Lactation after loss: supporting women's decision-making following perinatal death

Abstract

Offering sensitive and compassionate clinical and bereavement care following perinatal death is the innate focus of the caring healthcare professional and facilitating informed choice around the subject of lactation following loss is an integral part of this. However, evidence suggests that there may be a deficiency in the provision of lactation advice and support following loss. Contributory factors may include a lack of awareness of lactation options following bereavement amongst midwives, as well as an absence of clarity around where the responsibility for offering lactation support and advice lies. This paper presents the literature surrounding the support of women's decision-making for lactation following perinatal death, explicating the physiology of lactation in the antenatal and postnatal periods, and exploring the challenges and opportunities for the midwife when supporting grieving mothers to decide the best option for them and their family.

Keywords

Stillbirth | Neonatal death | Bereavement care | Lactation

Perinatal death affects 5.4 out of every 1000 births in the UK (Draper et al, 2019) and is classically defined as a stillbirth (where a baby is born in the UK with no signs of life after 24 completed weeks' gestation) or a neonatal death (where a baby is born alive but dies within 28 days of life). However, the gestation of pregnancy or timing of baby loss is not necessarily reflective of either the intensity of grief experienced by the mother (Brier, 2008) or the incidence of lactation after loss. This means that the prevalence of support requirements around lactation following loss is likely to be higher than generally perceived.

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Pregnancy and baby loss have profound and enduring effects on women and their families which extend to broad aspects of their psychological and psycho-social well-being (Burden et al, 2016; Coffey, 2016; Heazell et al, 2016; Nuzum et al, 2018). Offering sensitive and compassionate clinical and bereavement care is the innate focus of the caring healthcare professional following perinatal loss and facilitating informed choice around the subject of lactation following loss is an integral part of this. However, research findings demonstrate that around a third of bereaved mothers are not advised about management of lactation (Redshaw, 2014) and lactation suppression is only discussed with half of mothers (Draper et al, 2015).

Lactation following loss is an area that may often be disregarded or shied away from by healthcare professionals and women may feel that their choices are not explored or validated (Smith and Hinton, 2018). There may be a lack of awareness amongst midwives of lactation options following bereavement as well as an absence of clarity around where the responsibility for offering lactation support and advice should lie, particularly in the longer term and once a woman has been discharged from midwifery care. This may result in physical effects for bereaved women such as breast engorgement, pain and mastitis, and the additional psychological distress of dealing with such symptoms alongside the grief for their baby (Kennedy et al, 2017).

Midwives are experts in the care of pregnant women and are knowledgeable about the physiology of lactation in the antenatal and postnatal periods, and provide breastfeeding advice on a daily basis to the mothers of healthy neonates. This paper argues that the midwife's expert knowledge should therefore also be applied, sensitively and appropriately when a baby has died, further exploring the barriers and opportunities for supporting women's decision-making around lactation following perinatal death. The general paucity of the literature and lack of inclusion in standard midwifery texts demonstrates the need for improving both knowledge and skills in this specific issue.

The physiology and timing of lactation in the antenatal and postnatal periods

The actuality that her body will produce breastmilk following the stillbirth or early neonatal death of her baby may come as a complete shock to a mother (Cole, 2012). However, utilising their understanding of the physiology of lactation during pregnancy and postpartum, the midwife can be mindful of the need to prepare women in order to avoid the potential additional distress of unanticipated lactation.

Under the influence of oestrogen, the breast changes that will go on to support lactogenesis (the production of milk by the mammary glands) commence as early as 3–4 weeks of pregnancy and result in ductular sprouting and the beginnings of lobular formation and branching (Lawrence, 2016). Full lactation is possible from 16 weeks' gestation (Lawrence, 2016) and the breasts can now secrete small amounts of colostrum (Stage I lactogenesis). This means that even when pregnancy loss occurs at this early gestation, a woman, particularly where multiparous, may produce breastmilk following birth. Prior to birth, the limited quantity and composition of colostrum is dictated by the high levels of progesterone and oestrogen circulating in the pregnant woman's blood (Neville et al, 2001). Following birth, a sharp decrease in the levels of progesterone, as well as changes to the mammary epithelium, results in the increased volume and altered composition of the breastmilk (Stage II lactogenesis) which is commonly known as the mother's 'milk coming in' (NHS, 2019).

The process by which breastmilk production ceases (involution) occurs due to both the lack of the stimulation of a baby suckling and engorgement of the breast as the milk is not emptied and subsequent compression of the blood vessels (Lawrence, 2016). Where a bereaved mother is not supported to manage involution, engorgement and pain can occur (Busta Moore and Catlin, 2003). Addressing the subject of lactation as soon as is appropriate may decrease the prevalence of such unanticipated discomfort and distress (Britz and Henry, 2013).

