"Powerless Responsibility: A feminist study of women's experiences of caring for their late preterm babies"

Problem: There is minimal research exploring women's experiences of caring for a late preterm baby. The emphasis in the literature is mostly baby centric.

Background: The number of babies born late preterm is rising and women's views are largely unknown.

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

Methods: A feminist lens was the key philosophical underpinning. Semi-structured interviews were undertaken with 14 women.

Findings: Women who become mothers' of late preterm babies have a complex journey. It 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, and they are required to care for their babies within parameters determined by others. Institutional and professional barriers to mothering/caring are numerous.

Discussion: Some of the women who were separated from their babies immediately after birth had difficulties conceiving themselves as mothers, and others faced restrictions when trying to access their babies. Women described care that was centred on their babies. They were allowed and expected to care for their babies, but only with 'powerless responsibility'. Many women appeared to be excluded from decisions and were not always provided with full information about their babies.

Conclusion: Women whose babies are born late preterm would benefit from greater consideration in relation to their needs, rather than the focus being almost exclusively on their babies.

Keywords:
Scientific mothering, late preterm, powerless responsibility, feminism, women's experiences, mothering

Introduction

Statement of significance:

Issue:	The number of babies born late preterm is rising and women's views of caring for these preterm babies are largely unknown.
What is Already Known	There is a body of research exploring women's experiences of caring for preterm babies in general, however the bulk of the studies focus

	on babies born 'very preterm' (<32 weeks gestation) and 'extremely preterm' (<28 weeks gestation). Those caring for LPBs are often subsumed within these publications.
What this Paper Adds	Women who are caring for late preterm babies have significant unmet needs. These revolve around not being unnecessarily separated from their babies, requiring more information and a lack power and jurisdiction around decisions regarding their baby/babies.

This paper reports on some of the findings from a larger qualitative study which explored women's experiences of caring for their late preterm baby/babies (LPBs). This is especially relevant as the number of LPBs (defined as those born between 34 and 36 completed weeks gestation) is rising[1] and there is currently a lack of research in this area. Furthermore, 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. A previous publication[2] has explored women's experiences of feeding their late preterm baby/babies. In this, women's knowledge and its perceived place in a healthcare environment was highlighted. This paper explores in more depth the mix of knowledge, responsibility and powerlessness that women who birth late preterm babies can experience.

Late preterm babies are an increasingly important sub-group of the premature baby population, accounting for 70% of premature babies, with their numbers on the increase[1]. In North America, the rising incidence of preterm births has been attributed to an increase in late preterm births[1]. In the United Kingdom (UK) whether babies born in the moderate to late preterm gestation range (between 32- and 36-weeks' gestation) has increased is unclear, as national data on gestational age is not routinely recorded at the registration of live births[3-4]. However, 7% of all live births in 2010 in a particular geographical area of the UK (England and Wales) were preterm, with the majority of these (5.9%) occurring within the moderate to late preterm range[5].

Understanding service users' perspectives of healthcare is considered important[6] but is generally achieved using large scale quantitative surveys[7], which do not allow individual experiences to be explored in depth. In addition, despite including maternity services, such surveys tend not to distinguish preterm birth experiences from general maternity experiences, and late preterm babies have not been, to date, considered separately[8]. Two existing neonatal surveys[9-10] are also predominantly positivist surveys of large cohorts of parents, do not consider late preterm babies separately, and combine the experiences of mothers and fathers[8], despite evidence that women experience neonatal care differently from men[11]. There is a body of research exploring women's experiences of having a preterm baby, but most of the studies focus on babies born 'very preterm' (<32 weeks gestation) and 'extremely preterm' (<28 weeks gestation)[12] . Those caring for late preterm babies are sometimes subsumed within these, but not considered as a separate entity[8].

Although there is a growing body of literature related to late preterm babies, this generally focuses on the babies' physiological and physical needs[13-14,] or quantification of what women do for them. Only one existing study[15] explores the emotional responses of women with late preterm babies. A question which arises from the research concerning late preterm babies is therefore: 'where is the woman?' The aim of this study was to uncover the woman's voice by asking: "What are the experiences of women who are caring for a late preterm baby?"

