

Infant Nutrition

Lactation following bereavement: how can midwives support women to make informed choices?

Judith Kennedy, Anna Matthews, Laura Abbott, Jacqueline Dent, Gillian Weaver, Natalie Shenker

ORIGINAL

Introduction

Perinatal loss, defined as the death of a baby within the neonatal period, stillbirth or late miscarriage (determined for the purpose of this paper as 20 weeks' gestation), has been identified by multiple agencies and organisations as a focus for increased parental support. However, the lactation needs of mothers are broadly overlooked, which can lead to engorgement, mastitis and psychological harm. The most commonly offered option of pharmacological suppression is controversial due to a lack of efficacy, and concerns about physiological effects (Cole 2012). Women may already have stored frozen expressed breast milk (EBM) within the neonatal intensive care unit (NICU), or be discharged home before their milk comes in several days later. In our experience, information and guidance for bereaved mothers about lactation and EBM are often lacking.

For preterm neonates, the use of human milk for nutrition has been demonstrated to have significant health benefits compared to artificial formula (Quigley & McGuire 2014). Incidence of infection-related events, such as urinary tract infections, necrotising enterocolitis and sepsis can be reduced, and lengths of stay in the NICU are shortened when

human milk is used (Maffei & Schanler 2017). While mother's-own-milk (MOM) is the optimal form of human milk, the use of donor human milk can act as a bridge whilst a mother establishes her milk production, or in instances where MOM cannot be used. Milk banking has been carried out in the United Kingdom (UK) for over 80 years, based on the voluntary



donation of milk from women screened according to national guidelines (NICE 2010).

Current research describes a diverse population of milk donors in the UK, for whom key motivators to donate were the encouragement of health professionals alongside the sense of altruism gained from the experience (Thomaz *et al* 2008). For bereaved parents, with appropriate support, milk donation may aid the grieving process, but previously the evidence had not been examined in a systematic manner. Expressed milk belongs to the mother and its fate after infant loss is her decision. However, bereaved mothers are often overlooked as potential milk donors (Carroll *et al* 2014). This study aimed to search the literature and examine local practice in order to explore the experience of bereaved mothers; in particular regarding the subject of milk donation following perinatal loss, in order to guide training and inform recommendations for future practice.

Literature review in relation to milk donation and bereavement

The first phase of research involved an examination of available anecdotal evidence via internet searches, using keywords such as ‘milk donation’, ‘lactation’ and ‘bereavement’. To avoid bias, searches did not include words suggesting a positive or negative association. Results from this search included blogs, charity websites, online news articles and milk bank websites. It was considered that personal accounts published by milk banks were likely to demonstrate bias, so these accounts were excluded from the review. Following a review of anecdotal evidence, a literature review was conducted examining evidence regarding lactation options following perinatal loss, including milk donation. There was a wealth of anecdotal evidence, yet only a limited number of published articles were found. Seventeen articles were reviewed alongside National Institute for Health and Care Excellence (NICE) and Royal College of Obstetricians and Gynaecologists (RCOG) clinical guidelines. National Health Service (NHS) Trust bereavement care policies from hospitals local to the authors were examined, and professionals contacted to identify current practice. Finally, bereavement charities, often an important source of information for parents, were contacted to discuss what information they provided to bereaved parents regarding lactation and milk donation. Key themes were identified using a systematic approach, including benefits and drawbacks, individualised care and choice, and education and training.

Benefits: ‘expression brought an unexpected release’

The experiences of women who chose to donate following perinatal loss appeared mainly positive; several statements described milk donation as an experience which aided grieving: ‘*expression brought an unexpected release... gave me purpose... my milk*

could benefit others while giving my baby’s existence meaning’ (Anderson 2016); ‘*donating has helped us to heal*’ (Cruz-Chan 2016) and ‘*people said I was generous to donate EBM from weaning my lactation, but I was the one who benefitted*’ (Carroll 2013). This is mirrored in the published literature, where there is widespread consensus that milk donation provides bereaved mothers with catharsis and may aid the grieving process (NICE 2010, Britz & Henry 2013, Carroll *et al* 2014). Welborn (2012) expands on the theme, finding that women experience the period during which they express their milk transitional, allowing them time to accept their grief whilst having a tangible link with their baby. Moreover, perinatal mourning includes mourning for what may have been, including the aspirations parents held for their child (Leon 1990). The sense of legacy that parents report milk donation creates may therefore bring comfort (Welborn 2012).

