shown poor results throughout all surveys, yet quality improvements in this area appear not to have been taken on-board by NHS trusts (Fowler and Patterson 2013).

Previous CQC survey questions have been modified to reflect changes in policy, best practice, and feedback from stakeholders CQC (2015). As a caveat however, the CQC claim it is not possible to compare all questions across the years due to the need to add new questions and specifically for 2015, adjust existing questions (CQC 2015). CQC surveys follow a similar methodology but differ in a number of ways to those undertaken by the NPEU, which have smaller sample sizes and offer a national picture of women's maternity experiences, whilst the CQC surveys are larger and the organisation has a regulatory duty to ensure the results are used by NHS Trusts in England to improve care (Fowler and Patterson 2013). In addition, the CQC surveys assign 'scores' to individual NHS Trusts, which helps inform women as to where they might choose to birth their baby (Birthrights 2014).

Smaller scale surveys undertaken by Birthrights, the NCT and the NFWI, piloted their questionnaires through a mixture of paper copies and online methods, prior to utilising an online methodology. In addition, the NCT provided paper-based copies inserted into a magazine provided for NCT members. The NFWI survey questions were designed to follow on from previous surveys on birth experiences (Healthcare Commission, the NCT, and NPEU). This would enable the researchers to track trends and determine whether progress had been achieved. Further questions were also incorporated to understand whether women's experiences of care were reflective of recent guidelines, for example, vision set out by the DH and clinical guidelines devised by NICE (Bourke 2013). The NCT survey set out to replicate an earlier survey undertaken in 1999/2000 with questions designed to reflect recommendations as set in the NICE postnatal care pathway (Bhavnani and Newburn 2010).

It is not known how many women could potentially have responded to these surveys, for example 'mumsnet' (the UK's biggest network for parents) which hosted the Birthrights Dignity survey, suggests on its 'about us' webpage, that circa 9.4 million unique visits to the site per month (<http://www.mumsnet.com/info/aboutus>). The NCT, which has a readership of over 129, 000 members advertised its survey through a range of publications, whilst the WI survey invited a combination of its own and NCT members to share their experiences. All of these surveys would have attracted a group of women from a particular social class with particular viewpoints.

The sampling strategy for all three surveys would have been non-probability, in that any number of women who had given birth in the timeframes specified and belonged to the specified communities, would have been eligible to participate. In reality, any woman who had a baby as far back as ten years could have participated, and it is not evident whether the researchers controlled for this possibility (Duda and Nobile 2010). In addition, women who participated (mostly white) self-selected because more than likely they had an interest in discussing their care, resulting in potentially biased findings (Duda and Nobile 2010), therefore not representative of the population as a whole. The majority of respondents for the WI and Birthrights surveys were second time or more mothers, suggesting these women had a

previous experience to compare. The researchers of the NCT survey (Bhavnani and Newburn 2010) chose to only analyse experiences of first-time mothers (83%), as this group of women are known to have greater needs than those who have previously given birth. Thus, women with an increased interest in revealing their own labour and postnatal experiences would have been highly motivated to complete the surveys. It is also possible the surveys could be accused of being doubly biased, because the sample of women without Internet access and who were not members of the mumsnet community, or the WI and NCT organisations were excluded (Duda and Nobile 2010). Likewise, It is not known whether researchers controlled for multiple completions of the online surveys, especially from women who might have a vested interest in the results and whether they co-opted friends to complete in order to influence the outcomes (Duda and Nobile 2010). Therefore it can be queried as to whether the views of women responding to the three non-governmental organisations (NGO) surveys are representative of women's experiences of maternity care throughout England and if there are any comparisons with the findings of large scale surveys discussed previously.

1.3 CRITIQUING OVERALL EXPERIENCES:

Introduction

Despite most women being apparently satisfied with their maternity experience, there is a deep chasm between the 'ideal' and the 'reality, with many negative aspects of care reported in the surveys. Since the publication of Changing Childbirth (DH 1993), continuity of care and carer should have been a fundamental principle of midwifery practice, with relevant documents such as the NSF (2004), and Maternity Matters (2007) endorsing its principles of midwifery-led care with women at the centre of their pregnancies, having choice and being involved in their care (DH 2007). Regardless of government policy, the commitment to woman-centred maternity care remains rhetorical (Jomeen 2012) with too few women being offered continuity, choice, control (3 C's) and involvement in their care when accessing maternity services. The measured maternal satisfaction appears to be at odds with the lived experience.

1.3.1 Choice:

The premise on offering choice which is enshrined in the NHS Constitution (DH 2015) is to enable women a degree of control over their pregnancy, labour and birth experience. A supportive attitude enabling women to make choices appears to reverse a “patriarchal approach” that sees pregnant women as “patients” and doing as they are told (Mander and Melender 2009, p.638). However, presenting to a House of Commons Committee, Beverly Beech reiterated to the panel that choice for women in maternity care remained an illusion (House of Commons Health Committee 2003). Women, she added, are offered a specific list of choices and if they choose within those options, all is fine, however, choices outside of the set menu poses an “enormous battle” for women “to get what they want” (House of Commons Health Committee 2003, p.7). Organisations such as AIMS, of which Beverly is Honorary Chair, appear to have more insight into women’s lack of choices than the perspectives offered by the large scale surveys.

Policy states that women are offered a choice in the following areas of maternity care (Maternity Matters 2007) and ‘choice’ is enshrined in the NHS Constitution (DH 2015):

1. How they access maternity care
2. The type of antenatal care they receive
3. The place of birth (at home, in a midwifery led unit or in hospital with care provided by an interprofessional team)
4. How and where to access postnatal care (Jomeen 2009).

The National Maternity Review (NMR) (2016), similar to the many previous governmental manifestos on improving maternity services, has as its vision, a maternity service (in England) which promises a personalised service, where every woman has access to information to make decisions about her care, including access to individualised support. Women are therefore required to make choices and decisions as soon as they become pregnant and to continue making choices as they progress through their pregnancy (NMR 2016). The first contact with the midwife is an opportunity for women to discuss their maternity care options, and as

they progress through pregnancy, choices or decisions should be reviewed regularly and any changes should be facilitated by the midwife, including the obstetric team if relevant (NMR 2016).

All the large scale surveys demonstrate an improvement in the first two areas as set out above. Women's first point of contact is now mainly the midwife, an upward trend since the first CQC survey was carried out (2007) (CQC 2015). Women reported they 'almost' always felt involved during their antenatal care, with many experiencing an element of continuity during antenatal appointments, which provided them with a more positive experience. Equally, women who saw different midwives but did not mind also reported positive experiences. However, women who did not see the same midwife but wanted to, expressed negative responses (CQC 2015). The NPEU survey (Redshaw and Henderson 2015) for example, found that 19% of women saw five or more midwives which does not suggest continuity of care. The 2015 CQC survey highlighted 15% of women reported midwives were not aware of their medical history, in contrast to women who experienced continuity (73%) where midwives were always aware of their medical history. Knowing a woman's medical history has implications for the provision of safer care as set out in the vision by the National Maternity Review (2016). Overall antenatally, most women reported they felt treated with respect and dignity and felt listened to (CQC 2015; Redshaw and Henderson 2015).

However 'most women' does not inform which women were not treated respectfully. Respectful care should be provided to all childbearing women; however large surveys do not specify or identify who these women are, therefore making it difficult for NHS institutions to target and improve care for specific women (Wilcox 2016). The Dignity Survey (Birthrights 2013c) on the other hand does delineate between care settings, which provides context into where women did or did not receive respectful care. This will be discussed further on in the chapter. It appears therefore, that whilst many elements of antenatal care have improved over time, one aspect that remains 'wanting' are birth setting choices, with all surveys demonstrating this aspect of antenatal care has not improved significantly, although the 2015 CQC survey highlights that more women were

offered a choice of a midwife-led unit or birth centre (41%, 35% in 2013) (CQC 2015) but not, it seems, homebirth.

Only 12% of women participating in the WI survey were provided with all four choices for place of birth (Figure 1-3) (Bourke 2013), whilst in the NPEU survey (Redshaw and Henderson 2015), 25% of women were aware of all four options, 40% were aware of two or three, and for 33%, only one choice was made available. One would assume that for these women, their only option was an obstetric led maternity unit, whether they preferred it or not (Bourke 2013), suggesting choices for women in England are not equitable, with some having more choices than others (Jomeen 2009). For example, 68% of women in the WI survey were offered an option of a homebirth (Bourke 2013) unlike the Birthrights survey (2013c), where 26% of women reported a lack of a choice around birth settings (Birthrights 2013c). These statistics support the assertions put forward by Beech that choices for women remain an illusion.

1. Obstetric unit (usually consultant-led)- women have access to a range of healthcare professionals
2. Co-located or alongside birthing unit (AMU)
3. Free standing maternity unit (FMU) – staffed by midwives only
4. Homebirth (facilitated by midwives only)

Figure 1-3: Choice of place of birth for women

Findings from the WI survey indicate that women with increased options of birth settings “are far less likely to want to give birth in obstetric unit” (Bourke 2013, p. 65). Of note, demographics from the Dignity survey demonstrate that 13% of women had a home birth which is well above the national average of 2%, despite 26% of women not even having choice. The statistical details outlining where these homebirths occurred is not available (Birthright 2013c).

A recent publication by the National Audit Office (NAO) (2013) reports 87% of women gave birth in an obstetric unit in hospital in 2012, which may reflect the fact that women still perceive hospitals as the safest choice for them (Davis 2013). An alternative viewpoint is offered by Barber et al. (2006) who undertook a study to investigate factors influencing women’s decisions on where to give birth. Their findings suggest the greatest influence on decision making came from midwives. In

addition, the authors propose midwives did not use their influence effectively, as women were opting for hospital birth unaware of their local choices. Midwives it appeared, withheld information around choice of birth setting particularly in relation to midwifery-led units (MLUs) and homebirth, because in their view, provision of a homebirth service had a significant impact on maternity services as a whole (Barber et al. 2006). Whilst this was a locally based study (Portsmouth and Southampton) with findings relevant to the area, it may be possible the difficulties faced by these midwives (responsibility to provide women with informed choices versus impact on service) are equally applicable to midwives working elsewhere in England.

A study by McCourt et al. (2012) which sought to explore organisational strategies and midwives readiness to provide care for out of hospital births, discovered, despite support for choice of birth setting and midwifery-led care from key maternity professionals, NHS Trust capacity was wanting, including a perception that birth outside an obstetric unit was more costly. In addition, women and community midwives were aware that some professionals lacked confidence and were inexperienced at facilitating homebirth (Mccourt et al. 2012). Therefore, women's choices for birthplace setting are not only impacted by organisational factors (perceived impact on services and inexperienced midwives), but also by the provision of selected information by midwives (Barber et al. 2006; McCourt et al. 2012).

Maternity Matters (2007) and NICE guidelines (2014) recommend women who are low-risk should be able to choose a birthplace, in terms of the setting and the provider of the care (CQC 2015), however, are these recommendations applicable to women who commence their pregnancy as low-risk and become high-risk mid-way through. For example, any labour commencing prior to 37 weeks of pregnancy (Term) is known as preterm labour (Tucker and McGuire 2004) and is not considered normal despite onset because of the risks associated with preterm birth (Boyle et al. 2015). Normalisation of a preterm birth event especially towards the latter half of late preterm gestation would be unlikely and intervention highly probable (Boyle et al. 2015). Some of the women who participated within my

research wanted a home birth; however, under the circumstances their only choice was a hospital birth. They did not get a choice in who provided their care and where they received postnatal care unless an unexpected and unplanned homebirth took place (NICE 2015; DH, 2007), in which case they would be 'rushed' to hospital as an emergency.

Reviewing websites which provide information to parents such as Babycentre.co.uk, Tommys.org and Patient, clearly advise woman suspecting preterm labour to go to their nearest hospital for assessment. Women in spontaneous or threatened preterm labour would more than likely attend their local maternity services for help and support. A qualitative research study by Weiss et al. (2001) highlighted many pregnant women are unaware of preterm labour and/or preterm labour symptoms, and would, therefore, seek help and advice from healthcare professionals to verify the symptoms they were experiencing were indeed labour. I have been unable to find any evidence demonstrating women's refusal to attend hospital in the case of preterm labour.

Interestingly, anecdotal evidence revealed a woman in preterm labour was refused entry into two hospitals because of a shortage of maternity beds, resulting in the death of her baby (Hallam 2014). In terms of power issues between mothers and maternity services, a question that arises from this sad outcome is how the mother would have been judged had she, rather than the hospital, declined admission. It seems likely she would have been heavily criticised, as many women are when they choose to 'birth outside the system'. There was no similar outrage on behalf of the woman for the system letting her down. This highlights an inequality between women and the maternity system, imposed not only by the maternity services, but by society as a whole.

Choice for childbearing women extends further than antenatal care and place of birth. Women also have choices during labour and birth, and to be enabled to "make informed decisions and give informed consent to medical examinations or procedures" women need appropriate information (Birthrights 2013b, p.8). In their survey (Birthrights 2013c), 21% of women reported insufficient information relating

to options in labour and birth, with a small percentage of women (15%) unhappy with their choices around pain relief. The larger scale surveys have reported similar issues. Other choices revolve around women being enabled to move freely within the labouring room, electing where to give birth (bed/pool/floor) and in a position of their choosing. However, the large scale surveys consistently demonstrate many women continue to give birth on a bed, lying on their backs or with their legs in stirrups, birth positions not recommended by 'evidence-based practice'.

The CQC (2013; 2015) and the NPEU survey (Redshaw and Heikkila, 2010) demonstrate a rising trend of women undergoing a normal vaginal birth with legs in stirrups. The surveys do not unpick these statistics any further although the most likely explanation appears due to assisted vaginal births (Redshaw and Heikkila 2010), which highlights a weakness of quantitatively obtaining women's experiences of maternity services. Whilst the surveys recommend NHS hospitals review the practice of women birthing in lithotomy, a retrospective study by Bayes and White (2011) provides a possible explanation for why midwives place women into lithotomy. Case notes of low risk women birthing in lithotomy in a maternity unit staffed by midwives and student midwives were reviewed. The authors wished to understand the motivations, rationale and decisions of midwives, because as a position of birth, lithotomy is associated with an increased risk of perineal lacerations (Hastings-Tolsma et al. 2007). In 39% of cases reviewed, there was no documentation recording the need for lithotomy (Bayes and White 2011). Furthermore, discussions with the women were not documented, which brings to mind important issues of 'choice' and 'consent.' The authors concluded midwives provided non-evidenced practice because they believed women in lithotomy optimised their chances of a normal birth, since the environment of birth placed time constraints on women in labour (Bayes and White 2011).

Kitzinger (2005, p.16) is mindful that "the clock is an unevaluated technological intervention that has major impact on the conduct of birth". During a woman's labour, the time-frames of each 'mechanistic stage' of labour are plotted onto a graph (partogram), and any deviation from an "arbitrary clock first set in motion by Friedman's curve (a time-motion statistical analysis of the stages of labour devised

in the 1950s because of clinical concerns related to long labours)” (Simonds 2002, p.565; Walsh 2006), acceleratory interventions such as artificially rupturing a woman’s membranes (ARM) in the hope of speeding up labour, are utilised (Simonds 2002; Walsh 2006). Walsh (2006, p.1335), in his ethnographic study of a free-standing birth centre, portrays how time differs when women birth in a unit led by midwives. In these environments, midwives have time for chatting, which he terms a “time-rich activity”, in contrast to obstetric units where midwives frequently have to provide task-orientated, ‘doing’ care, which women are at the receiving end of.

Women informed the panel of the NMR (2016) they did not always feel the “choice was theirs to make with many feeling pressurised by their midwives and obstetricians to make choices that fitted their services”. An earlier study on informed choice in maternity care undertaken by Kirkham and Stapleton (2004) appears to support the assertions of women fifteen years down the line. The authors observed that many midwives appeared to “go with the flow” when providing information, which translated in ensuring that the majority of women adhered to medical authority by ensuring uptake of ‘choices’ were that which were deemed ‘right’ within the local context (Kirkham and Stapleton 2004). It therefore seems that “choice remains an aspiration and not a reality for many women” (Bourke 2013, p.7; House of Commons Health Committee 2003).

1.3.2 Continuity of care:

The literature is filled with key documents and research which attests to the benefits of continuity of care between women and their midwife (McCourt et al. 1998; Stevens and McCourt 2002; DH 2007; Hodnett et al. 2011; Davis 2012). Women experiencing continuity of midwife during pregnancy build up strong relationships and feel comfortable with their carer. If care is consistently provided, women appear to have better experiences during the antenatal, intrapartum and postnatal periods of maternity care (Davis 2012). The CQC survey (2013) highlighted in its key findings, that women who saw the same midwife during their antenatal and postnatal care tended to report more positively on some aspects of care, which

included women who were seen by different midwives but did not mind this. However, women who had not seen the same midwife but wanted to, tended to provide negative replies on those same aspects of care. Women who took part in the Healthcare Commission report (Commission for Healthcare Audit and Inspection 2007) stated when they had all or most of their care from the same midwife during pregnancy, they were more likely to be treated with respect, dignity, kindness and understanding. The 2015 CQC survey highlighted more women (36%, compared to 34% in 2013) saw the same midwife for their antenatal care.

During labour, knowing the midwife or continuity of carer is an important aspect of a woman's experience. A review of studies focusing on continuous support for women during childbirth provides strong evidence for the benefits of continuous labour support (Hodnett et al. 2011; Sandall et al. 2016). Women were more likely to birth spontaneously without the need for medical intervention; they were less likely to require medication for pain, more likely to be satisfied and had slightly shorter labours. When reviewing this aspect of a women's maternity experience, the national surveys revealed many women had not previously met the midwives who cared for them during labour and birth, a time when women often feel vulnerable.

Women who experienced long labours (usually first time mothers) had four or more midwives caring for them (Redshaw and Heikkila 2010), similar to the findings of the Healthcare Commission (2007) where 43% of women had three or more midwives look after them during labour and birth. Others reported being left alone in labour at a time when it worried them, although there were differences when considering type of birth and parity of women. This remains evident in the latest survey of women's experiences of maternity care (CQC 2015). Women who underwent an emergency operative delivery (OD) or an assisted vaginal delivery reported being left alone in early labour, and more women who were first time mothers were worried, as opposed to women who were into their second or third pregnancies (Commission for Healthcare Audit and Inspection 2007; Redshaw and Heikkila 2010; CQC 2013; Bourke 2013).

Overall the results suggest the model of care provided within NHS obstetric led maternity units is not reflective of a 'named and known midwife' or achieving 'one-to-one' care for labouring women. Furthermore, these workplace environments do not prioritise woman-midwife relationships (Kirkham 2010a). Walsh (2006) argues it is impossible to prioritise one-to-one care in centralised maternity services operating on 'industry standards', because of the unpredictability of not knowing when women in labour may come in, including the difficulty in catering for both high and low risk women in one environment.

It is not possible to determine whether women who undergo preterm labour and birth experience better continuity of care. The 2015 CQC survey invited all women with a live baby (with some exclusions) to participate and results are not delineated by gestational age. Women's experiences of preterm labour are explored in Chapter 2, however it could be surmised that, as most preterm births take place in hospital, there is every chance women experiencing a preterm birth will be subject to an industrial model of midwifery care.

One of the most critical aspects of a woman's experience is focused on dignity. Despite many women reporting a positive experience, others described they were not always treated with respect and kindness and felt they were not always talked to in a way they could understand (Commission for Healthcare Audit and Inspection 2007; Redshaw and Heikkila 2010; Birthrights 2013c). Context of care appears to impact on the way women are treated. Women in birth centres reported more respectful care, choice and control during their labour and birth (Birthrights 2013c). The views of women who experienced homebirth were excluded from the Birthrights survey on the grounds their experiences were not typical of the population at large (Birthrights 2013c). It would have added an extra dimension to the overall findings of their survey if women's views of respect and dignity were compared and contrasted between all three birth environments and not just between MLUs and obstetric units.

It is worth interrogating the Dignity survey to unpick what dignity means to women and midwives who participated, as it was the first of its kind in the UK (Birthrights

2013c). It could be argued the soft 'womanly' caring skills missing from large scale maternity surveys are being measured within this survey, since "dignity in childbirth is largely dependent on the care women receive from their professional caregivers" (Birthrights 2013c, p.5). The research was designed to obtain the views of women who had given birth in the two years previously, including midwives and student midwives (Birthrights 2013c). In addition to the online questionnaire, women were encouraged to expand on their responses in a free-text box. Midwives were interviewed on a one-to-one basis, whilst student midwives were invited to a focus group discussion (Birthrights 2013c).

The survey revealed that generally, the majority of women were satisfied with their care, with 82% of women reporting they felt the midwife respected them. However, despite an overall satisfaction, the survey exposed significant variation in choice and respectful care, which was dependant on context of environment, whether women were first, second time or more mothers, and the type of birth experienced (Birthrights 2013c). For example, those considered high risk, disabled, and with English as their second language were more likely to receive poorer quality of care (Birthrights 2013c).

The birth of a first child marks a defining point for a woman, she becomes a mother, however, her experience (positive or negative) during pregnancy and childbirth can have a profound effect on how she may feel about herself, her ability to be a mother and her relationships with others in her life (Redshaw and Heikkila 2010). The majority of women who participated within the Dignity survey felt their experience of childbirth had impacted on their feelings about themselves and their relationships with their babies and their partners (Birthrights 2013c). Midwives were mindful that if a woman's dignity was harmed during her labour, it had the ability to traumatise and stay with her for the rest of her life, in addition to making her distrustful of any care she might receive from NHS maternity services in the future (Birthrights 2013c).

Midwives understood dignity to consist of two elements: "first, bodily dignity; and second, a less specific concept involving emotional and psychological wellbeing,

described as ‘personhood’” (Hales 2013, p.23). When ‘dignity’ was discussed from the perspective of intrapartum care, midwives were aware aspects of midwifery practice in consultant-led LWs impacted on women’s experiences. Midwives described how women were frequently bullied into making the ‘right’ decision to suit staff, rather than being in the woman’s best interest (Birthrights 2013c). In other examples, midwives disclosed the extent of mechanisms utilised by midwifery colleagues to get women to comply. Women appeared coerced into decisions despite declining, by repeatedly being asked if they were sure they did not want a particular procedure/intervention, a strategy some midwives felt amounted to harassment. Bullying behaviours by maternity healthcare professionals tend to reduce women into docile recipients of care, rather than active contributors in decisions about themselves (Hayes-Klein 2013) which goes against the dimensions of care patients value highly (Richard and Coulter 2007)(Table 1-2). Some of the midwives described a culture where women were expected to conform without questioning, not realising they had a choice to accept or decline routine care/interventions (Birthrights 2013c).

Of note, and perhaps not fully understood by midwives who pressure women into decisions in line with hospital policy, is that in a court of law, coercion generally invalidates consent and hospital policies should not take precedence over a woman’s right to informed consent (Hayes-Klein 2013). Student midwives disclosed women who queried the status quo were labelled as challenging, and were unfavourably discussed by maternity care providers in the duty office or in staff-rooms (Birthrights 2013c).

Within institutional establishments such as the NHS where there are definite hierarchical structures, there appears to be expectations that those working within a hierarchy instruct those lower (Taylor 2010). Midwives are taught and guided by their professional requirements that communication between a woman and her midwife is vital and that care should be based on informed consent (Taylor 2010, NMC 2015). However, as highlighted within the Dignity survey above, it appears that instances of true consent are rare, with midwives preferring to accept the authority of obstetricians and institutional procedures. “Hierarchy, obedience and

fragmentation of care are usually to the psychological benefit of the professional” and not to the women themselves (Taylor 2010, p.248). Kirkham (2010b) emphasises how, within a hierarchical model of maternity care, it is difficult for midwives to trust women, when midwives are themselves controlled rather than trusted to use their midwifery skills. That in turn makes it challenging for midwives to facilitate women in exercising choice when midwives feel oppressed. When midwives are disempowered they will find it problematic to empower women (Kirkham 2010b).

The Dignity survey (Birthrights 2013c) provides an insight into women’s experiences of respect and dignity that is lacking from the large scale surveys as it includes the perspectives of both women and healthcare professionals. Birthrights Charity have committed to providing bespoke training for healthcare professionals working within NHS provided maternity services around respectful care, in an effort to directly improve care for women and families, change practice and strengthen the case for the use of human rights in maternity care (Birthrights 2016). Whilst the impact of their subsequent dignity in childbirth training on staff has not been formally evaluated, although demand is increasing (Schiller 2015), the 2015 CQC survey indicated that 71% of women who had a baby in an obstetric hospital, felt they were treated with kindness and understanding (compared with 66% in 2013) (CQC 2015). Schiller (2015, p.5) argues it is time midwives started framing their work by “bringing human dignity and respect into the lives of often-vulnerable women” and fortunately, midwives and women are now at the forefront of the growing human rights in childbirth movement, which has, as its aim, an improvement of childbirth for all women (Schiller 2015).

Kirkham (2011) questions whether midwives are ‘with institution’ rather than ‘with women’, as she considers clinical guidelines/protocols/ policies devised by NHS Trusts to manage risks, govern midwifery practice, which results in obedient midwives who provide standardised care to women, because they are fearful of deviating from pathways. Midwives participating in the Dignity survey confirm Kirkham’s views, since they disclosed some midwives stuck rigidly to guidelines/protocols, which ultimately had an effect of potentially “diminishing

women's dignity". Used as "bibles" to dictate routine or standardised care does not facilitate individualised midwifery practice or choice for women (Birthrights 2013c, p.19). Others have proposed that, unless differences in definition between guidelines, policies and guidelines are appreciated, midwives and other healthcare professionals will never be able to use them to their best advantage when supporting women who use maternity services (Frohlich and Schram 2015). As a consequence, women can find themselves on a treadmill where care satisfies neither themselves nor that of a midwife (Curtis et al. 2006; Kirkham 2007, 2010a; Pollard 2011).

The Dignity in Childbirth Survey (Birthrights 2013c) is an important survey, as it was the first to nationally explore women's experience of childbirth from a perspective of respectful care and choice in childbirth (Prochaska 2013). There is no way of knowing whether participants were women who may have undergone preterm labour resulting in a preterm baby. Does that even matter, since all women, regardless of gestational onset of labour should be treated with dignity and respect? Whilst all women are vulnerable in labour, many experiencing preterm labour are simply not ready or prepared and are usually fearful about their premature baby and for themselves (Lindberg and Ohrling 2008; Tooten et al. 2013). Goutaudier and colleagues (2011) in their mixed methods research on 27 women in the south of France, discovered women felt responsible for their preterm birth and experienced negative recollections and in addition, women who had undergone an operative birth were traumatised by their experience. Negative recollection of preterm birth experiences up to six years later has been reported by Latva et al. (2008). Women described their experience as 'terrible' or 'chaotic', were psychologically unprepared to give birth and were concerned that their baby may die. Separation from their baby added to these negative experiences (Latva et al. 2008).

Many of the feelings described imply a lack of control, which would impact on a woman's dignity and her sense of self during her labour, feelings which would continue into the postnatal period (Nolan 2015) and impact on her future on-going mental health, and indeed, her relationships with her baby and her family, as

confirmed by the Dignity Survey (Birthrights 2013c). Future surveys exploring dignity in childbirth should seek to make distinctions between women who birth at different gestations, as women in preterm labour are considered high risk and their perceptions of dignity may differ to women in Term labour.

Postnatal care remains one area of maternity services which has not improved since women began to be surveyed for their experiences. Many women have reported fragmented care, inconsistent advice and a lack of support and encouragement (Bhavnani and Newburn 2010). Others described their overall care as either 'fair' or 'poor' (Commission for Healthcare Audit and Inspection 2007). Bourke (2013, p.8) highlights women "face a postcode lottery of postnatal care", both in terms of variation in the quality and standard of care. For example, in the NCT survey, a quarter of women in London reported they were unable to see the midwife as much as they wanted during the postnatal period (Bhavnani and Newburn 2010). Issues impacting on midwives ability to provide continuity to women in London are reflective of a number of problems:

- 1) High immigration (Bourke 2013)
- 2) Increased birth numbers (London 22%) (Bonar 2013),
- 3) Newly recruited midwives working part-time (Bonar 2013),
- 4) Younger midwives unable to afford to live in London (Bourke 2013)
- 5) 80% of part-time workers are women and the majority of midwives are female (Bourke 2013) with multiple responsibilities.

The 2013 CQC survey reported women commenting on busy midwives which impacted on whether their needs were met. Maternity wards were described as "severely understaffed" with "over-worked" staff. Despite these working conditions, a number of women also reported midwives as caring and supportive whereas others were described as "bossy" or "pushy" (CQC 2013). The NCT survey (Bhavnani and Newburn 2010) which focused mainly on women's postnatal experience, revealed that 42% of women felt there were not enough midwives to provide care, either on the PNW or at home. Although Birthrights did not specifically survey women's views on postnatal care, many felt compelled to share

their experiences within a free-text box, revealing how let down they felt during the postnatal period (Birthrights 2013c). Clearly, postnatal care does not reflect women's experiences of antenatal care (NMR 2016).

The NMR (2016) revealed women wanted more postnatal care. Women described underfunded postnatal services, which resulted in midwives being unable to provide women-centred care. Women therefore, appear to experience significant unmet needs during the postnatal period (Bhavnani and Newburn 2010), a finding supported by quantitative surveys of maternity experiences (Commission for Healthcare Audit and Inspection 2007; CQC 2013; 2015) and qualitative research (see Beake et al. 2005; Wray 2006; Beake et al. 2010; Bailey 2010; Coates et al. 2014). Furthermore, women also reported more attention was paid to the needs of their baby rather than their own (Bhavnani and Newburn 2010).

It is not known whether women caring for late preterm babies would have similar perceptions, as none of the surveys (bar one, more in Chapter 2: 2.3) make a distinction between women with Term or preterm babies. Women with preterm babies have different needs (Erlandsson and Fagerberg 2005); consequently, poor postnatal care could potentially affect them disproportionately (Johnson 2008). There appear to be no studies to date that have explored women's experiences of postnatal care whilst caring for their LPBs. Therefore, as many of the surveys concur on postnatal care as being a key area of deficit in terms of quality, exploring the experiences of women caring for their LPBs during the postnatal period seems very important.

1.3.3 Involvement in care:

Key findings indicate more women compared to previous surveys felt they were always involved with their care during all stages of pregnancy and childbirth, although this was dependant on whether they had experienced continuity of care and were first or second time mothers (CQC 2013; 2015). The NCT survey (Bhavnani and Newburn 2010) which focused exclusively on first-time woman-mothers, reported 80% of women felt midwives were 'always or mostly' kind and understanding and treated them with respect (83%). However, one in eight women

were extremely critical of their care, and reported insensitivity, conflicting advice, a lack of care and emotional support including insufficient postnatal visits at home. Women who underwent operative births were the least satisfied with their care (Bhavnani and Newburn 2010). Similar experiences were reported by the Dignity survey (Birthrights 2013c). The organisation has recommended that future CQC maternity experience surveys should report results by type of birth. This would enable providers of maternity services to be made aware of how women undergoing assisted births are treated (Birthrights 2014). Factors impacting on first time mothers not feeling as involved or in control as they would like, are related to some of the following:

- Limited choices in birth setting (Redshaw and Heikkila 2010; CQC2015).
- Not having previously met the midwife during labour and birth (Redshaw and Henderson 2015).
- One or more midwives caring for them (26% had four or more midwives providing care) (Redshaw and Henderson 2015).
- Being left alone in labour at a time that worried them (CQC 2015).
- Giving birth in stirrups (22%) (CQC 2015).
- Poor postnatal care, as evidenced by all the surveys utilised.

Research has demonstrated that, when in control during pregnancy and childbirth, women report more positive experiences, such as a sense of achievement, which in turn impacts on their sense of self, their sense of being a mother and all the relationships within her circle (Birthrights 2013c; Meyer 2013). However, for women who are in threatened or established preterm labour obtaining information needed to participate in decision making can be problematic (Harrison et al. 2003). There is no doubt that women who are considered high risk are in need of expert care, however they need to be involved within the process and healthcare professionals can promote dignity and a sense of control by keeping women at the centre of care: “she is not the complication in itself, but rather the person who has complications” (Berg 2010, p.283).

The survey findings in this section provide substance for robust discussion for women, for organisations providing maternity services and for the midwifery profession itself (Hales 2013) although it appears that not all NHS Trusts are voluntarily implementing changes of benefit to women. A review of the evidence by Fowler and Patterson (2013) which examined the use of maternity surveys and their validity in improving maternity services for women and their families concluded that in some instances, those NHS Trusts who received adverse feedback failed to implement significant quality improvements, resulting in the CQC exercising its regulatory power to motivate Trusts to instigate change and increase standards.

1.4 Conclusion:

Whilst many influential documents contain positive messages around choice, continuity of carer, and being involved with one's own care, the reality appears somewhat different. Some women will be denied the opportunity to make choices, some will be left out of decisions about their care, and others will find themselves without the necessary help and support they need during the first few weeks following birth (Bourke 2013). We have also seen that the drive to restructure and centralise services to support a medical model of maternity care "based on a series of assumptions rather than evidence" (Bick, McCourt and Beake, 2004, p.164) has resulted in the majority of women birthing within expert-led institutions where intervention, increasing rates of operative births and fragmented care are the norm (Kirkham 1999; 2010a; 2011). Reorganisation of maternity service impacts greatly on women's choices especially around the four options to enhance care (see below) which have been endorsed by respective governments of the day and which are intended to promote informed choice and continuity of care:

- 1) Access maternity care
- 2) Type of antenatal care they receive
- 3) Access place of birth
- 4) How and where they access postnatal care (Jomeen 2009).

Women do not always have choice on where (homebirth rate of 2%) (Montagu 2008) or how to birth, with survey results indicating that women birth in positions not endorsed by research (30% lying down, 27% legs supported by stirrups) (Commission for Healthcare Audit and Inspection 2007). The latest survey of maternity experience by the independent regulator continues to highlight best practice is still not always followed, since 22% of women who had normal vaginal births did so in lithotomy (CQC 2015). In the Dignity survey (Birthrights 2013c) 52% of first time mothers were unhappy with their choice of position.

The research undertaken by Birthrights (2013c) reveals significant shortcomings in the current provision of maternity care. It has for one, highlighted how some women are bullied and coerced into making decisions about their care which would impact on their ability to make a free choice. It has also strongly demonstrated a two-tier system of care exists, in which a woman's risk factors was seen to have a powerful impact on the care she might expect to receive. Low risk women were perceived to have a better chance of receiving care that upheld and supported their dignity compared to those seen as high risk with context of care playing a part. Women who experienced maternity care outside of obstetric led units (birth units) had more positive experiences, describing respectful care, greater choice and control than the women who birthed in hospitals (Birthrights 2013c).

It must be acknowledged that whilst pregnancy and childbirth remain medicalised, women will continue to be influenced by the perception that sees birth as 'risky' (Jomeen 2009) with hospital as the only safe option in order to avoid making the wrong choice(s) and potentially being labelled as 'bad mothers' (Jomeen 2007; Jomeen 2012). This therefore places some women, especially those seeking an alternative to hospital birth, between a rock and a hard place. 'Society' demands women make safe and responsible choices throughout pregnancy (such as avoid alcohol, eating soft cheeses, the list is endless) (Jomeen 2009), however "with choices comes responsibility and thus choice can lead to public censure if the wrong choices are made" adding extra pressure onto pregnant women (Jomeen 2009, p.16) including being labelled as 'bad mothers' if they deviate from what is dictated by the dominant discourse (Jackson and Mannix 2004; Gotlib 2010).

So whilst choice to improve women's experiences of childbirth is strongly supported by numerous governments, to date, NHS funding increases have failed to keep pace with rising demand (Ham 2017) and the increasing demand of midwifery services in the face of continuing shortage of midwifery staff (RCM 2017) signifies that choices for childbearing women will remain limited and inequitable (Jomeen 2009). Furthermore, other influences such as low income, poor housing, or women who are disabled and of colour may impact on access to services, which in turn increases their risk which subsequently further undermines choices available to women (Jomeen 2009, National Maternity Review 2016).

In an observation-based study undertaken by McCourt (2006) which examined patterns of communication (midwives and pregnant women) during the antenatal booking consultation within models of care (conventional or caseload) and whether communication supported choice and control, concluded that although elements of both were evident, major changes were required to facilitate informed choice. Strikingly, midwives operating within a caseload model of midwifery care appeared to work in partnership with women, whilst those providing conventional care followed a "professional/client model" (p.1316), in which the midwife acted as "representative of the corporate body of the health service" (p.1315), a model of care which tends to not truly offer informed choice to pregnant women (McCourt 2006). It can therefore be concluded that choice, guaranteed by successive governments over the years has still not been fully realised and for genuine transformation to happen, issues of power, hierarchy, including structural changes within the provision of NHS maternity services are required (McCourt 2006).

Thus a woman's quality of maternity experience is impacted by many factors, not least the institution where birth occurs and the choices (or not) available to her. However, despite women having to fit into services designed to meet the needs of hospitals (Edwards et al. 2011), it is worth acknowledging change may be slowly occurring. The latest maternity services survey (CQC 2015) demonstrates a number of improvements from previous surveys, in areas such as choice of birth setting, continuity of midwife for antenatal care and a greater increase in women always being treated with dignity and respect during labour and birth. This suggests

perhaps, that improving quality of care requires multiple strategies to enhance women's experiences of maternity services, which need to be sustained for longer periods of time (Ahmed et al. 2014).

Exploring women's experiences of maternity services began to stoke the coals of my burgeoning feminist consciousness, as I began to realise feminism could be a methodology with which to explore and understand women's experiences of caring for their LPBs. From a feminist perspective, it can be ascertained that women's rights are not always adhered to or upheld within the NHS system of maternity services. For example, whilst the surveys undertaken by the NPEU, CQC, NCT, NFWI and Birthrights have reported positive aspects of maternity care as stated by women, many lack choices around managing their own pregnancy and birth, others are not as involved with care as much as they would like, information provided by healthcare professionals is not always objective and unbiased, and some women are coerced into providing consent for procedures they may not always want.

Whilst respect and dignity have improved with the 2015 CQC survey demonstrating an improvement since 2013, women are still reporting their basic right to dignity, privacy and respectful care are not being upheld. These negative aspects to women's experiences have continued, despite the publication of many women-centred documents promoting choice, continuity, control and involvement. Women are still fighting against a tide which prioritises pathology over normalisation, paternalism instead of informed choices, and subordination of woman and midwife through oppressive policies and guidelines (Klima 2001).

Therefore, whilst all the surveys cited have their strengths and limitations, an in-depth exploration and understanding of individual experiences is warranted, to gain more insight into what actually matters to women. Although women who have experienced a preterm birth are not excluded from participating within any of the government and non-governmental maternity surveys, their individual experiences as a mother of a preterm baby and for the purposes of this study late preterm, do not stand out from any other woman's experience. Women birthing LPBs would almost certainly be categorised as a high risk group of women, they would have to

give birth in an obstetric unit, which makes theirs an important albeit under-researched perspective to explore. For these reasons a qualitative feminist methodology to explore women's experiences on caring for their late preterm babies has been carried out.

The following chapter will explore women and their preterm babies.

CHAPTER 2 WOMEN AND PRETERM BABIES

Introduction

This chapter consists of two main sections. The first considers women's experiences of preterm labour. Although maternity services surveys invite all women to participate, the particular experiences of women in preterm labour are not easily extrapolated. Therefore, a mini literature review which considers women's experiences of preterm labour was examined from two perspectives: their experiences at home on bed rest or restricted activities and experiences within hospital as a 'patient'. This section sets the scene as it explores women's experiences before birth and the concept of mothering and motherhood. The second section explores parent's perceptions of neonatal care by examining national surveys. By the end of this chapter there will be a clear understanding of the background and literature relating to women's experiences of preterm labour and parents perceptions of neonatal care.

2.1 WOMEN'S EXPERIENCES OF PRETERM LABOUR

Large scale maternity service surveys target all women who have had a baby/babies in a certain year and between certain periods, with the results indicating "the average or typical quality of experience for that population" (CQC 2015, p.14). The surveys in general do not distinguish between women with Term or preterm babies; therefore it is not known whether women undergoing preterm labour and birth experience maternity services differently to their counterparts. In the survey by Redshaw and Heikkila (2010) women were asked two questions about specific pregnancy related problems which affected them or their baby, and whether these problems necessitated an overnight stay in hospital. Twenty four percent of women identified problems such as pre-eclampsia or threatened preterm labour, and 19% were required to have an overnight antenatal stay. The women reported their care as 'very well' (62%) or 'quite well' (30%) coordinated. The survey does not however, make any further reference to women with preterm babies. The extent of satisfaction is, as identified in the previous chapter, mixed, with some women sometimes appearing satisfied but equally, some significant evidence of poor

quality provision. A limitation of reporting women's experiences obtained from quantitative surveys is that in-depth exploration that would be required to glean such information is not conceivable. It is not possible therefore, to extrapolate from maternity surveys, the experiences of women who commence their mothering role early, and in some cases unexpectedly and in full view of healthcare professionals, if their baby is transferred to neonatal intensive care (Flacking et al. 2007; Fenwick et al. 2008; Goutaudier et al. 2011).

In order to gain a full insight into the existing evidence, a review of the literature was undertaken to determine whether surveys which specifically examined women's maternity services experiences from a preterm perspective were available. An initial search revealed three papers, none of which were surveys, nor did they reflect women's preterm experiences and were medically orientated scientific papers. The search was therefore expanded into a general search for 'women and experiences of preterm labour (PTL) which revealed 237 articles. After application of full text, peer reviewed and English language, 144 articles remained. Following removal of duplicates, 81 papers were available. The search was further narrowed to focusing on 'high-risk pregnancy', 'experience' and 'qualitative and qualitative research methodology' resulting in 17 relevant studies. The majority of papers (11) emanated from the US and Canada, whilst the rest stemmed from Sweden (2), the UK (3), one each from Australia and Israel and one from France. Although the countries represented have differing maternity services, women's experiences of PTL appear to be similar.

Maternity care and experience is particularly relevant to women, and feminist writers over the years have examined discourses around medicalization of childbirth in great depth, see for example, Oakely (1980; 1981; 1984), Kitzinger (2005), Wolf (2001), and Rich (1976), however attention has not focused specifically on women who experience preterm labour and birth and large scale surveys do not distinguish between women's preterm and Term experiences. As I used a feminist lens through which to explore women's experiences of caring for their LPBs, I included feminist terms such as feminism*, gender, discipline*, maternal body, and medicalization into a further search, which revealed two more studies relevant to

women's experiences of preterm labour. The final number of papers reviewed was 19. The search did not reveal any quantitative surveys exploring women's maternity experiences of preterm labour and birth.

The following section will therefore consist of two parts as the literature can be grouped into two distinct environments: women's homes and hospital. The Dignity survey (Birthrights 2013c) and qualitative research (Walsh 2000; 2004; 2006) revealed that women's experiences of maternity care differed within environments (obstetric hospital versus midwife-led maternity unit), therefore it may be possible to draw some correlations between a woman's preterm labour experience at home and as an in-patient.

2.1.1 Preterm labour at home

Eight qualitative studies which focused specifically on exploring women's experiences of preterm labour at home were identified. The studies can be further divided into 'at home and bed rest/activity restricted' (May 2001; Adler and Zarchin 2002; Durham 1999; Alcalde 2011), 'at home and on sick leave' (Höglund and Dykes 2013), 'at home and clinic attendance' (O'Brien et al. 2010), and 'at home and at risk of preterm birth' (previous history) (Palmer and Carty 2006). The final paper explored women's experiences at home and in hospital (Mackinnon 2006).

A large population-based cohort study which looked at patterns and outcomes of preterm hospital admissions undertaken in New South Wales, Australia, revealed the most common reason for admission was suspected preterm labour (Badgery-Parker et al. 2012). Most of women were later discharged (71.9%), however, management of women with threatened preterm labour remains a problem, both in terms of an appropriate plan of care and how to plan resources (Badgery-Parker et al. 2012). The study was not designed to explore that which matters to women, such as their views about their hospital admission, or indeed being discharged back home, although the authors acknowledge women are removed from their family and their social support systems. The following section therefore explores some of these issues.

Mackinnon's (2006) study which explored the social organisation of women's preterm labour experiences provides an insight into how women, under the threat of a preterm birth, coped whilst at home. They reported feeling fearful, alone and they struggled to keep their pregnancy going. As they cared for themselves and their families sometimes from their bed (prescribed to maintain pregnancy), women described lives that were suspended. They felt a "personal responsibility for preventing preterm birth" and were cautious in the way they practised their lives (MacKinnon 2006, p.703), a similar finding to Höglund and Dykes (2013). MacKinnon suggests that discharging women home with the threat of PTL shifts the responsibility from the institution onto the community, with the impact being carried by the woman and her family. She does not, however, recommend women remain in hospital either, which can also negatively impact upon their lives (MacKinnon 2006).

Alcalde (2011, p.210), in her feminist non-medical analysis of pregnancy bed rest, posits bed rest as a "window through which to understand the limits of normative ideas of pregnancy and the centrality of self-discipline and control in women's lives". I agree with her statement, as the studies reviewed for this section paint a rather grim picture of restricted activity (bed rest) and its impact on women's lives, and one which clinicians should take note of, and consider in conjunction with women. It is a reality not described in pregnancy books, women's magazines or the media in all its forms (Alcalde 2011), or indeed in any of the maternity service surveys. In the O'Brien et al. study (2010), women did not find their pregnancy enjoyable as they were under the constant threat of PTL and the imposition of treatments and activity restrictions affected them deeply.

Women find being confined to bed rest emotionally distressing and a burden on themselves and their families (Durham 1999; May 2001; Adler and Zarchin 2002; Mackinnon 2006; Höglund and Dykes 2013; O'Brien 2010). Prescriptions for bed rest or restricted activity varied (Mackinnon 2006), some were confined to bed for 20 hours per day (May 2001), whilst other women were told to adjust their daily life by taking more rest, but were unsure what that entailed (Höglund and Dykes 2013). For most women, restricted activity meant relinquishing daily chores within the

home and if the housework was not done, it was left incomplete (Durham 1999). Ironically, women in May's study (2001, p.34) "had to avoid all physical work and sexual activity", but weekly appointments to have their cervix checked by the physician were mandatory, even if it involved long distance travel and extended clinic waiting times. Women reported trying to lessen the burden on their husbands/partners, and many, weighing the risks between going into established PTL and managing the demands of home, usually gave in to domestic responsibilities (Durham 1999). Undertaking traditional 'women's work' caused conflict in some households, because husbands had to come home after a busy day at the 'office' to manage domestic responsibilities. Many found it difficult coping with both demands (May 2001; O'Brien 2010). Not only were women restricted in what they could do, they were also unable to continue with paid work, which meant for some households, there was a loss of income and families struggled to pay bills, food and other necessary items. Most importantly however, having a job outside the home may have been a significant aspect of a woman's identity (May 2001; Alcalde 2006).

Despite a lack of evidence (Goldenberg et al. 1994), bed rest and/or restricted maternal activity to prevent preterm birth remains a widespread strategy utilised by obstetricians (Bigelow and Stone 2011) and therefore begs the question why it is prescribed so often. A review of the literature by Sosa et al. (2015), which consisted of examining randomized, cluster-randomized and quasi-randomised controlled trials (RCT) to assess clinical outcomes in women at high risk of spontaneous preterm birth who were prescribed bed rest, either at home or in hospital, found two trials that could be considered. Of those, one was excluded because it combined data from single and multiple pregnancies, leaving the other (1266 women) suitable for meta-analysis. Within this group of women, 432 were prescribed bed rest at home and 834 received a placebo (412) or no intervention (422). Rates of preterm birth was similar in both groups, leading the authors to conclude there was no evidence "either supporting or refuting the use of bed rest at home or in hospital to prevent preterm birth" (Sosa et al. 2015, p.3). The authors acknowledge bed rest could impact on women and their families, but clarify that

thus falls out of the scope of their review, which by its nature, adopted a positivist stance in which generalizability, rather than explication of individual circumstances was the aim. They therefore counsel clinicians to discuss with women who are at an increased risk of a preterm birth, the advantages and disadvantages of bed rest. However, there is also little or no additional evidence from observational or qualitative studies as to the perspectives of women on this matter. Thus the evidence that exists suggests no proven benefits of bed rest during pregnancy (Goldenberg et al. 1994; Bigelow and Stone, 2011; Biggio Jr, 2013) or of its effects in women's subjective well-being.

A question therefore arises as to what midwives and women should do with this inconclusive evidence, and, if women were fully informed, whether they would choose to confine themselves to bed rest. Women trust healthcare professionals and are often unaware they can decline interventions (Stephenson 2013) especially as it is not clear from the literature whether medical clinicians fully appreciate the difficulties for pregnant women at risk of preterm birth, who are prescribed bed rest or restricted activity.

Durham's study (1999) depicts three phases women go through when faced with preterm birth. In the first, women are aware of the risks and the importance of their role in preventing preterm birth (activity restriction), and in the second, the reality of being confined to bed and the chaos it entails becomes evident. Finally, women begin to prepare for parenthood once restrictions are lifted (Durham 1999). After a period of weeks of accepting their role, women tended to enter phase two, where they began to resist the dominant discourse by pushing the limits of activity restriction, because of their limited choices and therefore viewed this as a necessary compromise (Durham 1999; May 2001; Alcalde 2011).

Alcalde (2011) depicts these acts of defiance as women trying to reclaim back some of their power and personal agency. Reclaiming control places women at risk of being thought of as medically non-compliant and as 'bad mothers', since societal view of motherhood demands women put aside (sacrifice) their own needs for that of the unborn baby (Adler and Zarchin 2002; Palmer and Carty 2006; O'Brien et al.

2010; Alcalde 2011). One of the mothers in May's study (2001) reported a conflict in her mothering role. Should she comply with bed rest for the sake of her unborn baby or be a mother and undertake activities with her toddler? She, like others, took a chance by "doing too much", even though she was aware her uterus might start contracting again. To counteract "doing too much" she doubled up on her tocolytic medications without informing her medical team. She was risking her own health, but the tension "to be a mother" to her young child was overwhelming (May 2011, p.38). Alcalde (2011) terms this sacrifice for optimal pregnancy outcomes as the 'disciplining of the maternal body'. She describes how women, when prescribed bed rest, lose control over their bodies, which in turn produces feelings of failure and self-blame, common themes throughout all the studies.

Bed rest as a biomedical practice marginalises women into situations over which they have little control (Alcalde 2011), and does not take into consideration that women continue to bear the burden of household responsibilities (Browne 2014). It raises a question of what support mechanisms are available to women as they struggle to uphold their responsibility of "keeping the baby in" (Mackinnon 2006, p.703)? In the O'Brien et al. (2010) study, women valued contact with their consultants, others described family and friends as a source of support (Höglund and Dykes 2013).

However, the Adler and Zarchin study (2001) which evaluated the effectiveness of a "virtual focus group" as an online peer support group for women on bed rest at home, demonstrated the value of women in similar situations supporting each other. Women shared experiences and spurred each other on, which enabled the difficulties presented by bed rest/restricted activity to be overcome (Adler and Zarchin 2002). The published literature focusing on peer support groups highlights the many positive effects of women supporting each other; see for example, an evaluation of a newly established breastfeeding support group undertaken by Alexander et al. (2003). The researchers discovered that the group, which was run by women trained in breastfeeding support, was valued not only for its breastfeeding advice, but also for the psycho-social benefits of meeting and sharing experiences with women in similar situations.

In conclusion, the studies exploring women in PTL at home demonstrate bed rest and/or activity restriction has the potential to impact on the wellbeing of women. Although UK maternity services surveys invite all women to participate, the particular experiences of women in PTL at home on bed rest or restricted activities are not considered when the surveys are designed and evaluated.

2.1.2 Preterm labour in hospital

In this section 11 studies were identified which illustrated women's experiences of PTL in hospital. Many of the quoted studies explored the experiences of women which were related to PTL.

Women as 'in-patients' experiencing symptoms of PTL, underwent similar experiences to women at home. In both situations women experienced feelings of powerless and loss of control (Gaucher and Payot 2011; Barlow et al. 2007; Richter et al. 2007), and whilst women at home were 'present' but with limited ability to undertake 'domestic responsibilities', those in hospital worried about being away from home and the impact of their absence on their husband and extended family (Leichtentritt et al. 2005; Rubarth et al. 2012). The change in a woman's normal role as a mother, a wife, and as a worker, forced a change in the role of others, as husband/partners took on increased responsibility within the domestic realm which resulted in a change for the worse in personal relationships (Stainton et al. 2005; Leichtentritt et al. 2005; Lederman et al. 2013; Gaucher and Payot 2011). Women felt their partners blamed them for experiencing PTL (Stainton et al. 2005) and men expressed anger and resentment at having to take on parental responsibilities (May 2001). Where partners were supportive, anxiety was less and in some situations, a woman's high-risk status brought some couples closer (Lederman et al. 2013; Danerek and Dykes 2014). Despite worries about the unborn baby and the uncertainties facing them, women continued to maintain long distance surveillance over their households, a coping strategy which helped reduce the burden of being in hospital (Richter et al. 2007; Rubarth et al., 2012).

Alcalde's (2011) perspective on women sacrificing their own needs as the disciplining of the 'maternal body' to optimise pregnancy outcomes was very much

in evidence throughout the studies pertaining to home and hospital. Women agreed to the restrictions placed upon them whilst in hospital (Lederman et al. 2013) and others were willing to do 'whatever it takes' to have a healthy baby (Rubarth et al. 2012; Gaucher and Payot 2011; Leichtentritt et al. 2005). Women were less concerned about themselves and more fearful for the baby (Leichtentritt et al. 2005). Many expressed boredom (Leichtentritt et al. 2005; Richter et al. 2007), frustration at being in bed all day (Leichtentritt et al. 2005), a sense of being confined and feeling alone (Lederman et al. 2013), even though many interruptions in the form of clinician rounds and housekeeping duties took place. Interestingly, in the Danerek and Dykes study (2014) women on prescribed bed rest described their experiences as being "forgotten and unseen" especially when staff appeared stressed or busy (p.419). Mackinnon's ethnographic study (2006) describes a similar situation, only she terms it as nurses "nursing the chart" (p.14), since the gaze of the professional was turned away from caring for women and was instead, focused on institutional priorities. There are correlations with how nurses and midwives currently provide care in today's NHS.

Women at home, after a period of time, began to resist the dominant discourse of prescribed bed-rest by pushing the limits of their restricted activities, yet resistance was not evident within the studies focused on women's hospital experience. Indeed, one woman described herself thus, "I was a very, very good patient and I did everything that I was supposed to do, you know" (Harrison et al. 2003, p.111). There may be several explanations for a lack of resistance, not least fear and uncertainty with some women expressing fear of losing their child (Rubarth et al. 2012), giving birth to a disabled child (Leichtentritt et al. 2005), separation issues and whether their baby would survive (Lederman et al. 2013). A further consideration may be women are more able to comply with bed rest in hospital, because they are completely separated from their normal domestic activities, whilst women at home were constantly faced with the reality of their enforced bed rest. Women in hospital are in turn, more exposed to the 'professional gaze' than women at home, and anxiety of managing the 'risks' (reduce the chances of having a preterm baby) possibly serve to keep them subordinate (MacKinnon 2006).

Comparable concerns were expressed in Mackey and Coster-Schulz's (1992) study. Women wanted a healthy baby born at term, although the treatments they had to undergo to prevent PTL and any potential side effects on the unborn baby caused anxiety. An interesting feminist perspective is provided by Williams and Mackey (1999). They undertook secondary analysis of interview data of 29 women who participated in the original study undertaken by Mackey and Coster-Schulz (1992) and sought to critique and 're-present' women's experiences of PTL. Many in the original study were provided with a range of medications to forestall PTL, such as tocolytic therapy. Women were advised to continue with treatment until the "safe zone of 36 weeks" was reached, an implication which suggests that by then, "women were no longer responsible for the fate of their unborn child" (Williams and Mackey 1999, p.36).

There is no clear evidence tocolytics prescribed to prevent or forestall PTL improve outcomes and latest guidelines suggest it is reasonable not to use them (Royal College of Obstetricians and Gynaecologists (RCOG) 2011). However, if obstetricians wish to temporarily delay to enable the unborn baby to receive a course of corticosteroids, or transfer the woman to a hospital with neonatal intensive care facilities, then tocolysis can be considered (RGOC 2011). However, use of these drugs does not come without their own set of problems. Side effects such as a lowering of blood pressure (BP) an increase in heart rate, headaches, nausea and many more have been documented (de Heus et al. 2009). Women may also be offered medication to counteract side effects such as nausea, treatment options which present an interesting dichotomy. Throughout pregnancy women are advised to abstain from utilising prescribed or non-prescribed medication if at all possible, to prevent any untoward effects on the unborn baby, yet when women in PTL become obstetric patients, a plethora of medications (usually ineffective) are prescribed in an effort to stop birth from occurring prematurely (Williams and Mackey 1999). A systematic review to determine how effective medical interventions that aim to reduce the rates of preterm birth were, was carried out by Wisanskoonwong et al. (2011), which concluded that at the level of an individual woman and at a population level, interventions are not effective because rates of

preterm birth continue to rise. More recently however, evidence from a systematic and network meta-analysis study appears to suggest that certain medications such as prostaglandin inhibitors and calcium channel blockers had the highest probability of delaying birth (for circa 48 hours) and improving neonatal (notice order of preference) and maternal outcomes (Haas et al. 2012).

None of the studies explored within this section consider women's experiences of medication to prevent PTL whilst on bed-rest (this is a missed opportunity in my view), although both May (2001) and Rubarth et al. (2012) briefly make reference to the issue in which women describe how medication affected them.

"You're being told to 'stay on the couch, take your medicine every two hours' even though it makes you feel like you want to jump out of your skin" (May 2001, p.42).

"The nifedipine is giving me the worst headaches I have ever felt" (Rubarth et al., 2012, p.5)

There is a need to qualitatively research women's experiences when undergoing long term tocolytic therapy. The established literature, although full to bursting on which tocolytic is the most effective in terms of cost and such like, does not have any published studies which explore women's views on how the medication affects them day to day.

As previously alluded, women in PTL will sacrifice much, seeing themselves and their needs secondary to that of the unborn child and this may have an effect on how they perceive their experience. The health of a woman and that of her unborn baby are inextricably intertwined, they are biologically linked, yet viewed by others as independently viable (Ludwig 2008). Music (2013, p.12) interestingly, compares an unborn baby as a "cosmonaut in charge of a spacecraft", a view which regards women as a vehicle for their baby, driving her through the pregnancy, thus raising an image of duality – each with their separate agendas (Smith 2014). When considering 'duality' within the spectrum of PTL, most women would not see themselves in competition with their baby, but rather, one of unity, since in most cases women accepted treatment to optimise outcomes both for themselves (albeit reluctantly) and their babies (Ludwig 2008; Gaucher and Payot 2011).

Bed rest is another unproven treatment. The documented harmful effects of bed rest for general conditions are muscle and bone density loss, blood clots, cardiovascular irregularities and changes in the endocrine and immune systems (Biggio Jr 2013). Based on these known and harmful side effects, people who have experienced heart attacks, lung infections and postoperative recovery are not encouraged to lie in bed for prolonged periods of time. The same recommendations have been extended towards women who are at risk of complications during their pregnancies, yet bed rest as a treatment for women at risk of preterm birth (including other pregnancy complications) persists, despite a lack of evidence (McCall et al. 2013).

None of the studies reviewed discussed the physical effects on women of enforced bed rest; although in the Rubarth et al. study (2012, p.5) women were asked to complete a journal in which to document the effects of bed rest. Physical symptoms such as “sore legs from not walking about”, “feeling sore everywhere”, and “feel like I got hit by a bus last night” were described by the women and women often lacked rest and sleep. Others compared their bed rest to being in prison and a prisoner chained to a bed, because they were attached to machines in order to monitor the wellbeing of the unborn baby (Rubarth et al. 2012).

A further concept explored by May (2001, p.16) but not evident within any of the other studies, was women reporting they received “little, if any advice....about the realities of deconditioning and the need for physical reconditioning in the postpartum period”. Women stated they felt dizzy and weak, and in the opinion of the researchers (all experienced perinatal nurses), women appeared to experience symptoms well beyond those usually seen during the postnatal period. A study which examined postpartum symptoms after antepartum bed rest suggests women’s symptom’s decreased over time, although still in evidence at six weeks (Maloni and Park 2005).

Maternity surveys in England have repeatedly signposted the postnatal period as the one area in need of service improvement with women continuing to complain about the care they received, denoting postnatal reforms have lagged behind other

areas. Although maternity surveys inquire whether women required an antenatal admission, it is not an in-depth exploration and therefore it is largely unknown whether admission during the antenatal period affected women's recovery postnatally, although women have reported the baby was of more interest to the professionals than their own health (Bhavnani and Newburn, 2010).

The risks of all prescribed treatments should be discussed with women at risk of PTL to ensure informed decision making (RGOC 2011), yet it appears many women either do not understand the implications of a course of treatment (Mackey and Coster-Schulz 1992), or consent to treatment without all the relevant information (Williams and Mackey 1999; May 2001). Noteworthy is the study by Harrison et al. (2003) which examined women's satisfaction with their involvement in health care decisions during their high-risk pregnancy. Of the 47 women interviewed, fourteen were satisfied with passive involvement in decision making and entrusted the healthcare professionals to make the right decision for them and their baby, including one woman who reported her willingness to follow doctors' orders because they were more capable than she was in making the correct decision (Harrison et al. 2003).

Women accept treatment as not many alternatives are available except to have their baby preterm, others have defined this as 'ambivalence' towards their situation, as, on the one hand it would be easier if they gave birth, and on the other, a need to prolong pregnancy to benefit their baby (Leichtentritt et al. 2005). Women studied by Gaucher and Payot (2011) appear to have given up when faced with bed-rest and a prolonged hospital stay by declaring "we let ourselves go...we are powerless....we let go and we let them do anything to us".

Although the study by Mackey and Coster-Schulz (1992) is over 24 years old, there are parallels with contemporary practice when considering consent around treatment. While the Dignity survey (Birthrights 2013c) was not related to preterm birth and/or treatment of such, it specifically asked women whether they had consented to examinations or procedures. It is difficult to infer from the survey at what gestation women gave birth as it is not reported, however 12% of women

reported having ‘things done to them’ without their consent and this was more common with women who were first time mothers and those who had undergone an instrumental delivery. Context remains an important factor; women reported consent was more likely to be obtained when they gave birth in birth centres rather than in busy obstetric units. Barlow et al. (2007) ascertained that women in PTL needed staff to provide additional information and/or explanations and it needed to be consistent. Women at all stages of their pregnancy journey, whether high or low risk, birthing at home or in hospital, have the right to make their own decisions about their bodies even if it is a decision healthcare professionals might disagree with (Birthrights 2013a; Alcalde 2006).

When comparing women who are at threat of PTL with women’s experiences of maternity services in general, it is difficult to draw many comparisons because the studies drawn on within this section have mostly emanated from the US, Canada, France, Sweden, Australia and Israel which have different systems of healthcare than England. Two exceptions are the studies undertaken by Barlow et al. (2007) and O’ Brien et al. (2010) both of which explored women’s experiences of preterm labour (PTL). The former examined hospital admission in a maternity hospital in England, and the latter studied women at threat of PTL attending a specialist preterm antenatal clinic. A central theme to emerge from the Barlow et al. (2007, p.431) study was the concept that women reported “not being believed and not being taken seriously”, similar findings to Mackinnon (2006) and Palmer and Carty (2006).

Therefore women in PTL face an unknown future, will their pregnancy continue to Term or will they give birth early, not knowing the extent or risk of complications their baby may experience? Women in these situations live with the constant tension between preventing PTL and the worry of “trying to keep the baby in” (Mackinnon 2006, p.703), and whilst they may reach Term gestation, the journey towards that point is filled with feelings of self-blame, failure and worry about outcomes (Mackinnon 2006; O’Brien et al. 2010; Gaucher and Payot 2011).

It is worth considering what is a mother and/or mothering at this point. Is it for example, the individual experience of a woman facing the birth of her baby or a responsibility a woman has, in accordance to rules set by culture or social group in which she exists (Ambrosini and Stanghellini 2012)? Additionally, do we know how women really experience motherhood (Ambrosini and Stanghellini 2012)? Becoming a mother changes a woman's life and certainly impacts on and requires an identity adjustment (Laney et al. 2015), for example she is faced with re-examining who she is, her physical appearance, her sexuality and her autonomy both before and after the birth of her children (Laney et al. 2015). Furthermore, becoming a mother involves assimilating assumed ideals about how one ought to mother with the lived reality of motherhood (Laney et al. 2015) which can become an area of conflict when individual ideologies of motherhood come up against the 'master narrative' (Porter 2010). Within this narrative, there are two overriding themes: the first is 'who', which translates to which group of people should be responsible for a task, in this case mother-work and within patriarchal motherhood it is mainly women (Porter 2010). The second relates to the 'how', which essentially is the job description that ensures mothers and indeed society understand what a 'good mother' is (Porter 2010). Adrienne Rich (1976), a radical feminist termed this as the 'institution of motherhood'.

Rich differentiates between "two meanings of motherhood, one superimposed on the other: the *potential relationship* of any woman to her powers or reproduction and to children; and the institution, which aims at ensuring that that potential – and all women – shall remain under male control" (Rich 1976, p.13). She further maintains that while motherhood as an institution is a male-defined site of oppression (Rich 1976; O'Reilly 2008) and functions in a way that separates mothers from each other (D'Arcy et al. 2011), women's own experiences of mothering can be empowering (Rich 1976; O'Reilly 2008).

Motherhood as an institution therefore abides by a set of rules and regulations foisted upon and internalised by mothers (and the wider society) that prescribe not only how to mother but who is a 'good' or 'bad' mother (Green 2015). As a narrative it does not take into account women's individuality (their likes/dislikes,

skills, talent and so on) and the expectation is that all mothers should mother in the same way (Porter 2010). As a consequence, when women fail to reach the ideal, they more than likely blame themselves or feel guilty about their shortcomings (Laney et al. 2015).

Almost on a daily basis women are bombarded with messages from the media in all its forms promoting the stereotypical 'good mother' (white, heterosexual, stay at home 'mum', supported by her husband) against the warnings about the dangers of 'bad' mothers (Green 2008). Bad mothers as a label can be applied to all women regardless of their race, sexual orientation, religion or socioeconomic status but in particular three categories are relevant to the overall 'bad' label which are the 'selfish mother', 'the non-traditional mother' and the "wayward' offspring mother' (Gotlib 2010). Selfish mothers, such as those who work outside the home are putting their own needs before those of their children, whilst the non-traditional mother may be unmarried and on benefits and thus unable to provide what the master narrative believes essential for being a 'good mother' (Gotlib 2010). She could also be an older mother, a lesbian mother or a mother without a partner none of which fit with the stereotype of a traditional family. In all of these situations she is perceived as being unable to provide stability, nurturing and support that children require (Gotlib 2010). The 'wayward' mother is the worst offender. She is often the woman of lower socioeconomic status and her children are in prison, unemployed, take drugs or have alcohol addiction (Gotlib 2010). Experts, through research and studies, use 'wayward' mothers as "proof that certain kinds of mothers produce maladjusted or even criminal offspring (Gotlib 2010, p.102). There is no consideration on the effects of poverty, sexism, and racism impacting on how these women 'mother' (Gotlib 2010).

The prevailing discourse of 'good' or 'bad' mothers serves to control women and ensures their continued uptake of caring for children and links their "identities to their role as child raisers and nurturers of others" (Goodwin and Huppertz 2010, p. 6). Feminists recognise that the needs of mothers and children do not conveniently overlap, "mothers are not 'rational men' looking to maximize their own advantage in any situation, rather they/we have been schooled to put children's needs first"

(D'Arcy et al. 2011, p.40). However, if, as Rich decrees, mothering can be liberating, it is only by starting from women's experiences is it possible to understand the complexity of motherhood (Ambrosini and Stanghellini 2012) which my study aims to do. In addition, throughout my thesis I have paid attention to the use of my language which, I hope, is thoughtful and 'respectful' to women (Jackson and Mannix 2004).

Finally, women at increased risk of pregnancy related complications (such as PTL) are "frequently filled with self-accusations" (Berg 2010, p.183) as they have failed to achieve the ideal of being the 'perfect mother' (Green 2010), who is a woman who has achieved a healthy pregnancy by avoiding all substances harmful to the unborn baby, resulting in a birth at Term. In patriarchal motherhood there is a prescribed way to be a 'mother' (Rich 1976) and women who have not reached this pinnacle are deemed 'bad mothers' and blamed by society for their situation (Jackson and Mannix 2004; Gotlib 2010; Green 2010). This is borne out by a study undertaken by Stainton et al. (2005) in which husbands appeared to blame their partners for PTL. Indeed women blamed themselves as they struggled to keep the pregnancy going (MacKinnon 2006).

For women who consider themselves as bad mothers, the consequences are real as they have reported feelings of being fearful, alone (Mackinnon 2006), emotionally distressed and feeling a burden on partners and family (Durham 1999). Women in PTL sacrifice much in order to put their baby and families first (Alcalde 2011) which is the expectation of institutional motherhood (Rich 1976). Any deviancy from this model of mothering puts women at risk of being thought of as being medically non-compliant (Adler and Zarchin 2002; Palmer and Carty 2006; O'Brien et al. 2010; Alcalde 2011) and 'bad mothers'. Experiences of women in PTL also highlight the gendered nature of their domestic situation and of many women in general. Not being able to undertake traditional 'women's work' caused conflict in some households, as husbands appeared to resent having to pick up the family responsibilities (May 2001; O'Brien 2010).

There is a need for balanced care when caring for women at high risk (Berg 2010), in order to avoid an experience of being “forgotten and unseen” (Danerek and Dyke 2014, p.419). These women are vulnerable and need to have an element of control over their lives/experience, to avoid lessening their feelings of being a mother (Green 2010) and to be recognised and accepted by healthcare professionals as mothers in waiting (Berg and Dahlberg 1998).

The majority of women in England continue to give birth in NHS hospitals which were designed to treat the sick but which have also medicalised and pathologised childbirth (Crossley 2007). Most pregnant women are there because they are experiencing a ‘wellness event’ with only a small proportion of women experiencing an ‘un-well event’ (PTL), despite feeling well in themselves (Leichtentritt et al. 2005). The contrast between a wellness event (pregnancy and childbirth) and un-wellness event (PTL) and becoming an ‘obstetric patient’ makes for a multidimensional maternity experience which no survey will uncover. For example, the maternity surveys cited previously would not have exposed the “embodied work performed by women in preventing preterm labour” (Mackinnon 2006, p.15), nor detect the loneliness and lack of mutual support reported by some women (Adler 2002; Richter et al. 2007; Rubarth et al. 2012). Additionally, maternity services surveys would not unpick the effects of enforced bed rest for women at risk of PTL and the consequences upon their physical health which are apparent for some six weeks post birth (Maloni and Park 2005).

Barlow and colleagues (2007) suggest a longitudinal approach to researching women in PTL is required, whereby women are followed through birth and into the postnatal period. In addition, the perspectives of healthcare professionals involved in the care of these women (Barlow et al. 2007) are warranted. I would agree these are under-researched areas and much needed in the UK, but would add research is required in understanding how these women care for their (late) preterm babies. The following section will therefore examine two surveys published in 2011 and 2014 which explored parent’s experiences of neonatal care. I will be making reference to the wider research and literature which explores women’s experiences

of having a preterm baby, and will aim to demonstrate how these experiences are not easily generalized through standardised surveys.

The following section does not address the literature relevant to women with late preterm babies (LPBs) as this is discussed in Chapter 3, although as previously indicated, this sub-group of preterm babies are generally not dealt with separately within the literature. Therefore, drawing on evidence from the general preterm population will include their experiences. In addition, the strengths and limitations of using quantitative research to explore women's experiences are likely to be applicable to exploring the perspectives of women who birth late preterm as at any other time.

2.2 NEONATAL SURVEYS:

Introduction

The previous section highlighted a rather fraught experience for women in preterm labour and I wondered whether their experiences improved following the birth of their baby. A search on a university library database was unsuccessful in retrieving any surveys pertaining to women's experiences of preterm birth; however a search on Google proved fruitful. Three surveys were retrieved, two of which explicitly reported on parents' experiences of neonatal care (Howell and Graham 2011, Burger 2015), and the third focused on issues linked with organisation of neonatal care, transfers and the role of neonatal networks (Redshaw and Hamilton 2006). Included within this survey was an exploration of parental experiences on admission to the neonatal unit, care whilst in the unit and any travel difficulties if their baby had been transferred out and cared for in other neonatal units (Redshaw and Hamilton (2006). The following section will therefore explore parent's perceptions of neonatal care by examining the surveys in more detail and making reference to the wider preterm literature.

2.3 PARENT'S EXPERIENCES OF NEONATAL CARE

Methodological processes underpinning the neonatal surveys were equivalent to the maternity services surveys. There are similarities in terms of respondents, the

majority were white (97%), more than half were aged between 31 and 35 years (although the 2011 and 2014 surveys demonstrate the age group of women between 35 or more as a close second) and the greater part were first time mothers. The majority of babies born were preterm and the most common reason for admission to neonatal care was preterm birth.