Methods

Study design:

A feminist approach to research was used in this study. Whilst no single definition of feminist research exists, Harding[16] and Reinharz[17] describe it as research which must make a difference to women, it is research on women, by women and for women. It also studies the conditions of women in patriarchal societies, with the intention of highlighting sexist practices, including exposing governments and communities that disregard or ignore that which is important to women[17]. It demonstrates an organizational view of the 'now' and a vision for the future[18]. In addition, from a midwifery perspective it "improves care for childbearing women and empowers and celebrates

women's knowing"[19 p39]. These principles were congruent with the ethos of this study, which was to explore women's perspectives, and give them a voice as 'producers of knowledge'[20].

Study setting and ethics

Women who were caring for late preterm babies were recruited for this study from an NHS Foundation Trust Hospital in the South West of England, a medium sized acute care maternity unit where approximately 2,500 women give birth. Ethical approval was obtained from the NHS Research Ethics Committee, SouthWest5 (University Hospitals, Bristol NHS Foundation): 10/H0107/64 and from the Research and Development (R&D) Department at the local NHS hospital where recruitment took place: 76/2010/2011.

Participants

Women who were resident on the postnatal ward were approached one or two days following the birth of their baby and were provided with a letter of invitation and an information pack by a third party who was not involved in the study. Those who wished to participate returned a signed reply slip, and a meeting with the researcher was arranged. Written consent was obtained at the time of the interviews, where women were assured that their participation was voluntary and that non-participation or withdrawal from the study at any point, would not affect their current or future treatment or that of their baby/babies. In addition, interviews could be ceased at any point and the researcher conducting the interview was able to direct women who experienced any distress to the relevant sources of support. None of the women who participated required extra support following the interviews. Fourteen women consented to participate during Phase one with one woman withdrawing her participation at Phase two. Data were anonymised, and the names used for the women in this paper are pseudonyms. The women were between 22-37 years of age, had birthed one or two late preterm babies and gestational age ranged from 34-36 completed weeks of pregnancy.

Data collection

The literature review established that women's voices were often unheard, therefore one to one semi-structured interviews were chosen to ensure that individual woman's experiences of caring for their late preterm babies would be heard. Feminists have regularly utilized interviews to change or make more visible the lives of women[21, 16].

Two phases of data collection were planned. During Phase one, women were interviewed shortly after birth, either within the postnatal ward office or their own individual hospital room, and the second phase (between eight and 12 weeks later), at a location of their choosing. All the women chose to be interviewed in their homes, usually in their 'front room' with babies, pets and on some occasions, husbands present. Women consented to their interviews being digitally recorded.

The median length of each interview was 40 minutes and were transcribed verbatim. Transcripts were sent back to the women either through the post or attached to an email, depending on their preferences. An important aspect of utilizing feminist principles during data collection was to minimize power relationships between the researcher and the researched[21], therefore women were invited to comment on their transcriptions, as this would reduce misrepresenting their story and acknowledged they were the experts of their experience[22]. The women who chose to respond felt that the transcriptions were a true reflection of the interviews. In the second interview the first author discussed some of her emergent findings with some of the women, in order to check their interpretation and beginnings of analysis of their comments, for example, by saying "last time we met you said ... I thought from that that you felt ... is that right, do you think?" By the time the study was completed many of the women did not respond to telephone contact, because the first author believed they had relocated. The first author was able however, to share her key findings and analytical thoughts with one woman who agreed with the interpretation of her experience. A limitation of the study is that no other women were available for such discussions.

Analysis

Thematic analysis is a broad category of analytic techniques that involve identifying meaningful patterns in textual data and organising these 'themes' to show relationships between them[23]. There are many different forms of thematic analysis; Template Analysis (TA) is one such[23] and was used within this study. TA allows some theoretical or practical themes to be defined in advance, but also encourages the development of themes that emerge through the analysis process[23]. It can therefore, be seen to be positioned between inductive (bottom up) and deductive (top-down) forms of thematic analysis[23] Originally, whether some of the guided questions used during data collection could be used as broad 'a priori' themes on an initial template was considered. This would be deemed a top down approach to theme generation[23] and, whilst appropriate for some studies, it was unsuitable for this study, with its emphasis on finding the 'woman's voice'. Seeking to apply 'a priori' themes would not have enabled the data to speak to the researcher, as in doing so, analysis and any deep engagement with data would have been stifled[24].

Another feature of TA 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[23].The researcher chose a mixed approach to developing the template, by reviewing several transcripts before constructing a basic thematic template, which ensured that she was immersed in the women's data and had time to reflect on their words. 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 supervisors providing critical feedback at key points in the development of the final template[23].

