“His tummy’s only tiny” – Scientific feeding advice versus women’s knowledge. Women’s experiences of feeding their late preterm babies.

Abstract:

Objective: This paper reports on one element of a study exploring the experiences of women who are caring for late preterm baby/babies (LPBs) and focuses on their experiences of breastfeeding.

Design: As this study aimed to privilege women's experiences, a feminist approach was utilised, with individual qualitative interviews in two phases conducted with a purposefully selected sample of women who were caring for a late preterm baby or babies. Template Analysis linked to Birth Territory Theory (BTT) was used to identify key issues and experiences of women.

Setting and participants: Women (N=25) were recruited from an NHS Trust Hospital in the South West region of England.

Findings: 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 and greatly impacted on women’s experiences of caring. 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).

Key conclusions and implications for practice: The current approach to caring for women and their late PTBs tends to result in feeding becoming a source of stress and anxiety for women, rather than a positive experience. To resolve this, staff caring for women who have LPBs should focus on supporting women to trust their instincts, and to guide them in developing confidence in their ability to read their babies’ cues, rather than in focusing on strict regimes of feeding. This should include individualised consideration of whether supplementation is required in the early days.

Keywords: Feminism, women’s experiences, preterm birth, late preterm, breastfeeding, motherhood

Introduction:

This paper reports on one element of a larger study that has been reported on in full elsewhere (MAINN Conference 2017) addressing the question: “What are the experiences of women who are caring for a late preterm baby. The data reported on here concern women’s experiences of feeding their babies, as this was found to be one of the most challenging elements of their transition to motherhood.
Documents such as the National Service Framework for Children, Young People and Maternity Services (NSF 2004) and Maternity Matters (2007) endorse the principle of women being at the centre of their pregnancies, having choice and being involved in their care (DH 2007). Nonetheless, there is evidence that women are not routinely offered continuity, choice, control and involvement in their care when accessing maternity services (Jomeen 2012).

Any labour commencing prior to 37 weeks of pregnancy (Term) is known as preterm labour (PTL) (Tucker & McGuire 2004). Late preterm is defined as a birth occurring between 34 0/7 and 36 6/7 completed weeks (March of Dimes 2006). A preterm birth, even towards the latter half of late preterm gestation is unlikely to be regarded by professionals as a normal event, because of the risks associated with preterm birth, and intervention is therefore highly probable (Boyle et al. 2015). This has the potential to impact on the woman’s subsequent early experience of being a mother, and of feeding her baby.

When women feel in control during pregnancy and childbirth they report more positive experiences, including a sense of achievement. This in turn impacts on their sense of self, their sense of being a mother, and all the relationships within their circle (Birthrights 2013; Meyer 2013). However, for women who are in threatened or established PTL obtaining the information needed to participate in decision-making can be problematic (Harrison et al. 2003). At present there is little evidence comparing the experiences of women in England who are in this position with women’s experiences of maternity services in general. Published studies on this subject have mostly emanated from the US, Canada, France, Sweden, Australia and Israel (see for example: May 2001; Leichtentritt et al. 2005; Alcalde 2011; Rubarth et al. 2012; Höglund and Dykes 2013) which have different healthcare systems than England. Two exceptions are the studies undertaken by Barlow et al. (2007) and O’Brien et al. (2010) both of which explore women’s experiences of preterm labour (PTL) in England. Barlow et al. (2007, p.431) found that women reported “not being believed and not being taken seriously.” Mackinnon (2006) and Palmer and Carty (2006) reported similar findings in Canada and the US respectively.

Women in PTL live with the constant tension between preventing PTL and the worry of “trying to keep the baby in” (Mackinnon 2006, p.703). Although they may reach Term gestation, the journey towards that point is filled with emotional distress, including feelings of fear, worry, self-blame, failure, being alone and being a burden to partners and family (Durham 1999, Mackinnon 2006; O’Brien et al. 2010; Gaucher and Payot 2011). These feelings can also influence women’s experiences directly after their baby is born, including their experiences of feeding their baby.

