An exploration of the experiences of mothers as they suppress lactation following late miscarriage, stillbirth or neonatal death

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Abstract

Objective. To explore the experiences of bereaved mothers as they suppress lactation following late miscarriage (>20 weeks), stillbirth or neonatal death.

Method. A qualitative, focused ethnographic approach was used involving in-depth interviews with 15 bereaved mothers, who attended a maternity hospital in Dublin. Data were collected from January to August 2012.

Findings. Three key themes were identified: (1) suppression of lactation following the loss of a baby: silent tears; (2) mothering; (3) supportive care needs and the bereaved mother’s experience. This paper focuses on the first global theme. The majority of bereaved mothers found engorgement and leaking milk particularly challenging both physically and emotionally following the loss of their baby; especially as their baby’s funeral or wake took place during this period. The study highlights a number of areas where women could be better prepared for this experience.

Conclusion. The findings highlight that the majority of bereaved mothers will require improved guidance and support with their breast care needs following the loss of their baby with awareness and sensitivity to their shortened motherhood.

Key words: Bereaved mothers, perinatal death, pregnancy loss, engorgement, suppression of lactation, breastfeeding, evidence-based midwifery

Introduction

The death of a baby is described as one of the most difficult losses to bear (Norlund et al, 2012; Mander, 2006). The baby’s death is further compounded with physiological lactation, which develops between 48 and 96 hours following the birth. Colostrum is present in the breasts from 16 weeks’ gestation (Inch, 2009), therefore, a mother who delivers after 16 weeks will secrete colostrum, even though she has delivered a non-viable infant (Lawrence and Lawrence, 2011). While engorgement plays a role in decreasing milk supply (Cole, 2012), engorgement and fullness in the breasts is often an unexpected shock for a grieving mother (Pugmire, 1999). The grieving experience is often compounded by breast discomfort and leaking milk experienced as a consequence of the physiological suppression of lactation (Cole, 2012; Spitz et al, 1998; Mines, 1982). This is further accentuated if a baby dies following a period in the neonatal intensive care unit, given that in general the mother’s milk supply is already established with hand expression and/or the use of an electric breast pump/or breastfeeding (Busta-Moore and Caitlin, 2003). Mothers will, therefore, require further support and anticipatory guidance with their breast care needs following the loss of a baby.

In Ireland, the funeral service takes place within a short timeframe following death, usually three to four days. On many occasions, a traditional Irish wake precedes the funeral service. This is where the deceased person’s body is laid to rest in the family home. During the traditional wake, the family home has an open door, providing family, friends and neighbours an opportunity to visit, offer support and comfort the bereaved family. Food and drink (usually tea) is provided and people sit around talking. The traditional wake is an old Irish way of celebrating life. It is during this period that a mother is also experiencing physiological lactation.

The suppression of lactation following the loss of a baby has been addressed in the literature: Cole (2012), Busta-Moore and Caitlin (2003), Pugmire (1999) and through support material, however, there is a lack of evidence-based research exploring mothers’ experiences of suppressing lactation following perinatal death. This study set out to explore the experiences of 15 mothers who had experienced a late miscarriage (after 20 weeks of pregnancy), stillbirth or neonatal death, as they suppressed lactation following the death of their babies. The study hospital was a large tertiary referral centre in Dublin with approximately 9000 births during 2011, of which 66 perinatal deaths were reported. In addition to this, some mothers also experienced a late miscarriage from 20 weeks’ gestation. Bereaved mothers at the hospital received a pilot breast care leaflet with information on the suppression of lactation. The study sought to provide information to assist in the development of guidelines for bereaved mothers on the suppression of lactation.

Method

A qualitative-focused ethnographic approach was used to explore the perspectives of bereaved mothers recruited at a large maternity hospital in Dublin. In a focused ethnography, the number of participants is limited and the objective is to obtain information from people who have knowledge and experience of the subject matter (Meucke, 1994). As a clinical midwife specialist in lactation, the topic area was known to the researcher and this knowledge was used to set the direction for the research, as suggested by McNeill and Nolan (2011). In accordance with Richards and Morse’s
(2007) description of how a focused ethnography may be used to study a subcultural group, bereaved mothers following perinatal death with engorged breasts and breastmilk were defined as a subculture of bereaved mothers.