Consideration should be given to the physical benefits that gradual weaning, rather than immediate suppression, provides regardless of donation intention. The physical challenges women face as a result of their milk coming in can exacerbate the grief they experience. McGuinness *et al* (2014a) highlight the impact of physical pain, stating that women felt unable to be embraced and comforted due to painful breast engorgement. Woo & Spatz (2007) state that expressing milk in order to achieve involution, thereby suppressing lactation, helps reduce the risk of engorgement, mastitis and physical pain. While this paper does not address the long-term benefits associated with periods of breastfeeding, the effects of breastfeeding on women’s health, such as reducing the risk of breast and ovarian cancer (Victoria *et al* 2016) and reducing the development of postnatal depression (Hartmann 2017) are undeniable. Despite this, currently RCOG guidelines (Siassakos *et al* 2010) do not recognise expression to wean as an option for bereaved women and favour pharmacological suppression, such as cabergoline over other non-pharmacological means, such as ice packs and well-fitting brassieres. However, one woman, when advised to suppress through pharmacological means, stated: ‘*Suppression of lactation at doctor’s orders brought physical and emotional suffering*’ (Anderson 2016). While further research would clarify the optimal suppression method, women should be offered comprehensive advice on all lactation options.

Drawbacks: ‘a second bereavement’

Although the process of milk donation may offer catharsis, Carroll *et al* (2014) reminds readers that grief is individual and every woman’s experience of lactation following bereavement will be different. While the emotive accounts mentioned above suggest the benefits associated with milk donation, not all women may find the process beneficial. Lactation, to some, can be a physical symbol of what they have lost

(Welborn 2012). This is demonstrated by women describing wanting to suppress lactation as quickly as possible: *'I didn't want to have my supply reminding me of what I couldn't bring home'* (Anonymous 2016). One woman who had donated her breast milk following bereavement reported that although the experience aided her grieving, when she ceased donating she experienced *'a second bereavement'* (Cruz-Chan 2016). This highlights the critical importance of ongoing care and emotional support to ensure the well-being of donors (Cole 2012).

Choice and individualised care: *'I wish I had been given the option of a milk bank'*

Modern midwifery practice is based on the provision of individualised care; the Nursing and Midwifery Council (NMC) professional standards assert that midwives must treat people as individuals, recognise diversity and choice, and uphold dignity (NMC 2015). A theme of milk donation as an overlooked option became apparent, illustrated by: *'I wish I had been given the option of a milk bank... it would have helped knowing a baby was getting what my baby no longer could'* (Anonymous 2016). The literature highlights the importance of choice for women suffering perinatal loss; Carroll *et al* (2014) indicate that such choice can be empowering for women, especially at a time of utter devastation. However, women can only make informed choices regarding lactation when they are aware of all options available to them (Kobler 2012, Welborn 2012).

Carroll *et al* (2014) identified the possible options available to women as follows:

- Suppression of lactation, by pharmacological or non-pharmacological means
- Donation of stored EBM
- Donation of EBM through expression as a method to wean their milk supply
- Establishment or continuation of lactation.

The last option, establishing lactation following perinatal loss, either for milk donation or to maintain a connection to the lost child, is the most divisive. If a mother chooses to continue to express and donate milk, Hartmann (2017) emphasises that it is the responsibility of milk banks to ensure the act of donation causes no harm. He also points out that continued lactation may compromise well-being, by deferring an individual from resuming required medications. Carroll *et al* (2014) add that milk banks should consider the impact of sustained lactation on relationships and family planning due to lactational amenorrhoea. The support offered to parents when considering their lactation options and the ongoing support provided if women choose to donate their breast milk is critical in ensuring the well-being of women and their families, and is an area for future research within the field of milk banking in the UK and internationally.