Women in PTL sacrifice much in order to put their babies and families first (Alcalde 2011). This is the expectation of institutional motherhood (Rich 1976), and women who deviate in any way from this risk being considered medically non-compliant and “bad mothers” (Adler & Zarchin 2002; Palmer & Carty 2006; O’Brien et al. 2010;
Alcalde 2011). The experiences of women in PTL also highlight the gendered nature of their domestic situation (and of many women in general) including the conflict caused in some households if PTL diminishes their ability to undertake traditional ‘women’s work’ (May 2001; O’Brien 2010).

Following preterm birth some women may encounter further challenges, with their immediate environment dominated by the perceived need for monitoring and interventions for their baby. Women’s experiences of feeding their babies, which is often seen as “women’s work” may also be affected by their environment and the expectations on them as “good” mothers (Lupton & Fenwick 2001). Consequently, their experience of labour, birth, and the environment in which they find themselves may influence the way in which women with LPTBs experience early motherhood.

There is a small but growing evidence base around the experience of mothers of LPBs regarding feeding, which suggests that LPB ability to breastfeed may be affected by their physical and metabolic immaturity (Engle et al. 2007). Some of the specific challenges they may face include a poor suck, sleepiness and poor attachment techniques (Meier et al. 2007; Briere et al. 2015, Nagulesapillai et al. 2013)). Mathur (2008), Mathur and Dhingra (2009) and Nagulesapillai et al. (2013) further suggest that difficulties with attachment may result in poor breast stimulation and reduced lactation production. As well as the LPB’s physiological immaturity, early separation from their mother may affect their ability to breastfeed. Meier et al. (2007), Briere et al. (2015), Nagulesapillai et al. (2013) and Ayton et al. (2012) for example, discovered that LPBs were less likely to be put to the breast promptly than their term counterparts. In addition, Zanardo et al. (2011) and Brandon et al (2011) both found that women’s postnatal psychological distress is probably worsened by late preterm birth, which might impair both initiation of and ongoing breastfeeding for women. Feeding was an important issue for all the women involved in this study, and is therefore the focus of this paper.

Methods:

The approaches to data collection and analysis used in this study were based on feminist principles. Feminism, which challenges structures and ideologies that oppress women, is ideally suited as a framework for research in midwifery (Barnes 1999; Brooks & Hesse-Biber 2007). One of the challenges for midwifery and midwives is providing women centred care in hospitals that are traditionally patriarchal (Stephens 2004). This makes feminist approaches to research particularly appropriate for examining women’s experiences in hospital environments. Feminist research is generally agreed to refer to research that exposes women’s experiences (Monroe-Baillargeon 2004). It is also characterised by:

- a deliberate minimisation of harm or control in the research process (Devault 1999, p.31)
• demonstration of an organizational view of the ‘now’ and a vision for the future (Cook & Fonow 1986)
• from a midwifery perspective, an improvement in care for childbearing women, empowerment and celebration of women’s knowing (Yuill 2012, p.39).

This study aimed to achieve these elements of feminist research, and to capture the women’s concrete experiences: experiences which women perform daily such as caring for their families (DeVault 1996), and from which they have developed specific and “unique knowledge and skills” (Brooks 2007, p.57). Women themselves are best placed to understand these experiences (Yuill 2012). As a result, a qualitative methodological approach, wherein understanding the experiences and perspectives of individuals is the aim, was considered appropriate to utilise alongside feminist principles.

Interviews are a gold standard tool for understanding the authenticity of another’s experience (Oakley 2005; Hewitt 2007; Ryan et al. 2009). In this study, to explore in depth, women’s experiences, two interviews with each woman were conducted, the first a few days post birth and the second between eight and 12 weeks later. The first interview was conducted in the hospital environment, in either an office or the woman’s room. The second interviews took place in women’s homes. Interviews were semi structured, with the guides shown in Appendix 1 & 2, and Oakley’s (1981, 2005) approach (Table 1) adopted to guide and structure discussions.

