

Research Article

The LISTEN (Lactation Support after pEriNatal loss) Project: Pathways of Loss and Lactation Care in Italy

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Introduction: In the aftermath of perinatal loss, the physiologic onset of lactation presents a complex array of emotional responses for women, including grief and despair. Effective lactation management is essential for maternal health, yet it is often inadequately addressed by health care professionals, potentially compromising the physical and psychological recovery of the bereaved mother. The aim of this study was to investigate how Italian health care providers support women in managing lactation after a perinatal loss.

Methods: This study employed a web-based, cross-sectional design. Participants involved in perinatal bereavement care were asked to answer a survey consisting of 3 areas: sociodemographic information, knowledge and experience of perinatal loss, and lactation after perinatal loss.

Results: A total of 1227 health care professionals participated in this study. A significant majority (60.2%) had received formal training on perinatal loss care, expressing high satisfaction with an average score of 4.7 out of 5. However, less than half (42.5%) reported having a guideline for bereavement care in their workplace. Despite the opportunity, 25% of the respondents did not provide lactation information. Discussions predominantly centered on pharmacologic suppression of lactation in cases of stillbirth (89.5%) and neonatal death (83.8%), as well as complications associated with these events. Postdischarge follow-up was reported as lacking by 78.2% of the sample.

Conclusions: The discrepancy between the training of health care professionals and their practice highlights a critical need to enhance the implementation of bereavement care guidelines and follow-up support, underscoring the importance of integrating lactation management into the perinatal loss care continuum.

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Keywords: bereavement, lactation, management, midwives

INTRODUCTION

Perinatal death is an acknowledged global burden that affects millions of families every year.^{1,2} In Italy, approximately 4 per 1000 newborns are stillborn or die within the first week of life, with significant regional variation between the north and south.³ This event has a huge impact on parents' psychological well-being, with several long-term consequences, such as posttraumatic stress symptoms, anxiety, and depression.⁴ In such circumstances, women must cope with the onset

of lactation, which can be both physically and emotionally demanding.⁵

In this setting, health care professionals play a pivotal role in helping women to manage lactation after a perinatal loss. Respectful care could enhance the likelihood that lactation will positively contribute to the grieving process.⁶ Unfortunately, the literature highlights that lactation care provided to women is often inadequate and not tailored to their individual needs.⁵ This aspect of postnatal care is usually neglected by health care practitioners, and it often receives limited attention within perinatal bereavement care guidelines.^{7,8} In the United Kingdom, the National Bereavement Care Pathway provides the only known guidance on lactation management, emphasizing the importance of women's informed choice.⁹ In other countries, such as the United States, professional associations have published statements on this topic, grounded in the international literature,¹⁰ but no formal national guidelines are available. The situation is similar in Italy, where only recent recommendations address care around stillbirth¹¹ and provide very limited guidance regarding lactation.

Beyond its biological function, breastfeeding holds deeper significance within the mother-child dyad; it is closely tied to the mother's emerging identity and, for some bereaved women, may serve as a meaningful emotional connection to their deceased newborn.^{6,12} Considering such psychological and relational implications, the assumption that immediate lactation suppression represents the best option for women

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Quick Points

- ◆ The LISTEN study highlights health care professionals' emotional difficulties in managing lactation after perinatal loss.
- ◆ The absence of a standardized perinatal care guideline emerged from the data, impacting the quality of care after loss.
- ◆ Lactation management after loss is often inadequate, with limited use of milk donation options.
- ◆ Standardized national guidelines and continuity of bereavement care are urgently needed to support grieving families.

after perinatal loss—often perceived as a way to quickly conclude the traumatic experience—should be avoided, as individual preferences and needs may vary. Other options, such as milk donation, may better align with women's needs, offering an opportunity to transform their loss into a meaningful act of giving,^{6,9} which could protect against perinatal depression.¹³

Health care professionals involved in bereavement care often overlook the topic of lactation after perinatal loss.^{5,6} This may be due to a lack of knowledge about this specific issue and the commonly held belief among health care practitioners that pharmacologic suppression of lactation is the best course of action for the well-being of all women.^{6,14} Many of them lack adequate training to support parents experiencing perinatal loss¹⁵; this absence of formal education increases the risk of burnout¹⁶ and posttraumatic stress disorder symptoms.¹⁷ Specifically, the emotional exhaustion component of burnout can lead to emotional disengagement, potentially undermining the effective shared-decision-making process in bereavement care.

The LISTEN (Lactation Support after pEriNatal loss) study aimed to investigate the knowledge, thoughts, feelings, and experiences of Italian health care professionals who are specifically involved in lactation care after perinatal loss. The objective of this study was to deepen understanding of lactation following perinatal loss, with the aim of supporting health care practitioners in assisting women through this complex and emotionally challenging experience.