There are some significant demographic differences in gestational age at birth between the 2006 survey and the two later ones. The average gestational age was 29 weeks in the Redshaw and Hamilton (2006) study, which meant a prolonged hospital stay, with length of residency for babies within neonatal care averaging two months. A range of problems were experienced by preterm babies, for example, respiratory problems requiring ventilation (Redshaw and Hamilton 2006). The 2011 and 2014 surveys highlight that 41% of women gave birth between 33 and 37 weeks gestation, which suggests many of these babies could be defined as late preterm, which is birth occurring between 34⁺⁰ and 36^{6/7} weeks gestation (Engle 2006; Raju 2006b, Jorgensen 2008b; Shapiro-Mendoza and Lackritz 2010). Interestingly, the next highest number of neonatal admissions was from the group of women whose babies were 38 weeks gestation or more (40%).

The 2006 survey, unlike the 2011 and 2014 surveys, provides an insight into the circumstances preceding preterm birth. For example, over half of the women (57%) responding required an antenatal hospital admission, with the median stay totalling 10.22 nights. Threatened preterm labour was one condition amongst others which necessitated admission, although pregnancy-induced complications such as high blood pressure, pre-eclampsia, placenta praevia and intra-uterine growth restriction were some of the other recorded complications which could also have resulted in a preterm birth (Redshaw and Hamilton 2006). Women were not surveyed on their emotional responses to being an in-patient, although the authors acknowledged the medical problems experienced by the women would have caused anxiety, which ultimately, would have affected the wellbeing of themselves and their families (Redshaw and Hamilton 2006).

The previous section highlighted the uncertainties experienced by women in PTL and their fears about future outcomes. The three surveys demonstrate that a large proportion of women only became aware their baby would require a neonatal admission during labour and birth or soon thereafter, which suggests women at a lower gestation are more prepared for a neonatal admission than women whose babies would be considered late preterm.

Similar to the surveys undertaken to explore women's experiences of maternity services, the aims of the two latest neonatal surveys was to:

- Understand parents' experiences of neonatal services.
- Provide information on the current provision of neonatal care.
- Identify areas for improvement (Howell and Graham 2011; Burger 2015).

The response rate was 50% for the 2011 survey (Howell and Graham 2011) and even lower for 2014 – 37.6%, therefore, as with the maternity surveys, the generalisation of the findings must be questioned. It is worth noting the majority of respondents were mothers (82%), with only 3% of fathers participating, and 14% of parents together (Howell and Graham 2011, Burger 2015) similar to the participant response rate in the survey carried out by Redshaw and Hamilton (2006). Therefore, were the women reporting their views, or the combined views of themselves and their partners? It appears that distinctions between experiences from a gender perspective are important, especially as the majority of women are responsible for mothering.

Mothering a potentially sick or term baby on a neonatal unit has a number of implications for women as they become mothers. They are required to practice mothering in a public area under the vigilant gaze of 'experts' unlike women who become mothers to babies who are well (Lupton and Fenwick 2001). Generally these women (after a short stay in hospital) begin mothering at home where they get to learn and care for their babies in a more private setting (Lupton and Fenwick 2001) although they are still somewhat at the mercy of experts in the form of societal expectations of motherhood, friends and family (Goodwin and Huppatz 2010). Nowhere is this more evident than in Millers study (2007) which reported on

women's experiences to first time motherhood. The longitudinal study which interviewed women at three key points in their motherhood journey (antenatal, intrapartum and postnatal periods) revealed how, during the early transition to motherhood women came up against the dominant discourse which caused confusion amongst them (Miller 2007). The confusion appeared due to the social construct of motherhood which has created a 'master narrative' that expects women to 'mother' in specific ways (and which men are exempt from), and which implies all women's experiences of mothering are the same. All women it seems are aware of the 'shoulds', an unreachable pinnacle of motherhood (Porter 2010; Goodwin and Huppatz 2010). Thus it could be argued that by combining the experiences of mothers and fathers when so few men responded as 'parent's experiences', fails to take into account what it means for women who have undergone a preterm labour and birth and their experiences of becoming a mother in a public arena where the unspoken emphasis is on women to be 'good mothers' and attention is concentrated wholly on the baby with little consideration for the mother (Porter 2010).

In addition, the two contemporary surveys do not explore whether women were hospitalised prior to the birth of their baby, nor whether any of them underwent interventions during their labour leading to operative or instrumental births, all of which would have impacted on their subsequent experience of maternity and neonatal services. There is also no differentiation in the findings as to whether 'parents' were mothers, fathers or same sex couples.

The results from the 2011 and 2014 survey of parent's experiences of neonatal care have some resemblance with women's experiences of maternity services. Overall, the majority of parents were satisfied with the care received and were positive about many aspects of their experience. Many parents had confidence and trust in the staff caring for their baby and were treated with respect and dignity. Areas where the experience was less positive focused on communication with a doctor (they wanted more), additional written information, increased involvement in decisions relating to their baby, less conflicting advice about their baby's condition, more hands-on care such as KC, and extra support prior to and following discharge.

The questionnaires would have been more meaningful if there had been opportunities for parents to share additional detail around certain aspects of what the experience meant to them, although the 2014 survey invited narrative feedback. Over 3,700 participants provided additional commentary which was presented as a 'word cloud' within the document. I tried to access the free-text statements by contacting the Picker Institute which carried out the 2014 survey, but was informed verbatim comments were not publicly accessible, since only individual NHS neonatal units had access, to assist with understanding experiences of care in their unit and identifying areas for improvement (Tallett 2015).

The themes used within the next half of this section were identified as important when exploring the literature which qualitatively studied women's experiences of PTL whilst hospitalised and discussed in section 2.1.2. One further study reporting on non-clinical issues and how these affected a family's journey through neonatal care was identified and contributed to the themes (Poppy Steering Group (PSG) 2009). The themes illustrate aspects of care which would improve women's experience prior to and following birth of a preterm baby:

- Before the baby is born
- First sight of baby
- Separation from baby
- Women's status as a mother – will it be acknowledged?
- Involvement in baby's care
- Information and support parents
- How long will the baby be in hospital for

2.3.1.1 **Before the baby is born**

- Antenatal preparation:

Having a baby admitted into a neonatal unit is a stressful event whether the baby is born Term or preterm (Lau and Morse 2003; Wigert et al. 2006; Lindberg and Öhrling 2008; Tooten et al. 2013) with women feeling unprepared for motherhood in an unfamiliar environment (Lindberg and Öhrling 2008). In the situation where women are predicted to give birth preterm, the toolkit for high quality neonatal

services recommends women and their partners have an opportunity to visit the neonatal unit and meet key staff (NHS and DH 2009). Preparation before birth helps parents adjust and be better prepared (Poppy Steering Group (PSG) 2000; Gaucher and Payot 2011; Trajkovski et al 2015). It is difficult to gauge what this preparation consists of, however parents from the POPPY research reported they wanted to know whether there would be opportunities to hold their preterm baby and information on breastfeeding.

In addition, clear and detailed information about a unit and its facilities was needed and a tour was highly valued, because it enabled parents to view where their baby may end up. Furthermore, it was an opportunity to be introduced to the staff who would be caring for their baby (PSG 2009). These opportunities are supported by qualitative research undertaken by Gaucher and Payot (2011). Women were interviewed on their concerns around preterm labour (PTL) and their expectations regarding antenatal consultations with a neonatologist. They reported wanting information on the short and long term complications specific to their baby's gestational age, including knowing about the technology used to support their child (Gaucher and Payot 2011).

An interesting flipside would be parents going to the unit and introducing themselves first and foremost as the parents and main carers of their baby. However, that would require a very assertive couple as when women and their partners enter a neonatal intensive care unit (NICU) they are moving into a highly technical terrain imbued with expert knowledge, including rules and regulations (wash hands before touching your baby, visiting times), all of which exert a powerful control over parents (Lock and Gibb 2003). A small UK study which explored mother's perceptions of family centred care (FCC) in NICUs (Finlayson et al 2014), revealed women were initially happy to hand over care responsibilities and defer to expert medical knowledge, however, trying to redress the balance of power as women got more used to the unit was difficult. This resulted in women being unable to form meaningful relationships with healthcare professionals including disrupting their ability to bond with their baby (Finlayson et al 2014).

The neonatal surveys continue to demonstrate a large proportion of parents are not offered an opportunity to visit NICU and meet staff prior to the birth of their baby (Howell and Graham 2011; Burger 2015). Visits to the unit are, it seems, prioritised for babies born at an earlier gestation, with lower birth-weights and who generally end up spending a longer time on a NICU. It is understandable that parents of these babies are afforded this opportunity, however as evidenced by the 2014 survey, the greatest proportion of babies were born between 33 and 37 weeks of pregnancy (41%), and 66% of these women (and their partners) were unaware during pregnancy and labour their baby might need care in a neonatal unit (Burger 2015). Preparation as a marker of good practice does not appear to be working for the majority of women and their partners whose babies are admitted onto a neonatal unit.

Women who experience PTL often have to find meaning in their experience (Barlow et al. 2007), with many feeling shocked they have become mothers to a preterm baby (Lindberg and Öhrling 2008). If women are not aware their baby may be removed for neonatal care, it makes for a traumatic experience. No explanations are offered examining why some women (parents) may have an opportunity to visit a NICU and others not, although the survey undertaken by Redshaw and Hamilton (2006) which explored staff capacity in NICUs, suggests a major problem for managed clinical neonatal networks is inadequate nurse staffing, therefore it is possible to infer that neonatal staff may not always have time to show parents around.

2.3.1.2 First sight of baby

Maternity services surveys reflect most women have early contact with their babies by experiencing skin-to-skin care (S2S) and an early breastfeed (Redshaw and Heikkila 2010; CQC 2013). This initial contact is often denied to women who birth prematurely or have a sick newborn, although the 2011 neonatal survey indicated 85% of parents were able to touch their baby before admission. Unfortunately, for at least 15% of parents, they were unable to experience early contact because of medical reasons impacting on their baby's health (Howell and Graham 2011). Early

contact between mother and baby was not revisited in the 2014 survey (Burger 2015).

In a study undertaken by Obeidat et al. (2009) women who were separated from their babies immediately after birth felt alone, disappointed and insecure, especially following the powerful experience of giving birth. Others have expressed it as, instead of experiencing the joy and happiness of a newly born child and being a mother, there was just sadness as the first moment with their child is brief or for some women, as we have seen, none at all (Lindberg and Ohrling 2008; Howell and Graham 2011; de Cássia de Jesus Melo et al. 2014). Arnold et al. (2013) undertook a qualitative semi-structured interview study of 32 mothers and seven fathers of very preterm babies (less than 32 weeks). When asked “when did you first see/touch your baby” half of the parents (mothers) did not remember anything during and immediately following birth. One of the mothers had undergone an OD and had not realised her baby was born. Those who were shown their baby could not remember seeing them. A number of mothers recall this period of their birth as a “distortion of time”, although fathers also appeared to have difficulty recalling events. In many situations women rely on their partners for explanations of events surrounding the difficult circumstances of their birth (Arnold et al. 2013, p.3). None of the parents in this study were able to hold and briefly touch their baby until they were able to go up to the neonatal unit.

An early study undertaken by Redshaw and Harris (1995, cited Redshaw 1997) which examined maternal perceptions of neonatal care, concluded that women, irrespective of their pregnancy or birth experience, found separation as “the worst and most painful aspect of having a baby admitted to a neonatal unit” (Redshaw 1997, p.113). This has since been supported by many contemporary studies, see Erlandsson and Fagerberg (2005); Jotzo and Poets (2005); Latva et al. (2008) and Hall et al. (2013).

2.3.1.3 Separation from baby:

As established, women who begin motherhood early are traumatised and find the enforced separation from their baby extremely difficult. Being cared for on the PNW with other mothers and their Term healthy babies contributes to these feelings (Howell and Graham 2011). Research suggests these women should be treated sensitively and provided with emotional support, but has found this is not necessarily the case (PSG 2009). For example, women in the POPPY Project reported they found it difficult being on a ward with other postnatal mothers when their baby was on a NICU and one of the mothers repeatedly had to ask about her baby because she was unable to get out of bed to provide his care (PSG 2009).

The 2011 neonatal survey disclosed that 59% of women were cared for on a routine PNW and over half of these women (32%) were bothered by this (Howell and Graham 2011). There was no further exploration of these findings. Adding to this difficulty was distance, because for some mothers, their baby/babies had been transferred to a unit in another part of the country. The toolkit for high-quality neonatal services specifically recommends keeping mothers and their baby/babies together during admission (NHS and DH 2009), yet one in ten parents disclosed their baby was transferred to a regional unit. Of those parents, 33% were cared for in a separate hospital to their baby. The 2014 survey demonstrates that 23% of parents had their baby spend most of its time in another unit, whilst 15% stayed in two or more different units (Burger 2015), suggesting this aspect of neonatal care has only marginally improved.

Two issues are immediately apparent, firstly, organisation of care in NHS hospitals in England do not facilitate enhancing mother-baby relationships when a baby is ill or preterm, and secondly, managed neonatal networks inflict an even greater separation since mother and baby are cared for in separate hospitals, and often a long distance from their own local support systems. In the survey by Redshaw and Hamilton (2006), parents were questioned about the impact when their baby was transferred to another unit. Narrative feedback afforded providers of healthcare, commissioners of services and staff an opportunity to appreciate the difficulties

faced by parents. Some were required to travel 120 miles to be with their baby, others had no money and relied on relatives for transport to the hospital. The impact on women who are ill is even greater as the following quote reveals:

“I was concerned I wouldn’t get to see my baby as I was so poorly at the time.....I was confident that she would be well looked after, but I hated her having to be taken away” (Redshaw and Hamilton 2006).

Many studies indicate a woman who has experienced a preterm birth has themselves become a preterm mother and thus begins a journey of motherhood with a sense of guilt and one of abandonment and separation (Holditch-Davis and Shandor Miles 2000; Erlandsson and Fagerberg 2005; Lindberg and Ohrling 2008; de Cássia de Jesus Melo et al. 2014). Women revealed in Erlandsson and Fagerberg’s (2005) Husserian phenomenological study that it was the organisation, the staff and other circumstances which impacted on the separation. These women, whose needs whilst on the PNW were not met, wanted to be cared for in the same environment as their baby (Erlandsson and Fagerberg 2005). Other women have found it frustrating being in close proximity to mothers resident on the PNW with Term babies (Broedsgaard and Wagner 2005). Baum et al.(2012) suggest all women who birth prematurely should be in a postnatal room with other mothers in the same position.

In Broedsgaard and Wagner’s study (2005) women would have preferred to be resident on a mother-infant unit within the neonatal unit. The 2011 neonatal survey revealed that women whose baby had greater medical needs, such as a birth weight of less than 1000 grams, were more likely to be cared for in a separate room or area following birth (Howell and Graham 2011) although this was by no means consistent throughout all the neonatal units surveyed. Women whose baby weighed more than 2500 grams had no options and were admitted onto the PNW (Howell and Graham 2011). Of note, the section on key improvements in the 2014 survey revealed women continue to be cared for in the same environment as mothers with Term babies, and for many, it ‘bothers them’, although on a positive note 42% of women stayed in a separate room/area (Burger 2015). I was unable to

ascertain whether this was on the neonatal unit or on a PNW within a side room. A further marker of good practice which currently seems unachievable.

In 2010, Ortenstrand and colleagues (2010) reported on a RCT that was undertaken in two Level 2 NICUs in Sweden. The main aim was to evaluate the effectiveness of a new mode of family care where parents could reside with their premature baby 24 hours/day from admission to discharge. The principal outcome was to determine total length of stay (LOS), and at least one parent was required to stay 24 hours a day during the entire period of hospitalisation. Both of the neonatal units involved had separate rooms for all families, including beds for both parents with en-suite facilities, and the rooms contained the necessary equipment for the baby. The findings demonstrated that providing facilities which kept parents and babies together reduced overall length of stay by five days (Ortenstrand et al. 2010). Although the study evaluated LOS, the advantages of keeping parents together with their baby would negate the consequences of separation and promote closeness (Flacking et al. 2012).

Women interviewed in Flacking et al.'s (2006, p.74) study saw separation as "a sign of being unimportant as a person and a mother". Like others in similar positions, women were cared for on a maternity unit whilst their baby was on NICU, and separation continued until their baby was discharged home. As a result of not feeling like a mother, women felt they were visitors on the neonatal unit, and described staff as being at the centre of their baby's care. It is thought-provoking noting women describing themselves as visitors, when the focus should be as mothers caring for their babies. An obvious question is, do mothers 'visit' their babies? Can there be another way of describing what a mother does instead of perpetuating the word 'visit' as is evident on the neonatal surveys. At least five highly relevant questions about the parent's experience contained the word 'visit', for example: "When you first visited the unit, were you able to speak to a doctor or nurse about your baby's condition as soon as you wanted?" and "When you first visited your baby, were you given enough information about the neonatal unit (such as rules, procedures and facilities for parents?" (Howell and Graham 2011, p.66, 67; Burger 2015, p.87, 92, 95). Visiting times, rules and procedures all suggest

an environment into which a woman and her partner must fit, rather than an environment which promotes a woman's transition to motherhood by truly placing her (and partner) at the centre of their baby's care (Johnson 2008). It is worth pondering why parents did not object to the use of 'visit' when the surveys were initially designed.

Both neonatal surveys do not pose questions enquiring how women felt at being separated from their baby, which research has shown to be a major issue (Redshaw 1997; Erlandsson and Fagerberg 2005; Wigert et al. 2006; Baum et al. 2012), rather it asked whether a member of staff had spoken to them about their baby's condition and treatment and for how many hours did they wait until this happened. Whilst the majority of parents stated they were seen by a member of staff (78%), 22% reported no. When asked about the timing, 59% of parents were seen within an hour, 20% seen after an hour but less than two, and 10% of parents only seen four or more hours after their baby's birth (Howell and Graham 2011). There is no explanation for these delays, or indeed how these parents may have felt. The 2014 survey highlights 91% of parents were able to see their baby on the neonatal unit as soon as they wanted (Burger 2015), which is an improvement from the earlier survey but still leaves just under 10% of parents who did not.

Hall et al. (2013, p.112) illustrates how women in their study felt after their preterm baby was taken away. Previous to birth, they interpreted a pregnant woman and her unborn baby as "continually affecting each other but still evolving individually". Once that relationship was interrupted with the baby removed and placed into an incubator, in an unfamiliar environment surrounded by technology and highly trained professionals, a woman became a mother in limbo, similar to women in Watsons' (2011) study, but most of all, women were left with a "feeling of an empty body and a missing relationship" (Hall et al. 2013, p.112).

One of the strategies used by neonatal units during a time of separation is to provide women with photographs of their baby, as research has indicated this helps with mother-baby bonding (PSG 2009). Of the parents who responded to the survey question about a personal photograph (Burger 2015), just under half were provided

with one (46%), with 23% stating no, but would have liked one. Whilst it seems an easy thing for staff to do, the 2014 survey demonstrates only 46% of parents were provided with a photograph and 25% were not but wanted one. Parents who were not offered a photo (29%) took one for themselves (Burger 2015). No clarification is provided as to why some parents are offered a photograph and others not. It may be nowadays many parents have cameras on their mobile phones and therefore do not need an instant 'polaroid image' when they can do it themselves. Certainly many parenting websites dedicated to premature babies advise taking a series of images throughout the baby's stay to record milestones and so on.

2.3.1.4 Women's status as a mother – will it be acknowledged?

The above identified theme is not asked on either neonatal survey despite questions being constructed in part with the help of parents (Howell and Graham 2011; Burger 2015), yet it was an important issue for women in the research undertaken by Gaucher and Payot (2011). Women beginning their journey as preterm mothers begin under societal discourses of good mothering which demands women mother in specific ways (Mackinnon and McIntyre 2006). Women who are high-risk antenatally for a preterm labour or birth, often feel guilty and blame themselves for their preterm birth, even if they have done everything society has deemed right during pregnancy. This resulted in perceptions which undermined feelings of being a good mother even prior to the birth of the baby (Mackinnon and McIntyre 2006). Women felt they were 'poor mothers' as they had done a poor job in caring for their unborn baby (Mackinnon and McIntyre 2006). Thus, the mothering discourse which "shapes the identities of mothers and the meaning of mothering for individual women" (Goodwin and Huppatz 2010, p.6) has impacted on women at risk of preterm birth, as they have already positioned themselves as either good or poor mothers in trying to maintain their pregnancy (Goodwin and Huppatz 2010).

'Poor mothers' as a theme was evident in the studies utilised in section 2.1 which examined bed rest or restricted activity, as most women, in wanting to be seen as 'good mothers', complied with medical instructions at the expense of their own

emotional and physical wellbeing to ensure an optimal outcome for their baby (May 2001; Mackinnon 2006; Alcalde 2011; Rubarth et al. 2012). In the feminist research undertaken by Alcalde (2011, p.8), women viewed their bodies as “preventing them from doing things that were central to their identities as women, wives, mothers and professionals”. In May’s study (2001) domestic tensions were still high three months postnatally, as women acknowledged activity restriction had severely impacted on their marriages.

When women arrive on the neonatal unit to see their baby for the first time, many professionals would be unaware of their journey preceding birth including how women feel about themselves as mothers. The neonatal and the maternity surveys do not seek this information. As a former healthcare professional involved within neonatal intensive care nursing, the experiences of women undergoing restricted activity at home or in hospital to a prevent preterm birth was certainly not within my consciousness and I would hazard a guess I was not alone in that.

A qualitative study that interviewed 30 mothers of very-low-birth-weight babies all reported difficulty in accepting they were mothers, as they acknowledged they did not have a baby inside or one on the outside (Baum et al. 2012). Activities that occur after a preterm baby is born, such as separation and admission onto a NICU, do not facilitate a woman to be a mother to her baby. Therefore the question as to whether a woman’s status as mother will be acknowledged by healthcare professionals is not easily answered within quantitative surveys. The reasons for this would be that such surveys require exploration of a phenomenon that is not easily amenable to succinct statements and quantification. In addition, it would be difficult for such tools to articulate the way in which women would know whether or not professionals acknowledged women's status. For these reasons, exploration of this issue would best be achieved by a qualitative study which would enable a deeper understanding from a woman’s perspective.

2.3.1.5 Involvement in care:

To minimise separation, Erlandsson and Fagerberg (2005) suggest keeping mother and baby together and treating both as a single unit, if this cannot be adapted through the provision of beds for women on a neonatal unit, then a strategy of early involvement in caring for their babies is desirable. The toolkit for high quality neonatal services (NHS and DH 2009) recognises this by promoting an approach known FCC which promotes parents to be at the centre of their baby's care journey when they are hospitalised through illness or prematurity. Furthermore, parents should have physical and emotional contact with their baby at the earliest opportunity. This would include hands-on care such as nappy changing and KC (PSG 2009). Nearly all parents responding to both surveys were definitely involved in the care of their baby (81%), with 14% responding yes to some extent and 5% not as involved as much as they wanted (Howell and Graham 2011; Burger 2015).

Research has indicated women need to be integrated quickly into the neonatal unit, as they need to adjust to a new and frightening environment, whilst at the same time learning the 'rules, policies and procedures' (Lindberg and Ohrling 2008; de Cássia de Jesus Melo et al. 2014). Two elements of FCC which would enable women to integrate and facilitate involvement, centres around the ability to provide KC with their baby and arranging care to fit in with parents 'visiting times'. A policy of unrestricted FCC, in which parents are the primary carers with the support of healthcare professionals, will enable parents to feel less like visitors (Flacking et al. 2012).

2.3.1.6 Kangaroo Care:

When considering Kangaroo Care (KC), similar results were demonstrated by the 2011 and 2015 surveys. Over half of the parents definitely had as much KC as they wanted, 21% said yes to some extent, with 19% not as much as wanted (Howell and Graham 2011). In the latest survey parents seem very aware of KC with only 2% of parents not knowing about it, as opposed to 11% in 2011. Redshaw and Hamilton's (2006) survey which questioned parents about KC revealed 30% 'always'

had KC, 44.7% 'sometimes' had KC and 24% never provided their babies with KC. It is not known whether the statement 'never' is intended to portray parents as not knowing about KC, or were not provided with opportunities (Redshaw and Hamilton 2006), however in my opinion it is more than likely to be the latter factor. The two contemporary surveys demonstrate a positive upward trend in the majority of parents experiencing this beneficial contact with their babies (Howell and Graham 2011; Burger 2015).

KC has many documented benefits for both term and preterm babies, and indeed for mothers themselves, see (Bergman 2003; Roller 2005; Leonard and Mayers 2008; Heinemann et al. 2013; Rodgers 2013; Conde-Agudelo and Diaz-Rossello 2014; Stevens et al. 2014). Seminal research undertaken by Uvnäs-Moberg (2000 cited Erlandsson and Fagerberg 2005) in Sweden demonstrated women who experience S2S with their babies are primed to release the hormone oxytocin necessary for successful breastfeeding. Oxytocin has also been associated with enhancing maternal attachment with their babies (Lee et al. 2009), although women who are separated early or experienced minimal contact are more likely to experience postnatal depression (Uvnäs-Moberg 2000 cited Erlandsson and Fagerberg 2005). KC has also been shown to increase a woman's ability and confidence to care for her baby (Conde-Agudelo and Diaz-Rossello 2014), therefore it should be viewed not as an intervention, but rather, as routine care which keeps mothers and babies together, promotes bonding, reduces postnatal depression and facilitates sustained breastfeeding (Rodgers 2013).

2.3.1.7 Baby's care fitting in with parents:

Parents were required to respond to a question in both surveys about whether staff arranged care for babies (such as weighing and bathing) to coincide with their visiting times. It seems, on reviewing the responses, that on the whole, parents were facilitated to provide care when they were on the unit. In 2011 21% answered 'no' to the question 'I was not involved as much as I wanted', although a marked improvement was evident in 2014, with only 4% of parents feeling their involvement could have been greater. Although the surveys are reporting on

parent's experiences, qualitative research which focuses just on women and preterm babies, is quite specific in reporting on the impact on women when trying to involved with their babies in the neonatal environment. Holditch-Davis and Shandor Miles (2000) describe women's experiences are very much at the mercy of healthcare professionals, with some staff more helpful than others, which can impact both negatively and positively on a woman's self-esteem and her ability to parent (Holditch-Davis and Shandor Miles 2000). Fenwick et al. (2001b) termed nursing behaviours which situate women at the margin of their baby's care as 'inhibitive nursing' resulting in women feeling disenfranchised and unimportant, with the well-being of their baby of more significance. Therefore, the priority of neonatal staff must be to promote mother-baby attachment through shared or co-care (Erlandsson and Fagerberg 2005; Johnson 2008).

FCC invites healthcare professionals to "stand in the shoes of parents" (PSG 2009, p. 5) in an effort to improve a family's experience when they are coping with a sick or premature baby. Mothers and fathers should be core within a pathway of flexible and individualised care for their baby (Staniszewska et al. 2012), and FCC, which promotes family involvement has been supported by many studies, see for example, Moore et al. (2003); Malusky (2005); Corlett and Twycross (2006); Shields et al. (2007) and Mikkelsen and Frederiksen (2011). Despite the abundance of literature supporting the benefits of FCC, parents still report being at the receiving end of "non-family-centred care" (Staniszewska et al. 2012, p.244). A similar finding was reported by a study that explored fathers' satisfaction with a family-centred model of postnatal care (Hildingsson et al. 2009). Two cohorts of fathers between 2004 and 2006 completed a questionnaire which asked their views on satisfaction with postnatal care before and after the introduction of a new family-orientated model of care (Hildingsson et al. 2009). The researchers found that one third of fathers were dissatisfied, leading the authors to hypothesise that "fathers are still trapped behind the glass wall", as they felt they were not provided with full opportunities to be involved in the care of their infants and their partners (Hildingsson et al. 2009, p.286). This research took place in a Nordic country where

the ideology of gender equality is accepted (Perälä-Littunen 2007). In Finland for example, shared parenting is classed as good parenthood (Perälä-Littunen 2007).

A qualitative study (Perälä-Littunen 2007) which explored what qualities were required to be a good mother and a good father revealed that participants more often than not described what a good mother was. In a country which is officially committed to the ideology of gender equality including having it written into family policy (Perälä-Littunen 2007, p.341) it appears that the 'good mother' overshadowed the father, which implies that the mother is still "seen as the model against which the father is compared". In terms of 'gender equality' a mother remains the norm (Perälä-Littunen 2007). It seems there is still some way to go before true gender equality is achieved especially when considering what a good mother and a good father is. A way to achieve this is for new parents to be viewed as family unit by healthcare professionals beginning early in the postnatal period and by providing family centred care (Hildingsson et al. 2009). For motherhood to become empowering and child-centred (Rich 1976; D'Arcy 2011) fatherhood, which also continues to struggle under patriarchal family structures, needs to be reconceptualised so that value fathering is acknowledged alongside mothering (D'Arcy 2011).

Findings from the POPPY study which explored parents' experiences of caring for a preterm baby and their perceptions of the support and information provided to them, discovered parents connected their role as one of "separation, marginalisation, lack of responsibility and loss of nurturing and protective role" (Staniszewska et al. 2012, p.246). These experiences have similarly been identified by research undertaken with women who have experienced preterm birth, see in particular, Erlandsson and Fagerberg (2005); Baum et al. (2012); Hall et al. (2013); Lindberg and Ohrling 2008; and de Cássia de Jesus Melo et al. (2014).

The POPPY study, commendable in its use of parents in developing the final model of FCC for neonatal units and for reviewing parental transcripts, fails to acknowledge, in my opinion, the woman's voice, since the report focuses on

parent's experiences despite the majority of participants being once again women – similar to the two national neonatal surveys (Howell and Graham 2011; Burger 2015). The consequences of healthcare professionals not adhering to the principles of FCC, appears to impact more on women than their partners, as illustrated by a study undertaken by Finlayson et al. (2014). This may be due to organisational structures rather than fathers being disinclined in undertaking FCC (Hildingsson 2009). Women found it difficult to undertake their mothering role and described this as “being in limbo”, which resulted in them feeling vulnerable and ultimately deferring to authority to maintain their “equilibrium” (Finlayson et al. p.213). The authors conclude FCC remains rhetorical (Finlayson et al. 2014), similar to maternity care where for many women, continuity of care, choice and control and involvement during their maternity care remains as elusive.

Despite its strengths and contributions to FCC, the POPPY study, in keeping with the two neonatal surveys, did not explore women's views or circumstances leading up to the birth of their preterm baby. As a result, these and the links between them and the women's experiences of becoming a mother remain largely unknown. This is one of the gaps in existing knowledge this study aims to fill.

2.3.1.8 Information and support for parents

A constant theme throughout the neonatal surveys is parents' reporting a lack of information and support. Cleveland (2008) undertook a literature review to answer two questions: 1) what are the needs of parents who have infants in the NICU and 2) what behaviours support parents who have infants in the NICU. Six needs were discovered after 60 studies between 1998 and 2008 were analysed, one of which was “a need for accurate information and inclusion in the infant's care and decision making” (Cleveland 2008, p.672). Parents wanted to be actively involved in decision making; however advice and information received from professionals needed to be accurate and understandable. Parents felt inconsequential and powerless when the required information and support was not forthcoming.

In a qualitative study undertaken by Lindberg and Öhrling (2008), women described their difficulties understanding and absorbing information, especially following an admission of their baby to a neonatal unit and they were in shock about the whole event. There is therefore, a need to explore the optimal time to provide parents with appropriate information and how it should be provided (Lindberg and Öhrling 2008). Redshaw and Hamilton (2010) suggest as parents progress along their journey from being an outsider and finally, becoming fully integrated within the unit, their information needs will vary depending on where they are within that pathway.

The 2014 survey continues to demonstrate that information needs for parents have still not been met (Burger 2015). Parents required written information to understand their baby's condition and on-going care and treatment, including information on support groups such as Bliss (Burger 2015). Similar to women on bed rest who supported each other through a virtual focus (Adler and Zarchin 2002), parents of preterm babies on a NICU reported sharing experiences with other parents in a similar situation was beneficial (PSG 2009; Staniszewska et al. 2012). Information needs were also wanted in areas such as help with travelling expenses, parking costs and food vouchers (53% in 2011 and 46% in 2014) suggesting a marginal improvement only (Howell and Graham 2011; Burger 2015).

2.3.1.9 How long will the baby be in hospital for?

2.3.1.9.1 Preparing for discharge and the transition to home

Following publication of the Toolkit in 2009 (NHS and DH), NICE in its quality standards on specialist neonatal care recommends parents should expect a coordinated approach between relevant healthcare professionals “to ensure a safe and effective transition from hospital to home” (NICE 2010, p.21). In addition, the Toolkit outlined three further markers of good practice whereby parents:

- 1) Are involved in discharge planning from admission with plans continually under review.
- 2) Have appropriate information and training before being discharged home.

- 3) Have access to overnight accommodation to help boost their confidence in caring for their baby (NHS and DH 2009).

Both surveys indicate the majority of parents definitely felt prepared for their baby's discharge from neonatal care, and were offered overnight accommodation (Howell and Graham 2011; Burger 2015). However, it is difficult to infer from the surveys whether parents were involved with discharge planning from admission onwards. Parental responses from the POPPY study suggest otherwise (Staniszewska et al. 2012). Parents were not always provided with a target date for discharge and did not receive clear and consistent advice regarding the discharge process. For one parent (gender not identified) discharge happened suddenly and they felt unprepared for going home and for being at home (Staniszewska et al. 2012), which suggests some parents are not receiving enough information and support prior to and whilst at home. The quantitative nature of the neonatal surveys lacks the finer detail around important issues such as the discharge process and the importance for parents of being aware of an end point, which only becomes evident through qualitative research. The research undertaken by Staniszewska et al. (2012) clearly demonstrates that parents were not involved in discharge planning from admission and were not experiencing a coordinated and seamless pathway to home as recommended by NICE and The Toolkit (National Institute for Health and Care Excellence 2010; NHS and DH 2009). This is one of the gaps in existing knowledge this study aims to fill.

2.4 Conclusion:

Parents responding to the neonatal experience surveys appear satisfied with their care just as women have reported when maternity surveys are published. 'Patients' are, it has been suggested, reluctant to criticise those that cared for them (and their babies) (van Teijlingen et al. 2003), with Sandin-Bojö (2008) indicating that those who use particular services such as maternity or neonatal facilities, are unaware of what care should look like and therefore only evaluate their current situation. Therefore, whilst positive experiences have been reported, it is clear from the surveys that improvement in many aspects of care is needed. In terms of evaluating

services, it would be useful to specifically evaluate women's experiences of neonatal care as research has demonstrated that mothers and fathers experience neonatal environments differently (Obeidat et al. 2009).

A comparison between mothers' and fathers' experiences of the attachment process in a neonatal unit revealed striking differences (Fegran et al. 2008). Mothers' experienced attachment as one of surrealism and a lost relationship with their babies, which required re-building, whereas fathers, although shocked, were ready to be involved straightaway and their relationship with their baby was a new beginning (Fegran et al. 2008). Their study therefore highlights that each gender had different starting points when first encountering their premature baby, important differences not detectable within generalised quantitative neonatal experiences surveys, but which should be acknowledged when supporting parents (Fegran et al. 2008).

If the aim of neonatal surveys is for neonatal networks and individual neonatal units to prioritise areas for improving parental experiences then considerations which are gender specific should be considered. Women tend to spend more time on a neonatal unit (Latva et al. 2008; Finlayson et al. 2014) and are exposed to many shift changes and different nurses caring for their baby (Finlayson et al. 2014). Conflicting advice and information impact on a woman's ability to mother her baby (Finlayson et al. 2014), with secondary analysis of a primary study (Wigert et al. 2010) undertaken by Lantz (2013) revealing that if women were exposed to criticism or poor treatment by staff it impacted on their presence at the neonatal unit. Women in the study by Finlayson et al. (2014, p.122) reported they were criticised by the nurses for their mothering which made them feel "incompetent, naïve and disrespected". Lantz's (2013, p.62) analysis further revealed women were unlikely to challenge if they perceived staff as behaving inappropriately or disrespectfully towards them and often relied on fathers to take on this "confrontational role". Women shied away, preferring for fathers to be at the receiving end of any repercussions (Lantz 2013).

Key feminists (for example bell hooks) remind us that an important issue arising from the feminist movement has centred around encouraging men's equal participation in parenting, not only to promote gender equity, but also to build better relationships with children and between mothers and fathers whether they are married, live together or separately (hooks 2000; Green 2015). A survey therefore, reporting on parents experiences of neonatal care is possibly an attempt to be inclusive and gender neutral (as parents could be gay, straight, male, female, trans, disabled) (hooks 2000; Green 2015), although in this context it is safe to assume the survey was capturing views from traditional mother/father relationships thereby assuming shared and equal parenting. Additionally, a further aim may be to reflect that neonatal care over the last 15 to 20 years has embraced the concepts of family-centred care (FCC) (Widding and Farooqi 2016).

However, from a feminist perspective I question the value of a survey that reports on parental experiences as 'one', as it was mainly women that responded which suggests that women on the whole, remain responsible for childcare. Research undertaken by Miller (2011b) which explored men's narratives and practices around first-time fatherhood and by Sevon (2011) whose study set out to make sense of the gendering of parenthood during the transition to motherhood from the perspectives of seven Finnish first-time mothers, revealed that whilst fathers wanted to be involved in childcare and certainly were more so than their fathers, "the pace of change is slow" and it was customarily, "the mother who is left holding the baby" (Miller 2011b, p. 1107; Sevon 2011).

These important findings are relevant, because although the research conducted above did not specifically relate to mothers/fathers of preterm babies, fathers from both countries (UK and Finland) are entitled to paid paternity leave and rights to request 'flexible working' (albeit only two weeks in the UK and far more generous in Finland (Miller 2011b; Sevon 2011), many fathers negotiated their way out of full time childcare responsibilities (Miller 2011b; Sevon 2011). They did so by falling back on hegemonic discourses of masculinity (Miller 2011b) by returning to paid work (valued more than caring for babies/children) and being the main

breadwinner, choices on the whole not easily available to women-mothers (Miller 2011b; Sevon 2011; Green 2015). Furthermore, within the discourse of fatherhood, fathers are not generally exposed to the same level of scrutiny as mothers (Jackson and Mannix 2004; Goodwin and Huppertz 2010), since women are expected to mother within a framework of rules, regulations and surveillance (medical and the 'other') which dictates not only how we should be 'a good mother' but also who is a 'bad mother' (Rich 1976; Goodwin and Huppertz 2010). These dichotomies and the polarisation between each make women feel anxious and guilty about their mothering (Sevon 2011; Green 2015).

Mothers of preterm babies are particularly vulnerable since research has highlighted that they experience shock, stress, feelings of being alone, disappointment, insecurity and begin motherhood with a sense of guilt (failure of their bodies) (Holditch-Davis and Shandor Miles 2000; Lau and Morse 2003; Erlandsson and Fagerberg 2005; Wigert et al. 2006; Lindberg and Öhrling 2008; Obeidat et al. 2009; Tooten et al. 2013; de Cássia de Jesus Melo et al. 2014). None of these societal expectations upon women as mothers of preterm babies are evident within a generic survey of parental experiences of neonatal care. Instead the work of being a mother is not recognised despite childcare falling mainly upon women and more importantly, research by Lupton and Fenwick (2001, p.1019) vividly portrays how the women they studied, found it difficult to achieve the "ideals of good motherhood". This mothering journey occurred within environments where they struggled to gain control of the situation they found themselves in, whilst at the same time trying to overcome feelings of grief and alienation. Included within the melting pot of their experience was being labelled as good or bad mothers by healthcare professionals which has important consequences on how they felt about themselves (Lupton and Fenwick 2001), feelings or experiences not easily discernable within gender-neutral surveys.

Likewise, the surveys of neonatal care are being inclusive by reporting on parental experiences to reflect the move towards FCC, women's voices are yet again silenced as revealed by research on mother's perceptions of FCC undertaken by Finlayson et al. (2014). Discussed previously, women were initially glad to hand over care to

‘powerful others’ (medical and nursing staff), however, reclaiming the balance of power back in their favour was troublesome, resulting in mothers having less than meaningful relationships with staff which in turn disrupted the women’s ability to bond (another powerful discourse) with their baby (Finlayson et al. 2014). Organisations responsible for carrying out NHS maternity surveys invite all women who have given birth between certain months in a particular year to participate within its survey, and quantitatively reports on their experiences of maternity services. Term and preterm mothers become one and it is not possible to unpick the unique experience of a woman who has experienced preterm labour and birth and their voice is largely lost. The same concept is equally applicable when considering the neonatal surveys. The experiences of women with preterm babies of all gestations are grouped together, therefore understanding an experience, whether it is caring for a baby at 24 weeks or at 35 weeks gestation is any worse or better for women is impossible to identify.

Qualitative research exposes these experiences in greater detail, with the bulk concentrating mainly on PTBs born in categories known as ‘very preterm’ (<32 weeks gestation) and ‘extremely preterm’ (<28 weeks gestation). However, a focus that is becoming increasingly important are babies born late preterm, as this group accounts for the largest percentage within the spectrum of prematurity (80%) with numbers rapidly rising (Cheong and Doyle 2012). Many North American papers publishing on preterm birth rates have one common factor: the rise of preterm births during the past twenty or more years is down to a rise in late preterm births (Davidoff et al. 2006; March of Dimes 2006; Engle et al. 2007; Rojas 2007; Santos et al. 2008; Kramer 2009; Martin et al. 2009; Cheong and Doyle 2012; Shapiro-Mendoza and Lackritz 2012; Barfield and Lee 2014). The following chapter will provide an overview of late preterm birth.

CHAPTER 3 LATE PRETERM BIRTH

Introduction:

This chapter provides an insight into late preterm birth by considering definitions, factors contributing to an 'alleged' rise in numbers, and problems associated with this sub group of preterm baby following birth. By the end of the chapter you will have a clear understanding of late preterm birth and its implications.

3.1 AN OVERVIEW OF LATE PRETERM BIRTH

Despite advances in technology, improved access to antenatal care and many public health initiatives to prevent preterm birth (Goldenberg et al. 2008), rates have risen worldwide (Saigal and Doyle 2008; Lawn et al. 2010). Percentages vary according to geographical variations, with rich and highly developed countries such as the United States of America (USA) having a rate of 12%, followed closely by some Sub-Saharan African countries with rates as high as 18% (Behrman and Butler 2007; Blencowe et al. 2012b; Morken 2012). Northern European countries have a preterm birth rate varying between 5% and 10% (Blencowe et al. 2012b). In England and Wales, 7% of births were classed as preterm, i.e. occurring between 24 and 36 completed weeks gestation (Term gestation = 37 weeks) (ONS 2013), a statistic which has remained relatively stable for the last 15 years (Macfarlane and Dattani 2010).

In the UK it is not clear whether the moderately to late preterm range has increased, as nationally data on gestational age is not routinely recorded at the registration of live births (Tucker and McGuire 2004; Moser et al. 2007; Dattani et al. 2012). However, a recent publication reporting on gestation-specific infant mortality for 2010 in England and Wales provides some insight into percentage rates for live babies born within the moderately late preterm rate. Statistics revealed 7.0% of all live births were preterm, with the majority (5.9%) occurring within the moderately late preterm range (between 32 and 36 weeks gestation) (ONS 2013). It is not evident whether these statistics represent a rising trend as is apparent in the US, since preterm statistics in the UK do not distinguish between

babies categorised as late and moderate preterm (ONS 2013). The true number of late preterm births is therefore hidden, as they are not identifiable as a separate subset of the preterm range (Jensen 2011). The literature indicates the classification of preterm babies and in particular late preterm is inconsistent which undoubtedly adds to the confusion when trying to decipher rates.

3.2 DEFINING LATE PRETERM BABIES

Despite inconsistencies concerning definitions of sub-groups of preterm babies (Engle et al. 2007; Mohan and Jain 2011), there is general agreement within the literature that babies born between 23 and 27 weeks gestation are categorised as 'extremely preterm', and those born between 28 and 32 weeks as 'very preterm'. The most inconsistent category is that which is variously known as moderate and/or late preterm, as gestational age within this sub-group of premature baby ranges between 32 to 36^{6/7} weeks gestation (Tucker and McGuire 2004; Blencowe et al. 2012a; Shapiro-Mendoza and Lackritz 2012).

Babies born moderately late preterm have been described as 'near term', 'late preterm', 'marginally preterm', 'moderately preterm', 'minimally preterm', 'early term' and 'borderline preterm' (Engle 2006; Engle et al. 2007; Shapiro-Mendoza and Lackritz 2012). Even the category known as 'near term', which suggests birth outcomes should be favourable as the baby is close to the appropriate gestation for birth (Term), is unreliable, as ranges vary from 35 to 37 weeks gestation, 34 to 36 weeks gestation and finally, 35 to 36^{6/7} weeks gestation (Engle 2006; Raju et al. 2006). It was becoming clear, at least in the US, that a consensus had to be reached around defining babies known as moderately late preterm, as numbers had risen by 20% over a ten year period (Engle 2006; March of Dimes 2006; Raju 2006a) and clinically managing these babies was becoming problematic (Engle 2006). Risks were underestimated due to this group of preterm babies labelled as 'near term', which implied outcomes would be similar to those born at Term (Raju et al. 2006).

As the mounting body of knowledge around 'near term' babies increased, experts were not in agreement on the severity of issues and the impact these 'near term' babies had on healthcare systems (Raju et al. 2006). Many appeared to be at

greater risk for mortality and morbidity, due to immaturity at birth, which required admission to a NICU for medical care and treatment (Engle 2006; March of Dimes 2006; Raju et al. 2006). Accordingly, members of the National Institute of Child Health and Human Development (CHHD) recommended categorising babies born between 34th and 37th weeks gestation as 'late preterm', which would enable correct identification for the targeting of appropriate care and for researchers to investigate the correct population for the purposes of improving outcomes (Raju 2006b). The March of Dimes Foundation – a non-profit organisation in the US dedicated to improving the health of babies and the prevention of preterm birth, followed suit and formally adopted 'late preterm' as a definition for births occurring between 34^{0/7} and 36^{6/7} completed weeks (March of Dimes 2006).

Bliss, the UK charity dedicated to supporting premature and sick babies and their families have not implemented these recommendations. Its' website continues to define babies born between 35 and 37 weeks as 'moderately premature'. Tommy's, a charity which funds research into prematurity have embraced the definition utilised by the World Health Organisation (WHO) (WHO 2013). Their definition of 'moderately preterm' consists of a range of babies born between 32 and 37 completed weeks of gestation. Whilst the definition of a LPB is widely accepted by key organisations and charities in the US, in the UK its acceptance remains inconsistent, with the term 'moderately preterm' rather than 'late preterm' more commonly utilised.

It has become evident that LPBs should not be referred to as 'near term' or even as 'moderate preterm', as these labels do not accurately define the potential complications these babies are at risk for following birth (Engle 2006; Engle et al. 2007). I acknowledge that despite my research being carried out in England, the definition of 'late preterm' widely used in the US/rest of the world to indicate a baby born between 34^{0/7} and 36^{6/7} completed weeks of gestation, will be implemented throughout my thesis, because it is the dominant definition and reflects the prevailing view that babies born late preterm are developmentally and metabolically immature (Engle 2006; Raju 2006b; Jorgensen 2008b; Shapiro-Mendoza and Lackritz 2012). More recently however, a number of current UK

publications are beginning to refer to this group of babies as ‘late preterm’ – see for example, Boyle and Boyle (2011); Boyle (2012) and Boyle et al. (2015).

3.3 WHY HAS THE PRETERM BIRTH RATE INCREASED IN RECENT YEARS?

The rise in late preterm birth is not easily explained (Martin et al. 2009), however a number of explanations have been proposed. Women commencing their families later in life (>35 years of age), the escalating problem of obesity amongst childbearing women and caesarean sections resulting from increased obstetric interventions are some of the suggested theories (Behrman and Butler 2007; Engle et al. 2007; Martin et al. 2009; Mally et al. 2010). Many of the studies emanate from the US; therefore a key issue was whether any of proposed theories were transferable as my study took place in England. The following section will explore these issues.

3.3.1 Maternal age:

A report published by the ONS (2012) indicated nearly half (49%) of all live births in England and Wales were to women aged 30 and over. The trend in delaying childbearing until the age of 30 and beyond appears to be international. The significance for women who are considered ‘old’, namely over the age of 30, and contemplating starting a family, lies in the realms of declining fertility (American Society for Reproductive Medicine 2012), which may result in women seeking assisted reproductive technology (ART) in order to become pregnant (Balasch and Gratacós 2011). Women prioritising their career over motherhood is seen as problematic, not least by the medical fraternity, because women of ‘advanced’ age are at increased risk for a number of pregnancy related complications such as: gestational diabetes, pregnancy induced hypertension and pre-eclampsia and multiple pregnancies (both natural and through assisted technology), many of which may lead to an increased risk of interventions, such as induction of labour, caesarean operations and in some instances late preterm birth (Engle et al. 2007; Gibson 2007; Jorgensen 2008a; Jorgensen 2008b; Li et al. 2014).

Searches on databases reveal publications which attest to harm delayed motherhood presents for future offspring with titles such as: 'Delayed motherhood increases probability of sons to be infertile', 'Delayed motherhood has metabolic consequences in the offspring' and 'Delayed motherhood is a public health issue'. However, a feminist perspective would argue the movement for equality from the 1960s onwards has enabled women opportunities for education, to enter the paid workforce and to control their bodies and motherhood through easily obtained (for some) contraception (Budds et al. 2012), therefore delaying motherhood is a choice many women choose. These choices have implications for women, since if they are 'choosing' late motherhood, society at large appears critical (Budds et al. 2012).

The maternity and neonatal surveys report the age range for participants (women) was between 30 and 35 years of age. Whilst it is not known whether a woman's age in England has contributed to an increase in late preterm births, the two neonatal surveys highlight that 41% of women gave birth between 33 and 37 weeks gestation, many of which would fall under the definition of late preterm.

3.3.2 Obesity:

A similar international trend is seen when considering obesity (Huda et al. 2010). The Centre for Maternal and Child Enquiries (CMACE) (2010) estimates approximately 38,478 (4.99%) pregnancies in the UK are classified as obese (Body Mass Index (BMI) >35 – Class 11 & 111), with those classified as 'super-morbid obese' (BMI>50) affecting 0.19% of all women giving birth. Women who are obese and become pregnant face many challenges, not least adverse outcomes for both her and her baby, resulting in on-going health issues for the dyad (Huda et al. 2010; Vasudevan et al. 2011).

Rates of maternal obesity vary within the UK, with Wales having the highest prevalence of obese women in the categories Class 11 and Class 111, and England the lowest. Super-morbid obesity was not significantly different between the countries within the UK. However, the proportion of women aged 35 years or more increased with each BMI group, with 31% considered super-morbid obese (Huda et al. 2010; Vasudevan et al. 2011), and it is believed the trend of increasing obesity

and 'advanced age' may be some of the key factors influencing the late preterm birth rates (Jorgensen 2008a; Gyamfi-Bannerman 2012). However, this view is not universally held, and neither is obesity the only 'weight' related issue linked to preterm birth. Research undertaken by Hendler et al. (2005) discovered that pre-pregnancy obesity, defined as a BMI >35 was associated with less preterm births, whereas maternal thinness was associated with an increased preterm birth and specifically spontaneous preterm birth.

Society again, is critical about women and obesity during pregnancy. In the document 'The Health of the 51%: Women', the UK's first medical woman officer in her introductory letter, advocates 'recognising obesity at the level of a "national risk" (Davies 2015 p. 1) which suggests that it is a structurally located societal problem rather than a matter of individual failing or blame. Her statement implies however, that obesity is on a par with terrorism (Bristow 2016) because high levels of obesity are endangering potential generations, as future offspring's risk of obesity could be closely linked to a mother's diet, health and lifestyle (Davies, 2015; Hanson et al. 2015; Bristow 2016; Schiller 2017). Mother blame, a discourse that holds "mothers responsible for the actions, behaviour, health and well-being of their children" (Jackson and Mannix 2004, p.150) is evident within Davies' message.

Blaming women for the outcomes of future generations is reductionist and scaremongering, as it suggests that once a baby is born its entire future has already been influenced by the maternal in-utero environment (Richardson et al. 2014; Bristow 2016). A newish field of research known as 'developmental origins of health and disease' (DOHaD) is currently studying how the uterine environment impacts on future health and disease (Richardson et al. 2014) with contemporary research appearing to demonstrate that fathers and grandparents also 'affect descendants' health' (Richardson et al. 2014, p.132). Therefore exaggerations and oversimplifying the 'obesity message' risks "burdening women with guilt and onerous responsibility" (Richardson et al. 2014; Davies 2015 pg.10), although Davies 'balances' the blame message by suggesting that providing women with knowledge empowers them into better choices and a healthier lifestyle. Bristow (2016) on the

other hand, disagrees, believing it scares women including putting them under the spotlight in a way that men are not (Jackson and Mannix 2004) resulting in increased surveillance and regulation during pregnancy (Richardson et al. 2014). Additionally, society continues to blame women rather than trying to improve underlying factors that impact on their decisions and choices.

Obesity therefore, provides another stick with which to beat women up with. Instructing women on what and how much to eat, what to drink and avoid gaining too much weight, reduces women's autonomy and the freedom to choose how they wish to spend the nine months of their pregnancy (Bristow 2016). Pregnancy fat-shaming reflects the notion that "pregnant women are imperfect vessels to be policed, restricted, monitored and improved" (Schiller 2017), views and attitudes that feminism has been trying to eradicate since the 60s.

3.3.3 Obstetric interventions and caesarean operative deliveries:

About 70% of preterm births occur spontaneously, i.e. unknown cause; however this phenomenon has decreased over the years as non-spontaneous, also known as 'provider initiated' or 'medically initiated' have increased, with the main upsurge in births categorised as late preterm (Iams and Donovan 2011; Barfield and Lee 2014).

Maternal infections, preterm pre-labour rupture of membranes (PPROM) and pre-eclampsia are some of the factors that can be attributed to spontaneous preterm birth (Steer 2006; Goldenberg et al. 2008), resulting in no one single measure being effective on its own in prevention (Steer 2006). Undeniably, if a woman is suffering from pre-eclampsia unresponsive to treatment, then obstetric intervention is required and labour must be induced to protect her and her unborn baby (Steer 2006). Significantly, many of the causes attributable to preterm labour are not treatable, with birth being the only available option (Steer 2006).

Whilst obstetricians in the main agree on treatment options for managing preterm labour (both spontaneous and non-spontaneous) (Gyamfi-Bannerman 2012), concerns have been expressed on whether non-spontaneous or medically/provider

initiated processes resulting in late preterm birth are 'always' medically necessary (Iams 2011; Gyamfi-Bannerman 2012). Iams (2011) believes expediting delivery at an earlier gestation and specifically at late preterm, has led to a reduction in stillbirths, this is however, disputed by Silver (2011), who maintains evidence supporting a reduction in stillbirths is insufficient. Other authors argue the increased rate of late preterm births is associated with physician practice patterns, women's preferences and physician pecuniary stipend (Holland et al. 2009; Morais et al. 2013).

On the matter concerning women's preferences, an interesting study undertaken in Brazil, which has the highest OD rates in the world (36% +), disputes the prevailing view (at least in Brazil) that it is solely women responsible for the high caesarean rates (Hopkins 2000). Hopkins' analysis of doctor-woman discourses during labour and birth and women's narratives, revealed the majority of Brazilian women do not actively seek operative births, preferring to birth vaginally. Obstetricians therefore, appear to utilise subtle mechanisms in order to get women to 'request' caesareans, and in the face of obstetric knowledge and authority women are powerless to resist (Hopkins 2000). She concludes by maintaining obstetricians play a major role in perpetuating the myth that Brazilian women 'want' a caesarean birth (Hopkins 2000).

Fear of litigation has been another influencing factor for physicians to electively induce labour or perform an elective caesarean operation between 34 and 36^{6/7} weeks gestation (Power et al. 2013). Gyamfi-Bannerman et al. (2011) in their retrospective cohort study which explored non-spontaneous late preterm birth, its causes and outcomes within a well maintained database, concluded over half of late preterm births were considered non-evidenced based (NEB), and therefore potentially avoidable. Media attention has not focused on these important issues, yet seeks to blame women for their part in requesting operative births without any underlying reason (Sinha et al. 2011). The context of childbirth in the UK is different to that of the US, therefore can financial reward for doctors and fear of litigation contribute to an increase in late preterm births in the UK?

There are no significant studies originating from the UK verifying or debating whether medical practice, combined with a fear of litigation, has impacted on late preterm birth rates, therefore this may be explained in part by examining the provision of and organisation of healthcare. Women seeking maternity care are cared for in the main by midwives with input from obstetricians when needed. Most women will give birth within a NHS hospital which provides care free at the point of need. Midwives and doctors receive a monthly salary; therefore, financial imperatives are not a motivating factor to expedite birth by OD and hence, not a valid contribution to support an increased late preterm birth rate. It appears in countries where private healthcare options are available for maternity care, rates of obstetric interventions are higher, leading to an increase in caesarean operations (Hopkins 2000; Roberts et al. 2000; Coulm et al. 2012), although within the UK, intervention appears to be driven by the environment of care.

A Cochrane review which assessed effects of care in a hospital birth centre compared to care in a conventional setting concluded many benefits were available for women who wished to birth in birthing centres (Hodnett et al. 2012), such as women were more likely to undergo a spontaneous vaginal birth without the need for analgesia, more satisfied with care and are women more likely to be breastfeeding beyond the 6 week point. In addition, birth in an alternative institutional setting reduced the probability of labour being augmented, assisted vaginal birth, caesarean birth and episiotomy (Redshaw et al. 2011; Hodnett et al. 2012). Whilst the majority of professionals working in birthing centres are midwives who play a part in outcomes for women, many of the advantages within these environments are applicable in conventional settings when women experience midwife-led continuity of care (Sandall et al. 2016). As discussed in Chapter 1, women birthing babies within centralised maternity services, experience care within a culture where midwives are constrained in their practice due to policies/guidelines, which in turn impacts on their ability to practice autonomously and to provide one to one care during labour. These constraints do not facilitate meaningful relationships between a woman and her midwife (Kirkham 2011) and may lead to increased interventions. Research undertaken by McCourt et al. (1998)

clearly demonstrates women who received one-to-one care throughout their maternity experience were overall more positive about the care they received.

A project launched by the NHS Litigation Authority (NHS LA) to review maternity claims between April 2000 and March 2010 highlighted, of the 5.5 million births in England only “0.1% were subject to a clinical negligence claim” (Anderson 2013, p. 24). The most frequent claims related to antenatal ultrasound investigations (failure to detect an anomaly), CTG interpretation, management of labour fetal heart rate monitoring (14.05%), operative births (13.24%), cerebral palsy (10.65%), perineal trauma and uterine rupture (Anderson 2013). It is claimed therefore that the majority of births do not lead to a clinical negligence claim, supporting the view that birth within NHS institutions is ‘safe’ (Anderson 2013). Anecdotal evidence suggests women do not always sue for monetary gain but for answers. (<http://www.netmums.com/coffeehouse/pregnancy-64/birth-stories-762/794235-looking-into-suing-nhs-neglect-all.html>) and whilst many women seek to address issues related to their births by complaining to their local NHS Trust, it is only when women feel their complaints have not been dealt with seriously, do they seek legal advice (Robinson 2002).

Research undertaken by Symon (2000) to quantify the problem of litigation and defensive clinical practice, ascertained midwives and obstetricians believed litigation claims were growing which had resulted in a rise in defensive practice. A number of obstetricians claimed they carried out more interventions and induction of labour because of the fear of litigation, and 36 obstetricians reported carrying out more caesarean sections (CS) than they previously did. Although there was some ambiguity as to what constituted defensive practice, both midwives and obstetricians agreed CS was the top of the list (Symon 2000). The statistics provided by Anderson (2013) do not support the practitioner’s perceptions that there is a rise in litigation. It is therefore not possible to determine whether defensive practice in the UK has resulted in an increase in late preterm births.

3.3.4 Conclusion

There appears to be a lack of evidence in the UK concerning rates of late preterm births as a result of medical intervention, however increasing trends in maternal obesity and advanced age may be some of the key contributing factors (Jorgensen 2008a; Gyamfi-Bannerman 2012). The Chief Medical officer, the media and society appear to agree therefore, that there is an optimal age and weight that women should aspire to, prior to becoming mothers. At this point, a mother provides a positive in-utero environment which would be of maximum benefit to the future health of the unborn child (Davies 2015). All the attention is on her and *her* influence on a 'vulnerable fetus', it is certainly not focused on the role of societal factors that impact on choices and decisions (Richardson et al. 2014). Feminist work has done little in reducing 'mother-blame' (Jackson and Mannix 2004) as it is evident selective interpretations of research (obesity for example) continue to lay the blame on women for outcomes in child health (Jackson and Mannix 2004; Richardson et al. 2014).

3.4 WHAT ARE THE ISSUES ASSOCIATED WITH LATE PRETERM BIRTHS?

Many babies classed as 'late preterm' are similarly, although incorrectly, referred to as 'near term', which implies they are comparable in appearance and weight to babies born at term and are considered functionally mature (Tomashek et al. 2006; Jain 2007; Mally et al. 2010; Wright et al. 2012). Implications for practice revolve around healthcare professionals viewing these babies as healthy, and as such, are treated as normal Term babies, without being screened for problems commonly associated with preterm birth (Jenkins 2005; Brandon et al. 2011; Wright et al. 2012). Interestingly, according to Ramachandrappa and Jain (2009) this group of preterm babies were the first paediatricians learned to treat, and so successfully, they were no longer considered high risk. This success resulted in LPBs being cared for in a variety of environments, specifically, neonatal units, special care units, transitional care units (TU) and on PNW s. In England it is not known where the majority of LPBs are cared for, however findings from the neonatal surveys (Howell

and Graham 2011; Burger 2015) reveal that 41% of women with babies born between 33 and 37 weeks gestation were admitted onto neonatal units.

It appears the issue with LPBs being cared for on units other than a NICU, is that they are managed as 'near normal' babies without staff or parents appreciating or recognising the problems these babies may experience (Khashu et al. 2009). Parents may be informed by healthcare professionals that although their baby is small, and is only 'slightly premature', the message, which is meant to reassure and comfort, does not provide the full picture (Jenkins 2005; Bakewell-Sachs 2007; McGrath 2007; Jorgensen 2008b). The literature suggests healthcare professionals are not adequately prepared in terms of knowledge, skill and experience (Bakewell-Sachs 2007), which may impact on the way parents perceive and ultimately care for their LPBs (Jorgensen 2008b).

Underestimating a LPB's needs and treating them as normal appears to be non-evidenced based, because on-going research has demonstrated they are at risk for short and long term complications that could have far reaching consequences (Engle et al. 2007; Jorgensen 2008b), such as poor neurodevelopmental outcomes, which may only become evident when the child attends school (Petrini et al. 2009; Cornette 2010). Important to note that long-term outcomes are under-appreciated as many LPBs are not, at least in the UK, followed up long term (Boyle and Boyle 2011).

3.4.1 Medical conditions impacting on late preterm babies:

Late preterm babies (LPBs) are at higher risk of death and/or complications in the early neonatal period, because of physiological immaturity (Engle et al. 2007; Jain 2007; Wright et al. 2012). Until recently, management of LPBs was based on general principles of neonatal care. Clinical experience and knowledge inferred from caring for very preterm and term babies dictated how these babies were managed (Engle et al. 2007). Research currently highlights LPB's are at risk from some of the following conditions after birth:

- 1) Respiratory distress

- 2) Apnoea
- 3) Temperature instability
- 4) Metabolic disorders such as hypoglycaemia and infection
- 5) Hyperbilirubinaemia
- 6) Feeding difficulties (Wang et al. 2004; Engle et al. 2007; Jain 2007; Ramachandrappa and Lucky 2009; Mally et al. 2010).

In addition, the literature further indicates LPBs are more likely to be readmitted to hospital following an early discharge than full term babies (Escobar et al. 2005; Jenkins 2005; Tomashek et al. 2006; Engle et al. 2007; McLaurin et al. 2009; Mally et al. 2010). Reasons cited for readmission were jaundice, infection and breastfeeding related problems.

3.5 Conclusion

In this chapter I have provided an overview on late preterm births by considering factors which may have contributed to a rise of this preterm population, the correct definition and the problems associated with being born late preterm. The literature suggests these babies' needs are unique, however, there is no consensus in which environment their care should take place. Furthermore, parents and healthcare professionals appear to underestimate care needs and treat LPBs as 'near normal' (Khashu et al. 2009). The emphasis in the literature is, however, almost always on the baby. Many publications are scientifically 'late preterm centric' with parents hardly being mentioned, or they fall into a category of 'What Parents of Near Term Infants Need to Know' or exhorting healthcare professionals to be the advocate for LPBs, all of which point to health professionals leading the way towards knowledge production. An alternative view is healthcare professionals focusing on women's descriptions of caring for their LPB, which would enable identification of strategies that empower and support women to provide care. Further exploration is required to understand women's experiences of caring for LPBs; therefore the following section explores the literature relating to women caring for their late preterm babies.

CHAPTER 4 WOMEN’S EXPERIENCES OF CARING FOR A LATE PRETERM BABY

Introduction

This chapter concentrates on the literature review which was undertaken to determine whether women’s experiences of caring for LPBs was evident amongst the scientific papers examining late preterm babies. Women’s experiences can be categorised within three main activities: breastfeeding, KC and psychological issues. By the end of this chapter there will be a clear understanding of the background leading to the creation of my research question.

4.1 LITERATURE REVIEW

The needs of LPB’s have been unrecognised for many years (Ramachandrapa and Lucky 2009; White 2009; Mally et al. 2010) and only recently have healthcare professionals begun to consider the potential differences in risks faced by these babies when compared to their Term counterparts (Mally et al. 2010). Up until this realisation, LPB’s have co-existed with very early preterm babies and more mature Term babies at great disadvantage to their outcomes, both in the immediate period following birth and in the long term (Engle et al. 2007; Jorgensen 2008b; Petrini et al. 2009; White 2009; Engle 2011). In the last ten years there has emerged a fairly large body of literature reporting on outcomes, see for example Wang et al. (2004); Laptok and Jackson (2006); Engle et al. (2007); Khashu et al. (2009); Kitsommart et al. (2009); Kramer (2009); McLaurin et al. (2009); Ramachandrapa and Lucky (2009); Vachharajani and Dawson (2009); Mally et al. (2010); Engle (2011); Wright et al. (2012) and Forsythe and Allen (2013). The focus for the majority of these publications has been intended in the main, on improving knowledge and education of healthcare professionals who come into contact with LPBs.

A small number of published papers advocate educating families around care needs (Jenkins 2005; Medoff-Cooper et al. 2005; Bakewell-Sachs 2007; McGrath 2007; Pados 2007; White 2009; Souto et al. 2011) but none report on experiences. For example, Escobar et al. (2006) reported on short term outcomes of babies born between 35 and 36 weeks gestation and concluded management of LPBs warranted

greater consideration. The authors recommended researching care for LPBs in different settings and by different healthcare practitioners; however, exploring women's experiences were not part of their suggestions. The emphasis for many of the scientific papers focuses on prevention of issues that may impact on the health of the LPB, and the role of the parent (usually the woman) is to recognise and identify problems early, so the baby can be "treated quickly to prevent further morbidities" (Forsythe and Allen 2013, p.4).

A large Brazilian birth cohort study (n=4,588) investigated outcomes of late preterm babies three months post birth (Santos et al. 2008). An element to the data gathering involved questioning mothers (96%) through the use of a standardised questionnaire. Information on breastfeeding, symptoms of diseases and use of the healthcare services was elicited. The majority of questions were pre-coded with a small number of open questions post coded. Thus, while the study sought to establish maternal antenatal characteristics associated with late preterm births and the consequences on infant health of those born late preterm, there is no reported feedback on quality of care and experiences of women.

A recent pilot project to determine whether first time mothers of LPBs would benefit from a tailor made programme of education was undertaken by Nair and Hill (2015). The aim was to educate and increase women's skills and confidence to prevent any of the known co-morbidities of LPBs, which could result in readmission to hospital following discharge, including reducing use of emergency departments (ED), compared to a control group who received standard postnatal teaching. Although the authors make frequent reference to parents (30 were eligible for inclusion) it appears only mothers (15) were randomised into an intervention group (one to one instruction of 15 minutes, in addition to an education brochure specifically designed for parents), and into the control group (15) with normal postnatal teaching (not specified). The randomised group were provided with questionnaires prior to and following the one-to-one instruction session to assess parental knowledge. Both groups were followed up through telephone contact one month following discharge (Nair and Hill 2015).

Data was analysed quantitatively which revealed no readmissions in both groups, although one baby from the control group was taken to ED due to jaundice. An early discharge (no further details provided) was blamed for the peak in jaundice (Nair and Hill 2015). There was no discussion on whether there was any available healthcare support for the women post discharge, therefore a peak in jaundice in the community need not necessitate readmission if postnatal support was easily accessible. The authors do not report on the outcome following the visit to ED. Statistical analysis of the data revealed significant gaps in parental (women's) knowledge in recognising risk factors that could impact on their baby's health, such as jaundice and infection. It is not known whether the control group had similar difficulties, as the main aim of the pilot was to examine acceptability of the teaching intervention (Nair and Hill 2015). The women who received intervention reported increased confidence in taking care of their LPB, although it is unknown whether the control group felt likewise, essentially therefore, the study is lacking a comparison between the two groups of women to determine whether one-to-one intervention is necessary.

The authors propose 'mothers' (note not parents, a term used frequently within the publication) should receive increased education in conjunction with an individualised discharge plan, which would "definitely result in more positive results" (Nair and Hill 2015, p.8). Therefore, in their view, standardised interventions/protocols should be developed to provide evidence based care for all LPB's. In addition, the authors propose that an increased level of healthcare professional knowledge around LPB's could prevent unnecessary transfers and separation of mother and baby. Finally, the authors believe collaborative working between nurses and doctors would enhance care for LPB's, but within this paradigm of professional led care, there was no mention of how mothers themselves could contribute to the well-being of their baby/babies (Nair and Hill 2015).

4.1.1 Women's experiences of caring for their late preterm babies

I used a generic tool for assessing the quality of research used within this section (Hewitt-Taylor 2011). The following databases were utilised to inform my review: the mySearch platform, EBSCO Service, Academic Search Complete, CINALH Complete, E-books, ERIC, Medline Complete, PSYch Info between 1980 and 2014 to ensure I included studies that may have defined late preterm babies as moderately preterm including the current definition. I searched for women and caring for late preterm babies, including women's experiences, late preterm infants, mothers and mother's experiences. There were many hits for late preterm infants (2,865) (infants being the most common term), however whittling it down to late preterm infants and women's experiences, the results after removal of duplicates, revealed 57 papers, none of which were relevant to my study. These studies were mainly focused on treatment of prevention of late preterm birth, mortality rates, developmental outcomes and so on. From my previous practice of working in a neonatal unit and reading further around late preterm babies I realised that I needed to amend my search to include words such as: postnatal depression, psychological, emotional, and kangaroo care which revealed further qualitative studies that were of interest to my search. Articles with full text were kept, online or available via inter library loans.

| Inclusion Criteria | Exclusion criteria |
|--|--|
| 2000 – 2014 | Studies before 2000 (majority of publications focusing on late preterm babies appear to have been published post 2000) |
| Women's experiences, motherhood, mum (synonym), mother, breastfeeding focusing on women's perspectives , parental perceptions, mother and father | Very preterm babies |

| | |
|---|---|
| (33) 34 ^{6/7} – 36 ^{6/7} | Term babies |
| Western countries (developed) | Non-western (or developing) |
| Research, expert opinion, case reports, systematic reviews, and commentaries, qualitative, quantitative | Guidelines / leaflets for parents |
| English language and journal articles and books and reports | Newspaper articles and non-English language |

Table 4-1: Search strategy

Articles that studied and reported on gestations between 30 -36 weeks were excluded although those between 33 – 36 weeks were kept, as the gap between 30 and 36 weeks is fairly wide in terms of preterm ability but 33 and 36 weeks is closer. One article was excluded because it was a repetition of another, same study, same authors but different order of authorship. Although a formal appraisal including a rating quality was not utilised, the principles for critiquing relevant research was followed (Hewitt-Taylor 2011).