- 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

Table 1: Oakley’s feminist guide to interviewing

With the women’s consent, interviews were digitally recorded and later transcribed verbatim. Each interview lasted between 25 and 60 minutes, (the majority around 40 minutes). Women were not led to discuss their experiences of feeding by specific questions, however they spent a lot of time during interviews discussing their feeding experiences. This therefore became an important part of the study as women’s voices made it a significant aspect of their experience.

Sample:

A purposive sample of fourteen women participated in the study. Purposive sampling was used as the study sought the perspectives of women who were the ‘experts and
authorities' on their experience of caring for a LPB (Coyne 1997; Brayton et al. 2016). In addition, the sample was intended to consist of a group of women experiencing a similar situation, to enable comparisons to be made between their experiences (Kuzel 1999). Of the fourteen women who participated in the first interview, thirteen agreed to be re-interviewed. All the women described their ethnicity as white. Eleven identified themselves as British, two were from different Eastern European countries and one was from South Africa. The characteristics of the women can be seen in Table 2.

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Table 2: Characteristics of the women

Ethical Considerations:

Ethical approval was obtained from an NHS Research Ethics Committee and from the Research and Development Department at the NHS Foundation Trust Hospital.
where recruitment occurred. Eligible women were given a letter of invitation and an information pack. Those who wished to participate returned a signed reply slip, and a meeting with the researcher was arranged. Women who chose to participate in the study were asked to sign a consent form. Participation was voluntary and women were assured that non-participation, or withdrawal from the study at any stage, would not affect their current or future treatment or that of their baby/babies. Interviews could be terminated at any point, and the researcher was able to signpost women who experienced any distress to appropriate support resources. Data were anonymised and the names used for participants in this report are pseudonyms.

Data analysis:

Women were provided with text versions of their interviews and invited to discuss these and the interpretation of them with the researcher. This was an important part of the collaborative, woman centred research process. After this process was complete, Template Analysis (TA) as described by King (2012) was used to aid analysis. Data analysis was also guided by Birth Territory Theory (BTT), (Fahy and Parrat 2006), 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. This theory can be extended beyond where women birth their babies to how maternity services are organised and managed (Fahy 2008). Therefore, aspects of BTT were used to explore the territory where women began their experience of mothering and mother-work, followed by their experience in their own territory (home) (Fahy et al. 2008, p.ix).

Findings:

With women’s experiences of caring for their LPBs as a central starting point, a conceptual diagram was devised to illustrate the overarching themes derived from TA for the whole study (not depicted here). All the names of the themes represented the woman’s voice. This paper reports primarily on women’s experiences of breastfeeding, and therefore the theme discussed here will be based [What was worrying me was the] Feeding. The illustration below simplifies the overall conceptual diagram and demonstrates how the theme Feeding was linked to other thematic areas in the larger study.
Feeding their babies greatly impacted on all the women’s experiences. A lower level theme that influenced their experience of feeding was whether the baby gained or lost weight. This issue is included in the findings reported here. Twelve of the fourteen women wished to breastfeed, however many of the babies experienced difficulties with feeding, and were supplemented with formula.

Separation from baby:

Separation from their babies impacted on many women’s experiences of feeding. For example, Gill explained: “I think my milk went down a little bit then, because we were apart from each other […]”

Once she was reunited with her baby, Gill solved this problem by providing her baby with constant skin to skin care. The following quote 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.

Marylyn was concerned about her ability to breastfeed, and being separated from her son heightened this concern:

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.
Overfeeding:

Some mothers felt that the feeding regimes outlined to them were inappropriate and would result in counterproductive overfeeding. Marylyn, for example, instinctively knew that her baby was being overfed and explained to staff that she wanted his top-ups reduced, so as to stimulate him to wake up and breastfeed:

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.