The impact of service provision and pathways following loss

For the mother of a baby who dies before or shortly after birth, lactation may occur while she is on the postnatal ward but is equally likely to occur when she has left in-patient care and is at home. For the mother whose baby has been admitted to neonatal intensive care, lactation may happen as she is trying to navigate the postnatal recovery period as well as the bewildering environment of the neonatal intensive care unit. The death of her baby may take place after she has been discharged from her own inpatient care thus limiting the opportunity for the midwife or neonatal nurse to discuss lactation options. A recent confidential enquiry into term intrapartum-related stillbirths and neonatal deaths demonstrated that there were issues around the provision of community midwifery following bereavement with just under one third of women not having documented evidence of community midwife visits (Redshaw et al, 2017). A potential outcome of this lack of community midwife provision is the loss of support to grieving mothers at a time when they are experiencing lactation; often coinciding with significant grief events such as their baby's funeral (McGuinness et al, 2014).

Women's experiences of grief and responses to lactation following loss

There is no one-size-fits-all approach to discussing lactation options when a baby has died and it is imperative that the midwife avoids judgement about what is a normal grief response (Oreg, 2019). A notable model of grief outlines the five stages of denial, anger, bargaining, depression and acceptance which are often not navigated in sequential order (Kübler-Ross, 2014). This model may be useful to illuminate the challenges the midwife faces in providing timely and sensitive lactation advice to mothers in the very early and raw stages of grief for their baby.

For a significant proportion of mothers, lactation following the death of their baby is a distressing physical experience (Sands, 2016), typified by the paradox of the emotional grief experience and the physical symptoms; exemplified by the phrase: 'her breasts don't know that her baby has died' (Weaver, 2018). A bereaved mother, Maxine, explains her feelings:

> ***'You notice – you know – every single drop of milk you lose … and it's—your body is so, so cruel. Because my body thinks it's just had a baby. And it doesn't have a baby (Smith and Hinton, 2018).'***

Some mothers may have a strong sense of their breastmilk being an emotional link to their deceased baby (Weaver, 2018) and wish to prolong lactation for this reason. Breastfeeding is an expression of motherhood and bereaved mothers may feel that they have been 'stripped of their identity' (Welborn, 2012); the continuation of lactation, either for personal or donation reasons, may be a means, therefore, to reconstruct their identity as a healthy female (Rossetto, 2014). Sensitive conversations around lactation options, including the possibility of milk donation, provide the bereaved mother with the possibility of exploring the association between grief and the altruistic act of gifting her breastmilk (Oreg, 2019).

Evidence around management of lactation following loss

It is clear from the literature that much of the evidence for provision of lactation options following the death of a baby is inconclusive or has limitations. Facilitating the bereaved mother's choices around the management of her breastmilk following loss, however, may be informed by the options explored below:

Lactation suppression by non-pharmacological means

Non-pharmacological methods for lactation suppression include the avoidance of breast stimulation, the wearing of a well-supporting bra, the application of cold cabbage leaves (Wong et al, 2017), jasmine flower and ice packs. While the anecdotal evidence and application of such methods is familiar to midwives, peer-reviewed research studies are few and inconclusive as to their benefits (Oladapo and Fawole, 2012).

Lactation reduction regime and measures for comfort

A modified approach to suppression by non-pharmacological may circumvent the abrupt cessation of lactogenesis, avoiding some of the more extreme effects of breast engorgement and associated symptomology for the grieving mother. This method involves hand expression of the milk from the breast with a gradual reduction over days of the frequency and length of expression to provide a more natural approach to lactation suppression (Busta Moore and Catlin, 2003). Supplementary non-pharmacological comfort measures such as those described above may also be used alongside this expression reduction regime.

Lactation suppression by pharmacological means

Bereaved mothers may choose to suppress their breastmilk using pharmacological means. This is supported by the national guidance as almost a third of women who opt for non-pharmacological methods are 'troubled by excessive discomfort' (Siassakos et al, 2010). The medication Cabergoline is advocated over Bromocriptine due to the reduced incidence of rebound lactation and better side effect profile (Siassakos et al, 2010; Oladapo and Fawole, 2012).

Expression of breastmilk and establishment/continuation of lactation for personal reasons

Research literature contains very little about the experiences of mothers who choose to establish or continue lactation for personal reasons but anecdotal accounts suggest that mothers may experience a 'second bereavement' when breastmilk ceases (Kennedy et al, 2017). Bereaved mothers may wish to maintain their breastmilk supply as a connection to their baby or may wish to store expressed breastmilk as a memory making occasion and breastmilk expression may provide a 'transition period in grief' (Welborn, 2012).