I have previously highlighted that neonatal surveys report on parental perceptions of neonatal care as one collective experience, despite the majority of respondents being mothers (women). Furthermore, qualitative research has demonstrated mothers and fathers appear to experience the neonatal environment and their preterm baby differently, therefore my focus at this point was on understanding the experiences of women with LPBs which impacted on my decision to exclude a paper which, although it utilised the term late preterm baby, it included the experiences of fathers. The final sample consisted of eight papers. See Figure 1-4 for a summary of the studies utilised within this section. Roughly the literature under review in the following section can be categorised within three main activities: breastfeeding, KC and psychological/emotional issues.

| Author/ date/co untry | Aim of study | Study design | Main findings | Strengths and Limitations |
|--|--|---|---|---|
| Nagulesapi llai et al. (2013). Canada | To compare breastfeeding difficulties attributable to the baby and mother/milk and exclusive breastfeeding between a group of late preterm (LP) infants and term infants. | Quantitative questionnaire at 3 key stages | Breastfeeding difficulties attributable to the baby, but not the mother. Women who were breastfeeding LP at hospital discharge, were less likely to report exclusive breastfeeding at 4 months after controlling for household income level, mode of delivery and postpartum maternal physical health. | Mothers of LP infants need increased support to establish successful breastfeeding. The prospective nature of data collection minimized the risk of recall bias, and the population-based sample that allowed for study findings to be generalizable to pregnant women in urban centres in Canada. No exploration of why so many women had operative births, the severity of newborn problems or length of neonatal care required by the LPBs. No recommendations in regards to the mother's emotional well-being. No acknowledgement on the impact of her domestic responsibilities and/or other life responsibilities when considering duration of breastfeeding. |
| Ayton et al. (2012) Australia | To investigate and examine the factors associated with initiation of, and exclusive breastfeeding at hospital discharge of, late preterm compared with babies at 37 weeks mother and baby pairs. | A retrospective population-based cohort study | Late preterm and 37 week gestation infants had low rates of initiation of breastfeeding within one hour of birth. After multiple regression analysis, late preterm infants were less likely to initiate breastfeeding within one hour of birth and were less likely to be discharged exclusively breastfeeding from hospital compared to 37 week gestation infants. | The cohort of babies studied were within the LP range. A late preterm birth is predictive of breastfeeding failure. Women's experiences leading up to and during birth is not acknowledged, neither are their experiences noted during the postnatal period. |
| Boucher et al. (2011) Canada | Explored the maternal experience of breastfeeding initiation and progression in the NICU | Qualitative, descriptive design | Mothers described their breastfeeding experiences in terms of maintaining milk production, the regimen of the NICU, mother as learner, personal motivation, and forming attachments | Qualitative in nature with women able to describe their experiences. Sample was quite diverse in terms of gestational age which may have impacted on the success of breastfeeding. The study included mothers both with and without previous breastfeeding experience, and previous experience may influence the NICU breastfeeding experience. Further, the sample was limited to English- and French-speaking mothers, restricting the inclusion of ethnic minorities. Mothers were interviewed only once. |
| Zarnado et al. (2011) Italy | Examined the relationship between psychological distress of mothers who delivered late preterm, tested by three complementary validated scales, and early lactation performance, defined according to WHO guidelines | Prospective case control study | Late preterm gestation has a negative effect on mothers' psychological profiles in the puerperium, with the resulting levels of anxiety, depression, and psychological distress correlating negatively with their early lactation performance | Psychological distress in the postnatal period, potentially exacerbated by late preterm delivery, impairs breastfeeding in early life. Alleviating maternal mood states, and providing additional lactation guidance and psychological support during the first days postpartum could be beneficial for stimulating successful breastfeeding in more vulnerable women. Potential for misclassification of breastfeeding pattern, since |

| | | | | |
|--------------------------------------|--|---|---|---|
| | | | | impaired lactation and early formula supplementation were determined irrespective of the reasons given for formula feeding. In addition, researchers did not investigate if the presence of obstetric problems or emerging breastfeeding difficulties influenced the onset of mood states in vulnerable women. |
| Brandon et al. (2011) USA | To compare the emotional responses of mothers of late-preterm infants (34 0/7 to 36 6/7 weeks gestation) with those of mothers of full-term infants | A mixed method comparative study. | Mothers of late-preterm infants experienced significantly greater emotional distress immediately following delivery, and their distress levels continued to be higher at one month postpartum on each of the standardized measures. Mothers of late-preterm infants also discussed the altered trajectories in their birth and postpartum experiences and feeling unprepared for these unexpected events as a source of ongoing emotional distress. | Mothers of late-preterm infants have greater emotional distress. It is not a single event that leads to different distress levels in these mothers but rather the interaction of multiple alterations in the labour and delivery process and the poorer-than-expected infant health outcomes. Small sample size and follow-up data to only one month following delivery. No baseline measures of emotional distress before delivery to compare to the postpartum and one month data. The tertiary referral setting resulted in a study population with high rates of maternal and infant complications in the late-preterm and full-term groups. Therefore, study findings may not be transferable to infants and mothers cared for in community hospitals. |
| Anderson et al. (2003) USA | To describe the type and percent time of contact 0-48 hours post birth for mother-preterm newborn (infant) dyads given kangaroo care (skin-to skin) or standard care (controls). | RCT | Amount of SS was much less than expected | Attempts to provide humane care in highly technical environments. Randomized controlled trial, minimization method resulted in well balanced groups. Mothers were reluctant to hold their infants, especially those admitted to the NICU. Other mothers seemed poorly motivated to experience skin-to skin care. |
| Gregson and Blacker (2011) UK | To compare the efficacy of Kangaroo care (skin-to-skin contact with mother) with standard care (next to the mother in a cot) for premature, low birth weight and babies of diabetic mothers in a transitional care ward setting. | Cohort study | There was a significant reduction in mean length of stay in the study group compared to the control. There was also an increase in exclusive breastfeeding rates on discharge from hospital in the study group. There were no differences in feeding outcomes at 6 weeks or in admission to NICU. | The cohort of babies studied were within the LP range. Kangaroo care is a simple intervention that reduces length of hospital stay and improves breastfeeding rates on discharge from hospital for babies cared for in a transitional care/postnatal ward setting. Parents rated Kangaroo care highly. Lack of certainty regarding the amount of time participants performed Kangaroo care, lack of clarity of the definition of Kangaroo care for participants when they were asked to score and comment on their experience, and missing data for feeding outcomes at 6 weeks. |
| Baker et al (2013) USA | To compare maternal competence and responsiveness in mothers of late preterm infants (LPIs) with mothers of full-term infants | Non-experimental repeated-measures design | No difference in the perceptions of LPI and term mothers related to competence or responsiveness | The cohort of babies studied were within the LP range. Small sample size, self-report, attrition of participants, the possibility of socially desirable answers versus true feelings, reading level, participant burden, and English language-only survey tools |

Table 4-2: Summaries of the studies

4.1.2 Breastfeeding:

LPBs are physiologically and metabolically immature (Engle et al. 2007) which may have a bearing on their ability to successfully breastfeed (Meier et al. 2007). The literature concurs that a number of barriers impact on a woman's ability to breastfeed, these may consist of a poor suck, baby being sleepy and separation of baby from mother (Meier et al. 2007; Briere et al. 2015). A Canadian study undertaken by Nagulesapillai et al. (2013) had two objectives: 1) to compare breastfeeding difficulties attributable to either the baby or the mother/milk, and 2) exclusive breastfeeding between a group of LPBs and Term infants. Data was utilised from an established prospective study which commenced in 2008. Women who self-identified as having had a baby between 34^{0/7} and 36^{6/7}, and those who had given birth at Term were required to complete a questionnaire at three points, twice antenatally (<25 weeks and 34-36 weeks) and once postnatally at four months. Women and their LPBs numbered 173 compared to Term babies (2,778) – both groups of women had babies admitted to NICU, although for LPBs, admission was proportionally higher compared to Term babies (19.1% versus 2.5%). An equal proportion of women from both groups underwent operative births (23.7% and 28.9% respectively). There is no further exploration on reasons for the operative births, or indeed, the severity or length of neonatal care required by the LPBs. There are well documented studies demonstrating the negative associations between operative births and the initiation of breastfeeding (Dewey et al. 2003; Scott et al. 2007).

Statistical analysis undertaken by Nagulesapillai and colleagues (2013) demonstrated that women with LPBs were more likely to be non-Caucasian, foreign-born and report lower household income levels compared to women of Term infants. At four months postnatal, these women were also more likely to have poor emotional health and less likely to be exclusively breastfeeding than women with Term babies (Nagulesapillai et al. 2013), which suggests babies were mixed fed. The researchers identified breastfeeding difficulties were attributable to the baby, for example, poor attachment techniques and being sleepy, although interestingly, there was “no independent association between late preterm and

term birth and breastfeeding difficulties associated to the woman or her milk” (Nagulesapillai et al. 2013, p.354). Their findings which indicate LPBs lack skills to attach appropriately to the breast resulting in poor breast stimulation and reduced lactation production, are supported by other studies, see for example, Walker (2008) and Mathur and Dhingra (2009).

The authors conclude by recommending women of LPBs should be provided with increased support and care to “optimize breastfeeding success, monitor health and optimize growth and development” (Nagulesapillai et al. 2013, p.354), however, consideration of supporting and enhancing women’s emotional health or their domestic situation is not a recommendation. Whilst it is not evident within the study, it is possible that the women in the study with LPBs have poorer living conditions than women with Term babies and may have had to return to work to boost family income. These factors in conjunction with their poor emotional health and their domestic situation would have impacted on their ability to exclusively breastfeed. The focus of the study was evidently towards the baby, with minimal concern for the woman.

A similar quantitative approach was undertaken by Ayton et al. (2012). Their study set out to examine factors associated with initiation of and exclusive breastfeeding at hospital discharge between late preterm and Term mother and baby dyads. Similar to the study by Nagulesapillai et al. (2013), a high rate of LPBs were born by OD (61%). For LPBs born vaginally, initiation of breastfeeding within one hour of birth was ‘significantly lower’ when compared to Term babies and those born by operative birth were “80% less likely to be put to the breast within one hour of birth” (Ayton et al. 2012, p.3). It is not known whether this was due to babies being unwell at birth and subsequently transferred for neonatal care or organisational factors. LPBs were also 60% less likely to go home breastfeeding (Ayton et al. 2012). The authors acknowledge a concerted drive to reduce the number of operative births (which is commendable) within this population should be undertaken, in order to improve mothers and their LPBs’ chances of commencing and maintaining exclusive breastfeeding. Reducing operative births would also improve early skin to skin contact between a woman and her baby, which in turn may reduce separation

and increase the success of breastfeeding. An operative birth should not preclude women and their babies from experiencing skin to skin care unless the baby is extremely unwell (Carmichael and Matulionis 2014). However, both of the studies mentioned above do not centre the woman, her experience leading up to and during the birth is not acknowledged, neither are her experiences noted during the postnatal period, all of which are serious drawbacks and highlights my study was necessary.

Despite an awareness of the difficulties surrounding LPBs and breastfeeding, there is little known about women's breastfeeding experiences. I identified one study which utilised a qualitative descriptive design where women (n=10) who had babies on a NICU were interviewed (Boucher et al. 2011). The babies ranged from between 33 and 36 weeks gestation, therefore, although not strictly within the accepted definition of a LPB, it is close enough to draw some parallels. On closer inspection however, it appeared the babies were born between 27 and 34 weeks, therefore each started from very different timelines, with some resident on NICU between two and seven weeks. These discrepancies would separately impact on a baby's ability to breastfeed. However, the study was focused on exploring maternal experiences of breastfeeding initiation and progression within a NICU, so it is possible that these differences would make for a richer experience (Boucher et al. 2011).

The women (an equal balance between first and second time mothers) were interviewed face-to-face by two members of the research team not known to them. Content analysis was used to analyse data and a number of categories were collectively derived from the women's experiences which revealed mothers were concerned about a number of issues:

- 1) Women were anxious about their ability to sustain milk production to meet the demands of their baby
- 2) Women found NICU regimes restricting, as feeding regimes were based on the routines of the unit rather than on the baby's needs

- 3) Seven of the women had not breastfed before and thus had to learn techniques (Boucher et al. 2011).

Women were motivated to succeed with breastfeeding because their babies were preterm, and despite feeling their role as a mother in NICU was limited, women saw breastfeeding as an opportunity to form attachments (Boucher et al. 2011).

Whilst there is no definite conclusion to the paper, a number of key themes were drawn together. Firstly, breastfeeding is more than just the physical act of feeding; it becomes an important element of mother-baby attachment because of known factors which impact on a mother's ability to bond with her baby within NICU. Secondly, women were well aware of the health benefits of breastfeeding and saw it as a way they could enhance the health and well-being of their own baby, and thirdly, women wanted to be recognised as the mother of their baby and breastfeeding distinguished them from the nurses (Boucher et al. 2011). The sample of women were only interviewed once and were French and/or English speaking (thus excluding any ethnic minority women); however the wide range of gestational age of the babies may have affected the success of breastfeeding, therefore it is not known if breastfeeding continued beyond discharge or what it meant for other cultures not represented within the study. However, the research does afford a small window in which to view some of the difficulties faced by the women (Boucher et al. 2011) which are not evident when considering the two earlier quantitative studies.

4.1.2.1 Psychological issues and lactation performance

Zanardo et al. (2011) whilst also examining breastfeeding performance, undertook a slightly different approach. Theirs was a prospective study which examined the relationship between psychological distress of mothers who birthed LPBs and early lactation performance. Women with LPBs (n=42) and a control group of mothers of Term babies (n=42) were matched for parity and delivery route and were asked to respond to three questionnaires: the Edinburgh Postnatal Depression Scale (EPDS), the State-Trait Anxiety Inventory (STAI-Y) and the Psychological Stress Measure

(PSM). All three tools examine how a person is feeling, for example, how they have felt in the past seven days, how are they feeling now and how they have felt over the past month. The scales were administered to the women by a trained interviewer at 10am on days three and four postpartum, with each interview taking around 30 minutes to complete (Zanardo et al. 2011).

After statistical analysis, state anxiety, depression and stress levels of mothers who had LPBs were all significantly higher in comparison to mothers of Term babies (Zanardo et al. 2011). In addition, despite being considered 'healthy' and cared for in a regular nursery, only 21% of women were able to feed their LPBs compared to 81% of women with Term babies. The authors conclude by stating psychological distress probably worsened by late preterm birth, impairs initiation and on-going breastfeeding for women with LPB's (Zanardo et al. 2011). A number of issues were not considered by the authors when interpreting the results. Although both groups of women had high OD rates (n=25), no attention was paid to factors leading up to birth, such as: were women with LPBs high risk due to their obstetric history, therefore, were they already anxious prior to due to their health or that of their unborn baby? Were there opportunities for women to experience early skin to skin contact with their baby? Did early separation occur? It is known many of these factors impair a woman's ability to successfully breastfeed. Women would also have been medicated (pain as a result of their operative birth), therefore what support was available to help facilitate breastfeeding in the first few days? The babies had a mean gestation of 36.3 weeks, why were they cared for in a nursery? It is not clear whether mothers and their babies were kept together although being in a nursery suggests separation. Feeds were supplemented with mother's breastmilk, why was formula necessary if the babies were deemed 'healthy' and why was supplementation provided by bottle? All of these interventions would have impacted on the women and their babies, and finally, the surveys were not designed to enable women to describe their experience. Their perspective would have added depth and quality to the results.

Brandon et al. (2011) undertook a mixed methods comparative study which recruited 29 women of LPBs and compared their emotional responses to 31 women

of Term babies. They sought to compare these two groups of women because the bulk of the literature is focused on the emotional responses of women with very early preterm babies, which in their view is not generalizable to women of LPBs. A questionnaire comparable to those utilised by Zanardo et al. (2011) was used alongside two open ended semi-structured interviews. Women were recruited whilst resident in hospital and contacted again one month later for a telephone interview. The initial interview asked the women to describe the story of their birth and subsequent care received by their babies. The second interview explored how women were finding motherhood since the first meeting (Brandon et al. 2011).

The questionnaires, designed to elicit maternal emotional distress were statistically interpreted and the interviews were analysed using content analysis aided by a computer package. The scores from the questionnaires indicated women with LPBs had increased anxiety, depressive and post-traumatic symptoms and worried about their babies' health following birth and at one month, more than women with Term babies (Brandon et al. 2011). These results are similar to Zanardo et al. (2011) with one marked difference: Zanardo and colleagues did not follow women up post discharge, which suggests, from the results of the Brandon et al. study (2011), that the effects on women as a result of a late preterm birth continue for some time in the postnatal period.

The qualitative findings provide a much richer picture of the women's experiences (Brandon et al. 2011). The strongest theme to emerge was that of "altered trajectories" for those with a LPB as opposed to the more "transient challenges" for women of Term babies (Brandon et al. 2011, p.725). Events that preceded a late preterm birth impacted on the experiences of women post birth such as: medical interventions provided for the woman and her unborn baby, unexpected mode and timing of birth and babies with outcomes poorer than expected, although both groups of women shared similar concerns about their "altered birth plans", such as labour being induced and augmented, episiotomy and the possibility of an operative birth (Brandon et al. 2011, p.727). Women in the late preterm birth group also described having to "hold it together" after receiving "bad" news following a scan (Brandon et al. 2011, p.727), which is similar to the experiences of

women explored in Chapter 2 who were on restricted activity (hospital/home) for the prevention of preterm labour and birth.

Whilst both groups of women had concerns about the health of their baby, these were more prevalent amongst women with a LPB, especially those women who expressed distress about the timing of their baby's birth and possible outcomes (Brandon et al. 2011). Unsurprisingly, emotional responses peaked when women were discharged home without their baby, which suggests their baby's condition may have warranted an extended stay on the neonatal unit. Like numerous studies have demonstrated, women in Brandon and colleagues study (2011, p.278) were "heartbroken" their baby was cared for by nurses. Others cried every time they left the hospital and reported feeling scared and afraid of missing "something that was going to happen when he was there and I was home" (Brandon et al. 2011, p.278). Women in the Term group were not separated from their babies and were discharged home together (Brandon et al. 2011). The study did not explore whether women who were separated from their babies were provided with facilities to room in, whilst their babies was receiving neonatal care or even prior to discharge.

Comparable to studies mentioned previously, women with LPBs in the Brandon et al. (2011) study experienced feeding difficulties, which were related to either breast or bottle. Many problems related to the baby's prematurity, for example, an inability to coordinate suck, swallow and breathing reflexes. Women of Term babies also reported feeding problems, however, unlike PTBs, these were not related to the baby but directly to the woman (Brandon et al. 2011). Women described being unable to read their baby's feeding cues and expressed concerns their perceived milk supply was inadequate. Other women were more concerned with how their baby reacted to formula feeds (such as colic or constipation), rather than feeding ability (Brandon et al. 2011). Significantly however, women in the late preterm group were separated from their baby for varying lengths of time and discharged home without their baby. Both of these practices would have impacted on a woman's ability to initiate and sustain breastfeeding. A further important theme to emerge concerned weight gain, as both groups of mothers appeared to equate "infant size with health" (Brandon et al. 2011, p.728). The authors further believed

healthcare providers caring for women shared similar ideals; therefore “neonatal weight gain” became a concern for all mothers, although it was “more intense in the context of small babies” (Brandon et al. 2011, p.728).

The authors conclude by concurring somewhat with the findings from the Zanardo et al. (2011) study. Women with LPBs experience psychological problems and need support in the early days (Brandon et al. 2011). Similarly, whilst Brandon and colleagues explored events leading up to birth which was in my opinion, a major omission in the Zanardo et al. (2011) study, both studies acknowledge the emotional distress felt by women in the postnatal period was directly related to their experiences which preceded birth. However, findings from the Brandon et al. (2011) study confirm women with LPBs should not be treated as a normal Term dyad and recommend women are provided with extra support during their baby’s stay in hospital and for at least one month postnatally (Brandon et al. 2011). Zanardo and colleagues (2011) support the concept of extra help, although their focus is on the need for women to be provided with additional lactation guidance and psychological support to ensure breastfeeding is successful. The Brandon et al. (2011) study was focused on women and its approach in utilising both a quantitative and qualitative approach to understand a woman’s experience with a LPB is praiseworthy.

4.1.3 Kangaroo care:

Kangaroo Care (KC) has been shown to have many benefits for mothers and babies (Leonard and Mayers 2008; Rodgers 2013) and whilst there are numerous studies examining the positive benefits between mother-baby dyads, and in particular the preterm dyad, little is known about the effects of KC or skin-to-skin care (S2S) on women who have a LPB (Chiu and Anderson 2009). Anderson and colleagues set out to “describe the type and percent time of contact 0-48 hours post-birth in two groups of similar mother-preterm dyads given S2S or standard care” (Anderson et al. 2003, p.604).

Their sample consisted of 48 mothers and babies, with the majority being categorised as late preterm (=33). Based on the lack of evidence of S2S on mothers of LPBs, it is interesting to speculate why the authors wanted to describe how much time and type of contact the research group had, rather than exploring what it meant for women. The research was published in 2003 (accepted in 2002) and there is no indication as to when the study began, therefore it could be safe to assume S2S or KC was only just beginning to be established in 'western' neonatal units, despite benefits being known as early as 1978 that it was a safe alternative to incubators in countries where resources were scarce (Conde-Agudelo and Diaz-Rossello 2014).

Women were assigned to standard care which consisted of wrapped holding (WH) or the KC group for S2S and WH (Anderson et al. 2003). KC is generally defined as placing a baby naked (with nappy) in the vertical position directly onto the woman's skin usually between her breasts and under her clothes (Charpak et al. 2005). It can be provided continuously (24 hours per day) as an alternative to an incubator, or intermittently – ideally for up to two hours per time (Charpak et al. 2005). It is not known from Anderson and colleague's study whether KC was designed to be continuous or intermittent. Thirty two babies were separated from their mothers and nursed on a neonatal unit. Depending on the randomisation, either WH or S2S occurred within this environment. The remainder of mothers and their babies were cared for on a PNW (Anderson et al. 2003).

The results indicated women and their babies randomised to KC had less S2S than anticipated, despite researchers being on hand to facilitate and encourage it. They hypothesised this was due to S2S sessions being interrupted by hospital routines, or visitors interrupting mother-baby contact (Anderson et al. 2003). Not taken into consideration were the circumstances leading up to birth, although only women who were 'healthy' were included into the study. We have seen from Chapter 2 that women who are at threat of a preterm labour and birth often deemed themselves 'healthy', and were only on restricted activities or bed rest (hospital or home) to protect the unborn baby. The evidence effectively demonstrates that prescribed restrictions had physical and mental effects upon healthy women, which

might have impacted on their ability to undertake KC following birth. Many women underwent epidurals; others had operative births (Anderson et al. 2003), factors which would have affected their postnatal recovery. In addition, research has demonstrated women experiencing late preterm labour have many anxieties, is their baby going to survive, separation, concerns around short and long term outcomes and caring for their baby in an alien and highly technical environment. We know from qualitative research (see for example: Fenwick et al. 2001b; Erlandsson and Fagerberg 2005; Fenwick et al. 2008; Flacking et al. 2012 and de Cássia de Jesus Melo et al. 2014), that women do not consider themselves as mothers of their preterm babies and feel disempowered whilst in neonatal units.

Women who were randomised to KC on the PNW had S2S for 22% of the time as opposed to women on NICU, who only experienced KC for 7.5% of the time (Anderson et al. 2003), which suggest environment of care impacts on a woman's ability to provide KC. A recent descriptive study undertaken by Blomqvist et al. (2013) provides an explanation as to the barriers perceived by parents in providing KC on a neonatal unit. Barriers were divided into three distinct categories although there were overlaps. The first category was reported as relating to parental factors, where parent's perceived NICU routines and staff attitudes impacted on KC opportunities. Whilst these had links with institutional factors it was the parents' perceptions that were being reported on. Others found providing continuous KC as frustrating as it restricted their ability to freely move around. In the category related to infant factors, women reported that breastfeeding and breastmilk expression impacted on and interrupted their ability to provide KC. Additionally; equipment attached to the baby (tangled leads, bleeps/noises from the machines) disrupted KC and repeated alarms bells stressed parents. Finally, environmental factors were reported, which included privacy issues, uncomfortable chairs, limited facilities (for staying overnight) and noise from other babies and staff (Blomqvist et al. 2012).

Although the babies in the Blomqvist et al. study were of a much lower gestation which necessitated an extended stay on NICU than the babies in the study carried out by Anderson et al. (2003), correlations are possible. A large cohort of babies

were admitted to NICU in the Anderson et al. study, with the authors acknowledging that although KC was shorter than expected, it took place earlier than normal and for longer than was generally “allowed in a culture which routinely separated mothers and their preterm babies”, common practice in US hospitals at the time of the study (Anderson et al. 2003, p.609). Whilst the authors anticipated women would want increased KC because they were on hand to facilitate and support, in reality women preferred wrap holding. A qualitative element to their research may have uncovered why women appeared to prefer this type of contact in preference to KC.

Whilst Anderson and colleagues (2003) claim the strength of their study was based on it being a well-designed RCT, in my opinion it was overly positivist and did not seek to explore human dimensions. On several occasions the authors report how they thought women should respond to their *well-designed RCT*, for example, in their discussion they inform the reader “only an occasional mother had the kind of experience we envisioned” (Anderson et al. 2003, p.609, 610) and further on, “mothers seemed poorly motivated to experience S2S care” (blaming women). Whilst I feel the study did measure important outcomes which serve to highlight institutional and staff practices, it would have greatly benefitted from exploring women’s views of KC/S2S with their babies and some of the issues raised by the authors themselves. Finally, the study could be praised for attempting to demonstrate the benefits of KC for mothers and babies at a time when neonatal care was less humanised than it is now.

A cohort study undertaken by Gregson and Blacker (2011) to examine KC in late preterm or low birthweight babies on a transitional unit (TU)/ PNW, had LOS as its main outcome. Secondary measures examined breastfeeding at discharge, parental satisfaction and whether KC prevented NICU admissions. Babies were allocated to a study group or control group although it is not clear how randomisation occurred. Babies in the control group received standard care which included KC although women were required to put babies into a cot. In the study group women were encouraged to provide KC for as long as possible during a 24 hour period and to avoid using cots.

All measures were successfully achieved, women appeared to go home one day less than the control group, were breastfeeding and no babies were admitted into NICU. Of note more women from the study group were exclusively breastfeeding at discharge than women in the control group. Large amounts of breastfeeding data was missing at six weeks (Gregson and Blacker 2011), therefore an opportunity to detect whether sustained and prolonged periods of KC during hospitalisation and at home (women were encouraged to provide KC following discharge) improved long term breastfeeding has been missed. Women in the study group provided feedback via Likert style questionnaires which examined parental satisfaction, overwhelmingly demonstrated that women loved providing KC, whilst analysis of their diaries revealed KC helped with bonding and enhanced breastfeeding (Gregson and Blacker 2011).

The authors claim KC is a simple and effective intervention, easily instigated on TU/PNWs and would reduce length of stay and improve breastfeeding rates for LPBs (Gregson and Blacker (2011). The study did not examine barriers to undertaking KC, instead the researchers believed more women could have been encouraged to experience an increased level of KC during the study, had staff been more 'static' on the PNW and had more experience (Gregson and Blacker (2011). There is no further exploration on the nature of staff permanency or whether the perceived 'inexperience' was related to busy staff, including an understanding that other peoples' research is not always a priority for staff that are not 'static' and appeared to be rather busy attending to postnatal mothers and babies with increased needs. The study has however, positively highlighted that keeping mothers and their LPBs together has certain benefits, women enjoyed KC contact, bonding was enhanced and successful breastfeeding was achieved.

4.1.4 Competence and responsiveness in mothers of late preterm babies

Both the studies undertaken by Zanardo et al. (2011) and Brandon et al. (2011) reveal that women with LPBs experience psychological distress in the days following the birth and for some time after, although not a great deal is not known about their transition to motherhood (Baker et al. 2013). Baker et al. (2013) set out to

achieve this by undertaking a study to examine competence and responsiveness in mothers of LPBs compared to mothers of Term babies. Maternal competence was portrayed as “maternal intelligence that influences infant development and includes elements of sensitivity, responsiveness and synchrony.....and continually changes as the infant grows and is based on verbal and nonverbal feedback from the infant” (Mercer & Ferkeitch, 1995; Rubin, 1984 cited Baker et al. 2013, p.302). A woman-mother, who demonstrates warm and soothing behaviours towards her baby when he/she provides cues, is described as exhibiting “maternal responsiveness” traits which enhances synchronous relationships between the dyad (Baker et al. 2013, p.302) an image which in my view, conjures up the stereotypical mother as recommended by the institution of motherhood (Rich 1976)

Women were recruited in the early postnatal period over a period of six months and were required to complete two surveys, the first during their hospital postnatal stay and the second at six weeks postpartum. The surveys consisted of 160 questions with Likert-type responses (Baker et al. 2013) which must have been onerous for the women to complete with a new preterm baby on board. To lessen “survey burden” women were allowed as much time as needed, and were rewarded with local department store gift cards each time they completed the questionnaires (Baker et al. 2013, p.307). The ‘sweeteners’ were not enough as the response rate decreased between the two measurement points. An abbreviated version of the tool is presented and it looks complicated.

Standard demographics were collected, although information on the women’s educational background and whether they were in paid employment was not, factors acknowledged by the researchers which may have impacted on their competence to mother their baby (Baker et al. 2013). How these factors may have impacted on competence is not expanded upon. Interestingly, of the 21 women with LPBs, 20 identified as Non-Hispanic or Latino which did not appear to have a bearing on the outcomes unlike the women studied by Nagulesapillai et al. (2013) which demonstrated women from a non-Caucasian background had a number of factors impacting on their ability to exclusively breastfeed. Finally, the survey did not provide women with an opportunity to narratively expand on their experience.

Survey data was statistically analysed which revealed there were “no significant differences in maternal competence or responsiveness between the two groups of mothers or between the measurement times” (Baker et al. 2013, p.306), despite women with LPBs experiencing higher stress levels at birth and again 6 weeks postnatally. It appears levels of stress did not impact on women’s ability to care and respond to their babies. Interestingly, Zanardo and colleagues (2011) reported similar results of stress and anxiety in women with LPBs, although in their view stress impacted on a woman’s ability to initiate and successfully breastfeed. The studies which examined breastfeeding ability in LPBs, and quoted earlier, highlighted that breastfeeding difficulties are related to the baby and these factors may have caused a mother to feel stressed. It appears therefore, that women in the Baker et al (2013) study experienced minimal difficulties in adjusting to their role as mothers of LPBs, despite the well documented complexities of being born within this gestation. It is not known what method of feeding was chosen by the women for their babies.

Maternal competence and responsiveness appear to be linked to how satisfied women are with life, their own self-esteem, the support structures available to them and low levels of depression and stress (Baker et al. 2013). Although the final numbers included for analysis was small which makes generalisation of the findings somewhat questionable, the most important implication in the authors’ view is for an appropriate environment to be provided, where mothers can be supported in their transition to mothering and learn to care for their LPB. What type of environment this would consist of, is not explored any further.

The percentage of LPBs in the sample population available to the authors was 5%, much lower than the national average of 8.28% at the time the study was undertaken (Baker et al. 2013). The hospital environment is credited with influencing outcomes as prevention of late preterm births became a priority for obstetric services a year prior to data collection, as a concerted effort was undertaken to reduce elective births prior to 39 weeks gestation. Preceding the intervention, the hospital where recruitment took place had 20 late preterm births per month as opposed to 10 which is a laudable achievement (Baker et al. 2013). An

exploration of factors contributing to early elective births would have been of interest. The study would have benefitted from exploring women's individual circumstances; for example, most babies were kept in hospital for five days, therefore what factors during this period helped a woman to competently care for her LPB? On return home what support structures were available? These questions made my study even more important.

4.2 Conclusion

This chapter has demonstrated the majority of the literature focusing on LPBs is devoted to research undertaken from a positivistic perspective with authors reporting on short and long term morbidities. Focusing the search to concentrate specifically on women's experiences, a single study was revealed (Brandon et al. 2011), which utilised a mixed methods approach to explore the emotional responses of women with LPBs. The remainder of the studies utilised quantitative methods to uncover psychological issues, or measured activities women 'do' with their babies, such as breastfeeding and skin-to-skin contact. Furthermore, there is an abundance of research exploring women's experiences in caring for extreme/very preterm infants, and although women and their late preterm babies are sometimes reported on within this pool of 'rich' information, data findings are generally presented as one and women's experiences of caring for their LPBs remains largely invisible. Therefore the literature has demonstrated a lack of in-depth knowledge into women's experiences of caring for LPBs including an absence of literature which explores women as 'knowers' within this context.

Therefore my overarching aim, to try and uncover the woman's voice since it was missing from the bulk of the literature pertaining to LPBs, influenced the creation of my main research question: "What are the experiences of women who are caring for a late preterm baby?" Secondary questions focused around the early postnatal experiences (care whilst in hospital) and later, five to eight weeks post discharge (care and support at home). Therefore I anticipated by studying women's experiences in two phases, I would be able to portray how women found their

experiences of caring, thereby adding to the growing body of knowledge around LPBs.

The following chapter will explore the methodology and research design utilised within my study.

CHAPTER 5 METHODOLOGY

Introduction

The aim of my study was to address my overall question: “What are the experiences of women who are caring for a late preterm baby?” Therefore the methodological approach and research design utilised to achieve my aim will be outlined within this chapter which is divided into three sections. Section one considers feminism and its application within midwifery and why it was chosen as a philosophical framework for my study. Section two considers the research process in its entirety, from theory to practice and finally, section three considers data analysis through the use of TA. The final aspect of this section considers how the application of Birth Territory contributed to my findings. In all three sections I reflect upon issues that impacted during the preparation and the conduction of my study.

5.1 DEFINITION OF FEMINISM:

Feminism, as defined by bell hooks (2000, p.viii) is a “movement to end sexism, sexist exploitation and oppression”. As a definition she is quite clear sexism is the problem which, due to a socialization which commences at birth, men and women both “accept sexist thoughts and actions”. Reinharz (1981, p.3) offers two further interpretations of the term ‘feminist’, it can describe “a person who holds feminist beliefs or acts in accordance with feminist principles”, or it can signify “beliefs or action”, in other words, feminism can represent either the ‘person or the ideology’. Ideology and ideas are not sufficient cautions Brooks and Hesse-Biber (2007, p.3), as feminism must be “*rooted in the very lives, struggles and experiences of women*”.

Similar explanations put forward by DeVault (1999, p.31,33) indicates that feminists “believe women have been subordinated through men’s greater power.....they value women’s lives and concerns and work to improve women’s status”. Whilst there appears to be diversity of definition amongst feminists, Chafetz (2004) appeals for one which would be all inclusive and suggests four principles:

- 1) “.....gender is a system of inequality between male and females as sex categories by which things feminine are socially and culturally devalued and men enjoy greater access to scarce and valued resources
- 2) Gender inequality is produced socio-culturally and is not immutable
- 3) Gender inequality is evaluated negatively as unjust, unfair
- 4)feminists should strive to eliminate gender inequality” (Chafetz 2004, p. 965, 966).

Feminism is not, however, limited by its definitions as debate continues within the feminist literature as to the causes and meaning of gender inequality and how to change or improve societies where it exists (Chafetz 2004; Mackay 2015). Of note, all of the above draw attention to one indisputable fact: the definitions describe patriarchy (although in existence long before feminism existed), a term developed in the 70s by feminists to describe the mechanisms “of male power (predominantly white) privilege, domination and violence” (Browne 2014, p.9). Indeed bell hooks described patriarchy as a

“political-social system that insists that males are inherently dominating, superior to everything and everyone deemed weak, especially females, and endowed with the right to dominate and rule over the weak and to maintain that dominance through various forms of psychological terrorism and violence” (hooks n.d., p. 1)

Rich (1976, p.57) describes patriarchy as the “power of the fathers: a familial-social, ideological, political system.....” In her definition men, through various mechanisms such as force, ritual, tradition, language, customs, division of labour, education and etiquette, decide what part a woman can or cannot have and the female is “everywhere subsumed under the male” (Rich 1976, p.57). Her definition does not however, suggest that no woman ever has agency, for in her seminal publication on mothering and motherhood where motherhood as an institution, and a male-defined site of oppression strongly dictates how women should mother, women’s own experiences of mothering outside of patriarchy can be source of power and agency (Rich 1976, O’Reilly 2004). Her influential book helped feminism and feminists contemplate mothering by way of functioning as both oppressive and liberating, although it could be argued that given the male-dominated cultures

where men's lives over women take precedence, their devaluing of women's knowledge and experiences and their failure to consider women's personhood beyond motherhood (Kinser 2010) will never be realised when patriarchy as a system of social governance remains in place (Mackay 2015). For example, in 2017, women continue to remain oppressed within many aspects of childbirth, despite the best efforts of feminism (Yuill 2012). When I started my midwifery training and education in 1988, I discovered that postnatal care was called the 'Cinderella service' of maternity care (Yuill 2012), today women are still complaining of poor postnatal care due to chronic underfunding and understaffing particularly in England (Warwick 2014; Paparella 2016). These cutbacks which affect mothers disproportionately indicate that women who are overwhelmingly the ones left holding the baby, are not truly valued by society (Yuill 2012; Warwick 2014).

Within this paradigm there exists a contradiction of expectations, on the one hand there is 'patriarchy' which defines how women should mother and in the second there are patriarchal institutions such as the government and the NHS which decide on which services to fund. In the current climate where postnatal services lag behind other maternity services such as antenatal care (Paparella 2016), women are left to get on with the job of mothering without extra support (Wray 2006) which flies in the face of patriarchal motherhood and sets women up to fail (Porter 2010). That these avenues remain dominated by men both in the UK and worldwide is no coincidence as patriarchy persists within the 21st century with both men and women wedded to its thinking (Browne 2014; hooks n.d). Privileged and privately (mostly white) educated men continue to hold power in all aspects of society (government, education, the police force, management and the media). Society is therefore shaped by just one half of the population which in essence overwhelmingly contributes to the normalisation of its group perspectives and its images of power (Mackay 2015).

5.1.1 Feminism and midwifery:

Stephens (1999, p.476) declares feminism to be about “women demanding their full rights as human beings and challenging the relations between men and women that keep women subordinate and second best”. She further views feminism as a means of questioning why women’s work should be valued less than that undertaken by men. This is particularly relevant when considering NHS maternity services and the gendered professions of midwifery (female) and obstetrics (male) (Stephens 1999; 2004).

Midwife means ‘with women’ and traditionally, women as midwives were the custodians and sharers of epistemological knowledge around childbirth who attended women in birth, usually in their homes surrounded by female friends and relatives (Brodsky 2008; Green 2008). As medicine in all aspects became more professional (and masculinised) with knowledge around anatomy increasing, but only for learned and literate men (women were commonly excluded from accessing written texts), male medical practitioners with their obstetric tools began to encroach on midwives birth territory by setting about discrediting midwifery knowledge (experience and wisdom passed down, intuition and caring) and claiming scientific male knowledge as more superior (Cahill 2001).

Doctors, who had begun to organise themselves into one professional group which reflected those in political power in terms of gender, class and race, now became the dominant group and “operated both exclusionary and demarcatory strategies of the subordinate group, the midwives, through the downward exercise of power” (Cahill 2001, p.337). Gender played a role in tactics employed by doctors, as midwives were excluded from receiving formal education and were not able to register on the medical register based on their lack of training, resulting in doctors effectively side-lining women (midwives) and subsequently gaining overall dominance in childbirth (Cahill 2001).

During the 20th century, in line with industrialization and a rise in scientific knowledge and technology, other ‘scientific’ interventions were introduced by obstetricians into the childbirth arena (Dornan 2008). However, despite the

medicalization of pregnancy and a period when women had very little options to step outside their accepted roles within society, the role of the midwife which had re-gained some prestige as a profession was “recognised as a social good” (Murphy-Lawless 2006, p.442). Women continued to call the community midwife who listened and provided compassionate care and whose services were paid for by the government (Allison 1996; Murphy-Lawless 2006).

By the 1960s however, the pre-eminence of medicine in western society considerably marginalised midwifery approaches to care, as midwives and women were absorbed into medically orientated healthcare systems designed to treat illnesses (Pollard 2011). With the move into NHS hospitals came the inevitable, further medicalization of birth and domination of medical expertise over midwifery knowledge (Murphy-Lawless 2006; Kirkham 2010a; Davis 2012). Midwifery practice now became defined and limited by obstetrics (Cahill 2001), with feminine values of caring, cooperation and negotiation, a core concept of the midwife-women relationship, much less valued than positivistic scientific approaches to care (van Teijlingen 2015). A professional hierarchy ensued, resulting in NHS midwives reflecting the subordinate role of women in society (Stephens 1999).

The NHS as an institution and those that work within it, mirror society, in that it operates as a system of patriarchy. Within midwifery services, obstetricians and senior managers are situated top of a pecking order, midwives somewhat lower and pregnant women positioned at the bottom with little or no power (Stephens 2004; Keating and Fleming 2009). Murphy-Lawless in her article on birth and mothering in today’s social order draws our attention to how a system of patriarchy fails to consider women’s experiences as authentic forms of knowledge by citing a particularly relevant quote

“Traditional midwives’ knowledge is not power, midwifery knowledge is not power, women’s knowledge is not power because their knowledge has little status within the dominant scientific system” (Hillier, 2003 cited Murphy-Lawless 2006)

Feminism therefore, which challenges structures and ideologies that oppress women, is ideally suited as a framework for research in midwifery (Barnes 1999;

Brooks and Hesse-Biber 2007). As identified previously, one of the challenges for midwifery and midwives is providing women centred care in hospitals which are traditionally patriarchal. This makes feminist approaches to research particularly appropriate for examining women's experiences in hospital environments and one which shaped my methodology.

I am mainly attracted to the principles of radical (second wave) feminism, in view of its emphasis on challenging patriarchy and sexism, and as a theory through which to examine women's experiences, appears eminently suitable for my midwifery research (McLoughlin 1997). From its beginnings in the late 1960s to the present, radical feminists continue to focus on women's issues not always discussed openly and honestly across society, such as sexuality, control of fertility (abortion rights), violence against women (rape and abuse) and the use and exploitation of women's bodies in pornography (Hughes 1998; Weedon 2007). That these issues remain prevalent suggests women remain oppressed (Chardon 2013), with feminists arguing that chances of effective transformation in society will not be achieved because patriarchy endures (Kaufmann 2004).

Although feminism has not stood still and is in its third wave, there appears to be a split between the first two waves and the third, in terms of ideology and vision. Third wave feminism evolved in response to women who felt judged by radical feminists. These 'new' feminists argued that, despite wearing stiletto heels or enjoying pornography or requesting a caesarean section on demand, it did not mean they did not believe in feminism or women's rights (Kaufmann 2004). Others called third wave feminism as a movement away from that which their mothers might have participated in and wanted it to concern the lives of real women who 'had it all' – juggling a career, family and so on (Bobel 2010). It has variously been referred to in the US as "lipstick feminism", "girlie feminism", "riot grl feminism", "cybergrrl feminism", "transfeminism" or "grrl feminism", and in Europe as "new feminism" (Kroløkke and Sørensen 2006, p.15). Women identifying with third wave feminism saw themselves as strong, not toeing the feminist party line, revelling in their femininity and being all inclusive, for example a feminism that represents the

experiences of all women, different cultures including men, an inclusivity that acknowledges 'human complexity' (Kroløkke and Sørensen 2006; Munro 2015). In contrast, at its core, radical feminism centres only women and seeks to analyse and examine experiences from their standpoint (Klima 2001).

Whilst the main tenet of radical second-wave feminism was centred on a strong philosophy that, as a group of sisters, women could empower each other (Kroløkke and Sørensen 2006), third wave feminists appear orientated towards individuality, for example, they would not consider gender discrimination as a group problem or one affecting 'sisters' but rather, one that affects individuals (Farmer 2008). These women see no harm in individuality, they consider the time is right to put themselves first, as opposed to perhaps their mothers, who always put themselves last (Farmer 2008). On the other hand, individual emancipation asserts Munro (2015), only leads to a weakening of the third wave feminist movement, since change as a mass protest has far more impetus than change only effected by individuals. This is one of the aspects of third wave feminism that does not inspire me.

The first and second waves of feminism were highly charged politically, with women actively campaigning for their rights at work, in reproduction and an end to sexism (German 2003; Chardon 2013). The third, with its emphasis on micro-politics, absence of academic theory (although its use of internet to disseminate ideas and to reach a wide audience has been effective) and lack of political agitation, has been critiqued for its non-existent tactics, unlike the rather rebellious approaches undertaken by their 'sisters' of the preceding waves of feminism, which appeals to me much more (Coleman 2009; Chardon 2013). In addition, third wave feminism appears to be focused on the perspective of the individual in question, rather than the perspective of others. As such, I felt my own stance of actively seeking to move outside my own views and perceptions in order to understand those of other women, was potentially at odds with this.

Coleman (2009) questions whether third wave feminism is waving or drowning in its continued resistance to second wave feminism, as it appears many young women are not aware of the battles fought by women during the 60s and 70s and consider themselves as having it all with no need for feminism (post feminism). Recent discourse on feminism reveals a different picture. Huge inequalities still exist both within the public and private lives of women (Cochrane 2008; Chardon 2013). They continue to be discriminated against in the workplace due to pregnancy and childbirth (Cochrane 2008; Tyler 2008), wage inequalities (Smith 2015) and single mothers, working mothers, stay at home mothers and childless women are routinely demonised in the media (Tyler 2008).

At Westminster the majority of politicians are white males (Mackay 2015), which has led to the 50:50 Parliament campaign being initiated. Its website informs us there are 32 million women in the UK amounting to 51% of the population, yet only 148 women are politicians, the majority - 77% are men (502). The campaign is calling for a debate and a plan for a better gender balance in parliament (<http://www.5050parliament.co.uk/>). When considering gender imbalance within the UK government, I agree with Stephenson when she asks readers to envisage whether the language of birth could ever take place in a male dominated political arena, and whether men would be able to understand or value physiological birth by summing up: "Can we begin to imagine a discussion involving love hormones and vaginas in parliament" (Stephenson 2013, p.3). To my thinking, I would suggest feminism as a movement is far from over and rather than individuals standing up, we need the collective power of women to challenge oppression which continues in all walks of life.

Whilst the majority of third wavers continue to consider radical feminism as belonging to their mothers and old fashioned, with some even viewing feminism as unnecessary (Coleman 2009), radical feminists continue to champion women's rights, believing many women remain oppressed as a result of their 'gender' (Kroløkke and Sørensen 2006; Weedon 2007) and patriarchy remains the default

position for many women in society, regardless of their historical, cultural, socio-economic or ethnic status (Kaufmann 2004; Weedon 2007).

If we accept that operationally, NHS institutions are run along commercial lines which imply efficiency with maximum productivity for minimal cost, it is not a system within which human relationships can flourish (Kirkham 2017). Moreover, the NHS is an organisation in which the biomedical discourse of childbirth prevails (Stewart 2010), a form of scientific knowledge that values male knowledge (based on science and rationality) to the detriment of female (midwifery) knowledge (Murphy-Lawless 2006; Stewart 2010; Kirkham 2010a; Davis 2012). As such, the traditional medical model, which is prevalent in the NHS, could be considered patriarchal. Having worked as a midwife within the NHS and experienced first-hand aspects of oppression on my practice and others by male doctors, my stance towards midwifery and radical feminism being mutual bedfellows was strengthened, especially as both appear to offer a new vision for women's health/maternity (Klima 2001). By critically examining the provision of maternity services and midwifery through the lens of radical feminism, the potential for transformation could be significant for women (and midwifery) (Klima 2001).

Many midwives and others (such as neonatal nurses) have become part of the biomedical system and instead of being 'attuned to a woman's needs at any particular moment' (Stewart 2010), have become regulated and constrained by guidelines/protocols and/or by the expectations of professional colleagues (Stewart 2010). Midwifery work at its purest can be viewed as feminist because it is connected with creating meaningful relationships between ourselves and women; it is about women-centred care (Kirkham 2011; Walsh 2016). Our role therefore, should be to support women to make the right decisions for themselves, and by doing so we avoid patriarchal behaviour (Stewart 2010). Yet Walsh and colleagues question why there are apparently so few midwives declaring themselves as feminists (Walsh et al. 2016)? It is a question I would ask myself. I consider myself to be a feminist yet up until recently I was not open about my feminist views. Walsh and colleagues speculate that this is due to the internalised negative stereotypes

about feminists arising from second wave feminism (Walsh et al. 2016). I would concur with their speculations and it is only now I feel confident to 'out' myself. Actively engaging with feminism forced me to examine my worldview. I had an epiphany when I realised I was that 'mother' who subscribed to the institution of motherhood, I practised intensive mothering following the birth of my son. In the workplace I was at times critical of women who did not always come to NICU to care for their babies without thinking about the wider picture. Women were treated as a 'kind of biological NICU' having to be present to ensure better outcomes for their babies (Lindemann Nelson 2000), which suggests the institution of motherhood is the discourse from which mothers are held against and judged.

A radical feminist healthcare model requires the experiences, stories and lives of women as the starting point in any healthcare encounter (Klima 2001). We need to recognise that care during pregnancy and childbirth is not just about producing optimal outcomes for babies, but for women as well (Lindemann Nelson 2000). If we as a profession begin to embrace feminist principles and consider a model of midwifery care where the power and control is shifted away from the institution and professionals towards the woman herself (Leap 2009), we can seek to transform midwifery and neonatal care into one where "women are equals and in control over their own bodies – what is done to them, when and how and by whom" (Stewart 2010, p.285) including empowering and celebrating women's knowledge (Yuill 2012). I agree with Stewart when she declares "it is time to change some of the ways we think and act" (2010, p.285).

5.1.2 What is feminist research?

There is no easy definition for what feminist research is, although Harding (1987a) and Reinharz (1992) both agree it is research which must make a difference to women, it is research on women, by women and for women. Feminist research also studies the conditions of women in patriarchal societies, with the intention of highlighting sexist practices, which includes exposing governments and

communities that disregard or ignore that which is important to women (Reinharz 1992; Sarantakos 2005).

Kelly (1978) however, argues not all research on women and by women can be classified as feminist research. Two midwifery research papers dating back to the 1980s provide examples of her reasoning. In the first, a RCT conducted by Sleep et al. (1984) explored perineal management policies (routine episiotomies) aimed at minimising trauma to the vagina during birth. The research was instigated by women's consumer groups, and not obstetricians, in response to concerns about midwifery practice. Midwives added their voice to the consumer campaign, as they too were unhappy at having to undertake procedures they thought unnecessary and which 'forced' them into practising by stealth, such as dropping sterile episiotomy scissors onto the floor as the baby's head crowned, in order to avoid 'compulsory' episiotomies (Beech 2004). Practice where professionals do 'good by stealth' is in Roberts (2000) view, passive-aggressive behaviour and is considered an act of resistance in defiance of the oppressor.

In the second piece of research, a RCT was undertaken in Ireland to examine women's discomfort at undergoing rectal examinations when compared to vaginal examinations during labour (Murphy et al. 1986). Although rectal examinations had fallen out of favour in many parts of the world, it remained prevalent in Ireland at the time as part of strictly enforced hospital policies (Murphy et al. 1986).

Both studies were conducted on women and women's concerns were the focus, yet according to Kelly (1978) these studies cannot be referred to as feminist research as they were not undertaken for feminist reasons. Whilst the authors make no feminist claims, I would like to defend the studies on the basis that the conclusions had important outcomes for women and contributed to a reduction of oppressive and unnecessary obstetric practice. The findings in the study by Sleep et al. (1984) indicated there was no evidence to support the benefits of routine episiotomy or claims that reduced use decreased postpartum morbidity for women. As a seminal piece of research it benefitted future childbearing women.

What sets the Murphy et al. study (1986) apart is that women's feelings were considered, unusual for a RCT. In addition to the randomisation, a semi-structured questionnaire included an open question, which asked women to describe "the nature of any discomfort in their own words" (Murphy et al. 1986, p.94). Although the trial was considered small, the results clearly answered the main question - women described their feelings of rectal examinations as painful and uncomfortable. The authors concluded by recommending the routine use of rectal examinations during labour be reassessed and women's feelings regarding such examinations should be considered (Murphy et al. 1986).

Routine use of episiotomy and rectal examinations were part of a dominant medical discourse surrounding childbirth, women had no choice but to be at the receiving end of such care, however of note, following publication of the episiotomy trial, women used the research to empower themselves by asking pertinent questions of maternity care professionals (Beech 2011). Whilst I agree with Kelly's (1978) assertion that the two RCTs cannot be considered feminist research as the methodology was firmly in the camp of positivism or empirical science (Baldwin and Huggins 1995), the findings improved aspects of childbirth for women, an outcome which feminist researchers seek. An editorial on episiotomy from the British Medical Journal in 1982 reflected the tension at the time between medical professionals and consumers of maternity care when it referred to:

"the increasing insistence with which individual women, and sometimes well-organised groups, are asking whether some procedure is manifestly to the advantage of mother or baby or amounts to unnecessary interference by doctorIt would.....be a pity if clinical practice were changed on insufficient evidence because of a patient-led protest. The answers should come from clinical research" (Oakley 1984, p.255).

Therefore, when considering what feminist research is, there is some consistency within the literature in that it is research exposing women's experiences (Monroe-Baillargeon 2004), it is a "science that minimises harm and control in the research process" (Devault 1999, p.31), it is research which demonstrates an organizational

view of the 'now' including providing a vision for the future (Cook and Fonow 1986) and finally, from a midwifery perspective it "improves care for childbearing women and empowers and celebrates women's knowing" (Yuill 2012, p.39). Kelly (1978) however, attempts to answer the question "what is feminist research" by examining at which point feminism enter the research process. She describes three stages (see below) which I have chosen to apply throughout my research journey.

- 1) Choosing the research topic and formulating hypotheses
- 2) Carrying out the research and obtaining the results
- 3) Interpreting the results (Kelly 1978, p.227)

The following sections will examine my research journey through these three stages.

5.1.3 Choosing the research topic and formulating hypotheses:

It was necessary for me to consider my position as a feminist and how it influenced my research questions and indeed the research process. Brayton and colleagues (2016, p.1), similar to Kelly (1978), believe the "motives, concerns and knowledge" brought by the researcher to the process makes it uniquely feminist, with these principles fulfilled through utilising either qualitative or quantitative methodologies, the latter modified to meet feminist philosophies (Reinharz 1992). Additionally, it is also the "relationship between the process and the product" which should concern those undertaking feminist research (Letherby 2004, p.176). All elements of the research journey, from construction of the question, from theory to the practice (the doing) and dissemination of findings (the product) including acknowledgement of the relationship between the researcher and participants must be evident throughout (Letherby 2004; Brooks and Hesse-Biber 2007).

5.1.4 My positioning:

5.1.4.1 My personal self:

I was born in apartheid South Africa, a deeply patriarchal country where the colour of your skin and your gender determined your place in society. Women were not

encouraged to work outside the home, unless you were a woman of colour. It was acceptable for domestic servants (majority were women) to work in the homes of white people. These women were often badly treated and put aside their own families to care for white children and white families. I was the first child of four and we were classified 'white'.

My parents, despite the state inflicted dogma, were liberal in their thinking (unusual for the time), at least politically, and we grew up being highly aware of the injustices that apartheid had on people of colour. As I matured into a young person and began to express ideas of my own, I came across many barriers intended to set me on the 'right pathway.' At school, until we could choose our subjects, we were taught sewing, cooking and typing, whilst the boys had fun in woodwork sessions and other 'masculine' subjects. We were being groomed for our future roles, as wives and mothers or possibly 'secretaries.' Female teachers were never in positions of authority, it was always male teachers who were or became head masters, deputies and so on.

The dominant ideology was just as harmful to boys/men. If boys did not play rugby at school they were considered 'girlie' (sexist) or even worse in those days as 'gay.' As a young woman suppressed by hierarchy, patriarchy and everyday sexism I was powerless to change anything and just had to comply. However, during my teenage years I was sure of some things. I did not want to end up like my mother, who, despite being well educated and highly intelligent, was trapped in motherhood. I wanted to be independent and to travel the world and thus, was very strategic in how I planned my way forward.

At nineteen years of age I applied and was successful in gaining a place to train as a nurse. This career pathway offered me two choices, 1) I would earn a salary so I could travel and 2) I would end up with a qualification which would open doors whilst travelling. Having left a highly structured environment I entered another, where as a student nurse (nearly all women) we were at the bottom of the hierarchy and trained (rote learning) in the British style of nurse training. No

questions were encouraged and we were treated as work horses, running and staffing wards and being handmaidens to doctors who were overwhelmingly male.

My whole life has been hampered by patriarchy and sexism, which bell hooks (2000, p.14) terms “the enemy within.” I cannot hand on heart articulate I have never had a non-sexist thought, infact I’ve held many because I am not free of patriarchy, for example within the team I work in, I have found myself competing with and being resentful of colleagues (females) at times, instead of being supportive. It is this notion of sexism and patriarchy that interests me and is one of the factors that motivated my desire to utilise feminism within my research.

5.1.4.2 **My professional self:**

My first encounter with preterm babies was as a student midwife. The hospital in which I trained had a special care unit that looked after babies who were known as ‘feeders and growers.’ Sick and extremely preterm babies were transferred to a larger hospital with facilities to provide neonatal intensive care. I spent about six weeks in the unit and enjoyed my time which was spent feeding, bathing and dressing babies ready for their mothers. These memories bring me shame, I treated the babies as if they were my ‘barbie dolls’ as I so enjoyed dressing them up ready for parental visiting. At the time this was considered appropriate and standard practice. I certainly did not reflect on how my actions impacted on women-mothers as they arrived on the ward at set times to ‘visit’ their babies. I felt I was doing a good job (paternalistic care). Following qualification I found employment on a NICU because of the (un)availability of midwifery positions.

Once I was fully immersed, I began a slow realisation that preterm babies belonged to their mothers/partners and so commenced my conversion where I stepped back from being the primary care provider (at least when parents were unavailable) to one where I daily set out to facilitate FCC. I remain interested in why, when evidence clearly demonstrates women (and their families) should be at the centre of their baby’s care, professionals’ still control women’s interactions with their sick or preterm babies. My experience within neonates led to a full time lecturer post.

My expertise and my scholarship has always centred on the baby, for example, I facilitate and lead on educating student midwives around newborn issues and I am unit lead for examination of the newborn. It is this leaning which has, in some ways, impacted on my feminist positioning within my research, as my professional role has at times hampered my efforts to place women at the centre of my study. The dominance of the research, and day to day practice which focuses specifically on the (late preterm) baby rather than their mothers, led me for much of the time; however reflexivity and regular supervision helped with refocusing my feminist lens. At the same time it has been important for me to take steps to ensure my own perception that women's voices have become lost in the focus on the baby, has not clouded my ability to focus on what the women themselves were saying. I have had to challenge throughout the research process, my own tendency to focus on the preterm baby, rather than on the woman, but also whether how I interpret what women say has been influenced by my own beliefs and feminist lens.

5.2 RESEARCH QUESTION:

My research question: "What are the experiences of women who are caring for a baby/babies who is considered late preterm" is located in the epistemological framework of exploring women's 'concrete experiences' as a starting point from which to build knowledge (Brooks 2007). My secondary questions were:

- 1) What are the early postnatal experiences (first few days after birth) of women who are caring for their late preterm baby (LPB) by considering some of the following issues:
 - To document the current situation in relation to care on the postnatal ward or special care baby unit
 - To document the current situation regarding the discharge process
- 2) What are the later postnatal experiences (5-6 weeks after birth) of women who are caring for their LPB's by considering some of the following issues:
 - To identify what support was available in the community and who provided this support

- What are the needs of these women especially is discharged home early (less than 24 hours post birth).

DeVault (1996) describes concrete experiences as those which women perform on a daily basis, such as caring for one's family and from which women have developed specific "knowledge and unique skill sets" (Brooks 2007, p.57), with women best placed to understand their experiences (Yuill 2012). I am strongly influenced by feminist thinking that takes into account issues of gender, patriarchy and inequality within any given situation.

5.2.1 Significance:

The literature review revealed a number of issues which helped to focus my research questions. Firstly, feminist research has paid little attention to women in preterm labour and subsequently when they become mothers to preterm babies. We know from Williams and Mackey's (1999) feminist critique of women's experiences of preterm labour that choices available for women are few, which consist in the main, on prevention of preterm labour or having their baby/ babies early (Williams and Mackey 1999; Wisansoonwong et al. 2011). Women who are in preterm labour or become mothers to preterm babies are firmly within the domain of medicine and appear to exist in a state of uncertainty, with little control over immediate or forthcoming events (Williams and Mackey 1999; MacKinnon 2006).

Secondly, an abundance of literature is concentrated on LPBs and their outcomes derived from positivist and empiricist research methods. It is also knowledge generated through what 'others' deem important (paternalistic), for example, obstetricians and neonatologists measuring what 'they' think should be known about LPBs. Using a feminist lens, the obvious question is 'where is the woman'? Women are there but only as 'problems' to be managed so that reasonable outcomes can be achieved for the unborn/born baby. We do not know about the human experience for the mother, the meaning of a LPB for her and the context or the individual circumstances of women and their families is largely unknown. This struck me particularly when I critiqued the two neonatal surveys (Howell and Graham 2011; Burger 2015), which, despite parents being involved in the design

and formulation and refinement of questions, remained largely a traditional positivist method for surveying the views of large numbers of parents.

As previously established, the surveys are entirely appropriate and necessary, but their failing in my view was the reporting of experiences as 'one'. The majority of participants were women (over 85% for both) and a number of questions asked and reported on as 'parents' would have had a far greater impact on women as opposed to fathers. No consideration of gender differences between the experiences of men and women as mothers and fathers with a baby on NICU is evident from the survey findings. I wanted therefore, to use aspects of feminism epistemology to uncover the experiences of women caring for their late preterm baby/babies. I believe my overall aim of seeking to explore these experiences is a feminist topic and if the purpose of research is to "explore the unknown" (Kelly 1978, p.226) then my interests in exploring women's voices is based on feminist values. My feminist epistemological lens offered me an opportunity of understanding the world of women who care for LPBs, and what I learned from their experiences (Brooks 2007).

5.2.2 My research process:

Feminists had been arguing for many years as to whether feminist research should be undertaken qualitatively or quantitatively, with DeVault terming this the "Great Divide" (1996, p.35), based on the concept that qualitative research with its approach of discovering that which was significant in a person(s) experience was considered feminine, whilst quantitative research – a collection and interpretation of statistical facts was masculine (Stanley and Wise 1993; Brayton et al. 2016). Letherby (2004, p.180) however, argues approaches considered feminine and/or masculine continue to endorse sexist views, for example:

"A continued association of the interview as 'women's work' compounds more established sexist views about women as good listeners and ignores the hard emotion work which is now an acknowledged aspect of the research undertaken by male and female researchers".

She further contends that associating men with quantitative methodology reinforces stereotypes about men, suggesting they are better than women with statistics and lack emotional “skill” (Letherby 2004, p.180). It appears more appropriate therefore for feminist researchers to concern themselves with the “relationship between processes and product/doing and knowing within research” (Letherby 2004, p.181). I knew I wanted to better understand women’s experiences of caring for their LPBs, therefore my position was not so much on which methodological stance was more feminist, but which one best fitted my research question and which one would best gain women’s perspectives. Therefore, a qualitative methodology which would give voice to the invisible by enabling me to engage in an in depth exploration of individual's women’s views was chosen to answer my research question and in the following section I will make clear the methods underpinning my research.

5.3 FROM THEORY TO PRACTICE: THE METHOD

5.3.1 Sampling

When initially deciding on sample size, several factors were considered. The first important factor was the phenomenon under study. The literature review established there is very little known about women’s experiences in caring for their LPBs, therefore guided by my aims, I decided on a two phase approach to data gathering to uncover and explore women’s experiences. Phase One interviews took place in the first few days following birth and was designed to explore women’s early postnatal experiences of caring for their LPBs by considering where care took place (on the PNW or on a special care baby unit (SCBU) and to explore the discharge process. Phase Two was scheduled to take place approximately five to six weeks after the women had been discharged. This was on the basis of understanding how they managed once back in their own homes, including support required and who provided it.

The ideal number of participants in qualitative research remain elusive (Mason 2010). Guidelines range from six (for phenomenological studies) to twenty/thirty (grounded theory studies) (Guest et al. 2006). The ideal sample size depends in part upon the purpose of the research (Baker and Edwards 2012): reviewing sample sizes for research on the experiences of women, fathers and parents with a baby or babies on a neonatal unit therefore seemed important. Studies that used one off individual interviews had between 5-12 participants (Roller 2005; MacDonald 2007; Leonard and Mayers 2008; Lindberg and Öhring 2008; Fegran et al. 2008; Hall and Brinchmann 2009; and Hollywood and Hollywood 2011). In comparison, a longitudinal study by Jackson et al. (2003) recruited seven sets of mothers and fathers and interviewed them on four separate occasions (56 episodes of data collection). In-depth interviews with larger sample sizes were undertaken by Flacking et al. (2006), and Sloan et al. (2008) with each study interviewing 21 and 25 participants respectively. Lee et al. (2005) interviewed 50 women, five times, over a period of five days. Therefore whilst the literature on sample size did not provide a clear answer, as a guiding estimate I set my target sample at between 15 and 20 women. This seemed likely to allow in depth exploration of women's experiences but also provide diversity and variation of experience (Patton 2002).

In order to explore my broader research question, I decided my sample strategy had to be purposive, in that I invited women who were the 'experts and authorities' on their experience of caring for a LPB to be part of my research (Coyne 1997; Brayton et al. 2016). This is referred to as a fixed sampling strategy as it would consist of a group of women experiencing a similar situation, which enabled me to compare and contrast their experience (Kuzel 1999). A disadvantage of purposive sampling is based on results not being generalizable (Bowling 2014), however the overall purpose of my study was not to provide generalizability of women's experiences, as I make no claims to speak for all women with a LPB, instead I provide new knowledge which has been grounded in the reality of their experience (Brayton et al. 2016). Thus purposive sampling was an appropriate strategy for my research study, as the data collected revealed rich information of their experiences of caring for their LPBs.

I interviewed fourteen women during Phase One and of those, one woman declined to participate at the next stage, which resulted in thirteen women re-interviewed for Phase Two. Although I did not reach my sample target, my focus was more on sample adequacy as opposed to sample size (Bowen 2008). I used TA, which, as a technique for organising and thematically analysing data (King 2012) helped me to decide when I had achieved sample adequacy. TA is described in more detail in section 5.10 but for the purposes of illuminating whether I had achieved 'saturation' a short explanation is necessary at this point.

The basic framework for TA revolves around the development of a coding template (King 2016), whereby themes, identified as having significance to the research question by the researcher are organised within a template. In reading the women's accounts of their experience, I developed 'themes' from chunks/sections of text that appeared to have particular significance to the women (King 2012). For example, 'I needed to be there' (going to see their babies on the neonatal unit), 'going home' and 'being in NICU' seemed important issues to all the women. As themes develop inductively by focusing on what the women said, each one is arranged within a hierarchy whereby similar groups of codes as relating to a theme are clustered together to generate higher order codes (King 2012). As an illustration, an overall theme from my final template was called '[They wouldn't tell me definitely that she could] GOING HOME' which encompassed lower level themes such as 'Doing things' (Gained weight) and 'Feeding her on my own' (Gave me the best chance of going home) (King 2016). The template thus continues to develop and be modified as it is applied to all the available data (King 2016). At completion of my template and before interpretation was undertaken, it became clear that whilst all the interviews contained a richness of information (Bowen 2008), the women were describing similar experiences for both phases of data collection, I therefore felt saturation of experience had been achieved (Guest et al. 2006; Mason 2010; Dworkin 2012).

5.4 DATA COLLECTION

5.4.1 Interviewing

Interviews were chosen as the method of data collection. Qualitative studies within healthcare research and social science mostly favour the use of interview as a data gathering tool, mainly as this is thought to be the gold standard in understanding the authenticity of another's experience (Oakley 2005; Hewitt 2007; Ryan et al. 2009). I established, following the literature review, that the presence and voice of women was at times invisible, their views not known or incorporated into one with fathers, therefore my research had to utilize a method which would provide a window to their experiences (Monroe-Baillargeon 2004). Any number of approaches could have been chosen as there is no one method that feminists haven't used (Fonow and Cook 2005; Brayton et al. 2016), therefore whatever is finally chosen must be adapted to meet feminist principles (Oakley 2005). I decided to use one to one interviews to explore *individual* women's experiences of caring for their LPBS, as it appeared an ideal method to explore their issues in depth. Feminists have regularly utilized interviews to change or make more visible the lives of women (Oakley 1981; Harding 1987a; Fonow and Cook 1991), see for example research by Peckover (2002), McCormick and Bunting (2002) and Parry (2008). Part of the preparation therefore entailed me considering whether to undertake structured or unstructured interviews (Rose 2001).

As my approach was qualitative which is seen as 'less structured and more flexible' (Rose 2001, p.7), I decided against structured interviews as I would have entered the process with researcher priorities (Rose 2001), a standpoint not in alliance with feminist research. A semi-structured interview enabled me to explore and clarify issues and the atmosphere between the women and myself was fairly relaxed (Bowling 2014). One disadvantage of structured or semi-structured interviews is the opportunity for interviewer bias to arise (Bowling 2014). Although I was mindful that interviewing was not a method intrinsically feminist, I was strongly influenced by the approach advocated by Oakley (1981). She was one of the first feminist sociologists to illustrate in her seminal research on motherhood how she carried out interviews with women, which strongly contradicted the traditional masculine view of objectivity and rationality, which had previously informed the conduct of research interviews. Therefore I had to consider a number of issues when

interviewing and Oakley's (1981, 2005) approach guided me throughout each interaction and consisted of the following:

- The interviewer reveals her own identity (subjectivity) during interviews, not only through the asking of questions but also through the sharing of knowledge (reciprocity)
- A collaborative model of research where power relationships between the researcher and researched were lessened
- Reflexivity (Oakley 1981; Landman 2006).

Awareness of these processes is important in that it provides context for how the research/interviews were conducted, an essential aspect of feminist research (Richards and Emslie 2000), with feminist researchers generally considering themselves part of the data collection and knowledge production, rather than sitting outside of it (Kelly 1978; Fonow and Cook 1991).

I shall consider each of the above in the following section:

5.4.2 Identity:

Initially, within the design of my research, I indicated I would be disclosing my professional background to the women, which is contrary to positivist principles demanding objectivity (Hewitt 2007), however, as I was undertaking research which fell outside the positivist paradigm I was not aiming to achieve objectivity. Instead, it was important to acknowledge, rather than deny my own experience of working within NICUs, including my previous research interests which have all influenced my research. In addition I wanted to respond to women as equals during the interviews, thus it would be impossible not to reveal my background (Parr 1988; Lavis 2010). Indeed Lavis (2010) suggests that researchers require a number of identities to enable or enhance the success of an interview.

My letter of invitation identified me as a midwifery lecturer; there was no need to reiterate it again during any of the interviews that took place. Most women assumed I knew what they were talking about, as they occasionally made use of

abbreviations or the language commonly used by professional staff, and I did not feel the need to seek clarification as I knew what they meant. If I wanted to clarify their understanding, I usually probed in more depth to gain further knowledge. At other times women looked to me for interpretations around issues they themselves raised. Part of my philosophy was that I would openly and honestly answer women's questions (Oakley 1981).

I was also mindful in avoiding answering any questions that could have driven the interview down a particular avenue that was of my making rather than that of the women (Parr 1988). Therefore my professional background and experience could be both an enabler and disabler during the interview (Parr 1988b), however I was aware of the dichotomy of my position, and situated myself in the paradigm that these experiences enhanced my connectedness with the women which in turn enhanced their trust and rapport with me (Probert 2006). I was genuinely interested in actively listening to their experiences and was committed to accurately representing their experience after analysis and writing up of the data (Dwyer and Buckle 2009). Holding an insider-outsider position enabled me to help one woman following an interview, although she was unaware. (Appendix 1)

Other concerns around disclosing professional background center on whether participants would divulge information because they were distrustful of professionals (Richards and Emslie 2000). I did not find this a problem. When I interviewed Linda and explored her views on a particular situation regarding postnatal staff, she enquired whether I was sure I wanted to hear her thoughts. I replied I did, she then proceeded to describe her feelings in an open and very honest way.

“they are like matrons (laughter) I’ve had *huge* problems with midwives here, *huge* problems, they've got absolutely *no* bedside manners *at all*, um, the majority of them it’s just a job, and as far as I am concerned being a midwife you *can-not* afford to think of it of a job (*Hmm*) um, it has to be a passion, it has to be within you, um, you have to enjoy it (*Hmm*).” (Linda – Phase One).

5.4.3 Power:

Power relationships have been reported in detail in the literature as existing between the researcher and the researched, causing a hierarchical relationship between the two (Cook and Fonow 1986; Harding 1987b; Oakley 2005; Barnard 2009). Firstly, hierarchy exists before meeting participants because the researcher has, on the whole, decided the research agenda (Barnard 2009). It was my previous clinical experience and following on from primary research conducted for my Master's degree (Cescutti-Butler 2001; Cescutti-Butler and Galvin 2003) and my ongoing interests in preterm birth (Cescutti-Butler 2009) that defined the basis of my research question, and unfortunately did not involve collaboration with women (Gustafson 2000).

I was always aware there would be a power imbalance, as ultimately I was there to ask questions of the women, however I tried very strongly to create an equal relationship with them (Acker et al. 1991). I endeavored to create an environment where the woman would feel comfortable and able to talk freely without feeling I would be judgmental or critical, and I believe this helped create a fairly good relationship between ourselves. I did struggle at times with maintaining a non-judgmental attitude, because on some occasions I found myself expressing disbelief when women described their experiences. It was not that I did not believe their story; it was rather an expression of dismay at the callousness of their treatment by some healthcare professionals. It was important that a trusting relationship was developed, as I hoped to re-interview the women six to eight weeks later, and as such, a detached style of interviewing would not be conducive in developing an authentic two-way discourse (Oakley 1981; Gustafson 2000).

Finally it could be reasoned that, when I walked away from each interview I was in control and the balance of power had shifted back to me as researcher (Letherby 2004). To lessen this imbalance, all the women received a text document of their conversation, except for interview twelve which had not been recorded. The interview transcripts were sent either through the post or attached to an email, depending on the women's preferences. They were invited to comment on their

transcriptions (Barnard 2009) as this would reduce misrepresenting their story and acknowledged they were the experts of their experience (Hewitt 2007).