METHODS

The LISTEN study was an anonymous, web-based, mixed-methods, and cross-sectional study hosted on the Qualtrics platform (www.qualtrics.com), provided by the Florence University PeaRL laboratory. It was distributed through the online channels of the CiaoLapo Foundation, an Italian charity for perinatal loss support, from January to December 2023, in collaboration with several Italian hospitals. All data were collected and analyzed anonymously.

The research design and data collection were conducted by the first and corresponding authors, both of whom are physicians. The first author is a psychiatrist and perinatal health researcher who studies quality of care and the psychological impact of care on patients. The corresponding author is a pharmacologist and a researcher in perinatal health and pharmacology. All authors were informed by the literature on high-quality perinatal care and on care after perinatal loss.

Participants were considered eligible to complete the survey if they were health care professionals involved in bereavement care after a perinatal loss. The survey was voluntary and

anonymous; no personal data were collected, and individual respondents could not be identified in any way. Informed consent was obtained at the start of the survey, after participants had read the participant information and met the eligibility criteria. Data were acquired in compliance with the General Data Protection Regulation (European Union 2016/679). The research proposal was approved by the Florence University Commission for Ethics (prot. 25810, June 2, 2023). The Checklist for Reporting Results of Internet E-Surveys checklist was used to guide the reporting of survey results (Supporting Information: Appendix S1).

The survey consisted of questions across key domains, including (1) sociodemographic information; (2) knowledge and experience related to perinatal loss; and (3) knowledge and experience regarding lactation following perinatal loss.

Questions on domains 2 and 3 were based on international guidelines,^{8,12} Italian national recommendations on perinatal loss care,¹¹ and existing literature on lactation management after perinatal loss.^{5–7} Open-ended questions were included to explore this complex topic in greater depth and provide insights that could support health care practitioners in clinical practice. To strengthen the methodological approach, we adopted a triangulation design,¹⁸ analyzing qualitative and quantitative data in parallel, then comparing and integrating the results to ensure a comprehensive interpretation.

Statistical Analysis and Data Presentation

Survey responses were downloaded and extracted from the online survey tool Qualtrics and imported into Stata BE 18 (StataCorp) for statistical analysis. Incomplete records were excluded, and descriptive statistics were used to analyze quantitative data. Categorical data were presented as frequencies and percentages and compared using the χ^2 test. Continuous data were reported as mean values with SDs or as medians with interquartile ranges and compared using the *t* test, the Kruskal-Wallis test, or the Mann-Whitney test, as appropriate. All results were considered statistically significant at $P < .05$.

Qualitative content analysis was conducted on open-ended questions, supported by artificial intelligence (AI), as previously described in the literature on AI-assisted qualitative research methods.^{19–21} This approach diverges from classical thematic analysis, as it focuses on the classification and quantification of content categories rather than the interpretive construction of themes. The analysis followed an inductive logic, combining AI-assisted keyword and content categorization with full manual verification. Two language models (ChatGPT and Claude) were used to generate initial content clusters and relevant keywords. These outputs were then

independently reviewed and refined by 2 researchers (C.R. and L.M.), who manually coded and classified responses using MAXQDA 2018. Discrepancies were discussed and resolved through consensus. This approach ensured methodological rigor and consistency while enabling the efficient organization of a large volume of qualitative data. Frequencies and importance ratings for each content category were calculated by combining absolute mention counts with a normalized score (from 0 to 10) that weighted the recurrence of each category against its perceived qualitative richness. Further details of this process are provided in Supporting Information: Appendix S2.

Graphs were plotted using Tableau Desktop 2023.3 (Tableau Software, LLC) or Stata BE 18 (StataCorp).

RESULTS

Sample Characteristics

A total of 1227 health care professionals participated in this study, with the majority being women (97.5%). The largest group consisted of midwives (76.8%). More than half of the participants (51.4%) had less than 10 years of work experience. The majority of participants worked in public hospitals (80.2%), primarily in labor and delivery rooms (56.9%) and maternity wards (43.1%). Table 1 provides a detailed overview of the participants' demographic and professional characteristics.

Perinatal Loss Management

More than half of the participants reported having assisted in cases of stillbirths (69.7%) and neonatal deaths (53.1%). Additionally, 60.2% of the respondents had attended specialized formal training on perinatal loss. Such training was highly valued, receiving a mean usefulness rating of 4.7 on a Likert-type scale ranging from 1 (not useful at all) to 5 (extremely useful), as shown in Table 2.