Expression of breastmilk with the view to donate

The option to commence or maintain their lactation for donation purposes is one that the midwife may feel less equipped to deal with; the incidence of donation following loss potentially being led by individual motivated bereaved mothers (Kennedy et al, 2017). It is possible to hypothesise that the midwife may be reluctant to offer this choice due to a lack of knowledge of milk donation processes and provision but further research is needed to investigate this. Milk donation in bereaved circumstances is explored further below.

Donation of previously expressed and stored breastmilk

As an alternative to discarding expressed breastmilk, donating previously expressed and stored milk 'respects the value of the milk' (Carroll et al, 2014) and again provides the mother with the opportunity for philanthropic giving which may have an influence on the nature of her experience of grief and loss (Oreg, 2019). Where time has allowed for the establishment of her milk expression (eg in the case of a baby who dies towards the end of the neonatal period), approaching a mother sensitively about her wishes for previously expressed and stored breastmilk is advocated (Sands, 2016).

Supporting choices when a baby is expected to die following birth

Discussing options with parents when a baby is expected to die following birth or where care is reoriented to palliation is challenging but may be facilitated by specialist individualised care plans. A recently published perinatal bereavement programme incorporated an individualised antenatal neonatal lactation consultation, alongside opportunities to discuss memory making and milk donation as a standard (Cole et al, 2018). Utilising two case studies to establish the usefulness of this programme, the importance of continuity and ongoing professional support to the bereaved mother before and after the death of her child, was clearly demonstrated (Cole et al, 2018).

Supporting a mother to express some colostrum or use her previously expressed breastmilk to feed her dying child, should she wish to, has been proposed to bring a sense of normality within a tragic situation and support positive memory making (Britz and Henry, 2013). Where the mother wishes to donate her breastmilk in the longer term, practical and emotional support, including the opportunity to use a breast pump before and following the baby's death, is helpful. However, the professional's initial priority is to facilitate the bonding process between the mother and her baby

through skin-to-skin contact and breastfeeding where possible and wished for, as well as involving her family in engaging with the baby and supporting her (Spatz and Cole, 2020).

Barriers and challenges to offering lactation support following loss

As well as the challenges of timing of lactation support discussed earlier in this paper, the literature suggests that some healthcare professionals may feel averse to discussing lactation options with bereaved or soon to be bereaved mothers as they feel they are 'acting in their best interests' by not broaching the subject (Britz and Henry, 2013). A lack of knowledge and awareness of options for lactating bereaved mothers may also affect the midwife's confidence in their ability to provide advice. This is illustrated by the experience of the mother who, when asked about lactation suppression medication, was told that her milk would not come in as she would not hear the sound of her baby crying (Nordlund et al, 2012); here, the advice was both insensitive and inaccurate.

It may be unclear who is responsible for offering support with lactation choices and the responsibility for ongoing psychological well-being of bereaved mothers who choose to donate may be undetermined (Carroll et al, 2014), with mothers typically discharged from midwifery care by the time ongoing donation is established. Involving clinical bereavement specialists (bereavement specialist midwives or nurses) in the provision of lactation support to all bereaved mothers may improve the quality of advice and continuity of care. However, such bereavement specialists are not situated in every hospital (Sands and Bliss, 2018) and the lack of a nationally recognised job specification for them (Sands, 2015) could suggest that the provision of lactation support may not be explicitly defined in their role.

Milk donation following loss in the UK

The provision of milk banks has increased in recent years with 16 milk banks in the UK (European Milk Bank Association, 2016). While there were no published studies found relating to the prevalence of donation and the provision of support in bereaved circumstances, personal communication between the author and the seven UK-based milk banks that responded to enquiries about this (Dickens, 2019), revealed that while the proportion of bereaved donors was very small, there was an aspiration to enable bereaved mothers to donate even if they lived an extended distance from the nearest milk bank and to provide sensitive information and support (Northwest Human Milk Bank, 2019). Bereaved mothers would benefit from midwives being familiar with the pathways for facilitating milk donation pertinent to their geographical location.

Wider considerations for milk donation following loss

An aspect of prolonged breastmilk expression following loss that warrants further consideration may be the maternal health benefits associated with extended breastfeeding (Chowdhury et al, 2015) including the reduction in rates of breast and ovarian cancers, and diabetes. While there is no evidence that breastfeeding prevents postnatal depression (PND), PND has been associated with shortened breastfeeding durations (Chowdhury et al, 2015). Furthermore, there is a lack of critical enquiry in the literature regarding how this may relate to maintaining lactation after loss and the provision of informed choice to bereaved mothers. The assertion that the altruism of breastmilk donation following loss may lead to a reduction in the incidence of PND (Hartmann, 2017) is an area warranting further research enquiry.