Cultural appropriateness

The health professional's role involves tailoring the information and support they provide as appropriate to the individual mother (McGuinness *et al* 2014b). Alongside personal choice, Chen *et al* (2015) suggest cultural differences may determine the way a woman chooses to suppress her milk; this should be taken into consideration. Islamic law and 'Mahramiat' dictate that women may only donate to recipients that they know. Some Asian cultures would not acknowledge the birth of a stillborn child, and therefore the lactation issues suffered by a mother would not be addressed (Chen *et al* 2015). Gribble (2013) cites potential objections of some mothers to the inherent anonymity of the process of milk donation to milk banks, as in this situation they would not have information about the recipient of their milk. In such cases, mothers would prefer informal milk sharing. In an increasingly multicultural landscape, knowledge and awareness of society's diversity is required for health professionals to support all women in their care.

Education and training

Bereaved mothers are often overlooked as possible milk donors, despite NICE (2010) clinical guidelines recommending that this choice is offered. Carroll *et al* (2014) suggest that professional reluctance to discuss lactation options is a factor in overlooking this population of donors. Hughes & Goodall (2013) recommend that more knowledgeable professionals within the midwifery department or NICU support women and their families in making informed choices; staff members with experience in bereavement care are more likely to provide information in a compassionate and sensitive manner. McGuinness *et al* (2014b) acknowledge that grief affects a mother's ability to fully understand information given by health professionals. Therefore, when discussions are taking place, written information should be provided to supplement and support the advice provided, especially when in-depth discussions may be unlikely (Stapleton *et al* 2001). One immediate outcome from this work is to enhance and disseminate currently available information from the UK Association for Milk Banking (UKAMB) (2017) that would be available in hospital and community health care settings for easy dissemination to bereaved mothers.

The way in which a mother manages her grief can often be affected by the care she receives from health care professionals (Kohner & Henley 2001). The anecdotal evidence demonstrates that many women feel unprepared for lactation following bereavement; one woman reports: *'having to lead myself blindly due to inexperience in the realm of lactation after perinatal loss'* (Anderson 2016), while another states: *'when I left hospital, my breasts started leaking... I didn't know what to do'* (Cruz-Chan 2016). Studies have demonstrated that health professionals are the

main motivators in milk donation, therefore training is key (Thomaz *et al* 2008). However, the concept of milk donation following bereavement appears mainly to be driven by the women themselves, rather than being an option provided by health care professionals: 'I knew there was a high demand for breastmilk so my husband and I decided to donate' (Cruz-Chan 2016). Welborn (2012) states that health care providers are key to educating mothers but often lack the tools to address lactation. This is demonstrated through the current lack of training in lactation options and milk donation following bereavement in the UK. A review of bereavement training available from the Royal College of Midwives (RCM 2015), Sands – the stillbirth and neonatal death charity (Schott *et al* 2007) and local policy (Local Trust A 2016) identified a paucity of information and guidance on lactation care and options after perinatal loss. In consideration for the future generation of midwives and neonatal nurses this lack of training should be addressed; Hollins Martin *et al* (2016) explored students' experiences of caring for bereaved women and highlighted that greater training is needed in all bereavement care, not only lactation options. Researchers agree that robust national guidance and protocols should be adopted regarding lactation and donation after perinatal loss (Carroll *et al* 2014, Sereshti *et al* 2016). Given national guidance often dictates local policy (Sheldon *et al* 2004), an implication of this would be greater education and increased visibility of milk banks.

Limitations

One limitation within the review included the possibility of bias within the published studies; therefore, the authors excluded evidence available from milk banks alongside the recorded experience of milk bank staff. A further limitation of the study is that existing studies only include women who choose to donate their milk, and the opinions of those women who do not are not documented in current research.