Interpretation of the themes developed through TA were aided by Birth Territory Theory (BTT)[25], a concept which explores the relationship between the birth environment, those occupying the terrain (birthing women and healthcare professionals) and how the juxtaposition of power, control and territory impact on women physiologically and emotionally during birth[26]. The underpinning philosophy(ies) of BTT were utilised to examine the environment where women in this study

embarked on their caring and mother-work experiences (Labour Ward (LW) and Postnatal Ward [PW]) and eventually their experiences once back in their own sanctum (home)[25].

These environments (LW, PNW and home) do not exist outside "the gendered, political, economic, social and legal networks of power within a given culture"[27 p.ix]. According to Fahy and colleagues, women, midwives and doctors are influenced (consciously or unconsciously) by these networks, which restricts what can be done within these environments, for example power, in the form of medical domination, can impact negatively on women and midwives[26]. Women in these situations become passive, obedient and fearful, emotions which do not facilitate empowered decision making for herself or for her baby[25] .

Whilst the midwife's role is to be 'with woman' and to empower them, there is evidence (see:28, 29) that territory (environment), 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"[26p.6, 27, 30].

Reflexivity

Feminists consider themselves part of data collection and knowledge production, rather than sitting outside of these processes which is acknowledged through reflexivity[22]. Reflexivity was used throughout all stages of the data collection and analysis process, which enabled the researcher (first author) to address the subjective influences of her own knowledge and experiences[31]. An extract from the researcher's reflective diary demonstrates how she struggled to remove her 'professional hats' (as a midwife who had specialised in neonatal care):

> 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. […] 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. 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.

Reflexivity and supervision (by second and third authors) kept the researcher grounded as she re-examined issues within the data and analysis to ensure this was what the women said, and not her own thoughts leading or interpreting them in a particular way.

Findings:

A conceptual diagram (Figure 1) was devised to illustrate the overarching themes derived from Template Analysis, with the names of themes representing women's voices. The entirety of the diagram is beyond the scope of this paper; however, it demonstrates how the themes reported on fit the study as a whole, and the complexity and interlinking nature of the themes that were developed to explore women's experiences. Within each individual quote […] indicates that a quote has been shortened, and [p] represents a pause within the woman's spoken words.

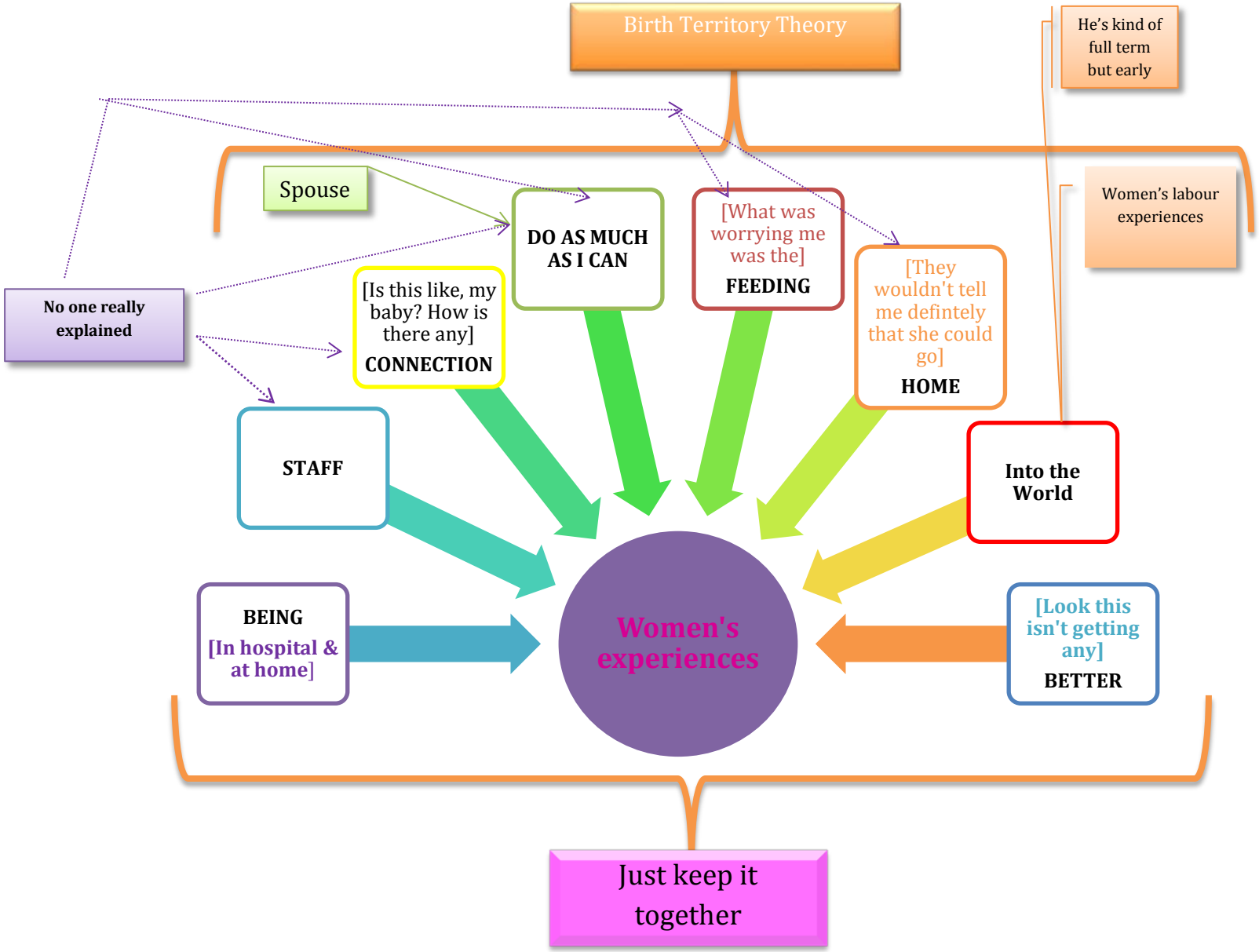
Birth Territory Theory
He's kind of full term but early
Spouse
DO AS MUCH AS I CAN
[What was worrying me was the]
FEEDING
Women's labour experiences
No one really explained
[Is this like, my baby? How is there any]
CONNECTION
[They wouldn't tell me defintely that she could go]
HOME
STAFF
Into the World
BEING
[In hospital & at home]
Women's experiences
[Look this isn't getting any]
BETTER
Just keep it together

