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ORIGINAL ARTICLE

Milk Donation Following Perinatal Loss: Insights from a Survey across Italian Human Milk Banks

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Abstract

Background/Objectives: Milk donation after perinatal loss has been increasingly recognised as a potential healing practice for bereaved mothers. However, lactation support offered to bereaved mothers within hospital settings is still limited. The study aimed to explore the experiences and current practices of Italian Human Milk Banks (HMBs) regarding milk donation after perinatal loss, and to identify barriers and facilitators towards the implementation of this practice, in order to inform future quality improvement initiatives.

Methods: An online survey was distributed to Italian HMBs between June and September 2023. Close-ended questions were reported as frequencies. Open-ended responses were analyzed through a comparative analysis.

Results: Forty-three Italian HMBs were contacted, and 34 replied (response rate 79%). Milk donation was offered as a possible option to manage lactation to bereaved mothers in 22 out of 34 Italian HMBs (65%). The lactation counselling was conducted by the HMB personnel in 18 out of 34 centers, by neonatologists in 17 centers, by neonatal nurses in 12 centers, by obstetricians in 4 centers. Twenty-two HMBs (65%) reported to have received from the mothers themselves the request to donate milk after losing their baby. Interviewees reported as main barriers towards implementation of this practice: lack of psychological preparation of the HMBs staff to handle the proposal of milk donation after a loss, to support the mother in processing the death through a gift to life and lack of adequate communication skills.

Conclusions: In order to offer bereaved mothers adequate lactation counselling, specific training should be delivered to the healthcare workers involved, focusing on psychological, communication, and sociocultural aspects.

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- Milk banking

Introduction

Mother's own milk is the gold standard for infant nutrition and is the preferred choice for all newborns. Thanks to its unique composition in nutrients, bioactive components, and immunological factors, it supports optimal growth and brain development, reduces the risk of infections and immunological conditions [1-3].

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For the most vulnerable infants, such as those born prematurely or with medical complexities, mother's milk is even more critical. It reduces the risk of life-threatening conditions like necrotizing enterocolitis, promotes intestinal maturity, and enhances long-term neurodevelopmental outcomes [4-5].

When mother's own milk is not available or not enough, Donor Human Milk (DHM) obtained from a Human Milk Bank (HMB) is the best alternative [6]. A HMB is a facility established with the purpose of selecting, collecting, processing, storing and distributing human milk donated by healthy mothers with a proper lifestyle who breastfeed during the first year of their child's life and produce more milk than their offspring needs.

In addition to these regular donors, there is a special category of women who can donate their milk to a HMB. Those are women who experienced a perinatal loss and who decided to prolong lactation with the aim of donating their milk to a HMB.

Perinatal loss represents an extremely complex grieving experience. The term comprises miscarriage (unintentional end to a pregnancy before 20 weeks' gestation), stillbirth (death of a fetus after 20 weeks' gestation), and neonatal death (death of a newborn in the first 28 days after birth) [7]. Alongside the extreme emotional and psychological pain, mothers may experience intense physical symptoms related to the onset or continuation of lactation. In those scenarios, mothers may choose to either suppress lactation or continue it with the aim of donation. Milk donation after loss has been increasingly identified as a potentially therapeutic ritual, offering bereaved mothers a way to process their loss and reconstruct their shattered maternal identity [8-13]. However, this practice remains underexplored and inconsistently implemented across different healthcare systems and cultural contexts [14].

Healthcare professionals and HMB staff play a critical role in providing lactation counselling. For bereaved mothers, milk donation may be beneficial, yet integrating this practice into milkbanking systems requires adequate staff training to support both the mothers and the milk bank personnel involved.

Data on the current practices and attitudes towards milk donation after perinatal loss remain limited, particularly in the Italian context. The absence of standardized protocols and the variability in how milk banks approach this sensitive issue underscore the

need for a deeper understanding of the barriers and facilitators shaping this practice. Italy has the most extensive network of HMBs in Europe; hence, HMB staff can play a vital role in addressing this issue.

This study aimed to explore the experiences and current practices of Italian human milk banks regarding milk donation after perinatal loss. Additionally, we sought to identify perceived barriers and facilitators to implementing this practice, as reported by milk bank personnel, to inform future quality improvement initiatives.

Materials and Methods

Participants

Our survey targeted personnel of Italian HMBs. In case of more contact details per HMB, all of them were contacted. The level of the analysis was the human milk bank for questions regarding experience and current practice in milk donation after perinatal loss, and the individual for questions regarding perceived barriers and facilitators towards implementation of this practice.

Survey design

Questions were developed and agreed upon by members of the Scientific Committee of the Italian Human Milk Bank Association (AIBLUD). Ethical clearance was evaluated and approved by the AIBLUD Board of Directors.

The survey was uploaded online using the Jisc Online Survey tool. The questionnaire was tested on a convenience sample of Italian milk bank coordinators to confirm its acceptability and ready comprehension.