Only 42.5% of participants reported the presence of a perinatal loss care guideline in their workplace, and 31.5% indicated the existence of a formalized support pathway for parents' psychological care. Regarding the timing of guideline implementation, 23.2% of respondents reported that the guidelines were implemented within the past 5 years, 43.5% indicated they were established more than 5 years ago, and 33.3% were unsure of when implementation occurred. Participants emphasized the usefulness of having a guideline on bereavement care after a perinatal loss, assigning a high score of 4.8 on a Likert-type scale ranging from 1 (not useful at all) to 5 (extremely useful) (Table 2).

Participants rated the difficulty of emotional and clinical management of perinatal loss using a Likert-type scale ranging from 0 (not difficult at all) to 10 (extremely difficult). Although emotional management was similarly high in both scenarios, the clinical management of neonatal death was perceived as slightly more challenging than that of stillbirth (5.3 vs 4.9; $P < .01$) (Figure 1).

We also investigated whether attending specific courses or working in settings with specific guidelines had any impact on the difficulty ratings. However, our findings did not reveal a significant difference in difficulty ratings between partici-

Table 1. Main Characteristics of the Sample

Variable	Value, n (%) (Total N = 1227)
Sex	
Female	1196 (97.5)
Age, Y	
<35	602 (49.1)
35-50	476 (38.8)
>50	149 (12.1)
Job	
Midwife	942 (76.8)
Nurse	157 (12.8)
Psychologist	20 (1.6)
Physician	81 (6.6)
Other ^a	27 (2.2)
Years of work	
<10	631 (51.4)
10-20	386 (31.5)
>20	210 (17.1)
Main type of practice	
Public hospital	984 (80.2)
Accredited private hospital	88 (7.2)
Community	73 (5.9)
Private hospital	8 (0.7)
Private practice	74 (6.0)
Main setting	
Birth room	698 (56.9)
Maternity ward	529 (43.1)
Nursery	127 (10.4)
Neonatal intensive care	103 (8.4)
Other ^b	141 (11.5)

^a Includes health care assistants, lactation consultants.

^b Includes outpatient clinic, emergency room, pediatrics, screening services, psychiatric and psychological services.

pants who had received specific training and those who had worked in settings with guidelines. It is worth noting that participants with specific training in stillbirth management reported a slight decrease in emotional difficulty, although the statistical significance was only borderline (4.7 vs 5.1; $P = .05$) (Figure 2).

Knowledge of Lactation After Perinatal Loss

We also examined participants' training in lactation suppression techniques. Participants were asked to self-report their training on a Likert-type scale ranging from 1 (not trained at all) to 5 (very trained), with a mean (SD) score of 2.7 (1.0). Additionally, they were asked to rank the degree of usefulness for various lactation management interventions on a scale from 0 (not useful at all) to 10 (very useful). All treatments were considered moderately effective (mean [SD], 5.2 [3.2]), with hand expressing considered slightly more effective than the others

Table 2. Professional Experience of Perinatal Loss	
Variable	Value (N = 1227)
Assisted SBs, n (%)	855 (69.7)
Clinically hard: SB (0-10), mean (SD)	4.8 (2.3)
Emotionally hard: SB (0-10), mean (SD)	7.7 (2.1)
Assisted NNDs, n (%)	651 (53.1)
Clinically hard: NND (0-10), mean (SD)	5.3 (2.4)
Emotionally hard: NND (0-10), mean (SD)	7.8 (2.2)
Education on perinatal loss	
Attended a course, n (%)	739 (60.2)
Usefulness of course, mean (SD) ^a	4.7 (0.6)
Guidelines for perinatal loss	
Guidelines available, n (%)	522 (42.5)
Specific guidelines for psychological support, n (%)	386 (31.5)
Usefulness of guidelines, mean (SD) ^a	4.8 (0.6)
Duration of guidelines availability, n (%), y	
<5 y	120 (23.2)
>5 y	225 (43.5)
Don't know	172 (33.3)
Community resources, n (%)	
Available	345 (28.1)
Not available	605 (49.3)
Don't know	277 (22.6)

Abbreviations: NND, neonatal death; SB, stillbirth.

^a Measured from 1 (not useful at all) to 5 (very useful).

(mean [SD], 6.5 [2.9]; $P < .01$) and tight bandages considered less effective (mean [SD], 3.7 [3.1]; $P < .01$) (Figure 2).