From a feminist perspective I was interested in exploring further why women volunteered to be part of my research because, although the participants were unaware my research design did not include women in its inception (from the outset my research was 'on women' and 'not with women') (AIMS 1997), without their consent and participation I would not have any research. A qualitative study undertaken by Dixon-Woods et al. (2006) which explored why women consented to surgery even when they did not want to, discovered some women, when faced with a consent form and an authoritative figure, rarely "disobeyed professionals request for a signature" (p.153). Women's autonomy in these situations was, in the authors view, restricted according to the rules of the "game" and the "power relations contained therein" (Dixon-Woods et al. 2006, p.157). An alternative perspective is provided by Baker and colleagues who studied the views of a group of postnatal women who consented or declined to participate in midwifery research (Baker, L. et al. 2005a). Although there were a number of reasons which influenced their decision, some women consented for altruistic reasons and a desire to give something back to the hospital and to demonstrate their "gratitude by helping" (Baker, L. et al. 2005a, p.62). Participants in a study undertaken by Peel et al. (2006) provided comparable views including finding interviews therapeutic. I would like to think the women who participated within my research had similar reasons to those expressed above and not because they were approached by a figure of authority (local co-ordinator (LC) and felt unable to say no. I was also aware many more women (than the final sample) approached by the LC declined, therefore I am hopeful the women who both declined and consented to participate in my research exercised informed consent as autonomous agents (Dixon-Woods et al. 2006). I am grateful for their contributions.

Figure 5-1: Reflection: why do women consent to partake in research

5.4.4 Reflexivity:

Feminists consider themselves part of data collection and knowledge production, rather than sitting outside of these processes, but of importance is acknowledgement through reflexivity (Kingdon 2005; Hewitt 2007). Reflexivity as a tool enables feminist researchers to "reflect upon, critically examine and analytically explore the nature of the research process" (Fonow and Cook 1991, p. 2). I have previously discussed the involvement of 'self', where, by having some experience of the phenomenon I am researching, I am able to positively share the language of the women I interview (Holloway and Biley 2011). My background

knowledge of midwifery and neonatal experience shaped my ideology and influenced the data I presented (Holloway and Biley 2011).

To lessen any unfairness towards the data and understanding of the women's experiences, I reflected by examining my own notions of reality and motivations and put them to one side (Seidman 1991; Charmaz 2004; Probert 2006), through the use of an electronic reflective journal. This enabled me to learn about the women's experiences from their perspective rather than imposing my values on their meanings and actions (Charmaz 2004). It was also utilised to record any issues, ideas, and questions that were worthy of follow up or to be explored in more detail further on (Fonow and Cook 1991; Clarke 2009; Holloway and Biley 2011). One of the questions I pondered frequently was why women did not question professionals more: My reflection is within Figure 5-2.

Many of the women appear to be passively involved in the bigger decisions revolving their baby but very active in the 'caring activities' so have the really important decisions been left to the experts? When I asked whether they had questioned certain decisions, most women had not and seemed surprised as the following quote suggests "Gosh I should have asked all these things shouldn't I, I didn't think too" (Kate). I was definitely approaching this round of questioning with my professional hat on (and my cultural background because I ask questions all the time). Is it fair to expect women to question healthcare professionals, after all, their baby may be in need of further or specialised care and was in the appropriate environment? Why would they – they trust the professionals looking after them and their baby. I seem to be making an issue of something that was not of concern to some women. Kate on reflection however, did require further information. She wanted to know what was wrong with her baby and was informed by one of the midwives on the ward "there were too many possible things that could go wrong." Kate felt this was 'a cop out' (her words); the midwife should have been able to provide further information. Therefore, do women not seek out information on decisions because they have intuitively picked up on non-verbal cues from healthcare professionals and this stops them from asking questions? Is this a problem for them? Or was I asking them to challenge decisions which were not important to them? Indeed, Kate provided some insight into why she did not ask further questions. She expected to be informed rather than having to ask questions about her baby's health.

Figure 5-2: Reflection: not asking questions

5.4.5 Ethical considerations

Whichever approach is undertaken within feminist research researchers should seek to “minimise harm and control in the research process” (Harding 1987a; Reinharz 1992; DeVault 1999, p.31 ; Sarantakos 2005), therefore the following section outlines how I approached ethical concerns.

5.5 PROCESS OF RECRUITMENT

5.5.1 Hospital and the process of informed consent:

At a NHS Foundation Trust Hospital in the South West of England where data collection was carried out, the Postnatal and Neonatal Services Manager agreed to be my first point of contact (local collaborator- LC) and was provided with an information pack outlining the research (Appendix 2). She used the daily postnatal sheet (Appendix 3) to identify women and their eligibility against the inclusion/exclusion criteria (Appendix 4). Each woman was approached and provided with a letter of invitation (Appendix 5) including an information pack (Appendix 6). It was anticipated women would self-select and indicate their interest by a signed reply slip incorporated within the information letter. An envelope was provided for their convenience. Once I had received the reply slip, I was able to contact each woman and agree on a time and date.

The consent form (Appendix 7) stated participation in the study was voluntary and non-participation would not affect any current or future treatment for them or their baby/babies. Prior to signing the consent form I ensured each woman fully understood the purpose of the research and their role. If requested, I clarified any points. The signed consent form was kept by myself and a copy was given to the woman. Permission to digitally record the interviews was obtained at the same time. Following completion of the first round of interviews, all the women agreed to be contacted for the subsequent one. The day before the second interview was due, I contacted the women to ensure it was still convenient.

5.5.2 Confidentiality and anonymity:

As a senior midwifery lecturer I base my practice as an educator and a practising midwife on the principles set out by the Code of Practice for Nurses and Midwives (Nursing and Midwifery Council (NMC) 2015). I respected and upheld confidentiality of personal data obtained during the research as I normally would do during my daily work based activities. Once the woman had signed the consent form she was assigned a unique code. It was used on the recording device and subsequently on all data. Only I am able to go back to the original consent form to identify the woman's personal details which are kept in a locked filing cabinet at work. These details will be destroyed following completion of the research study. The women were informed their data would be anonymised and they would not be identifiable. Women agreed their direct but anonymised quotations could be published within my research and in any future publications.

During transcription of the interviews, all names, places and personal details were removed from individual transcripts. Computer files are stored on a password protected computer, both at home and at work and known only by me. The digital recorder is kept in a locked filing cabinet. The audio recordings will be deleted off the computer once the research is completed. They have been deleted off the recording device. Paper based data will be shredded and disposed of accordingly.

5.5.3 Protection of women:

Women were asked to recount their experiences of caring for their LPBs. This recall might have caused some distress, therefore women were informed that at any point during the interview it could be terminated without reason and if they wished, they could refuse to discuss matters any further. If I had felt the session needed terminating because a woman was distressed, I would have taken steps to do so. Every effort was made to ensure the sessions were handled discreetly and sensitively. If women had been distressed I would have suggested follow up support with their Community Midwife (if still under midwifery care), the Health Visitor (HV) or their GP. In the event, none of the women became distressed and only one woman withdrew from participating during Phase Two.

5.5.4 Researcher safety:

I undertook a risk assessment to ascertain my personal safety as I was going into women's homes and travelling some distance to get there. Please see the completed risk assessment form (Appendix 8).

5.5.5 Consideration of practice related issues:

The potential for adverse effects could have arisen if poor standards of practice were identified by the women. I would have informed them I was obliged to take the issue further but would have encouraged them to do so in the first place. If women were unwilling, then I would have taken the issue to my named Supervisor of Midwives (SoM) (NMC 2012, 2015). I had a designated SoM at the NHS Trust where the research was undertaken. No issues of bad practice were identified.

5.5.6 Obtaining ethical approval:

Ethical approval was obtained from an NHS Research Ethics Committee and from the Research and Development (R&D) Department at the local NHS Foundation Trust Hospital where recruitment took place. Approval letters are shown in appendices 9 & 10.

5.5.7 Interview process:

For Phase One fourteen women were recruited and interviewed between April 2011 and August 2012. In the ward environment I had, with the agreement of the LC, a dedicated postnatal office within which to undertake interviews. If women were resident in a side room they were offered a choice to stay in their room or, if they preferred, be interviewed in the ward office. Most women chose to stay in their rooms and many kept their LPBs with them during interviews.

I upheld the women's privacy at all times but occasionally staff on the ward knew why I was there and who I was going to interview. When interviews took place in the office interruptions rarely occurred; however, when they were held in the woman's hospital room, disturbances were frequent, despite a notice on the door

requesting privacy. These disruptions mostly took the form of refreshment rounds, menu options and such like. Other unavoidable interruptions involved the care needs of babies. I would work around these as helpfully as I could. The following extract highlights some of these issues:

I met Gill the day before and was able to arrange an interview for the following day. I arrived on the ward expecting to find Gill in bed 10 but she had been moved overnight into a side room. With her consent the interview took place in her room. This was fortunate because she was in the process of feeding her daughter and also needed to express her breasts following the feed. I hung the sign 'Do not disturb' on the outside of the door and explained why I had done so. I could tell she was uncomfortable about the sign as she thought NICU staff would want to come and check on her baby. I removed the sign and reassured Gill I would fit in with what she wanted. If staff needed to undertake care on her daughter I would work around her requirements. The interview proceeded fairly smoothly; Gill fed her daughter, and then expressed her breasts. These were necessary activities which did not detract from the interview itself. Things came to a natural end and once I had switched the recorder off, we informally continued chatting on issues such as bonding, breastfeeding and skin to skin. I felt in retrospect it was a good interview, I did not miss any important cues and was able to explore some issues in greater depth. I enjoyed meeting Gill after a short absence of any contact with women.

Figure 5-3: Diary entry: Do not disturb

To facilitate the interviews, I prepared a semi-structured flexible guide (Appendix 11) as so little was known about these women's experiences. Critics might consider utilizing a prepared guide as a means of controlling interviews because I had pre-determined questions I thought important in advance of meeting the women (Rose 2001), in reality the guide was used as an aide memoire to prompt conversation, or to remind me to ask women to comment on what other women had mentioned in relation to their experience. Only once did I rely on it faithfully. The following diary extract demonstrates how I felt when I relied on the guide:

"[...] Mandy waited for questions and was happy to answer, but did not offer more than what I asked, which led me rather reluctantly down the pathway of being more directive during the interview, rather than a more casual conversation between us. I had to utilize all the prepared questions resulting in our interview being a question and answer session, despite me trying to make it more relaxed. As a result, the interview ended up being rather short [.....]."

An opening question: “Tell me about your experience of caring for your infant so far” was utilized to put the women at ease. Each interview (bar one) was digitally recorded, with the woman’s consent. Interview 12 was not recorded because I had forgotten to switch the recorder on, however detailed notes were taken soon after, which aided with recalling the most salient information. Gaps were clarified at the second interview.

5.6 PHASE TWO:

This round of data collection was designed to take place about five to six weeks later in the community – namely in the women’s homes or any place of their choosing. In reality, most interviews took place between eight and 12 weeks. Reasons for the delay were my own personal workload and some of the interviews would have fallen over the Christmas period and therefore I delayed them until the New Year, as I did not want to impinge on family time. In retrospect, had I gone as originally planned between five and six weeks, I don’t believe my data would have been as rich as it would have been too early after birth with not enough time for the women to settle down.

As with Phase One, a pre-prepared but flexible proforma was utilised to explore certain aspects of their experience (Appendix 12). Of the fourteen women who took part in Phase One, all were contacted and thirteen agreed to be re-interviewed. One of the women did not respond to my messages. Following completion of her first interview, she had provided me with her husband’s mobile phone number as she could not remember hers and each time I tried to arrange the second interview through him, she did not respond. I therefore decided she no longer wanted to participate and took this as a sign of her withdrawal of consent.

Each digitally recorded, semi-structured interview lasted between 25 & 60 minutes, (the majority around 40 minutes) and took place in the women’s homes, as this was the most convenient option for them. The interviews were held in the woman’s ‘front room’ with babies, pets and on some occasions, husbands present. On one particular occasion, one of the women had requested her interview take place at midday; her husband, who worked locally, came home for lunch at the same time.

On reflection, I wondered if this had been deliberate. The couple had a number of unresolved issues about how the woman had been treated during her pregnancy, labour and postnatal episodes, and once the recorder had been switched off; the husband proceeded to vent his feelings. We had a discussion and I provided a number of options they could utilize to seek further support, such as contacting the SoM on call or contacting the Head of Midwifery. These 'off the record' discussions occurred fairly frequently and in keeping with my feminist philosophy I did try and help if possible. For example, Gill shared with me a letter concerning her baby's blood results and asked me to explain the neutrophil count. I was able to provide some information based on my previous knowledge and experience of working on NICU.

During a number of interviews there were distractions that I was unable to control. In some recordings, the noises from washing machines are clearly audible, and in another, one of the women had a very excitable dog that constantly interrupted proceedings. Another woman had an unexpected delivery of a food shop and I entertained her three young daughters whilst she unpacked. This particular interview was quite fragmented, as her daughters constantly interrupted whilst she was talking, at times I lost my thread as did she. Despite these interruptions when analyzing this woman's interviews, I felt the context of our encounter provided some insight into her domestic situation, she was a stay at home mother coping with three young children and this was her life at the moment, responding to the demands of her children yet still helping me out.

I really enjoyed meeting the women at this point in their lives. Often I did not recognize them as they had changed so much from our first encounter. They greeted me at their front door, looking 'human' and 'fantastic', unlike in hospital where they were often lying in bed, wearing nightclothes and looking tired. I did however, observe some unusual care practices. One woman from a country in Eastern Europe added sugar to her baby's bottled water because he was constipated, and she was at her wit's end. She also laid him to sleep on his front. I was concerned at this practice (professional hat on again) and queried why she had adopted this sleep position. He would only settle in the prone position, but pointed

out he was on a baby monitor as he was part of the Care Of the Next Infant (CONI) scheme, as her partner's child (from a previous marriage) had died from Sudden Infant Death (SID).

Another woman also slept her baby prone and we discussed her decision. However, the 'safety aspect' of the discussion was not initiated by the woman, rather, it was myself who raised it based on my knowledge that preterm babies were at higher risk of cot death and wanted to explore whether she was aware of the risk factors. The following extract illustrates aspects of our discussion:

“Woman: Yes, well I did with her (pointing to her daughter), but it changes all the time, (laughs) so I never know any more. In my personal opinion I just think that everybody is different and (pause) one baby might like to sleep on its back and be absolutely fine, whereas another one likes to be on their front and be absolutely fine, so I don't think any baby is the same, and to have rules and regulations, just doesn't work sometimes. But that's my personal opinion.

Luisa: So you put him on his front based on what you saw at the Unit, or because of your experience?

Woman: I did try putting him on his back, but he didn't want to, because he had been used to being on his front, he liked it. So this is how he likes to be” (Phase Two).

It is quite obvious the woman knows her mind and is aware of any implications. She understands the bigger picture because the standard public health message for all babies to sleep on their backs does not make allowances for those babies who may not want to. The woman was not intimidated by my line of questioning and held firm in her views.

All the women were thanked for their participation and three women expressed an interest in knowing the final outcome of my research. Interviews were transcribed and sent back to them, a process sometimes known as 'member checking' and is included as a means of validating elements of the research process (Carlson 2010). Not many of the women responded or got in touch after receiving their transcripts and it got me thinking as to why this might be.

5.7 MEMBER CHECKING

The transcripts were long, about 20-30 pages, as each recorded interview was fully transcribed (Riley 2000) as speech spoken by the women (Reinharz 1992), and included the particular vernacular used by the women ('ums, ah's, you know'), including my own ('ja's') (Appendix 13) . Two of the women spoke English as their second language and I did not attempt to 'homogenise' their words when typing up their transcripts. All transcripts were edited and tidied up for better flow, although always maintaining the women's actual words. Enabling women to read a text version of their interview was an important part of the collaborative process however, as I did not receive any feedback, perhaps the women found it tedious reading through long scripts (Gustafson 2000)? This certainly came through when I asked Lisa and Linda if they had read theirs, as I had managed to get their first transcripts back to both of them before our second contact. Both women just laughed and in reality why would they? It was only important to me and they were both busy with their newborn babies. Lisa made reference to its length and that it had put her off. I had fallen into several member checking traps as discussed by Carlson (2010). I had not pre-warned the women their scripts would be lengthy, I had not considered literacy issues or even how the women might feel or think whilst they were reading their transcripts. The women who did not speak English as a first language might have felt embarrassed seeing their spoken words in a written format. In the event, only one woman provided feedback "I'm happy with it though it made me realise I repeat myself alot & talk gibberish half the time! Please keep me updated with your studying, I'm still very much interested!"(Email correspondence).

A summary of each interview was documented immediately post event, as well as recording any questions that arose. This strategy helped inform later interviews (Riley 2000) as well as improving my interviewing skills (Reinharz 1992). (Appendix: 14)

5.8 CHARACTERISTICS OF THE WOMEN:

All the women (names changed) declared their ethnicity as white. Two of the women were from different countries in Eastern Europe and one was from South Africa. The rest of the women stated they were British.

Gill: 32 years old and married. She went to college and studied beauty therapy. She is a mother of three daughters and was a housewife.

Mandy: 29 years old and engaged to her partner. She left school with GCSE's. Mandy is a mother to a son and a daughter. She was a domestic cleaner.

Linda: 30 years old and married. She is a mother of twins (boy and girl). Linda had been a hotel manager

Freya: 22 years old and was engaged. She is a mother to a son. Freya was a cashier.

Connie: 21 years of age and married. She is a mother to a daughter. Connie described her occupation as a sales assistant.

Nicola: 34 years of age and married. She is a mother to twins (boy and girl). Nicola's occupation was as a cleaner/DIY person.

Medina: 31 years old and co-habiting with her partner who worked away from the family home during the week. She is a mother to two daughters. Medina was educated to university level and was working as a carer.

Valerie: 24 years old and married. She is a mother to a son. Valerie described herself as a community healthcare assistant.

Fiona: 23 years old and co-habiting with her partner. She is a mother to a daughter and a son. Fiona had a National Diploma in Animal Management.

Lisa: 33 year old married woman. She was a university graduate and is a primary school teacher. She is a mother to a daughter.

Mary: 36 year old woman living with her partner. She is a mother to a son and daughter. Mary was a customer assistant for a supermarket.

Marylyn: 30 year old woman, not living with her partner. She is a mother to 5 children (one deceased). Marylyn declared her occupation as a housewife.

Kate: 31 years of age and married. She is a mother to a son. Kate was a software engineer.

Jane: 37 years old and married. She is a mother to three daughters (two are twins). She was a dental nurse.

5.9 DATA ANALYSIS:

5.9.1 Data transcription

I utilised a mixed approach to data transcription, I transcribed many myself and outsourced others. Both approaches enabled me to be fully immersed within the data and I did not notice any difference in the quality of data analysis processes between the two. I checked the transcripts for accuracy by reading and listening to the interviews at the same time. During this process I added any 'ums, ahs, intonations and emphasis as spoken by the women (King and Horrocks 2010). When women laughed or indeed myself, I added 'laughing' within brackets and when we both laughed I added 'laughter'.

Analytical thoughts began during the process of data collection and following fieldwork. I recorded my initial ideas, thoughts and feelings within my electronic reflective journal and memo's which were part of a computer-assisted qualitative data analysis software package (CAQDAS) known as NVivo. A number of different methods are available to researchers when it comes to data analysis, and I have incorporated various strategies whilst engaging with my raw data (Thomas 2003). I carefully scrutinised all transcripts to ensure familiarity with the contents (Simons et al. 2008). My thoughts initially focused on what I was reading and I formulated and recorded ideas within the margins of the transcripts (Riley 2000). Seidal (1998) describes this as 'noticing', one of three steps in his cyclical and recurring model for analysing qualitative data.

5.9.2 CAQDAS:

By the time I had undertaken ten interviews (five in Phase One and five in Phase Two) I was aware I had accumulated a large amount of data that required processing, I therefore made the decision to utilise NVivo to help with volume of data (Welsh 2002). As a piece of software it made the administrative and

organisational aspects of my research easier to handle. For example, I was able to import all my interviews into a folder where I could individually code text on screen. Codes are known as 'nodes' on NVivo and although nodes can be developed both inductively or deductively I chose to develop mine inductively, as I wanted to prevent any "existing theoretical concepts from over-defining the analysis and obscuring the possibility of identifying and developing new concepts and theories" (Lewins and Silver 2007; Lewins et al. 2011, p.84). Details of how the software enabled me to develop themes for my template will be discussed within the section dealing with development of my template.

5.10 TEMPLATE ANALYSIS

5.10.1 Why Template Analysis?

I was attracted to Template Analysis (TA) as it offered structure and flexibility whilst undertaking analysis (King 2012). It was originally conceived by Crabtree and Miller (1999) and adapted and expanded upon by King (2004). It is a technique for thematically organising and analysing textual data, as opposed to a distinct methodology and, as such, can be "used within a range of epistemological positions" such as from a positivistic paradigm or a "contextual constructivist" position. This latter position, which proposes several explanations can be made of any experience, depending on the position of the researcher and context in which the research took place, is a standpoint which suited my research approach entirely (King 2004; 2012, p.427; King 2014).

Whilst TA has similarities to grounded theory (GT), in that it provides specific procedures for data gathering and analysis, unlike GT, researchers utilising TA are not obliged to adhere to GT procedures, and can adapt TA to suit the requirements of their study (King 2012). For example, one of its features is to identify, although not mandatory, some themes in advance known as "a priori" (King 2004, p.256), which are themes suspected to be relevant to the analysis and defined in advance (King 2004; Clarke and Gibbs 2008; King 2012). Originally I considered whether some of the guided questions used during data collection could be used as broad 'a priori' themes on an initial template. This would be considered a top down

approach to theme generation (King 2012) and, whilst appropriate for some studies, it was totally inappropriate for my research with its emphasis on finding the ‘woman’s voice’. By seeking to apply ‘a priori’ themes I would not enable the data to speak to me, and in doing so, I would be stifling analysis and any deep engagement with my data (Waring and Wainwright 2008).

Another TA feature is the development of an initial template following analysis of one or two transcripts. Subsequent transcripts are then analysed using the initial template and it is refined as the process proceeds (King 2012). I chose a mixed approach to developing the template, by reviewing a number of transcripts before constructing a basic thematic template, to ensure I was immersed in the women’s data and had time to reflect on their words.

5.10.2 Developing the template

In this section, I will describe the development of my final analytical template by illustrating each step with examples of its’ construction.

5.10.3 Creating the template

In the first instance, descriptive codes were identified from each of the interviews which would be of interest to my research question: ‘What are the experiences of women who are caring for their baby / babies that are considered late preterm’ (King and Horrocks 2010). As the list grew it was used against each transcript. After five transcripts the list consisted of 58 nodes and at this point I began to merge many of the nodes into broader codes or themes, a process in TA known as hierarchical organisation of codes (King 2012). Within TA, hierarchy does not necessarily indicate levels of importance; rather it is a system that enables the researcher “access into the participants’ experience so that they can explore the meanings within the text” (Hardy et al. 2014, p.594). Lower themes were modified as recommended by King (2012).

An example of my first attempt at developing a workable template is illustrated in Figure 5-4.

| THEMATIC AREA | LOWER LEVEL THEMES |
|-------------------------|---|
| Control | <p>Women's bodies:</p> <ul style="list-style-type: none"> HCPs deciding what's best for women or not believing women's bodies <p>Failure:</p> <ul style="list-style-type: none"> Women feeling guilty about their bodies failing them by not being able to mother properly, preterm birth etc <p>Women gaining control:</p> <ul style="list-style-type: none"> This is where women assert themselves in any decisions involving them and their babies <p>Input into decisions and care options:</p> <ul style="list-style-type: none"> How much control do women have when care treatment or care options change? |
| Facilitative behaviours | <p>Believing:</p> <ul style="list-style-type: none"> This is when a woman presents at hospital/GP/any other healthcare professional and having her concerns taken seriously and being believed <p>Not believing:</p> <ul style="list-style-type: none"> Where concerns are not taken seriously and where the woman does not know best about herself or her body/baby <p>Relationship Building:</p> <ul style="list-style-type: none"> Where staff were supportive in helping women to care <p>Barriers:</p> <ul style="list-style-type: none"> Behaviours which did not facilitate women to care for the babies |

Figure 5-4: First attempt at a template

I was subsequently challenged by my supervisors to consider whether any of the themes/nodes generated were directly related to 'women's words' or to 'professional speak'? I reflexively sat back and recognized I was still under the influence of my professional background because, although it had led me towards my research, it was also a barrier. I was producing higher level codes/themes directly from two perspectives: my professional experience and my fixation with

the 'baby'. I was not from seeing the data from the woman's perspective. Removing myself and enabling it to become a template reflecting women's experiences was a difficult process, as I had to question my claim to authoritative knowledge, was it mine or the women's knowledge driving the template (Kingdon 2005)? My initial attempts at coding were in all probability stating that which was already known and the codes were not going to yield information to develop any new understanding. I therefore, would have failed in my main research aim, which was to uncover women's experiences from their perspective. Please see Appendix 15 which provides an insight into removing my 'professional hats' (Rawnsdon 2016).

I returned to the data and explored each pair of interviews individually. In undertaking this approach I was able to focus on the women, their experience, what it meant to them and how it was different, but in some cases, similar. This helped me step outside my own experience and descriptive examination and I started to view the data more analytically. The women's words as codes/themes opened up the data to new possibilities. See Figure 5-5 which consists of a shortened version of the first round of codes. Appendix 16 provides the full list.

| |
|---|
| I have been in a hospital |
| I listen |
| Absolutely fine |
| Different with the different staff |
| The treatment I received was horrendous |
| Hard work |
| Get 'spouse' more involved |
| Labour |
| Never want to be induced again |
| Prepare to be induced |
| Not dilated much |
| Signs of labour |
| I was convinced I was in labour |
| You don't really see the signs |
| It was seriously forced into it |
| Got weighed |
| I'm going to have somebody coming over to check him |
| The midwife just sort of left me to it |
| Staff have been fantastic |
| Feelings following birth |
| You can't |
| I don't want them involved in their care |

| |
|--|
| It was offered but I just felt that was a burden |
| Incompetent |
| His weight has helped |
| Skin to Skin |
| Being in NICU |
| Nurses got annoyed |
| They explained it all to me |
| They never took him away |
| Preparation |
| Better chance of survival |
| Just said he was a premature baby |
| Know what to expect |
| No preparation |

Figure 5-5: Women's words as codes

As can be observed, I had a large number of codes therefore, as previously discussed, the next step was hierarchical coding – those providing an overarching description and insight into women's experiences were coded at a higher level with several lower levels providing the finer detail of what made up that experience, this enabled distinctions to be made between and across each woman's experience (King and Horrocks 2010). NVivo was especially useful for developing the template as it enabled me to see, for example, how many women's experiences were impacted on by their chosen method of feeding. See Figure 5-6 for a snapshot of my next template.

| Initial Template (Women) Revision 2 | | |
|---|--|-----------------------|
| Thematic area | Lower level themes | Impact on experience? |
| <ul style="list-style-type: none"> I couldn't breastfeed | <p>Women's preferences / wishes for feeding their baby:</p> <ul style="list-style-type: none"> I didn't like that drip thing; I don't want to demand; I want a routine; Important to establish breastfeeding Mother's don't know best? | Yes |
| <ul style="list-style-type: none"> Going to leave her here | <p>Women worried about being discharged home without their baby:</p> <ul style="list-style-type: none"> I want to be back with them I needed to be there | Yes |

| (separation issues) | | |
|--|---|---|
| <ul style="list-style-type: none"> I felt over the moon | Women taking control of their situation whilst in hospital <ul style="list-style-type: none"> Feeding baby up Weight gain Go home | Yes Feel this is NB but only 2 sources and 4 refs. Look at depth of comments |
| <ul style="list-style-type: none"> Not completely prepared for it | Women knew what was going to happen having experienced a previous LPB <ul style="list-style-type: none"> Also not having had any previous experience | Yes - Phase two data could be coded within this |

Figure 5-6: Initial template Revision 2

Appendix 17 provides the full template of 24 highest-order and lower-level codes (King 2004). The template was applied against each transcript in turn and modified accordingly. I analytically explored whether similar codes could be merged into higher level codes and whether some could be deleted, but remained open to the fact that these may become important as I continued to revise the template against the data. For example, I decided the thematic code 'Going to leave her here' which concerned women being worried about being discharged home without their baby could be merged with 'Did see them briefly', as overall, that thematic code dealt with separation of mothers from their babies and leaving a baby behind fits with 'separation' as an underlying theme. Women were also anxious about seeing their babies following separation at birth; therefore the theme became 'Is this like, my baby? How is there any connection?' I developed and modified the codes iteratively as I continued to revisit my data, which enabled me to associate my emerging thoughts with the themes that developed as I progressed through analysis (Srivastava and Hopwood 2009; King 2014).

Critics of CAQDAS have alleged that undertaking analysis with computer software distances a researcher from his/her research (Bringer et al. 2004). I did not encounter this issue as I was able to attach memo's and reflective notes to themes/women's transcripts, which kept me focused and enabled me to easily view how I interrogated the data, my thoughts and ideas as my template developed (Bringer et al. 2004). For a detailed overview on my thoughts when considering if

some themes overlapped or could be amalgamated, please see Appendix 18 which is an extract from my research journal. In addition, TA facilitates parallel coding of segments of text, meaning the same quote(s) from individual women were classified within a number of different codes at the same level (King 2012). In particular, during Phase Two many of the women spoke of their experiences during their in-hospital stay, so segments of these interviews were inserted into codes developed from Phase One. CAQDAS enabled me to search for parallel coding. The final template, which was applied to all transcripts, had themes amalgamated from both phases of data collection. All themes developed were grounded in the data, with my supervisors providing critical feedback at key points in the development of the final template (King 2010). Figure 5-7 provides an illustration of the final template. For a full overview please see Appendix 19.

| Initial Template (Women) Revision 3 – Final | | Impact on women's experience? |
|--|--|--------------------------------------|
| Thematic area | Lower level themes | |
| Hit and miss | Feeding babies <ul style="list-style-type: none"> • I didn't like that drip thing • I don't want to demand • I want a routine • Important to establish breastfeeding / support for breastfeeding Involvement of spouse <ul style="list-style-type: none"> • Using formula so partners can get more involved with feeding. • Involvement in other ways, nappies | Yes |
| I felt over the moon (ownership) | Women feeling in control whilst in hospital | Yes |
| Not completely prepared for it (readiness) | Previous LPB <ul style="list-style-type: none"> • No previous experience | Yes |
| We are not here for me, we are | Woman realises she is not at | Yes |

| | | |
|---|--|-----|
| here for him | the centre of care- her baby is | |
| Is this like, my baby? How is there any connection? | <p>Women first met their baby after birth</p> <ul style="list-style-type: none"> • Get over there • I didn't see him straight away I needed to be there • I want to be back with them the first time I held him • They never took him away <p>Separation</p> <ul style="list-style-type: none"> • Leaving babies behind | Yes |
| More than happy to come down here | Support for women once their baby discharged by NICU | Yes |
| Spoke to the doctors (medical decisions) | <p>Women discussing issues with the doctors</p> <ul style="list-style-type: none"> • Feeding • Discharge • Weight • Other health related matters | Yes |
| Hands on | <p>Level of involvement with baby</p> <ul style="list-style-type: none"> • NICU • PN | Yes |
| She'll be home soon | <p>Do parents know when this may happen</p> <ul style="list-style-type: none"> • I don't know why I am here • I'm expecting to be here for awhile • My goal is next week • They haven't said. | Yes |

Figure 5-7: Initial template version 3: final

5.11 Section four: BIRTH TERRITORY THEORY

Birth Territory Theory (BTT) is a theory devised by Fahy and Parrat (2006) from their own empirical research which describes the relationship between the environment

of birth (terrain), those caring for women (power (jurisdiction) and control, and how a combination of these factors impact on a woman physiologically and emotionally during birth. The basis of BTT is grounded within a Foucauldian perspective derived from the works of Foucault who analysed and wrote extensively on the intrinsic links between power and knowledge, particularly medical power and how it (power) functioned within institutions such as hospitals (Foucault 1973; Fahy 2008a). Foucault was instrumental in articulating “the ways in which power relations act upon us, discipline us, and actually ‘make’ us” (Ells 2003, p.213).

BTT is thus based on the hypothesis that when midwives “create and maintain ideal environmental conditions, maximum support is provided to the woman and the unborn baby during labour and birth”, and as a midwifery theory it goes against the dominant medical philosophy which views women’s bodies as broken or defective (Fahy and Parratt 2006, p.49; Fahy et al. 2008). When “the physical, the social and the metaphysical space and the issue of power and who is in control of the space” (Fahy 2008b, p. 14) are aligned, then women will harness their own powers during birth, resulting in a more positive experience for themselves, both in the short term and longer in the postnatal period (Fahy and Parratt 2006).

I undertook to explore the literature to determine whether the theoretical framework of BTT had informed and/or guided any other research within midwifery and/or childbirth. Meyer (2013) who reported on a concept analysis of control in childbirth, chose BTT as her main framework to guide analysis. She distinguished four characteristics which would enable healthcare professionals to better understand the association between control in childbirth and satisfaction with the childbirth experience. These were:

- decision-making
- access to information
- personal security
- physical functioning

In her view, use of BTT fitted perfectly within the concept of control, because of its emphasis on terrain and jurisdiction and how each impact on a woman's birth experience. In addition, Meyer (2013) asserted that although overall, control in childbirth is not directly addressed in BTT; nevertheless including the concept of control into BTT strengthens it as a theory.

In a paper which explored how birth spaces can be constructed to boost feelings of safety and security in labouring women, Stenglin and Foureur (2013) utilised concepts of BTT and 'Binding' which "theorises the way people's emotions can be affected by the organisation of space" (Stenglin 2008, p.426). A limitation of BTT is that it "does not explore in depth the dynamic unfolding nature of space" (Stenglin and Fourer 2013, p.820) therefore 'Binding' theory of 'space' was used by the authors in a further attempt to build on BTT developed by Fahy and colleagues. The biomedical model of childbirth requires most women to birth in obstetric hospitals, in environments where childbirth is seen as risky (Scamell 2011), therefore space occupied by labouring women shapes their behaviours (Davis and Walker 2010). Binding as a theory, therefore provides healthcare professionals with a further theoretical tool that heightens awareness that birth spaces can be an environment which evokes feelings of insecurity and security in labouring women (Stenglin and Foureur 2013).

For the purposes of my research, BTT seemed an appropriate theory to examine and analyse in detail women's experiences of caring for their LPBs, because, although concerned mainly with where women birth, BTT can be extended wider to view how maternity services are organised and managed (Fahy 2008b). A review article undertaken by Meedya et al. (2015), to explore strategies to enable women to achieve breastfeeding for six months postnatally, utilised a theory of self-efficacy and BTT, to examine concepts of cognitive processes and environment and how each may impact on prolonged breastfeeding. The authors concluded that systems based on self-efficacy concepts are helpful, however it should be in conjunction with an awareness of how environments impact on women and their babies (Meedya et al. 2015).

Therefore, aspects of BTT was used to explore the territory where women in my study began their experience of mothering and mother-work (LW and PNW), and finally their experience once back in their own territory (home). These territories (LW, PNW and home) do not exist outside “the gendered, political, economic, social and legal networks of power within a given culture” (Fahy et al. 2008, p.ix). In the authors’ views, women, midwives and doctors are influenced (whether it is consciously or unconsciously) by these networks, which restricts what can be done within these territories, for example power, in the form of medical domination, impacts negatively on women and midwives (Fahy et al. 2008a). Women in these situations become passive, obedient and fearful, emotions which do not facilitate empowered decision making for herself or for her baby.

Whilst the midwife’s role is to be ‘with women’ and to empower them, there is evidence (see: Keating and Fleming 2009 and Scamell 2011) that territory, which can oppress women, may have a similar effect on midwives themselves. If midwives, like the women with whom they work become submissive within hospital territory and elsewhere (for example, in the community), they may themselves become complicit in “medical gazing by, surveillance of and reporting on the women” (Fahy 2008a, p.6; Keating and Fleming 2009; Newnham 2014; van Teijlingen 2015).

A similar concept was investigated by Peckover (2002), where she examined whether the tensions between the HV role when working with women at risk of domestic violence was one of support or surveillance. A number of women perceived they were under the surveillance of HVs and practised resistance by not allowing HVs to visit them at home, or not disclosing episodes of violence. HVs have a complex role, one that is supportive and another that includes an element of policing and the power inherent within that role, therefore HVs need to be mindful of this complexity (Peckover 2002).

The final TA, Figure 5-8 consisted of 12 conceptual themes used against all the transcripts to explore women’s experiences of caring for their late preterm baby/babies. For the complete TA please see Appendix 20.

| Final template | |
|--|---|
| Thematic area | Lower level themes |
| [They wouldn't tell me definitely that she could] GOING HOME | Doing things Gained weight Feeding her on my own Gave me the best chance of going home They let me go home At home |
| BEING [in hospital and at home] | I was put on a postnatal ward It was so nice to be out of hospital A very good hospital Labour ward |
| [It was just not the best] EXPERIENCE | Postnatal experience I'm here just for them Baby on the neonatal unit |
| STAFF | Health Visitors Midwives Neonatal staff Doctors Professionals know best Having to ask somebody to please stop what they are doing OTHER SOURCES OF SUPPORT Information off the internet |
| [Look this isn't getting any] BETTER | Feeling guilty I was concerned about taking anything Poorly throughout my pregnancy I'm still having some of that pain in my side Left a hole and it wasn't healing |
| [Is this like, my baby – how is there any] CONNECTION | Preparation Not emotionally prepared Knew what to expect They never took him away Get over there I didn't see him straight away I needed to be there I want to be back with them The first time I held him Leaving babies behind |

Figure 5-8: Final Template

5.12 Conclusion

This chapter has outlined my methodological approach and research design utilised to achieve my research aims. A feminist lens has been my key philosophical underpinning. To achieve this, I have utilised semi-structured interviews with women. A central issue throughout my methodological decisions and development has been to remain true to the women's voices. The use of reflection and developing a reflexive approach to analysing the data gathered, alongside TA, was crucial to achieving this. These strategies enabled me to develop findings that are focused on women's experiences. These will be presented in the next chapter.

CHAPTER 6 FINDINGS

Introduction

This chapter presents the themes that have been derived from TA that was carried out on the women's interviews. Some of the women's experiences have played a much larger contribution towards the development of some themes and aspects of those women's experiences will be utilised as mini vignettes as recommended by King (2012), to illustrate context and their unique experience of caring for their LPBs. The rest of the theme presentation will follow the usual convention of utilising short quotes. Pseudonyms have been used in order to protect the women's anonymity. Quotes in bold beside some of the women's quotes demonstrate the applicability of BTT. Within quotes '[p]' denotes 'pause.'

Some of the lower level themes have not been reported on separately, for example the theme 'Spouse'. Comments about partners were made by five women that were helpful in clarifying certain aspects of their experience which therefore necessitated devising a theme to capture their experience and include within my template (King 2014). During the interpretation of the final template it became evident that 'Spouse' was not strong enough to be reported on its own, but mindful of its importance in understanding aspects of women's experiences it was incorporated within the theme 'Do as much as I can'.

The theme 'Into the World' which consisted of two main lower level themes: 'He's kind of full term but early' and the women's 'Labour experiences' will not be reported individually, since it became clear during the final analysis that elements of the women's labour experiences (Into the World) fitted better into other themes, such as 'Connection', 'Staff', 'No one really explained', 'Being' and 'Look this just isn't getting any better.'

'He's kind of full term but early' which relates to information provided to women prior to and following birth in relation to the problems their baby may have experienced, has been incorporated into theme Connection under the lower level theme: Preparation. In addition, aspects of an individual baby's experience impacts

on his/her mother's experience of caring, therefore relevant quotes will be added where necessary within the appropriate themes (for example, Connection, Do as much as I can, Feeding and Being).

Throughout the analytical process I took the woman's age, her parity and previous experience into consideration when exploring experiences of caring. These elements making up part of a woman's experience were not identified as separate themes, but women spoke about some of these issues, for example, previous experience and I will include the relevant quotes where necessary.

With women's experiences of caring for their LPBs as a central starting point, a conceptual diagram (Figure 6.1) has been devised to illustrate the overarching themes which were derived from TA. All the names of the themes represent the woman's voice.

Each of the major themes as represented on the conceptual map will be presented in terms of how women experienced caring for their LPBs. The theme 'Into the World' is the starting point for all the women concerned, however, as mentioned previously is not discussed separately. Therefore the chapter is divided into the following themes:

- ❖ [Is this like my baby? – how is there any] **CONNECTION**
- ❖ **BEING** [In hospital and at home]
- ❖ **DO AS MUCH AS I CAN**
- ❖ [What was worrying me was the] **FEEDING**
- ❖ [They wouldn't tell me definitely that she could go] **HOME**
- ❖ **STAFF**
- ❖ [Look this isn't getting any] **BETTER**
- ❖ **JUST KEEP IT TOGETHER**
- ❖ **HE'S KIND OF FULL TERM BUT EARLY** [not reported separately]
- ❖ **NO ONE REALLY EXPLAINED** [not reported separately]
- ❖ **INTO THE WORLD** [not reported separately]

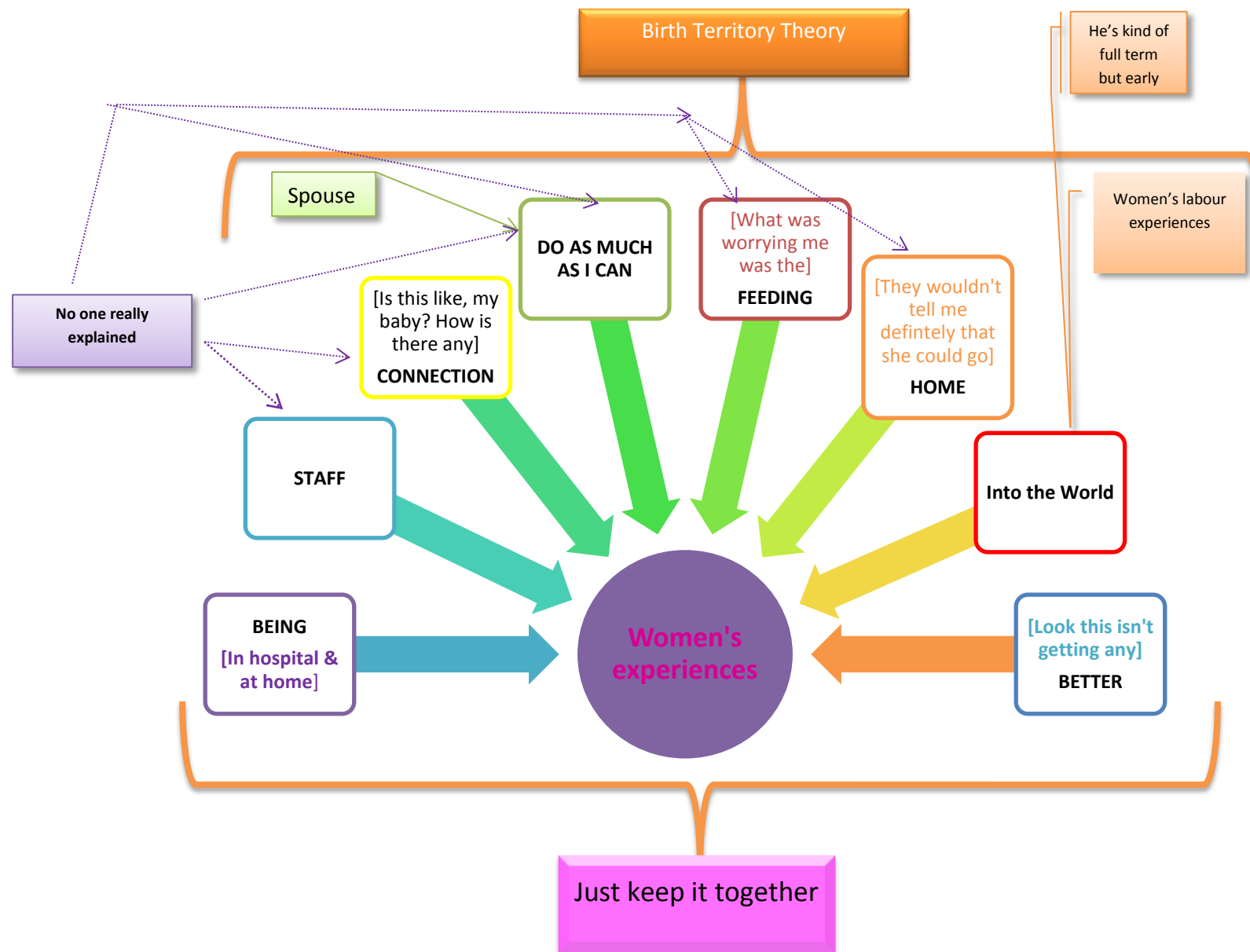


Figure 6-1: Conceptual map illustrating overall thematic themes

6.1 [Is this like my baby? – how is there any] CONNECTION



Figure 6-2: Thematic area: [Is this like, my baby – How is there any] CONNECTION and its lower level themes

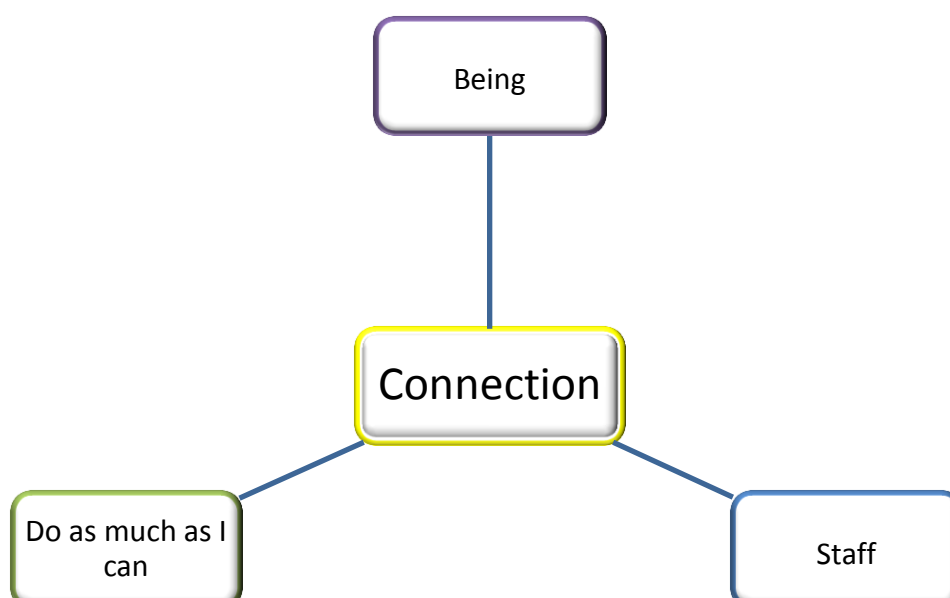


Figure 6-3: Illustration depicting CONNECTION and its links to other major thematic areas

The first major thematic area is called 'Connection' (Figure 6-3) and is concerned with whether women were able to connect with their babies following birth. It includes a number of lower level themes which are important when considering women's experiences, such as 'Preparation' which is linked to whether women were prepared prior to birth for their baby's transfer to the local neonatal unit (LNU). 'Get over there' describes women meeting their baby on the LNU, which appeared to affect their connection with their baby. Quotes describing women's experiences of not being separated from their baby are included within this lower level theme. Connection as a theme links to Being, Do as much as I can and Staff (Figure 6-3).

6.2 PREPARATION:

Prior to birth, some of the women were prepared for the possibility their baby/babies may be transferred to the LNU. Preparation consisted of either physically visiting the unit, or verbal explanations focusing on baby outcomes. In instances of a planned induction of labour (IOL), some women were able to familiarise themselves with the unit including meeting members of staff:

"Yes, the Special Care, they show us around just in case they warn us of that, he may be ok not to go in an incubator for example, as he's four weeks early he might go. And we need to be prepared for that [.....] where exactly the baby stays and where we stay and visitors, what we can use and how the baby's being looked after, they did show us [.....] Yes, prepared [...] because when I START I was five weeks early." [Freya Phase One]

For Gill however, preparation was unsettling. She was reluctant to visit the LNU but was persuaded by her friend who had a preterm baby. Although Gill was somewhat reassured following her visit, she remained worried:

"[...] my worry AFTER going up there, [.....] was thinking I might have to leave her and go away, because I know they don't have a transitional unit up there, so *that* was my *biggest* worry, because to think you have to leave your baby." [Phase One]

Whilst some women did not visit the LNU, there was preparation by medical staff. Linda was informed her twins may be transferred to the LNU because of 'breathing

problems'. Fiona was mindful of a potential preterm birth which might necessitate an admission to the LNU because her baby's growth had faltered. She was reassured by the consultant her baby would be fine any time after 34 weeks.

The following vignettes illustrate two women's experiences and their preparation for their baby's admission to the neonatal unit.

Mary:

Mary unexpectedly discovered she was pregnant seven weeks before she gave birth. Her previous pregnancy, eight years earlier resulted in a late preterm birth. During her current pregnancy Mary had been admitted into hospital for an abnormally high BP which would not settle. Medical professionals appeared reluctant to medicate Mary:

"They said they couldn't, because of how far, because I was pregnant with her, they didn't want to do anything to her (oh ok) with medication but as soon as I had her, they started pumping tablets into me." **[Unborn baby needs before woman?]**

Mary was being monitored on the Day Assessment Unit (DAU) as an in-patient, when her baby, in Mary's words, "twice on the baby monitor she disappeared completely". A further exploration revealed:

"They thought she just moved (ok) but when they turned the fetal heart beat up they couldn't find it or hear it (ok) so they threw me, didn't literally throw me, (laughs) it felt like it at the time onto my left side, and she done a little bit of a jump and come back (Yup) so then we were going a good hour and a half and she decided "no I've had enough of this" and done it again andwent "nooo I don't need this". So she was impatient to come out (ok), I wasn't ready for her but she was ready." **[Not ready for her baby]**

Mary's son had been admitted to the LNU; she was therefore prepared based on her previous experience, although her expectations were somewhat shattered when she eventually got to see her daughter:

"so I think when I went up this time I knew what to expect, but [name removed] wasn't in that same box, she was in the same bay as [name removed] was, but she was in a proper bed with no tubes and it's like "hang on why's my daughter here then?" that, to me, didn't

make sense, to me NICU is babies who are seriously ill and need care, my daughter didn't look seriously ill, but she was in this special unit and it was only because they said "because she's so small and so early, we need to keep an eye on her."

Mary's perception of neonatal units is to care for sick babies, and was puzzled as her baby appeared well:

"her temperature, and just checking she was feeding, because of her being so small, but they sat me down and they explained everything and I just sat there and went [p] "I feel calm and ok with her being here I just didn't understand, to me she looked perfect, I didn't understand why to start with, and once they had explained it all, it was like "I trust you's, you know you looked after my son, I know she's going to be ok." [Lacks trust in her own ability and accepts expert authority?]

Marylyn:

Marylyn was pregnant with her fifth child (her fourth baby had died of Sudden Infant Death (SIDS) and had been 'poorly' all through her pregnancy as a heart problem, previously undetected, had developed. The team were concerned about Marylyn's health and induced labour at 34 weeks gestation. Marylyn was aware her baby might go to the LNU:

"We'd already spoken about it previously, because obviously this has been on-going throughout the pregnancy, and Mr [name removed] my obstetrician explained the reason he wanted to get me to 34 weeks [...] [p].... he explained that 34 weeks it had a better chance of survival and being healthy and things like that. [...] They said that it was his lungs that would need the most help, which they were absolutely right, that was his problem when he was born [p].....They told me to expect a 3-4lbs baby; he was 5lbs 12 oz. And they just said obviously everything's not quite mature yet so it may take a bit of time, and they said that I should look at him being in NICU for 2-4 weeks. And then when I saw Dr [name removed] about the Coni Scheme he said that at 34 weeks they don't even really consider it a problem anymore because everything they have on the medicine side to help them, most of the time he said they're absolutely fine."

There appeared to be no discussion on how *she might feel* following a late preterm birth.

All her previous four births were normal, with the last at home, therefore found IOL traumatic, “Awful, I never ever want to be induced again!”, which consisted of multiple attempts to ripen her cervix (largely unsuccessful) and eventually one of the obstetricians declared “I will not be beaten by those waters, I AM breaking them” (laughs). And he did!” The following quote reveals how the process impacted on Marylyn:

“It wasn’t not, not for love nor money! (Referring to her cervix). The amount of stretches and sweeps I had, and gels and ... oh my God, poking around. It was just awful, I was so sore inside afterwards, it was just awful. They said to me they needed to do another internal, and I was like do you really have to, I’ve had enough now.”

Despite the ‘slow’ start to cervical dilatation, once the membranes were ruptured, Marylyn’s labour progressed and her son was born two hours later. Regardless of assurances that ‘most of the time they are absolutely fine’ he was extremely unwell and was quickly taken away for resuscitation which, despite an awareness of potential problems was still shocking for Marylyn:

“Oh God (said in a sighing way) [p].....When he was first born, I luckily didn’t see his condition. I knew it was bad because he was told to be taken straight out, [..]. I made my partner go with him because I didn’t want him to be on his own. He wasn’t breathing. When he was born I did catch a glimpse of him. He was very purple, almost black [.....]

Interestingly, when I interviewed Marylyn during Phase Two, she reflected on her experience:

“You still not completely prepared for it, not emotionally prepared for it. I knew that there was a chance he was going to go there, but [p] see I don’t know if it’s different for me because of my experience with [baby that died] maybe I was more worried and more anxious, because of my previous experience, because I can’t compare it to anything else because, my other children weren’t preterm, so I don’t know if that is how all preterm mothers feel anyway or whether for me it was slightly worse because of what happened with [baby that died] I don’t know. I probably never will know.”

Marylyn’s memories of her days in hospital remained quite raw two months later and she spoke eloquently about her experience.

Finally, Medina, whose previous baby was late preterm instinctively knew her second pregnancy would result in a preterm birth, was still unprepared:

“No I think you never prepared you know for that kind of situation, you hope, you hope that everything with baby being born premature everything will be fine, I don’t know, maybe because [first daughter] was fine so that was my idea that everything will be fine [.....] I must say I was much more calmer, but the midwives said ‘your child must go to NICU’ I said ‘fine, whatever she needs’, you don’t think about yourself, you think about your child.” [Phase Two] [Baby’s needs before a woman?]

For the women in my study who experienced unexpected and spontaneous preterm labour, there was no time to consider visiting the LNU or even discussing any possible outcomes for their baby with the relevant medical professionals. Section 6.2.5 provides further insight into their experiences. Of the fourteen women interviewed, twelve were separated from their babies for varying lengths of time due to an admission onto the LNU.

A lower level theme within Connection is concerned with whether women were able to meet their baby following birth and if they were aware if their baby / babies were ‘ok.’ The following section will explore women’s early contact with their babies’ and whether they were enabled to experience physical contact, such as S2S, which is discussed further on in the chapter (6.3).

Linda, who gave birth to twins via operative delivery, saw her son briefly before he was taken away, but became alarmed when there was a delay in seeing her daughter who was born shortly thereafter. Both Linda and her husband were concerned by a lack of communication between themselves and the staff in the operating theatre:

“..... I looked at him, he cried, I cried, and then they took him off and then she was born and eventually she cried and he still hadn’t come back to me and I looked at [husband] was looking at everybody to see and we couldn’t hear [boy twin] anymore no one came to.....[husband] was looking around to see if everything was alright, just to see a concerned face or to see any hint that something was going on but he couldn’t find anything um eventually I said you know “where’s my son” “is he ok”, and they brought him to me, by that stage she had already come to me.”

Nicola heard her son cry following his operative birth, but not her daughter. She had early contact with her son but the delay in meeting her daughter worried her. She was unable to explain the delay.

Marylyn, whose baby was rushed away as he required resuscitation was still desperate to see him and fortunately, was afforded an opportunity:

“Yes, so he was taken off, [...] I was crying quite a lot, I thought he’d died and I was beside myself and I wouldn’t believe them when they was telling me that he hadn’t. And they were like, ‘he has to go’, and I was like “I just need to see him; I need to know he’s alright!” And they literally brought him in, I saw him, I held him for two seconds and he was gone.”

Kate had a semi-emergency OD (undiagnosed breech position) and was not expecting any baby related problems; however Kate was not able to meet him immediately:

“...they held him up, I didn’t see him but my husband saw him, and then my husband went with him to where the paediatricians were and saw him for a bit, I think it was about half an hour before I saw him (oh ok) which I found odd as well. I accepted it because I thought it's more important they sort him out make sure he’s fine, and then they just brought him past on his way out and just put at my head so I could see him. ” **[Baby’s needs before woman?]**

Kate accepted the delay as his needs appeared greater than hers, but was shocked when he was admitted to the LNU:

“I found all that very stressful actually afterwards, (oh ok) because he went up to NICU to start with, (ok) so I obviously realised that at stage that there might be a problem [...] but then I came onto this ward, um postnatal, and all of a sudden he appeared and they brought him down within an hour (oh ok) so at that point I naively assumed he was absolutely fine, there was no problem, so it all came as a bit of a shock when there were some problems, um I did almost feel like we were left to work that out for ourselves because nobody ever specifically said “this is what might happen, this is what is happening with him” um yeah, I kind of assumed I would be here for a while because I’d had a section, not because of him, and then a few days in, the penny suddenly dropped, ‘we are not here for me, we are here for him’ (ok) yeah.”

Kate realised the priority during her postnatal stay was her baby.

All the women whose babies were admitted were anxious to see them, and went to great effort to get to the unit, including those who had undergone a surgical delivery. Overall it appears, whilst 'preparation' and 'information' can be provided, these elements do not appear to address the possible emotional needs a woman may experience. In addition 'preparation' tended to be related to the baby and not to women.

Jane:

The following vignette illustrates Jane's experience of 'knowing and not knowing' based on her previous experience of a late preterm birth. An acute abdominal pain earlier in the day had made Jane seek medical help (she was expecting twins) and she was admitted onto the LW of the local hospital for assessment. Jane was aware the earlier pain she had experienced was not 'labour pains'. Her cervix was assessed and Jane was informed she was not in labour, despite her uterus experiencing 'tightening'. She was prescribed Paracetamol. The immediate concern for Jane and the medical professionals was focused on the unborn twins, who on monitoring, at least initially, appeared well, although one of the babies kept on experiencing bradycardias. The plan was to transfer Jane to a large tertiary unit about 100 miles away because local neonatal cots were unavailable. Jane was not entirely happy as she had already transferred from her local hospital to the one where our interview took place. Unfortunately, the same twin daughter continued to experience bradycardias, whereupon Jane was rushed off for an emergency operative delivery, where it was discovered her uterus had ruptured:

"Hmmm, since the morning [the pain], seem quite a rare case because generally that happens and its fatal [...] I was having an epidural which tend to relax you and give you oxygen, the babies were out as quickly as they could, and obviously at 34 weeks generally the babies are fine."

There did not appear to be time to inform Jane and her husband about possible outcomes and, although she hoped her babies would be fine at 34 weeks gestation, she was troubled based on her previous experience:

“I must admit I was a bit concerned about it because of our older daughter had been born at 34 weeks and she got NEC, (necrotising enterocolitis) for weeks (ok) [...] I knew that if she had been given breast milk at that stage, she'd probably wouldn't have got the infection, so I know they told me, the paediatricians told me that they have donor milk, so that put me at ease a bit, but obviously they [twins] were delivered, they were fine, I took some time to patch me up a bit, obviously they were taken off to the ICU and I was brought back to the ward. But so, it wasn't quite what I had in mind, obviously with what happened with our elder, but with twins you expect them to be born earlier anyway, I was just relieved they were ok.”

Unlike previously, where she was not able to meet her daughter due to undergoing a general anaesthetic (GA), Jane was awake and introduced to her twins when they were both stable. Although the context of Jane's previous birth was different [country in Europe], the following quote demonstrates how she felt when she missed out on that initial meeting, although firstly, she makes reference to meeting her twins:

“they did hand them to me briefly because they were stable enough, and I think the next day is when I obviously got to see them up there, but it was nice, because I actually got to see them, whereas when [first daughter] was born I was not allowed to, epidural didn't work, everything else didn't work and I ended up under GA so that was upsetting, because I didn't get to see her and I don't know, lots of people have I don't know end up having general anaesthetic don't they, that was hard to make [.....] I found that distressing whereas it was actually nice I got to actually seeing them you know brief as it was.”

Jane found it difficult connecting with her first daughter: “by not seeing her immediately after and because it was in a separate building, up a hill, the initial seeing, it was, “is this like my baby” how is there any connection when I don't..., I don't know I found that hard..... and at times you felt that baby was their baby not yours” however, an early connection with her twins meant “they are our babies.”

Although Jane's experience was more positive second time round, for Fiona it was the opposite. Her first baby was born at Term and postnatally there were no issues. Labour was induced at 34 weeks and four days because Fiona's baby had stopped growing. Fiona had a quick labour with her baby 'shooting out' still in 'his waters':

“[...] they put him on me for skin-to-skin (ja) and then five minutes later he’s rushed down to the resus table because he wasn’t breathing properly (ok) and then straight into the incubator and up to NICU. So (ok) I hardly got any time with him and then he was up there, [p] in a strange way, it felt like I hadn’t had a baby (ja) because I had no tears, no stitches, no pain, no swelling, nothing.... like that. Um and obviously I had no baby with me, (ja) so it was the most bizarre thing.”

Fiona had gone through a labour and had no baby to validate her experience.

Some of the women were never separated from their babies despite the circumstances surrounding their birth. Lisa presented on the LW in strong labour, where it was discovered her baby was in the breech position, which necessitated an operative delivery. However, as Lisa was being prepped for theatre, the baby’s cord suddenly appeared which necessitated an emergency Caesarean Section (CS) under GA:

“I woke up feeling quite drowsy, not...in a semi-lit room with people looking over me. My husband there, holding the baby saying, “It’s a girl!”And then I just had the baby put on my chest.”

Freya and Valerie were never separated from their babies:

“The whole time, they never took him away or were concerned about anything..... But at the same time I spend so much time next to my baby, it’s like 6 days today [...] I feel absolutely natural and normal now. I’m not scared to hold him or to feed him, or to change his nappy or if he cries. Or to bath him.” [Freya] [Elements of integrative power]

“He was absolutely fine, yes. Just small, really, just – but no, no, they had no concerns at all..... I was given him straight away, while they were all doing all the cleaning up and things I had him. (ok) [...] but there was nothing of any concern, so they were (ok) they were all happy.” [Valerie]

Women appeared to have undergone a varied experience both in terms of preparation, meeting their baby early and information needs.

6.3 BEING [In hospital and at home]

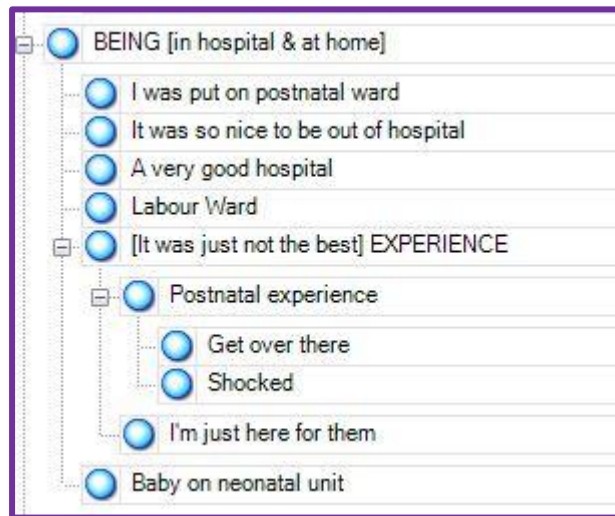


Figure 6-4: Thematic area: BEING [in hospital and at home] and its lower level themes

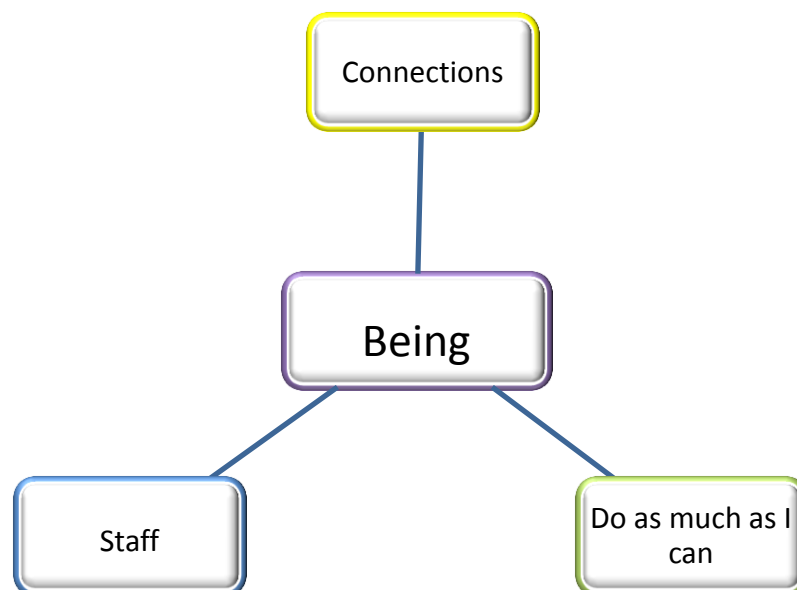


Figure 6-5: Illustration depicting the theme Being and its links to other major thematic areas

This overall theme explores women's experiences within the environment of hospital and home. It links with 'Connections, Staff, Do as much as I can' because these all themes (such as interactions with staff and being physically able to undertake caring) impacted on how a woman was able to care for her baby. The

experiences can be broken down into whether a woman was resident on the PNW, the LW and whether her baby was on the LNU. Most women were transferred to the PNW and accommodated on the general ward or in a side room. Being offered a side room was important for some of the women. A couple of women were kept on LW because there were no postnatal beds. The location of LW in relation to where the baby was cared for had an impact on their experiences.

6.3.1 'Being' on labour ward:

In the situation where women had to stay on LW, it was not problematic unless they wished to access their baby, whereupon location became a barrier. Marylyn was resident on LW and did not mind. However, negotiating access to her baby on the LNU via the PNW was problematic:

"The nurses or midwives on the post natal ward however have upset me quite a few times because I have to keep going ... obviously I'm here, my baby's over there and I WANT to be with my baby..... But where I'm backwards and forwards quite a lot, the nurses and midwives on postnatal get cross because I keep ringing the bell! I've been tutted at, I've had comments made to me, and I got upset about it. And I'm walking round the hospital half asleep; walking into the wall in fact I'm so half asleep. But the midwife moaned at me this morning for ringing the bell, so I said "well I have to go and feed my baby". "Well we've just had a woman who's had a C section." So I said "it doesn't mean you can't open the door." **[Disintegrative power & midwifery domination]**

I wondered why Marylyn had been offered a side room on LW.

"The midwives here have said that there were no side rooms over there, and they didn't think it was very fair for me to go into the main ward with all the mums who had their babies whilst mine was in NICU, and they know how I felt about this pregnancy because of recent [.....] and all the memories it's brought back, and just how tough I'm finding this. I think they've just given me my own bit of space I can come back to when I need it."

Marylyn was resident on LW for a week, despite being offered a room on postnatal: "I don't like the midwives there!" Eventually she accepted a side room on postnatal, based on the proximity of the ward to the LNU and relationships with the postnatal midwives appeared to improve:

“I just kept myself to myself in my room most of the time and they seemed a lot nicer once I was over on their ward, not ringing the bell all the time.”

Linda also found being on LW challenging as she had to rely on staff to get to the LNU:

“Up in NICU it’s been absolutely awesome, getting from Labour Ward to NICU was bit of a mission, until I insisted especially because I had my catheter in still I asked for that to be taken out and I literally forced myself onto my feet so I could walk I was up and walking the next day.”

When I explored why she forced herself to walk so soon after her operative delivery, she replied she did not want to be a burden on staff. Nicola expressed similar views, because as soon as the epidural had worn off, she was up walking to LNU only hours after her operative birth. Being a burden to staff is briefly explored within the theme ‘Staff’ (6.7).

6.3.2 ‘Being’ on postnatal ward:

The majority of women were admitted onto the PNW and where they were cared for was important, with side rooms being favoured by all those who had access to them. Gill spoke of the importance for her when I interviewed her during Phase Two. She had written down some points so she wouldn’t forget to tell me.

“but um a good thing that really happened, was really I forgot to mention, was um (laughs) I was given um [p] because I didn’t have my baby with me, I was put on postnatal ward, they then moved me at that point to a separate room because I was crying, because every baby made me cry, um.” [Terrain]

Reflecting further on this interview I am dismayed at myself for my lack of woman centeredness. Gill had gone to the trouble of writing down some important points to remind her when we met up. I was grateful and touched she had gone to so much effort but, and it’s a big BUT, I don’t appear to have appreciated how difficult it was for Gill being separated from her baby. How precious that photograph was – a polaroid image gave her comfort because her baby, although not sick, was on another ward and she was on her own in a side room at a distance with only a photograph to show she had a baby. Again I was still too focused on the ‘baby’, my professional background impacting on the ‘insider/outsider debate is it helpful or a hindrance when undertaking research, in my situation it has been a hindrance at times.

Figure 6-6: Diary extract

Fiona, although provided with a side room, spent the majority of her time on the LNU and used her room for meals and for sleeping:

“[...] when a baby is up in NICU, they put their mums into the side rooms although there was only two, they still put the mums in there so then they not mixed in with the mums with the babies (ja) so, I think that would be a bit worse (Laughs) (ja) mums with all their babies (ja) but, yeah, that’s what side rooms are for.”

Having a side room did not lessen the impact of separation:

“Weird, the weirdest feeling. Although I was in a room and I have my own privacy and things, I still had my door open just to see people walking by. It sounds ridiculous, but to be honest I wasn’t in there majority of the time, [...] I was mainly spending time with him, just sitting there watching him or having skin-to-skin contact. (Hmm) And so [p] and then just sleep so [p] [...] it was weird not having him.” [Disembodied mother?]

Nicola, who had twins on the neonatal unit, felt similar to Fiona:

“I’m glad to be in a room [side room] like this as well which is nice. The first night I couldn’t sleep even though I had the anaesthetic and everything [.....] No you could just hear people feeding their babies and things like that, so and I didn’t have mine and it didn’t feel right. So in the end I thought, no I’ll wait for my legs to come round and I’m going! But once I’d seen them I felt more at ease and then fell asleep. Until the morning and then I was happy to know they were coming to me. Because I thought I’d really have to keep going up there ...”

Although Mandy appreciated having a side room, she really wanted to be resident on the same ward as her baby:

“I could still hear all the babies [in side room] it was nice because I could have people in and shut the day, but it wasn’t nice to hear all the other babies and mums [.....] I’d like to have been able to stay in actually the same bit with her, well they are doing it aren’t they, they’re changing it so parents can stay I think that would have been nicer rather than being on a ward with the ward babies, I think that would have been a lot nicer to meet people like my baby in NICU to deal with because you can hear all the other babies crying we didn’t have ours it was hard.” [Terrain]

Women resident on the PNW had mixed experiences based on the staff caring for them and their baby/babies and how infant feeding proceeded, although the theme 'Feeding' will be explored in section 6.4. In addition, some staff impacted strongly on a woman's experience and I will explore this within the theme 'Staff' (6.7).

Freya and her baby were kept together on the PNW for around ten days and, although at times she found it noisy and somewhat oppressive, on the whole she appeared grateful:

"It wasn't a bad experience I can't complain about anything, and uh yeah I am very thankful to anybody that helped me and uh [p] yeah especially in the hospital [.....] Yes, I just feel a little bit tiny tired, because obviously waking up every two hours, so feeding at night is not the best. And I have been in a hospital. It's something to be at home and different being in hospital on a bed all the time. I feel light headed. Obviously it's a nice place but it's all the time – obviously there is noise, there are so many people like babies crying all the time. But aah, yeah, I feel I should be OK here. It's quite noisy, but that's probably what I knew from the beginning. I just feel light headed, I've been here so long, I just need to go back to normal life, to go to town maybe for an hour and just be with my baby without doctors and midwives around!" [Terrain]

Kate felt mostly safe and secure, although she found it upsetting seeing other women with their Term babies as did some of the other women (for example, Fiona, Mandy and Nicola):

"[...] I found it very upsetting because I see all these other women coming in with their full term babies and, even if they've got problems they come in and go and I'm still here. I said to my husband this morning women who have yet to go into labour, go home before I do (laughter) but um yes I found that quite upsetting in a way, seeing those women coming and going with their babies, and here we still are." (laughs) [Elements of sanctum]

Reflecting back on her experience during Phase Two, Kate's perspective had altered slightly:

“um out of 10 I would give it, somewhere between 6 and 7, I think because some days I would have really good days and some would be really bad days, [.....], days where I got disheartened, looking back, they were little blips overall because over those days when we were in hospital generally, he made good progress, but I’d have those days where you felt like you weren’t, so maybe looking back, I would try not to get so despondent at the little things, trouble is at the time little things seem really huge.”