Participants

Using a purposeful sampling approach, 27 women, who had experienced the loss of a baby within the previous six to 12 months, were invited to participate and, of these, 15 women agreed to participate. Mothers were recruited from three categories: 1) Late miscarriage >20 weeks’ gestation; 2) stillbirth, and 3) neonatal death. The purposive sample included mothers who gave birth to their baby at the hospital or when their baby was transferred to the hospital for further care. A varied age profile and mixed socio-economic class was sought.

Initial contact was made with the bereaved mother by the clinical midwife specialist in bereavement who informed women of the study and asked if they would be willing to participate. These details were then passed on to the researcher, who then contacted each woman to answer any further questions. Details of the study were subsequently posted to each woman, who then had an opportunity to discuss participation with a family member. Women who wished to participate were asked to return the signed consent form in a stamped addressed envelope. This contact was followed up with a telephone call or a reminder letter, where the consent form was not returned.

Data collection

Data collection comprised individual semi-structured interviews, which took place between January and August 2012. Most interviews were conducted in the participant’s home. The humanistic approach of the psychologist Carl Rogers (1967) guided the interview technique. Rogers pioneered the concept of congruence, empathy and unconditional positive regard. During the sensitive interviews, these concepts facilitated trust between the mothers and the researcher. Good communication skills and assisting mothers to feel comfortable during the sensitive interview process was particularly important. A growing body of research describes how research participation with the bereaved may serve the interests of participants and be therapeutic, educational or empowering (Hynson, 2006; Dyregrov, 2004).

Ethical considerations

Ethical approval for this study was obtained from The National Maternity Hospital and university human ethics committees. In light of the sensitive study topic and in order to safeguard the wellbeing of the participants, the clinical midwife specialist in bereavement at the hospital was available for support and counselling, however, this support was not requested. Written contact details of bereavement support groups were also issued post-interview.

Reflexivity

Reflexivity was central to the study where the researcher was conscious of the dual role of clinical midwife specialist in lactation and researcher. On a practical level, the researcher brought prior knowledge and understanding to the field, while, at the same time, the researcher was cognisant of any influence, intentionally or otherwise during data collection and analysis.

Data analysis

The transcripts were read until the researcher became familiar with the text. The coding framework used was based on the theoretical interests guiding the study: the physiology of mammogenesis (Pollard, 2012); attachment theory (Bowlby, 1974, 1969) and recent grief theories (Stroebe and Schut, 2010, 1999; Walter, 1996) along with salient issues that arose within the text (Attride-Stirling, 2001). Bias was addressed through discussion with an experienced academic. Thematic network analysis (Attride-Stirling, 2001) was utilised to identify three global themes, one of which is the central focus of this paper.

Findings

A total of 15 women agreed to participate in the study; five had experienced a late miscarriage, three had experienced a stillbirth, and seven had experienced a neonatal death. The age range was from 28 to 44 years and for the majority of women (11/15) this was their first pregnancy (see Table 1). There was an even mix of professional and non-professional women in the sample and although the majority of women were Irish nationals, three non-national women also participated.

The findings reported in this paper are from the first global theme – suppression of lactation following the loss of a baby: silent tears (see Figure 1). It describes two organising

<table>
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<th>Table 1. Description of the participants</th>
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<td>Participants (n=15)</td>
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<td>Gestation/weeks</td>
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<td>– 24+6 days to 42 weeks (neonatal death)</td>
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<td>– 29 to 38 weeks (stillborn)</td>
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themes: managing physically and managing emotionally. The findings describe that in the midst of a mother grieving the loss of her baby, sore and engorged breasts compounded this grief experience. Emotional pain exacerbated the physical pain of engorged sore breasts and leaking milk.