The survey comprised seven closed-ended questions and two open-ended questions. Approximately ten minutes were necessary to complete it. The questionnaire utilized for the survey is available in Table 1.

The first seven questions investigated the experience and current practice of Italian human milk banks regarding milk donation after perinatal loss, particularly: whether this practice was active in the specific HMB; which mothers this option was offered to (mothers who lost their baby before birth; mothers who lost their baby in early infancy; bereaved mothers already donors in the HMB); who was in charge to offer this option to the bereaved mothers; whether the request of donating milk after loss has

Table 1: Questionnaire utilized for the survey.

1. In the hospitals affiliated with your HMB and/or in your HMB, are mothers affected by perinatal loss offered the option to donate their breast milk?
2. Is this possibility offered to mothers who became donors before the loss of their baby?
3. Is this possibility offered to mothers who were not yet donors of babies who received care in the NICU/neonatology department/PICU/pediatrics department?
4. Is this possibility offered to mothers who lost their baby before birth?
5. Who is responsible for offering this opportunity to mothers? (HMB staff, medical-nursing staff of the department that provided care for the baby)
6. Have you ever received this request from parents?
7. How many cases of post perinatal loss donation do you recall/estimate to have occurred at your HMB?
8. What do you think are the main facts hindering the practice of offering bereaved mothers the opportunity to donate their milk?
9. The Italian Association of Human Milk Banks (AIBLUD) intends to launch an initiative to promote the possibility of donating breast milk to mothers affected by perinatal loss. We would be grateful if you could share your experience and/or your thoughts on this topic.

ever been expressed by the bereaved family first; how many cases of milk donation after loss happened in the HMB.

Finally, the last two questions, which were open-ended, explored the perceived barriers and facilitators towards the implementation of this practice.

Recruitment

The invitation to fill in the survey was sent by email, together with a cover letter explaining the rationale of the survey, to all Italian HMBs coordinators in June 2023. Two reminders were sent in July and September 2023.

Data analysis

All returned questionnaires were reviewed separately by two researchers specialized in different disciplines (SG - neonatology, AF - anthropology).

For the first seven questions, which were investigating current practice and experience of HMBs in donation after loss, one answer only was accepted per milk bank. Hence, in case of multiple responses from the same milk bank, answers from the same milk bank were screened for homogeneity of content and accepted as a single answer.

Conversely, for the last two questions, which were exploring barriers and facilitators towards the implementation of this practice in Italian HMBs, all answers were accepted independently.

Descriptive data were reported as frequency for categorical variables. Open-ended responses were analyzed through a comparative analysis: responses were grouped in semantic patterns, and unique statements highlighted. A semantic analysis was also

conducted on certain expressions recurring in the responses, which constituted the keywords of the answers provided.

Results

Sixty-seven persons working in 43 Italian HMBs were contacted, and 41 responses from 34 HMBs were received. Hence, the response rate was 61% on the individual level and 79% on the HMB level. The higher numbers of responses were from HMBs located in the North of Italy (95%) followed by the South (87.5%). The lowest rate of responses was from HMBs located in the Center of Italy with 53% (Figure 1).

Milk donation was offered as a possible option to manage lactation to bereaved mothers in 22 out of 34 Italian HMBs (65%). Among centers that offered this option, it was proposed mainly to mothers who lost their baby in the early neonatal period (18 out of

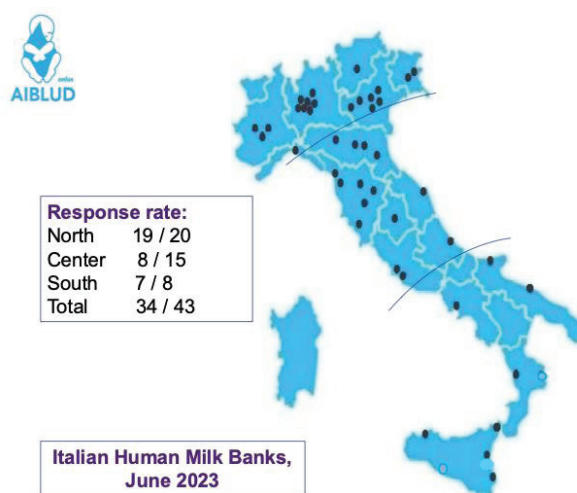


Figure 1 Response rate from Italian Human Milk Banks according to geographical area.

34 HMBs) and to bereaved mothers who were donors already before the loss (16 out of 34 HMBs); less commonly, this option was offered to mothers who lost their baby before birth (four out of 34 HMBs).

Lactation counselling was held by HMB personnel in 18 out of 34 centers, by neonatologists in 17 centers, by neonatal nurses in 12 centers, and by obstetricians in four centers.

Twenty-two HMBs (65%) reported receiving requests from mothers themselves to donate milk after losing their baby.