However, what Kate found most upsetting about PNW routines was her husband going home each evening:

“I’m looking forward to having my husband there as well to help [at home], because [..] one of the things I hate about being here, I hate it come the time, he's got to go home, it gets really emotional for me because you know just want to be a little family and he has to go, and he can't help, whereas once we're home he's going to help me with the feeding [..] by bottle feeding with some expressed milk during the night, so I can get some sleep yeah he's going to be there for us isn't he, so yeah I think that's what I'm mostly looking forward to actually, being at home, being a family and have my husband to help.”
[Gendered caring]

Lisa felt comfortable although found the postnatal environment noisy:

“I felt very comfortable there and [p] safe and supported, both me and baby. I think there were, you know, a couple of things that you would sort of think, “Oh God, I’d sleep better in my own bed. I wish I was at home.” And there were a couple of nights where there were just babies screaming constantly. She was really quiet when we were there. [...] She’s young and a tiny baby will sleep more and is quieter. She’s not going to go competing with all the others in the ward and so we’d have this lovely, tranquil, quiet section of the ward. And then all the others were just screaming. So I think I might have slept better somewhere else.” [Terrain]

Marylyn however, felt the opposite to Lisa:

“Yeah, I did feel I was like in prison, it was awful. [Long p] In the last sort of week, I went out a lot more at the hospital, I took him, because he was in my room with me, I was like, because they had pushchairs there, I was like “can I just take him out for a walk”, I just got fed up of being confined in those 4 walls, it was um, I don't like hospitals anyway, I.... it just freaks me out and I did find it just awful, it was making me really, really down.” [Terrain & surveillance]

Although Mary was complementary of staff, she found the structure of the hospital depressing and couldn't wait to be discharged. At one point she discussed running away:

"I mean, the nurses are lovely but [name removed] Hospital is just so horrible, it's not, its I think because it's an old building, and it's just depressing, [...], I mean I've left her now to come here, and yesterday I walked out of the door and up to the top of the slope with my partner because his car was parked at the top, and he went "are you coming up the car" and I went "no I'm going back" and I come running back and he went "where are you going" and I said "I'll see you later" and he's like "what are you going to do if they say go home and leave her here" and I'm like "you've got no hope, I'll camp in the grounds in a tent I'm not coming home without her" (laughter) and he went "why" I said "cos I can't, she's my daughter I can't, I wouldn't do it with [first child]". I was ready to go home after a week, I was ready to go home after a week after having [first child] but because he was here for three, it's like "I'm sorry I'm not going home" I don't drive and my partner works away a lot, so it's like when he's gone I've got no way, apart from a bus, and I can't get here quick enough, so I'm going home with my daughter when she's ready, but 10 days is long enough now". **[Terrain]**

Mary, Marylyn and Connie all had an antenatal admission in hospital which impacted on their experiences postnatally. Unusually, Connie went home the same night of her baby's birth who had been admitted onto the LNU:

"I've been here for a week and I just [p] wanted my own bed [p] really, but other than that I would probably have stayed, it was just because I've been here, if I'd only been here a couple of days I would probably have stayed, but, just because I've been here for a week I've had enough." **[Craving sanctum]**

The following diary entry provides an insight into privacy issues relating to women who were provided with a side room:

Listening back on the recordings recently, I noticed a number of issues relating to privacy I hadn't previously considered. I've already made reference to the fact many of the interviews were interrupted despite a notice on the outside of the door requesting people to respect a woman's privacy. In some cases interruptions were due to babies needing an element of management which appeared to be necessary, but possibly could have waited until the interview was completed. All the women

had their babies with them and were providing care. I did however become aware of 'inappropriate' interruptions. In one instance, a member of staff barges in. In another, there is a knock on the door and it is the refreshment round. On a further occasion there is a knock on the door, however the person does not wait to be invited and enters the room regardless. This 'lack of respecting a woman's privacy' reflects Birth Territory theory which theorises on territory and a woman's lack of power within her birthing space. Women in labour have minimal control or jurisdiction over who enters their birth space and as a concept is equally applicable/transferable to women who are resident in side rooms on the PNW. For women who were accommodated within bays on the PNW, there is absolutely no jurisdiction on who enters their space, which consists only of their bed/bedside cabinet and their possessions crammed around them. Curtains provide only 'not visible' privacy as conversations can still be overheard as well other women's crying babies. I also became aware of background noises. In one of the interview there is a rumbling similar to a trolley pulling items, doors closing and people talking in corridors. The rooms are not insulated to protect women from other people's activities. But what struck me most about the side rooms was the noise of other women's babies crying and in one instance a baby was consistently shrieking.

Figure 6-7: Diary entry: Privacy

6.3.3 'Being' baby on neonatal unit:

The thematic area 'Connection' with its lower level theme 'Preparation' highlighted whether women were prepared for their baby's transfer to the LNU. Despite preparation, it was still a shock for some women to see their babies covered in equipment and wires, and for others, they weren't sure why their babies had in fact been transferred.

Medina heard her baby scream robustly but the situation soon changed:

"..... they noticed that her skin was nice pink but not pinkish enough and then she was a bit, I don't know after a couple of minutes they check her lungs, they decided something was not completely right just you know"

Medina's baby was transferred over to the LNU which she accepted:

"I was quite happy for her to go to NICU just to make sure everything was fine [.....] You know it was a bit strange for me I must say, because I was here and she was there, but she was doing really well."

Nicola had been prepared by the community midwives that her twins might be born preterm, however:

“Yes, I was quite shocked over that. I got told they would breathe on their own and everything [...]. They won’t be as fragile as you think they will be.”

Fiona’s baby required extra support as well:

“I just wanted him to get better [...] they didn’t keep me informed on anything that was going on at the time, they did sit me down after and say, “Look, we had to have him on the resus table for five minutes,” and then obviously, they’d take him up. They did stop by my room as they were taking him up (Hmm) um so I could just see him and then take him on.”

Fiona was distressed when she finally saw her baby:

“It was awful seeing him with all the machine around him and everything, I just felt so helpless. Um [p] it was just the weirdest, the weirdest thing. Because obviously with [daughter], I just had her and that was it; that was my full time Mum care.”

Mary was scared to touch her baby, despite her previous experience:

“When I first went up to see her in NICU and they wanted me to change her nappy I’m like “I can’t, she’s too tiny, I’ve got great big hands and this little thing just fits in them.”

During Phase Two Mary revealed further insights into her experience:

“[.....] you see my son was born at 36 weeks as well, and I wasn’t scared with him because he was bigger, he was nearly 6lbs when he was born, but because she was so tiny I wouldn’t pick her up, [partner] would have to pick her up and hold her and change her, and I’m like “no I’m going to break her she’s too tiny” but they are very strong [.....] yeah it took me a week to pick her up [.....] Yeah I wish I had picked her up sooner, but we make up for it now don’t we.” **[Lacks jurisdiction in her ability as a mother?]**

Marylyn’s earlier vignette (6.1.1) demonstrated her distress following her son’s birth. The next extract outlines the importance of needing to be with her baby, although initially, staff tried to dissuade her from going to the LNU. She knew what she wanted and set out to achieve it:

“And I literally never wanted my placenta taken out of me so quickly, it was like, hurry up, I just want to GET DRESSED and get over there.

They were like, “you can’t!” and I was like “I can!” So I think I didn’t wait very long, [.....] I chucked some clothes on and we were straight over there and they were preparing him to go on the CPAP [....]. He was really struggling to breath [.] he was grunting, it was awful, it was horrible. He went on the CPAP for a bit [...] And then they told me he had to be ventilated and what they had to do to ventilate him. I had to leave the room, I was just hysterical again.” **[Strong mothering instinct]**

Her need to be with him was stronger than her squeamishness:

“[.....] I NEEDED to be there with him.....The only bit I didn’t want to see was when they ventilated, and that was purely because they told me they were going to stop his breathing to tube him and everything, and then have to resuscitate him, and I knew that would be just too traumatic for me to see.”

Marylyn was desperate to cuddle her baby and after two days he was ‘allowed’ (her words) out of the incubator:

“So Monday was the first day I held him and I cried, I couldn’t stop crying. The first time I held him he had his CPAP on, so I couldn’t really see his face properly or anything.”

As far as Kate was concerned, her baby was healthy at birth and was shocked when he was taken to the LNU:

“I think part of the reason I got so upset was because it was such a shock that he needed these things, because to me he looked like a normal healthy baby because he didn’t have tubes or monitors on him or anything, he just looked normal so, yeah I think they need to take the time to explain these things to parents.” (Phase Two)

Jane was relaxed about her twins being on the LNU:

“Initially because [twin 2] was smaller they did put an IV line in her [.....] but in the end they never used it [.....] I think they spend one night, that evening, in an incubator but by the next day they were out of it actually then they went on a heated bed but they were able to maintain body temperature which was great so that was turned off, so they weren’t in there for very long.”

Gill accepted her baby was on the neonatal unit, even though she appeared well at birth. I asked Gill why her baby had been admitted:

“No because I knew that she would probably need to be because she was a bit small.....um when I came down here [postnatal

ward], I wasn't sure whether or not, I could go up to see her, or she could come down to see me, so it was getting these guys with those guys, liaising so (laughs) and in the end I knew those things, I was well enough I could get in my wheelchair.”[Information needs?]

Gill had an OD and, similar to Nicola, Linda and Marylyn put aside any thoughts of her own discomfort to get to the neonatal unit:

“yeah, but it outweighs it doesn't it [her own pain], I knew I just needed to get to the chair and I would be fine once I'm in it, and then I was wheeled up there, and she was in an incubator, and I was able to hold her and then feed her as well (breastfeed her) yeah [...]”

6.3.4 'Being' a very good hospital:

On the whole, regardless of issues, most of women were complementary of the hospital and praised it and the staff highly. Jane who had requested to be transferred to [name removed] Hospital found all the staff, from the cleaners to highly professional medical staff, cared about her wellbeing. She “couldn't fault any member of staff actually which is amazing really”. Interestingly, in retrospect she was unhappy with one of the doctors who cared for her during her labour and her reasons are explored further on. The 'wordle' below visually depicts some of the women's views about [name removed] hospital. **[Terrain]**

Being at home gave Marylyn time to reflect on her experience:

“didn’t really sort of hit me either until I came home, and just how hard it was in there when I came home, I spent the next day in tears more or less the whole day because it was just so [p], such a relief, just to be home and the worrying, I because felt like a huge weight had gone [p] it was, it was really hard” [p]. **[Sanctum]**

Lisa attended a Sure Start Clinic run by HVs, which provided classes on parenting and so on. Fiona attended a local Sure Start breastfeeding support group in her local market town which she found beneficial.

Quite a few women used the World Wide Web to research minor baby problems, whilst others like Linda, used formula milk company helplines for advice on feeding.

“Can I tell you what really did help me? The online chat service that [name removed] offer. That lady gave me so much advice, more than the health visitor has ever given me. She helped me with regards to why they were so niggly, and with the feeds.”

One of the issues problematic for Linda was the (non) availability of HVs when she was experiencing problems with her twins:

“in the middle of the night or at the weekend, my health visitor is not available. There is no 24 hour call number Nothing, which is why I phoned [formula company]. I chatted online to the [formula company] adviser.” **[Integrative power]**

Most of the women appeared to be the main carers. Occasionally husbands were present when I interviewed women for Phase Two and interactions took place within the context of their domestic responsibilities – see 5.6

6.4 DO AS MUCH AS I CAN

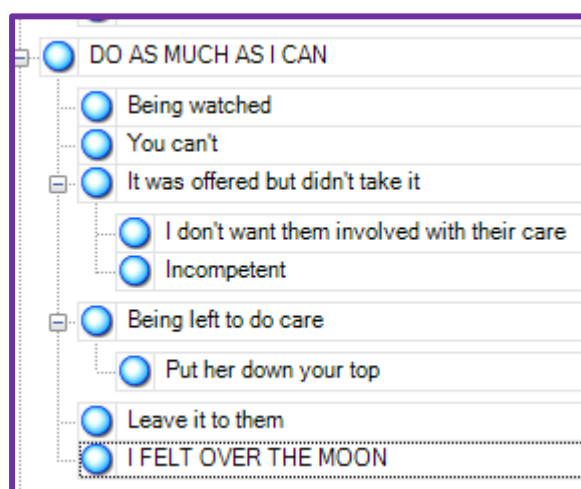


Figure 6-9: Thematic area: DO AS MUCH AS I CAN and its lower level themes

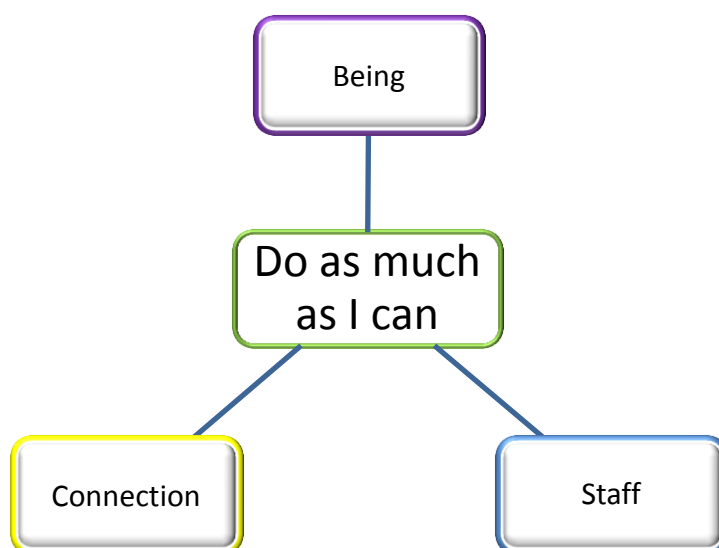


Figure 6-10: Illustration depicting the theme DO AS MUCH AS I CAN and its links to other major thematic areas

Women were keen to be involved in caring as much as possible for their baby/babies, including those who were separated; therefore 'Do as much as I can' reflects caring. This higher level theme has a number of lower levels which will be explored as the section proceeds. As a theme it links with 'Connection', 'Being', 'Feeding' and 'Staff', with all impacting on a woman's experience. For example, staff were involved daily with women, both for support with feeding or facilitating

women to care for their babies. Interactions with mothers in different environments both helped and hindered their experiences.

The theme Connection referred to how soon women were able to see and connect with their babies. Part of connecting would be providing skin to skin (S2S) care. I have included S2S care within this theme as opposed to being incorporated within Connection, as S2S was a way to provide comfort for babies and enabled women opportunities to get know each other.

6.4.1 Neonatal unit:

When babies are admitted onto neonatal units, providing opportunities for women to undertake S2S care becomes more challenging. Mandy was frightened because her baby had 'wires' coming off her (ventilated), although she was still encouraged to provide S2S care. Marylyn was unable to cope when she could not provide S2S:

"Yeah I mean obviously he couldn't have been put skin to skin because he wasn't breathing, but once they had established his breathing again I would have loved that for him to just been, because that is what I wanted straight away is that skin to skin contact, I had it with all my babies, to not have, it was heartbreaking, I couldn't cope with it at all, it was really strange, it's not something I was used to and especially considering my last birth was at home and everything else then to have that experience, it was awful."

Fiona describes the difficulties she faced due to his condition:

"Um [p] in the afternoon of him being born, I was able to have another skin-to-skin contact with him (ok) which I hate to say was difficult with all the machinery and wires and everything on him. (ja) It was really awkward but I got my cuddle that was all that mattered."

Fiona was also aware of the impact her undertaking S2S had on the staff:

"It seemed that every time he moved, it would set all the machines off. So...I think the nurses got a bit annoyed!"

6.4.2 Labour & postnatal ward:

Linda had S2S care with her twins in the recovery room: "Gosh! They were in the

recovery room for a while, having skin to skin". Freya was given her baby straight after birth, despite him being four weeks early and she was able to initiate an early breastfeed.

"[.....] He did pretty much breast feed a little bit straight after, they put him on me skin to skin, they checked him over, he was absolutely fine, [...]."

Lisa awoke from her emergency GA confused and was unaware of what had occurred:

"...I kind of vaguely remember being wheeled into the ward. And a lovely midwife started talking to me and sort of welcomed me in there [...] And she slept on me skin on skin all night."

Kate was only able to experience S2S with her son five or six hours later, as he had been rushed off to the LNU:

"[...] because I had him, and then I didn't even see him for about half an hour, because he was taken straight over to the paediatricians in the corner of the theatre, um and then when he was brought over to me, he was all wrapped in a blanket, and was just held by my face for me to see him, and just sort of touch his hand and his face, so I didn't have skin to skin probably for about [p] 5 or 6 hours."

The women did not spontaneously discuss S2S care except for Gill, who was passionate and provided S2S care for her baby for large portions of the day. Women only discussed S2S when I raised it as a question following Gill's interview. Gill was already aware of the benefits and was encouraged to provide almost continuous S2S by a neonatal midwife. **[Midwifery guardianship]**

6.4.3 Hands-on care:

When discussing 'hands on' care, it is situated within the context of environment and is linked to the parent theme 'Staff'. The following section will discuss women caring for their babies on the LNU and on the PNW.

6.4.3.1 Neonatal unit:

Linda, whose twins were initially resident on the LNU took charge of her babies early on:

“[.....] From day 1 I did everything. When they were feeding him I asked them if I could rather feed them. I was changing their nappies ... I hadn’t bathed them yet.”

Marylyn was concerned about bonding and became involved as soon as possible:

“Hands on, I’ve been changing his nappies and cleaning his mouth and things like that. They know that I’ve wanted to do as much as I can do for him because I was really worried about bonding. [.....] today he’s moving in with me!”

Jane explained her involvement in terms of ‘duties’ and of ‘visiting’ her babies at feed times, as she had gone home after a number of days as her babies were resident on the LNU:

“[...] visiting them at feed times you know, for every feed when I could, obviously changing nappies the whole thing, those sort of duties really. It’s quite nice because you can be so much more hands on, because they are not wired up to anything you can care for them, sitting cuddling, holding them, things I won’t be able to spend much time doing when I get back to be realistic about it [...]”

I explored why Jane had been discharged before her babies:

“initially leaving them was very hard, and now because obviously I still can’t drive because of my C-section, it’s difficult from that point of view but because I’m happy they are being cared for, I trust the staff, I can communicate with them, I don’t find it such a upheaval I suppose, I come in and get on I mean I would love to be able to spend all day with them but I can’t because of our toddler.....”

[Gender issues – difficulties faced by women]

Jane’s quote highlights some of the difficulties faced by women when their baby/babies are on a neonatal unit. Jane occupied a side room on the PNW, she felt well but had to go home because her husband was returning to work and she had to take over the care of their elder daughter. Part of Jane’s dilemma was that she was not given any idea as to when she might be able to take her babies home, she

also felt she was taking up a room which she did not need. The following quote illustrates the complexity she experienced:

“my husband needed to get back to work we had family helping out with our daughter, but also partly because I'm taking up a room here, [...] and I didn't need to be here, medically wise you know I was fit enough to go home and so you know and because they can't give me ANY idea when we going to be able to, [.....]but my daughter still needs you know me you can't expect family to come down here for weeks on end.”

Mandy was breastfeeding and regularly caring for her daughter, however, although she appeared to be encouraged to 'handle' her baby and get her out of the incubator, there were times when she felt under pressure to do so:

“[.....] because I was up every 2 hours and going up to NICU with my breastmilk and they were like don't worry we can give her one formula in the night, she was very much kept on about that, always skin to skin sometimes I didn't want to always keep getting her out because it was nice and warm up there but it weren't nice to keep getting her out especially I didn't like when she had that splint in her arm it wasn't nice keep getting her out.” **[Lacks jurisdiction]**

I asked Mandy to clarify what she meant by “she very much kept on by that”:

“it depends which one it was who was up there, some of them were good yeah but there's a certain one that just kept on and on making sure yeah..... um I know she was doing it for a good reason but sometimes I just thought why can't we just leave it for today, leave it til later because sometimes I'll go up there and she'll want me to take her out before daddy was there, and I wanted to wait til he was there so we could both hold her instead of keep getting her in and out.”

A philosophy of FCC on neonatal units encourages parental involvement by encouraging physical and emotional contact with babies as soon as possible following birth, including hands-on care such as nappy changing and kangaroo care. Women in my study were afforded these opportunities as they were encouraged to provide care, changed nappies and mostly were able to nurture their babies through skin to skin care.

Despite an earlier quote where Mary accepted the reason why her baby was on the LNU, she remained unsure. When I queried whether Mary could have observed her baby's temperature and feeding regimes on the PNW, she felt she could, although her quote does not demonstrate confidence in her ability to do so:

"but at the end of the day I knew if anything happened to her although I probably would have coped, yeah I would have been like "UUURG, what's going on, why's this happening" whereas they're trained to deal with it and.....probably wouldn't have screamed and shouted, probably wanted to kill somebody if anything happened to her, (laughs) but like I said, once they had sat and explained it all to me and it's like I know she's in the best place and now she's making up for it." **[Confidence as a mother?]**

Mary's baby stayed on the neonatal unit for three days, partly because she had required treatment for jaundice. Mary was not involved when the decision to transfer her daughter to her care was taken.

Some women were provided with caveats when caring for their babies. For example, staff said to Nicola:

"You've got to be very careful, you can help take over if you want, they are your babies, you do whatever you want, but we want to be in there as well....Basically when you change a nappy or help us feed them, that's all their energy being burnt up basically. So I said OK. He said give them cuddles still but don't let them wake up too much as they've got to start putting weight on." **[Disintegrative power]**

Connie was the youngest woman in my study (21 years of age) and, as highlighted earlier was discharged home at her own request. During Phase One which took place a couple of days after her baby was born, she felt fully involved with her baby's care:

"I'm doing, I'm pretty much doing everything while I'm here, well me and my husband, not just me, but we're pretty much doing everything while we're here..... I've not really had to do a lot because obviously I've done as much as I can (ja) but with the feeds and stuff if I'm here, I will do them and if there are bum changes as well, if they need to be done I'll do them, but I've not really [p] thought about it, I've just got on and done it, that's about it really she doesn't really do anything else, she's not a crier so I haven't got to

constantly settle her and [p] make sure she's alright so." **[Integrative power]**

Interestingly, when we explored her involvement further during Phase Two, she revealed she felt excluded from decisions relating to going home:

"Decisions apart from the going home – everything else, I did. Because there weren't really a lot, to decide after like when she pulled the tube out, and I said, "Don't put it back in" – they sort of listened to me and they didn't put it back in, did they? And other than that, other than literally the going home bit, I still think I was sort of involved in the decisions. But there weren't a lot of decisions to make, was there, really?"

Connie also disclosed she felt she was being watched all the time:

"It just – there was a couple of them that I didn't really – that didn't faze me, but then there was some more that were like really, I felt really were watching me to see if I was doing it right, even though there's no wrong or right way to do it, it just felt like some of them were like, "Hmmm." **[Disintegrative power/healthcare professional domination]**

We explored how it made her feel:

"That did make me feel a bit rubbish. To be fair, the whole time we were there, I felt like I was being watched, anyway, like constantly." **[Healthcare professional domination]**

Although no one had directly implied Connie was doing something wrong, she intuitively picked up on it during interactions with some members of staff when she chose not to follow their care routines:

"I think they got a bit funny when – because the way they do it in there, they change the bum before they feed – and I don't really get the logic in that, to be fair, unless they've done like a big massive poo [...] say if she did a big massive poo while feeding, that's like two nappies in the space of ten minutes. And I'm not made of money. So I started, to feed her, then change her. And I think they got a bit funny with me about that, because I was doing it the other way to they do it, sort of thing – to how they was doing it, but, it's my daughter, I'll do what I want, sort of thing." **[Displays assertive power]**

Marylyn had a similar experience when she was 'told off' by one of the nurses whose language appeared to undermine Marylyn's ability to breastfeed. Marylyn was so affronted by the nurse's attitude she demanded a meeting with a doctor:

"[.....] and one of the nurses was like, "well, he's not doing it, let me just get him his top up", and I was so cross, and I just gave my baby to my partner, and he was like "what are you doing, what's going on?". I said "where's the doctor, where's the doctor?" She said "I'm here". "Can I speak to you please?" She said yes, and I went "I'm going to cry now" and that was it, I just burst into tears. She took me into the office and said "what's wrong?" And it all came out. She said I agree with you, although we're here to look after [baby] we need to make sure you're OK too. And I want to listen to you. If we can come up with a plan together, then that's exactly what we'll do. We sat and came up with a plan together, and so far it's worked."

[Disintegrative & integrative powers demonstrated]

I revisited this scenario during Phase Two and asked Marylyn who she thought held power in the neonatal unit, the nurses or the doctors. She believed nurses held the 'power' and this may be why she felt unable to challenge the nurse's attitude:

"Because the nurse who was caring for [baby] she, I had the same problem with her the whole time um [baby] was there, um [partner] picked up from the first, when he came in to visit us [p] and I said to him [p] "this is [nurse], [baby]'s nurse today" as soon as she walked away he said "you don't like her do you?" and I was like "nope I don't'."

I asked Marylyn to explain what she did not like about this nurse:

"Because [p] she was younger than me (Hmm), she had no children of her own and she was [p] I felt she was very critical "oh you can't do that!"

[Healthcare professional domination]

Marylyn was an experienced mother and did not appreciate being spoken down to:

"I've had 5 children AND I do know what I am doing and I just didn't like her attitude, the way she was to me. He's my son (ja) yes he's in NICU and he's been looked after but it's not for them to tell me what to do with my own son um and I just didn't like her attitude and that's why I couldn't speak with her, I tried speaking with her and she was like "no no no you can't do that" and I was like "I can and I will" and "I'll just go above you" which is what I did."

[Terrain & regaining jurisdiction]

The reflection which follows explores aspects of power and who holds it within LNUs.

In examining myself during interviews I wondered why I did not ask Marylyn whether she felt she had power in the situation she described. Again my professional stance was leading me and I was not seeing the situation from Marylyn's perspective. As a previous professional on a neonatal unit I was well aware of 'power issues' between nurses, doctor's, midwives and women. Although she perceived nurses held power, in order to change the situation she interacted with the doctor and received a positive outcome. She had harnessed an inner power but one which she did not articulate or acknowledge. From a feminist perspective her comments on the nurse being younger than her with no children was interesting. I did not challenge her perceptions of why age and being childless should matter. On reflection I wondered whether Marylyn, through her criticism, was displaying internalised misogyny and sexism towards the nurse? Being young and childless should not preclude demonstrating empathy towards another, which the nurse in this situation certainly lacked, or was Marylyn simply trying to understand or find an explanation as to why the younger woman (nurse) was behaving towards her (mother) as she was. The important factor was that the nurse appeared critical towards Marylyn which may well have been influenced by conscious or sub-conscious patriarchy.

Figure 6-11 Reflection on 'power'

Gill believed she was involved with care decisions: "yeah I think... because they got me up there whenever she cried, which was good", however, I gently probed to understand whether she was involved with more than just being called by the nurses when care needed to be undertaken, such as, was she involved in decisions about what happened next: "I don't know really (laughter) maybe not, I guess you just leave it to them really don't you?" Gill did not think she had a say in the bigger decisions surrounding her baby:

"[...] [...]...you don't think you've got a say [...] I've just done what they said, best thing to do really."

She appeared afraid to ask questions:

"[...] I don't know, I think you're scared to ask too many questions, because you are worried what the answers are going to be, [...] a bit like the whole stay, [...] you want to take each day as it comes because if you've asked too many questions you might get an answer you don't like, maybe I guess. Maybe that's just me."

As revealed earlier, Gill was worried about leaving her baby behind. She did not want to be discharged home without her daughter and that may have prevented her from asking too many questions:

“yeah I think the biggest thing for me was the thinking I was going to have to leave my child, you know, and again, you don't ask the question because you know that it may not be the answer you like, and I'm sure there are a lot of moms who feel the same, [...] do some mums if they knew, if they could establish breastfeeding if they knew that would they be trying harder because it would mean staying with their child you know, or would that put pressure on them, I don't know um, but if they didn't know it in the first place, then I don't know.”

Of interest, Gill was eventually informed by a member of staff that breastfeeding dyads were never discharged separately, which provided her with some consolation. Her baby was suddenly brought back to postnatal:

“So the middle of the night they brought us down and said “we are going to bring her down to you”. At first I was like “Ohh bit scary” (laughter) but, [...] we can get breastfeeding established, so she was fine then and they had taken out the thing out of her nose and she was doing really well.” **[No involvement in decision to return baby]**

Fiona unfortunately, was unaware breastfeeding dyads were not discharged separately. Being privy to this information would have influenced her decision on whether to go home. She was informed her baby would be discharged on his due date, which meant Fiona would be resident in hospital for over ten days. She was torn between staying with her son or going home to care for her eldest child, as her partner was about to start a new job. In hindsight she regretted her decision:

“[...] my only thing I would have changed, I wouldn't have gone home. They said if I'd stayed in then he would have been down with me, [p] down in the post natal ward.” [Phase Two] **[Gender issues]**

6.4.3.2 Postnatal ward:

Some women described 'being left' to care for their babies, although it was not always negatively perceived. Medina's baby was transferred to her care but with input from neonatal staff:

"I don't know 5 days or maybe 5/6 days I was left more on my own when I started feeding her myself obviously the nurse was coming to check everything but obviously knew then that nothing was wrong we were just staying there because of her weight, [...] but yes if I wanted something I was going straight to the nurse and asking whatever I wanted to ask for, go to NICU and ask them." **[Midwifery guardianship?]**

Valerie was happy to be able to just get on with her baby's care:

"[...] Last night was probably the first night they've left me, yes, really, because I was trying to thingy [...] [p] get him on before and things like that [...] they would come and say, "Oh he's due he's feed now", formula feed like because that was my first night, really. [...] So yes, last night was – was quite good, I was left – not left – but, you know – I mean, I was happy, and yes – we did it ourselves. [...]."

Although Freya and I spent a lot of our first interview talking about infant feeding issues (more within the Theme 'Feeding' 6.5), she was never separated from her baby and was doing all his care from early on. She felt well supported by postnatal staff, although felt "they were checking on her" a little too frequently:

"[.....] last night they didn't check so much on me. They were checking quite often on me if I need something, if I needed painkillers.....perhaps [...] in the beginning because I was obviously a bit sore from the birth. But they were checking on me very often. They were very, very nice ladies....." **[Midwifery guardianship]**

Kate had an interesting experience. Her vignette will reflect a number of issues that are connected with caring, such as feeding and going home. Kate struggled with breastfeeding and was supported by staff, although at times support and advice was conflicting and even disempowering:

"[...] Oh, one night I got very upset because, there was a try on the breast first, and then the night staff came on and said "that was

wrong because I was tiring him out by doing that” [...] it’s just conflicting advice with every shift change really, and lots of different patterns [p] um depending on the midwives and what they thought the pattern should be for that day, or what the paediatricians thought the pattern should be for that day or night, yeah and someone did say to me “well we have to do that to find out what works best for him” I can kind of see, but same time it gets quite stressful (hmm) trying to remember what we are doing today.”
[Disintegrative power & terrain]

Because her baby appeared to tire easily when breastfeeding, staff suggested inserting a naso-gastric tube (NGT) so ‘top-up’s’ could be introduced. Kate did not want her baby to have a NGT but ultimately felt unable to resist, although paradoxically also wanted to be ‘led’ in some regards when considering what to do next:

“.....think because I tried to say no about the tube, and, in the end I felt a bit railroaded into it, [...] part of you thinks these are professional people they know what they are talking about, I should go with their advice, so you want to take their advice but then when you get 4 or 5 days in and you realise everyone’s got a different opinion even amongst the professionals, you think, maybe I should have said something, but I’ve never had a child before, and I don’t know what they need, so it’s very difficult.”

When our first interview took place, Kate was on the verge of being sent home:

“Um, I think looking back, more information upfront, would have been so much better, even if it was bad information, there are these risks um [p] but for me the fact that he came back from NICU within an hour, right on that first day and said to me “my baby’s absolutely fine and we’ve just got to wait because I’ve had a caesarean, and I’ve got to get over that, and then you will be going home”, I really would have loved somebody at that point to have sat down and said “he is a preterm baby, although he was close, he’s still preterm and there are these possibilities”, I know every baby’s different and they can’t tell you everything, but it would have been nice to have that, “we need to see how he does and you might be here for a little while”, um I think that would have set my expectations right at the start, I think that was the thing looking back that I really wished I’d had, um the staff changing is annoying with all their different opinions, but I accept that everyone has a different opinion, but its I suppose piecing together all those differences of opinions what made me realise, he has a problem, certainly rather than someone right at the

start “saying he's preterm, he could have X Y and Z”, or you could be here sometime.”[**Information needs**]

Part of caring was based on women understanding the overall situation in regards to their baby/babies’ wellbeing. I developed a theme called ‘No one really explained’ which encompassed a number of lower levels which centred on ‘asking questions’, ‘should have asked more questions’, and ‘I’m sat there wanting to know more’. These themes are briefly explained here. Kate’s quote above provides an illustration of how information would have helped her to understand her baby’s situation. However, on asking for more information she was not provided with satisfactory answers:

“I think I possibly did say this to one midwife later on in my stay, and I think I got the response that “well there’s so many things that could be wrong that we can’t possibly tell you” but that’s bit of a cop out really to me you know, I’m sure there must be a set number of things that come up quite often, I don’t expect them to tell me to the nth degree every little thing, there must be these things, breathing feeding sleeping whatever, that come up quite often with premature babies that they could just forewarn about which I would have liked.”

Caring for babies was encouraged but only under the supervision of ‘benevolent’ staff.

6.5 FEEDING

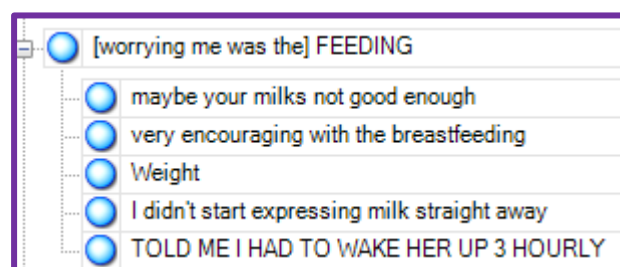


Figure 6-12: Thematic area: [worrying me was the] FEEDING and its lower level themes

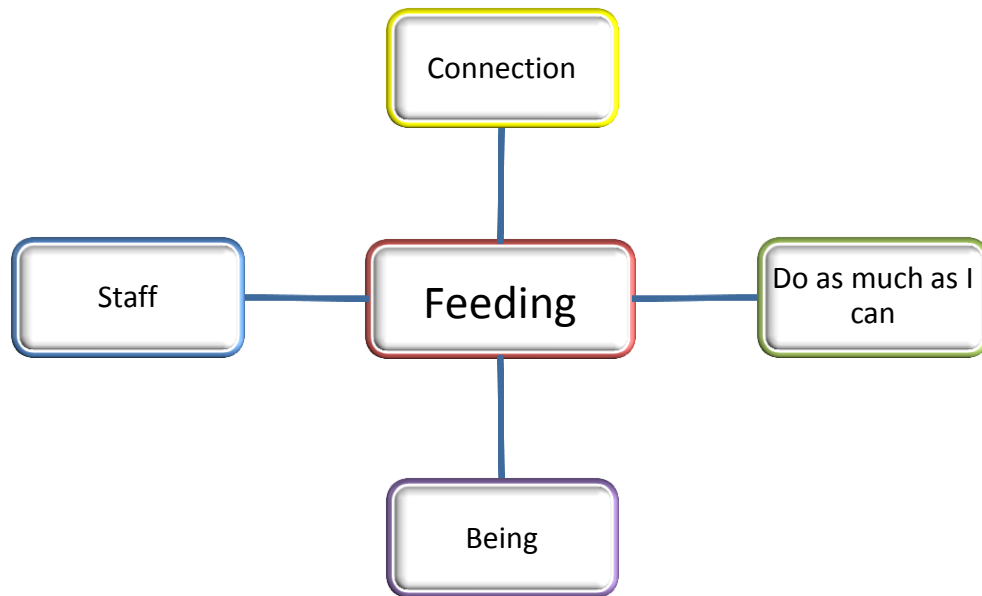


Figure 6-13: Illustration depicting the theme FEEDING and its links to other major thematic areas

Women's infant feeding choices greatly impacted on their experience of caring. The following section will explore the higher level theme Feeding and its lower levels, which includes 'expressing their breasts' and support from staff for women's feeding choices. The overall lower level theme which impacted on feeding was whether the baby gained or lost weight. Therefore quotes relating to weight will be discussed in conjunction with feeding. The theme Feeding, links with Connection, Do as much as I can, Being and Staff. All of these major themes were impacted on by the woman's infant feeding choices.

Women were encouraged to feed their baby in whatever setting they were in. Most of the women wished to breastfeed, with the exception of Connie and Nicola who formula fed their baby/babies. Marylyn was the only woman who was encouraged to express her breasts antenatally. Many women's babies were supplemented with formula, including those who were breastfeeding. In some situations formula was used to add volume to a breastfeed to encourage weight gain. Many of the babies experienced difficulties with feeding.

6.5.1 Neonatal unit:

Gill, an experienced breastfeeding mother, was aware her preterm baby may have difficulties:

“Yeah because I breastfeed my other 2 girls, but then I know that small babies don't necessarily feed straight away either..... some babies that are small, and even I think friends have told me that they haven't necessarily got the sucking action so it can be harder if they are little because they [p], they haven't got that suction?” **[Has mothering knowledge from previous experience]**

She was initially separated from her baby and was unable to express her breasts immediately and regretted not doing so, to ensure a good supply of stored breastmilk to avoid formula supplementation. She blames herself and not the situation she finds herself in:

“now when my milk came in I really wished because, she needed to go on top ups at some point but I didn't have enough, because I wasn't very good at expressing, I didn't.....and then you panic because you can't.... you know you need to express (ja) and um they needed to give her a bit of formula, (ok) now, to a breastfeeding mum who's got a baby who is new, putting a baby on formula can really, I think, distress you, (hmm) and so I REALLY WISH I had, even though she was fine and there was nothing wrong with her at the time, I wish when my milk had come in (hmm) because you have a lot (hmm) I had expressed then.”

Separation further impacted on Gill's reduced breastmilk expression:

“No she had the lights (overhead) yeah [...] and so I think my milk went down a little bit then, because we were apart from each other, and quite stressful because you realise you're not going home as soon as you think because she's got jaundice.” **[Terrain & disintegrative power]**

Gill solved her breastfeeding problems by continually providing her baby with twenty-four seven S2S care. Her following quote is particularly poignant as it affirms her belief in the wonders of her breastmilk:

“just I think is the best advice anyone could give anyone, if they can do it, do it, and it made my milk come in strong, it made my milk really, really good, it made her put on weight then because she had good milk, yeah.” **[Integrative power + positive mothering]**

Mary was unable to put her baby to the breast at birth despite asking for help, and began to express her breasts as soon as possible:

“[...] I couldn’t breastfeed her because there was nothing coming through to start with, but I had problems with my son, I couldn’t breastfeed him either, so I was trying to express milk and taking it up in a syringe to them, and they were feeding her with a cup (oh ok) because initially I was going to bottle feed her and then because things started to happen I went “no we’ll give this breastfeeding a go” and all I can say is good job they aren’t born with teeth because that hurt.”

Part of successful breastfeeding is correct positioning and attachment which Mary found difficult:

“She tried, but we couldn’t get her to position right, I couldn’t get her to position right, I think it was because of having the C-section I was still a bit sore, and just having her rest on me was hurting at the time, so I was expressing and they were giving it to her in a cup, and then, my milk just stopped coming in [.....].”

An operative birth is known to delay the onset of lactation.

Many babies were jaundiced, which is a common ‘condition’ in Term and preterm babies. Whilst Term babies do not always need treatment, preterm babies sometimes require phototherapy to clear excess bilirubin. Two babies in my study required treatment for jaundice which was provided on the LNU and was problematic for their mothers. It impacted on Mary, as her ability to successfully breastfeed was impaired because staff did not want her baby off phototherapy for long stretches at a time: “[.....] she wasn’t able to come out because she takes at least 25 minutes to feed, so they wouldn’t take her out for that long” resulting in Mary switching to formula. Despite wanting to breastfeed, the needs of Mary’s baby came before hers. However, her baby did not take easily to bottle feeding and had to be supplemented with NGT top-ups for a period of time:

“[...] she was feeding all day off the bottle, and then last night it was just like at half past three this morning she just went “HUH you’ve got no hope” and just would not wake up no matter what, I stripped her off she was just laid on the bed in her nappy and she just (SIGHS) and refused to open her mouth, her eyes or anything, “oh you little toad we can be going home today but no” [...] but hopefully because

she's only had that one, they might say "right if we take the tube out and try after 24 hours without the tube and then we can go home."

Although Mary was eager to go home, she was not overly keen to 'push' her daughter's feeding regime more than she had to. Her baby had to be completing all bottles without NGT top-ups, and Mary was aware of the consequences of 'forced' feeding:

"She has to take that 35 (MLs) no matter what, if after that she's still hungry then I might turn round and say "right can I give her a bit more" because she is wanting more, but I don't want to feed her too much that she's sick and puts herself back..... She's not been sick yet but I don't want to force her to have more milk, for her then to be sick, for them to turn round and say, "no she's gone back now, we have to stay longer." **[Integrative power]**

Nicola was suddenly informed her babies were coming down to the PNW. They were being fed by NGT and the occasional bottle:

"And then [...] about ten o'clock I think it was the next day, they wheeled everything in here and they said 'we're going to bring the twins down with you'. So I said 'OK', [...] he said 'they've got a tube as we don't know how their suction is going to be whether they can take a bottle or not, so we are going to feed them by tube.' **[Integrative power]**

Nicola now 'took over' managing her twins feeding:

"She kept throwing up, and two days they were trying that, and they said we could start to try bottle feeding her. So I bottle fed her the once and I realised her suction was alright, [...] So I started taking over the bottle and I think it was [...] Thursday, [...] I started to give it to them twice ... two bottles and then it progressed from there, and they've been on bottles, and I haven't let them go back on the drip." **[Integrative power]**

Marylyn was concerned about breastfeeding as she had not successfully breastfed her three daughters, but her first born son had breastfed until his death at 12 weeks. Once her current son had stabilised, she became focused on establishing breastfeeding:

“Because it wasn't started straight away - I know that it's really important to latch the baby on, more or less straight after them being born [...] and I was just worried that where he hadn't done it he wouldn't latch on [...] because that's what they say don't they, that you should do it straight away otherwise they don't.” [p]

His weight loss was a concern:

“[...] He's lost a bit of weight, I think they said it's 9.3%, so he's just on the line. If he loses anymore then we need to think again about what we're going to do. But at the minute I'm trying to establish breast feeding, I've been expressing like a cow for the last God knows how long! And making sure he gets all the colostrum and everything else.”
[Surveillance]

On the day of our interview, Marylyn's baby was transferred to her care. I enquired as to whether she knew when they might go home:

“They haven't said yet. [...] He got weighed yesterday, his feeds have only gone up really in the last 48 hours. But he went from being tube fed every hour and I spoke to the doctors because I wasn't happy with it. He wasn't going to my breast, I said he's not going to as he's constantly full; he's got a full tummy. I said, 'I know it sounds horrible, but not to give him anything for a couple of hours so that he's hungry, and then he will'. They listened to me and that's what happened, he did go to me. And bit by bit he's got rid of the glucose drip that he's on, is it glucose?” **[Surveillance]**

Marylyn was experienced in breastfeeding Term babies and instinctively knew her preterm baby was being overfed. She felt able to articulate to staff that she wanted his top-ups reduced, which would in turn, stimulate him to wake up and breastfeed without the need for further supplementation. However, discontinuing top-ups were dependant on several factors:

“It all goes on this weight tomorrow really because they were testing his blood sugars as well. Yesterday they needed to test his salt and his blood sugars to make sure he was getting enough from me, because obviously we can't work out how much he's getting from me, and they worked out he needs 50mls every three hours. And they said his sugars and salt levels will show whether he's getting enough, and his blood sugars were just brilliant. He had to have three done over three feeds, and each one just got higher. And they

were like, yes, that's absolutely fine. So it all depends really on his weight tomorrow." **[Surveillance]**

Although Marylyn was doing a brilliant job, she was "a bit hard on myself, I'm always being told off for it". I explored further:

"I feel quite guilty because I know if I hadn't been unwell he wouldn't have been born early. So I feel everything he's been through in the last six days is my fault, had I been better he would still be in my tummy where he should be. So I've got a lot of guilt going on [...] I think one of the mums over there, I think she's got twins and they were born at 29 weeks I think and, from what I heard she had pre-eclampsia, and I'm sure she feels that way. The twins have had all kinds of operations and blood transfusions, and all sorts from the sound of it, and I just think you feel awful because you know you're meant to grow your baby for forty weeks, not anything less than that!" **[Perceptions of mothering]**

Marylyn blames herself for her son's early birth even though she was extremely unwell herself.

Jane struggled to express enough milk to breastfeed both her twins:

"...[...] it's taken awhile for my milk to kick in and still I've probably got enough milk to feed one but not both, so this time round they are having a combination of formula and my breast milk [...], some is better than nothing and also you know I thought maybe preterm babies it's hard for them to get a hang of things anyway so I thought rather than try confuse them with bottle and breast [...] because initially they were tube feed [...] let's just stick with the bottle, we are still here, still struggling to get the hang of that, [...]"

Linda's intentions were to breastfeed her twins, and initially provided expressed breastmilk, but soon realised breastfeeding twins would not be sustainable as her husband was in the military, and if posted away she would have been unable to cope, therefore opted to formula feed.

6.5.2 Postnatal ward:

Successful breastfeeding was due on the whole to the support women received, which to quote Kate, was "hit and miss." Breastfeeding experiences appeared muddled and Freya's vignette provides us with a snapshot of how breastfeeding proceeded for many of the women and their babies:

“On Tuesday we wanted to try feeding like more, so I had to give him breast, because he wasn’t feeding much on breast, we had to give him a syringe. I’m sure it was Wednesday, I could feel he wasn’t feeding very well from breast, but he was taking from syringe which was good.” **[Surveillance]**

The following day her baby had lost “less than 20g” in weight, and Freya was advised she would need to stay in for a further two days and exclusively breastfeed, after which weight would be re-assessed. She persevered, feeding him between two and three hourly, but in her view he was still not breastfeeding well:

“I have a lot of milk, it keeps dripping on him, I think his mouth is a bit too small, maybe he’s a bit too little to catch on the nipple, so bless him, he was a bit struggling today. Then I had to wake him up all the time. But when I put my whole finger inside his mouth he is sucking it so well, but not my breast. So I was thinking in the morning he won’t be gaining weight.” **[Surveillance]**

Freya is fully aware his weight gain will be inadequate:

“After that test (weighing) I just said to my midwife, the one who is looking after me, I don’t think he’s breast feeding properly. My breast was absolutely huge, full with milk, really hard. I said there is so much milk, it is dribbling out of me, I have to use breast pads all the time, so he’s not getting milk. So she said you are right, she tried him on my breast a few times, and he’s getting a little bit, but he’s getting really tired and he can’t get onto the nipple. So she said you can try another day to see what’s going on or you can try something else if you want.” **[Surveillance]**

It was subsequently discovered Freya’s son had a tongue that was 80% tied (ankyloglossia). With her consent it was divided, but unfortunately breastfeeding did not improve. At this point she is keen to try an alternative approach:

“[...] I don’t want to try only on the breast, it’s not happening. So she asked me what I want to do, and I said I want to express my milk because I have a lot, and give him with a bottle. For example she said that’s one of the best options you can do. So we express for 2 meals, he should be taking for his weight, every 3 hours he should be taking 47 mls they calculated. So on the first bottle we gave him he did quite well, he did 35, just above 35, 37 maybe. And the midwife said that was quite good, and I said that never happened my breast was definitely not the same as before, they were soft and there was no dripping, my pads were absolutely dry. And on the second breast

feed just an hour and a half an hour ago he had 45 mls.”

[Surveillance & midwifery guardianship]

This strategy worked and Freya was advised to keep giving her baby bottles until he was strong enough to breastfeed. Freya seemed happy: “Yes, I think its good advice, otherwise he won’t feed. And if he won’t feed he won’t gain weight and he’ll have to come back”. Her baby’s weight gain became Freya’s main goal:

“I really want him to breast feed and I will try my best with breast feeding. I just want to make him stronger for a couple of days so he can have a proper feed and he can gain some weight tomorrow. That’s the most important for me at the moment, even if he has to be on the bottle for a while, I just want him to gain some weigh.”

During Phase Two I asked Freya how long it was before she went home. She had abandoned breastfeeding and resorted to formula which resulted in an improved weight gain and a discharge shortly thereafter. Attempts to breastfeed at home were unsuccessful and her milk supply soon dried up. Freya originally came from a country in Europe where women routinely breastfeed. She seemed disappointed:

“yeah I really wanted to (breastfeed) at least until he was 6 months old or something because I know it’s good for him and easier I suppose. Bottle is a bit different.”

Kate’s experience was similar to Freya’s and she found the different strategies utilised by staff as ‘emotionally draining’:

“rather stressful so far some days have been good, some days have been bad. There’s been days where I have just been in tears the whole time (ok) he’s had problems feeding, that was his main problem (ok) so he wouldn’t latch on to start off with, he would get tired, really, really quickly um so he wasn’t taking enough milk um so they suggested putting a tube down his nose, so he had a tube for a while (ok) um which I found very distressing, um so, yeah it’s been, I suppose quite emotional (ja) quite stressful at times, then there’s been good times when he does take a feed and you think you are finally getting somewhere, they are really happy moments, but overall I’d say it’s been stressful emotionally.” **[Surveillance, terrain]**

A previous quote by Kate highlighted conflicting advice when trying to breastfeed her LPB. When a NGT was suggested to support feeding, Kate and her husband, although seeking advice and support, believed NGTs were an intervention and tried

their hardest to resist:

“.....at that stage I still hadn’t got my head around the fact that he had a problem with his feeding and needed this, so um you know we were still piercing all that together, they kept on about it, said it was totally our decision but every time they came to help with a feed, it was kind of “what about the tube”, “what about the tube” um so we resisted for about a day and a half um I think at that stage emotion got the better of us we were both tired both, you know both getting quite emotional now, and he had one really bad feed and we kind of caved and said “ok have the tube!” **[Disintegrative power]**

Interestingly, an alternative perspective was offered by a member of staff on night duty:

“.....they had a totally different attitude, and that was the first time I felt anyone had actually sat down with me and listened to everything I was saying. There was one really good midwife that night, she sat and listened and she said “she didn’t think he needed the tube either so we wouldn’t do the tube that night” and we carried on doing the finger syringe feeding when he wouldn’t take from the breast, um [p] and it went really well that night, and then the shift changed the following morning, and then they decided that maybe he should feed from a cup [p] instead, because I think that day um the amount he needed went up something like 33-34 mls, so it was even more um that was when he had this bad feed he couldn’t take that amount (ja) with this little cup, and um that was the point when we said ‘the tube’.” **[Midwifery guardianship and surveillance]**

Following insertion of the NGT, Kate felt her baby had become “lazier” as prior he would “at least try on the breast.” Feeding advice in Kate’s view was conflicting and confusing:

“Um oh so much (laughs) um we kept having different strategies for feeding him, so it would change at almost every shift what we were going to do, and then in with that as well the paediatrician started coming down to see him, and they would have an idea as well about “we should do this, we should do that!”

There was further difficulty in understanding suggested feeding regimes:

“yesterday I think it was me and my husband commented that we had seen both midwives and paediatricians who talked about the cycle of breastfeeding and bottle feeding with expressed milk, and neither of us was sure as to what conclusion we had come to, and neither of us are stupid (laughs) you know, but by the time everyone

had gone we thought “not actually sure you know, is it 2 breastfeeds and then a bottle, or is it one breastfeed and a bottle? Not sure?”

We re-explored her breastfeeding journey during Phase Two, and despite conflicting advice, Kate was still breastfeeding many weeks later. Kate was an interesting woman because firstly, she revealed she was not maternal and became pregnant to please her partner and secondly, she was adamant she was not going to breastfeed. Kate admitted she was one of those women who looked down on other women breastfeeding in public. However, soon after her son was born and before any S2S contact occurred, she decided to breastfeed:

“....and I was absolutely devastated when they wanted to give him formula to start with, I know it was necessary to get enough into him, but all my hard work and they’re giving him formula anyway.”

Staff would not have been aware of Kate’s views of becoming a ‘mother and choosing to breastfeed’. Had they been, it might have made a difference in the subsequent management of feeding strategies.

Kate was also extremely proud she was still fully breastfeeding:

“.....but um yeah, it’s funny because a lot of the ladies in my NCT group who were going to breastfeed before they had them, absolutely going to breastfeed, although they are all doing it, they’ve introduced formula apart from me, whereas I wasn’t going to do it and now I’m totally breastfeeding and no formula.” (laughter)
[Integrative power]

Valerie’s baby had also struggled to breastfeed, despite having his ankyloglossia ‘divided’ shortly after birth. He initially experienced hypoglycaemia and was supplemented with formula, but was often sick following a feed. His hypoglycaemia quickly stabilised, at which point Valerie’s milk production increased but he would not attach to her breast. She thought he might find it easier now that her lactation had improved, “but no, he’s just too lazy and sleepy”. She was encouraged to try the syringe feeding method; however she did not like using the syringe. She suddenly had an epiphany, “I’ll just – I’ve got bottles, I can express and just bottle feed him”. At this point it dawned on her, “he was still getting the breastmilk, I

don't care where it's coming from." That realisation made her "feel a lot better again." **[Integrative power]**

However, he was still not completing his bottles, and was taking about 10 to 15 mls which meant that although "he was *happy* with that" [...] "they intervened and put the little tube down." At this point he was fed three hourly, and depending which member of staff was on, they either used the NGT to top his feeds up or not. Valerie was not happy with his feeding regime:

"but sometimes, depending on who was on, I don't know if I should say it or not really, but they didn't often use the tube, because they were like, "He's happy, he's content." It was kind of going against their views, and we found it really hard as well, because they were forcing it down, you could see, he went rigid when they did that, and I just thought, he's uncomfy, it's not – he's obviously taken what he wants – (Yes) at the minute I thought, I don't mind demand feeding just to get him up, because obviously his tummy's only tiny, so, that was horrible." **[Terrain, surveillance & disintegrative power]**

She found staff rigidity to 'topping up' his feeds difficult to understand, as some staff would not bother, and others were more vigilant. Valerie would have preferred a more flexible approach as she felt she knew her baby and his tolerance, but her concerns were not acknowledged as staff appeared to be 'following guidelines'. Valerie eventually discovered milk volumes for her baby had been incorrectly calculated, as an experienced neonatal midwife realised the volume he had to consume "seemed an awful lot", a fact that Valerie had instinctively recognised herself. His feed volumes were re-calculated, and following a suitable weight gain, Valerie and her baby were discharged home with feeding instructions: "every four hours, well, it was every three hours they still wanted us to feed him. So every three hours we were setting an alarm because he wasn't waking for it." The focus on weight loss/gain scared Valerie:

"the whole weight issue – because that really got me down, that was in my head constant, and if he didn't finish a bottle I was like, "[name removed], he's not finished", and, "Oh, they're going to take him back in hospital", and that – I think it was just scared really, isn't it, because obviously he was so thingy and there was – not the threat of hospital, but, you know, he might have been going back, it was like, we didn't want that." **[Surveillance]**

Most women were sent home with infant feeding regimes. Gill for instance, was told to wake her breastfeeding baby up three hourly **[Terrain]**. After persevering for eight weeks she made the decision to put her baby onto demand. **[Integrative power]** The HV agreed but warned Gill if weight gain became static, or her baby lost weight, they (meaning HV) would have to reconsider demand feeding. **[Surveillance]**

Mandy would breastfeed her baby on each breast and if her baby was not satisfied she would 'top her up' with formula. On enquiring if her HV was supportive:

"she's fine with that. She said if you're happy to do that that's fine obviously not to get too upset because she's not always breastfeeding because I had so much pressure with [son] to breastfeed and then I couldn't and then I broke down after a few days because he wasn't gaining weight because of all the pressure and this time I haven't let myself be pressurised into doing it, I wanted to do it and if she didn't then I wasn't going to be upset about it so." **[Terrain – sanctum, integrative power]**

Eventually all women relaxed feeding regimes, be that breast or formula, and fed babies on demand. Weight gains were regularly monitored by the HV. Two of the women (Mary and Jane) were concerned with their baby's lack of weight gain postnatally and eventually, after much toing and froing to community/hospital doctors, received a diagnosis of lactose intolerance and their babies were prescribed lactose free formula. Both women struggled to get their concerns acted on with Jane resorting to sending her husband to see the GP.

Medina and Fiona, both experienced breastfeeding mothers, were sent home with nipple shields to support breastfeeding. After a period of time both discontinued using these devices.

A number of babies who switched from breastfeeding to formula experienced severe constipation which motivated their mothers to try all manner of strategies. Linda tried cooled boiled water with sugar, massage, warm baths, Vaseline, orange

juice including changing formula, with no success. Lactulose was eventually prescribed to try and ease her twin's constipation. Similar strategies were utilised by Freya and Lisa, again with varying degrees of success. See diary extract below on sharing of 'constipation' experiences.

In the spirit of Oakely's philosophy I was able to provide information to one woman who was struggling with her baby's constipation. After she had shared her story I was able to share that several other mums in my study were experiencing similar difficulties. She was relieved it was not just her baby and that it was not "unusual then." Like the other mums she had tried a vast array of remedies even switching to soya milk which worked initially but constipation reoccurred. I do not believe women were warned that formula feeding causes constipation so they were surprised when it happened, leading them to seek advice from all and sundry including 'old wives remedies', a somewhat sexist remark!

Figure 6-14 Diary extract: Sharing with women

6.6 [They wouldn't tell me definitely I was] GOING HOME

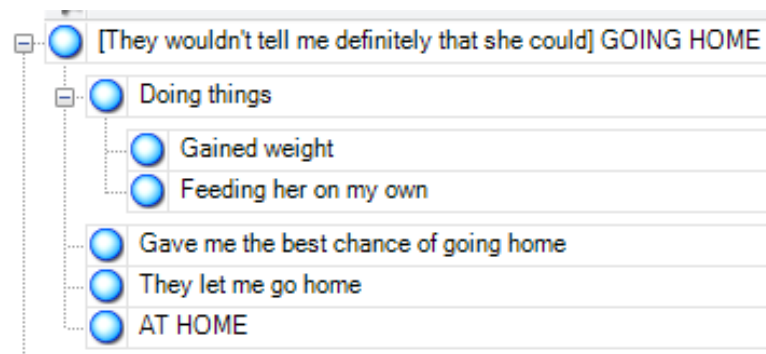


Figure 6-15: Thematic area: [They wouldn't tell me definitely that she could] GOING HOME and its lower level themes

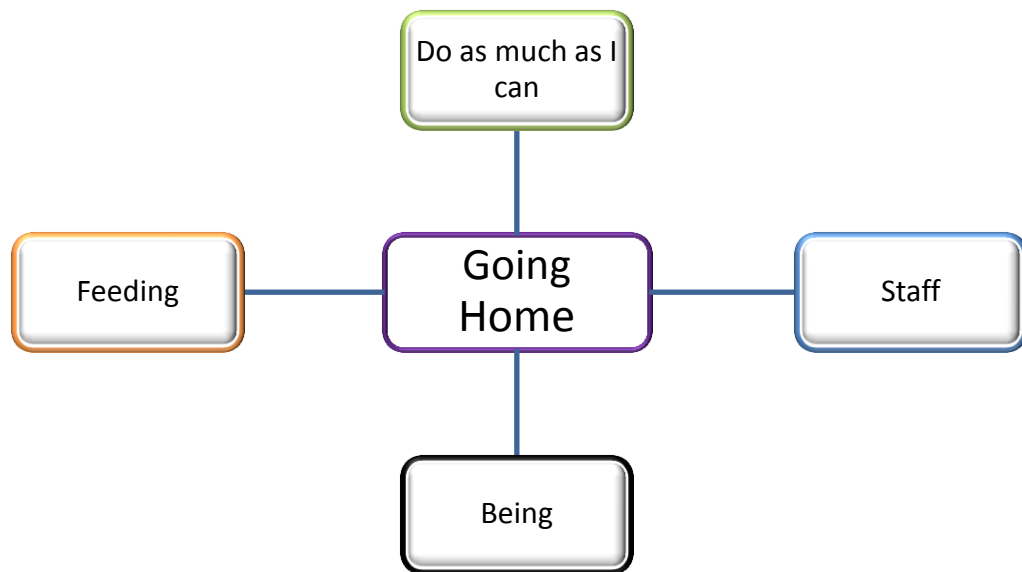


Figure 6-16: Illustration depicting the theme GOING HOME and its links to other major thematic areas

Women wanted to know when they could go home with their babies, and not knowing played a large part in their experience. Going home was dependant on a number of factors which I coded as ‘Doing things’, because women slowly realised that if their baby was achieving certain milestones or doing things, they could go home. As a theme ‘Going Home’ is linked to ‘Feeding’, ‘Staff’, ‘Doing as much as I can’ and ‘Being’.

It appeared when women asked for information on going home with their baby/babies, they were usually provided with answers that were non-specific and vague. An example provided below is similar to the responses received by other women in my study:

“..... I guess they don't tell you too much because, things could change [...] so yesterday she said “yeah you will probably be here for a few days” but in your mind you’re thinking, ok, is that, a few days? It all depends on her you see, which I can understand why they do that but you’re thinking is that Saturday, is it Sunday, is a few days?”(Gill) **[Disintegrative power]**

Fiona made tentative enquires as she would say, “How do you think she’s doing? What’d you think, you know, is a reasonable time scale for her to be coming home? And no one gave me sort of a straight answer” although she admitted she did not inform them that she wanted ‘to go home as soon as possible. She did not want to appear too eager, perhaps intended to portray herself as a good mother by putting the needs of her baby first.

Kate’s quote is informative as no member of staff volunteered information around discharge, although when asked, it was conflicting:

“No, it was about 2 or 3 days in, maybe 2 days in I did say something “when will I be oing home” because I didn’t want to seem too keen but yeah no one was kind of volunteering anything, and I asked a couple of people and got different stories, one person said “we say that you should be here until his due day” (oh right) and I’m thinking ‘good grief that’s the 8th of December that’s miles away’ so that, you know, that made me a bit upset and somebody else said “he would be here for a week” which is obviously very different, and I think somebody else said “you need to take it a day at a time and see what happens” um which was obviously more accurate um but yeah again it was one of those things where everyone had a different story.”[**Hesitant – lacks power**]

She downplays her need to go home by appearing “not too keen.”

When Connie requested a timeline, responses were vague:

“They just, [p] nothing specific, but they just like kept dropping it in the conversation like “oh she’ll be home soon and doing this soon and she’ll be home”. Today I sort of got a bit too intrigued and had to ask, so as long as she’s carrying on the way she is, like next week, the middle of next week she could be home by.”

I asked Connie what was required. She understood her baby had to be ‘doing things’ such as

“she just basically needs to gain a bit of weight, and as long as [.....] she doesn’t need the tube back up there, as long as she stays on the bottle feeds, she can, [p] come home.

In some instances staff were more explicit, by using standard practice which implies most preterm babies generally go home around their 'due date'. Knowing this information was not always reassuring, for example in Nicola's situation:

"I was "no!" And they told me that last Thursday, and I went a little bit downhill that night, and I was like, I really don't want to stay here for two weeks."

She felt her babies were well and did not understand why they could not go home sooner:

"To me they're doing brilliantly, and I know they'd be alright at home now as I know they're getting fed well, they're increasing their bottles each time, and they're taking it alright, they're not sick babies. That was just a one-off with this one." (Referring to girl twin).

[Integrative power]

Nicola lived in a small rural town ten miles away from the consultant led maternity unit and contemplated discharging herself and buying a car so she could travel back and forth, but realised it was not a feasible option.

A number of women only found out about discharge on the day, which did not always enable time for preparation, although for Medina, knowing at the last minute suited her because of her previous experience. Her first daughter had needed jaundice treatment at the last minute and that delayed their discharge:

"They told me on Saturday, the doctor came and said if she would get more weight, then probably because it was Easter Monday, [...] I was told that probably I would go home but I should be prepared to go home on Tuesday, so I like you know, I had mixed feelings, I said "fine, you know, whatever" one day won't make any difference, so, but they came on Monday you know, she put some weight, they said "you've been here you know so long just go home."

For others such as Freya, it was unsettling:

"So I was really upset in the morning, I have to be fair, I like cried and I wasn't happy about not going home and I was really concerned why he hadn't gained weight. I said to the midwife, and the midwife came later she said we are going to test him for they going to test him for jaundice to be on the safe side." **[Surveillance]**

Mary would not get her hopes up, because preparing for a certain day and it not happening would have made her cry:

“I would love to be home by Friday but I’ve got to think of what’s best for [daughter].” **[Baby’s needs before woman]**

Connie, although she was aware her baby had to be ‘doing things’ began to enquire: “Can we go home today?” “Can we go home today?” “Can we go home today?” She was then informed, “If you want to get home, you’ll get home quicker if you just stay.” So, I was like, “OK, I’ll just stay.” Although she was reluctant “no I didn’t want to” as she found it “just a bit boring to stay in for two days and two nights” and was not sure of its purpose:

“I was constantly wanting to do – wanted them to see me do the right thing, so I could just get – so I could get her home. So if that meant biting my tongue, saying nothing, that’s what I was doing, sort of thing”.

Although Connie was involved in caring for her baby almost immediately, the decision she felt most excluded from, was when her baby would be discharged home.

Fiona on the other hand, who had gone home without her baby, was pleased with the opportunity to stay overnight because it enabled her to fully establish breastfeeding.

It was a different scenario when women knew what was required and took matters into their own hands, for example Marylyn:

“because I knew what they wanted I knew that um [p], once he sort of gained weight once we stopped all the top ups completely (ja) and then he started to gain weight [...] they wanted him to be in hospital for at least 2 days with me breastfeeding before they would consider me being discharged with him (ja) and just to make sure that his weight gain was ok, so I knew what the plan was anyway.....and every day I was like " can we go home today – please?" (sing-song voice)(I laugh). They knew I wanted to be home for Easter because its [partner's] birthday on Easter Sunday (ok) and I said “I haven’t even got any Easter eggs for the children and I need to go home” so they let me go home.” **[Integrative power]**

Kate's baby suddenly turned a corner with his feeding and she changed strategy:

" [...] well I changed my goal posts because I didn't really realise what theirs were, as in the staff, I kind of assumed, I would have to breastfeeding properly to go home, because no one really said "what would let me go home" um so yeah I was trying to strive for that and then, again I don't know what made me realise, but I realised actually that wasn't the goal, if his weight was going up and he was feeding regularly by whatever form it was, as long as it wasn't obviously like tube or syringe, they would let me go home, so yeah that's the point when I thought right ok carry on with the nipple shield if it means we are going to go home." **[Integrative power]**

Now she knew what the 'goals' were Kate could plan for home but she did not know when and only found out serendipitously:

"[...] I only knew that today was an option, because last night I overheard on handover, behind the curtain someone said, "oh she can go home tomorrow" the other one said "yeah as long as the weight's gone up" and that was the first I knew that today was an option, just because I overheard it through the curtain (researcher laughs) so it would've been nice to have known." **[Integrative power]**

The women finally became aware of staff goals: their baby had to be gaining weight, feeding without the need for top-ups and/or breastfeeding successfully supported by weight gain. Unfortunately, for women like Freya, weight gain appeared to be the overriding goal, which impacted on her goal to breastfeed. Earlier quotes highlighted some of the difficulties she experienced, and although his weight was increasing by a few grams at each weigh in, it did not appear to be sufficient which, when she changed to formula, and a substantial weight gained was achieved (60 grams) they were both discharged.

Women were keenly aware of how much weight their breastfed babies had gained. Gill's quote emphasises her adoption of medical management of feeds including uncertainty:

"she had to be weighed this morning after being on the top ups, [...] she's gained 35 gramswhich is good because before she gained 15, so she's doubled her amount she's gained, [...] they

weighed her at 6 o/c this morning, because they know I want to go home so they said they going to give you the best chance, so that in the 24 hours we can, they can check her again tomorrow at 6, to see if she's um, either maintained I think, I think that's what they say, either maintained or gain. she started gaining weight, so were really pleased, not masses of weight, so they were happy so I could go home, [p] but they wouldn't tell me definitely that she could go home, wasn't until like the day I could definitely find out.”
[Surveillance]

Although Kate's breastfeeding baby had gained 50 grams, weight gain had to be 'approved' by the paediatricians before discharge could be authorised. Her quote describes her elation:

“yes I knew it had to be done before a feed, so they came with the scales and yeah he had gone up 50 grams - yah! (Brilliant) I felt over the moon so then they said they would go and speak to the paed and see what they said, and about 2 hours later they came and said “yes you can go!”

Women who breastfed had to prove breastfeeding was successful before 'being allowed' to go home, such as Kate above and indeed for Marylyn:

“[.....] he was doing really well his weight gain and [...]he had stopped having the top up, because that was the other thing they needed to make sure that his weight gained, with just me feeding him alone without the top ups so that was what they had to do, was wean him off having the top ups and then a couple for days of just me breastfeeding him and making sure he's gained weight [p] and that worked so....”

During Phase Two when women discussed the discharge process, words such as 'let me go home', 'we were released' and 'allowed to go home' were used. None of the women appeared to be fully active decision makers in the process.

6.7 STAFF

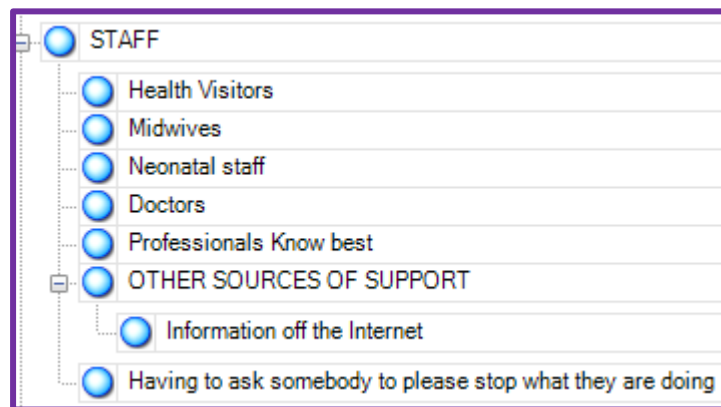


Figure 6-17: Thematic area: STAFF and its lower level themes

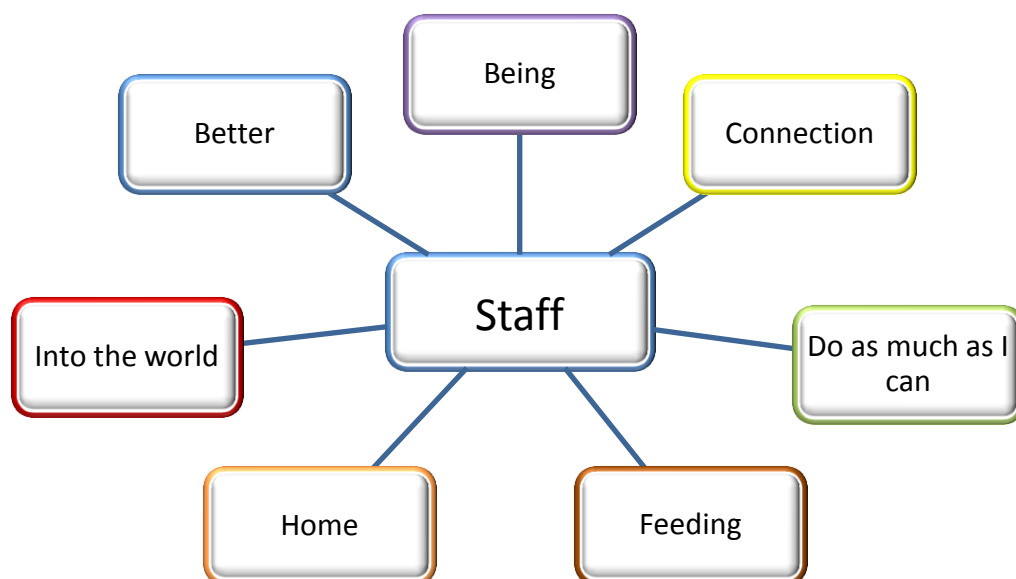


Figure 6-18: Illustration depicting the theme STAFF and its links to other major thematic areas

Earlier I highlighted how women's experiences were influenced by how staff cared for them which included the environment such as the neonatal unit or the PNW. The higher level theme Staff connects with all the major higher level themes as staff had an impact within each in relation to mothering and the following highlights how women perceived healthcare professionals overall.

6.7.1 Neonatal unit:

Those women who had babies on the neonatal unit were complementary, stating staff were “fantastic and supportive and have listened to what I want to do” (Linda). Medina, although she was based on the PNW, found the neonatal staff “very good”. Overall she was pleased with the care received from midwives as well. Fiona praised the neonatal staff for their considerate and kind approach towards her:

“because even when I went home without him, which was for a couple of days, they still said, “We’ll get you a sandwich or something and a drink. Just help yourself to whatever you want, go down to the postnatal ward and help yourself.”

Marylyn who had ‘clashed’ with one member of the neonatal team still found the rest of the staff “absolutely brilliant”. **[Professional guardianship]**

Although Gill was equally complementary, she felt some staff were more facilitative than others, and success with breastfeeding would just be dependent on that ‘extra special’ person:

“but I think that’s the thing with, when you come to hospital and have babies, all depends on if you have that one person that knows that, that gives you that bit extra help, or like with my [name removed], she was small and I had a wonderful midwife there that would come along and hand express, and I didn't mind, hand express it for me, get it into her, really determined to help me get her to breastfeeding, but if it wasn't for her, she hadn't been on maybe that day maybe I wouldn't have breastfeed, do you know what I mean?”
[Midwifery guardianship]

6.7.2 Postnatal:

Staff on the PNW received mixed praise. Some women felt very strongly about their (negative) interactions, whereas others were more positive. In addition, women’s views did not change between Phase One and Phase Two, with those who were positive remaining so, and those who were unhappy with their care had not changed their minds over time.