Conclusion

This review highlights the fact that lactation following bereavement is an overlooked issue. Although anecdotal evidence comprising women's individual stories is a valuable resource supporting midwifery's woman-centred philosophy, fundamental to practice is a formal evidence base. Given the current limited volume of research in this field, further studies are needed to examine the lactation needs of women following perinatal loss, to increase the visibility of milk banks, and ultimately broaden the evidence base. It should be emphasised that the authors do not intend for the rigorous recruitment of bereaved women at a vulnerable time to milk donation, but rather the option of milk donation to be offered in a compassionate and informed manner once a range of information has been discussed and a relationship of trust established with the family.

Individuality and choice are vital for woman-centred care; women should be aware of and supported in making informed choices regarding their lactation options. The option of milk donation may offer catharsis and aid the grieving process, and should be a visible option to women following perinatal loss. However, cultural differences alongside other potential drawbacks require a sensitive approach that needs further investigation to determine the best way to raise lactation issues and the option of milk donation. To empower health professionals to discuss all lactation options sensitively and confidently, further high-quality bereavement training is required, with a focus on the ethos of providing women with choice.

Acknowledgements

The authors would like to acknowledge the members of charities, support organisations and NHS Trusts who responded to our enquiries in such a timely and supportive manner.

Judith Kennedy, third year Student Midwife, University of Hertfordshire; Anna Matthews, third year Student Midwife, University of Hertfordshire; Laura Abbott, Senior Lecturer in Midwifery, University of Hertfordshire; Jacqueline Dent, Senior Lecturer in Midwifery, University of Hertfordshire; Gillian Weaver, Human Milk Banking Consultant, Co-founder and Director, Hearts Milk Bank: www.heartsmilkbank.org; Dr Natalie Shenker, Director, Hearts Milk Bank and Honorary Research Associate, Imperial College, London. JK and AM contributed equally to the literature review and preparation of the manuscript.

References

- Anderson A (2016). Breastmilk donation after stillbirth. *Evolutionary parenting with Tracy Cassels PhD*, 28 March. <http://evolutionaryparenting.com/guest-post-breastmilk-donation-after-stillbirth/> [Accessed 8 July 2017].
- Anonymous (2016). Lactation after loss – dealing with a breastmilk supply. *BellyBelly*, 8 November. <https://www.bellybelly.com.au/breastfeeding/lactation-after-loss-dealing-with-breastmilk-supply-after-loss/> [Accessed 8 July 2017].
- Britz SP, Henry L (2013). Supporting the lactation needs of mothers facing perinatal and neonatal loss. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing* 42(Suppl 1):S105-6.
- Carroll K (2013). Donating breastmilk helps bereaved mothers deal with loss. *The Conversation*, 7 November. <http://theconversation.com/donating-breast-milk-helps-bereaved-mothers-deal-with-loss-17426> [Accessed 8 July 2017].
- Carroll KE, Lenne BS, McEgan K *et al* (2014). National Stakeholder meeting on breast milk donation after neonatal death in Australia: a report. *International Breastfeeding Journal* 9(23).
- Chen FH, Chen SL, Hu WY (2015). Taiwanese women's experiences of lactation suppression after stillbirth. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing* 44(4):510-17.
- Cole M (2012). Lactation after perinatal, neonatal or infant loss. *Clinical Lactation* 3(3):94-100. http://lunalactation.com/final_clinical_lactation.pdf [Accessed 8 July 2017].
- Cruz-Chan W (2016). I donated 2,000 oz of breastmilk when my baby died and it helped me find purpose again. *BBC iPlayer*, 26 October. <http://www.bbc.co.uk/bbcthree/item/10d0f106-042d-403e-b651-9ab6dccc06e> [Accessed 8 July 2017].
- Gribble KD (2013). Peer-to-peer milk donors' and recipients' experiences and perceptions of donor milk banks. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing* 42(4):451-61.
- Hartmann BT (2017). Ensuring safety in donor milk banking in neonatal intensive care. *Clinics in Perinatology* 44(1):131-49.

