DEATH STUDIES
2025, VOL. 49, NO. 9, 1232–1245
https://doi.org/10.1080/07481187.2024.2390905

Routledge
Taylor & Francis Group

Transforming care for pregnancy loss: A qualitative study on advancing practices and addressing existing needs

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ABSTRACT

Recent years have seen significant growth in the body of knowledge and the development of guidelines on pregnancy loss. This qualitative study analyses how these advancements have been implemented with a focus on health literacy, hospital protocols, and societal responses. Thematic analysis of semi-structured interviews from bereaved parents (n = 11) and healthcare professionals (n = 7) in Italy uncovers significant lapses in health literacy and societal reluctance to address pregnancy loss, which obstructs informed parental decision-making. The research indicates a movement toward more sensitive healthcare, yet disparities remain in the treatment of early versus later losses and uneven psychological support provision. The research underscores the need for standardized practices and combined psychological care for both parents and for reform in legal policies regarding bereavement and maternity leave. Despite progress in institutional and societal approaches to managing pregnancy loss, considerable challenges persist.

Introduction

The phenomenon of pregnancy loss presents a profound challenge in modern societies, where scientific perspectives dominate death's understanding, public rituals diminish, and community support wanes, leaving those affected often isolated (Frost et al., 2007; Hiefner, 2020; Rajan, 1994). Miscarriage (defined under Italian law as a pregnancy loss before 180 days) and stillbirth (defined as a pregnancy loss after 28 weeks or 180 days) are often viewed through the lens of disenfranchized grief—marked by limited social recognition, scant rituals, and a clinical approach to what is a deeply personal loss (Brier, 1999; Cassidy 2023; Hazen, 2003).

Research since the 1980s has thoroughly documented the impacts of these losses, such as grief, depression, stigma, and effects on self-esteem for both women and their partners (Cassidy 2023; Cecil, 1994; Lee et al., 2023; Lovell, 1983; Wonch Hill et al., 2017). Indeed, research shows that people dealing with miscarriage and stillbirth typically find themselves in a state of mourning similar to the (individual) grieving process experienced after other losses, while the intensity of the grief reaction is always modulated by personal experiences such as previous losses, the presence of other children and infertility (Brier, 2008; Obst et al., 2020; Volgsten et al., 2018). In recent decades, there has been a notable shift in breaking the cultural silence surrounding pregnancy loss, with the legitimate grief experienced by both mothers and fathers gaining recognition (Brier, 2008; Lasker & Toedter, 1994; Mergl et al., 2022).

This change has spurred the development of postnatal healthcare guidelines focused on clear communication, meaningful farewells, and a respectful hospital environment. However, the ongoing debate on pregnancy loss extends beyond medical settings, as the handling of early death is also a societal debate. And here too, much has been negotiated in recent years: For example, legal frameworks in various countries, including Italy, have evolved to meet the needs of bereaved parents more sensitively by allowing the burial of early embryos and fetuses since 2017.

However, despite the wealth of global literature and evolving legislation, questions remain: Are the needs

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of bereaved parents now adequately met, and has society become more sensitive to their situation? This qualitative study explores how recent advancements in understanding and managing pregnancy loss are reflected in both institutional and societal contexts. Located at the intersection of medical sociology, health communication, and bereavement studies, it seeks to capture nuanced individual and professional perceptions of miscarriage and stillbirth care and response. By doing so, it contributes new insights to the ongoing scholarly discourse on managing and understanding pregnancy loss.

Material and methods

Objective of the study

The objective of this study is to capture the nuanced individual and professional perceptions of advancements in the care of pregnancy loss and societal narratives concerning the death of the unborn. To this end, a qualitative approach is employed to analyze how these changes are perceived and experienced both by individuals directly affected and by healthcare professionals.

Research design

A qualitative descriptive study design (Bradshaw et al., 2017) was selected to accurately document the experiences of parents who have suffered pregnancy losses, alongside the viewpoints of healthcare practitioners. By utilizing a qualitative descriptive approach, this study engages directly with the complexities of personal and professional experiences, offering a comprehensive understanding of the dynamic interplay between clinical practice and societal attitudes toward pregnancy loss. The flexibility of this design is suitable for exploring the intricacies of societal discussions and the evolution of care, thereby enriching the ongoing discourse with new empirical data.