Gill and others were aware of how busy midwives appeared to be on the wards, and in some cases this 'busyness' determined whether they sought their help. Earlier in the theme 'Being' I gave an account which described Linda and Nicola's efforts to get themselves to the neonatal ward soon after their operative births. Both contributed similar reasons for walking so soon after an operation. Firstly was the overriding and understandable need to see their baby/babies, and secondly and quite significantly, a reluctance to bother staff. Linda was unwilling to interrupt staff activity so she could be wheeled to the neonatal unit, and Connie observed staff "running around for everybody" and preferred not to get in the way, so took herself and her "handbag catheter" to the unit.

Gill became quite emotional when discussing staff activity:

"all the NICU staff are just wonderful, [...] and all the postnatal. I think all midwives, [...] makes me feel very emotional talking about it, because I think you know they work such long hours and they give 100% and they are always happy, even though they are tired, [...] I think [p] just wonderful, and just the fact they keep happy all the time, and be positive, yeah [p]" **[Healthcare professional guardianship]**

Support was important to those women who breastfed, with Freya endorsing the help she received:

"Yes, I've had very good help. Every time I wasn't sure about how I feed my baby, I would ring the bell and they would come and show me different ways to sit, or with the pillow, or how to hold him, maybe under my armpit, and how to hold the head, how to hold my nipple on top of his lips so he can catch on the nipple and actually feed. They really helped me and really gave me quite a bit of advice." **[Midwifery guardianship]**

Medina was equally positive about the midwives indicating whenever she asked for help it was forthcoming, even to the point of placing her baby into the nursery for a period of time so she could have a good sleep.

Other interactions between staff and women were less positive. Earlier quotes by Marylyn demonstrated her negotiation with staff to gain entry to the LNU and her anger for the way she was treated. Marylyn and Linda were not inhibited when discussing interactions with midwifery staff. Linda, similarly to Marylyn, was especially angry about some of the midwives she met whilst on the PNW:

“Because they are rude and bossy and forceful.....I understand they are midwives but I am their mom and there a line that they tend to cross and I don’t like that [..]. The staff on NICU are more sympathetic, more understanding, a lot more friendlier, a lot more supportive than the midwives down here [...] They are like matrons I’ve had huge problems with midwives here, huge problems, they’ve got absolutely no bedside manners at all, um the majority of them it’s just a job, and as far as I am concerned being a midwife you cannot afford to think of it of a job it has to be a passion, it has to be within you, you have to enjoy it.” **[Midwifery domination]**

I explored whether Linda could provide examples where she felt she had been treated without due consideration and she shared the following which had occurred antenatally:

“And I was told “no that’s normal” “well it’s not normal for me” “yes but that’s normal you carrying twins” ok but “how normal is normal for carrying twins if my BP is normally, for me, low”? My temperature, for me personally, is 35. So when you take my temperature and its 37 that’s not normal so don’t tell me that’s normal because I’m carrying twins stuff like that, there was just noted down “....ok” blood in my urine “that’s normal”, they would write it down. Well this could be the reason why, if it’s not better by such and such a time, then this is what it could be. That was not explained to me, [.....] I know little bit more than the average Joe Soap walking on the street when it comes to, how to deal with things and how things are done, within a medical environment so I know they see a lot of people every day, I was just made to feel that I was just IN THE WAY.” **[Midwifery domination]**

During Phase Two Linda had not changed her mind. She would not be drawn into any further conversations about her experiences, despite her husband’s urging. At that point I could see she was not going to budge and therefore closed that aspect of the conversation down.

Although relationships improved when Marylyn was eventually moved to the PNW, she was still angry:

“It’s like I said to them, I can’t help it. I’m on labour ward and my baby is on NICU. What do you want me to do? I’m not going to NOT go and visit my baby just because you don’t want to open the door. Or feed my baby. I mean midwives are meant to tell you that “breast is best” and encourage it, not tut at you because it’s inconveniencing them to open the door for you at 3 o’clock in the morning. I mean I doubt that they’ve got much going on over there at 3 o’clock in the morning because all the mums have had their babies. This is labour ward, they had five women delivering the other night, and they still managed to let me in the door without giving me any kind of aggro over it, and still making sure I was OK when I came through the door. So it doesn’t take a lot.” **[Midwifery domination]**

During the first interview Marylyn had indicated she was going to write a letter of complaint to the postnatal manager. I followed this up during Phase Two:

“[.....] I will write that letter, and have to write it on my list of things to do, because I think, I think if they knew how they made me feel, [p] I think they would actually be quite shocked, that’s how they made me feel, [p] and, they wouldn’t do it to another mother in that situation because I’m sure, it will happen, it probably already has happened again, because it happens, these things happen, [p] um and they did make an already hard situation, harder it [p] really sort of did affect me [p].” **[Midwifery domination]**

Kate was fairly satisfied with her interactions with staff, although once again, like Gill, it was dependant on some staff going the ‘extra mile’:

“there were a couple of midwives who were very, very, good, who did take the trouble to sit down with me, um and it was more on the night shift I think, so I don’t know whether they are less busy maybe, um but certainly on a night shift there were a couple I remember, who took the time to sit down with me when I was having, you know, a crying session and they would try and help me through it, but in general, certainly in the day time that didn’t happen [...].” **[Midwifery domination]**

6.7.2.1 Doctors:

Interactions between women and doctors differed, depending on the situation the woman was experiencing. Valerie and Jane had less than satisfactory experiences with doctors who were managing their antenatal / early labour experiences, and will be expanded on more when discussing the theme 'Women's Health', although it is worth exploring Jane's experience in more depth at this point, as her in-hospital experience has correlations with GP interactions once she and her twins were back home. As previously reported, Jane had presented on the LW after feeling a sharp pain and reported a "twang" sound emanating from her abdomen. Jane experienced "intense pain, because obviously my abdomen filled up with" including severe pain across her shoulders. Jane was aware the pain was different, "I knew it was my ABDOMEN that was the problem". She described herself as having a high pain threshold and because she was not showing the intensity of her pain, she felt the doctors were not taking her concerns seriously:

"Not really no, I don't know, they were willing to send me off weren't they, down to [large referral hospital] because they didn't think there was anything wrong with me or anything particularly wrong with them, so um (laughs) not a great start. I don't know, because I've got a fairly high pain threshold, you just go into function mode, just deal with it, unless you make a big fuss about it, but just because you don't make a big fuss, doesn't mean there's nothing wrong."

Reflecting back on her experience she was happy overall except for her interaction with one of the doctors:

"Looked after me, I couldn't fault them, I couldn't really, yeah, apart from the doctor not listening, I told you, (laughs) anyway a ruptured uterus but um." **[Healthcare professional guardianship]**

Jane's twin daughters experienced a number of feeding problems during their hospital postnatal stay. Weight gain was initially an issue for both babies; however, whilst feeding became established for one of the twins, the other continued to experience problems. Jane was advised she could have taken one of her twins' home, but she did not want to separate them. **[No consideration of home situation - gender issues?]** The ongoing difficulties with one of the twins continued, however

despite Jane's misgivings, they were eventually sent home. The twin with problems continued to experience issues at home, since she failed to gain weight and had a continual "runny bum all the time". Jane suspected her baby had a milk intolerance and therefore asked the GP if lactose free milk could be prescribed:

"she was sceptical about the whole thing really, [...], oh she got us an appointment, she wouldn't obviously prescribe, but um she wasn't going to put her name on it, [who the GP?] yeah, so we took her to the hospital and the doctor there was like a bit "well I'll give it a bit more time and she's a healthy baby" but as a parent you think "why is my baby not gaining weight"? **[Not being listened to = 'neurotic mother']**

Following a hospital consultation she noticed blood in her baby's nappy so Jane returned to the children's outpatient department as she was aware blood in nappies could be a sign of intolerance, "no they just assessed her, I mean from their point of view, she was a totally healthy, blah blah blah". She went on to describe her baby as "skin and bones." Eventually Jane, at her wits end:

"after a bit of persuasion, [husband] took her back on the Sunday to see another female doctor, and she agreed that she would give it to us to try, and she has put a lot more weight on with it, she seems happier and it would have explained a lot in hospital, why she didn't want to feed, you know why she was refusing it, why she was just fussy, if it's causing a baby discomfort, they are not going to want to take it are they?"

I asked why she had felt the need to send her husband:

"Because I felt they weren't taking any notice of me and I was hitting my head against a brick wall (laughs) (and spoken very quickly). Sometimes as a wife, as a mother, you look like, I don't know, I think the GP impression "oh yeah you're trying to get free milk" (laughs) don't know and then the guy at the hospital, that's why I send my husband on the Sunday, 'you speak to them and deal with it', and you know the lady there was a lot more sympathetic about it and since we've been back for another appointment a month after,[.....] but she definitely seems a lot happier." **[Disintegrative power & gender issue?]**

Jane had to send her husband to achieve the outcome she knew was right for her baby.

6.7.2.2 Health Visitors (HV):

All the women and their babies following discharge were seen briefly by the community midwives who weighed babies and generally supported infant feeding. HVs were the next professionals to have regular contact. On the whole, all the women valued seeing their HV, with the exception of one or two. Women viewed the HV role as one of weighing babies and providing advice, which was welcomed by some, whilst others, like Lisa, took aspects of it “with a pinch of salt”. Gill found her HV supportive and encouraging: “she said [...] “you’re doing a wonderful job you really are doing a good job”. Previous experience of HV’s was not as positive:

“she’s very good she’s the best health visitor I’ve ever had actually because she’ll come round for an hour, to be with me and apparently she’s meant to be really busy as well, which I think is wonderful, so yeah, she’ll actually talk to me, not asking questions, but she’ll just ask me how my days gone and stuff, and then through that gets information I guess, so yeah she’s been really good.” **[Healthcare professional guardianship]**

Other HV’s came across as ‘too textbook’ and could have been less prescriptive and more individual in their advice:

“[...] the babies were going to become overweight, they were going to become obese. This was how much they should haveShe was very text book, whereas the textbook as far as I’m concerned is guidelines and every person is different and every child is different. My babies were not happy on first milk, they were happy on hungry baby milk, and there was nothing wrong with them when I gave them hungry baby. Boy twin had terrible colic and I gave him Infacol, and she raised her eyebrows because he was too young for it.” [Linda]

“I think the health visitors I’ve seen now are really quite good as well. I do think it’s probably [...] a lot of advice they give, a lot of it is very valuable and a lot I take with a pinch of salt. The weaning thing we had last week was just the longest list of do this, don’t do this, don’t do this, don’t give them that until they’re nine months, don’t give them that until they’re six months, and I was just sat there like, [p] I haven’t taken any of this in.” [Lisa]

As Lisa’s quote demonstrated, the HV appeared to offer too much advice and the best way forward in Lisa’s view, was to “work with what works for your baby, everyone’s different”. HV’s she felt, had to provide professional information which

meant they could not deviate from the expected pathway or provide an individualised approach:

“They’re just doing their job and they’ll often say off the record “we’d do this and that, but professionally this is the advice I have to give you”. And sometimes you’re like I don’t want to hear the professional advice, I want to hear real, realistic [p] so maybe some of the more traditional and older [p] advice seems to work as well as a lot of the newer stuff. But I also know they’ve got to cover themselves haven’t they, [p] they can’t possibly tell us to do something that they shouldn’t.”

Others defied HV advice, such as sleeping their babies on their backs. Linda’s twins were suffering from suspected colic and would only settle prone when put down to sleep:

“But the only thing that helped my babies sleep at night and stop crying was to put them on their tummies. The health visitor today told me off, and as far as I’m concerned if they’re happy they are happy.”

Freya’s baby also slept prone, although he was on a monitor because her partner’s son had died from SIDs. Staff from the Care of the Next Infant (CONI) scheme advised Freya to sleep her baby supine, however she was reluctant “because uh he don’t like sleeping on his back for some reason [p] and uh I just put him on one side most of the times he likes sleeping like on his stomach as well.”

Others were afraid of HV ‘censure’ so persevered with back sleeping. All the women were aware of the ‘Back to Sleep’ recommendations.

6.8 [Look this isn't getting any] BETTER:

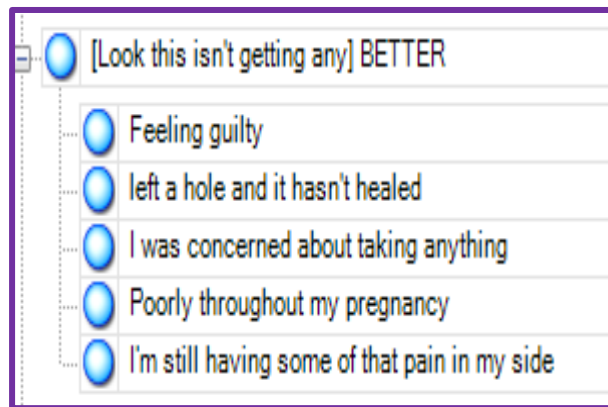


Figure 6-19: Thematic area: [Look this isn't getting any] BETTER and its lower level themes

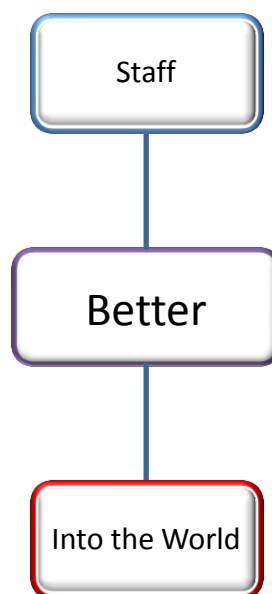


Figure 6-20: Illustration depicting the theme BETTER and its links to other major thematic areas

The higher level theme 'Look this isn't getting any better' was devised to illustrate health issues experienced by some of the women. It contains a number of lower level themes, such as 'Feeling guilty', which although it appears here as a lower level theme, it is not specifically reported on at this point as it had parallels with a number of other major themes such as 'Being' where it appeared to have a greater impact on women's overall experiences. The theme 'Better' links with 'Into the

World’ (not reported separately) and ‘Staff’. Staff had an impact on a woman’s experience in that it related to whether she was believed or not, in relation to her own physical health issues.

Marylyn, Jane, Mary, Linda, Valerie and Connie had health issues antenatally which necessitated obstetric intervention, resulting in a LPB. Jane was not unwell, rather her uterus had ruptured, which subsequently impacted on her (pain) and her unborn babies. Her caesarean wound took some time to heal. Gill experienced a number of problems related to breastfeeding. She suffered twice from mastitis, including thrush. With the second bout she developed flu like symptoms, but was unwilling to medicate because she was breastfeeding. After discussing it with her GP she reluctantly took Neurofen “only once” and resorted to alternative methods:

“[.....] just burnt myself in the shower just before each feed, just hot, hot, hot water in the area, and massaged very gently circular, I get the information off the internet, most of it.” (Phase Two)

Lisa had sore nipples for the majority of her breastfeeding experience and would pump off the side affected to relieve the pain.

Connie went home three hours post birth with “injections” and was advised to go to the PNW for her daily check-ups when she returned to the unit care for her daughter. She had experienced pre-eclampsia antenatally. On discussing her postnatal care Connie felt she hadn’t received much:

“I don’t suppose I really had much care and support, to be fair. They sort of messed up my postnatal all my – not appointments, [...]– I was supposed to go over there for a postnatal check –for the first ten days – and it got to like, the third or fourth day, and they were like, “Oh, you don’t have to come in anymore.” So, right, OK. And then like two days later, in the NICU unit, one of the nurses said, “Have you been to your postnatal yet?” I was like, “No.” “So are you not supposed to go?” And I was like, “No, they told me not to bother coming anymore.” She was like, “Really?” I was like, “Yes.” (Phase Two)

When Connie returned to the ward it appeared there had been a communication misunderstanding:

“So she rung over to the labour ward, no maternity one, they do postnatal – and said – and asked if I was supposed to go over there, and like, “Yes”. I was like, “Right, OK, well, they told me not to bother.” Went over there, and they were like, “Why haven’t you been coming?” The nurse – apparently the nurse had told them it was because I didn’t want to go. It’s like, “No, I didn’t say that, I was told not to bother coming anymore because I didn’t need to.” They were like, “You need to come for the first ten days, if you’re up here you might as well come.” It’s like, fair enough, I will, I – it didn’t bother me; it was like, over the corridor, so it didn’t bother me having to go.” (Phase Two)

Communication issues began following Connie’s request to go home:

“They just always seemed to be – that whole hospital just seems to beat around the bush, if you ask me. Like the – even on the labour ward – when I – apparently I self-discharged myself, but they didn’t tell me I was like self-discharging, they – they like said, “Yes, it’s fine if you go home.” (Phase Two)

Mary was discharged home with an open wound which she was not aware of until the dressing was removed:

“I didn’t even know there was a hole there, it was only because they took the dressing off to change it and it’s like “oh ok” so I come home with dressings and antibiotics.” (Phase Two)

Whilst at home the wound would not heal, although Mary felt well in herself and was not in any pain. She eventually made an appointment to see her GP who referred her back to the hospital. Swabs were taken and Mary was prescribed a repeat dose of antibiotics. By the time I visited her during Phase Two the wound had healed. She was perplexed as to why she had been sent home with an open wound:

“I didn’t understand why they let me out with it, because when I went back in, when the doctor sent me back in to have it swabbed again even the nurse on the ward turned around and said “why did they send you home with this?” and I said, “I don’t know I’m not a nurse, you are, you tell me.”

It was during this interview Mary revealed she had been “down” and “depressed” and had “cried a lot.” Fortunately her partner was aware of her mood changes and when she eventually “broke down” in front of the HV, support was put into place to help Mary through her postnatal depression. Please see Appendix 14 which is a reflection following my first interview with Mary.

Valerie’s experience of her health during the antenatal and postnatal periods is worth discussing in detail. For much of her pregnancy she had experienced pain in her side and repeatedly visited the GP and eventually was referred to the DAU at her local hospital. There Valerie was assessed by the relevant medical professionals but felt their main concern was for her baby:

“I think I felt every time I was there, obviously they checked the baby and he was fine, and that was it. So I do know where they’re coming from, because obviously yes they have got medical knowledge, but their main concern is the baby and not much else. So I just sometimes felt like, “Oh, the baby’s fine, there’s nothing else they’re going to do for me.” You felt like it doesn’t matter about you, as long as the – obviously it doesn’t, in a way, but as long as the baby’s fine, but then, obviously you go to the doctors and they’re like, “But you’re pregnant.” (Phase Two)

On return to her community Valerie felt the local knowledge of her GP was limited “they’re not up date with all pregnancy and babies and things, as such, if you know what I mean, like the conditions or whatever”, therefore the GP would phone DAU for further advice. Valerie knew there was nothing wrong with her baby or the pregnancy:

“[...] they were like, “Well, there’s not much else we can do for her. If she wants to come in, come in and get the baby checked”, and I was like – by this point I knew the baby – it was nothing to do with him, I was like, “The baby’s fine, I know that”, I said, “it’s not –” I said, I think from the beginning I knew it wasn’t the pregnancy, like the baby – after, obviously, being checked out for the first few times, I was like, I know it’s not the baby, I never thought it was, but they still don’t seem to notice.”

Valerie was unhappy at her treatment by one of the doctors, who appeared dismissive of her issues:

"[....]I don't think he believed me, either, and stuff, because I went in and he was just like, "Oh, just go home." (Phase Two)

When he realised Valerie had returned because her pain persisted but it was not labour related, he was unsympathetic:

"[....] he kind of walked in the door and kind of went [sighs] like that, as if to say, "You again", and I was like – like he said, "Oh, you", like that, type of thing, and I thought, "Yes, it's me back again because you never sorted me the first time."

She eventually went into spontaneous preterm labour. Whilst on the PNW, Valerie's husband was contacted by the GP who advised Valerie to pick up antibiotics from the community pharmacist. Postnatal staff had trouble finding the results of a urine test and Valerie was unhappy the GP was aware of the results before the hospital. On return to the community she was determined to find out what the issue was. She had a baby to think about and could not afford to be sick. In addition, her husband was in the Forces and she was often left on her own for weeks at a time. During Phase Two she continued to experience pain in her side. It had not resolved many weeks later.

6.9 JUST KEEP IT TOGETHER:

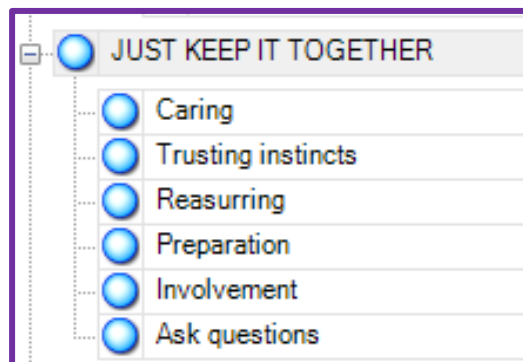


Figure 6-21: Thematic area: JUST KEEP IT TOGETHER and its lower level themes

See conceptual diagram: **Figure 6-1**

A parent theme called 'Just keep it together' was devised to incorporate women's advice for other women with a LPB. The following section will summarise three

broad themes that emerged from the women's advice which focused on 'caring', (which included 'reassuring other mums') 'trusting instinct', and 'involvement' (which included 'ask more questions'). For a full appreciation of their advice please see Appendix 21.

Firstly, advice around caring suggested that women should be led by their babies. If women desired, they should be aware that a strict routine would not be feasible and the day was to be broken down into small episodes of care that fitted around the baby's needs, such as 'little feed', 'short feed' repeat. Women were encouraged to remain calm and to enjoy their baby and not to become upset if caring activities, such as feeding, took longer. If women were becoming stressed then calling on family and friends would be helpful. There was no advice provided for women who did not have close family and friends to call on, however because late preterm babies take longer than term babies to establish feeding, a woman had to be patient and eventually her baby would get there. Panicking was not good for the baby as they would detect the mother's stress which in turn would stress them.

Some of the women urged women to rely on their 'maternal instinct and trust' to guide caring and defined these values as the 'strongest instinct in the world' which in their view, was only available to women who have had a child. The woman in particular who was quite vocal in offering advice based on trust and instinct was a strong assertive mother and interestingly, the same advice was not provided by other women whose discourses highlighted definite examples of using their 'instincts'.

Finally, women felt that other mothers should know that involvement with their late preterm baby was vital. A part of this involvement is seen as preparation, which would, in part, be facilitated by asking questions, including questions about any potential problems with their late preterm baby. It appeared from analysis of this data that the emphasis on asking more questions may have been influenced by women not being listened to when they experienced their own problems antenatally. It was also considered important for women to be involved with the practicalities of their baby's care, beginning as soon as possible.

6.10 Conclusion:

The themes as 'women's words' identified within this chapter were generated from the women's interviews and reflect their experiences of caring for their LPBs. For some, their journey began at home with the rupture of their baby's membranes, for others it was on a hospital LW where their labours were induced and in Marylyn's situation, quite brutally. We know when a baby is born a mother is too. Her experience following birth has the ability to affect her, her baby and others around her for many years to come. My findings have revealed some women were treated respectfully, others were not. Care for LPBs was managed by healthcare professionals and to some extent this management disadvantaged women. Many women appeared to be excluded from decisions, and were required to follow 'orders' and were not, at least initially, empowered to be the primary carers for their baby/babies. However, despite the machinations of a paternalistic NHS where care appeared 'directed', the women showed remarkable resilience. They ended up managing as best they could, and once they realised the playing field, took matters into their own hands and 'played the game' in the best possible way to get their babies home. At home, despite ongoing 'long-distance surveillance' for a period of time, they were eventually able to relax the rules and become the woman and mothers they wanted to be.

The following chapter will discuss these findings by examining how territory and those that work in it affects a woman's ability to undertake mother-work for her baby/babies.

CHAPTER 7 DISCUSSION: “Powerless Responsibility”

Introduction

This chapter will be used to explore the accounts of the women in the context of existing relevant evidence and theory to conceptualise and discuss the meanings of the findings. The broad heading illustrates the overall concept of ‘Powerless Responsibility’ which describes the conditions in which the women in my study undertook the care of their baby/babies. Whilst they were encouraged to mother their baby/babies, women did not have the ‘authority or agency to determine their own experiences of mothering’ (O'Reilly 2004, p.7). Each subheading is a conceptual description of the section to follow, and the women’s words with a purpose of illuminating the themes further as a sub-subheading directly beneath. I acknowledge women’s lives are different depending on their own social contexts, therefore the aim of my study was not to generalise my findings/discussion to all women who are mothers to LPBs, rather it was to explore how individual women in my study experienced caring for their babies whilst in hospital and later in their own homes (Hesse-Biber 2014).

Much of the feminist discourse on women’s health issues between the late 1960s and the early 1990s has focused on critiquing the medicalization of childbirth and promoting women’s reproductive rights, rarely has it paid attention to women who experience high risk pregnancies which result in preterm labour and birth and who go on to become mothers of preterm babies. With the exception of Alcade (2013) and Williams and Mackey (1999), who utilised feminism to explore women’s experiences of preterm labour and women confined to bed rest due to their high risk pregnancy, there is little in the literature which examines women’s experiences of caring for preterm babies through a feminist lens. My study, exploring women’s experiences of caring for their LPBs differs from the published literature, as it has examined and reports on some of the missing perspectives of these women’s experiences. The following discussion will highlight how the findings from my study fits with, but also differs from the existing evidence related to women, their experiences of maternity services, late preterm babies and caring.

7.1 Devaluing women and their embodied knowledge

“You get that urge to push, and they were telling me I weren’t allowed to push”

“Birth is the entrance to society and is therefore controlled by those who hold power in that society and birth takes place within the belief system of that society” (Kirkham 2015, p.210).

The issue of ‘not being believed’ by those ‘holding power’ was highlighted by some women in this study. The biomedical paradigm of childbirth within medicalised institutions has been associated with women’s lack of trust in their own bodies, over-reliance on healthcare professionals and anxiety (Oakley 1984). However, for some of the women in my study, including first time woman-mothers, the problem was not so much women’s inability to read their own bodies, as midwives and doctors’ failure to acknowledge and act upon women’s understanding of what was happening to them. In essence, the overriding concern was for babies and only when ‘others’ felt it was right was intervention instigated.

Jane, who presented in hospital with acute abdominal pain at 34 weeks gestation knew “something was not right”, similar to concerns expressed by women in a study undertaken by Palmer and Carty (2006) which explored managing preterm labour at home. Once in hospital “her cervix, as an indicator of fetal status became the locus of concern” (Williams and MacKey 1998, p.32) and Jane was informed by staff she was not in labour, *something she already knew*. Palmer and Carty (2006, p.509) describe how women reported “dissonance between what their bodies were telling them and what the healthcare providers were telling them”, when they believed they were once more experiencing symptoms of preterm labour. Like Jane and others in my study, women were aware of their ‘body knowledge’ and sought medical help to confirm symptoms (Palmer and Carty 2006). Although she “kept going on about her stomach”, the concern of medical professionals remained with Jane’s twins as she was repeatedly asked “can you feel the babies move?” Intervention only came about when one of Jane’s twins experienced a further bradycardic event whereupon she was rushed to theatre where it was discovered her uterus had ruptured.

Other examples from this study of how women were aware of their bodies but midwives were disinclined to believe them, include instances where women were ready to birth their babies, but midwives felt otherwise. In some cases, as described by Fahy (2002), this resulted in midwives seeking to use disciplinary power to control women, resulting in what Baker et al. (2005, p.327) describe as women adopting “parent-child behaviour”, or utilising “disintegrative power” (DP) (“an ego-centred power that disintegrates other forms of power in the environment”) (Fahy and Parratt 2006, p.47). The midwives in such cases were acting as experts, characteristic of paternalistic medical models of childbirth where scientific and institutional knowledge was prioritised over women’s knowledge (Baker S.R. et al. 2005). Interestingly, this was also prioritised over midwives’ own professional knowledge which should work with, and understand women’s bodies and women’s knowledge of their embodied experience (Keating and Fleming 2009; MacKenzie Bryers and van Teijlingen 2010; Meedya et al. 2015).

Stewart’s (2001, p.287) exploratory approach to understanding how health professionals, midwives and obstetricians in maternity services viewed evidence, concluded practitioners are more than likely to conform to evidence which promotes and maintains the ideology of an organisation, suggesting “that some types of knowledge are more legitimate than others”. My study suggests that outcomes in such cases was, as Fahy and Parratt (2006) describe, the women ultimately adopting a position of docility and following the midwife’s guidance. Devaluing women and their embodied knowledge in favour of expert knowledge has been described elsewhere in the feminist literature; for example see Oakley (1980), Hunt and Symonds (1995), Williams and Mackey (1999) and Kitzinger (2005). However, discussed in the section “Like being in a prison” (7.5), this resulted in longer term negative issues in the relationship between midwife and woman.

There was also evidence in this study that women felt professionals were not taking their preterm labour experience seriously, which is similar to a qualitative study undertaken by Sawyer et al. (2013), which appraised parents experiences and satisfaction with care during a very preterm birth. A further aim of their research was to discover domains associated with positive and negative experiences of care.

One domain that impacted negatively on women was staff professionalism, which centred mainly on whether women were listened to or believed when they were in labour and about to give birth. Although Sawyer and colleagues (2013) researched parents whose babies were born preterm, a national survey on women's experiences of maternity care reported on in 2006 revealed comparable findings (Redshaw et al. 2006). Many women in my study were 'delivered' of their LPBs in an environment where "female-gendered skills of support, caring and being with women" (Kirkham 1999, p.733) were subordinated within a "hierarchy of institutional expertise" (Freidson, 1970 cited Kirkham 1999, p.733) for maximum efficiency (male values) (Kirkham 1999). An ethnographic study exploring two NHS LWs provides ample examples of how midwives disregarded or disbelieved women, all of which served to illustrate how midwives "disempowered women at all stages in the childbirth experience" (Hunt and Symonds 1995, p.93; Keating and Fleming 2009; Nilsson 2014; Byrne et al. 2017)).

The findings from my study demonstrate that women in late preterm labour were not valued as individuals who were aware of their body knowledge (for example: knew they were in labour or their "waters had gone"). Instead, women were subject to an environment where the midwife as an "elite expert" (Thompson 2003, p.594) appeared to be 'with institution' rather than 'with woman', a system in which women are disempowered and care is depersonalised.

7.2 Transition to Motherhood

"I just need to see him; I need to know he's alright!"

For the women in my study, the transition to motherhood was complicated by a number of factors, such as their high-risk pregnancy which resulted in a preterm birth. This, by its very nature, implies a situation where women would have had little or no control over their own labouring body, or the type of birth they might have envisioned (Alcade 2013). Research has consistently highlighted the postnatal period as challenging for women as they start to negotiate their transition to

motherhood, and learn the skills required to care for their baby, including recovering their own health and wellbeing (Barclay et al. 1997; Ockleford et al. 2004; Thomas 2004; Wilkins 2006; Miller 2007; Beake et al. 2010; Miller 2011a; Wray 2012; Coates et al. 2014). Many women will be coming to terms with their birth experience and unrealised expectations (for example natural/normal birth with no intervention) and that instinctively they should be able to meet the needs of their babies (Miller 2007).

My study demonstrates the time immediately after their baby's birth was not what women had felt prepared for, with many shocked at the reality of their babies being smaller and needing more interventions than expected. Moreover, rather than feeling ownership, women felt they were "visiting" their LPBs on the neonatal unit. Studies which researched women's emotional responses following a LPB all concur from a psychological perspective that these women-mothers are vulnerable (Brandon et al. 2011; Zanardo et al. 2011). In this study, women felt vulnerable postnatally and separation from their baby increased this feeling. This is comparable to the findings from a phenomenological study of women's experiences of complicated childbirth undertaken by Berg and Dahlberg (1998), which demonstrated high-risk women were vulnerable during labour and to lessen these feelings women wanted a sense of control over their experience, despite the use of interventions and technology and to be recognised and accepted by healthcare professionals as childbearing women and mothers-to-be.

A recent publication (Byrne et al. 2017, p.5) which explored women's subjective experience of birth trauma in first-time mothers highlights how women felt they were "dismissed, dehumanised and passive" by healthcare professionals during the process of childbirth which limited women's control and participation in their own birth. Whilst the study in question does not particularly make reference to high risk pregnancy, many of the women who participated, experienced interventions (such as induction of labour, emergency C-section and others) which could have resulted from high risk situations. The women reported that the focus of professionals appeared to be on the wellbeing of the unborn baby which is a similar scenario to studies relating to complicated pregnancies and birth by Berg and Dalhberg (1998)

referred to previously and women with disabilities (Lipson and Rogers 2000). Their study revealed that obstetricians focused more on the well-being of the baby and “less attention to the woman’s physical condition except as it affects the baby” (Lipson and Rogers 2000, p.17). Women with continuing health problems in the postnatal period face additional challenges, such as the major physical and psychological processes of birth, whilst simultaneously adjusting to motherhood and caring for a new baby, all set against a postnatal environment of inadequate professional help and support (Thomas 2004).

It is worth noting that continuum of pregnancy, birth and postnatal events are “periods of time in which the health of the mother and the baby are held to be in changing relationships to each other” (Thomas 2004, p.87). Antenatally, pregnant women are subjected to a great deal of attention from medical practitioners (Thomas 2004) and are expected to conform to societal expectations in maintaining a healthy environment for the unborn baby (strong public health messages to avoid alcohol/smoking/soft cheeses and so on) (Rudolfsdottir 2000) to maintain a healthy maternal body which leads ultimately, to the birth of a healthy baby (Thomas 2004). This is none more so evident when considering women who are at risk of a preterm birth, and who describe their ‘work of pregnancy’ in terms of ‘keeping the pregnancy going and keeping the baby in’ (Mackinnon 2006), ‘disciplining of the maternal body’ (Alcalde 2011) and ‘forgotten and unseen’ by women requiring antenatal hospital admission (Danerek and Dykes 2014). This level of scrutiny is in complete contrast to the “paucity of attention to the postnatal maternal body” (Thomas 2004, p.87). The postnatal body appears less valued than that of the antenatal pregnant body and thus, for women whose illness developed prior to or during pregnancy and continue post birth are particularly vulnerable in their ability to function as mothers if attention is not paid to their well-being (Lipson and Rogers 2000; Thomas 2004).

7.3 Mothers as docile bodies – handing over decisions to (powerful) others

“Your child must go to NICU”

In my study, similar to the study by Berg and Dalberg (1998), some of the women separated from their baby immediately after birth had difficulties conceiving themselves as mothers, which included being fearful, and in some instances believing their baby was dead. Therefore, the findings from my study support the view suggested by Berg and Dahlberg (1998), in that, to compensate for the negative effects of a traumatic childbirth experience, keeping mother and baby together is advisable, as being close to one’s baby supported women to feel like mothers.

From this study it was clear in several situations separation was necessary, as some babies were clearly in need of intensive care, which could not be provided on the PNW. A prospective population-based study undertaken by Boyle et al. (2015) recognises this need. For the women in my study however, separation seemed randomly decided. This randomness is somewhat supported by a survey undertaken by Fleming et al. (2014) which reported that admission of LPBs to the PNW varied across England and more studies are required to establish what factors influence admission practices. Hawdon and Hagman (2011), both neonatologists, strongly support mothers and babies remaining together, unless there is a clear clinical indication for admission to a NICU. If an admission is required, then mothers need to be involved with decisions, and receive information on what care the baby will receive and how they can provide care (NHS and DH 2009). In Valerie’s situation, although her baby was considered ‘small’, he remained with her throughout, whereas Mary’s ‘small’ baby was admitted to the LNU. She was the only woman who questioned the decision and was informed that because her baby was small, staff needed to keep an “eye on her.” Mary accepted the expert knowledge and authority of the health professionals, but in doing so denied her own agency as a mother and her role in caring for her daughter. Mary also undertook a performance of being a ‘good patient’, or as reported by Fisher and Groce (1985) a ‘good woman’, since she did not make any trouble by interrupting

medical rules of where her baby should be cared for. Paediatric doctors, without consulting women, utilise authority provided to them by institutions to decide where women's babies should be cared for. They, and not the women, are the gatekeepers for ensuring the wellbeing of a LPB (Fisher and Groce 1985).

A report by Bergman (2014) argues there is no scientific evidence to support the routine separation of a mother from her baby, even when that baby is born preterm. The findings from this study support this, because although the actual actions of staff and mothers were not observed, some mothers reported that they were separated from their babies for no apparent reasons. A Foucauldian exploration of "links between knowledge, power and resultant discourses" can be utilised when analysing the implications around the random separation of mothers and their LPBs (Cheek and Rudge 1994, p.584). The overriding discourse is one of medical dominance in the form of authoritative knowledge, since 'others' decide for a woman where her LPB should be cared for, which reinforces the underlying philosophy of patriarchy. The baby or babies now become the property of the doctors and the hospital. Mary and others within my study became "docile bodies" handing over "decision-making to the powerful other" (Fahy 2002, p.8). Healthcare professionals need to assess whether interventions at birth are warranted and weigh the benefits and risks accordingly (Bergman and Bergman 2013). Interventions resulting in separation of the mother-baby dyad have the potential to harm both the mother and her baby/babies. However, whilst separation is therefore to be avoided where possible, this comes with a caveat. A key finding in my study was that avoidance of separation should not be a means by which women's own needs are disregarded or portrayed as unimportant.

Bergman (2014, p.1) advocates zero separation and endorses mothers' bodies as "biologically the normal place of care supporting better outcomes both for normal healthy babies and the smallest preterm infants", which taking a feminist standpoint, implies all future outcomes for normal and preterm babies rests solely on the shoulders of women-mothers. Bergman's statement appears to validate the

concept of western patriarchal motherhood which is characterised by a number of rules:

- 1) Only the biological mother can care for children.
- 2) Mothering must be provided 24 hours per day.
- 3) The mother always puts the needs of her children before her own.
- 4) The mother must turn to the experts for instruction (thus negating another patriarchal view that mothering comes naturally, a contradiction in itself).
- 5) Mothers must spend excessive amounts of time, energy and money raising their children.
- 6) The mother has full responsibility but no power from which to mother.
- 7) Mother-work, and specifically childrearing, is regarded as a personal, private undertaking with no political import (O' Reilly 2004, 2010, p. 20).

The above seven rules in essence describe what feminist writer Hayes (1996) termed 'intensive mothering' and certainly some of the women in my study were expected to devote their entire energy and focus on their babies, with their own needs secondary. The concept of intensive mothering appeared in the 1980s, with the intent of re-domesticating motherhood at a time when more women in North America (and the UK) were becoming educated and entering the workforce (Green 2010). Concurrently and alongside was the prominence of the 'professional', most notably, in medicine (Porter 2010), resulting in the professional being accorded greater respect whilst the status of women declined (Porter 2010). Within this paradigm of mothering, women are responsible for the total well-being of their children (Green 2010). All women, regardless of their background, ethnicity, race, social class or religion, including stay at home mothers or those employed outside the home are influenced by the expectations of intensive mothering. If women are seen to go against the ideal they are labelled as 'bad mothers' (Green 2004). It is against this backdrop that women in hospital caring for their LPBs (and to some

extent when at home) are expected to undertake mother-work. Mothers' become the central caregivers and all their energy and time is devoted to caring for their baby/babies.

Specifically, within the context of my research, we have an 'institution' (patriarchy) which defines how women are meant to mother and a physical institution, such as a NHS hospital postnatal environment or a NICU where a dominant 'unspoken oppressive paradigm' exists. In this environment, mothers are required to undertake "natural-intensive mothering (repression or denial of the mother's own selfhood)" alongside "powerless responsibility, which denies the women the authority and agency to determine her own experiences of mothering" or indeed, at least initially where and how her baby will be cared for (O'Reilly 2004, p.7). This suggests an interesting paradox of mothers holding a "powerless responsibility", as she is required to undertake mother-work "in accordance with the values and expectations of the dominant culture" (O'Reilly 2004, p.6).

If we accept, despite the patriarchal vision of motherhood, that mothering can also be fulfilling for women (Rich 1976), then the default position for mothers of late preterm and indeed well babies should be 'togetherness' rather than 'separateness'. Research exploring women's experiences as mothers of preterm babies have consistently reported separation as impacting on their self-concept as mothers – see for example studies by Erlandsson and Fagerberg (2005), Fenwick et al. (2001b) and Lupton and Fenwick (2001). Wigert et al. (2006) undertook to describe mothers' experiences when their full-term newborn child was cared for in a NICU. They discovered women's experiences of being mothers oscillated between exclusion and participation when separated from their babies. Existentially, women felt they were either not mothers or insufficient mothers. Fiona in my study perfectly sums up the situation faced by women when separation occurs:

"[...] not any stitches or a baby. I hardly got any time with him and then he was up there, (pauses) in a strange way, it felt like I hadn't had a baby (Ja) because I had no tears, no stitches, no pain, no swelling, nothing.... like that. Um and obviously I had no baby with me."

Women in this study indicated that having their baby/babies with them was important; therefore service provision should be developed to facilitate togetherness as opposed to separateness. This discussion has raised an interesting perspective that “patriarchal motherhood is to be differentiated from the possibility of potentiality of mothering (O’Reilly 2010, p.9) and ways in which healthcare professionals can support mothers in achieving this.

7.4 Postnatal hospital accommodation restricts mother-work

“I want to be with my baby”

Women in my study not only had no choice over being separated from their LPBs but some also faced restrictions when trying to access their baby to provide care, based on where they themselves were being accommodated, versus the need to keep mothers and babies safe within secure areas. The Toolkit for High-Quality Neonatal Services (NHS and DH 2009) has, as one of its principles (#3) ‘Care of the baby and family experience’, which recommends dedicated facilities are available for parents receiving neonatal care. As a minimum, there is overnight accommodation for parents and specifically, one room per intensive care cot located within walking distance (‘10-15 minutes’ walk in a dressing gown’) of the unit. Of note, the toolkit does not go as far as recommending accommodation within the neonatal unit itself.

This is in stark contrast to a regional/university hospital in Uppsala, Sweden, where the NICU has nine family rooms, to enable parents’ closeness and direct hands-on care (Heinemann et al. 2013). These rooms are sometimes available for parents who have a baby requiring intensive care. However, the structure and organisation of the intensive care rooms also facilitate parental contact 24/7, even if family rooms are not available, as the open bay intensive care rooms have an adult bed next to the baby’s incubator or cot, to enable parents to sleep overnight. One parent may use the bed, or both (Heinemann et al. 2013). It can be inferred at this point that separation therefore, is not necessary on medical grounds, even with a

critically ill baby; it is simply, at least in the UK, a structure or system of care that is imposed based on how NICUs are constructed.

Whilst all the women in this study who were separated from their LPBs were accommodated within walking distance of the LNU, principle three does not take into consideration 'what walking distance of 10-15 minutes' may mean for women like Mandy, Gill, Nicola, Kate, Linda and Jane. They had all experienced operative births and based on their immobility, were totally reliant on others to get to their LPBs. This study demonstrated for women in this situation, accessing their baby was problematic, despite their theoretical proximity. As revealed in the findings chapter, Linda and Marylyn who were initially kept on the LW due to non-availability of side rooms on the PNW, had their right for 'unrestricted access to their baby' (DH 2009) severely constrained (for example, locked postnatal entrance and 'disgruntled staff'). Staff were trying to respect and be sensitive to the fact that these two women would not want to be resident on the main PNW, surrounded by other newly birthed mothers and babies. This is considered good practice, as reported by Howell and Graham (2011) in their survey, which indicated when women are separated from their babies they want to be treated sensitively, which in this situation, necessitates providing women with a side room away from the general PNW. This sensitivity is not always met, due to organisational structures and the impact is felt by women. Gill was initially accommodated on the PNW and spent her whole time crying, because "every baby made me cry".

Neonatal surveys undertaken by Howell and Graham (2011) and Burger (2015) highlighted how mothers who were cared for on the same ward as those mothers who had their babies with them, were bothered by this. Gill was eventually moved to a side room and although she was grateful, it did not mitigate the loss she felt at being separated from her baby. Mementos in the form of photographs and her baby's first hat helped her cope. The most recent neonatal survey (Burger 2015) revealed, despite it being accepted and recommended practice for over 20 years, not all women (parents) received a photograph of their baby following birth. There is no narrative explaining why.

A qualitative study exploring parents' first experiences of their very preterm babies and NICU, revealed the birth of their baby and initial contact with NICU are important elements in a parent's journey (Arnold et al. 2013). Although parents in the study had preterm babies born at a much lower gestation (less than 32 weeks) than the women in my study, it does support the concept that separation may be eased if a photograph of the baby is provided prior to women (and fathers) going up to the neonatal unit, to reduce the impact of seeing their baby for the first time attached to monitors and technology and to improve bonding.

Research supporting whether a 'Polaroid image' does help with bonding is lacking, although a retrospective study which interviewed families many years later explored how mothers felt about their special baby photographs (Wilson et al. 1987). The researchers discovered 91% of mothers with babies on a NICU agreed a photograph of their baby was helpful during the days following birth and of those mothers, 94% felt the photographs made them "feel closer to their hospitalised baby" (Wilson et al. 1987, p.577). Interestingly, and something I have not considered is what impact these photographs may have on women years down the line. Wilson and colleagues appear to suggest women need to be aware that on relooking at the photographs, feelings may resurface and invoke difficult memories surrounding their birth and immediate postnatal period (Wilson et al. 1987). Certainly the literature supports preterm birth and subsequent hospitalisation as being highly traumatic events for women (Holditch-Davis et al. 2003; Lasiuk et al. 2013), with research highlighting up to six months post birth and longer in some cases, women continue to experience emotional responses comparable to post traumatic stress symptoms (Affleck et al. 1990; Holditch-Davis et al. 2003; Shaw et al. 2014).

I would argue, based on my findings, that potential long term distress at memories is not a reason to not provide women with a photograph. In the study quoted above (Wilson et al. 1987), the photos appeared to be a vehicle that unleashed 'suppressed trauma' which suggests, rather than not offering photographs, it should be recognised preterm birth may be traumatic and women offered

counselling. For Gill in my study, there is no doubting the comfort she gained from having her baby's first hat and photograph. Even though she was physically separated, she still felt emotionally connected (Flacking et al. 2012), as these items gave her "something to hold onto, I had no baby, that was like my baby." Some units across the UK utilise parent counsellors or psychologists to support parents (PSG 2009). However, recent neonatal services surveys highlight parents as reporting 'least positive experience' when asked if they were offered emotional support or counselling services from neonatal unit staff (Burger 2015). In a survey of practice and policy relating to the needs of parents admitted for neonatal care, Redshaw et al. (2010) exposed that 47% of units who participated, did not have the services of a social worker, psychologist, counsellor or psychiatrist which suggests that between 2010 and 2014 (Burger 2015) this aspect of neonatal care has not improved.

It was the scarcity of postnatal side rooms which impacted on Marylyn's experience. The side room on the LW where she was accommodated was quite some distance from the LNU, and in getting there, she had to negotiate a secure PNW. Security for mothers and babies in hospital is essential, and it has become mandatory for all hospitals to have locked and secure entrances to maternity wards and NNUs (DH 2013). In an ethnographic study which sought to explore birth recovery from the mother's perspective during the first seven months following birth, Wray (2012) undertook a period of nonparticipant observation in two UK maternity units. She discerned maternity staff spent a great deal of their time answering the door, or midwives constantly interrupted to verify visitors. On discussing the doorbell issue, Wray discovered that whilst staff appreciated the need for security, they felt policing visitors to the unit was "distracting and interrupted midwifery work" (Wray 2012, p.359). In the Hunt and Symonds study (1995) midwives resented answering the telephone when relatives enquired about the progress of a woman in labour because they felt extended conversations would detract from organisational work and prevent them from undertaking day to day duties.

7.5 Women-mothers as involuntary members of a healthcare environment

“Like being in a prison”

My study demonstrates that for Marylyn, although not a visitor but a mother trying to gain access to her premature baby, was not shown compassion by the PNW midwives. Instead, she was made to feel in the way and that she was disrupting the work of the midwives. The ‘telling off’ Marylyn received would leave her in no doubt as to who was in charge (Hunt and Symonds 1995). Therefore my findings suggest postnatal staff were too busy to answer the door bell and the unhelpful attitude Marylyn experienced towards her situation made it all the more difficult to cope with. She was extremely concerned about bonding with her son and felt guilt at his premature birth. She was determined to give him the best start by breastfeeding, which necessitated frequent trips to the LNU. Marylyn’s encounters with midwifery staff at the entrance of PNW coloured her perceptions of the postnatal midwives, which resulted in her refusing to be transferred to the ward which would have made physical contact with her baby easier. In Marylyn’s situation, the person(s) unlocking the door to the maternity unit also held the power (Peterson 2016).

The general PNW seems to be an inappropriate environment for most mothers of LPBs, despite women feeling “safe and secure”, as they found the environment noisy and at times oppressive, with some women equating part of their stay as “like being in a prison”. An essay by Peterson (2016), which draws on her own research on prison life, illustrates how she gained involuntary membership on an antenatal ward and compares her experience with those she researched in prison. She describes being “contained, constrained and confined” (Peterson 2016, p.1047), similar to her research participants, in an environment that was extremely noisy, and where “silence was an impossibility” (Peterson 2016, p.1048). Women in my study described being confined within four walls and some asked for permission to go for a walk. Requesting permission suggests women are not free to do as they like within a hospital setting, with others terming this lack of freedom and seeking permission as “internalised captivity” (Hunt and Symonds 1995, p.79).

In other situations, women in my study were at the mercy of other women's screaming babies which kept them awake at night. In Peterson's essay (2016, p.1048), inmates do not have a choice of "cellies" as roommates are "assigned" and not chosen, and certainly for the women in my study they were required to care for their babies in and amongst women who had Term babies and who were resident for short periods only. This is in keeping with a finding from Wigert et al. (2006) study, in which mothers described having nothing in common with other mothers who had their baby with them on the PNW.

Most women who occupied single rooms in my study had their doors closed for privacy which is comparable to that observed by Wray (2006), although interestingly, when interviews took place in side rooms I found women's privacy was often disturbed. (See Reflection 6-7). Despite women on the whole appearing satisfied with their care on the PNW /side room, they wanted to go home and be with their families. The women's views on going home in my study are similar to women who were studied by Beake et al (2005), who reported they could not wait to leave hospital due to a stressful postnatal environment and where home was a sanctuary which would enable rest and relaxation. A more recent study by Beake and colleagues (2010) reported comparable postnatal issues, for example, ward routines did not enable women to sleep or rest. Wray's (2012) ethnographic observations of two PNWs revealed postnatal environments as chaotic, busy and disordered. Women felt powerless to influence noise levels which emanated from staff interactions, televisions and the cry of babies. There was no protection for women from noise levels, even though "women occupy their own defined spaces on the ward and are separated from each other by curtains" (Wray 2006, p.522).

Postnatal wards in my research therefore, were not "homely settings (sanctum) constructed to enhance the privacy, ease and comfort of the women" as they begin to mother their babies (Fahy and Parratt 2006, p.46). Instead they were environments of shared space where women had no control over who entered and only curtains separated one from the other. Postpartum women in my study were involuntary members of a healthcare environment where they lacked agency over

their own experience and that of their LPBs (Peterson 2016). This is in stark contrast to how women experienced the postnatal environment in Walsh's (2007) ethnographic study of birth centres. It mattered that their environment was one where they could experience comfort, rest and relaxation and women appeared to enjoy being nurtured by the midwives. Walsh (2007) observed women being singled out for special care and by providing them with time, space and indulgence, midwives 'mothered' women as they transitioned to motherhood themselves. Women in my study were not able to give birth in settings such as a birth centre and receive postnatal care in more nurturing environments, more than likely due to the functioning of hospital institutions rather than an actual inability to create nurturing environments. For the women in my study, the environment of mother-work was not one of kindness, or facilitation with a focus on nurturing, but rather, one of instruction, emphasis on the baby and lack of empathy that can be observed when women are being 'cared for' paternalistically (Walsh 2005).

de Cássia de Jesus Melo and colleagues (2014) stress mothers of preterm babies need to be cared for themselves as women and that care needs must be individualised. The women in my study found their care was centered not on them, but on their babies and this accords with other literature which suggests the reality for mothers of preterm babies is that they find themselves in what MacDonald (2007, p.836) describes as "being in the hands of the healthcare system", which continues to treat mothers and babies as separate, with healthcare professionals appearing to pay more attention to the welfare of babies rather than women's health and wellbeing (Elattar et al. 2008; Bhavnani and Newburn 2010; Schmied and Bick 2014). My study confirms many women felt their own care was somewhat minimal and certainly secondary to that of their LPBs. Therefore it appears women of LPBs do not have a very different experience from other postnatal women in this respect.

The point expressed above supports a notion put forward by Rothman (1989) in her seminal publication 'Recreating Motherhood', that modern obstetrics in hospitals have successfully created a theme of alienation in childbirth, where the woman is viewed as separate from her baby, perpetuating the "technological mind-body

dualism and patriarchal alienation of the woman from her unborn baby” philosophy evidenced through the medical monopoly on childbirth (Rothman 2000, p.117). It matters that this philosophy extends into the postpartum period, because “women matter and their health matters” (Fahy 2012, p.151). Women it seems are not receiving women-centred care on PNWs, which appears contrary to the philosophy of midwifery of being ‘with woman’, and this is, to some extent, maintained when women are back in their home where healthcare professionals continue to focus on weight gain in babies.

Postpartum care is one area which has felt the full impact of health service reorganisation and a decline in resources (Davis 2013), to such an extent that postnatal services have “been diminished to the point of irrelevance” (Lewis 2013, p.158), which somewhat reflects the hierarchy of childbirth. Midwives appear to value antenatal and intrapartum care, with Wray (2006) in reflecting on whether postnatal care was based on rituals or purpose, frequently observed midwives relocated to LW, which implies perhaps subliminally, that postnatal care is not valued. Certainly midwives in Hunt and Symonds (1995, p.85) ethnographic study valued birth highly and a day spent on LW with only women in early labour and no births, was regarded as a “day where nothing much happened”, therefore the birth of a baby is seen as the ultimate prize for working in that environment. Cameron (2014) discerned within her community midwifery practice that experienced midwives were allocated to run community antenatal clinics, whilst more junior midwives and healthcare support workers undertook postnatal home visits. In her view, the perception that postpartum care is not as valued as, say, an antenatal clinic, continues to preserve the low status accorded to postnatal care.

A policy briefing reporting on the state of maternity services in England suggests an improving service in areas of antenatal and intrapartum care, however aspects of postnatal care continues to lag behind (Paparella 2016). For example, only 51% of first time mothers in the latest maternity services survey were definitely provided with enough information about their own physical recovery after the birth (CQC 2015). In my study, Mary was sent home “with a hole” which she only became aware of when the dressing was changed. When her caesarean wound did not

appear to be healing, she was referred back to hospital where staff queried why she had been sent home with such a gaping wound. Her response “I don’t know I’m not a nurse, you are, you tell me” appears rhetorical, in that Mary expected the nurse to be more knowledgeable about her health.

An early conclusion from the findings of my study suggests the specific needs of women who care for LPBs are at present not well catered for, and services require development in this respect. However, the manner in which these developments take place must be central to women’s needs as identified by themselves.

7.6 Relationships on postnatal wards and how they impact on mother-work

“The women up at the hospital I think were just (pause) brilliant, the way they helped us”

The discussion of the findings so far, seems to suggest midwives do not really value postnatal care of women. Whether this is really the case is important to explore. In an exploratory study undertaken by Cattrell and colleagues (2005), midwives recognised women felt vulnerable postnatally and needed emotional support, but barriers such as inputting data onto a computer and ritualistic day to day tasks prevented midwives from providing support needed by new mothers. This was reported by Kate in my study, as one of her earlier quotes demonstrated she received minimal emotional support from the postnatal midwives, at least during the day. It was only at night when the routine of the ward appeared quieter, were some midwives able to sit down and spend time with her. Her main emotional support however, was provided by her husband: “I don’t know what I would have done if he couldn’t come in”. Lisa, whilst she spoke positively about staff in general, was specific when it came to naming the “tag team” who provided support mainly overnight on the PNW: “midwife assistants” and “trainee midwives.”

Gill in my study was acutely aware of how busy the midwives were and became quite emotional when she discussed it with me. She made minimal demands on staff and made the link, that if staff were busy, the impact would be less

information for women like herself. Body language and actions which demonstrates busyness by midwives may deter women from expressing their own needs out of sympathy (Kirkham 2010b). Many of the women (for example, Linda, Nicola and Kate) who participated within my research were aware of 'busy midwives', and therefore just got on with what had to be done.

In the Cattrell et al. study (2005) it was important for midwives to spend time with women as the ability to provide continuity of care provided job satisfaction. Midwives were conscious that staff shortages impacted on time spent talking and assessing women's needs, which resulted in fragmented care. Like the women in my study who were aware of how busy postnatal staff were, midwives in Cattrell and colleagues study (2005) were equally mindful that their busyness was noticed, which resulted in women "not wishing to bother the midwife to ask questions or ask for help" (Cattrell et al. 2005, p.211). It can be deduced from my study therefore, that whilst some midwives did try support women postnatally, other women felt care was mainly directed towards their baby/babies. It appears women are at the receiving end of postnatal services where care is constrained due to a lack of staff. Busy midwives on PNWs have been noted in other studies (see Wilkins 2006; Wray 2006; Bhavnani and Newburn 2010). In these studies women did not wish to disturb the 'perceived experts' with what they thought were "trivial requests" for help (Wilkins 2006, p.175), whilst others felt their requests for help would divert staff from "duties and workloads" (Wray 2006, p.524). In the survey undertaken by Bhavnani and Newburn (2010), women reported being left alone, with no care provided, made to feel a nuisance and found getting any help difficult.

Key reports and government 'pledges' have consistently promised women choice and continuity of care, yet in my study this is not what women are recounting when questioned about their postnatal care. Midwives are also reporting they are unable to provide high quality in-hospital postnatal care because PNWs are inadequately staffed, staff are busy, women have minimal opportunities to rest and if LW is busy, postnatal midwives are redeployed away from postpartum care (CQC 2013; Schmied and Bick 2014; Royal College of Midwives 2014). The lack of 'investment'

in terms of finance and staff for postnatal services appears to imply women should naturally be able to 'mother', with not much help required (Wray 2006). Deery and Hunter (2010, p.47) in their seminal study on emotion work and relationships in midwifery, discovered when midwives work in hospitals/wards run on industry efficiency standards, tasks become priority over women-centred care and midwives become "obedient technicians in order to cope with whatever the working day throws at them". These relationships are neither satisfying to women nor to midwives (Deery and Hunter 2010). All these elements describe the background in which women in my study were trying to mother their LPBs. The diagram (Figure 7-1) illustrates the backdrop in which women were trying to undertake mother-work.

This situation presents a curious contrast in that, although the context of care implies women should 'naturally be able to mother' with not much help required, when healthcare professionals decide women need help, or are doing it wrong as evident within my study (issues around feeding and not over-tiring babies), there does not appear to be much enthusiasm for the idea she may know what she is doing. Therefore, when it suits, women should just be able to get on with it, but when not, they had better listen to the experts. Apple (1995) refers to this practice of mothering where women are informed by expert knowledge as scientific mothering, and it contradicts the ideology that mothering is natural and instinctive. Scientific mothering gradually evolved as medicine and science superseded women's domains of knowledge and women were required to follow the direction of experts. Women were therefore charged with the responsibility of the health and welfare of their families, but were denied control over child-rearing, as the scientific mothering ideology demanded total reliance on authoritative knowledge usually from expert 'males' (Apple 1995). The analogy of scientific mothering is evident within my study when we consider how women were responsible for mother-work, both from a caring and feeding perspective, but without any real power. This contrasts with the theories of mothering discussed previously where mothering as opposed to motherhood can be an empowering experience (Rich 1976).

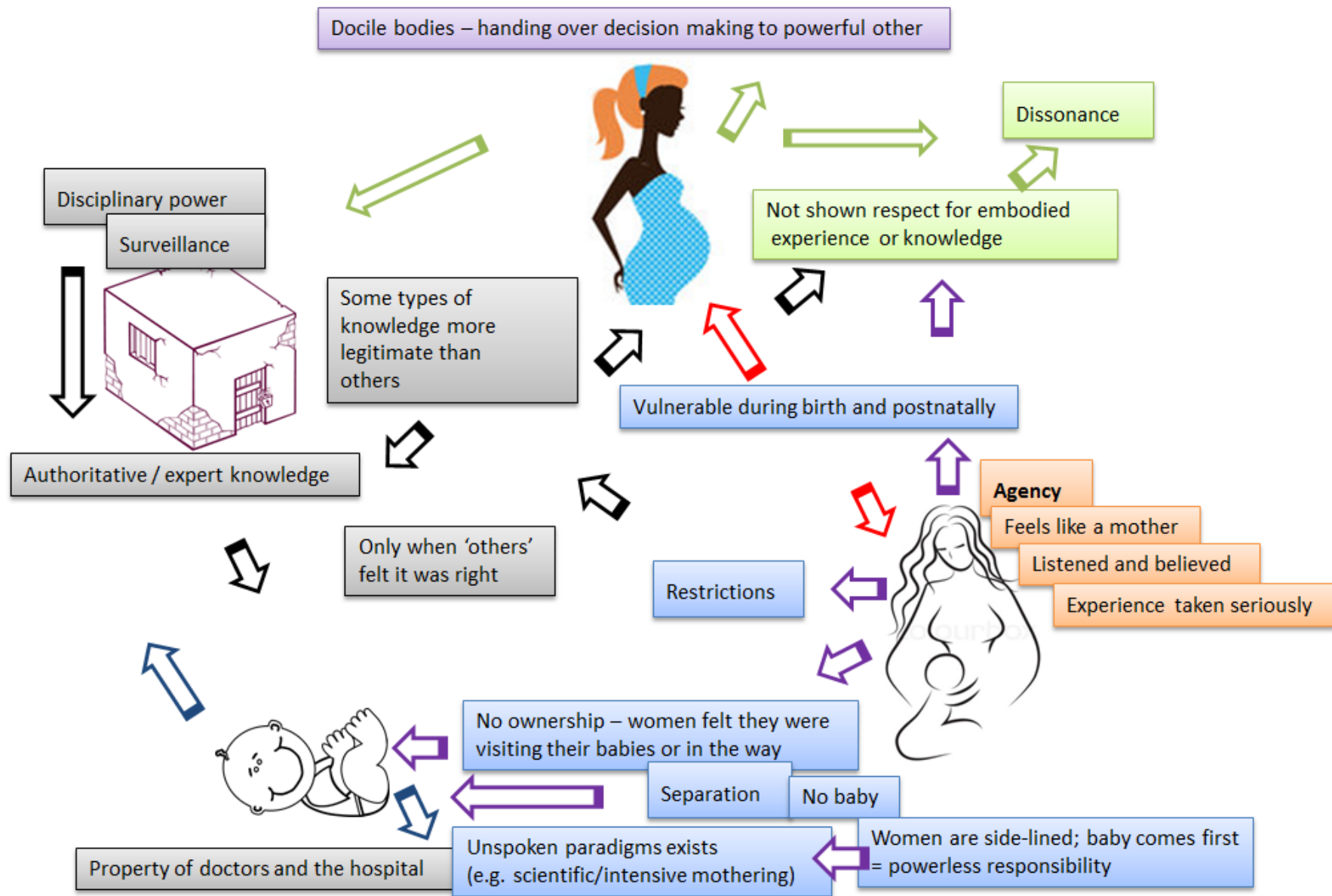


Figure 7-1: Barriers that contribute to powerless responsibility

7.7 Authoritative and expert knowledge and its effects on mother-work

“Don’t let them wake up too much as they’ve got to start putting weight on”

From the offset, women in my study wanted to assume an active mothering role by undertaking mother-work, such as feeding, changing nappies, cleaning mouths (for those being ventilated) and cuddles through S2S, or just holding their LPBs. Whilst the women would not perhaps deem these aspects of mother-work oppressive (O'Reilly 2010), they were often not ‘allowed’ the “authority and agency to determine [their] own experiences of mothering” (O'Reilly 2010, p.20). In this study, there was evidence that mothers were sometimes enabled to care for their babies, but with the caveat they should be careful and not overstep their place. This encouraged them to submit to medical power and show evidence of being what society deemed as being “good mothers” (Fisher and Groce 1985).

When Marylyn was asked what advice she would pass on, she suggests mothers should *ask* to care for their babies (in a LNU) because for her, doing mother-work reaffirmed her role as a mother. Her partner however, did not support her. He believed challenging healthcare professionals was unacceptable, however Marylyn was adamant, “I can, I’m his mom of course I can”. Her response suggests that she is sure of herself and was not about to adopt a submissive role. Marylyn is using her own power to determine her agency as a mother and perhaps to counteract medical power and the apparent inherent scientific mothering ideology (Apple 1995; Fahy and Hastie 2008), which dictated how she was to care and feed her baby.

7.8 How medicalised feeding models and scientific motherhood impact on mother-work

“Putting a baby on formula can really, I think, distress you”

Infant feeding was another aspect of mother-care where women seemingly came into conflict with staff, and all the women worked hard to ensure their LPBs fed appropriately. It is worth considering the impact of this mother-work within the

context of environments, where infant feeding is highly medicalised and whether women recognised, challenged and/or rejected the medicalised feeding model and scientific motherhood (Apple 1995; Murphy 2003). Similar to the findings in the study undertaken by Flacking et al. (2006), which explored 25 mothers of very preterm babies and how they experienced reciprocal breastfeeding, infant feeding in my study was controlled and evaluated on the basis of two practices: schedule feeding and weighing (Flacking et al. 2006).

In my study the emphasis on feeding, for both breast and formula fed babies appeared to be focused on volumes and schedules, resulting in weight gain as the ultimate goal. LPBs who spent time on the LNU including those on the PNW, were fed according to regimes that reflected organisational structures and timetables, as opposed to a baby's individual feeding pattern (Boucher et al. 2011), or indeed a woman's instinct to respond to her baby's feeding cues. The literature supports "structured feeding regimes" based on "predetermined goals for volume and calorific intake as well as weight gain" for preterm babies (Puckett and Sankaran 2008, p.113) with similar principles applied to LPBs in my study. LPBs have a propensity to sleep for many hours, therefore scheduled feeding, as opposed to flexible feeding has been proposed, since flexibility may cause a baby to fall behind in its daily requirements due to sleepiness and poor 'feeding techniques', resulting in a less than optimal weight gain (Ludwig 2007).

In a fairly recent article, McInnes et al. (2010) undertook to explore effective breastfeeding support within a NNU. Healthcare professionals were interviewed on their feeding management decisions when supporting babies to feed orally. The findings revealed staff decisions were inconsistent, with some believing structured feeding was 'too strict' and should be individualised, whilst for others, structure helped inexperienced staff, including benefitting babies by not over-tiring them. Certainly some women in my study were warned not to overtire their LPBs, both during feeding and whilst caring. Interestingly, although the study by McInnes et al. (2010) was not designed to explore staff views on how mothers might be affected by strict feeding regimes, my study quite clearly demonstrates the impact on

women. To maintain scheduled feeding, women set alarm clocks to wake them up three hourly, both in hospital and at home. The following quotes from two women highlight the dichotomy between being woken up naturally by one's baby and by an alarm:

"It's quite strange being woken up by your alarm clock to tell you to go and feed your baby! My head can't quite get around it. And I'm walking round the hospital half asleep; walking into the wall in fact I'm so half asleep." (Marylyn, Phase One)

"[.....]She'll moan at me in the night, she'll wake me up [.....] she'll start murmuring; I'll hear her, murmuring. A couple of times I've set my alarm (laughs) and I think I've slept through it, and it did feel good. I need some sleep because of my milk supply." (Gill, Phase Two)

Whilst feeding regimes prescribed by medical authority and enforced by others (midwives and nurses) appear to be of benefit to LPBs (Ludwig 2007; Cleaveland 2010; Munson et al. 2011), strict feeding schedules work against mothering in two ways. Firstly, it increases a woman's mother-work especially for women who are breastfeeding, as they are required to produce a certain amount of milk at fixed points in time, and secondly, alarm clock feeding goes against a woman's 'mothering' instincts and certainly reinforces the ideology of scientific motherhood (Apple 1995). It is also a form of medical power used to enforce feeding regimes (Fahy 2002).

Having established within the literature review that many LPBs appear to be treated by healthcare professionals as Term especially if their transition post birth is uneventful, a Term feeding protocol was not evident in the feeding strategies within my study. A review article published by Jensen (2011) in a professional journal aimed at neonatal nurses and doctors, suggests a mother is not to be trusted with her LPB, as although she may be aware her baby is experiencing "feeding difficulties", she might just "exhaust" her baby in attempting to provide sufficient milk". In addition "pleased their baby is sleeping well so soon after birth", a mother would not have the sense to "wake her baby in good time for the next feed" (Jensen 2011, p.129). The women in my study had no problems identifying

feeding issues and were quite precise in what those problems were: “baby tiring at the breast”, “not feeding well at the breast”, “he wouldn’t latch on to start off with, he would get tired, really, really quickly”, and worked hard at trying to overcome the difficulties.

7.9 Breastfeeding and expressing breastmilk as a form of regulation and control of women

“I know it was necessary to get enough into him, but all my hard work [expressing] and they’re giving him formula anyway”

Far from exhausting their babies, breastfeeding (and other forms of infant feeding) was hard work for the women in my study. Their experiences were further influenced by a postnatal environment that was industrial in purpose and where women were producers of a product (breastmilk) and their babies recipients of that product (Dykes 2005; 2006). Women’s descriptions focused on their struggles in keeping up with demand (sustaining milk production), or trying to get their babies to feed successfully, so the product could be consumed. In line with the wider literature around LPBs and breastfeeding, the women in my study experienced ineffective breastfeeding by their babies, and as identified by Demirci et al. (2015), their mother-work was “time and energy intensive” and consisted of a number of approaches to encourage babies to breastfeed (Demirci et al. 2015, p.65).

In my study, many of the problems experienced by the women in trying to get their LPBs to breastfeed have resonance with women in other studies (Sweet 2008; Boucher et al. 2011; Hurst et al. 2013). Women were asked not to over-tire their babies and were restricted to feeding for 20 minutes or so, they were constantly having to express their breasts, which reminds them they are unable to feed their babies effectively and finally, if they were incapable of expressing enough volume to match their baby’s requirements they were disappointed in themselves. Two factors work against women who are breastfeeding LPBs, firstly their confidence in themselves to produce enough milk for their baby is undermined by supplementation and secondly, which has been evident in my study, overfeeding

reduces or delays a baby's 'natural' feeding cues which in turn interrupts a woman's milk production (Mattsson et al. 2015).

Whilst feeding regimes prescribed by medical authority and enforced by others (midwives and nurses) appear to benefit LPBs (Ludwig 2007; Cleveland 2010; Munson et al. 2011), strict feeding schedules and 'top-ups' work against successful breastfeeding and ultimately serves to undermine a woman's confidence in her ability to breastfeed (McCarter-Spaulling 2008). If the women were unable to keep up with feeding regime, then feeds were supplemented with either expressed breastmilk or formula. When a woman is required to express her breasts to produce a certain amount at a fixed point in time, her breastmilk becomes objectified, since the focus becomes 'has she produced enough?' Kate was understandably distraught when staff supplemented her son's feeds with formula: "I know it was necessary to get enough into him, but all my hard work [expressing] and they're giving him formula anyway". Women who expressed their breasts experienced what Johnston et al (2009, p.905) describe as an "inefficient' breastfeeding body that is visible through its (in)ability to produce (in)sufficient breastmilk through breast expression", and summed up eloquently by Gill, "I didn't have enough, because I wasn't very good at expressing, I didn't.....and then you panic because you can't." Gill blames herself rather than the environment in which she is expected to undertake mother-work. Other women in my study experienced pain and discomfort in their efforts to produce enough breastmilk. Words such as 'exhausting, painful and being under pressure to keep up with demand' were utilised.

Feminist discourse focusing on breastmilk expression has portrayed it as a form of liberation for women, as it can be a method for managing the demands of breastfeeding, enabling shared parenting, the freedom to do other things, for entry back into the workforce and finally for 'negotiating public feeding' (Johnson et al. 2009, p.184; Ryan et al. 2013) However, for women who are mothers to preterm babies, like the women in my study, expressing breastmilk was not liberating, nor was it a lifestyle choice, instead it was a form of regulation (Johnson et al. 2009;

Johnson et al. 2012), as it became a matter of maintaining product over process (reciprocal breastfeeding relationship) (Demirci et al. 2015, p. 68), with Marylyn and Lisa referring to themselves as “cows” because they were constantly expressing their breasts to keep up with feeding regimes. Women referring to themselves as cows and as milking machines has been described elsewhere, see for example D’Ignazio (2016), Wilson (2012) and Swift and Scholten (2010).