- Hollins Martin CJ, Robb Y, Forrest E (2016). An exploratory qualitative analysis of student midwives views of teaching methods that could build their confidence to deliver perinatal bereavement care. *Nurse Education Today* 39:99-103.
- Hughes KH, Goodall UA (2013). Perinatal bereavement care: are we meeting families' needs? *British Journal of Midwifery* 21(4):248-53.
- Kobler K (2012). NICU bereavement breast milk donation. *Journal of Pain and Symptom Management* 43(2):453-4.
- Kohner N, Henley A (2001). *When a baby dies – the experience of late miscarriage, stillbirth and neonatal death*. London: Routledge.
- Leon IG (1990). *When a baby dies: psychotherapy for pregnancy and newborn loss*. New Haven: Yale University Press.
- Local Trust A (2016). *Pregnancy loss*. [Guidelines].
- Maffei D, Schanler RJ (2017). Human milk is the feeding strategy to prevent necrotizing enterocolitis! *Seminars in Perinatology* 41(1):36-40.
- McGuinness D, Coghlan B, Butler M (2014a). An exploration of the experiences of mothers as they suppress lactation following late miscarriage, stillbirth or neonatal death. *Evidence Based Midwifery* 12(2):65-70.
- McGuinness D, Coughlan B, Power S (2014b). Empty arms: supporting bereaved mothers during the immediate postnatal period. *British Journal of Midwifery* 22(4):246-52.
- National Institute for Health and Care Excellence (2010). *Donor milk banks: service operation*. London: NICE.
- Nursing and Midwifery Council (2015). *The Code: professional standards of practice and behaviour for nurses and midwives*. London: NMC.
- Quigley M, McGuire W (2014). Formula versus donor breast milk for feeding preterm or low birth weight infants. *The Cochrane Database of Systematic Reviews*, Issue 4.
- Royal College of Midwives (2015). One chance to get it right: bereavement care. *RCM i-learn*. London: RCM. <http://www.ilearn.rcm.org.uk/course/info.php?id=124> [Accessed 7 July 2017].
- Schott J, Henley A, Kohner N (2007). *Pregnancy loss and the death of a baby: guidelines for professionals*. 3rd ed. London: Sands.
- Sereshti M, Nahidi F, Simbar M *et al* (2016). An exploration of the maternal experiences of breast engorgement and milk leakage after perinatal loss. *Global Journal of Health Science* 8(9):234-44.
- Sheldon TA, Cullum N, Dawson D *et al* (2004). What's the evidence that NICE guidance has been implemented? Results from a national evaluation using time series analysis, audit of patient's notes, and interviews. *British Medical Journal* 329(7473):999.
- Siassakos D, Fox R, Draycott T *et al* (2010). *Late intrauterine fetal death and stillbirth*. London: RCOG.
- Stapleton H, Kirkham M, Thomas G (2001). Qualitative study of evidence based leaflets in maternity care. *British Medical Journal* 324:1-6.
- Thomaz ACP, Loureiro LVM, da Silva Oliveira T *et al* (2008). The human milk donation experience: motives, influencing factors and regular donation. *Journal of Human Lactation* 24(1):69-76.
- UK Association for Milk Banking (2017). *When a baby dies: advice for breastfeeding mothers*. http://www.londonneonatalnetwork.org.uk/wp-content/uploads/2015/09/When_a_baby_dies_SM2.pdf [Accessed 3 August 2017].
- Victoria CG, Bahl R, Barros AJD *et al* (2016). Breastfeeding in the 21st century: epidemiology, mechanisms, and lifelong effect. *The Lancet* 387(10017):475-90.
- Welborn JM (2012). The experience of expressing and donating breast milk following a perinatal loss. *Journal of Human Lactation* 28(4):506-10.
- Woo K, Spatz D (2007). Human milk donation: what do you know about it? *MCN - American Journal of Maternal/Child Nursing* 32(3):150-57.

Kennedy J, Matthews A, Abbott L *et al*. MIDIRS Midwifery Digest, vol 27, no 4, December 2017, pp 497-501.

Original article. © MIDIRS 2017.