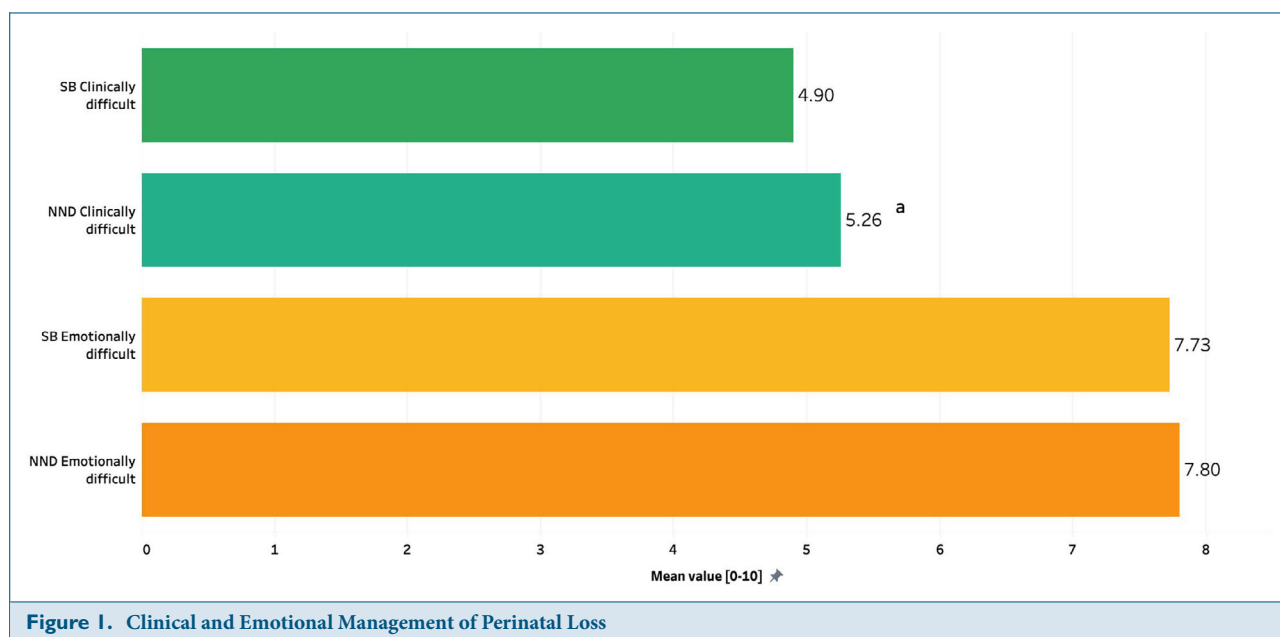
Participants agreed about the importance of educating women about managing lactation following a perinatal loss.

This was reflected in a high average rating (mean [SD], 4.7 [0.6]; range, 1-5). However, we found that approximately 25% of professionals, despite having the opportunity, did not provide this information to parents (Table 3). Additionally, approximately 10% were unsure of what information to convey, and a similar proportion (9.6% following stillbirth and 8.4% after neonatal death, totaling 78 health care professionals) did not consider providing lactation guidance as part of their professional responsibilities. Those who viewed lactation counseling as outside their professional domain were more likely to be physicians (13.6%) or psychologists (10.0%) and less likely to be nurses (7.6%) or midwives (5.6%; $P < .05$).

We also examined the significance of clear communication and the appropriate timing for discussing lactation with health care professionals dealing with stillbirth. Our respondents were asked to specify the most suitable time, and most (64.7%) believed that the optimal approach was to share this information within 24 hours of childbirth. Additionally, 10.4% of participants chose to provide these details immediately after birth, whereas 7.8% offered lactation management information only upon the woman's explicit request (Table 3).

Regarding the nature of information typically provided by respondents, pharmacologic suppression of lactation was a common topic, mentioned by 89.5% of participants in the context of stillbirth and 83.8% in cases of neonatal death. Additionally, complications like mastitis or leaking milk were frequently addressed, with 62.9% of respondents discussing these after stillbirth and 62.1% following neonatal death. General information about lactation was also commonly shared (Figure 3). However, the topic of milk donation was less frequently discussed, with only 21.8% of respondents providing information on this subject after stillbirth and 25.4% after neonatal death.

Table 4 shows that health care professionals tended to provide more information on milk donation to parents after neonatal death than after stillbirth, particularly regarding



^a $P < .01$ based on Kruskal-Wallis test with Mann-Whitney U test used for post hoc pairwise comparisons (comparing SB and NND clinical difficulty).

Abbreviations: SB, stillbirth; NND, neonatal death.