7.10 Breastfeeding equals being a ‘good’ mother

[“I’m right, aren’t I? I did not make up that information that ‘breast is best’?”](#)

Marylyn was the only woman in my study who strongly identified breastfeeding with her role of being ‘a mum’. She was quite adamant if a woman was going to have a baby then she should do the right thing by breastfeeding. Marylyn’s view is supported by the literature which suggests women with preterm babies can fulfil their ‘mothering role’ by breastfeeding (Flacking et al. 2006; Flacking et al. 2007; Meier et al. 2007; Edmunds and Nevill 2008; Boucher et al. 2011; Demirci et al. 2015). Indeed as Boucher and colleagues (2011, p.22) state “breastfeedingis closely associated with a mother’s idea of ‘good mothering’ because only she can offer her infant this particular type of nurturing”. In her blog Kasey Edwards (2016) believes the overriding public health message ‘breast is best’ provides women with two choices:

- 1) To breastfeed and be seen as a good mother or
- 2) To bottle feed and be considered a bad mother.

The subliminal and moral message portrayed by the ‘breast is best’ mantra suggests only breastmilk will do and any other milk is inferior, therefore why would a woman not provide her baby with breastmilk (Edwards 2016)? Marylyn, during Phase Two, described an altercation with a woman at the school gates, who did not, it seems, subscribe to the ‘breast is best’ message. She believed bottle feeding was just as good which was disputed by Marylyn, who argued research strongly supported the benefits of breastfeeding. She was left feeling slightly bemused after the woman refused to agree and walked off. Marylyn questioned her own knowledge: “I’m

right, aren't I? I did not make up that information that 'breast is best'?" Clearly the encounter described by Marylyn highlights her adherence to the dominant discourse that breastfeeding is associated with being a good mother and the baby's needs come before a woman's (Friedman 2009). The woman at the school gate appears to have challenged the legitimacy of the 'breast is best' message and disregarded scientific evidence that breastmilk is better than formula (Murphy 2003). The brief reflective account below highlights how I tried to reassure Marylyn based on the perceived health benefits of breastfeeding.

Marylyn was getting anxious during Phase Two as it was getting close to the time when her previous baby had died. I sought to reassure her by focusing positively on her son breastfeeding. She responded she had breastfed her previous son and that he died from SIDS and Respiratory Syncytial Virus (RSV) – breastfeeding is meant to be protective of both these incidents. Her comments made me reflect on my own views. Breastfeeding only lowers risks - see jpeg below, yet the discourse is so strong, one comes to believe and trust it. My reassurance may have made it worse for Marylyn; in her situation breastfeeding did not prevent her baby's unexpected death.

HEALTH BENEFITS OF BREASTFEEDING

Home > About Baby Friendly > UK Breastfeeding > Health benefits

The evidence is well-established, for both the benefits to mother and baby of breastfeeding, and the significant risks of not breastfeeding. Breastfeeding has some of the most wide-reaching and long lasting effects on your baby's health and development, more than anything else you can do for her.

Babies who breastfeed at a lower risk of

- Gastroenteritis
- Respiratory infections
- Sudden infant death syndrome
- Obesity
- Type 1 & 2 diabetes
- Allergies (e.g. asthma, lactose intolerance)

<http://www.unicef.org.uk/BabyFriendly/About-Baby-Friendly/Breastfeeding-in-the-UK/Health-benefits/>

Figure 7-2: Reflective account on health benefits of breastfeeding

7.11 Alarm clock feeding

"Is it 2 breastfeeds and then a bottle, or is it one breastfeed and a bottle? Not sure"?

Considering the message 'breast is best' within the context of a hospital institution and LPBs, it is almost as if routines/strict regimes/supplementation all go against women ever succeeding. Penny Van Esterik (1994, p.541), a well-respected feminist

states “breastfeeding is an important issue for women both from a human rights and feminist perspective since breastfeeding empowers women and contributes to gender equality”. Women in her view who wish to breastfeed but cannot because of inadequate support (family or professionals), by constraints in the workplace or “misinformation from the infant food industry – are oppressed and exploited”. I would concur somewhat with her statement as I believe the women in this study who wanted to breastfeed their LPBs were constricted by the institution, by separation which impacted on their ability to initiate breastfeeding, by conflicting advice and by demanding feeding schedules.

‘Breast is best’ also informs women they will enjoy breastfeeding (Friedman 2009), but my findings provide a different perspective. Women spoke of being tired, feeding to alarm clock times, snatched sleep in-between the relentless rounds of two/three hourly feeds, breastmilk expression, sleep, feed and so on, feeling stressed and finally, under pressure to produce set amounts of expressed breastmilk. It’s clear within the context of LPBs, at least initially, the message ‘breast is best’ is best only for babies (Friedman 2009). Certainly feminists have considered whether breastfeeding reinforces a gendered role for women, since a baby is entirely dependent on its mother for nutrition and ties her completely to the baby, day and night. When I visited Marylyn at home, her baby was at the breast the entire hour long interview. She revealed her son demanded feeding constantly and she was only getting about two hours sleep at night and not all at once either. She was a single parent and disclosed she couldn’t catch up with much sleep during the day because things had to be done in the house, “washing, ironing, cleaning and cooking”.

Friedman (2009) queries whether there can ever be a balanced approach to parenting when a mother is so central to a baby’s needs when she breastfeeds. It is however, worth considering breastfeeding within the preterm baby scenario, as it does offer women an opportunity to contribute to their baby’s wellbeing if they freely choose to do it , as it is not something staff can do (breastfeed) (Sweet 2008). I must position myself within this debate, both personally and professionally and

declare my pro breastfeeding stance. I fully embraced the 'breast at best' message when I worked on neonatal units and within my teaching at university. I breastfed my son based on the benefits of breastfeeding, although I did not find it 'easy' or 'natural'. I experienced pain from two bouts of mastitis and suffered with badly cracked nipples. I understand now, I was applying similar notions of motherhood as displayed by the women in my study, as I put my baby's needs before my own as I would not abstain from breastfeeding based on my difficulties. After six months I returned to work and reluctantly stopped breastfeeding. Professionally, I had to 'deconstruct' my experience, because at times I felt extremely judgemental towards women with preterm babies who appeared to make very little effort at succeeding in breastfeeding. In addition, analysing myself now from a feminist perspective, it strikes me I have perhaps wrongly endorsed the 'breast is best' message when working with women and their preterm babies. The *overriding* message 'only you can offer your infant this particular type of nurturing' may not be as innocuous as it sounds. It comes to mind it may have negatively impacted on women and their sense of self as a mother, especially if breastfeeding was ultimately unsuccessful. (See Appendix 21: Is Breast Best?) This is particularly relevant when taking into account the difficulties encountered by the women in my study.

7.12 Scientific feeding advice versus women's knowledge

"His tummy's only tiny"

Initially, the women considered health professionals to be the experts who communicated the instructions around infant feeding and they put those rules/instructions into practise, which were didactic and in some instances strictly enforced. Professional advice was deemed 'authoritative' (Murphy 2003), and women appeared powerless to alter the course of events, even when intuitively, they felt their babies were being overfed. Mary knew her baby had to have 35 millilitres "no matter what" at each feed and she strictly carried out her orders. She's afraid to offer more by responding to 'baby hunger cues' in case her daughter vomits. The punishment for not following orders was in Mary's view: "for them (staff) to turn round and say "no she's gone back now, we have to stay longer."

So, whilst on the one hand they appeared to value 'scientific-based advice', women were somewhat bewildered when, at times, their knowledge and common sense contradicted "expert opinion" (Apple 1995, p.174). Marylyn was breastfeeding her son, in addition, he also required nasogastric top-up's (as did all the babies in my study), and she was aware, that because of feeling 'full' he was not able to breastfeed effectively. Valerie expressed similar views. She was mindful of her baby being overfed and describes staff as "forcing it down" and found it difficult when staff appeared to adhere rigidly to prescriptive feeding volumes and regimes.

Overfeeding was common to all babies in my study, as it impacted on Marylyn's baby who appeared unable to breastfeed effectively, Valerie's baby never demanded feeds and both Nicola and Mary were particularly vigilant and tried to avoid overfeeding their baby / babies. In these situations, women and midwifery staff appear to be "subordinate to medical authority and the system" (Thompson 2003, p.598). In this study, guidelines for feeding LPBs appeared to be based on traditional medical models of prescribed volumes via oral or nasogastric tube as standard practice (Ludwig and Waitzman 2007), and a standpoint of paternal medical concerns around the fragility and abilities of a preterm infant (Puckett and Sankaran 2008). Understanding preterm baby feeding ability from this traditional standpoint only sees success of oral feeding when it is "characterised by volume intake or an empty bottle regardless of infant behaviour or caregiver manipulation of the bottle during feeding" (Ludwig and Waitzman 2007, p.155; Breton and Steinwender 2008).

Whilst overfeeding appears to be a common strategy (McInnes et al. 2010) grounded on justifiable medical concerns in ensuring the short (and long-term) health of preterm babies, the process of establishing full enteral feeds appears linked to a set of prescriptive rules (Murphy 2003). When asked what advice they would pass on, the women in my study were quite adamant that women caring for LPBS should trust their instincts to guide mothering, but in the face of prescriptive care this seems unlikely. Is it not also possible midwives could utilise their instincts

(based on their experiential knowledge and practice) to guide individual women such as Valerie and Mary, and not be so regimented in the management of feeds?

A study undertaken by Pollard (2011), which explored how NHS midwives contributed to either maintaining or challenging traditional paradigms relating to power, gender, professionalism and the medicalization of birth in English maternity care, discovered midwives sometimes challenged, but more often, reinforced the status quo. Midwives regarded themselves as “having less status” within the organisation which is reflected, at least in my study, in the way they were obliged to follow paediatric guidelines “whatever their professional opinion” (Pollard 2011, p. 617). I often encountered this attitude when connecting with staff on the PNW within my scholarship of practice as a newborn examiner and as an educator. Midwives frequently complained about undertaking unnecessary heel-prick tests on newborn babies for suspected jaundice. When I queried why they would inflict an invasive intervention on an otherwise healthy baby, the midwives stock answer was ‘paediatric orders’. They appeared powerless to resist, even though they recognized healthy newborn babies were experiencing normal physiological jaundice and exhibiting normal parameters.

It frustrated me that midwives would undertake the heel-prick, irrespective of their own professional or experiential views and a similar gendered hierarchal relationship is reflected in my study, because midwives appeared to privilege medical knowledge of infant feeding over their own or even that of the women they were supporting (Pollard 2011). In the Hunt and Symonds study (1995) it was clearly demonstrated midwives followed a medical model in providing care during labour, as they systematically devalued women’s previous knowledge and experience throughout all stages of labour and a similar contrast can be drawn here. The women in my study understood their babies and recognised what they could or could not tolerate unlike some of the neonatal nurses, midwives and doctors.

The power held by an institution and its workers such as described within my research, represents an environment where the “practitioners prime relationship is with the baby, and the woman is rendered ‘invisible’” (Thompson 2003, p.596). Midwives and other professionals operated by utilising disintegrative power and midwifery/medical domination over the women’s wishes (Fahy and Parratt 2006), which contributed to the medicalised discourse of infant feeding (Murphy 2003). Whilst women were committed to the present and future health and welfare of their babies in terms of feeding, they had no control of the rules which served to undermine them through a series of “quiet coercions” (Lupton and Fenwick 2001) such as a baby having to take 35 millilitres “no matter what” at each feed and her mother strictly enforcing the orders.

This study has demonstrated that women caring for LPBs frequently encountered contradictory advice regarding infant feeding and often felt their own experiences, intuition and instincts were devalued. Therefore my study concludes that the practice regarding the feeding of LPBs should be revisited in partnership with women, so their experiences, insights and perspectives can be used to develop satisfying, nurturing relationships whilst also meeting nutritional requirements.

7.13 How environments and staff can facilitate disempowered and empowered mothering

“They were really really sweet”

The women in my study were resident from between five and 12 days which would have enabled an element of continuity with postnatal midwives and getting to know each other, which may explain the positive endorsements the midwives received, although as noted previously, negative views were also expressed. Women whose LPBs were initially cared for on the LNU and later transferred to their care on the PNW, were wholesome in their praise of neonatal staff. What their quotes have in common is a sense of being listened to; explanations around procedures undergone by their babies, and neonatal midwives appeared

supportive. Fiona, whose baby remained on the LNU, felt staff “looked after mums” but conversely, revealed it would have been completely different on the PNW: “I may not have had that same kind of one-to-one support that I did”.

Alternatively it may be that Fiona and others (Gill) conformed to the neonatal nurses expectations of what they perceived were ‘good mothers’, in that Fiona did not make a fuss, she was not difficult or pushy, and she put her baby before her own needs, characteristics which neonatal staff ‘approve’ of and which serve to keep the women docile (Lupton and Fenwick 2001). It was evident within my study that nurses acted as gatekeepers or “protectors” of babies on the LNU since women were asked not to over handle or overtire their babies, activities deemed to “over stimulate” and therefore harmful (Lupton and Fenwick 2001, p.1017). When the women behaved and demonstrated good motherhood traits as all the mothers in my study did, neonatal staff appeared more supportive, they provided increased information and enabled greater access to babies (Lupton and Fenwick 2001), and for example, babies were returned to the women on the PNW when staff deemed the time was right without consultation or negotiation.

Linda, who was one of the most assertive women in my study, was constantly at odds with postnatal staff and the care she received made her feel angry and disempowered. This type of woman-maternity staff relationship has been described by others as an ‘asymmetrical doctor-patient relationships’ (Fisher 1984) which, although it describes a relationship where women were in a relatively weak position when negotiating with their physician, a parallel can be drawn in Linda’s situation. She was in pain following her operative birth and from a medical condition which impacted on her and her choices prior to birth and she was in unfamiliar surroundings. Linda was also worried about her twins who were separated from her initially. When I explored whether the conflict she experienced could be explained, she was unable to, although at the time she was incapable of openly challenging their attitude (Baker et al. 2005b). Her resistance to the asymmetrical relationship was not to ‘allow’ the postnatal midwives care for her babies.

Fisher and Groce (1985) who studied doctor-patient negotiation within the context of cultural expectations or assumptions about women, discovered doctors acted as 'secret apprentices' when consulting with women patients. If their views of the patient were that she was a 'good' or a 'bad' woman based on their norms of how a woman should behave, the medical consultation was influenced by their perceptions and the flow of information was structured on their terms. This model of medical discourse ultimately had consequences for the delivery of healthcare for the women in question. In my study, perhaps Linda was not acting in the midwives view, as a 'good woman', as she did not subscribe to the mantra as Jane did; "I am quite happy to take their advice, they are the experts and deal with lots of babies" and therefore, possibly an unconscious bias within the midwives themselves influenced the delivery of healthcare towards Linda (Fisher and Groce 1985). Similar attitudes were reflected by the neonatal nurses who were studied by Lupton and Fenwick (2001) in that the authors discovered that women labelled as 'difficult' were at the receiving end of coercive behaviour and subtle disciplining by the nurses. The behavioural nuances displayed by neonatal nurses/midwives towards mothers on a neonatal unit are not easily derived from quantitative generalised neonatal surveys examining parental perceptions of their care.

Environments need to support the transition of women-mothers to empowered mothering, however, despite some supportive relationships reported by women with their healthcare providers, mother-work on the LNU and PNW in this study was tightly regulated and supervised which can be attributed to an underlying paternalistic attitude towards women rather than staffing levels overall. The findings from this study demonstrate midwives are often not enabled to provide good postnatal care needed by women because tasks and processes appear to be priority. Therefore service provision around staffing PNWs without the need to deploy postnatal midwives to other areas of maternity care should be reviewed. A well-staffed PNW would enable women with LPBs to be nurtured as they learn to mother their preterm baby.

7.14 Not going home: Women's journey to home

"I just wanted my own bed"

Despite reporting "feeling safe and secure" on the PNW, women eventually wanted to go home because the environment was "getting to them". 'Not going home' was somewhat foisted onto the women, as there was no consistent view or clarity as to when they could expect to take their LPBs home. This resulted in poor communication between staff and mothers, in which mothers felt excluded from decision making and disempowered. Women who did go home without their babies because mother-work was calling, blamed themselves, rather than seeing it as inflexible decisions by staff, when informed some days later that, they could have had their baby with them on the PNW.

Reviewing the literature around LOS and optimal timing for discharge, there appears to be a consensus that LPBs should demonstrate physiological stability in a number of areas such as thermoregulation, stable blood sugars, respiratory stability, adequate feeding and resolution of jaundice (Medoff-Cooper et al. 2005; Whyte 2012; Jefferies 2014) before being considered ready for discharge. LOS according to the literature emanating from North America varies, from between 48 hours which is considered an 'early discharge' (Goyal et al. 2011), up to 72 hours (Pados 2007) and longer, for example in this study length of stay varied between five and twelve days. Whyte (2012) suggests 'healthy' LPBs may be ready for discharge well before their expected date of birth and barriers to early, and in some instances a graduated discharge (hospital bed maintained and mother and baby go home for the day) are inflexible guidelines and unnecessary investigations. He further maintains some stable moderate to LPBs will "do better at home and be safer and more successfully fed than in a nursery environment" (Whyte 2012, p. 157). In my study, women were ready for discharge come day five, and certainly by day ten were longing to leave, however as evidenced within the literature, the focus is on when preterm babies are ready to go, whilst my focus is on when women wanted to go home. For example Freya, who was a first time mother and

whose baby never left her, was extremely confident in her ability to care for him after two days.

Generally, it is not known whether women would feel confident taking their LPBs home early, although the literature suggests women of Term babies, especially first time mothers, may find the prospect of an early discharge frightening (Forster et al. 2008). Their study concluded that first time mothers had greater needs than women with a previous baby, since primiparous women were concerned about the safety of their baby and generally lacked confidence. Physical presence and availability of healthcare professionals helped women cope with early parenting and their changing role to motherhood (Forster et al. 2008). My findings however, reveal the early experiences of women in my study do not appear to reflect the views expressed above. Women had to cope with mothering in busy PNWs, they were at the receiving end of rigid scientific discourses around caring and feeding, and advice was conflicting. Despite this chaos, Kate was still breastfeeding, and remarked how, when she returned to her NCT group weeks later, unlike her, many of her peers were no longer exclusively breastfeeding. I queried why, and in her view, it was because she had a longer stay in hospital, despite ironically, her breastfeeding journey being “hit and miss” (top ups, weight loss/gain, feeding regimes, conflicting advice, minimal support).

Connie realised she had to “stay in” the LNU, more commonly known as ‘rooming in’, which enables parents to stay overnight for a period of time and care for their baby prior to discharge (Bennett and Sheridan 2005). Bennett and Sheridan’s small study explored mothers’ perceptions of rooming-in, and of the seven women interviewed, six found it a positive experience (Bennett and Sheridan 2005). The study makes no further recommendations about rooming-in, apart from it being a positive experience; however, from the findings of my study, I must question its usefulness for women like Connie who was already undertaking all her baby’s care. She was unsure as to the purpose of staying overnight, but thought it related to proving to staff she could wake up and feed her baby. She spent a lot of time on the LNU seeking the approval of the staff - “I was constantly wanting to do – wanted

them to see me do the right thing, so I could just get – so I could get her home”, exhibiting what others have termed the “parent-child attitude” towards healthcare professionals (Baker et al. 2005b, p.327). Connie was ‘forced’ to comply with routine expectations of what a ‘good mother’ should do in order to take her baby home (Lupton and Fenwick 2001). The good mother as social construction concept places pressure on women to conform to particular standards and ideals (Gotlib 2010). None of the women’s partners were offered opportunities to room in, either on the LNU or the PNW and therefore did not have to demonstrate they were capable of “doing the right thing”.

A Swedish study which explored men’s perceptions and feelings of staying with their partner and new baby (in the context of having a surgical birth), discovered fathers wanted to be involved to provide support (Johansson et al. 2013). Linda, Nicola and Jane were looking after twins and they, like some of the other women (Lisa, Mary, & Kate), had experienced operative births and were undertaking mother-work on their own, and more specifically, having to keep up with a demanding feeding regime that was volume and time driven. Johansson et al. (2013) recommend postnatal care should be focused towards the whole family and I would agree, as separating women from their partners reinforces mother-work as a gendered role and undertaking mothering as they did within the hospital environment left them overwhelmed and at times exhausted.

A systematic literature review undertaken by Ireland et al. (2016) suggests fathers’ needs are often overlooked when a baby is admitted onto a neonatal unit and research which has explored a father’s role during labour and the postnatal period has similar connotations (Johansson et al. 2013). Fathers want to stay close to their partners so they can provide support and be involved (Johansson et al. 2013). This was especially important when women had undergone operative births, with men recognising their help was important in these situations and “felt distressed and excluded” when forced to leave (Johansson et al. 2013, p.36). Fiona and Connie in my study frequently made reference to their husbands helping with caring. The men interviewed in Johansson and colleagues study (2013) believed they should be

able to room in to provide support to their partners and help with the baby. Kate found it distressing when her partner was forced leave at the end of the day. A model of supported care by the family (father/partner) reduces the 'burden' on women as being the sole caretaker of her baby. PNWs are, by their very nature, gendered environments because of the activities that take place within them (Rendell et al. 2000). Women are recovering from birth and undertaking mother-work such as breastfeeding, therefore it is reasonable to reflect on whether 'male' partners staying overnight would be welcomed by women who are in traditional relationships.

Research undertaken by the Fatherhood Institute reports 70% of men and women agree fathers should be able to stay overnight in hospital with their partner once their baby has been born (Fatherhood Institute 2008). It is not exactly clear where these statistics emanate from and neither is it clear what the rest of the respondents (30%) felt towards fathers staying overnight. However, like the women in my study, few hospitals are able to offer fathers overnight stays. The benefits, according to the Fatherhood Institute are:

- 1) Mothers 'feel safer and more relaxed' and
- 2) 'A new father has the same opportunity as the mother to bond with their child' (Fatherhood Institute 2008, p.7).

A trial responding to the needs of women was undertaken by an NHS hospital in South Yorkshire following complaint meetings where women felt vulnerable following birth, as their partners were not allowed to stay overnight (Merrills 2013). The trial had several aims, not least to provide an extended opportunity to facilitate family bonding, to encourage partners to be equals in the care of and decision making about their infant and finally, to assist fathers to support their partners with breastfeeding. Whilst the report does not indicate how long fathers/supporters/partners (no distinction between the three) were present on the PNW, or indeed what facilities were available (wards/side rooms, bathroom and toilet facilities), of 118 episodes of an overnight supporter being resident on the PNWs, 36 responses were received from fathers, with 35 (97.22%) positively

endorsing the trial. Of the thirty one women who participated, all reported a positive experience and recommended overnight partner stays to other mothers (Merrills 2013).

Women who chose not to have an overnight supporter felt it did not negatively affect their experience (Merrills 2013). However, three women were unsupportive as they felt uneasy using toilets at night in case they came into contact with a man unknown to them. One woman resident in a side room commented less positively. In her opinion, having to share a ward with men did not appeal, as she felt a female only environment “helps with the less attractive issues with becoming a new mother. And finally would men really help?” (Merrills 2013, p.56). It is also unclear from the report as to whether fathers had improved their knowledge around breastfeeding support, an important aspect of care where women require help.

Apart from the trial above and the report from the Fathers Institute, it has been difficult finding wider research exploring women’s views on male partners rooming-in on the PNW. Anecdotal evidence from the ‘Mail Online’ suggests ‘it’s wrong to let men stay overnight in maternity wards’ as women feel vulnerable with males sleeping in ‘their domain’ (Dickinson 2015). The same topic has polarised views on the popular social media website ‘Mumsnet’, with many women wanting their husbands to stay over but not, it seems, other people’s. The article by Dickinson (2015) provides an interesting perspective on women’s views. In it, women complained of a lack of privacy when intimate procedures were carried out (breastfeeding and catheter removal), as they were only separated from another woman’s partner by a ‘flimsy curtain’. Other women were concerned about the security and safety of their baby when unknown men were admitted to the ward at night (Dickinson 2015). As the women in my study indicated, the PNW was often noisy with crying babies, so additional noises of snoring men would worsen the environment (Dickinson 2015).

Many PNWs in the UK are ill equipped to enable partner’s overnight accommodation, both in terms of beds and toilet facilities. This is supported by

research undertaken by Symon et al. (2007), which set out to evaluate the impact of the interior environment on women and staff within a maternity facility, but was focused mainly on the delivery suite. The study found partners preferred not to leave their partner in labour to use the visitor's toilet and wanted instead, access to toilets directly within the environment they were in. Those who were required to stay overnight usually had to sleep on two chairs pushed together (Symon et al. 2007). Women on the PNW in Dickinson's article (2015) were 'forced' to share toilet/bathroom facilities with men because male partners appeared reluctant to use visitor toilets usually situated outside of maternity wards. Men also had to sleep on chairs and were on the whole uncomfortable. In the trial undertaken by Merrill (2013) men were provided with an easy chair for overnight sleeping. There was no reported feedback on whether the men found their facilities comfortable.

In Dickinson's commentary (2015) however, a number of women did not want their partners to stay over, as they appeared to value the time getting to know their baby on their own. Whilst there was no mention in any of the articles of women being victims/survivors of domestic violence and/or sexual abuse, these aspects of a woman's life must be considered when contemplating accommodating men as fathers/partners on the PNW. Indeed, some women on the 'Mumsnet' forum made specific reference to their experience of sexual abuse and encountering strange men on a PNW would be frightening. All women are vulnerable during the postnatal period; not least those who may have experienced abuse.

Montgomery et al. (2015) sought to explore the impact childhood sexual abuse had on the maternity care experiences of adult women. Their study, in line with others, revealed many women with a history of childhood sexual abuse, experience normal pregnancies and births and are not distinguishable from other women during their encounters with maternity services. In addition, many women do not disclose their abuse to midwives involved in their care. Interestingly, and in common with my study, the women in Montgomery and colleagues study (2015) were aware of 'busy midwives' and did not want to bother them. Their silence therefore, makes it difficult to provide appropriate care and sharing a postnatal environment with men

who are strangers may invoke traumatic memories or make it all the harder to bear (Montgomery et al. 2015). Overall, it appears local policy dictates as to whether individual hospitals encourage rooming-in. In general, repeated NHS patient surveys reveal many patients find it unacceptable having to share a room and toilet facilities with members of the opposite sex (Richards and Coulter 2007), therefore to enforce it on newly birthed women seems unfair. The following quote (grammar not corrected) in response to Dickinson's article (2015) demonstrates an alternative perspective:

"I'm a Midwife and I work on the post-natal ward and I have to say I 100% agree with the women in this article. Having partners stay overnight is the worse. They press the buzzers and demand food. We try to explain to them that their not the patient so can't be fed and then they complain. One guy even came all the way from his house changed into his wife's dressing gown and slippers and had a shower on the ward. They argue with other patients and demand that other members of their family be let into the ward all hours of the early morning and night. Not all partners are like this tho some are really nice and friendly and just keep to themselves. At the minute we're trying to change the rule back so that partners can no longer stay on the ward." (<http://www.dailymail.co.uk/femail/article-3211972/Why-s-wrong-let-men-stay-overnight-maternity-wards-Mums-feel-vulnerable-dads-sleeping-domain.html#ixzz4Gko9LCdH>)

I agree there should be equal parenting as there is no doubting the positive effects on the family unit as a whole when fathers are involved (Burgess 2006; Fatherhood Institute 2007, 2008; Plantin et al. 2011). This is borne out through a study by Redshaw and Henderson (2013) which quantitatively examined secondary analysis of data on 4616 women obtained from the 2010 national maternity survey. In the original survey women were asked to specifically comment on partners' engagement in their pregnancy, labour and postnatal events. The findings were largely positive, in that the majority of fathers were actively engaged throughout the spectrum of childbirth (Redshaw and Henderson 2013). In particular, postnatal health for women was improved when partners were supportive and engaged (Redshaw and Henderson 2013). Additionally, first time fathers were more involved in caring for the baby (nappy changing and so on) than were multiparous fathers. Other positives were improved breastfeeding rates in the first few days and at

three months. It is worth noting however, that there was a reduced response from women who were young, single, from a BME background and those living in deprived areas (Redshaw and Henderson 2013). These women would require increased support from midwives and HVs (Redshaw and Henderson 2013). Finally, it could be argued that as the majority of women completed the survey on their partner's behalf, the findings may not accurately represent the views or involvement of fathers. Indeed women may have wanted to portray their partner in a particular light (Redshaw and Henderson 2013), although with anonymous surveys there would be no underlying reason for women to 'fudge the truth' of partner's involvement.

In one of its documents The Father's Institute makes reference to a statutory duty (the gender duty) which requires public bodies to provide equality between women and men in their services (Equal Opportunities Commission 2007; Fatherhood Institute 2008). What they hope this will achieve is fathers get a better deal from hospitals, schools and other service providers (Fatherhood Institute 2008). However, I would argue perhaps we should consider improving women's experiences during the postnatal period before fighting for men's rights to be resident on PNWs. Feminists should be working to achieve a world where postnatal care is improved for women-mothers as it is one of the most complained about areas of maternity services (Bhavnani and Newburn 2010; Gray 2010; Birthrights 2013c).

In view of the comments above in relation to other women's male partners on the PNW, postnatal hospital services could be reconfigured specifically with women, their partners and their LPBs in mind. Whyte's (2012) proposal of "rooming in or placing the baby under *family* (my italics) care" in hospital accommodation, other than within the neonatal unit or the PNW would be an important milestone, as it would enable a family to be involved with their baby's care outside the "directly monitored environment of the nursery" or indeed the PNW (Whyte 2012, p.156). Cambridge University Hospital has, for example, put forward a proposal seeking funding for a family-centred ward where babies that require extra care like those

featured in my study, could be accommodated with their mothers and partners (Addenbrooke's Charitable Trust 2014). The design of the unit would include single beds (although I would suggest double beds) in small wards, a number of side rooms with ensuite facilities, cots for babies, separate bathrooms with toilet and shower facilities and a communal kitchen area and sitting room (Addenbrooke's Charitable Trust 2014).

A similar concept has been instigated in Sweden whereby mothers, fathers and babies stay from between two and three days in a family room in a hotel (the unit has a registration desk, private rooms and eating facilities) under the care of a midwife during the day, and overnight, parents contact the traditional postnatal ward if they require help and support (Engström Olofsson, and Nystedt 2009). This innovative model of postnatal care has freed up beds on the traditional postnatal ward which has enabled fathers to stay overnight if their partner or babies are not eligible for family suites (Engström Olofsson, and Nystedt 2009). Interestingly, the main reason for a model of care 'hotel-style' was financial, as, not only is it available to postnatal parents but also to patients (surgical or undergoing chemotherapy/radiation) as it appears more cost effective for 'patients' who do not require care 24/7 and rooms can be rented by members of the family who live some distance away. Typically, the hotel unit is attached to a hospital, therefore 'patients' can be easily checked by healthcare providers, but generally, they are on their own (Engström Olofsson, and Nystedt 2009). It does not however, appear to be an alternative model of postnatal care for the women in my study.

Another option that might work, as suggested from my findings, is some women would have appreciated a "suspended discharge" whereby a woman takes her baby home "on a pass" (Whyte 2012, p.156), the hospital cot is retained for the baby including a bed for the mother. Hospital staff remain responsible for the baby, but not for his/her care because that is undertaken by the mother in conjunction with her partner and family (Whyte 2012). Indeed, one woman's discussion described this phenomenon as her ideal. When deliberating on 'suspended discharge' I believe it may not work for some or all women. I concur wholeheartedly with a

practice point highlighted by Whyte (2012) when he suggests some stable preterm babies will be safer and feeding would be successfully established at home rather than in a nursery or a busy PNW. Indeed, a seminal book published in 1997 based on a systematic analysis of the work of district midwives in Nottingham between the periods of 1948 and 1972, provides a fascinating historical insight into how low birthweight/premature babies were cared for (Allison 1997). During the period in question, the majority of preterm births occurred at home, despite some women with known risk factors booked for hospital birth. It was assumed women classed as high risk had quick labours and births and thus did not have time to get to hospital and others simply did not want a hospital birth. After the 1970s women were persuaded into having their babies in hospital as it was deemed the safest place (Kirkham 1999). 'The hospital' became pivotal in the history of power/knowledge interrelationships especially when considering birth. The rise of obstetric medicine happened because of 'the hospital' and it became a place of birth not because as an institution it was safer or better, but because they became sites of information which benefitted the emerging profession of obstetric medicine (Foucault 1980).

Midwifery records from Allison's research (1997) demonstrates that between 1948-1972, babies of all weights born in hospital or at home appear to have survived at similar rates. In his 1953 memorandum outlining policy for the care of low birthweight babies, the Medical Officer for Health acknowledged small babies born and kept at home usually "did better" (Allison 1997, p.34). A hypothesis of 'lack of stress' is proposed for why small babies appeared to have a similar chance of survival when born at home especially to families classified as social class V. Although neonatal care has changed dramatically from the period under scrutiny in Allison's book, there remain some contemporaneous parallels.

At the time, premature babies born in hospital were routinely separated from their mothers and nursed in clinically sterile environments by many different healthcare professionals (still relevant today), in contrast to preterm babies born at home and nursed by their mothers who were supported by their extended family and friends not least the premature baby midwife, who had specialised knowledge in caring for preterm babies. Being at home with their premature babies "gave mothers a sense

of ownership and control and allowed for early bonding” although this perspective is derived from midwifery recollections and not from women’s words (Allison 1997, p.101). My findings demonstrate women had very little ownership over what happened to their LPBs whilst in hospital and some worried over bonding.

It is worth noting the study highlights the “extent to which low birthweight babies born at home were **not** a sample of carefully selected babies, born to low-risk mothers in good social condition” (Allison 1997, p.101). Women today at risk of a baby born late preterm do not have a choice in place of birth, therefore would they welcome an early discharge with support similar to that provided by the premature baby midwife of yesteryear? What is known from my findings is the women appeared to have benefitted from their extended stay on the PNW as when they were discharged they felt confident in caring for their baby/babies, although possibly the same outcome could have been achieved with good support from midwives or an appropriate alternative such as a community neonatal team.

7.15 Women’s personal resistance in the face of powerless responsibility

“Oh you little toad we can be going home today”

The literature consistently emphasises discharge planning for preterm babies should commence on admission (PSG 2009; Phillips et al. 2013; Jefferies 2014) yet this was not evident in my study. Despite asking on numerous occasions, many of the women in my study never knew when they could go home with their baby/babies. Healthcare professionals either declined to commit to a day of discharge or alternatively, provided women with an estimated date which was predicated on a traditional estimation of a baby’s due date. Some women were upset with this information and others were content to wait until their baby was ready. What eventually became evident to the women was that going home was incumbent on their baby/babies gaining weight, which was the reward for good mothering.

To get to that point however, they had feed their baby/babies by following feeding policies based on preterm fragility and women appeared, at least initially, unable to influence any aspect of their baby's feeding except to enforce the regime as stipulated by others. Midwives and nurses as experts in infant feeding employed "tools of the trade" techniques (Burns et al. 2013, p.63), which consisted of NGTs, syringes (not evidenced based), nipple shields and a cup on occasions to ensure the babies received the product (breastmilk or formula). Women complied until a certain point and then attempted to resist the dominant discourse. Mary tried to pace her baby's feeds, Nicola "took over their care" and would not allow staff to reinsert feeding tubes and Linda would not permit midwives on the PNW to care for her twins. Small but meaningful acts of defiance by the women enabled them to "play the game" (Demirci et al. 2015, p.65) which was – weight gain equals going home. Freya and Valerie, for example, opted for a feeding method (formula) that would lead to 'instant' weight gain. In Valerie's situation she provided breastmilk in a bottle for her baby, hardly reciprocal, but pragmatic as volumes could be visibly gauged.

Similar findings are demonstrated from a small study undertaken in a neonatal unit in Australia, which described the experiences of seven women and two fathers who were caring for a baby born at 36 weeks gestation (Swift and Scholten 2010). Women shared how they considered "fudging the figures" so they could "escape prison" and get their baby home although they were not "allowed" to go home until their baby could feed properly resulting in weight gain (Swift and Scholten 2010, p.253). Another woman discussed stopping breastfeeding and putting her baby onto the bottle so she could "just get him home" (Swift and Scholten 2010, p. 253). Instead of infant feeding being a time for developing relationships, the women had adopted medicalised language to reflect their baby/babies progression, which was similar to many of the women in my study, who spoke about gains and losses down to the smallest gram, including quoting percentages (for example, 4% or 7.5%) when discussing their babies' weight. Adopting a discourse that reflected the environment in which they had to feed their babies may have provided the

women in my study with structure and an element of control in achieving the end point.

I agree with Dykes and Flacking when they assert that for breastfeeding to be successful between a woman-mother and her preterm baby, staff have to focus on enhancing breastfeeding relationships rather than just emphasising breastmilk as a product which needs “supervising, assessing, judging and evaluating” (Dykes and Flacking 2010, p.734). I would argue however, similar principles be applied to women who formula feed their preterm babies because, as my study demonstrated, their efforts whilst complying with scheduled feeding regimes were as much under scrutiny as those women who breastfed. Women and their LPBs in my study, comparable to the women studied by Swift and Scholten (2010), experienced conflicting advice and support in all aspects of care, not least infant feeding, and would have benefitted from input from healthcare professionals who had specific and detailed knowledge around caring for this group of preterm babies (Dykes and Flacking 2010). This input would need to be in conjunction with women-mothers to enhance their sense of self as a ‘mother’ and thus enable them to be primary carers and an active partner in all decisions relating their baby/ babies (McInnes et al. 2010).

Fortunately, the women in my study, despite the many obstacles to mother-work managed to “work it out” (Barclay et al. 1997, p.724). In their research which analysed women’s experiences of early motherhood, the authors assert that in order to “work it out, women require personal resilience” and those women with moderately high levels of self-confidence can easily negotiate their way through (Barclay et al. 1997, p.725). I agree partly with their stance, because, whilst the women in my study despaired at times, they demonstrated personal resilience whilst undertaking mother-work with powerless responsibility, it was however, by no means easy to negotiate their way through conflicting advice, lack of continuity of care, busy staff and not knowing when they could go home with their babies. Eventually, after working it out, the women were ‘allowed’ to take their babies

home under strict feeding instructions. Women had to maintain three hourly regimes including supplementing feeds if their baby/babies had not taken enough volume.

7.16 At home: women's terrain becomes a sanctum

"Every person is different and every child is different"

The women initially submitted completely to medical disciplinary power (Fahy 2002) because they were frightened. They were in no doubt as to the outcome if their baby lost weight – re-admission to hospital. Thus for several weeks they remained under the 'gaze of others' through long distance 'surveillance' and healthcare professional domination (Fahy and Parratt 2006), in the form of daily and then weekly visits from midwives/health visitors who came to the women's homes to weigh babies. By the time I visited the women during Phase Two they all exhibited much more confidence in "themselves, and their ability to mother" (Miller 2007; Brunton et al. 2011, p.3). Whilst initially the tension between intuitive mothering and professional advice was evident in the manner in which women had to undertake mother-work both in the hospital and at home (three hourly alarm clock feeding), which Murphy terms as being "governed at a distance' (Murphy 2003, p.455), the women eventually came to question healthcare professional input and began to rely on other sources of support (Miller 2007; Brunton et al. 2011). In Murphy's (2003, p.455) research in which she explored expertise and forms of knowledge in the government of families, women frequently "broke the rules around infant feeding specified by scientific experts". Women in my study displayed similar attributes. For example, after several weeks of scheduled infant feeding regimes, they abandoned 'orders' and took control over their "feeding work" (Murphy 2003, p.455). At home, women's terrain had become a sanctum where they appeared to be in control and able to reclaim their embodied sense of self as a mother (Fahy and Parratt 2006).

7.17 Being a ‘good mother’ – seeking alternatives to asymmetrical medical encounters

“Let’s go to the doctors about it”

The asymmetrical medical relationships encountered by the women in hospital continued somewhat whilst back in the community when concerns about their baby arose. In explaining how the women negotiated their role in ‘being a good parent’ and fulfilling an ‘active mother role’ when seeking help for their baby, I am drawing on the work of Gunnarsson et al. (2013) and Gunnarsson and Hydén (2009). Both of these studies explored how parents constructed themselves as responsible parents following their interactions with healthcare expertise when their child had an illness. In common with women studied by Miller (2007) and Hays (1996), women in my research became the authority on meeting and providing good care for their baby/babies. An aspect of good parenting indicates that when a problem presents, a good parent will respond quickly to their child’s needs (Gunnarsson and Hydén 2009), which in my study manifested itself in women becoming like “detectives” (Gunnarsson and Hydén 2009, p.169), to better understand and uncover what they thought was wrong (Gunnarsson and Hydén 2009). Part of the women’s strategies included trying a range of alternative methods to manage their baby’s problems (Gunnarsson and Hydén 2009), and eventually seeking medical treatment from authoritative experts (Apple 1995) not to “find out if something was wrong, but what was wrong” (Gunnarsson et al. 2013, p.450).

Gunnarsson et al. (2013) identified that knowing something to be wrong but also not being believed can threaten a woman’s perception of herself as a wife and mother. This point was illustrated in this study when Jane attributed one of her twin daughter’s lack of weight gain and a number of other symptoms to a milk intolerance, and wanted a prescription for a lactose free formula. She repeatedly visited the expert (GP) at her local medical centre, and described her encounters as “not taking any notice of me” and “hitting her head against a brick wall”. Similar to the situation of caring described previously where women with LPBs in hospital had to undertake mother-work with ‘powerless responsibility’, Jane was in a

comparable position. In seeking to do the right thing for her daughter and to validate her role as a responsible and competent mother (Gunnarsson et al. 2013), Jane sought expert advice, yet was not taken seriously or respected for her suspicions (Gunnarsson et al. 2013). This included her husband who thought she was “making a fuss for nothing”. Her descriptions suggest a lack of power and control (Gunnarsson et al. 2013), however, to reassert her moral agency as a good, caring and experienced mother (Gunnarsson et al. 2013) she resorted to sending her military husband (who eventually supported her), who succeeded where she did not. Despite these barriers Jane had eventually situated herself within the “active mothering role” (Gunnarsson et al. 2013, p.456) which revealed her as gaining control of the situation and as “having confidence and competence in having done the right thing and in being right” (Gunnarsson et al. 2013, p.456).

In conclusion, healthcare professionals need to recognise and acknowledge that women-mothers, who are in the main, responsible for their children’s health and well-being, and the parent who most often takes their children to the ‘expert authority’ (Gunnarsson et al. 2013) when they perceive something is not right, do not enter medical encounters as “blank pages” (Gunnarsson and Hydén 2009, p. 172) as they have already examined their child’s problem in detail (Gunnarsson and Hydén 2009). In instances such as Jane’s described above, suggest women-mothers do not ‘reject “professional expertise and authority” (Gunnarsson et al. 2013, p.455), instead they seek a consultation of shared decision-making to confirm the next step/diagnosis (Gunnarsson and Hydén 2009). Positive interactions support a woman’s agency and her perceptions of a good and competent mother which then enable her to undertake her mother-work with ‘powerful responsibility’.

7.18 Conclusion

This study which was carried out in South West England has demonstrated the numerous barriers faced by women when caring for their LPBs. The diagram (Figure 7-3) below illustrates the factors that need to be in place to enable women-mothers to care with 'power and responsibility.' The following chapter will discuss the recommendations as derived from my findings.

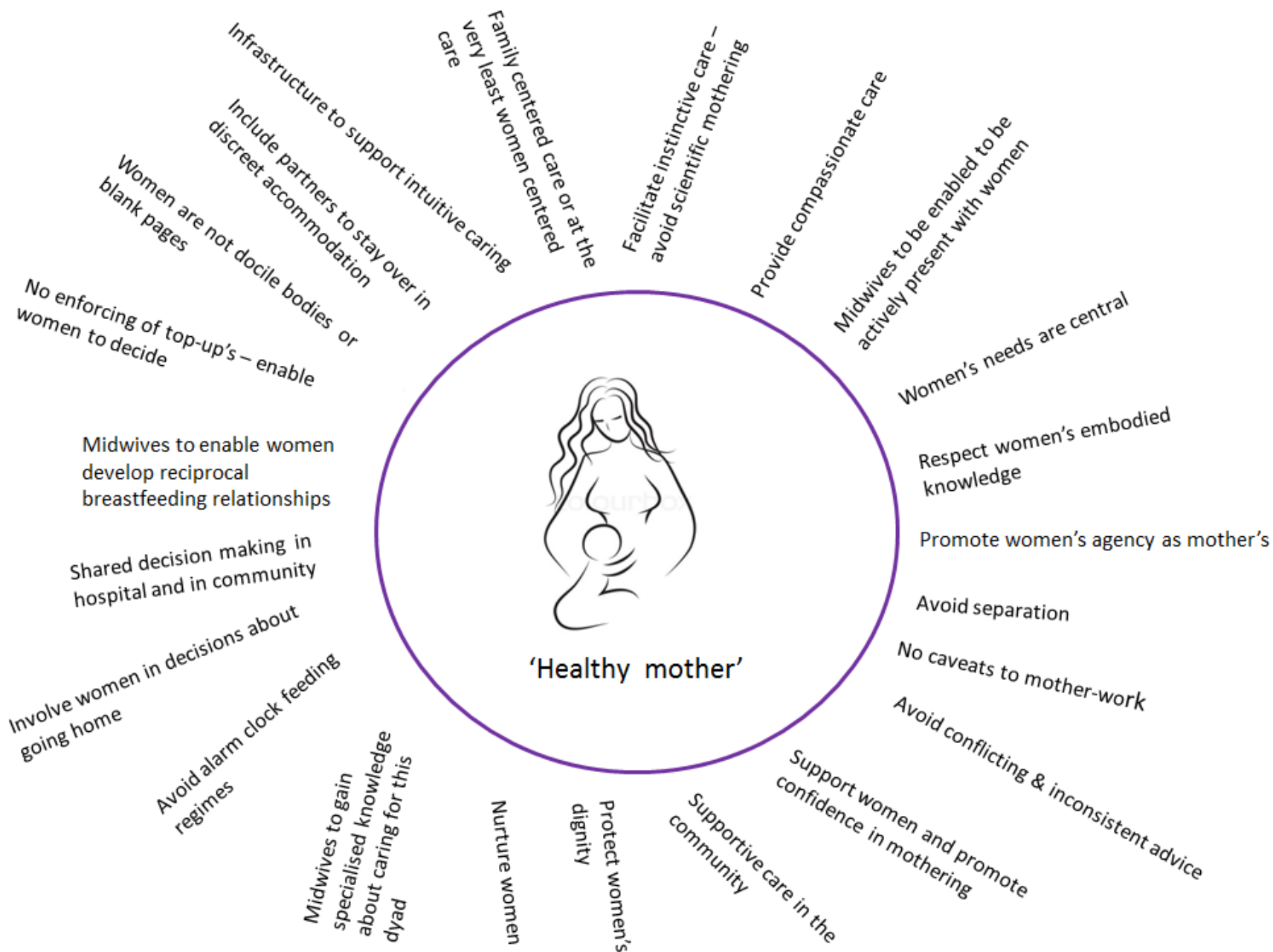


Figure 7-3: Factors needed to support mother-work

CHAPTER 8 THE WAY FORWARD

Introduction

This study has explored women's experiences of caring for their late preterm baby/babies using a feminist lens. The findings demonstrate each woman's experience was/is diverse and my research has concluded there are some overriding themes that merit consideration in practice.

8.1 CONSIDERATIONS FOR PRACTICE

8.1.1 Women's Needs

There is a requirement to recognise and provide for the needs of women who have undergone preterm labour and birth, including the needs of their babies; however recognition of these needs begins during the intrapartum period. As my findings demonstrated, many of the women found the period before birth stressful, as a high risk pregnancy, such as preterm labour, denotes uncertainty, stress and anxiety and may negatively impact on a woman's experience (Berg and Dahlberg 1998) despite reassurances that birth at late preterm gestation was considered 'safe' by the medical profession. Healthcare professionals need to recognise that women with high risk pregnancies based either on their own health or that of their unborn baby can be a traumatic experience and to enable a 'healthy mother' to be born, separation of women from their babies should be avoided if at all possible (Berg and Dahlberg 1998).

Following birth, women in my study were highly committed to their babies but had to undertake mother-work at least initially within environments which appeared wholly focused on the child with little consideration for the woman-mother. Mother-work was conditional and regulated on factory standards, they were invited to participate but caveats were always present 'don't over handle the baby', 'don't tire the baby' and infant feeding was planned with alarm clock precision. Babies,

whether breast or formula fed, were subject to strict feeding guidelines/supplementation/volumes dictated by doctors and enforced by nurses and midwives. Women were powerless at times to influence feeding and regimes did not facilitate instinctive mother-care or enable babies to demonstrate innate feeding behaviours (such as rooting and early feeding cues). The main conclusion derived from this study is therefore, that if a woman-mother's needs are met, in areas such as shared decision making about where, how and why, regarding their baby's care, then their babies needs will be more effectively addressed. Woman's needs should also be central when communicating this information. In addition, women themselves need nurturing as they commence their journey of caring for their LPBs. Berg (2005, p.19) states "balanced care of women at high risk is of utmost importance" and although she is specifically referring to midwives and their relationships with women during high risk pregnancy, labour and birth, the principles are applicable to all healthcare professionals working with women and their LPBs. The basis for relationships in the postnatal period should be one of protecting a woman's dignity, where she experiences a caring relationship with all professionals situated on the basis of respecting her embodied knowledge, together with a balance between medical and women's perspectives (Berg 2005).

8.1.2 Environment of Care

There is also a need for the physical infrastructure of maternity units to provide better care options for women who are caring for LPBs. The environments where mother-work was carried out in my study, most notably the PNW, was noisy (other peoples' babies) and at times oppressive. Women were aware of how busy staff were, which resulted in doing things for themselves (such as walking to the LNU not long after their operative delivery, catheters in tow) and for others it meant staff were unable to provide information and one-to-one care. These women put aside their own needs because they were in sympathy with the busy staff and did not want to further 'burden' them. It is somewhat ironic therefore, that some members of staff were unable to display similar feelings to women in their care. A couple of the women described midwives as "rude and bossy" whilst another was "tutted" at

when she rang the doorbell at the entrance of the PNW. Staff demonstrated both facilitative and inhibitive types of behaviour (Fenwick et al 2001b) when supporting women to care for their LPBs, with the focus of care mostly on the preterm baby.

A commentary by Hunter et al. (2008) highlights how organisation of care within maternity services has an impact not only on women and their families, but also on those who provide it. Meaningful relationships are not forged between a woman and a midwife when care is provided under industry standards and is disjointed. The authors consider 'meaningful relationships' as vital, as both women and midwives benefit. Women are supported on their journey through childbirth and into motherhood and midwives are able to be "actively present", "the anchored companion" and undertake "genuine caring" for women (Hunter et al. 2008, p. 134). Whilst many of the women in my study appeared complimentary of staff and found some supportive, it was "dependant on how busy the team was".

Another key conclusion revolves around the gendering of care whilst women are in hospital. A policy of not enabling fathers/partners to stay overnight does not take into consideration the needs of women who have undergone operative births and are caring for their LPBS and in particular, women caring for twins. Separation of a woman from her partner subtly reinforces a woman-mother as being totally responsible for her baby's welfare. My study has demonstrated that women caring for LPBS have greater needs and planning provision of care and the physical infrastructure of hospitals should take into account the extra time and input these women-mothers need, not only from healthcare professionals, but also from their partners.

8.1.3 Separation

This study has demonstrated that women can, and do, 'bond' well with their babies regardless of early separation. There is a strong societal discourse prevailing about mothers and the importance of bonding with their babies immediately after birth, which partly arose following early maternal-infant attachment work undertaken by Klaus and Kennell in the 70s (Klaus et al. 1972 cited Klaus 2009). Their research, conducted on a sample of 28 poor single mothers (a very small, non-representative

sample of women), demonstrated there was an early critical period after birth lasting between two and three hours in which, if women were kept with their babies (providing skin to skin care), they demonstrated better attachment strategies as opposed to women who were separated (Klaus 2009). A more recent study (Bystrova et al. 2009) appears to support these earlier findings of a sensitive period for attachment following birth.

What do these findings mean for women in my study who were separated from their babies? Certainly some of the women were worried about bonding, felt guilty and blamed themselves for their baby's preterm birth. The literature exploring women's experiences with their preterm babies, overwhelmingly demonstrates that women with babies on a neonatal unit do not feel like a mother based on the many interventions and procedures these babies undergo, including the organisation of neonatal care women are required to follow. In addition, the experiences of women and their LPBs is generally subsumed within the bulk of general preterm literature which is focused on reporting the difficulties experienced by women caring for babies at the lower end of prematurity, therefore it is not known how women with LPBs fare in relation to 'bonding'.

At the other end of the scale, research undertaken by Miller (2007, p.355) demonstrates that over time, first time mothers of Term babies "get there", they "come to be the authority on meeting their child's needs and learn through practice the skills of mothering". Normally, women and their Term babies are not separated, unlike the women in my study, the majority of whom were separated from their babies, therefore will they also "get there" and become an authority on meeting their baby's needs?

As stated previously, it is desirable to keep women and their babies together, but if separation occurs, is all lost because women have failed to meet the 'required standard?' A systematic review undertaken by Herbert et al. (1982, p.219) which examined key studies exploring maternal bonding appears to suggest there is no robust evidence from human studies supporting the concept "of a sensitive period in the formation of mother-to-infant attachment", as many variables (for example,

social class, a woman's age, type of birth), may impact on a woman's ability to connect with her baby. In addition, bonding as a concept is difficult to conceptualise, does it for example concern maternal behaviour such as gazing, smiling and touching and so on, or describe a special relationship between a woman and her baby (Herbert 1982).

Herbert et al. (1982) strongly believe a sensitive period for the development of maternal-baby attachment immediately following birth is overly emphasised by healthcare professionals because if separation does occur, the relationship is not irreparable, although acknowledge separation does have an effect on women. Therefore, to lessen the effects, a woman should be encouraged to be responsible for her baby's care which would in turn improve her self-confidence and her ability to care (Herbert et al. 1982), all of which I have revealed through my findings and within the discussion chapter. Empowering women to care for their babies if separation has occurred would help lessen feelings of guilt and self-blame for a preterm birth (Herbert et al. 1982) as evidenced by Marylyn in my study, who strongly identified with several dominant discourses of motherhood (breastfeeding and bonding). She also had the sickest baby (in the short term only) and was initially hard on herself, since she blamed herself for her son's early birth. However, many weeks later she felt more secure in herself:

"I said to somebody the other day its really silly now to think I was so worried about bonding because, I completely adore him and you can tell by the way he stares at me all the time that we've bonded and I'm the only person he will smile at and he won't even smile at his dad, and [.....] yet I had *absolutely* nothing to worry about but it was just one of those things I *was* worried about" [Phase Two].

All the women I interviewed during Phases One and Two had become authorities on their baby/babies and appeared well connected, although I was only in their lives for a brief moment in time.

8.1.4 Planning for Home

The study also concluded that there is a need for a co-ordinated and well planned

discharge process, as a better planned route would have been helpful to the women-mothers. This is supported by Whyte (2012) and others, who recommend planning for discharge should be evident from admission and women need to be part of the process from the onset. My study demonstrated that requests for discharge dates were nebulous and in some cases, women found out on the day in question. Other women were only allowed home if they could prove to staff they were capable and competent in caring for their preterm baby. In my study, women often spoke about conflicting and inconsistent advice. Many professionals appeared to be involved in managing the women's babies, often with different methods of dealing with problems. This was difficult for the women. Therefore, to promote a better coordinated approach to discharge, my study concludes there is a need for some midwives to be supported to gain specific knowledge on the idiosyncrasies of late preterm babies to enable women to be supported more effectively in the caring of their babies, enabling a smoother pathway towards home. Alternatively, women could be discharged home early and supported to care for their LPBs in the community by specially trained staff.

Finally, there is a need to recognise women's own expertise, strength and resilience in knowing what is best for their babies. Surveillance and disciplinary power was ever present between the women and the healthcare professionals and these seen/unseen concepts dominated women's experiences with their baby/babies. Whilst at certain points during their hospital stay, they were able to resist the underlying powerful discourse (asymmetrical power relationships), women did not remain 'docile bodies' and took matters into their own hands. They showed remarkable resilience and strength despite the obstacles (Ruddick, 1982 cited Nicolson 1993). On return to their own homes, surveillance continued in the form of health visitors who visited frequently to monitor women and their baby's weight gain. Women were well aware of the underlying threat to their mother-work: a 'return to hospital' if weight gain was unsatisfactory. Gradually however, women became more confident and this was clearly evident when I visited them in their own homes. The women 'looked different', they were not tired weary looking 'patients' on a hospital ward in their dressing gowns, but instead were women who

knew what they were doing. They appeared secure in their mother-work and their biggest rebellion was dropping the three hourly feeding regimes imposed on them by others, therefore, eventually, all the women adjusted infant feeding and infant care practices to fit their lifestyle.

8.2 LIMITATIONS:

- The area in which the research was undertaken is a fairly affluent small market city, therefore experiences of the women in this study was very much influenced by who they were, where they lived and by the institution in which they gave birth: a medium sized acute care maternity unit where approximately 2,500 women give birth. Women for example, who live in large inner cities of the UK and give birth in NHS hospitals where the birth rate may exceed 6000, may have a vastly different experience and therefore comparing one institution with another might have produced different findings.
- The outcomes of the babies at birth were not severe, only one of the babies was extremely unwell, therefore time spent on the LNU was fairly short – up to five days at the most, before being transferred over to their mothers on the PNW. Women whose babies are sicker and have a longer episode of care on a neonatal ward may have a more complicated experience.
- My study does not represent women's experiences from an ethnic and minority background, women of colour, disabled women or women from the LGBT community. All the women in my study were in 'traditional male/female relationships'.

8.3 REFLEXIVITY:

In the methodology chapter I argued there was no easy definition for what feminist research was, although based on the views of various imminent feminist academics

for example, Harding (1987a) and Reinharz (1992), I decided my stance would follow the approach that feminist research must make a difference to women, it is research on women, by women and for women. As indicated previously, my feminist stance was not greatly developed at the start and only matured towards the latter half of the process. Therefore in retrospect, I am similar to healthcare practitioners who demonstrate paternalistic attitudes to pregnant women, as I did not involve women in formulating my research at the outset and am guilty of what Cheyne and colleagues (2013, p.706) term “academic paternalism”. In their project working with women to develop questions for research that were of value to them, the researchers found women were quite capable in identifying what was important to them and therefore, had I engaged a group of women to work with me at the beginning, my PhD journey might have undergone a different trajectory. In future I would wish to undertake research where women have had an opportunity to shape the process and be involved throughout (Better 2006).

As a researcher utilizing feminist methods I acknowledged during the process of data collection and knowledge production it was not always possible to be entirely objective and completely neutral (DeVault 1996; Crotty 1998), as I brought with me, my professional knowledge and experience and “needed to be able to recognise the influences, advantages and disadvantages that brought” (Appleton 2011, p.2). Therefore to enhance research integrity, reflexivity was utilized during all stages of the process, through the use of an electronic diary and with regular supervision with my supervisors (Appleton 2011; Blythe et al. 2013). Data collection was conducted in the ethos espoused by Oakley (1981), and power relations between myself and the women was minimised. The process of interviewing was by no means ‘hygienic’ (Oakley 1981, p.58) since interviews were frequently interrupted due to hospital routines and domestic responsibilities (washing machine noises, home delivery of shopping and so on) in the women’s homes. At times, especially during Phase One my questions appeared overly focused on the baby and I did not always pick up on cues from the women. In some instances during Phase Two I was able to revisit areas where I thought I was not focused enough on the women.

I acknowledge the experiences belong to the women but as the researcher I drew on my professional knowledge, my own previous experience of working within neonatal units, my earlier research on how parents view staff competency in a NICU (Cescutti-Butler 2001), to examine and interrogate the data. To begin with, I was so swayed by my own experiences as I strongly believed women with preterm babies in hospital faced many difficulties. Therefore the data was in danger of becoming mine rather than that of the women, as the first initial development of a template demonstrated (see Figure 5-5).

Reflexivity and supervision kept me grounded and I re-examined issues within my data and analysis to ensure this was what the women said, and not my thoughts leading or interpreting them in a particular way. I further realized that maternity services in which healthcare professionals are meant to provide women with choice, continuity and involvement in their care (and/or their baby/babies) reflect instead, services which do not necessarily deliver on these elements of care and are structured around professionals, leading me to consider how this impacted on women. In other instances reflection made me question many of my previously held beliefs. Please see Appendix 21 which outlines my dilemma when considering the message 'Breast is Best.'

A major source of learning has been how very challenging it was to rid myself as a researcher, of preconceived ideas. For example, during my viva I was asked whether I considered my thesis as scientific. The question threw me because my first reaction was no. But having thought about it, yes of course, I have made transparent my use of feminism and how it impacted on the research process. I have undertaken my research ethically and have tried to foreground women as producers of knowledge. In view of these principles I can be confident that my thesis adds to the small but growing body of knowledge around women and late preterm babies.

In addition, I have learned that interrogating myself has been as vital as (and sometimes more difficult than) seeking to ask questions that are probing enough to gain an in depth understanding of women's experiences. I also regret waking up to

feminism so late in my career. It has opened my eyes and forced me to re-examine a world where women continue to experience inequalities due to their gender. It has made me a better person and healthcare professional. As recommended by Walsh et al. (2015) I have introduced gender issues including a feminist lens into my teaching both at undergraduate and postgraduate levels.

Although I am in control of the data presented within this thesis, all of the women were provided with transcripts of their interview. Most did not provide feedback on the contents and I have reflected in chapter 5 on why this might have been the case. During the long process of my research I have lost touch with most of the women. Several were married to army personnel and have moved on from their contact addresses and others have not responded to telephone contact. I was able however, to share some of my findings and analytical thoughts with one woman who agreed with my interpretation of her experience. I cannot guarantee the rest of the women would have agreed with my findings and discussion of their experiences.

My research was not co-created with women; I believe however, my qualitative approach to researching their experiences of caring for their LPBs was appropriate. My aim was to construct a window through which to view and capture the reality of their experiences (Seibold 2001). This I believe has been achieved and I hope is a fair reflection of their experience. I am also somewhat reassured my focus wasn't completely out of sync with women's priorities when considering the project undertaken by Cheyne et al. (2013), in which women unanimously agreed postnatal care and improving quality of care were important issues for research. Improving postnatal care has been highlighted by quantitative maternity services, see for example those undertaken by the CQC (2013; 2015) Bhavnani and Newburn (2010) and qualitative research undertaken by Beake et al. (2005), Wray (2006; 2012) and Beake et al. (2001).

8.4 ORIGINAL CONTRIBUTIONS:

This thesis has provided areas of original contribution to knowledge in the following ways.

- 📌 The experience of women caring for their LPBs was largely unknown despite these babies being the largest growing preterm population.
- 📌 My thesis explores these women's experiences using a feminist lens including applying aspects of Birth Territory Theory which has not been done previously. It has highlighted that mother-work occurs in environments where women lack control over many aspects of their mothering and where paternalism directs activities.
- 📌 The system in which care occurs, perpetuates a structure many women with children are already aware of – they carry the burden of childcare. It commences in hospital where women are denied support from their partner/families overnight and have to struggle on, regardless of their own health/needs and devote their time wholly to meeting the needs of their babies.
- 📌 Whilst this study has illustrated many aspects of mothering that are affected by having a LPB, a major focus for the women was on feeding. It is evident from the literature that feeding regimes are of benefit to LPBs (Puckett and Sankaran 2008), however these same regimes work against mothering and women's instincts when trying to manage the demands of their baby against the demands of a medicalised feeding model (Ludwig 2007; Cleaveland 2010; Munson et al. 2011). Importantly, the latter of the two demands, reinforces the ideology of scientific motherhood which places women in a position of little or no power with minimal ability to determine the feeding needs of their babies and/or recognising their own domains of knowledge. Women's mother-work is greatly increased when adhering to feeding regimes and requiring women to feed their babies with alarm clock

precision does not take into account, consideration of their own needs and the many factors they are expected to cope with.

Women veered towards putting aside their wishes (for example an early discharge) so that they could be viewed as 'good mothers' and tended to blame themselves if feeding did not proceed accordingly, rather than criticise the environment and the processes they were required to mother in. The biomedical discourse was evident and enforced by most healthcare professionals. Inconsistent feeding advice and support caused women to feel stressed and was likely due to the lack of formal training that healthcare providers receive around the feeding abilities of LPBs. Failure to recognise these needs may have led to an extended hospital stay and for some women, inability to breastfeed successfully.

Many of the women in my study wanted to breastfeed and the fact they were unable, due to constraints within the postnatal environment and/or a lack of enhanced support is "an important issue for women both from a human rights and feminist perspective since breastfeeding empowers women and contributes to gender equality" (Van Esterik, 1994, p.541). Feminists may consider these women as "oppressed and exploited" (Van Esterik, 1994, p. 541) because women in my study were hindered by the environment of care, by unnecessary separation in some instances which impacted on their ability to initiate breastfeeding and by medicalised feeding routines enforced by authoritarian 'others'. My findings demonstrate that some women blamed themselves for their baby being born late preterm, therefore having to discontinue breastfeeding because of institutional and human factors/barriers in some instances may have added to the feelings guilt already present and impacted on their sense of self as mothers.

🌸 My thesis contributes to the small but growing research around the experiences of women who are considered high-risk. Whilst some of the

women in my study experienced a normal vaginal birth, events leading up to their particular births were far from 'normal'. Therefore in my view, important considerations for future research could be focused on empowering and enabling dignity and autonomy for women in preterm labour. Researching these experiences would provide healthcare professionals with increased knowledge and understanding when caring for these women both during the intrapartum and postnatal periods.

8.5 MAKING A DIFFERENCE:

Feminists should undertake a methodology to support research that is of value to women with the findings/discussion leading to change or action benefitting women (DeVault 1996), therefore I hope the findings of my study will make a difference to women with LPBs and for those who care them, by advising on the difficulties these women encounter as they commence their mothering and mother-work.

I will disseminate my findings (have already undertaken a conference presentation – MAINN 2017) and the new knowledge gained from my thesis at conferences which are aimed at neonatal nurses, midwives and doctors specialising in neonatal care and publish within relevant professional journals. There are opportunities to add my findings on social media pages such as Maternity Experience (#mat experience: <http://matexp.org.uk/>) which is a platform for identifying best practice across the nation's maternity services. On a political level, it would be helpful if I could influence organisation of care and resources within institutions and the communities which provide care by highlighting the difficulties experienced by women and their LPBs. I am also a member of the Preterm Birth Clinical Study Group (CSG) which is a RCOG specialist group, supported by British Maternal and Fetal Medicine Society (BMFMS) (I subscribe to this organisation), British Association of Perinatal Medicine (BAPM) and by Action Medical Research. It is one of 11 CSGs managed by the RCOG. The aim of the Preterm Birth CSG is to identify important research questions around preterm birth and to work with the

originators of supported studies to improve clinical outcomes following preterm birth by prevention or intervention.

8.6 RECOMMENDATIONS:

- 📌 There is a need to qualitatively research women's experiences when undergoing long term tocolytic therapy. The established literature, although full to bursting on which tocolytic is the most effective in terms of cost and potential side-effects, does not offer any published qualitative studies which explore women's views on how tocolytic therapy affects them day to day.
- 📌 Women and their LPBs should only be separated when absolutely necessary, namely, for assisted respiratory support and other intensive care procedures. Being small should not be a justification. If a baby is transferred to a neonatal unit then the decision must be discussed at the time with women and their partners.
- 📌 Triage of a woman and her LPB should begin immediately and there should be adequate skilled staff to facilitate this.
- 📌 Skin-to-skin care should be instigated as soon as reasonably possible, unless life threatening situations are present, with appropriate staff skilled in caring for LPBs and adequate staffing levels to promote and support skin-to-skin care. Skin-to-skin care in this environment should be sustained so the benefits have an impact, such as improved thermoregulation, commencement of 'bonding' and early breastfeeding.
- 📌 If a LPB stabilises appropriately, then a woman and her baby/babies should be transferred together to an appropriate environment, which the findings of this study suggest is not the PNW or the neonatal unit. In my discussion chapter I highlighted the possibility of parents having beds by their babies' cots in NICU, therefore I would recommend, based on the importance of

non-separation, that this option be explored further, or a separate ward for mothers of LPBs.

- 🌸 Seek to create an environment where women can do mother-work based on 'instinct' and feed babies on demand and in recognition of early baby feeding cues. Keeping women and their babies together will facilitate knowing behaviour for the dyad. Whyte (2012) recommends an approach to feeding which is baby-led, in that he or she controls the timing and the amount of milk. Support women to decide how much volume should be provided if supplementation is required in the early days, minimising the need for strict 'top-up' guidelines. The women went home with instructions to 'top up' their baby, so this principle could be utilised early on, with women deciding the need in conjunction with healthcare providers. Research into this model of care is needed.
- 🌸 I would recommend further research is undertaken to explore women's views on partners staying overnight. Whilst there is a view that advocates fathers should, and have a 'human right' to stay with their partners on the PNW, there is very little, apart from anecdotal evidence, to inform us what women think of this arrangement.
- 🌸 The environment should also offer women of LPBs a space for them to come together to share their experiences, as my findings demonstrated women did not like sharing the same space as women with term babies. Women who are caring for LPBs could be invited to contribute to a 'wish list' of how they would envisage the environment.
- 🌸 A discharge plan should be formulated with women from the outset thereby giving control to the woman on how far she can 'push' her baby towards the journey home.
- 🌸 There is a need for dedicated staff who understand the particular requirements of women caring for LPBs. Busy midwives who are caring for

women with high risk needs do not appear to have time to sit and provide emotional care for women with LPBs. These women need to be nurtured as woman-mothers first and foremost, similar to that experienced by women who give birth in birth centres (Walsh 2007).


🌸 Research undertaken by Boyle et al. (2015) highlights the demands LPBs have on specialist neonatal services. LPBs were in hospital for longer periods of time, those that required only a postnatal stay had higher demands than Term babies and were less likely to be breast fed, all similar to my findings, except I have provided women's perspectives. Therefore I propose opportunities be developed to enable a team of midwives to undergo specific training to enable them to become 'premature baby midwives' comparable to those reported by Allison (1996). These specially trained midwives supported women to care for their preterm babies at home. Women in my study had a need for support with infant feeding, in addition to reporting conflicting advice and feeling bullied into trying feeding methods they did not want to use. Premature baby midwives would have increased knowledge of these babies and their feeding peculiarities and should be employed to work specifically in hospital or community environments to support women. Further research on this model of care is recommended. Workforce planning must take into consideration the needs of women and their LPBs.

🌸 Environments of care could promote a shared model of mother-work between the woman and healthcare professionals. If women wish to go home before their baby is ready as they often were in my research, I propose the following two recommendations as advocated by Whyte (2012).

- 1) Facilitate a complete discharge home with community support. I undertook a pilot project with one of my supervisors (JH-T) a few years ago exploring an early discharge programme for smaller but healthy preterm infants. Prior to commencing the pilot I

interviewed women on their views on an early but supported discharge to home care. The women were completely supportive of the project (Cescutti-Butler 2009) and in due course it was successfully undertaken with both women and staff benefitting. Unfortunately due to organisational issues the next stage of formally creating a permanent early discharge programme never materialised. However, in the context of women and LPBs it could work, because as my findings reveal, women were regularly monitored following discharge, initially by midwives followed by HVs. In addition, women policed themselves. They did not appear to have any problems in maintaining a feeding schedule for their babies in the days following discharge.

- 2) A suspended discharge which enables babies to go home 'on a pass' but return daily for evaluation or care. Hospital staff maintain responsibility for the dyad but without direct administration of infant care and their 'bed' is kept open (Whyte 2012). This particular recommendation does not take into consideration woman's needs, such as, travelling back and forth to the hospital may be cost prohibitive to some, women who had undergone an OD would be reliant on family/friends for transport, childcare responsibilities and so on. Research exploring suspended discharge would be of benefit.

 I concur wholeheartedly with a practice point highlighted by Whyte (2012) which suggests that some stable preterm babies will be safer at home and feeding would be successfully established rather than in a nursery or a busy PNW. However, we do not know whether women would endorse this approach. For instance, many commented in my research their extended stay on the PNW benefitted them, as when they were discharged they felt

confident in caring and with feeding their baby/babies. This is a further avenue worth exploring.

🌸 I would recommend all healthcare professionals who specialise in neonatal care are facilitated to explore the experiences of women who are at threat of preterm labour or who labour and birth a preterm baby.

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Legislation

Health and Social Care Act 2012

Appendix 1: Holding an insider-outsider position

I had just finished interviewing Valerie and as I walked past her bed on the ward, I noticed she was standing next to her husband crying on his shoulder. I immediately became concerned, thinking perhaps the interview had upset her. I asked if I could help and she indicated that during our interview, her baby had been seen by a doctor and an intravenous device had been inserted into his arm. As a midwife I was aware of the implications of this, her baby would require intravenous antibiotics (we had discussed issues with her baby during our interview) and Valerie would not be going home that day. She had been very excited about the prospect of being discharged. After further discussion, it became clear that both Valerie and her husband were unsure of processes. I was relieved the interview was not the reason for Valerie's distress and I tried to reassure her and her husband. Fortunately I was able to speak to the midwife caring for the family and she assured me she would speak to the parents forthwith. I left the ward feeling annoyed and reflected within my research diary:

"I was angry Valerie and her husband had not been informed of the possible outcomes in relation to their baby son but mostly, I was angry that her excitement at going home had been shattered. I was glad that I was able to help in a small way by speaking to the midwife who I knew very well."