Participants

The study comprised in-depth interviews with affected parents (n = 11) living in the Province of Bolzano, Italy. Additionally, to enable data triangulation, expert interviews (n = 7) were conducted to ensure a comprehensive understanding from both the perspective of the affected individuals and that of professional service providers. Participants for this study were initially recruited through a single call for participation distributed via local women's networks, targeting individuals who had experienced miscarriage or stillbirth within the past five years, including both men and women. Following this initial recruitment, the study employed snowball sampling, a technique where existing study subjects recruit future subjects from among their acquaintances. This approach was particularly effective for reaching a broader community of parents who had undergone similar experiences, allowing us to tap into their networks and identify additional individuals willing to share their personal stories. The initial contacts served to expand our participant pool significantly by referring us to other parents who had gone through similar losses.

Recognizing the need for expert insights, we specifically sought out professionals with substantial experience and expertise in the fields of obstetrics, midwifery, and bereavement counseling. These experts were identified through professional registries and networks, ensuring that we engaged knowledgeable individuals who could provide an in-depth perspective on the healthcare system's handling of pregnancy loss. Both parents and experts live in the Province of Bolzano, in Northern Italy.

Data collection and analysis

Interviews were conducted using a semi-structured questionnaire designed to allow flexibility and depth in responses, which was developed by our interdisciplinary research team of medical doctors, sociologists, and therapists. The semi-structured format allowed for adaptability in uncovering topics significant to the participant and further exploration of concepts that surfaced throughout the interviews. The topic guide contained questions about personal experiences with pregnancy loss, the emotional and psychological impact, available support systems, and the perception of medical and societal responses to their situation (Appendix A).

All interviews were conducted face-to-face. Alongside the experienced interviewer, either an experienced midwife or a psychologist was present to provide support and accompany the participants, should there be a need after the interview. All audio records were transcribed verbatim using the f4 transcription software. This task was managed by a member of our team with significant expertise in transcription, which ensured professional-level accuracy in the transcriptions. All participants were offered the opportunity to review their transcripts as a form of validation.; however, only one participant chose to do so.

Thematic analysis, as outlined by Braun and Clarke (2006), was employed to examine the interview data.

MAXQDA software facilitated data organization and the coding process. This choice of software supports efficient management of qualitative data, enhancing the precision and replicability of the coding process. The researchers engaged deeply with the material by reviewing the transcripts to gain a comprehensive understanding. The coding of the interviews was performed inductively, allowing for the emergent identification of potential themes. This approach is particularly suited to semi-structured interviews where the flexibility of the questioning approach means that while certain areas are explored as per the researcher's interest, the conversation can still flow naturally and participants can introduce new ideas and topics. This makes the inductive approach ideal, as it can accommodate and find patterns in these spontaneous elements, adding richness to the findings that might not emerge in a more structured interview format. Four independent researchers undertook the coding process for all interviews to ensure thoroughness. Discrepancies in coding and the preliminary themes were meticulously examined and reconciled collaboratively within the research team. Subsequently, the identified themes underwent a rigorous internal review and were cross-checked with the full set of interview transcripts to ensure consistency and accuracy.

Results

In total, 18 adults participated in semi-structured interviews (Table 1).

The thematic analysis conducted on the qualitative data yielded a structured overview of key themes and sub-themes across three distinct dimensions: individual, institutional (medical-professional), and societal (Table 2). Within the individual dimension, themes such as the onset, progression, and termination of pregnancy were examined, along with personal reactions and coping strategies, and the dynamics of dealing with the event as a couple. At the institutional level, patient-doctor interactions emerged as major category, including communication, the roles played by healthcare professionals, and the personal impact of pregnancy loss on medical personnel. Clinical routines were also scrutinized, with an emphasis on the strategies employed, as well as the symbols and rituals that have emerged in clinical practice. The societal dimension encapsulated themes related to the responses and support mechanisms emanating from the social environment, the effectiveness of such responses, the support required, and the aspects found to be helpful by those affected.

Table 1. Participants.

Parents ($n = 11$)				
	Age	Gestational week	Recurrent miscarriages	Educational level
Female participants (Miscarriage[a])	32	8	No	University degree
	36	11	No	University degree
	40	13	No	University degree
	32	8	Yes	University degree
		10		
Male participants (Miscarriage[a])	32	8	Yes	High School
		10		
	38	7	Yes	High School
		11		
Female participants (Stillbirth[aa])	29	40	No	University degree
	33	25	No	High School
	35	25	No	University degree
Male participants (Stillbirth[aa])	46	26	No	High School
	39	25	No	High School
Experts ($n = 7$)				
Job role	Gynecologist		Female	
	Pediatric nurse		Female	
	Anesthesiologist		Male	
	Midwife		Female	
	Grief counselor		Female	
	Bereavement photographer		Female	
	Psychologist		Female	
Total interviews		N = 18		

[a]In Italy, miscarriage is defined as the spontaneous death of an embryo or fetus within the first 180 days of gestation.
[aa]In Italy, stillbirth is defined as the loss of a fetus after 180 days of pregnancy or 28 weeks of gestation.