Breastfeeding support was ‘hit and miss’:

Although many women described an instinctive knowledge of what would work for their babies, the success of breastfeeding was also influenced by support from others, which Kate described as “hit and miss.” Even if, as described above, some staff listened to women, this was not always the case and many women’s breastfeeding experiences appeared muddled. Freya provided 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 could feel he wasn’t feeding very well from breast, […].

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.

Freya eventually abandoned breastfeeding and resorted to formula: her baby’s weight gain improved and she was discharged home where her attempts to breastfeed were unsuccessful. Freya seemed disappointed by this: “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.”

This feeling of disappointment at their baby being fed using formula was echoed by Kate: “….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.”

Kate’s experience of support was like 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.

Kate reported that she found the feeding advice offered conflicting and confusing:

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!”

When a nasogastric tube was suggested to support feeding, Kate and her husband, although seeking advice and support, 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!”

Following this, Kate felt her baby became “lazier” as previously he would “at least try on the breast.”

Feeding regimes:

Many women felt that although staff promoted the use of feeding regimes, these were not always easy to understand in terms of their structure or value. Kate explained:

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 two breastfeeds and then a bottle, or is it one breastfeed and a bottle? Not sure?

Some women would have preferred a more flexible approach, as they felt they knew their babies, but their concerns were not always acknowledged as staff often
prioritised ‘following guidelines’. Valerie found staff rigidity to ‘topping up’ her baby’s feeds difficult to understand, as some staff would not bother, and others were more vigilant. 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.

Marylyn eloquently described what it was like to have to adhere to feeding regimes:

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.

Mary was advised that her baby had to be completing all bottles without nasogastric top-ups before she could go home with her daughter. Despite being desperate to return home, Mary wanted to avoid ‘forced’ feeding and its consequences:

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.

When women were unable to keep up with the required feeding regime, they often blamed themselves: As Gill explained: “I didn’t have enough, because I wasn't very good at expressing, I didn’t.....and then you panic because you can't.”

At home:

Most women were sent home with infant feeding regimes. For example, Valerie’s feeding instructions were: “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.”

Gill was also told to wake her breastfeeding baby up three hourly.

“[.........] 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.”

Discussion:
All the women worked hard to ensure their LPBs fed appropriately, however their views on this sometimes conflicted with those of staff who generally controlled and evaluated feeding on the basis of schedules and weight gain. As described by Ludwig and Waitzman (2007), Breton and Steinwender (2008) and Puckett and Sankaran (2008), these regimes involved prescribed volumes of milk, predicated on concerns over the fragility of preterm infants and were used regardless of other considerations. As a result, in this study, overfeeding through adherence to prescribed regimes was common, with both women and midwifery staff appearing to be “subordinate to medical authority and the system” (Thompson 2003, p.598) in this respect. Many women in this study began their experience of mothering in an environment where “female-gendered skills of support, caring and being with women” (Kirkham 1999, p.733) were secondary within a “hierarchy of institutional expertise” (Freidson, 1970 cited Kirkham 1999, p.733) for maximum efficiency (male values) (Kirkham 1999). Whilst on the one hand women appeared to value expert, scientific-based advice, they were somewhat bewildered when, at times, their own knowledge and common sense contradicted “expert opinion” (Apple 1995, p.174).

Within these regimes described in this study, women were restricted to feeding for 20 minutes or so, to avoid over-tiring their babies, and were constantly having to express their breasts, reminding them that they were unable to feed their babies effectively. If they could not express enough to match their baby’s requirements they were disappointed in themselves. Two factors worked against women who were breastfeeding LPBs. Firstly, as identified by Mattsson et al. (2015), their confidence in themselves to produce enough milk was undermined by supplementation. Secondly, this study illustrated how overfeeding reduced or delayed babies’ ‘natural’ feeding cues which in turn interrupted women’s milk production. Whilst concerns have been expressed over mothers exhausting their babies through attempting to feed them (Jensen 2011), in this study it was the mothers who became exhausted by striving to adhere to imposed feeding schedules.