Managing physically
Sore breasts
In this study, mothers generally described varying levels of engorgement from the second to the fourth day following the loss of their baby. Mothers described the physical discomfort, pain and sensitivity of their breasts. First-time mothers experienced a significant level of engorgement and were quite shocked by the physicality of it, with some describing their breasts as like rocks. Some of these mothers also leaked milk and needed to wear breast pads. Mothers who had breast-fed previously experienced marked engorgement and leaking milk. The majority of mothers had been discharged from hospital before these symptoms developed:

“I believe my milk came in on about the third or fourth day... I was quite surprised at how full my breasts became” (Sarah, 26+6/40 P2).

“I remember just the filling up and the pain... just the ongoing pain for at least, whatever it was, eight to 10 days afterwards, so definitely, it was definitely my experience... filling up and the leaking and just trying to manage it and reduce it and ease it off” (Anne 41/40 P1).

A number of mothers used chilled or frozen cabbage leaves in their bras and found this very soothing for hot, tender breasts: “I did find it helped, I really did.” Two mothers, however, were not supportive of the idea of using cabbage leaves in the bra: “I didn’t want to do that.” And: “It was cold from the fridge, the leaves were getting warm.” And: “I was swapping them in and out the whole time and I think it was just stimulating the breast further.”

The symptoms of engorgement and sore breasts challenged mothers physically as their baby’s funeral or wake took place during this period. At the funeral, Anne describes being hugged while having sore, tender breasts as very painful. She remembers placing one arm across her chest to protect herself from the pain of engorgement as people hugged her closely:

“I do remember ending up structuring myself so that my left arm was doing the hug... I put my right arm in, like in front of my chest, almost able to push the person back if they were getting a little bit too close” (Anne, 41/40 P1).

One mother was dealing with breasts full of milk and hosting a wake in her home:

“It was a very busy day... I meant to go up and express, but I never got a chance” (Anna, 24+6/40 P2).

Jill describes her experience of sore breasts on the day her baby was cremated:

“I shed a few tears over the time as I remember thinking I really don’t need this” (Jill, 20/40 P1).

An interesting aspect of women’s experiences was the silence surrounding the painful engorgement they experienced and this was particularly evident at the wake and funeral:

“The pain was unbearable at times... I ended up just putting out my hand so I didn’t have to hug anybody” (Cora, 27+4/40 P3).

Experiences of mothers as they managed leaking milk
Participants suggested that the experience of leaking milk brought additional challenges. Providing milk for a baby continues the attachment of mother and baby after the birth. Having breastmilk and leaking milk challenged mothers’ self concept:

“I had to put in two or three pads at a time because I felt that it was coming through one” (Cora, 27+4/40 P3).

“When I was in bed, I woke up and I had a massive leak. My pyjamas were completely drenched – you could wring them out, they were that bad” (Janice, 35+5/40 P1).

The majority of mothers interviewed experienced engorged breasts and leaking milk, which continued over a longer timeframe than would be expected – some reported it continuing for two weeks. Mothers were generally unprepared for the length of time they would experience this. Sarah described her experience:

“I think probably... the leaking ended maybe after two weeks, but I could actually get milk out of my breast 1 remember... six weeks after” (Sarah, 26+6/40 P2).

Managing emotionally
Providing breastmilk for a baby is deeply connected with motherhood and descriptions of mothers as nurturing and nourishing. To have milk and no baby compounds the loss further. One mother described it as feeling as though her milk is just for her baby, who is not with her any more.

Unexpected
The descriptions of some mothers suggested they had not expected to lactate or did not expect it to be as challenging an experience as it was. Some mothers felt their baby was not alive therefore their body would know this and not produce milk. The production of breastmilk was particularly a shock...
for mothers at an early gestation:

“The pain was just painful and the fullness was just uncomfortable, but I found the fact that it started to leak was emotionally very difficult” (Cait, 23/40 P1).

Melanie described: “It was one of the worst things… (to) go home without a child and have your breasts so painful and like rocks and kind of go: ‘Why can’t this just go with the child?’ That was the biggest thing for me” (Melanie, 25+4/40 P1.)

Another mother, Sally said: “(I) just got the breast pads and literally just waited it out til it stopped... and then eventually it just went” (Sally, 28+6/40 P2).