Table 2. Overview of the main themes and sub-themes.

Dimension	Main theme	Sub-theme
Individual	Health literacy	• Lack of awareness • Lack of health-related information regarding miscarriage and stillbirth
Institutional	Patient-doctor interaction	• Balancing empathy and professionalism • Navigating grief and loss at different stages of pregnancy
	Evolving hospital practices and Attitudes in managing pregnancy loss	• Hospital protocols and professional attitudes • Psychological support and midwifery in pregnancy loss recovery • Addressing fathers in the context of pregnancy loss
Societal	Reactions and support from the social environment	• Silence, empathy, and recognition • Legal frameworks

Individual dimension

Health literacy

Lack of awareness. Awareness regarding pregnancy loss remains limited. This scarcity of public discourse means that many individuals remain unaware of how common pregnancy loss is until they experience it themselves or through close social connections. This pervasive silence not only underscores the societal taboo surrounding such discussions but also perpetuates

a cycle of ignorance. This cycle further entrenches the stigma associated with pregnancy loss, as the subject remains enveloped in secrecy and is rarely addressed openly in public forums. A particularly telling reflection of this taboo is the common societal practice of not announcing pregnancies until after the 12th week, intended to avoid public acknowledgment of a loss should it occur. In our cohort, all affected parents spoke of a profound silence that still surrounds the topic.

> And then you realize that it happens to many more people, only people don't talk about it. People just don't talk about it. (Mother, gestational week: 8)

Healthcare professionals, who regularly encounter these cases, recognize that misunderstandings and silence about pregnancy loss are more common outside the medical community. They note that over the past three decades, there has been significant progress in destigmatizing the issue within hospital settings. While providers appear well-informed about the common occurrence of miscarriages, they recognize that this awareness is not as widespread among the general public.

> We know that in these first twelve weeks of pregnancy, the risk of experiencing a miscarriage is between 30–40%. This means that a considerable number of women are affected, yet unfortunately, it remains a significant taboo. The reluctance to engage with and openly discuss the topic persists on various levels in public discourse. (Healthcare Worker)

> I find this so regrettable because it remains a taboo that children die during pregnancy. We talk little about it, we talk far too little about it. (Healthcare Worker)

Lack of health-related information regarding miscarriage and stillbirth

The frequency of miscarriages and stillbirths is not well understood by the public, indicating a significant gap in health literacy concerning pregnancy loss. Our interviews suggest that individuals enter these experiences without basic knowledge of the medical processes involved in miscarriage or stillbirth, the safe options for removing a deceased fetus, the fact that a deceased fetus poses no immediate health risk in the absence of complications, or what such a loss physically entails. This lack of information can lead to intense feelings of guilt and powerlessness among parents, complicating their grief and decision-making processes. For example, one mother described her unexpected need to decide on a delivery method for her deceased baby, a decision she was initially unprepared to make:

> "We won't be having the birth today; we will try tomorrow with a natural birth." I initially resisted the idea completely. I couldn't imagine giving birth to my child naturally under these circumstances. (Mother, gestational week: 40)

This systemic lack of preemptive health education places grieving parents in a position where they are overly reliant on the immediate guidance provided by medical professionals. This can result in a form of 'nudging' by healthcare providers at a moment of extreme vulnerability:

> The next morning, the doctor came to me with the midwives and they, I'll just say it like it is, persuaded me to agree to a natural birth and they gave me a mild labor-inducing drip to intensify the contractions and after a few hours I gave birth naturally. And in hindsight I am very glad that I did it (*voice breaks*), because it was simply an important and despite everything for me also a very beautiful experience. (Mother, gestational week: 40)

Furthermore, the pervasive lack of comprehensive health information leaves individuals wrestling with unwarranted self-blame. This sense of personal failure is deeply intertwined with a lack of accessible and comprehensive information about pregnancy loss, which may leave individuals grappling with unfounded guilt. One mother states:

> And the worst part is that you always blame yourself. What did I do wrong? (Mother, gestational week: 11)

Our analysis reveals that in the case of stillbirths, there is a relatively high level of understanding, empathy, and an effort to collaboratively find the "right" way forward, with medical personnel adhering closely to guidelines and a desire to provide the best possible support to unprepared parents. However, in the case of miscarriages, the effort and empathy regarding careful decision-making and communication are less pronounced (see "Institutional dimensions").