Women’s experiences were further influenced by an environment that was industrial in purpose and where they were seen as producers of a product (breastmilk), with their babies recipients of that product (Dykes 2005; 2006). Women’s descriptions focused on their struggles in keeping up with demand for the product, or trying to get their babies to consume the product. Many of these experiences have resonance with women in other studies (Sweet 2008; Boucher et al. 2011; Hurst et al. 2013). If women were unable to keep up with feeding regimes, 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, the focus being ‘has she produced enough?’

Women who expressed their breasts experienced what Johnston et al (2009, p.905) describe as an “inefficient’ breastfeeding body” characterised by its inability to produce sufficient milk. Although some feminist discourse portrays expressing breastmilk as a form of liberation for women: enabling them to manage the demands
of breastfeeding, share parenting, gain freedom to do other things and negotiate public feeding (Johnson et al. 2009, p.184; Ryan et al. 2013), this was not the experience of women in this study. For them it was neither liberating or a lifestyle choice, instead it was a form of regulation (Johnson et al. 2009; Johnson et al. 2012), becoming a matter of “maintaining product over process” (Demirci et al. 2015, p. 68). Some of the women in this study referred to themselves as “cows” because they were constantly expressing their breasts to keep up with feeding regimes, a feeling that has also been described elsewhere (D’Ignazio 2016; Wilson 2012; Swift & Scholten 2010). Some feminists have considered whether breastfeeding in fact reinforces gendered roles for women, as only the mother can meet the baby’s nutritional needs and Friedman (2009) questions whether equality in parenting can exist in this situation.

Boucher et al (2011, p.22) suggest that women often link breastfeeding with the concept of ‘good mothering’. Consequently, 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.

Within the context of LPBs, the strict routines and supplementation seen in this study go against women ever succeeding in this respect. ‘Breast is best’ also informs women they will enjoy breastfeeding (Friedman 2009), but this study provides a different perspective. Women described being tired, feeding to alarm clock times, snatching sleep in-between relentless rounds of feeds and breastmilk expression, and feeling stressed and under pressure to produce set amounts of expressed breastmilk. Within the context of LPBs, at least initially, it appears that breast is best only for babies (Friedman 2009). Similarly, medically prescribed feeding regimes appear to benefit LPBs (Ludwig 2007; Cleveland 2010; Munson et al. 2011), but strict feeding schedules and ‘top-ups’ work against successful physiological breastfeeding and by undermining women’s confidence (McCarter-Spaulding 2008).

Despite the challenges faced by women when breastfeeding their LPBs, it provides them with an opportunity to uniquely contribute to their baby’s wellbeing if they freely choose to do it (Sweet 2008). Midwives seemed unable to utilise their instincts to guide individual women, or to be flexible in managing feeding so as to enable breastfeeding to become a positive experience. As described by Thompson (2003, p.596) the environment was one where midwives’ prime relationship appeared to be with the baby, with the “woman rendered invisible”. Midwives and other professionals also often operated by utilising disintegrative power to dominate over women’s wishes (Fahy and Parratt 2006). 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 that served to undermine them through a series of “quiet coercions” (Lupton and Fenwick 2001).
Conclusion and recommendations:

The current approach to caring for woman and their late PTBs tends to result in feeding becoming a source of stress and anxiety for women, rather than a positive experience. To resolve this problem, staff caring for women who have LPBs should focus on supporting women to trust their instincts, and to guide them in developing confidence in their ability to read their babies’ cues, rather than in focusing on strict regimes of feeding. This should include individualised consideration of whether supplementation is required in the early days. Whilst feeding regimes have some benefit for LPBs (Puckett & Sankaran 2008), these work against mothering and women’s instincts. Keeping women and their babies together will facilitate knowing behaviour for the dyad, and early and continued opportunities for skin to skin contact. It will also enable staff to provide the type of tailored advice and support that would be likely to enhance women’s experiences of early motherhood.

Further research into this model of care is needed, to establish whether it enhances women’s experiences whilst also ensuring the safety and well-being of LPBs.

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