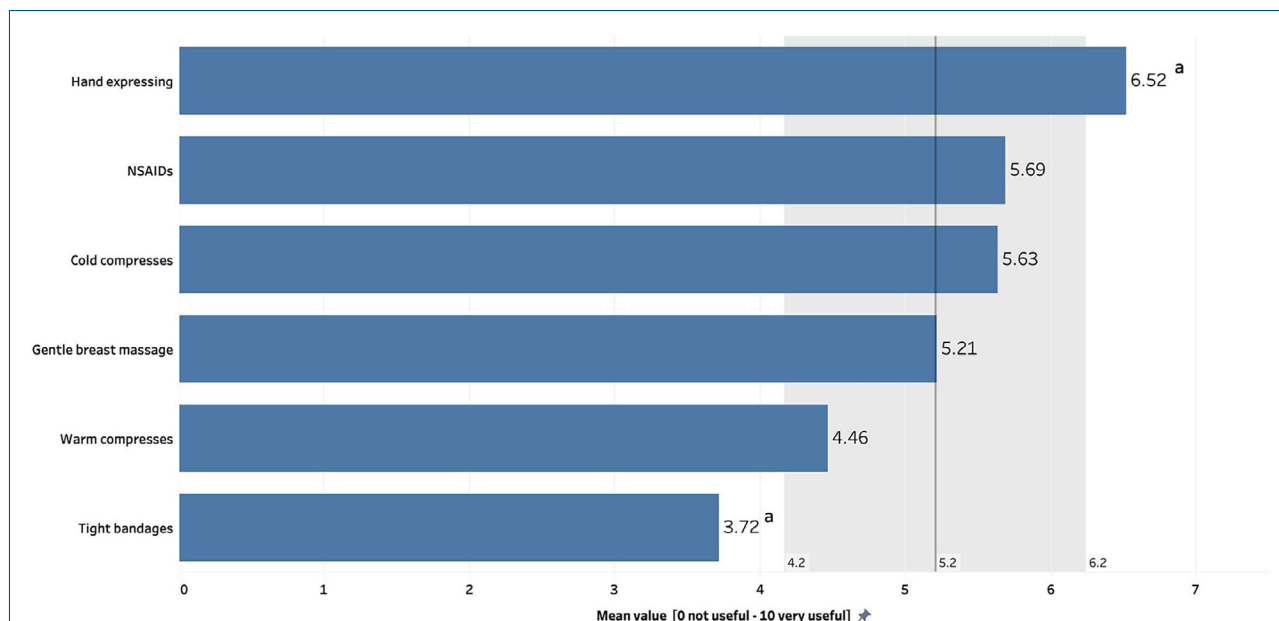


Figure 2. Evaluation of the Usefulness of Different Treatments

The vertical black line indicates the overall mean across all treatments. The shaded grey area represents the 95% CI of this overall mean.

^a $P < .05$ each practice compared with every other practice, based on Kruskal-Wallis test with Mann-Whitney U test for post hoc pairwise comparisons.

Abbreviation: NSAID, nonsteroidal anti-inflammatory drug.

Table 3. Personal Experience on Lactation Information on Perinatal Loss^a

Variable	After Stillbirth n (%)	After Neonatal Death n (%)
Gave information on lactation, total	716 (100)	533 (100)
Yes	542 (75.70)	401 (75.23)
No		
I did not know what to say	70 (9.78)	59 (11.07)
I never thought about it	35 (4.89)	28 (5.25)
It is not my professional duty	69 (9.64)	45 (8.44)
Timing of communication, total^b	539 (100) ^c	
Within 24 h	349 (64.75)	
Before birth	66 (12.24)	
Immediately after birth	56 (10.39)	
Only when asked	43 (7.98)	
Other	25 (4.64)	

^a Analysis restricted to those participants who had the opportunity to provide lactation information.

^b Timing of lactation information was assessed only for stillbirth because in neonatal death, timing varies (often days or weeks after birth) and is clinically managed differently.

^c 3 missing values.

milk storage ($P < .05$). Generally, written information on lactation management was lacking in discharge materials. Only 15.8% of health care professionals provided information through leaflets, although they were deemed quite useful (mean SD, 3.9 [0.9]). Supporting Information: Appendix S3 displays a map of respondents who provided information about milk management and the locations of human milk banks (HMBs) across Italy.

Follow-Up and Outpatient Services

Regarding follow-up programs, 267 health care professionals (21.8%) indicated that their facility offered a formal care pathway to support women postdischarge. Among these, 99 (37.1%) reported that women commonly brought up lactation management concerns during follow-up visits. The most frequently mentioned issues were emotional difficulties (35.6%), breast engorgement (16.9%), challenges with pharmacologic lactation suppression (14.2%), nonpharmacologic lactation suppression (6.7%), and mastitis (4.1%). Additionally, a mere 28.1% of health care professionals reported the existence of a dedicated outpatient service in their local community aimed at assisting parents with lactation concerns following a perinatal loss.