Nine HMBs out of 34 (26%) did not have any experience with mothers donating milk after perinatal loss. Other HMBs reported limited experience (one to eight cases per HMB), except for one HMB which reported more than 30 cases of bereaved donors in the last 18 years of activity.

When questioned about possible factors hindering the practice of offering bereaved mothers the option of milk donation, half of the responders referred to the problem of "secondary traumatization"[15], namely the difficulty of proposing to a mother who has just experienced a loss the idea of donating her milk as a gift of life, thereby intensifying her pain, as well as the anger and sadness of the loss. The most recurrent keyword was "grief," often associated with "fear," "anger," "sadness," "forget," and "overcome." Eight out of 41 responses (20%) specifically highlighted the lack of training for the healthcare professionals involved and the lack of psychotherapists who can guide the mourning process and the proposal of an altruistic dynamic. Nearly one-third of the responders reported that a practical hurdle is the early inhibition of lactogenesis as advised by the obstetric team. One participant mentioned the difficulty faced by the HMB staff in asking grieving mothers to undergo the serological investigations mandatory to become a donor. Finally, one responder reported the "skepticism" of healthcare providers regarding the usefulness of this practice for the mother's psychological well-being.

When asked which actions would favor the implementation of this practice across Italian HMBs, most participants highlighted the need for specific training to raise awareness and prepare the healthcare providers to face this situation efficiently. The most recurrent words were "preparation," alongside "counseling," "communication skills," "psychological support," and "knowledge."

Discussion

To the best of our knowledge, this is the first study to investigate the experience of milk donation after loss in Italy. We adopted the perspective of the HMB personnel to identify possible barriers and facilitators towards the implementation of this practice.

From our survey, it emerged just over half of the Italian HMBs had some experience with milk donation after perinatal loss. Interestingly, 65% of the HMBs had received at least once the request to donate milk from the grieving mother herself. This demonstrates the importance of providing appropriate breastfeeding advice and emotional support at a very sensitive time, and the importance of promoting initiatives that would favor the implementation of this practice.

From our study, most donations came from mothers who lost their baby after birth. This can be explained by the limited awareness of this practice in cases of prenatal loss, which also needs to be ritualized and processed.

For a woman who has just lost her baby, donating breast milk can be an act of substitution for the loss and a more conscious way of processing the grief she has experienced, sometimes even a symbolic gesture of life replacing death [11]. It is neither guaranteed nor certain that all women in such a situation will accept or want to donate their milk, but the proposal made by well-prepared healthcare professionals, equipped with skills in empathetic and effective communication, can represent a therapeutic tool in a dual sense, both for the donor and for those who will benefit from the gift.

The proposal to become a donor should hence be included in the psychological path offered to the mothers by the healthcare professionals as an aid for processing grief. If healthcare providers are doubtful or unable to effectively propose this practice, mothers will unlikely be engaged to do it. The lack of information prevents awareness and thus, women's consent to donate their milk [16].

It is well described in the literature the paucity of lactation information provided to grieving parents [12,14,17]. Indeed, most of our interviewees highlighted the total lack of psychological preparation and guidance to handle this situation. Training the operators is essential to overcome psychological and communication barriers with the mothers [15]. From our survey, it emerged that lactation counseling was



held by either the HMB staff, the neonatal staff, or the obstetricians. Hence, training should be delivered to all these categories.

Main strength of our study lies in its ability to combine the clinical aspects with an anthropological perspective and interpretation of the collected data. Moreover, the high response rate allowed us to draw a comprehensive view of the experience of Italian milk banks with regard to this practice. Main limitation was the involvement of HMB personnel only, not extended to the neonatal/obstetric staff or to the mothers affected by perinatal loss. This comes from the original idea of the study, which was to conduct a survey on milk banks exclusively, to see if and how HMB staff deal with the problem of perinatal bereavement management. Expanding the survey to include obstetricians, midwives, neonatal staff and bereaved mothers will be the subject of a later investigation.

Conclusions

This study highlights the therapeutic potential of breast milk donation in grief processing and emphasizes the need for systemic improvements to effectively support bereaved mothers.

The main finding of our study is a strong need for training courses to be delivered to HMBs personnel, neonatal and obstetric staff, in order to enable them to address this situation efficiently and provide mothers the best care possible in this difficult situation. Those training courses should cover the psychological aspects underlying this practice, as well as communication strategies to deliver appropriate lactation counselling in case of perinatal loss. Moreover, attention should be paid to the social, cultural and religious aspects (i.e. Islamic approach to human milk donation [18,19]) that may shape different attitudes towards this practice [20].

Further research is essential to refine practices and ensure equitable access to this option in diverse health settings.

Author Contributions

SG and GM designed the research study. SG, ND, PQ, IM performed the research. SG and AF analysed the data. SG and AF wrote the paper. GM, ND, PQ, IM revised the paper.

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Conflicts of Interest

The authors declare no conflicts of interest.

Abbreviations

The following abbreviations are used in this manuscript: HMB: Human milk bank.

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