Figure 1: Conceptual map illustrating overall thematic themes

This paper therefore focuses on findings related to aspects of caring and mothering, taken from 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**
- **STAFF**

Finally, women's views did not fundamentally alter between the two phases of data collection, however by Phase two, women had had an opportunity to reflect and comment on how events had affected them.

CONNECTION

The theme 'Connection' is concerned with whether women were able to connect with their babies following birth. Two women were never separated from their babies, and were able to connect with them immediately:

> *The whole time, they never took him away or were concerned about anything […]* [Freya].
>
> *He was absolutely fine, yes. Just small, really, just – but no, no, they had no concerns at all […] I was given him straight away […]* [Valerie].

However, twelve of the fourteen women were separated from their babies for varying lengths of time due to their admission to the local neonatal unit (LNU), which appeared to impact on their ability to connect with their babies. Fiona summed up the situation by saying:

> *[…] not any stitches or a baby. 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 because I had no tears, no stitches, no pain, no swelling, nothing [p], like that. Um and obviously I had no baby with me*

Some women were concerned by a lack of information about why separation from their babies was necessary. Mary explained that although her older son's previous admission to the LNU (he was a

late preterm baby) had prepared her for this experience, the lack of clear reason for her daughter being there puzzled her:

> *I think when I went up this time I knew what to expect, she was in the same bay as [previous child] 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*

Kate also recalled:

> *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*

BEING [In hospital and at home]

"Being" explores territory and whether women's experiences of caring occurred on the postnatal ward, the labour ward, the local neonatal unit or at home was noteworthy. After their baby's birth, most women were transferred to the postnatal ward. However, two women remained on labour ward as there were no appropriate postnatal beds. Marylyn explained:

> *The midwives here have said that there were no side rooms over there (*postnatal ward*), 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[…] I think they've just given me my own bit of space I can come back to when I need it*

Remaining on labour ward only became problematic when women wished to access their babies, whereupon their location created a barrier, as Marylyn described:

> *The nurses or midwives on the postnatal ward however have upset me quite a few times because I have to keep going [p], obviously I'm here, my baby's over there and I WANT to be with my baby [p], 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"*

Linda also reported:

[…] 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

Most of the women were admitted onto the postnatal ward, where all those who had access to them preferred side rooms to the general ward. Gill recalled:

[…] a good thing that really happened, was really I forgot to mention, was um (laughs) I was given um 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 [...]