Open-Ended Questions

The majority of health care professionals (76.2%) responded to the open-ended questions aimed at exploring the key challenges in delivering bereavement care following stillbirth and neonatal death. Specifically, respondents were asked to identify 3 main aspects for each topic addressed. Their insights are crucial for improving support, including lactation management. The analysis highlighted key themes in professionals' experiences of perinatal loss: the central role of communication, the challenge of finding words to convey empathy within professional boundaries, the shared emotional burden (pain, helplessness), bureaucratic obstacles, the effort to suppress emotions, and—unique to stillbirth—the silence symbolizing both absence and societal taboo (Table 5).

Communication emerged as a central issue, with many respondents expressing uncertainty about how to convey empathy without causing additional harm: "I would like to know how and what to say to couples to make them understand that

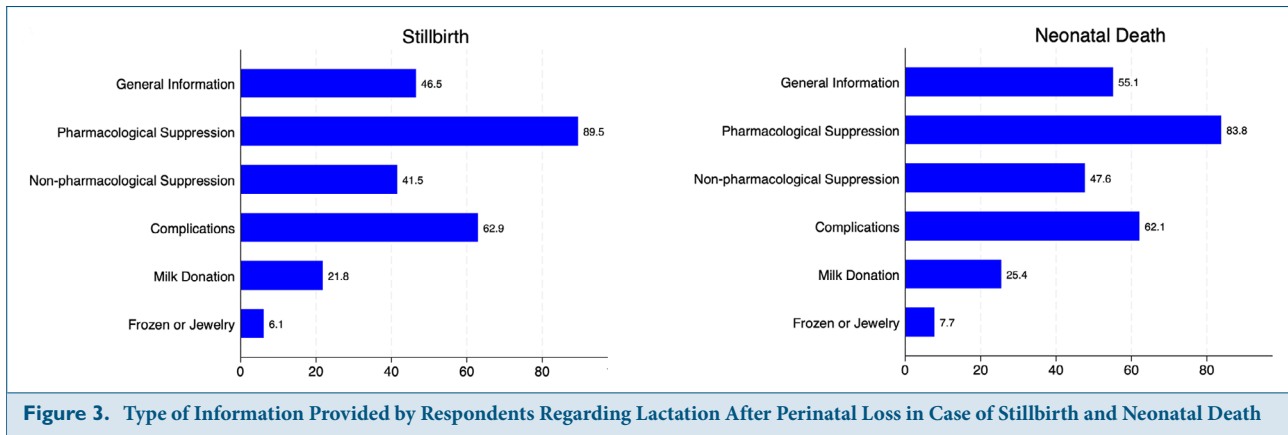


Figure 3. Type of Information Provided by Respondents Regarding Lactation After Perinatal Loss in Case of Stillbirth and Neonatal Death

Type of Information	Stillbirth n (%) (n = 118)	Neonatal Death n (%) (n = 120)	χ^2 , P Value
Inclusion/exclusion criteria	56 (47.5)	68 (56.7)	1.66, 0.19
How and where to collect milk	84 (71.2)	95 (79.2)	1.62, 0.20
How to store milk	70 (59.3)	87 (72.5)	4.03, 0.04
How to transport milk	52 (44.1)	65 (54.2)	2.04, 0.15

^a Analysis restricted to those participants who had provided information on milk donation.

Theme	Mention Frequency	Normalized Score	Description
Communication	66	8.6	Key element for providing sensitive, supportive care in perinatal loss.
Finding the words	60	7.4	Challenge of expressing empathy and comfort appropriately.
Empathy	39	5.9	Crucial for connecting emotionally with parents while maintaining professionalism.
Pain	30	4.5	Women's physical pain and the shared emotional suffering.
Helplessness	25	3.8	Professionals' sense of powerlessness and emotional strain.
Bureaucracy	13	2.3	Particularly in stillbirths, adds complexity to already difficult moments.
Not crying	9	2.7	Struggle to manage personal emotions while staying composed.
Silence	8	1.7	Unique to stillbirths; symbolizes absence of sounds and societal silence.

^a Key themes were identified based on mention frequency and a normalized score from 0 to 10.

I am there for them. One always has the impression of saying useless, superfluous words (MW01).” Others stressed the need for dedicated psychological support: “I wish the presence of a psychologist in obstetric wards were mandatory (MW02).” The importance of multidisciplinary pathways was also underlined: “I wish there were a pathway for the multidisciplinary care of couples. At present, in my reality, they are only referred to a team of psychologists or psychiatrists (MW03).” Alongside requests for stronger institutional frameworks, respondents pointed to the urgency of follow-up and continuity of care: “In the puerperium there is a void; not only physical and emotional, but also in care. Psychological support

and a follow-up visit should be guaranteed to all (MW04).” Many respondents highlighted the necessity of guidelines and training: “Protocols are needed! Training is needed, as well as collaboration with parents’ organizations, which should be present in every hospital (MW05).”