Institutional dimension

Patient-doctor-communication

Balancing empathy and professionalism. In our cohort, medical staff relay the distressing news of a pregnancy loss using a standard phrase, such as "we can no longer detect a heartbeat." This is particularly common in the early stages of pregnancy. Especially in cases of early pregnancy loss, it becomes apparent that medicalization of the situation and transition into

clinical routine may be used as a coping strategy by professional healthcare providers.

> First, he conducted a long ultrasound, didn't say much during that, and then he turned to me and said that he couldn't find any heartbeat. (Mother, gestational week: 13)

> And what was certainly lacking for me was a bit of humanity. The doctor, the statement "There is no heartbeat anymore," and then immediately back to routine. So, like what's the next step, […] what happens now. No word of sympathy, no time […]. (Mother, gestational week: 8 and 10)

> […] because you think, "Oh God, how do I say this now? How will the woman react when I tell her? And what do I do with this woman's reactions? How do I handle it?"(Healthcare professional)

Healthcare professionals emphasize a balanced approach in supporting patients while maintaining their own emotional boundaries.

> As helpers, it is crucial for us to navigate this delicate balance, where, on one hand, we support women in their actions, in what they are currently going through and experiencing. On the other hand, we must not immerse ourselves too deeply in the situation, so that, when a woman has a strong experience of grief, we can still endure it and maintain the necessary distance. (Healthcare Worker)

Navigating grief and loss at different stages of pregnancy. Our findings show that the emotional burden on medical personnel intensifies with the progression of the pregnancy. The later the stage, the more challenging the situation becomes for healthcare professionals, sometimes leaving them at a loss for words. A woman whose unborn child passed away at the 40th week of gestational age recalls:

> Neither my partner nor I were effectively told "The child is dead." I don't know if the doctor or the midwives had some kind of fear to pronounce it. The doctor only said she was sorry, and I automatically understood what was going on. They brought my partner to me without telling him anything. They just told him to come in, and when he saw me crying, he understood on his own what had happened, but it was never directly spoken out loud. (Mother, gestational week: 40)

There is a notable difference in the emotional handling of stillbirths versus miscarriages. Stillbirths receive more empathetic responses, while miscarriages are treated more clinically. Furthermore, the emotional impact on healthcare providers is affected by various factors, such as whether the couple has experienced repeated miscarriages and undergone fertility treatments. However, aside from medical checkups (e.g., for thyroid diseases and immunological disorders), no additional support measures were apparent following recurrent miscarriage and fertility treatment. The feedback from parents echoes findings from existing research, highlighting that experiencing multiple pregnancy losses leads to more profound grief reactions. However, emotional experiences, as existing literature on the subject already shows and as confirmed by our cohort, do not necessarily align with gestational age, and early losses can be just as intensely experienced.

> From the perspective of the helpers, every stillbirth is, of course, an even greater challenge than a miscarriage. (…) Because from our perspective as helpers, it is, of course, more dramatic the closer the child comes to the due date. (Healthcare Worker)

> And with the second miscarriage, it knocked the ground out from under both of our feet. (Mother, gestational week: 8 and 10)

Differences in managing miscarriages and stillbirths are observed not only emotionally but also in clinical practices since the type of support and interventions for parents shifts markedly with the timing of the pregnancy loss. In cases of stillbirth, there is now a focus on facilitating a natural birth process, which is (meanwhile) perceived as less risky physically and more beneficial for emotional processing by healthcare workers. Conversely, early losses often lead to a more immediate medical intervention, such as curettage, leaving some women feeling rushed in their grief process. The option of waiting for a "natural miscarriage" appears not routinely offered; a woman who was given the opportunity to wait expressed gratitude in hindsight for that option.

> They said that the curettage can be done today or tomorrow. So, I had no choice. I remember just thinking: "Not today. I want to go home." And then it was the next day, but in hindsight, that was still much too soon. And then the surgery was on the following day. And that was it. (Mother; gestational week: 8 and 10)

> I was told to wait for a spontaneous miscarriage and let nature or my body decide. In hindsight, that was actually the best thing that could happen for me. Even though the idea was initially very daunting and frightening, to have the dead child inside me for weeks – it ended up being three weeks. (Mother; gestational week: 11)

Evolving hospital practices and attitudes in managing pregnancy loss

Hospital protocols and professional attitudes. Generally, parents perceived it negatively and in no way supportive when the medical staff trivialized the loss

or was unable to express sympathy. Noteworthy, however, while some parents reported negative, trivializing, and low-empathy interactions, all of them also recounted receiving helpful, understanding, and empathetic interactions during their contact with various healthcare professionals.