Of interest when I returned to interview Valerie for Phase Two I started by asking about what had happened next:

"The midwife – I can't think of her name now – [name removed] – she came over and she was *absolutely lovely* about it all. They – in the end they tried to put the needle in him for the antibiotics and things, so that's what they were doing – (OK) and stuff, [...] they offer, but obviously it's not nice for us to watch, but that's all it was. But he didn't need it in the end either, they got the results wrong, it was mine." (Valerie – Phase Two)

I was shocked that the intervention her baby had undergone (unnecessarily as it turned out) was intended for Valerie and her disclosure enabled me to delve a little deeper into her wellbeing.

Appendix 2: Information pack for Local Collaborator



Study Title: Women's experiences of caring for a late preterm infant.

Background:

Despite advances in technology, improved access to antenatal care and public health initiatives to prevent preterm birth (Goldenberg et al. 2008) rates have risen worldwide (Saigal and Doyle 2008). The highest increase has been in births that are considered 'late preterm', i.e. infants who are born between 34 and 36 completed weeks of pregnancy (Engle et al. 2007). The needs of late preterm infants have been unrecognised for many years (White 2009) and it is only recently that healthcare professionals have begun to consider their requirements (Bakewell-Sachs 2007). There is very little research that focuses specifically on late preterms; and scarcely anything reporting women's experiences of caring for a late preterm infant. It is for this reason that I wish to carry out this qualitative study to address this gap.

What is the aim of the study?

To explore the experiences of women who are caring for a late preterm infant.

Who is eligible to take part?

Inclusion Criteria:

- Women who have an infant/infants born between 34 (lower limit of gestation) and 36 6/7 completed weeks of gestation.

Exclusion criteria:

- Women who have an infant(s) with a major congenital abnormality
- Women with multiple gestations above twins
- Women who are known to have abused substances during pregnancy.
- Women who are gestational or insulin dependant diabetics during pregnancy
- Women who have a stillborn infant or whose infant has an early neonatal death
- Women under 18 and over 45 years of age
- Women who are unable to consent for themselves

What is my role?

I am asking for your help in identifying potential participants. During your daily ward round of the postnatal ward I would like you to identify any women who have a late preterm infant born between 34 and 36 completed weeks of pregnancy and

check the woman's suitability for inclusion in the study against the above criteria. If a woman is eligible then I would like you to provide her with an information pack containing details of the research study. I have supplied you with 20 information packs. If you require any further packs please don't hesitate to contact me. My contact details are at the end of this leaflet.

I would be grateful if you could return to the participant later in the day and collect the envelope supplied for the participant and contact me on my mobile number: XXXXXX

What are participants expected to do?

Women who agree to take part in my research study will only be contacted by me once I have received their reply slip. I will then arrange to interview them whilst they are inpatients on the postnatal ward. A second interview with the woman's consent will take place 5-6 weeks following discharge from hospital.

Who is organising and sponsoring the research?

The study is being undertaken as a research project for my doctoral studies. The School of Health and Social Care at Bournemouth University is sponsoring the research. No application for external funding will be made.

Who has reviewed the study?

- The South West 5 Research Ethics Committee
- The School of Health and Social Care Postgraduate Research Committee
- Regular and ongoing review by 2 academic supervisors
- Information and Governance at XXXXX NHS Trust Hospital

Who do I contact for further information?

If you require any further information please contact:

Luisa Cescutti-Butler

PhD Researcher

XXXXXXX

lcbutler@bournemouth.ac.uk

Dr. A. Hemmingway

1st Supervisor

XXXXXXXXX

ahemmingway@bournemouth.ac.uk

Dr. Jaqui Hewitt-Taylor

2nd Supervisor

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References:

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Appendix 3: Daily postnatal sheet

Appendix 3: 101-010794: SouthWest5

Thursday February Day Shift 2010

| | Name | Situation | Day | Para | Gest | Feeding | Dis | Baby | Important Info |
|----|---------|------------------------|-----|------|------|---------|------------|------------|---|
| 1 | Bethany | NBFX 21.37 | 1 | 1 | | C&G | | NICU | Catheter in situ |
| 2 | Trixie | EMLSCS @ 02.29 | 0 | 3 | | BF | | Male | Observe pv loss |
| 3 | Shelley | SVD 11.17 | 1 | 2 | 38.1 | BF | 11/02 ? | 3308kg | |
| 4 | | | | | | | | | |
| 5 | | | | | | | | | |
| 6 | Sian | SVD 0355 | 0 | 2 | | BF | | 3.472Kg | |
| 7 | | | | | | | | | |
| 8 | | | | | | | | | |
| 9 | | | | | | | | | |
| 10 | Ana | SVD 05.42 | 1 | 2 | | BF | 11/02 ? | 4226kg | Raised BP in past |
| 11 | | | | | | | | | |
| 12 | Maria | EMLSCS GA 01.09 FTP | 0 | 1 | term | BF | | 4.330Kg | GDM (diet)Hypoglycaemic protocol / Next BM due 0810 |
| 13 | Tracey | SVD | 0 | 2 | | | | TWINS NICU | |
| 14 | | | | | | | | | |

Appendix 4: Inclusion and Exclusion Criteria



Inclusion and Exclusion Criteria:

Inclusion Criteria:

- Women who have an infant/infants born between 34 (lower limit of gestation) and 36^{6/7} completed weeks of gestation.

Exclusion criteria:

- Women who have an infant(s) with a major congenital abnormality
- Women with multiple gestations above twins
- Women who are known to have abused substances during pregnancy.
- Women who are gestational or insulin dependent diabetics during pregnancy
- Women who have a stillborn infant or whose infant has an early neonatal death
- Women under 18 and over 45 years of age
- Women who are unable to consent for themselves

Appendix 5: Letter of invitation to women



LETTER OF INVITATION TO POTENTIAL PARTICIPANTS

Study Title: Women's experiences of caring for a late preterm baby.

Dear ,

I am a senior midwifery lecturer studying for a PhD at the School of Health and Social Care, Bournemouth University. As part of my research I am interested in finding out more about your experience of caring for a late preterm baby. A late preterm baby is a baby born between 34 and 36 completed weeks of pregnancy.

There is very little research about women's experiences of caring for a late preterm baby and it is for this reason that you have been given this invitation and information pack.

I would value hearing your story of what your experience has been like so far, and therefore I would like to invite you to take part in this research study. I enclose an information sheet which contains information about the study and your possible involvement in it.

When you have had time to consider this request, I would be grateful if you could advise me of your decision by completing and returning the enclosed reply slip in the envelope provided, and the postnatal manager: Mrs [name removed] will collect the envelope. If you wish to make further enquires about taking part in a research project, please ask the ward staff to contact the Customer Care office based at the hospital: contact details as follows: Tel no: [X] or the office is based on [name removed] of the north [name removed] building in the [name removed] Unit. Open Monday to Friday – 8.30-4.30.

If you wish to take part, with your permission, I will telephone you to arrange a convenient time and date to meet.

Please do not hesitate to contact me or one of my supervisors if you have any further questions. My contact details are below. I have also obtained ethical approval from the Southwest Research and Ethics Committee to undertake this study.

Thank you for taking the time to read this letter. I look forward to meeting you in due course, should you decide to accept this invitation. Declining to participate will not affect your current or any further care that you may receive from [name removed] NHS Foundation Trust Hospital.

Yours sincerely

Luisa Cescutti-Butler

PhD Researcher

01202 961550

1st Supervisor: Dr. Ann Hemmingway: xxxxx

2nd Supervisor: Dr. Jaqui Hewitt-Taylor: xxxxx



Study Title: Women's experiences of caring for a late preterm baby.

REPLY SLIP should you wish to participate

I have read the information sheet provided and decided that I wish to take part in the above research project.

NAME:

SIGNATURE:

CONTACT PHONE NUMBERS:

MOBILE:

HOME:

DATE:

Appendix 6: Information pack for women



Information about the research

Study Title: Women's experiences of caring for a late preterm baby.

Introduction:

- You are being invited to take part in a research study. Before you decide to take part, it is important for you to understand why the research is being undertaken and what it will involve.
- Please read the following information carefully and if you wish discuss it with others, please contact the Customer Care office based in the hospital.
- Take time to decide whether you wish to take part.
- Thank you in advance for reading this information sheet.

What is the purpose of the study?

I am carrying out this study to explore your postnatal experience of caring for your baby but we may also spend time talking about your baby's birth.

Why?

A mother's view of her experience of caring for a baby who is 3-4 weeks early has not been looked at in depth before. I hope to discover what it is that you and your baby need in terms of care and advice in the postnatal period.

Who will be participating?

I plan to invite 15-20 mothers to talk about their experiences.

Do I have to take part?

No. Participation is entirely voluntary. Even if you begin to participate you can withdraw your consent and participation at any time. You may not wish to participate at all. I will not know you have been approached.

What will happen if I take part?

We will meet initially at a mutually convenient time when I will explain the study in full. If you agree to participate, I will ask you to sign a consent form.

What do I have to do?

You will be asked to participate in two interviews over a period of approximately two months. The interviews should not last more than an hour. During the interviews you are more than welcome to have your baby with you.

- The first interview will take place while you are still in hospital. Therefore I would be grateful if you could return your reply slip indicating your interest within 24 hours as this will enable me to interview you in the hospital setting.
- The second interview will take place about 5-6 weeks later in your home (with your consent), or at any other location of your choice.
- With your consent, the interviews will be digitally recorded.
- As it will be quite a long time before we meet again after our first interview it may be helpful for you in the meanwhile, to occasionally jot down any thoughts or feelings that you think you would like to share with me at our second interview.

What are the possible disadvantages?

When recounting your story you will be recalling your experiences with your baby so far. This may cause you some distress, therefore, at any point throughout the session, you may decline to discuss matters or you may end the interview without reason. Every effort will be made to ensure that the sessions are handled discretely and sensitively.

What are the possible benefits of taking part?

- I cannot promise the study will help you personally; however it is an opportunity to take part in research that aims to have a positive impact on any future service developments for families and their preterm baby (ies).
- By sharing your story you may be able to make sense of your experiences thus far.

Will my taking part in this study be kept confidential?

Absolutely. I will make a record of your name, address and contact details. These records will be kept in a locked filing cabinet to which only I will have access. When I make the written records of the interviews and when the findings are published, I will use pseudonyms for you, and any other personal details that might lead to your identification will be changed. When writing up the research some of your comments will need to be used in their original form as direct quotes; however, all direct quotes will be anonymised and you will not be recognised.

I will not be informing your GP or any other healthcare professional that you will be taking part in my research. However if you need to see one of them as a result of taking part, I have written a letter and enclosed an information sheet concerning the study for you to keep at your home. Please feel free to pass on the letter and information sheet provided by myself for your GP or any other relevant healthcare professional if you feel it necessary.

There might be occasions where I may need to share information with other healthcare professionals. If this arises I will discuss any concerns with you in the first instance. For example if you were provided with advice on infant feeding that may be incorrect or information around expected weight gain is misleading.

What will happen to the results of the research study?

The results of the research findings will be used in writing up my PhD thesis. In addition, I aim to publish articles in research journals and to present my findings at national and international conferences. I will also present the results to NHS Trust representatives, so that they can improve their care. If you would like a report at the end of the study, please contact me.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been considered by the South West 5 Research Ethics Committee.

Contact for further information

If you require any further information please contact:

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I hope you have found this information sheet useful. Please feel free to keep it for later reference or dispose of it if you are not interested. If you wish to take part, please complete the reply slip contained within your letter of invitation and return in the envelope provided. Please hand the envelope to a healthcare professional on the ward to put into the internal post.

Thank you for thinking about taking part in the study

Appendix 7: Consent Form



Study Title: Women's experiences of caring for a late preterm baby

Please initial box

1. I confirm that I have read and understood the participant information sheet for the above research study. I have had the opportunity to consider the information and ask questions which have been answered satisfactorily.

☐

2. I understand that my participation is voluntary and that I am free to withdraw from the research study at any time without giving any reason and without our medical care being affected.

☐

3. I understand that data collected from the study may be published and any information obtained will be kept confidential and I will be anonymous.

☐

4. I agree to the recording of my interviews

☐

5. I agree that my individual quotations may be used within the research and within any outside publications

☐

6. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory bodies or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records

☐

7. I agree to take part in the above research.

☐

Name of Woman:

Signature:

Date:

Name of person taking consent:

Signature:

Date:

Appendix 8 General Risk Assessment Form

Before completing this form, please read the associated guidance on 'I: Health & Safety/Public/Risk Assessment/Guidance. Use this form for all risks except from hazardous substances, manual handling & Display Screen Equipment (specific forms are available for these). If the risk is deemed to be 'trivial' there is no need to formally risk assess. All completed forms must give details of the person completing the assessment. Risk assess the activity with its present controls (if any) -then re-assess if action is to be taken and after further controls are put in place.

The completed form should be kept within the School/Service/Department.

| |
|---|
| <p>1. Describe the Activity being Risk Assessed:</p> <p>Researcher undertaking qualitative research involving interviewing participants in their own homes.</p> <p>2. Location(s):</p> <p>Participants own homes in XXXXXX and surrounding areas.</p> |
| <p>3. Persons at potential Risk (e.g. Specific Staff only, General Staff, Students, Public etc.):</p> <p>Participants</p> <p>Other family members who may be at risk</p> <p>Researcher</p> |
| <p>4. Potential Hazards i.e. <u>What Could Happen?</u> (NB: List hazards without considering any existing controls):</p> <p>Participants could be vulnerable to verbal or physical abuse from the researcher as she will be going into their home.</p> <p>Health and Safety issues within homes.</p> <p>Participants may become distressed.</p> <p>Safeguarding children issues.</p> <p>Researcher vulnerable to verbal or physical abuse because going into private residences</p> <p>Poor standards of practice identified.</p> |

5. Control Measures Already In Place:

Participant will be provided with written information outlining purpose of study and invited to participate. When consent for an interview is obtained the researcher will discuss how confidentiality will be maintained and emphasise that the participant can withdraw from the study at any time without it affecting any current or future care

Voluntary nature of participant opting into the research

Researcher will clearly discuss with participants purpose of research, and will inform participants that confidentiality will be maintained unless bad practice is identified and then the appropriate authorities would be informed.

Interviews will only take place during the day

Participants will have contact details of the Supervisors involved in the supervision of the research student. These details are on the information sheet provided by the researcher.

If the participants become distressed as a result of discussing their experiences the researcher will suggest to participants to seek follow-up counselling from her community midwife (if still under her care), the Health Visitor or the GP.

If any issues arise which relate to Safeguarding Children the researcher will raise these with the woman herself and she will contact the Lead for Safeguarding Children at the Trust where the research was undertaken.

If poor standards of practice are raised by participants the researcher will discuss any issues which need addressing with her Supervisor of Midwives in accordance with the researchers professional documents. (NMC 2008).

Researcher will identify known contact (research supervisor and next of kin) who will be aware of location and timings of each visit, and will telephone when she has returned to base

Researcher has recently had her honorary contract with the NHS Trust renewed where the research will be undertaken, and this required CRB clearance.

6. Standards to be Achieved: (ACOPs, Qualifications, Regulations, Industry Guides, Suppliers instructions etc)

Code of Professional Practice (NMC 2008)

Lone working health and safety policy Bournemouth University p43-44

Bournemouth University Research Ethics Code of Practice: September 2009

Midwives Rules and Standards- NMC 2008

| | | | | | |
|--|-----------------------|-----------|-----------------------------|------------------|--|
| Code of Professional Practice for Nurses and Midwives – NMC 2008. | | | | | |
| <p>7. Are the risks adequately controlled (bearing in mind 4. & 5.)? Write 'Yes'</p> <p>If Yes, Step 8: <u>Ensure that those affected are informed of the Risks and Controls:</u></p> <p>Confirm how you have done this (e.g. written instructions):</p> <p>Participants will receive a participant information sheet, noting outline of study, and details of confidentiality. Participants will need to sign a consent form prior to the interview commencing.</p> <p>Instructions for supervisors and next of kin when researcher is undertaking interviews in participant's homes.</p> <p>Then, complete boxes below and the assessment is finished until the review date(s):</p> | | | | | |
| 9. Person(s) Who did Assessment: | Luisa Cescutti-Butler | 10. Date: | 11 th March 2011 | 11. Review Date: | |
| 12. Checked By: | | 13. Date: | | 14. Review Date: | |
| If No (to Q7) go to next section and estimate 'Residual Risk'. | | | | | |

| <p>1 Estimating the Residual Risk:</p> <p>15. Choose a category that best describes the degree of harm which could result from the hazard, then choose a category indicating what the likelihood is that a person(s) could be harmed. Check only ONE box within the table which matches both of your choices.</p> | | | |
|--|--|--|--|
| Degree of harm | Slightly Harmful <small>(e.g. minor injuries such as minor cuts/bruises not always requiring first aid)</small> | Harmful <small>(e.g. serious but short-term injuries such as broken bones or curable disease)</small> | Extremely Harmful <small>(e.g. would cause fatality, major long-term injuries or incurable disease)</small> |
| HIGHLY UNLIKELY | TRIVIAL RISK <input type="checkbox"/> | TOLERABLE RISK <input checked="" type="checkbox"/> | Moderate Risk <input type="checkbox"/> |
| UNLIKELY | TOLERABLE RISK <input type="checkbox"/> | Moderate Risk <input type="checkbox"/> | Substantial Risk <input type="checkbox"/> |
| LIKELY | Moderate Risk <input type="checkbox"/> | Substantial Risk <input type="checkbox"/> | Intolerable Risk <input type="checkbox"/> |

| | |
|--|-----------------------------|
| 16. Then note the advice below on suggested action and timescale | |
| Residual Risk Level | Action and Timescale |

| | |
|--|---|
| Trivial Risk <input type="checkbox"/> | No action is required and no documentary records need to be kept. |
| Tolerable Risk <input checked="" type="checkbox"/> | No additional controls are required. Consideration may be given to a more cost-effective solution or improvement that imposes no additional cost burden. Monitoring is required to ensure that the controls are maintained |
| Moderate Risk <input type="checkbox"/> | Efforts should be made to reduce the risk, but the costs of prevention should be carefully measured and limited. Risks reduction measures should be implemented within a defined period. Where the moderate risk is associated with extremely harmful consequences, further assessment may be necessary to establish more precisely the likelihood of harm as a basis for determining the need for improved control measures. |
| Substantial Risk <input type="checkbox"/> | Work should not be started until the risk has been reduced. Considerable resources may have to be allocated to reduce the risk. Where the risk involves work in progress, urgent action should be taken. |
| Intolerable Risk <input type="checkbox"/> | Work should not be started or continued until the risk has been reduced. If it is not possible to reduce the risk even with unlimited resources, work has to remain prohibited. |

| | | | | | |
|--|-----------------------|------------------|-----------------------------|------------------|--|
| 17. If 'Moderate' 'Substantial' or 'Intolerable': What New Control Measures are to be Considered to reduce risk? | | 18. Referred to: | | 19. On Date: | |
| <u>20. Ensure those affected are informed of the Risks & Controls</u> Confirm how you have done this e.g. written instructions: | | | | | |
| 21. Person(s) Who did Assessment: | Luisa Cescutti-Butler | 22. Date: | 11 th March 2011 | 23. Review Date: | |
| 24. Checked By: | | 25. Date: | | 26. Review Date: | |

Appendix 9: NHS SW Ethics Approval letter



17 March 2011

Luisa Cescutti-Butler
Bournemouth University
605, Royal London House
Christchurch Road
Bournemouth
Dorset
BH1 3LT

Dear Luisa Cescutti-Butler

Women's experiences of caring for a late preterm infant
RDMC 76/2010/2011

Thank you for the documentation relating to the above study.

is responsible acting as a Participant Identification Centre (PIC) and, in accordance with IRAS guidance, formal research management and governance approval is not required. We note that may identify and refer NHS patients as potential participants to Bournemouth University.

Foundation Trust has reviewed the request to refer patients, including any resource implications or data protection issues, and this letter confirms their permission for to act as a PIC and proceed with the identification and referral of potential participants.

Please be aware that the R&D office must be notified of the following as they arise:

- Serious adverse events/SUSARs at Foundation Trust
- Amendments
- Progress reports
- Closure of the study
- Planned monitoring and audits visits by the Sponsor

Please do not hesitate to contact me if you require any additional information or support. I wish you every success with the study.

Yours sincerely

R&D Manager

R&D Consortium comprises:

NHS

Appendix 10: R&D Approval letter



17 March 2011

Luisa Cescutti-Butler
Bournemouth University
605, Royal London House
Christchurch Road
Bournemouth
Dorset
BH1 3LT

Dear Luisa Cescutti-Butler

**Women's experiences of caring for a late preterm infant
RDMC 76/2010/2011**

Thank you for the documentation relating to the above study.

_____ is responsible _____ acting as a Participant Identification Centre (PIC) and, in accordance with IRAS guidance, formal research management and governance approval is not required. We note that _____ may identify and refer NHS patients as potential participants to Bournemouth University.

_____ Foundation Trust has reviewed the request to refer patients, including any resource implications or data protection issues, and this letter confirms their permission for _____ to act as a PIC and proceed with the identification and referral of potential participants.

Please be aware that the R&D office must be notified of the following as they arise:

- Serious adverse events/SUSARs at _____ Foundation Trust
- Amendments
- Progress reports
- Closure of the study
- Planned monitoring and audits visits by the Sponsor

Please do not hesitate to contact me if you require any additional information or support. I wish you every success with the study.

Yours sincerely

R&D Manager

R&D Consortium comprises:

NHS

Appendix 11: Interview proforma: Phase One

- Demographic information:
 - Age
 - (What sort of birth did you have?)
 - (Did you have a boy/girl?)
 - Any other children and ages?
 - Occupation
 - Marital status
 - Ethnicity
 - Educational level
 - Region of domicile –first 3 characters of postcode.

Main opening question to:

- Tell me about your experience of caring for your infant so far.

It is anticipated that women will discuss some of the following topics:

- Their birth experience
- Their experience on the postnatal ward
- Care and support provided to them on the postnatal ward
- Interactions with staff
- Visiting hours
- The postnatal environment
- Their understanding of their preterm infant
- Care and support for their preterm infant
- Care and support if their preterm infant is being cared for on the neonatal intensive care unit (NICU)
- Arrangements for and feelings about leaving hospital with their infant
- Arrangements for and feelings about leaving hospital without their infant

The following prompts will be used if needed to uncover depth around certain issues:

- Care provided on the postnatal ward:
 - How did that make you feel?
 - Can you tell me a bit more of that in detail?
 - Who provided the help?
 - What else could have been helpful?
- Their understanding of a preterm infant:
 - Clarify the terms used by the women and their understanding of the terms
 - Clarify any technological terms used by women
 - Their understanding of the definition of a late preterm infant
 - If premature birth was induced for maternal medical reasons or for the health of their unborn infant what were they told

- Was the woman informed that her infant may experience problems following birth and what these problems may consist of?
- Was the woman prepared for her infant to go to NICU?

Appendix 12: Interview proforma: Phase Two

Participant's Homes.

Main opening question:

- You have been home now for a few weeks. What has been your experience so far in caring for your infant?

It is anticipated that women will discuss some of the following topics:

- The discharge process
- How she felt leaving hospital
- How she felt arriving home
- Help and support received at home
- Problems with her infant
- Possible readmission
- Health professional contact/support

The following prompts will be used if needed during this phase of interviewing to uncover depth around certain issues:

- Help and support received at home
 - Who provided the help and for how long?
 - Any follow up care provided?
 - What other help or support would have been helpful?
- Problems with her infant(s)
 - Clarify details about any problems
 - Any risks discussed with the woman prior to discharge in relation to her infant's ongoing health
 - Was the infant readmitted to hospital following discharge and if so reasons for admission?
 - What would you say to other mothers of a late preterm baby?
 - What would you like to say to your health professionals?

Appendix 13: Extract of an interview – Phase One

Luisa

Tell me about your experience for caring for your infant so far?

Kate

Um, (pause) rather stressful so far (Ja) um (pause) some days have been good, some days have been bad. There's been days where I have just been in tears the whole time (ok) he's had problems feeding, that was his main problem (ok) so he wouldn't latch on to start off with, he would get tired, really, really quickly um so he wasn't taking enough milk um so they suggested putting a tube down his nose, so he had a tube for a while (ok) um which I found very distressing, um so, yeah it's been, I suppose (pause) quite emotional (Ja) quite stressful at times, then there's been good times when he does take a feed and you think you are finally getting somewhere, they are really happy moments, but (pause) overall I'd say it's been stressful emotionally

Luisa

Ok can I take you back to before he was born and just lead me up to that period before he was born, I guess everything's normal to a certain point, so what happened at that point?

Kate

Um had a very good pregnancy all the way through, um and then (pause) we discovered he was breech, I can't remember what stage, maybe at the 20 week scan I think they might have said he was breech, and um from that point on he was always breech and he never showed any signs of turning (ok) so they were keeping a close eye on that, um (pause) then in the last week before I went into labour I was (pause) really unwell, um I think where his head was sort of around my belly button area was really sticking out, and it just felt like there was lots of pressure everywhere, I could barely get out of the sofa without feeling sick um (0:02:52.4) and just really run down all the time. That was for about a week, um so then I was going to go to the doctor on the Monday morning at the midwife's suggestion to get signed off work, as I hadn't started my maternity leave, but that night my waters broke while I was in bed, (oh ok) and I had no idea what was going on as I wasn't expecting it, um because he was only 35 weeks in so I wasn't expecting it, to start off I thought I had wet myself because you know you just think 'oh god', so then we phoned up the hospital and they said "best to come in because of his being 35 weeks and being breech" they wanted me to come in, and that's when arrived and everything got going.

Luisa

Ok so at the point where your waters broke (Yeah) were you doing anything, were you just like in bed sleeping?

Kate

It was in the night so we were just in bed asleep yeah

Luisa

And they it just woke you up when you thought you had wet yourself

Kate

Yeah, just like a gush of water and actually I think the pressure as well went down at that point (oh ok) bizarrely I felt the best I'd felt in about a week because I had that bad week, and all of a sudden 'aaah' (laughter) yeah

Luisa

So they asked you to come in (yeah) so explain to me from when you got here

Kate

Um we got here and they took me into one of the little rooms on the labour ward and they put me straight onto a monitor, one for his heart beat and one to see if I *was* in labour, because we weren't sure, because I had no pain at all at that stage (ok) um and after half an hour on the monitor, I'd gone from being in no pain at all to *a lot of pain* and I didn't even know if they were contractions or not because I didn't know what they were supposed to feel like (0:04:47.3) but they said they were, and they were coming every um 2-3 minutes (oh ok) so they gave me a vaginal examination and um I was 4-5cms dilated already, (pause) so at that point the doctor said um to do a scan to check he was still breech which he was, um and they went through the options and said, um we advise caesarean, but it's your choice and um they went through all the risks, pros and cons and um we straight away said "caesarean". It wasn't what I *wanted* (hmm) originally but, when it came to it I just wanted to make sure he was ok so, we went for the caesarean (ok) and then it was all pretty quick after that. They rushed me down to theatre and under the knife, and out he came.

Luisa

Oh ok so why was it if you were just contracting and 4 to 5 (yeah). Why was it a big rush in the middle of the night? Did anything change?

Kate

Um I think because I had gone from no pain to 4-5cms in half an hour, I think they thought it was progressing so quickly that if they didn't rush me down quickly, he might start coming (ok) yeah

Luisa

So in the time between you maybe coming here and going for your section, did anybody say anything to you about what his outcomes might be, born at his age?

Kate

No

Luisa

No. So nothing was spoken about in terms of him?

Kate

No. I found all that very stressful actually afterwards, (oh ok) because he went up to NICU to start with, (ok) so I obviously realised that at stage that there might be a problem because they whisked him off to NIC, but then I came onto this ward, um postnatal, and all of a sudden he appeared and they brought him down within an hour (oh ok) so at that point I naively assumed he was absolutely fine, there was no problem, so it all came as a bit of a shock when there were some problems, um I did almost feel like we were left to work that out for ourselves because nobody ever specifically said "this is what might happen, this *is* what is happening with him" (0:07:03.5) um yeah, I kind of assumed I would be here for a while because I'd had a section, not because of him, and then a few days in, the penny suddenly dropped, we are not here for me, we are here for him (ok) yeah

Luisa

So he was born at 35 weeks exactly

Kate

35 and 4 days

Luisa

35 weeks and 4 days and what was his birth weight?

Kate

I don't know in kilograms but it was 6lbs 5

Luisa

And you had a section (yes) did you have an epidural (yes) so ok you were awake when he was born (yes) so tell me about what happened around that point?

Kate

Um oh, that bits all a bit blur, because I was having quite strong contractions by that point, so I remember we went into the theatre, lots of people and bright lights (Ja) and they were moving me around onto beds, and um trying to reassure me because I was very nervous um and they got me to sort of sit on the bed and lean over to put the spinal block in, um and then they layed me down on the bed, um then they were spraying me with the water to see if it was taking (oh ok) um and it did really well on one side, but the right side took much longer, so I was starting to get really nervous, um but eventually it did take um they gave it an extra couple of minutes they said if it hadn't by that time it would be a general anaesthetic, but it did take and it was fine. The screen went up, and then the anaesthetist started talking to me, just about anything in general to keep me occupied, yeah no pain at all obviously, but felt all the tugging and pulling um which does feel a little like you're being winded, um it was fine, I was *really* nervous about caesarean beforehand, but actually when I was there, everyone was really good at calming me down so that was really good (ok) and they held him up, I didn't see him but my husband saw him, and then my husband went with him to where the paediatricians

were and saw him for a bit, I think it was about half an hour before I saw him (oh ok) which I found odd as well I accepted it because I thought it's more important they sort him out make sure he's fine, and then they just brought him past on his way out and just put at my head so I could see him.

Luisa

Ok so that was your half an hour when he was on his way out? (Um) or had you seen him before that?

Kate

He was out, my husband had seen him when they held him up, I didn't at that point, and then it was half an hour of me being stitched up and things while they were I suppose seeing to him and checking things over with him, and then after that they brought him round and just sort of put him by my head for a bit.

Luisa

Do you know what the problem was that he took so long to come and see you?

Kate

No I don't

Luisa

Did your husband say anything about it? (No) so you've never really known what the issue was in relation to why it was so long before you met him

Kate

I assume there was an issue, I don't actually know, I assume they were doing checks, that was my assumption

Luisa

Did you hear him cry when he was born (yes) he cried, (he did yes) and then he was taken to NICU, do you know why he was taken to NICU (no) No, have you ever found out?

Kate

No (laughter). Gosh I should have asked all these things shouldn't I, I didn't think too, but um I just assumed because he was early and they wanted to check things over (0:10:39.2)

Luisa

Ok so he basically went to NICU, you got sorted out (yup) got brought back to postnatal (yeah postnatal) and then he was back with you (yes) ok so then what happened after that?

Kate

Um then it would have been about 6 or 7 in the morning, so um he was fast asleep me and husband were just having a quiet word really, to pull ourselves together I

suppose after it all, um and then what happened (pause) there was a shift change, so, oh yeah just before the shift change they decided to come and get him to try and take some milk (ok) so um I want to breastfeed, so they um helped me to express some, and they gave him that

Luisa

How did they give it to him?

Kate

Um I think with a syringe, (ok) I think, yeah they were expressing into a little syringe, that's right um

Luisa

Any reason why he didn't go onto your breasts at that point?

Kate

I honestly can't remember, I can't even remember if we tried or not, I really can't remember (ok) um (pause) I don't remember him being put there, I obviously can't swear to that (ok) um, (pause) yes so we expressed, um didn't get much at all, sort of 0.1 millimeter sort of thing, um which they gave him and he took, and then we kind of went on like that all day, sort of just expressing really small amounts (ja) um I think I got up to 0.2mls (laughs) at one point, (researcher laughs) and um (pause) yes so that was the first day, and then I was quite surprised the 2nd day when all of a sudden somebody said "he should be having 22mls" (oh ok) because the first day everyone was saying "I was doing really well and everything was great", I was expressing, getting stuff out for him, and it was fine, he didn't need much anyway because he newborn, and then all of a sudden on the 2nd day it was like, we've got a problem because he needs to be having 22mls. That's a big jump, um so yeah that was all a bit of a shock (0:12:47.8)

Luisa

So tell us why suddenly that all changed? Do you know?

Kate

I don't know, um, (pause) sometimes I feel like it's different with the different staff (ok) um, different people have different ideas what they should be having, shouldn't be doing, so I don't know whether it was just that, or whether that is genuinely what happens, a baby doesn't need much on the first day and a lot more on the second day, I don't know?

Luisa

So on the first day in terms of his feeding, who was looking after you in terms of staff (baby lets out a squawk)

Kate

Yes, (who was it) it was J.....

Luisa

Was it midwives or staff on NICU?

Kate

Midwives here

Luisa

Midwives here, ok so then on the second day (it was midwives) so it wasn't, (no it was somebody else) and they said he should be having X amount? (yes) ok so how did they manage to give him that?

Kate

Um I carried on expressing as much as I could, and then they said they needed to get fluids into him, he had to be topped up with formula which um having decided to breastfeed I wasn't *overly* keen on but then I felt I had to take their advice if he needed to take 22mls and I couldn't give it him, (Ja) and then formula it had to be, so that's what we did, we topped him up (0:14:09.4)

Luisa

*Ok I just want to explore that second day because its interesting is that did they do a blood test for example to see what his blood sugars were (****reflective note 1 on Nvivo****)*

Kate

Yes they did

Luisa

And what was the result of that?

Kate

They were always fine

Luisa

They were always fine? (Yeah) so as far as you know it wasn't the blood sugars driving the change in the volume? It was just somebody else came on and said "this is what he should be having"?

Kate

I believe so (ok), although I have got the impression where, at some points they do talk to the paediatricians (ok) behind the scenes and I'm never aware of it, so I don't know whether they were in communication with them or not, at that stage

Luisa

Ok so had you not seen a Paed yourself?

Kate

Not at that stage (ok) other than the one who had brought him down from NICU if that was a paediatrician, I don't know (oh I don't know) yeah

Luisa

Ok so the second day he was having formula top ups, what sort of advice or were you given about the formula?

Kate

Um none, I was just asked what I wanted, SMA, C&G and Aptamil and which one did I want, so that was what I was told

Luisa

And how did you choose?

Kate

Um because we originally we were going to formula feed at home and I'd already decided if I did it would be Aptamil (ok) so that's how I chose because I had already chosen at home (ok) so yeah

Luisa

So why did you change your mind?

Kate

Um I honestly don't know, you mean about breastfeeding? (Ja) I don't know, before I was pregnant I was the least maternal woman in the world, and my husband was really the one that wanted a little one and I came round to it and I said "I'm never doing that breastfeeding thing, that's horrid" (researcher laughs) "I'm not doing that" and as soon as he came along I don't know if its hormones or what, it just all changed, and I thought I really want to do the best thing for him and I know that's the best thing so (good on you) it just seemed the natural right thing to do (Ja, brilliant) yeah so (laughs)

Luisa

It's funny how you change isn't it? That's the thing about breastfeeding that people say, don't always ask about it beforehand because often you change when you've had your baby you know so

Kate

I never thought I would do it not in a million years (fantastic) so yeah

Luisa

Well done you

Kate

Yeah really pleased that we have

Luisa

So let's go back to the formula thing, so 2nd day he was having top ups and you are still expressing, just talk me through the next few days? (0:16:29.7)

Kate

Um he was being syringed still at that stage on the second day, um and they were trying to get me involved as well, so I was doing finger in his mouth to get him to suck, and he was taking it, but there was a concern that because where he was so young, he was getting too tired to take the syringe feed, (ok) so the 22mls he should be having, he wasn't taking all of it at every feed, so then they started talking about having the tube down his nose, which (pause) both me and my husband *really* didn't want, just the whole idea seemed very very invasive and not right and at that stage I still hadn't got my head around the fact that he had a problem with his feeding and needed this, so um you know we were still piercing all that together, they kept on about it, said it was totally our decision but every time they came to help with a feed, it was kind of "what about the tube", "what about the tube" um so we resisted for about a day and a half um I think at that stage emotion got the better of us we were both tired both, you know both getting quite emotional now, and he had one really bad feed and we kind of caved and said "ok have the tube" (ok) um (pause) and yeah I got very upset at that point because I didn't really want him to have it, but um his dad went with him when he had it done, and he came back, and then they started doing um trying to get him to latch onto me, and when that didn't work trying, then doing it down the tube, the feeds

Luisa

Ok so the 22mls he's having, how many hours was he having that? What was the regime?

Kate

Every 3 hours

Luisa

Ok so at some point he must have been feeling quite full which is when you had the bad feed I suppose?

Kate

Yeah, they said it wasn't that, he was *just so tired* (oh ok) that he struggled to keep himself awake he might need it, but he couldn't keep himself awake, because he's too little that is what they said (ok) but then going back to the staff changes, um I found when they started suggesting tube during the day, we resisted all that day, we were quite upset about it and the night staff came on and they had a totally different attitude, and that was the first time I felt anyone had actually sat down with me and listened to everything I was saying. There was one really good midwife that night, she sat and listened and she said "she didn't think he needed the tube either so we wouldn't do the tube that night" and we carried on doing the finger syringe feeding when he wouldn't take from the breast, um (pause) and it went really well that night, and then the shift changed the following morning, and then they decided that maybe he should feed from a cup (0:19:43.3) instead, because I

think that day um the amount he needed went up something like 33-34 mls, so it was even more um that was when he had this bad feed he couldn't take that amount (Ja) with this little cup, and um that was the point when we said "the tube" (ok) yeah

Luisa

And just going back to when you were talking to that midwife in the evening what kind of things were you talking to her about?

Kate

Um (pause) my feelings on the tube and I didn't really want to have it um (pause) and how I thought we had been making progress with the finger syringe feeding, and she agreed, she was sort of saying that "the tube has its place but didn't think in this case it was right" partly because it can make them a bit lazy with feeding, because obviously they just feel perfectly full all the time, um and I think in some ways she was right because after he had the tube, um he did seem to become much more lazy, whereas before when we were doing the finger and syringe feeding, we would always put him to my breast first (Ja) and he *would* try (hmm) um after the tube, I've not been able to get him to latch on since, (ok) so now we are breastfeeding we are having to use a nipple shield, because he's not making the effort to kind of latch on himself, (ok) and to begin with, I think it took us over a day to get him even remotely interested in my breast after the tube, (ok) um so I think in some issues she was right (ok) (0:21:23.3). I suppose every child is different (pauses) (laughs)

Luisa

Ok so that's day 3 tube feeds and then, so what's happened, how many days is he now?

Kate

He's 8 or 9, he was born last Monday (oh ok) so he's 8 or 9 days

Luisa

Ok so basically at day 3 he went on tube feeds ok so tell me know what's happened from day 3 to more or less when you started the breastfeeding without the tube?

Kate

Um oh so much (laughs) um (pause) we kept having different strategies for feeding him, so it would change at almost every shift what we were going to do, and then in with that as well the paediatrician started coming down to see him, and they would have an idea as well about "we should do this, we should do that"!

Luisa

Why did they suddenly become involved?

Kate

I don't know, all of a sudden they just said "oh the paediatricians are going to come and see you" and oop there they appeared!

Luisa

So there was no major specific problem that you are aware of in terms of him

Kate

Not that I'm aware, but then I find these things were never really discussed with me so much, (ok) you know it just (pause) yeah they said "the paediatricians are going to come and see you" and they did (ok) and they just sort of had a look at him to check they thought he was healthy in all other respects, and then they looked at his feed charts to see what was going on, and then suggested "I want you to do X, Y and Z". Um I think that happened a couple of times, (pause) um yeah so it was, (pause) um trying to think of what patterns we had now, sometimes it was try him on the breast first and if he didn't take that then use the tube, sometimes it would be try him on the breast first, then if he doesn't take that, try him with finger and syringe and if he doesn't take that, try the tube. Um what else did we have? Oh, one night I got very upset because, (pause) there was a try on the breast first, and then the night staff came on and said "that was wrong because I was tiring him out by doing that" (****reflective note 3****) um so yeah, it's just conflicting advice with every shift change really, and lots of different patterns (pause) um depending on the midwives and what they thought the pattern should be for that day, or what the paediatricians thought the pattern should be for that day or night, um (pause) yeah and someone did say to me "well we have to do that to find out what works best for him" I can kind of see, but same time it gets quite stressful (hmm) trying to remember what we are doing today, (pause) and yesterday I think it was um, (pause) me and my husband commented that (pause) we had seen both midwives and paediatricians who talked about the cycle of breastfeeding and bottle feeding with expressed milk, and neither of us was sure as to what conclusion we had come to, (pause) and neither of us are stupid (laughs) you know, but by the time everyone had gone we thought "not *actually* sure you know, is it 2 breastfeeds and then a bottle, or is it one breastfeed and a bottle? Not sure"?

Appendix 14: Reflection following an interview: Phase One

'Mary'

| | |
|--|----------------------------------|
| Were the necessary formalities observed at the start (introductions, confidentiality etc) | Yes |
| Were the rights of the participant respected (consent, sensitivity)? | Yes |
| Was a non-judgemental stance maintained towards the participant's answers? | Yes |
| Was the session monitored appropriately in terms of: <ul style="list-style-type: none">• Participant's key points• Reading between the lines• Being aware of the 'fob-off' answer• Looking for the answer simply aimed to please the researcher | Yes |
| Were field notes taken after the interview in relation to: <ul style="list-style-type: none">• The impact of the context• Relevant non-verbal communication (gestures etc)• Any relevant distractions | See below for reflection on i/v. |
| Were prompts, probes and checks used to good effect where appropriate? | Yes |
| Were the appropriate courtesies given at the end (thanks, reassurance)? | Yes |
| Did the researcher keep the interview to time? | Yes |

Phase One:

The interview was conducted in the secondary P/N office without any outside interruptions. Mary's responses were mostly quietly spoken, but at times she responded very animatedly, and the following minute would drop her voice and become serious. I did not know what to make of her communication style.

She spoke freely about the circumstances leading up to her birth, and I guess her 'excitability' stemmed from the fact she had only found out she was pregnant seven weeks previously, when her brother-in-law had said: "that gyms not doing you any good, putting weight on." Mary denied his assertions (and what right does he have to comment on her body in that manner) and felt her weight gain was due to her underactive thyroid. Her GP however, confirmed she was pregnant and Mary

responded “don’t be so silly” whereupon her life descended into turmoil (escalating Blood Pressure and admission into hospital to control it) culminating in a late preterm birth and all that it entailed.

Unfortunately I entered the interview with some preconceptions (unsolicited) as my local collaborator had indicated to me “how could Mary not have known she was pregnant?” Judging Mary such as she was, suggests all women’s pregnancies are the same. As Mary said, hers was “the perfect pregnancy, no morning sickness, no *nothing*”. Indeed she thought she was infertile as her previous pregnancy was through IVF. In Mary’s situation the many common denominators of pregnancy were absent, unlike her first pregnancy where she experienced “the morning sickness, the back ache, the headaches”. When Mary realised she was indeed pregnant, she was: “*Scared and shocked*. (laughter) [...] because it’s like, ‘hang on a minute I’ve had no symptoms and you’re telling me I’ve got like 7 or 8 weeks and this baby’s going to be here’ (laughter) and then it’s like (pause) I wanted to know *how* it happened. You sat at the doctors, you’re 36 years old and you’re going “how did I fall pregnant” and he just looked at me and went “what” “I don’t mean it like that, I know *how* I fell pregnant but how?” and he went “that’s not something I can answer, if you don’t know”, and I was like “I don’t know” (voice lowers a little).

Of course all women’s pregnancies as lived experiences are different, yet women who do not know they are pregnant are often ridiculed or gossiped about, just as Mary was. A search on ‘Google’ revealed a surprising number of journalistic articles relating to women being pregnant and not knowing. It appears to be known as a ‘cryptic pregnancy’ and can be attributed to psychological or psychiatric issues or denial, although in the main, most women who unexpectedly give birth without knowing they were pregnant, are normal, well educated women (Pincott 2011, http://www.huffingtonpost.com/jena-pincott/pregnant-without-knowing-it_b_1078776.html). As indeed was Mary.

The interview with Mary was a wake-up call – firstly not to process ‘gossipy’ information prior to meeting women, and secondly, that old adage – ‘don’t judge a book by its cover’ was particularly poignant, as Mary’s story was I felt, sad at times

although she appeared positive and upbeat. And as a postscript she was eventually diagnosed with postnatal depression and that might explain her hyper-excitability during our first interview

Reflection 15: Professional Hats

Removing my Professional Hat!

I have struggled with the concept of removing my professional self from the analysis. I was immersed but not 'with woman' as I remained for quite some time focused on the baby. My professional background led to my research, but it was becoming a barrier because I started to produce codes utilising professional language. This would have produced results from a professional perspective which was not the aim of my research. Initially my focus was on late preterm babies and I became very fixated on the main and secondary questions which related to 'neonatal outcomes' and I couldn't move away from those issues. Therefore my first attempt at coding was not going to uncover the heart of women's experiences and I was devising that which was perhaps already known. Medical or professional ways of looking at the data only presents a view of the world that is medically orientated. It does not open up the data to looking at it in other ways. If I continued at this rate I was not going to discover any new understanding and I would have failed in my main research aim, to explore the women's experiences of caring for their LPT babies.

My supervisors became an essential part of the process. I was gently but repeatedly encouraged to examine my data as individual case studies: I was to view each experience as different. This approach enabled me to step outside my own experience and being descriptive and to start to view the data more analytically, by looking at it from each woman's eyes. I began by revisiting the data and devising codes from the women's words. The data began to reveal new possibilities and further helped my understanding of the women's experiences. For example data from just one interview (Marylyn) provided my revised template with 25 codes which 'jumped out' at me. Had I not removed my professional hat, all the rich data from the women would have been lost and their experiences would have remained invisible.

Appendix 16: Complete list of women's words as codes

Defining codes:

| |
|---|
| I have been in a hospital |
| I listen |
| Absolutely fine |
| Different with the different staff |
| The treatment I received was horrendous |
| Hard work |
| Get 'spouse' more involved |
| Labour |
| Never want to be induced again |
| Prepare to be induced |
| Not dilated much |
| Signs of labour |
| I was convinced I was in labour |
| You don't really see the signs |
| It was seriously forced into it |
| Got weighed |
| I'm going to have somebody coming over to check him |
| The midwife just sort of left me to it |
| Staff have been fantastic |
| Feelings following birth |
| You can't |
| I don't want them involved in their care |
| It was offered but I just felt that was a burden |
| Incompetent |
| His weight has helped |
| Skin to Skin |
| Being in NICU |
| Nurses got annoyed |
| They explained it all to me |
| They never took him away |
| Preparation |
| Better chance of survival |
| Just said he was a premature baby |
| Know what to expect |
| No preparation |
| Struggling to breathe |
| MOVING IN |
| I'm glad to be in a room like this |
| Main postnatal ward |
| moving in with me |

| |
|--|
| Going home |
| I don't know why I am here |
| I'm expecting to be here for awhile |
| They haven't said |
| My goal is next week |
| Hands on |
| Spoke to the doctors |
| More than happy to come down here |
| I haven't been worried about looking after him |
| Meeting baby |
| I didn't see him straight away |
| I needed to be there |
| the first time I held him |
| They never took him away |
| I want to be back with them |
| Get over there |
| Normal birth |
| I'm just waiting for the doctors to say what to do now |
| We are not here for me, we are here for him |
| Know what to expect |
| She sat and listened |
| Left a little bit |
| Caved in |
| Shared Care |
| I felt over the moon |
| Going to leave her here |
| Helping Me |
| Seemed normal |
| Feeding |
| I didn't like that drip thing |
| I want a routine |
| I don't want to demand |
| Important to establish breastfeeding |
| Just done what they said |

Appendix 17: Initial Template Revision 2

| Initial Template (Women) Revision 2 | | |
|---|---|---|
| Thematic area | Lower level themes | Impact on women's experience? |
| <ul style="list-style-type: none"> I couldn't breastfeed | Women's preferences / wishes for feeding their baby <ul style="list-style-type: none"> I didn't like that drip thing; I don't want to demand; I want a routine; Important to establish breastfeeding Mother's don't know best? | Yes. Most definitely has a major impact. |
| <ul style="list-style-type: none"> Going to leave her here | Women worried about being discharged home without their baby: <ul style="list-style-type: none"> I want to be back with them I needed to be there (separation issues) | Yes |
| <ul style="list-style-type: none"> I felt over the moon | Women taking control of their situation whilst in hospital <ul style="list-style-type: none"> Feeding baby up Weight gain Go home | Yes Feel this is NB but only 2 sources and 4 refs. Look at depth of comments |
| <ul style="list-style-type: none"> Not completely prepared for it | Women knew what was going to happen having experienced a previous LPB <ul style="list-style-type: none"> Also not having had any previous experience | Yes - Phase two data could be coded within this |
| <ul style="list-style-type: none"> We are not here for me, we are here for him | Woman realises she is not at the centre of care but her baby is | Yes |
| <ul style="list-style-type: none"> Did see them briefly | The woman first meet her baby after birth <ul style="list-style-type: none"> Get over there; I didn't see him straight away; I needed to be there; I want to be back with them; The first time I held him; They never took him away | Yes Could this be incorporated with #2? |
| <ul style="list-style-type: none"> More than happy to come down here | Supports for the woman and her baby once the baby has been discharged by NICU <ul style="list-style-type: none"> Which healthcare professional cares for | Phase two data could be included |

| | dyad? | within this code |
|--|---|--|
| <ul style="list-style-type: none"> Spoke to the doctors | Women discussing issues with the doctors: <ul style="list-style-type: none"> Feeding, discharge, weight and any other health related matter | Some of the women's health could be included from Phase two data? |
| <ul style="list-style-type: none"> Hands on | Women caring for their baby: <ul style="list-style-type: none"> Undertaking physical care | Yes – incorporate with #18? |
| <ul style="list-style-type: none"> She'll be home soon | Proposed time / day of discharge <ul style="list-style-type: none"> I don't know why I am here I'm expecting to be here for a while; My goal is next week They haven't said | Yes |
| <ul style="list-style-type: none"> Bringing baby down | Baby moves from one environment (NICU) into the woman's room on either postnatal / labour ward <ul style="list-style-type: none"> I'm glad to be in a room like this Main postnatal ward Moving in with me | Yes |
| <ul style="list-style-type: none"> Struggling to breathe | Baby has difficulties at birth <ul style="list-style-type: none"> Requiring assistance with breathing | Outcomes impact on experience? |
| <ul style="list-style-type: none"> He's kind of full term but early | Before baby was born <ul style="list-style-type: none"> Just said he was a premature baby No preparation Know what to expect Better chance of survival | Not knowing outcomes, does it matter to women's experience? Merge with #2? |
| <ul style="list-style-type: none"> You can't | Staff attitudes towards women <ul style="list-style-type: none"> I don't want them involved in their care Incompetent It was offered but didn't take it | Yes |
| <ul style="list-style-type: none"> Being in NICU | Preparation before baby born and where the baby may be transferred/cared for <ul style="list-style-type: none"> Experience of baby on NICU | Yes |
| <ul style="list-style-type: none"> I cried | Women's emotions whilst in hospital <ul style="list-style-type: none"> Quite tearful, Shocked, | Yes |

| | | |
|---|--|---|
| | <ul style="list-style-type: none"> • Feel guilty • Get over there • Traumatic birth | |
| <ul style="list-style-type: none"> • Staff have been fantastic | Experience of care | Yes |
| <ul style="list-style-type: none"> • The midwife just sort of left me to it | Level of involvement <ul style="list-style-type: none"> • Baby on NICU and on PN | Yes although not many were just left to get on with it and did it impact on experience? Could this be incorporated with #9? |
| <ul style="list-style-type: none"> • I'm going to have somebody coming over to check him | Knowledge of post discharge support | ? |
| <ul style="list-style-type: none"> • Got weighed | Weight <ul style="list-style-type: none"> • Losses • Gains • Feeding volumes | Yes – Link up with 1. Can be applied to Phase Two. |
| <ul style="list-style-type: none"> • Wet myself | Prepare for being induced <ul style="list-style-type: none"> • Not dilated much, • You don't really see the signs, • Signs of labour, • Never want to be induced again, • It was seriously forced into it, • I was convinced I was in labour | Before birth would have impacted on experience |
| <ul style="list-style-type: none"> • Get' spouse' more involved | Changing feeding methods | Link with #1? |
| <ul style="list-style-type: none"> • I listen | Assimilating advice provided by HCP's <ul style="list-style-type: none"> • I think it's good advice; • I want to try something else, • Conflicting advice | Yes |
| <ul style="list-style-type: none"> • I have been in a hospital | Environment of care | Yes |

Appendix: 18: Extract: Reflecting on amalgamation of themes

(* all names changed)

Looking now at incorporating some themes within others to make the template more analytical, so themes that may be similar could be merged into higher level thematic areas and maybe even delete some that are not relevant for now, but remain open to the fact that these may become important as I apply the revised template to the transcripts.

Did see them briefly

- Get over there;
- I didn't see him straight away;
- I needed to be there;
- I want to be back with them;
- The first time I held him;
- They never took him away

The above thematic area refers to how soon women saw their babies once they were born. This is an issue for women. Some of the quotes included within the theme are very telling:

Nicola* picks up her 'handbag catheter' and walks up to see her twins on NICU after caesarean surgery

Mary* describes her daughter in the following terms: "Like the film Alien – this thing just coming out and screaming"

Jane* even doubts it is her baby (previous experience): "Is this like, my baby? How is there any connection?"

Going to leave her here

- Women worried about being discharged home without their baby:
 - I want to be back with them
 - I needed to be there = separation issues

I feel 'going to leave her here' could be merged with 'did see them briefly', as overall it deals with separation/seeing baby briefly/ as women were anxious about only seeing their baby quickly after birth and then only having good physical contact sometime later. Theme to be changed to: "Is this like, my baby? How is there any connection"?

Struggling to breathe

- Baby has difficulties at birth:
 - Requiring assistance with breathing

He's kind of full term but early

- Just said he was a premature baby;
- No preparation;
- Know what to expect;
- Better chance of survival

Struggling to breathe deals with the baby's condition following birth and whether they required assistance. 'He's kind of full term but early' as a thematic area sums up why women were undergoing an induction of labour/spontaneous preterm labour, as the baby would be 'ok' based on its preterm gestation. Can the 'difficulties at birth' lower level theme be merged into 'kind of full term' as an overall higher level thematic area to describe outcomes for babies born at this gestation? I don't have a theme that pertains to any medical problems experienced by babies following birth. Does this impact on the women's experiences? Yes, since for some women it was a shock when their baby was taken away. Rereading the quotes already applied to the higher thematic area of 'He's kind of full term but early', I now think any medical problems experienced by babies could be inserted into this thematic area. This was discussed during a supervisory session where it was agreed the themes could be merged.

The midwife just sort of left me to it

- Level of involvement once baby on NICU and on PN

The above thematic area can be merged into '**Hands on**' as well as the lower level theme which reflects involvement of spouses with the baby: '**Get' spouse' more involved**'

- Here women talk about using formula so partners can get more involved

with feeding:

- Partners were involved in other ways, nappies etc. Slight dilemma as it could be merged with 'Feeding' as women may have changed from breast to artificial because partner wanted to be involved – see Mary Lisa and Linda?

Is it worth contemplating why women change from breastfeeding to formula so that partners can help. I have always believed women should breastfeed if that is what they want and partners can help by changing nappies, helping the woman to get comfortable, bringing her a drink and a myriad other ways. However considering it from a feminist perspective breastfeeding can restrict women's choices and if switching to formula helps a woman cope with her situation is that such a bad thing? Does it support a better gender balance in maintaining/running a home? Is it important to women to continue to breastfeed? What are the women saying?

Looking at the quotes of '**spoke to the doctors**' and '**staff have been fantastic**' there is a difference between how women describe the different professionals involved in their care. It appears from many of the quotes that women were spoken to or awaited decisions around feeding etc from doctors. Staff which included nurses and midwives were rated as fantastic and helpful by a number of women but on the whole, appeared to provide conflicting advice. I think conflicting advice is an issue. **I need to look at this again with different eyes.** Keep the two themes distinct for now. I need to remove my professional hat and avoid looking at the issue on divisions of labour and professional distinctions and look at what was missing for the women and what they found useful, no matter who provided it. If there was a lack of clear decision making then that would impact on a woman's experience, is it a lack of information possibly?

Could I merge '**I felt over the moon**' into the theme '**I cried**' which is about women's emotions whilst in hospital? 'I felt over the moon' describes when things went well, for instance, see quote from Kate*:

“Oh nervous, spent all night trying to make sure he fed as much as possible, and kept him as warm as much as possible so he didn’t lose any weight that way, and as soon as 9 o/c came which was his feed, rang the bell, say “can we weigh him” because no one had offered to weigh him. I thought I’m going to get him weighed (linked reflective note 2) um yes I knew it had to be done before a feed, so they came with the scales and yeah he had gone up 50 grams - yah! (Brilliant) *I felt over the moon* so then they said they would go and speak to the paed’s and see what they said, and about 2 hours later they came and said “yes you can go.”

She took ‘control’ of her situation by making sure she did everything that ‘was prescribed by hospital protocol’ (not left to women to make decisions on the best way to care for her baby) and when baby had put on weight (gold standard) she ‘felt over the moon’. She had passed the hospital test! I think this is important in its own right because ‘they’ (midwives on the postnatal ward?) would go and speak to the doctors, once again illustrating the difference between the two professions. Does that even matter to women? Do the two professions impact separately on their experience? Do they provide similar information or is it conflicting?

I reflected on why Kate suddenly felt empowered:

“Because she had heard a ‘plan’ about her and her baby although it was not directly shared with her. Wouldn’t it make sense to have this plan right at the beginning and say to women you will go home when your baby is feeding and putting on weight so straight on there’s a goal and women know what it is?” (Diary entry: 12/06/2012). (linked reflective note 2).

‘Got weighed’ is another interesting theme. Nearly all the women mentioned it as one of the reasons for staying in. They could only be ‘allowed’ home if their baby put on weight. It didn’t really matter by how much (one woman mentions 20g) but as long as it was on the up. Is this a good thing or is it something that controls women, not being trusted to be responsible for weight gain (feeding issues linked here in relation to top ups and/or changing to formula so weight gain is greater) and only when baby is gaining, can women be trusted to go home. This is despite some women absolutely hating being in hospital (Mary for example, who almost walked out but others also spoke about being in a hospital environment and not liking it – “it felt like a prison”) but putting up with its confines for the sake of their baby(babies). My role is to comment on what the women felt about this. Did they

feel it was good their baby was being looked after or could they have made suggestions to the plan? How does weight intersect with other aspects of a woman's experience? Women continued to discuss weight gain when they were at home. Midwives and health visitors came on a regular basis to weigh babies. These descriptions from Phase's one and two can be coded together.

Appendix 19: Initial Template Revision 3

| Initial Template (Women) Revision 3 – Final | | Impact on women's experience? |
|---|--|-------------------------------|
| Thematic area | Lower level themes | |
| Hit and miss | <p>Feeding babies</p> <ul style="list-style-type: none"> • I didn't like that drip thing • I don't want to demand • I want a routine • Important to establish breastfeeding / support for breastfeeding <p>Involvement of spouse</p> <ul style="list-style-type: none"> • Using formula so partners can get more involved with feeding. • Involvement in other ways, nappies | Yes |
| I felt over the moon (ownership) | Women feeling in control of whilst in hospital | Yes |
| Not completely prepared for it (readiness) | <p>Previous LPB</p> <ul style="list-style-type: none"> • No previous experience | Yes |
| We are not here for me, we are here for him | Woman realises she is not at the centre of care- her baby is | Yes |
| Is this like, my baby? How is there any connection? | <p>Women first met their baby after birth</p> <ul style="list-style-type: none"> • Get over there • I didn't see him straight away I needed to be there • I want to be back with them the first time I held him • They never took him away <p>Separation</p> <ul style="list-style-type: none"> • Leaving babies behind | Yes |
| More than happy to come down here | Support for women once their baby discharged by NICU | Yes |
| Spoke to the doctors (medical | Women discussing issues with | Yes |

| | | |
|----------------------------------|---|-----|
| decisions) | <p>the doctors</p> <ul style="list-style-type: none"> • Feeding • Discharge • Weight • Other health related matters | |
| Hands on | <p>Level of involvement with baby</p> <ul style="list-style-type: none"> • NICU • PN | Yes |
| She'll be home soon | <p>Do parents know when this may happen</p> <ul style="list-style-type: none"> • I don't know why I am here • I'm expecting to be here for awhile • My goal is next week • They haven't said. | Yes |
| Bringing baby down | <p>Baby moves from one environment into another</p> <ul style="list-style-type: none"> • NICU • Woman's room on either postnatal / labour ward • I'm glad to be in a room like this • Main postnatal ward • Moving in with me | Yes |
| He's kind of full term but early | <p>Before baby was born and about the birth</p> <ul style="list-style-type: none"> • Any complications • Gestation <ul style="list-style-type: none"> ○ Just said he was a premature baby • No preparation • Know what to expect • Better chance of survival • Breathing difficulties • Problems in the postnatal period <p>(Being on NICU amalgamated into this level</p> | Yes |

| | | |
|---|--|-----|
| You can't (approaches to care) | <p>Staff attitudes towards women</p> <ul style="list-style-type: none"> • I don't want them involved in their care • Incompetent • It was offered but didn't take it | Yes |
| I cried | <p>Women's describing their emotions whilst in hospital</p> <ul style="list-style-type: none"> • Quite tearful • Shocked • Feel guilty • Get over there | Yes |
| Staff have been fantastic (praise) | Women describing their experience of being in hospital | Yes |
| I'm going to have somebody coming over to check him | Knowledge of post discharge support | Yes |
| Got weighed | Impact on journey and feeding | Yes |
| Wet myself | <p>Prepare for being induced</p> <ul style="list-style-type: none"> • Not dilated much • You don't really see the signs • Signs of labour • Never want to be induced again • It was seriously forced into it • I was convinced I was in labour | Yes |
| I listen | <p>Assimilating advice provided by HCP's</p> <ul style="list-style-type: none"> • I think its good advice • I want to try something else • Conflicting advice from HCP | Yes |
| I have been in a hospital (prison) | Acknowledging the environment of care | Yes |
| Don't be scared | Advice to mothers | |

Appendix 20: Final Template

| Final Template | |
|--|---|
| Thematic area | Lower level themes |
| [They wouldn't tell me definitely that she could] GOING HOME | Doing things Gained weight Feeding her on my own Gave me the best chance of going home They let me go home At home |
| BEING [in hospital and at home] | I was put on a postnatal ward It was so nice to be out of hospital A very good hospital Labour ward |
| [It was just not the best] EXPERIENCE | Postnatal experience I'm here just for them Baby on the neonatal unit |
| STAFF | Health Visitors Midwives Neonatal staff Doctors Professionals know best Having to ask somebody to please stop what they are doing OTHER SOURCES OF SUPPORT Information off the internet |
| [Look this isn't getting any] BETTER | Feeling guilty I was concerned about taking anything Poorly throughout my pregnancy I'm still having some of that pain in my side Left a hole and it wasn't healing |
| [Is this like, my baby – how is there any] CONNECTION | Preparation Not emotionally prepared Knew what to expect They never took him away Get over there I didn't see him straight away I needed to be there I want to be back with them The first time I held him Leaving babies behind |
| [What was worrying me was the] FEEDING | Maybe your milk is not good enough Very encouraging with breastfeeding Weight I didn't start expressing milk straight away TOLD ME I HAD TO WAKE HER UP 3 HOURLY |
| DO AS MUCH AS I CAN | Being watched You can't |

| | |
|------------------------------------|--|
| | <p>It was offered but didn't take it</p> <p>I don't want them involved with their care</p> <p>Incompetent</p> <p>Being left to care</p> <p>Put her down your top</p> <p>Leave it to them</p> |
| I FELT OVER THE MOON | Women's feelings when taking control |
| INTO THE WORLD | <p>Labour experiences</p> <p>Wet myself</p> <p>Being induced</p> <p>Not dilating much</p> <p>Not seeing or seeing signs of labour</p> <p>I was in labour</p> |
| NO ONE REALLY EXPLAINED | <p>Should have asked more questions</p> <p>I'm sat there wanting to know</p> |
| [HE'S KIND OF EARLY BUT FULL TERM] | <p>Before baby was born</p> <p>Just said he was a premature baby</p> <p>No preparation</p> <p>Know what to expect</p> <p>Better chance of survival</p> |

Appendix 21: Just keep it together

A parent theme devised to incorporate women's advice for other women with a LPB. Their advice is loosely grouped into the following headings: caring, trusting instinct, reassuring, preparation, involvement and ask more questions.

Caring:

Caring centred on advice which suggests women should not be too worried, and be led by the baby:

- ❖ Work with them rather than trying to do any form of routine, just forget that.
- ❖ Stay calm, don't expect too much too soon, because obviously for children born earlier everything will take a bit longer so, try to not compare your children with other children [...] and eventually they will get there, and just stay more relaxed.
- ❖ With premature babies like feeding or things like that, everything takes longer, so don't get upset. Just [p] be patient.
- ❖ But [p] just small amounts of everything, little short sleep, little feed, short sleep, and just go with what they want really.
- ❖ I think that everything is just little and often.

Some of the women focused on that which was important to them:

- ❖ Start expressing milk straight away.
- ❖ Put [your baby] down your top, and you can regulate everything, and get you home quickly. When they say skin to skin, [...] you know just for a little bit of a cuddle, but if you do it all day, then that can really [p] really help get them well.
- ❖ Don't think you're just going to be able to put the baby on and it's gonna be fine, because [...] you both need to learn. If you are having problems latching, don't panic. The last thing you need to do is panic because it sets the baby off (laughter) and they feel the stress! If they can, go to a breast

feeding group and get support – everyone will support you that breast feeds.

Trusting instincts:

Maternal instinct and trust was brought up by several women:

- ❖ Your maternal instinct is stronger than any other instinct in the world. No one will understand it until you have a child. And if your maternal instinct is telling you to do something, that's what you must do. If you feel really really strongly about something, and even if people are telling you that it's not a good idea, that this is how they should do it, this is how they did it, or this is what the NHS says you must do, if you've got a strong feeling that it shouldn't be done that way, or that your children won't benefit that way, that they'll benefit from a different method, then do that **[Strong mothering discourse & bonding]**
- ❖ Go with your gut instinct.
- ❖ Don't try and do too much [p] sort of reading and finding out because I find you can be pulled from pillar to post, "what should I be doing". I'm really [p] going more on instinct and that [p] seems to be doing alright really.

Reassuring:

Some women wanted to be reassuring:

- ❖ Don't be scared.
- ❖ Just enjoy your baby, no matter how small they are.
- ❖ They're playing catch-up and they just need to [p] have what they need when they need it, [p] and try and just [p] not worry too much.
- ❖ Don't worry too much, its maybe not as bad as you think it's going to be

Others had the support of family & friends:

- ❖ Just make sure you have people around you. I wouldn't have got through that whole week without my family, because they came up on the Wednesday – they were literally following me around the hospital. But I don't think I could've got through without all my friends and family.

Preparation:

Preparation was important to some women with advice focused on finding out what happens if:

- ❖ Baby is taken off, and what happens to them, because I never got any of that information.
- ❖ Being told what tube is down their nose, because I think that is quite scary for a mother to suddenly see all these tubes and wires, you could really get quite worried.
- ❖ Because I was told they might need top ups by formula, don't worry, [...] that helped, prepare me, so I didn't panic or worry.

Involvement:

When a woman's baby is unwell at birth it impacts on their ability to provide care, therefore some advice was focused on being involved:

- ❖ To ask to do these things because I just remember, feeling like I wasn't his mum and it was horrible and I just needed to do something for him [long p], and had I not asked if I could do it the nurses probably quite happily carried on doing it all for him, because I remember [partner] saying to me "you can't do that" and I was like "I can I'm his mom of course I can."
- ❖ I think I would warn another mother that it's just terrifying those first sort of 48 hours I suppose it was just awful.
- ❖ I would say to [p] to be involved as much as you can, ask the staff how you can be involved

Ask more questions:

Some women wanted women to be specific and ask questions:

- ❖ I would say ask more questions than I did, really find out what's going on because I think I left things a bit, to the professionals to get on with, I should have asked more questions especially with all the shift changes you get with the midwives [...] make sure you know why you are there, what's going on, what might happen.
- ❖ Actually I never asked why he was early, should have asked that, um I never asked [p] what problems he had, um I was kind of left to find that out, um I think I said before that it was a few days in and it dawned on me that we there for him and not for me and so I think I would ask those sorts of questions, I suppose at the time it's just all so much going and your hormones are all over the place um, I just didn't think to ask these things, um [p] how long I was going to be in hospital should have asked,

Although the women worried about many aspects of their baby's health, in retrospect some they worried unnecessarily:

- ❖ [...] I would say, "not to worry too much" because from my experience, now the more I talk to other mothers, the more I found out a lot of babies have ended up going back into hospital with feeding problems, even though they weren't sort of late premature babies um, so it's, I thought a lot of it was down to because he was premature the fact that he had so many feeding issues, whereas when I talk to other women the groups, I find maybe it was because he was premature, maybe it wasn't, because they said they've gone home, they've had um their child's weight has been going down and they have ended up going back into hospital and going onto the children's ward, and having a tube down their nose, and um the feeding, um and I think the lady I was talking to yesterday, she was in for 5 days, yeah, she went home, her little girl had feeding problems so she ended up going back in, I didn't get the impression she had a premature baby or anything, [...] its maybe not as bad as you think it's going to be" and now when I look back I think,

actually he's perfectly healthy, you know he didn't have to have any interventions with his breathing, anything like that.

- ❖ Ask more questions and don't be so laid back, I think, really. Push and don't be scared to ask. [...] well I'm scared, because I'm quite shy sometimes as well. I wouldn't be scared to ask, and just push, I think definitely, just push and push and don't take 'no' if I'm not happy, instead of just thinking, "Oh well, the baby's safe."

Asking more questions may been influenced by women not being listened to when they experienced their own problems antenatally.

Appendix 22 Reflection: Is Breast Best?

Is 'Breast is Best' for women with preterm babies?

Have I perpetuated the 'myth' of good mothering in a NNU? On countless occasions I have counselled mothers on the importance of breastfeeding their preterm baby and how, if they should decide to breastfeed, it was 'special' as only they could provide breastmilk for their baby. As professionals we could do everything else (!!!) except breastfeed their baby! The message that it was important to provide breastmilk fully endorses the dominant discourse that the baby takes precedence over the woman and NOT what was important for that woman. The 'breast is best' message from healthcare professionals may also have been conceived by women as subtle pressure to breastfeed aided and abetted by strong scientific discourses which endorse the benefits of breastmilk for all babies but especially preterm babies. In her book 'Is Breast best?' Wolf sets out to challenge the scientific discourse that breastfeeding is superior to bottle feeding (Wolf 2011). Her answer that breastfeeding 'is not best' based on examining the science around the health benefits of breastfeeding certainly challenged my personal views of breastfeeding. I believed that 'breast was best' and most definitely was best for preterm babies. Certainly countless research papers have extolled the substantial benefits of human milk for preterm babies – see for example Arslanoglu et al. (2010) and Henderson et al. (2007). Preterm babies are also particularly vulnerable to necrotising enterocolitis NEC (death of tissue in the intestine) with research suggesting preterm and low birth weight infants formula fed compared to (donor) human milk are at higher risk of developing NEC (Quigley and McGuire 2014).

What have I gleaned from my previous practice working with women who breastfeed their preterm baby? It requires an extraordinary amount of commitment; at best it is a celebration of their bodies. Their milk can sustain their baby (although it may need supplementation with additives (!)) and gives women an element of control over their babies. At worst the act of breastfeeding (not something I had previously considered) "tethers women to their baby and creates risks for them in a market that demands total commitment from ideal

workers”(Wolf 2011, p. 148). If women cannot physically put their babies to their breast to feed they are required to express their milk via a breast pump. I am aware from my previous professional practice how hard this activity is for women and to sustain breast milk expression for many weeks is not achievable for many. Whilst the breast pump can free women up to do different activities, for women with preterm babies it can “transform them into virtual machines whose primary function is milk production” (Wolf 2011, p. 148). These women may find the act of breastfeeding intolerable but persevere because staff on a neonatal unit, and society at large, require women to be the ‘perfect mother’ who puts aside any feelings of personal discomfort for the benefit of her baby. In these situations can breastfeeding be empowering for women? I would suggest it can, providing women are supported to do the best they can and not made to feel guilty if they cannot continue. Alternatively, as a healthcare professional I need to appreciate it can be oppressive for women on a neonatal unit, having to always express to order and having to ‘produce’. In addition the message that breastmilk is ‘free on demand’ does not acknowledge the time, effort and hard work women undertake in providing nourishment for their preterm (and term) babies.

Where do I position myself when I consider Wolf’s ultimate message that “the science today indicates that if breastfeeding has health advantages, they are for most babies in the developed world, marginal (Wolf 2011, p. 151). It has thrown all my previous knowledge into turmoil. I wholly subscribed to the health advantages of breastfeeding and now it appears the benefits may not be as robust as claimed by the scientific community. I work in a university that has ‘Baby Friendly’ accreditation – how do I support students to think differently (breastfeeding on a neonatal unit from a feminist perspective) when the message to breastfeed is strongly endorsed throughout three years curricula? The argument has always been that women choose to formula feed because they are not always aware of the benefits of breastfeeding. But if the benefits of breastfeeding have been exaggerated and formula feeding is a ‘healthy option’ for women (Wolf 2011, p. 151) then surely there an alternative message not being provided?