Lactation management was described as particularly challenging. Several participants admitted that their practice relied almost exclusively on pharmacologic suppression, often without adequate information: “In my experience, no advice is given on lactation inhibition other than drug therapy. Today is the first time I reflect on it (MW06).” Others noted the variability and cultural sensitivity of the issue: “The topic of

lactation is so variable and so complex that, in my opinion, a protocol is not possible at the moment. When I brought it up, couples culturally distanced themselves, and I understand this (MW07).” Some underlined the need to respect women’s autonomy: “Usually I meet women who prefer pharmacologic suppression, but I would also be ready to support natural suppression or collection. In these cases, the woman’s will and awareness are fundamental (MW08).”

Respondents also reported a pressing need for psychological and institutional support for themselves: “What is missing, in my opinion, is emotional and psychological support for health care professionals directly involved in the care of women and couples affected by perinatal loss (MW09).” This recognition of the shared burden reflects the broader theme of helplessness already identified in the quantitative analysis. At the same time, expressions of gratitude and commitment emerged: “I admire the immense work you do in trying to create a national pathway of care for couples who have experienced baby loss. Too often, this is considered a rare event, and many operators struggle to assist these families, partly because of the emotional implications for us as well (MW10).”

DISCUSSION

It is widely known that perinatal loss has a huge impact on parents’ psychological well-being.²² In the last 20 years, the literature has deepened the knowledge about the emotional burden of health care professionals who are at the forefront of perinatal bereavement care.^{16, 17, 23–25} Frustration, impotence, guilt, and a sense of personal failure are among the most common emotions experienced,^{23–25} and our results confirmed these data. Emotional issues could have hampered health care professionals’ attitude toward training on bereavement care. A sense of personal failure could play a key role in developing burnout syndrome, which is linked to a decrease in professionalism and personal job investment.²⁶ The emotional strain experienced by health care providers should be recognized, as their emotional responses play a crucial role in the care of bereaved parents. Professional knowledge and clinical practice cannot be fully separated from these emotional dimensions. McCreight²⁵ found that the perinatal loss had a strong emotional impact on nurses, enabling them to recognize their emotions as a valuable resource in clinical practice. Scheduled debriefing sessions with staff, grounded in a narrative approach, could support health care professionals in enhancing self-awareness and emotional insight. This strategy could shift the emotional experience of health care professionals from a barrier to a facilitator of clinical practice. Furthermore, our data have shown that emotional difficulty while assisting with stillbirth was lower in participants with specific training in perinatal loss bereavement care. Although the statistical significance of the result was borderline, previous research has demonstrated a positive correlation between specific trainings and health care professionals’ psychological well-being.^{16, 17} In this sense, training could be considered a protective factor.

More than half of respondents reported the absence of a formal guideline for perinatal bereavement care in their workplace. This is a crucial finding, as emphasized in the CLASS study: adherence to international standards is associated with

higher satisfaction with care and reduced grief and post-traumatic stress symptoms in bereaved parents. The stigma around perinatal death,²⁷ the lack of formal training around this topic,^{15, 28, 29} and the fact that Italian recommendations on stillbirth management were only recently published¹¹ could explain the delay in adopting national bereavement care pathways.

At the core of the LISTEN study, participants reported very limited training in lactation suppression techniques. This may help explain why a quarter of the sample did not provide any information about lactation management, either because they were unsure what to say to parents or because they believed that it was outside their professional responsibilities. This lack of knowledge may help explain why some nonpharmacologic interventions to suppress lactation were considered effective, despite the lack of scientific evidence of their effectiveness.³⁰ To date, there is no evidence supporting the effectiveness of nonpharmacologic interventions for lactation suppression compared with no intervention.³⁰ Pharmacologic therapy remains the only evidence-based approach for lactation suppression and should be offered when available, alongside the option of milk donation, in accordance with current guidelines for perinatal bereavement care.^{9, 12, 31} Although milk donation was only occasionally considered by our sample, existing literature highlights its clear benefits for some women who choose it.³²

We found that participants were more likely to provide parents information about milk donation after a neonatal death than a stillbirth. This finding could be explained by the fact that women with newborns or infants hospitalized in a neonatal intensive care unit (NICU) have typically already begun pumping or expressing milk. In such cases, health care professionals may feel more comfortable talking about this topic than they do following a stillbirth. Given the highly individualized nature of grief, health care professionals should engage in shared-decision-making around milk management^{12, 14, 33} to empower women during bereavement.