> We have specific rituals: when the child arrives, we always ask the parents if they would like to look at it, if we should leave it with them, if they would like to hold the child, and everything is offered very gently. (Healthcare Worker)

The growing empathetic approach, as compared to findings from earlier studies and data, signals a shift in the narrative around pregnancy loss. This change is reflected in hospital protocols and guidelines, which are indeed being implemented, thereby translating the theoretical knowledge generated in recent years into practice. This shift toward a more empathetic approach marks a positive change in hospital narratives and practices regarding pregnancy loss. Protocols and rituals are evolving to facilitate emotional recovery, encompassing strategies such as encouraging a natural birth in stillbirth situations, providing parents with opportunities to spend time with their child, enabling them to hold their child, including siblings in the goodbye process, generating lasting memories through photographs or hand and footprints, and, in certain instances, employing professional photographers specialized in capturing these moments.

> We take photos of the baby; we make prints of the feet and hands. We create memories. (Healthcare Worker)

> One positive aspect I found was that we weren't asked whether we wanted photos of the child or not. […] It was simply done, and then we were given the choice of whether we wanted the photos or not. […] I think we would have been completely overwhelmed by the decision in that moment. Because, of course, at that moment, you don't think, "This is something I want to remember for the rest of my life," but otherwise, the child disappears and was never there. […] (Father, gestational week: 25)

> Then logically, the question arises, what about the siblings? Should they come, should they see it, should they be involved? […] I have talked to a hospital chaplain in the meantime, and she encouraged me to involve them. She mentioned that it could help them process it better. […] So, they went to the hospital with us. […] For the children, it doesn't matter how it looks or whether it looks nice – that was not an issue at all. They saw it and remember it as something good, and they were able to process it well. (Mother, gestational week: 25)

Psychological support and midwifery in pregnancy loss recovery. The availability of psychological support varies, with some hospitals proactively offering it and others requiring mothers to request it. Many parents expressed a need for more accessible aftercare services. Midwives were frequently mentioned as a valuable source of support, offering less stigmatizing care than psychologists.

> Or what really helps is certainly the midwives and the community services. Someone who may accompany you even before birth, during pregnancy, and then can be there afterward as well. (Mother, gestational week: 8)

Particularly in cases of termination following abnormal prenatal diagnostics, the support appears lacking, leaving women to cope with heightened feelings of guilt and isolation.

> It seems like nobody was there; there was no midwife. I'm not sure if it's the midwife's responsibility, but there was no doctor, no psychologist […]. As I said, I didn't receive any professional help; it wasn't offered to me. Not after the appointment in (Location A), where I decided to terminate the pregnancy. Not even until the time of the termination, and not afterward either. There was essentially no help. Maybe I could have actively sought it, but I didn't think of it at that moment. (Mother, gestational week 13)

Addressing fathers in the context of pregnancy loss. Fathers frequently report feeling neglected in their grieving process, being advised to "be strong for the woman," with most healthcare efforts focused primarily on the mother. Although some healthcare professionals recognize the importance of acknowledging fathers' grief, our investigation could not identify any specific support measures for fathers in hospitals. The most common form of inclusion is allowing fathers to be present during discussions and during the stillbirth.

> But looking back, it has often been the case in this situation that you are really "only" the father. And the "only" is strongly emphasized there. All the help, all the emergency counselling, and so on and so forth, have all been focused on the woman. And I was always somehow there during conversations, but always "just there". (Father, gestational week: 25)

Societal dimension

Reactions and support from the social environment

Silence, empathy, and recognition. People's reactions to miscarriage and stillbirth vary outside the hospital. In private settings, empathy is common, but a broader

societal discomfort with early pregnancy loss remains observable. Similar to experiences in hospitals, outside in larger societal contexts, recognition of the loss progresses with the pregnancy. Early pregnancy losses are perceived less as a case of loss and mourning than later losses. Often, well-meaning but unhelpful clichés are used, inadvertently trivializing the grief experienced by parents.

> The worst thing, from my perspective, that can be done with an affected person is to say, "Okay, come on, you're still young, you can try for another child." As if the first one never existed, so it went wrong, okay, forget it, let's try again. (Mother, gestational week: 40)

Recognition of the grief associated with miscarriages and stillbirth is essential for bereaved parents. Simplistic remarks like "Don't think about it" or "It wasn't a real child yet" are harmful as they invalidate the parents' grief while respectful acknowledgment of the loss appears crucial for the bereavement process. The collective silence and avoidance surrounding miscarriage and also stillbirths are generally perceived as burdensome.