Jill commented on the unexpected relief from placing cabbage leaves on her breasts: “It was really nice to have that relief straight out of the freezer... I think I had gone a good few days before I had learned this trick... I was in a good few days of pain at the start before I had tried that” (Jill, 20/40 P1).

Upset

Participants described how emotionally sore breasts, leaking and visible drops of milk added to the upset that they experienced and compounded their inability to mother:

“Emotionally it was very hard to come to terms with, I felt like I needed to mother” (Amelia, 38/40 P3).

“I just remember it constantly being there that even towards the end of the two weeks or, whatever it was, when I kind of thought it was gone and I remember being in the bed... And I remember like feeling... I could feel it on my arm, you know the wetness and I remember getting really upset because I thought it had finished and I was like: ‘God when is it going to stop?’” (Jill, 20/40 P1).

Sarah described how she would put off having a shower every morning because the heat of the shower would make her breasts leak milk:

“I hated having a shower, I would put it off. I am in the shower with no baby and full breasts... and I am on my own, so I would cry in the shower regularly... it was just a very, very hard... hard time” (Sarah, 26+6/40 P2).

Two mothers were expressing milk for their baby. Anna had built up a good supply of breastmilk during the week her baby was in the intensive care unit. Following the death of her baby, Anna found comfort in donating her stored breastmilk to the human milk bank in Northern Ireland:

“I donated my milk... when the milk is no longer needed, I think it’s great that it can be used” (Anna, 24+6/40 P2).

The findings from this study highlight the physical, emotional and social consequences of the suppression of lactation in the aftermath of a baby’s loss.

Discussion

This study described the experiences of mothers and the varying degrees of breast engorgement following the loss of their baby, from as early as 20 weeks’ gestation. In keeping with the literature, the majority of mother’s experienced lactogenesis between days two to four following the birth/loss of their baby (Pollard, 2012; Riordan and Wambach, 2010). This was accompanied by varying degrees of breast pain, engorgement and leaking milk. The majority of mothers interviewed described engorgement as a significant experience for them. Leaking milk and the duration of the lactation process added to their physical and emotional discomfort.

Some mothers experienced a more intense leakage of milk during the night. The production of prolactin is described as circadian and increases during sleep (Donaldson-Myles, 2012). This is a possible contributing factor to the level of leaking milk experienced by some mothers in the study. Lawrence and Lawrence (2011) suggest factors such as psychogenic influences and stress can increase prolactin levels.

Non-pharmacological approaches to aid the suppression of lactation include wearing a good supportive bra and the application of cold compresses to the breast (Pollard, 2012; Walker, 2011; Riordan and Wambach, 2010) and the findings of this study are supportive of these measures. A number of mothers found the application of cool or frozen cabbage leaves soothing for hot, tender breasts. Lauwers and Swisher (2005) suggest that phytoestrogens present in the cabbage leaves may reduce swelling in the tissues while Humphrey (2007) suggests that it is the sulphur compounds and flavonoids that provide anti-inflammatory and anti-oedematous properties. This is supported in the findings of Arora et al (2008), Roberts (1995) and Nickodem et al (1993). More recently, Chiu et al (2010) reports Guasha (acupuncture) therapy as an effective technique in the management of breast engorgement, however, further research is indicated.

Pharmacological measures to suppress lactation include the drugs, bromocriptine and cabergoline; however, both are not recommended for routine suppression of lactation. The ergot alkaloid, bromocriptine, inhibits prolactin release and therefore stops lactation. Bromocriptine is administered over a 14-day period to prevent rebound lactation. While serious cardiac side effects have been documented (Iffy, 1996; Hopp, 1996; Ruch, 1989) with the use of bromocriptine for ablactation in the puerperium, a systematic review by Oladapo and Fawole (2012) did not show any clear evidence of serious adverse effects with the use of the drug.