Nonetheless, women having a side room did not lessen the impact of separation from their babies:

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 (Fiona).

Mandy also described how, despite appreciating having a side room, she really wanted to be resident with her baby:

I could still hear all the babies [in side room] it was nice because I could have people in and shut the door, 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

Kate also recounted being upset at seeing other women with their babies:

[…] 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

The women whose babies were on the local neonatal unit nonetheless generally accepted that their babies' needs had to take priority over theirs. Medina commented:

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

All the women described being happy to return home, to their own environment, with the support of their partner, family and friends. Feeding regimes became relaxed and women were able to utilise their own knowledge and that of others when caring for their baby/babies. This also 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*

DO AS MUCH AS I CAN

The theme 'Do as much as I can' reflects women caring for their babies and has links with 'Connection', 'Being', 'Feeding' (not reported here) and 'Staff', which all impacted on women's experiences. All the women in this study wanted to be as involved as much as possible in their babies' care. Linda, whose twins were initially resident on the local neonatal unit took charge of them early on:

> *From day one I did everything. When they were feeding him I asked them if I could rather feed them. I was changing their nappies*

Marylyn was also proactive in providing care for her baby 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*

Although some women were able to take the lead in their baby's care, others sometimes felt pressurised to comply with prescribed care regimes. Mandy explained:

> *[…] she was very much kept on about that, always skin to skin [p], 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. 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*

In some instances, caveats existed to women caring for their babies. Nicola recalled being told:

> *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 [p], 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*

Medina described how her baby's care was only transferred to her when the neonatal staff allowed this, and it remained under their overall jurisdiction:

> […] *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*

Connie initially described being fully involved with her baby's care:

> *I'm doing, I'm pretty much doing everything while I'm here, […] 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 […]*

Nonetheless, during her second interview, Connie reported a sense of being constantly watched:

> *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"*

This made her feel:

> *A bit rubbish. To be fair, the whole time we were there, I felt like I was being watched, anyway, like constantly*

Women also described a perception that failure to comply with expectations in relation to caring for their babies would incur sanctions:

> *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* (Connie).

Jane described the conflict which women who mother late preterm babies can experience when they also have other children to care for.:

> *Initially leaving them was very hard […] I mean I would love to be able to spend all day with them but I can't because of our toddler […]*

As well as the hands-on care of their babies, the extent of women's involvement in decision making was discussed. Connie described feeling excluded from decisions relating to her baby going home, and Gill also felt that she had no input into significant decisions about her baby:

> *You don't think you've got a say […] I've just done what they said, best thing to do really*

Many women also felt that they received inadequate information about their babies. Kate recalled:

> *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*

STAFF

The theme Staff connects with all the major themes as staff had an impact within each. The theme was considered in some depth, as staffing is a commonly cited issue in healthcare, and whether the researcher's own views influenced this being considered a separate theme was reflected on in depth. Careful review of the data however, revealed that the term "staff" was often used by women, and the qualities of individual staff members was important to them and was frequently discussed in their accounts. Staff tended to be important in terms of the qualities of individual staff members, rather than staffing levels. Women's overall views did not change between the two phases of data collection. Those whose babies were on the local neonatal unit were generally complementary about the staff:

> *Fantastic and supportive and have listened to what I want to do (Linda).*
>
> *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* (Fiona).

Views on postnatal ward staff varied. Some women expressed very negative views, whereas others were more positive. Many women reported how busy the midwives appeared to be, which sometimes deterred them from seeking help. For example, as described in the theme 'Being' some

of the women were reluctant to bother staff to assist them in accessing the local neonatal unit. Gill, however, included this busyness in her praise of the staff:

> *all the NICU staff are just wonderful, […] and all the postnatal. I think all midwives [p], 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 just wonderful, and just the fact they keep happy all the time, and be positive […]*

Medina was equally positive about the midwives, indicating that whenever she asked for help it was forthcoming, including her baby being placed in the nursery for a period so that she could sleep. However, other interactions between staff and women were less positive. Linda commented:

> *Because they are rude and bossy and forceful […] I understand they are midwives, but I am their mom [twins] and there a line that they tend to cross and I don't like that [p]. The staff on NICU are more sympathetic, more understanding, a lot more friendlier, a lot more supportive than the midwives down here [p], They are like matrons I've had huge problems with midwives here […], 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 it has to be a passion, it has to be within you, you have to enjoy it*

The women in this study had mixed experiences in caring for their late preterm babies, however their babies' care was often, overtly or covertly, managed by healthcare professionals. Women were allowed and expected to care for their babies, but generally only within parameters determined by others. Many women appeared to be excluded from decisions and were not always provided with full information about their babies. Although there was no suggestion that any of the babies in the study received anything other than good care, the way in which women were cared for, and communicated with, was sometimes lacking.