> Yes, I believe that there is a lot of uncertainty among many people in the environment because they might think, "I know what happened, but I don't know what to say, should I say anything at all, or should I say nothing," and then, I think, it often ends up with them saying nothing. (Mother, gestational week: 25)

> Don't withdraw based on the misconception that you are not needed because the other person's pain is too big. Be there for that person, show proximity and presence repeatedly, even if you might not receive feedback at times, and don't just silence what happened. It shouldn't be a taboo; people should talk about it, in my opinion. Move away from the attitude of quickly forgetting and moving on, in my view. (Mother, gestational week: 40)

Supportive responses that positively impact the grieving process include listening, validating feelings, sharing experiences, and allowing grief to be expressed without pressure to move on.

> No one can resolve it. No one can help. But taking time and being there is everything that's needed, and I believe, pretty much all that people from one's circle of acquaintances or relatives can truly offer. Time is everything. So, really being able to take time for long conversations, for long walks. Yes, and also just letting silence be okay. There doesn't always need to be someone saying something all the time. (Father, gestational week: 26)

Men report receiving less support than women, possibly because they do not undergo the physical aspects of pregnancy loss. Nonetheless, their emotional loss is significant, and insensitive remarks can be hurtful.

> I don't want to blame anybody, but the reality is that it's the woman who becomes pregnant and the woman who loses the child. Meanwhile, the man was at work before and returns to work afterwards. He lived his life before and continues to live the same way after. However, the fact that this situation creates a gap, a void, is something that few people recognize. (Father, gestational week: 8 and 10)

Legal frameworks. Our research has revealed that not all parents were aware of their right to bury early pregnancy losses, largely due to unfamiliarity with the legislative changes introduced in 2017. Additionally, in cases of early losses, medical personnel often failed to inform parents about their rights. Consequently, some parents were unable to officially bury their early embryos/fetuses and instead sought to create private memorials. On the other hand, having access to a grave has shown positive impacts on the grieving process by providing a physical space for mourning and remembrance.

> Somebody gave me the advice: "Give the child a place in your home. Purchase something symbolic for this child and give it space." And that's what I did, and it really helped me because we don't have a grave. We have nothing, except a small picture. (Mother, gestational week: 8)

> And two weeks later, we were able to bury it in our local cemetery, where we now have a grave that we can visit. And that's very important to me: to know where he is. (Mother, gestational week: 25)

This absence of formal recognition for early pregnancy loss is also reflected in policies regarding bereavement leave. The interviewees highlighted a societal expectation for rapid emotional recovery, which aligns with the legal stance in Italy, where early pregnancy losses do not qualify for bereavement or maternity leave.

> The miscarriage took several days for me, and during that time, I continued to work. There was a moment when I almost wanted to scream: "I can't talk to you right now, I'm losing my child!" (Mother, gestational week: 8)

> Maybe I was too vague or too general with the explanations, but in any case, there was absolutely no understanding. […] I only took one week off from work. And yeah, I noticed that people were wondering why I wasn't sitting at my desk three days later. (Mother, gestational week: 11)

> I wish that women in society might also find the courage to show weakness. That being weak is not something negative, but that being weak can also be something positive. And that one can also quietly say "Okay, I'm losing my child right now, I'm not working." But it's not that simple […] without then being labeled as a weakling […]. (Mother, gestational week: 8)

Discussion

Our findings illuminate a complex interplay between individual, institutional, and societal dimensions, revealing significant advancements but also persistent challenges in addressing the grief associated with pregnancy loss. Overall, over the past several decades, there have been noteworthy shifts in the institutional and societal management of miscarriages and stillbirths, yet notable gaps persist.

Health literacy

At the individual level, the study highlights a pervasive lack of awareness and health literacy regarding pregnancy loss, emphasizing the need for increased public education and open discourse. Indeed, general information about miscarriage and stillbirth appears to have not fully permeated the public consciousness and despite the relatively high number of affected individuals, health literacy in this area is astonishingly low, reflecting societal hesitancy to engage with and educate on these topics. Interestingly, our findings reveal that this deficiency in health literacy is not confined to less educated groups; even our cohort, which predominantly consisted of men and women from higher educational backgrounds, demonstrated significant gaps in understanding and awareness. This gap in knowledge not only perpetuates the cycle of silence surrounding miscarriage and stillbirth but also hinders parents' ability to make informed decisions. Indeed, low health literacy in turn leads to parents relying on the instructions and reports of medical personnel, which can lead to difficulties and limited informed decision-making processes in individual cases (Mitchell, 2016). While clinical guidelines have evolved and are designed to best assist and support patients, the standard (e.g. seeing and holding the fetus) may not resonate with all individuals, particularly when presented during moments of acute distress. Critiques from feminist scholars like Lisa Mitchell highlight that such norms, while well-intentioned, might impose additional emotional burdens on parents who might prefer not to engage in this way (Mitchell, 2016).