A European multicentre trial found cabergoline to be the drug of choice for lactation inhibition, where indicated, due to its single dose administration and lower rate of rebound breast symptoms and adverse events (European Multicentre Study Group, 1991). Pugmire (1991) offers the opinion that, for some bereaved mothers, milk suppression by medication is a valuable compassionate alternative. More recently, Oladapo and Fawole (2012) suggest there is weak evidence that some pharmacologic treatments are better than no treatment for suppressing the symptoms of lactation, during the first week postpartum. Further research is needed in this area.

Bereaved mothers found the experience of producing milk, while having no baby to feed, very emotional. Welborn (2012) describes the comfort bereaved mothers experienced through the donation of their breastmilk to a human milk bank and this finding was mirrored in the present study. This study also offered personal narratives of the challenges mothers faced managing engorgement at their baby’s wake or funeral,
providing insight for professionals involved in their care.

There are currently no available guidelines in Ireland to direct clinical practice in relation to the suppression of lactation following the loss of a baby. The present study found that bereaved mothers require information and supportive measures to manage their breast discomfort. A revised breast care information leaflet is now available at The National Maternity Hospital, a guideline is being developed and staff education sessions are ongoing.

Implications
The present study demonstrates the importance of the midwife addressing the emotional and physical aspects of the suppression of lactation with a mother following the loss of a baby from 20 weeks’ gestation. Information should be provided in verbal and written format with sensitivity to an individual mother’s emotional response to grief. The bereaved mother is often discharged from hospital within 24 hours following the loss of her baby, therefore she should be informed that her breasts may become engorged between the second and fifth day following the loss, and that the breasts may feel uncomfortable and leak milk for up to seven to 14 days. The baby’s funeral may take place during this period.

To relieve symptoms of engorgement, it should be suggested to mothers that they:

- Wear a good support bra continuously while the breasts feel uncomfortable
- Have breast pads to absorb leaking milk
- Use cold compresses to alleviate painful, engorged breasts
- Take regular pain relief
- Have a warm shower, but try to avoid the water jets directly stimulating the breasts
- Hand express a little colostrum/breastmilk for comfort if the breasts feel very full and uncomfortable
- Sleep in a semi-upright position where there is less pressure on firm, engorged breasts
- At the wake or funeral, if standing, place one arm across the chest to protect sore breasts when being hugged.

In situations where a mother was regularly expressing milk, to stop suddenly would lead to a build-up of milk, which may lead to blocked ducts or mastitis. Mothers should be advised to reduce their milk supply gradually for comfort, aiming to express less often and to shorten the duration of expressing. Alternatively, mothers may prefer the more structured weaning regime, as described by Busta-Moore and Caitlin (2003): day 1 – pump each breast for five minutes every four to five hours; day 2 – pump each breast for three to five minutes every six hours; days three to seven – pump each breast just long enough to relieve discomfort. Mothers may wish to donate their frozen breastmilk to a milk bank.

Limitations
This was a small qualitative study with a sample size of 15. Data saturation was achieved within the categories where mothers experienced breast engorgement and leaking milk and the findings provide considerable insight into the experiences of women. The study may be limited in relation to memory bias that may exist on the part of the mothers due to their grief experience.

The research was carried out at a Dublin maternity hospital and the results may not apply beyond this context. In order to minimise bias, the researcher used a reflexive diary and fully described the research process in reporting the findings. Notwithstanding these limitations, this study illuminates the experience of a very vulnerable group of mothers and has produced important findings for clinical practice. It also highlights the need for further research in this area.

Conclusion
This study is the first exploratory study that looked at mothers’ experiences as they managed breast engorgement and leaking milk following the loss of their baby. The findings from the first global theme ‘Suppression of lactation following the loss of a baby: silent tears’ have provided a deep and meaningful insight into the silent world of the bereaved mother. With cultural expectations of a wake and early burial within a few days following the loss, mothers experienced full engorged breasts and leaking milk, which is physically and emotionally painful for them. The findings from this study recommend that all bereaved mothers following a pregnancy loss from 20 weeks or neonatal death are provided with both verbal and written information regarding the suppression of lactation.

References


European Multicentre Study Group for Cabergoline in Lactation.

**References continued**