There are, however, challenges both universal to all milk donation and unique to donation in bereaved circumstances. For various medical and lifestyle reasons, not all mothers will be suitable to donate and sensitive counselling is essential to help with the disappointment of unrealised expectations (Britz and Henry, 2013). Mothers will need adequate information regarding the commitment of expression and how the stress associated with their grief may negatively affect their production of breastmilk (Britz and Henry, 2013). Many women choose to become pregnant within the year following the death of their baby (Wojcieszek et al, 2016) and will require advice regarding how lactation affects their menstruation and planning a future pregnancy (Carroll et al, 2014). Concerns may also be raised around the potential deferral of medication therapy when mothers are keen to prolong their lactation in order to donate and the resulting compromise to maternal health (Hartmann, 2017).

A consideration for the midwife counselling a Muslim mother is the concept of milk kinship. This belief that receiving milk from another mother creates kinship ties with any of her offspring, therefore prohibiting future marriage between them, may affect the acceptability of milk donation within the Muslim population (UK Association for Milk Banking, 2016). An understanding of this and reassurances around the traceability of milk donations would assist the midwife's discussion with a bereaved Muslim mother and the provision of informed choice. An understanding of the issues relating to other cultures or orthodox religions is a clear gap in the literature surrounding lactation after loss. An example of this may be a better understanding

of considerations surrounding the law in Judaism of pikuach nefesh and how the notion of the preservation of life in relation to human milk donation (Kassierer et al, 2014) may influence a Jewish mother's beliefs surrounding milk donation when her baby has died.

Sensitive counselling around all of the above considerations is important, undertaken in a timely manner with information provided by a healthcare professional who has established a relationship of trust with the family (Kennedy et al, 2017). As with all aspects of bereavement care, the role of the father or birth partner and wider family is critical in the support of the mother's lactation and donation choices (Spatz and Cole, 2020).

Pregnancies subsequent to perinatal death

There is a growing body of evidence surrounding the importance of individualised care planning in any pregnancy following perinatal death (Ladhani et al, 2018) and while not explicitly demonstrated within the literature, it would seem obvious that this should extend to conversations around feeding choices during a successive pregnancy. The author's clinical observations as a bereavement specialist midwife suggest that the subject of planned method of feeding in a subsequent pregnancy may be characterised by varied emotions relating to, where this was planned, the missed experience of breastfeeding the baby that died and the prospect of being able to breastfeed a subsequent child. Sensitive enquiry about previous lactation experience and birth planning that incorporates the woman's planned feeding choice and the encouragement of skin-to-skin regardless of feeding choices would seem beneficial.

Summary

This paper has explored the facilitation of lactation choices as an innate element of the midwife's role in care of the bereaved mother following perinatal death. It has been argued that knowledge of the physiology of lactation in the antenatal and postnatal periods should inform the midwife's discussions with grieving mothers, and how postnatal and care for the lactating mother is planned and executed. Grief responses and choices around lactation following perinatal death are highly varied and the individual and the midwife should be mindful of this and sensitive in their presentation of the options available to lactating bereaved mothers, including helping to manage expectations where some options may not be available to all. Furthermore, while there may be benefits associated with maintaining lactation following loss and with donation, more research is needed regarding all aspects of lactation management and bereaved parents' experiences.

Recommendations

- Collaborative, cross-discipline research exploring the best pharmacological and non-pharmacological methods of lactation management, and the experiences of bereaved parents with a variety of responses to grief and lactation
- Addressing significant research gaps, especially around the role of wider family involvement and the implication of cultural and religious considerations
- Detailed inclusion of lactation following loss options information within bereavement care training and national guidance
- Examination of national and local service provision and pathways for lactating bereaved mothers, and the impact of continuity of care models for this cohort
- Standardised collaboration between milk banks, hospital and community healthcare professionals to provide specialist learning for midwives and authoritative advice for bereaved mothers wishing to donate their breastmilk. **BJM**

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Key points

- The prevalence of research and training available to healthcare professionals caring for mothers experiencing lactation after loss is currently limited, however
- The midwife should be aware of the variety of grief responses and choices regarding lactation following perinatal loss and be prepared to offer sensitive and appropriate individualised care
- The midwife can use knowledge of the physiology of lactation to inform their own practice, maintaining an awareness of the options available and the potential opportunities and challenges to facilitating choice in bereaved circumstances

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CPD reflective questions

- At what gestation might a woman experience lactation subsequent to miscarriage, stillbirth or neonatal death?
- What are the potential options available to a bereaved mother experiencing lactation following loss and how are these reflected in your current practice?
- What are the potential barriers and challenges to offering individualised choice in relation to lactation following loss, and how can you use your knowledge of these to inform and develop your future practice?

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