Given the high incidence of pregnancy losses, increased awareness and open communication about the topic would be beneficial. However, the lack of communication and education about it leaves many unprepared for the realities of miscarriage or stillbirth, whether they are the ones experiencing it or their relatives and friends. This resulting uncertainty in dealing with the loss exacerbates the isolation of those affected and may complicate the grieving process. In cases of pregnancy loss, the societal and individual optimism bias, acting as a stress avoidance mechanism, may contribute to this lack of preparedness by encouraging a more positive outlook during pregnancy, potentially reducing anxiety but also hindering awareness and readiness for potential difficulties. Acknowledging the dual nature of optimism bias underscores the importance of initiating comprehensive health education about pregnancy-related challenges well before conception. This preparation is crucial not only for enabling parents to engage in informed discussions with healthcare providers but also for creating a supportive environment that can better navigate the complexities of perinatal loss. While it's true that one can never truly be prepared for death, being aware of its possibility is essential for fostering a more informed and supportive environment for navigating perinatal loss.

Length of pregnancy and its consequences in case of loss

The rationale for defining miscarriage and stillbirth is grounded in gestational age and length of pregnancy, where the length and size of the unborn lead to legal, social, ethical, and clinical consequences that do not always align with the parents' feelings and grief reactions. The relationship between the timing of a pregnancy loss and the subsequent intensity of grief is complex and cannot be definitively established due to the individual responses to pregnancy loss. While some research points to deeper grief following losses later in pregnancy (Cuisinier et al., 1993), a recent systematic review of available data concluded that there are pronounced grief reactions in both women who had miscarriages or stillbirths (Mergl et al., 2022). Recently, a study found that the fear of childbirth in later pregnancies does not differ significantly between women who have had a miscarriage and those who have had a stillbirth (Hamama-Raz et al., 2024). It has, however, been shown, that independently of gestational age other factors such as having no other children, previous miscarriage or

infertility treatment could increase negative emotional experiences after miscarriage (Lamb, 2002; Volgsten et al., 2018). Despite these findings, our results suggest that professionals generally associate the extent of grief with gestational age. Additionally, while our results indicate that health professionals are aware that previous perinatal loss had a negative impact on subsequent pregnancy loss(es) and thus these parents might be in need of extra care, our results do not indicate that there are any specific non-medical measures for parents after repeated loss, which are also not foreseen for by law (see "Advancing Legal Frameworks for Pregnancy Loss").

Grief after pregnancy loss is influenced by various factors, including the circumstances of the pregnancy, the grieving parent's personality, their previous life experiences, and the level of support from their social network. Literature has identified specific groups of patients that may benefit from targeted early recognition and intervention strategies, particularly those experiencing repeated losses, infertility, or sterility (Cousineau & Domar 2007; Kolte et al., 2015; Nakano et al., 2013; Tavoli et al., 2018). Addressing the needs of these groups is crucial and should not be overshadowed by a clinical focus on gestational age, as is currently supported by the prevailing legal Italian framework.

Clinical and psychological management

Clinical handling of miscarriages and stillbirths reveals a disparity in the approach to early losses compared to later ones. Although guidelines present expectant management or medication as viable alternatives to surgery for early miscarriages, women in our study were primarily directed toward curettage. They reported not being fully informed about their options or the specific medical justifications for this recommendation. This lack of information leaves them questioning the necessity of the procedure and highlights a gap in communication and patient education. Conversely, in the case of stillbirths, there is a clear preference and encouragement from healthcare professionals for natural childbirth, suggesting a more progressive and evidence-based approach to managing later-term losses. This discrepancy underscores the need for a consistent and informed approach across all stages of pregnancy loss, ensuring that women are equipped with the necessary knowledge to make informed decisions about their care.