Interestingly, participants tended to provide more information on lactation suppression or management following stillbirth than after neonatal death. This may be due to the absence of dedicated midwifery support for women in the NICU and the limited lactation support typically offered by NICU nurses in Italy—a concern supported by the literature, which highlights the lack of effective lactation support in this setting.³⁴

Italy has the highest number of HMBs in Europe,³⁵ reflecting a strong national commitment to neonatal care. However, our findings suggested a disconnect between the availability of HMBs and the information provided to parents following the loss of a child. This discrepancy likely stems from cultural factors and a lack of awareness rather than a shortage of resources.

Another important aspect of lactation management is the potential for complications, such as breast engorgement and pain, that can occur during the natural process of lactation cessation, whether or not pharmacologic or nonpharmacologic methods are used.⁷ Participants in our study reported encountering such issues at follow-up visits. To help manage these complications, women should receive in-person counseling supported by tailored written information.^{8, 9, 12, 31}

These materials should outline the pros and cons of each suppression strategy and provide guidance on what to do if complications arise.⁷ Supported informed decision-making can reduce both physical discomfort and emotional distress associated with milk suppression.

Regarding the more appropriate timing for discussing lactation management, guidelines from the Ireland Health Service Executive recommend providing this information immediately after diagnosis to support informed decision-making.¹² A lactation specialist consultation is advised.⁸ In our study, most participants reported providing this information within 24 hours of childbirth, although 7.8% did so only when women specifically asked. However, the 24-hour window between birth and discharge may give health care professionals too much discretion in determining when to initiate the conversation. Providing information at the time of diagnosis ensures that women have as much time as possible to make a decision.¹²

The qualitative analysis of participants' responses to open-ended questions offered valuable insights into the nuanced challenges faced in the context of stillbirths and neonatal deaths, confirming the quantitative findings. Challenges in communication and providing comfort highlighted the sensitive nature of offering support amid profound grief. Additionally, "navigating bureaucracy" emerged as a significant challenge, highlighting the administrative burdens that compound the emotional strain of perinatal loss. Managing personal emotions was also critical; feelings of helplessness were commonly expressed by participants and may impact the care provided to grieving parents. Together, these themes highlight the intricate nature of perinatal care and underscore the need for targeted training and emotional support for health care providers.

Ultimately, this study revealed both the inadequacy of follow-up programs and the limited awareness among participants regarding their availability. Major international guidelines on perinatal bereavement care consistently emphasize the critical importance of continuity of care.^{8, 9, 12, 31} For example, Salgado et al identify continuity of care as an essential component of the "perinatal bereavement safety thermometer," which highlights 10 essential factors influencing maternal psychological well-being and the grieving process.³⁶ Furthermore, couples who experience perinatal loss should be referred to specialized bereavement services capable of addressing the complex clinical and psychological needs that arise after such a loss.¹¹

This study highlights critical gaps within the Italian health care system that also resonate with challenges reported in other countries. Although our findings are grounded in the Italian context, where formal bereavement care pathways and lactation management guidelines are still emerging, the issues identified reflect a broader global need for structured guidance and professional training.

Strengths and Limitations

This study represents a significant step in examining lactation management following perinatal loss in Italy, providing a comprehensive perspective informed by health care professionals' emotional responses and knowledge. The

LISTEN study's large and geographically diverse sample provides a nationally representative view of this sensitive area of care. While offering valuable national insights, the study also underscores the need for further research in diverse cultural and health care contexts. Future studies should address response bias common in self-reported surveys and examine confounding factors that may influence health care providers' responses to better understand real-world practices and needs. Although based on self-reported data, the broad, population-proportional sample strengthens the study's validity. The dominance of midwife respondents reflects their central role in perinatal care, although future research should aim for a more balanced inclusion of physicians, nurses, and psychologists.

CONCLUSION

The LISTEN study highlights key challenges for health care professionals in managing lactation after perinatal loss, including limited knowledge, emotional strain, and the absence of structured guidelines. These findings underscore the urgent need for national guidelines that incorporate clear lactation support measures. To improve care, regular training should strengthen both communication and technical skills, particularly in lactation suppression, which is relevant not only for bereaved women but also for discontinuing lactation. Strengthening NICU teams, especially nurses and midwives, can further support complex lactation decisions. The fact that 25% of participants in our sample do not provide lactation guidance points to the need for standardized approaches. Expanding education on milk donation and improving follow-up care can offer additional support to grieving parents. Ultimately, a broader cultural shift toward patient-centered care is essential. Providing respectful, personalized information empowers women to make informed choices that reflect their individual needs and experiences.

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CONFLICTS OF INTEREST

The authors declare no conflicts of interest.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Appendix S1. Checklist for Reporting Results of Internet E-Surveys (CHERRIES)

Appendix S2. AI-Assisted Qualitative Analysis in the LISTEN Study

Appendix S3. Geographical Distribution of Respondents and Italian Human Milk Banks

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