Discussion

"Powerless Responsibility"

The broad heading 'Powerless Responsibility' illustrates the overall concept which describes the conditions in which the women in the study undertook the care of their baby/babies. The concept of 'powerless responsibility' was first described by Rich[32]. Her influential book helped feminism and

feminists contemplate mothering by way of functioning as both oppressive and liberating, with women in particular, who 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'[32,33]. These dichotomies and the polarisation between each, make women feel anxious and guilty about their mothering[34,35]. Whilst Rich's discourse on mothering does not suggest that no woman ever has agency or power in mother-work, in this study women's own knowledge and experience of their babies was devalued, and on the whole, women were denied the authority and agency to determine their own experiences of mothering[36].

This concept of women being knowledgeable yet powerless has been previously shared in a conference presentation and a recently published paper, where women were unable to influence feeding and feeding regimes, which ultimately did not facilitate instinctive mother-care or enable babies to demonstrate distinctive feeding signals[2].

The sub headings used in this discussion illustrate how women had responsibility but were powerless, and each sub-heading which follows beneath, are direct quotes from women and are used to illuminate how these themes were enacted.

Mothers as docile bodies – handing over decisions to (powerful) others

"Your child must go to NICU"

Some of the women in this study who were separated from their babies immediately after birth had difficulties conceiving themselves as mothers. This reflects the work of Erlandsson and Fagerberg[37] whose research highlighted the difficulties mothers experienced when they were separated from their babies following birth and then reunited at some point during the postnatal period. Although, as identified by Boyle et al[38], separation of mother and baby may sometimes be necessary, Hawdon and Hagman[39] recommend that this should only occur when there is a clear clinical indication. For women in this study the reasons for separation were not always clear, and some faced restrictions when trying to access their babies. Heinemann et al.[40] describe a Neonatal Intensive Care Unit

(NICU) with family rooms, and an adult bed next to every baby's incubator or cot even in the intensive care room, facilitating closeness and direct hands-on care for parents. It appears therefore, that separation is not necessary on medical grounds, even with a critically ill baby; it becomes so because of an imposed structure or system of care. The NHS and DH [41] recommend the provision of dedicated facilities for parents whose babies are receiving neonatal care, including overnight accommodation within easy walking distance of the unit. Whilst all the women in this study who were separated from their late preterm babies were accommodated within the stipulated distance, those whose mobility was restricted found accessing their babies' problematic, despite their theoretical proximity.

Fleming et al.[42] report variation in the location in which late preterm babies are cared for across England and recommend further exploration of the factors influencing this. In addition, the NHS and DH[41] state that if admission to a local neonatal unit is required, mothers should be involved with decisions, receive information on what care the baby will receive and how they can provide care. In this study, these recommendations did not always appear to be fully met, as health care professionals, not the women, made decisions concerning where babies would be cared for. Some women were not involved in these decisions and did not recall receiving information on why their babies needed to be admitted to the local neonatal unit, and the care they would receive there. In addition, women did not always feel able to seek such information, or to ask to be involved in decision making.

Mary exemplified and undertook a performance of being a 'good patient', or as reported by Fisher and Groce[43] a 'good woman', since she did not make any trouble ('docile body') [43] by interrupting medical rules of where her baby should be cared for. This reflects the work 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[44]. 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 late preterm baby [43].

Thus, in this study, an 'institution' (patriarchy), and a physical institution, defined where women should mother. It has been suggested in other studies that such environments (for example, local neonatal units and/or postnatal wards) require mothers to undertake "natural-intensive mothering (repression or denial of the mother's own selfhood)"[44] alongside "powerless responsibility" [32], wherein women are denied the authority and agency to determine their experiences of mothering including, at least initially, where and how her baby will be cared for[36, p.7]. The women in this study described situations which are consistent with these perspectives.

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"

Women in this study all wanted to assume an active role as mothers and were encouraged to do so. However, as described by O'Reilly[36], they were not permitted to determine their experience. Women's provision for their babies' needs occurred under the jurisdiction of health care professionals, with women submitting to medical power and to being what society deemed to be "good mothers" [43]. This creates the interesting paradox of mothers holding a "powerless responsibility" being required to undertake and be responsible for mother-work, but "in accordance with the values and expectations of the dominant culture"[45, p.6]. Women in this study were involuntary members of a healthcare environment where they lacked agency over their own experience and that of their late preterm babies [46].

The women in this study described care that was centred on their babies, not them. This accords with other literature (see 47-49) and supports Rothman's suggestion[50] that hospital obstetrics view the woman as separate from her baby. de Cássia de Jesus Melo et al.[51] stress that mothers of preterm babies themselves need individualised care as women. However, contrary to the philosophy of midwifery of being 'with woman', women in this study did not often appear to receive woman-

centred care. One detractor from this was women's perception of midwives' busyness, which has also been noted in other studies[52,48,53]. Midwives themselves have reported being unable to provide high quality in-hospital postnatal care because of inadequate staffing[49]. The lack of investment in postnatal services appears to imply women should naturally be able to 'mother'[54]. However, alongside this implication, women in this study described healthcare professionals as determining how they should care for their babies. Apple[45] refers to this practice as scientific mothering, contradicting the ideology that mothering is natural and instinctive. Scientific mothering evolved as medicine and science superseded women's domains of knowledge, effectively making women responsible for the health and welfare of their families, whilst simultaneously requiring them to comply with the advice and direction of expert males[45]. This situation was evident within this study, as women were responsible for mother-work from a caring and feeding perspective, but without any real power.

Where relationships with staff were positive, women reported a sense of being listened to and receiving explanations. It may however, be that, as researched by Lupton and Fenwick[55], when the women demonstrated "good" motherhood traits staff rewarded them with increased support and information. On the other hand, women who are labelled 'difficult' can also be at risk of experiencing coercive behaviour and subtle disciplining by staff[55]. This type of 'asymmetrical doctor-patient relationships' has been depicted Fisher and Groce[43] who studied doctor-patient negotiation within the context of cultural expectations or assumptions about women, and 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 woman in question. In this 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[43]. Similar attitudes were reflected by the neonatal nurses studied by Lupton and Fenwick[55]. The behavioural nuances displayed by neonatal nurses/midwives towards mothers on a neonatal or postnatal unit are not easily derived from quantitative generalised neonatal surveys examining parental perceptions of neonatal care[8]. Therefore, the necessity of qualitative research to inform health care practice and reform is vital.

Implications for practice

Women and their late preterm babies should only be separated when necessary, namely, for assisted respiratory support and other intensive care procedures[39]. 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. If a late preterm baby 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 postnatal ward or the neonatal unit. The researcher would recommend, based on the importance of non-separation, the possibility of parents (mothers) having beds by their babies' cots in NICU, or a separate ward for mothers of late preterm babies. In addition, the concept of having a separate ward for mothers (or both parents) of late preterm babies would also carry the benefit of decreasing the isolation that some of the women in this study experienced and would enable women-mothers to provide and receive social support from others with similar experiences. However, these options should be explored further. There is a need for dedicated staff who understand the unique requirements of women caring for late preterm babies. 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 late preterm babies. These women need to be nurtured as woman-mothers first and foremost, like that experienced by women who give birth in birth centres[56].

Limitations

This study concerned a small number of women in South West England. More research is needed

concerning the experiences of women who live in large inner cities of the UK and give birth to late preterm babies in NHS hospitals where the birth rate may exceed 6000. These women may have a vastly different experience and therefore comparing one institution with another might have produced different findings. In addition, this 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 this study were in 'traditional male/female relationships'.

Conclusions

The findings from this study demonstrate that women whose babies are born late preterm would benefit from greater consideration in relation to their needs, rather than the focus being almost exclusively on their babies. Midwives are often unable to provide the level of postnatal care that would facilitate this because tasks and processes, rather than individualised, woman-centered care, appear to be the priority. Service provision should be developed to facilitate togetherness as opposed to separateness for women and their babies, and women should be supported in a manner which enables them to make decisions about their baby's care, and to develop their own mothering styles and skills.

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Disclosures

None

References (additional references, that is, more than 40, approved by the Editor in Chief – email correspondence: 06/03/2019)

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