Although the need for follow-up and support after pregnancy loss is well-documented (Nikčević 2003; Geller et al., 2010), the availability of psychological support and interventions still varies across healthcare institutions. Previous research has identified gaps in the care provided post-pregnancy loss, highlighting women's dissatisfaction with the medical care they received (Koert et al., 2019). Although researcher keeps developing recommendations based on their findings, their implementation has not been fully successful. Indeed, the absence of standardized follow-up care in public health services reveals a significant gap in ongoing support for grieving parents. This inconsistency underscores the urgent need for improvements, advocating for an integrated care approach that includes routine follow-up and addresses both the clinical and psychological aspects of pregnancy loss.

Gender bias after miscarriage and stillbirth

A lack of support for men is noteworthy, with both healthcare workers and society yet to fully recognize a father's grief response. Research indicates that women tend to experience more negative emotional consequences such as depressive symptoms following a miscarriage compared to men (Huffman et al., 2015; Kong et al., 2010), but overall grief is common in both women and men after pregnancy loss (Kersting & Wagner, 2012). Similar dynamics are observed in lesbian couples, where Wojnar noted that biological mothers often grieve openly, while non-biological mothers tend to feel compelled to provide strong support for their partners (Wojnar, 2007). Disparity in grief can impact the dynamics between couples (Swanson et al., 2003) and it remains thus essential to involve men in the treatment and grief support process during and after a miscarriage, acknowledging the importance of addressing the emotional well-being of both partners. Our study indicates a significant shift, showing that fathers are now generally present during examinations, medical consultations, discussions, and stillbirth deliveries and many service providers are aware that they too are affected by grief reactions. Despite this progress, partners are often still primarily viewed as supporters rather than recipients of support, and specialized services for grieving fathers are notably lacking. Furthermore, the broader societal recognition of paternal grief following a pregnancy loss is still minimal, with persistent gender biases in legal and professional settings, which show no evidence of a shift in attitude toward male grief reactions.

Advancing Legal Frameworks for Pregnancy Loss

There are significant legal differences in the treatment of early pregnancy losses across various countries and regions. In Italy there have been several changes in

recent years: Since 2017, burial is also possible for fetuses under 20 weeks of gestation, but it appears only offered upon request of the parents, who are required to submit a burial application to the local health department within 24 hours after birth, along with a medical certificate stating the (assumed) weight and age of the fetus. Our data indicate that despite the existing law, not all parents are informed about this right. Also, evident gaps remain in the classification between miscarriage and stillbirth in Italy. A birth before 180 days of pregnancy is considered a miscarriage, while a birth after 28 weeks or 180 days is considered a stillbirth. However, 28 weeks does not correspond to 180 days, creating a legal gray area that allows medical personnel to make variable decisions, which in turn affect the rights afforded to parents. For instance, although burial rights are theoretically universal, the right to officially name the child is only granted in cases of stillbirth. Stillborn babies are registered at the local civil registry office, but the classification between the 25th and 28th weeks depends on medical assessment. In contrast, miscarriages do not allow for the registration of a child's name, unlike in neighboring Austria for instance.

The issue of burial practices for embryos and fetuses is highly complex and carries significant societal, political, and ethical implications because the public debate on pregnancy loss is often intertwined with the abortion debate (Mattalucci, 2022). Indeed, burial practices for miscarriages not only provide space for mourning but also lie at the heart of the debate surrounding reproductive rights and abortion laws. Burial practices can attribute specific symbolic meaning to embryonic or fetal tissue, which may conflict with women's rights to make their own reproductive decisions. Norms and regulations surrounding burial can influence personal and intimate decisions, subjecting them to public control and regulation, potentially limiting individual autonomy. Moreover, state promotion or regulation of certain burial practices may lead to the legal recognition of the fetus as a person, thereby bolstering arguments against abortion rights (Mattalucci, 2022). A study indicates that women have varying preferences regarding the disposal of fetal tissue depending on their circumstances: after the loss of a desired pregnancy, separating fetal tissue from other clinical waste for ceremonial disposal is favored, while after elective abortion, only separation from clinical waste is desired (Myers et al., 2015). In our cohort, comprised solely of parents who have experienced a wanted pregnancy loss, a clear desire for burial options was evident. Therefore, the burial options available since 2017 should be offered as a standard to all parents whose desired pregnancies are terminated spontaneously or due to a medical recommendation for intervention.

Building on these considerations, it can be observed that in Italy, a new law enacted in April 2024 continues to restrict women's access to abortion, based on the argument that an embryo only a few weeks old is considered a life worthy. On the other hand, however, after an early loss of a desired pregnancy it remains impossible for parents to register their child and thus give it the actual status of a "recognized individual". Paradoxically, while on one hand the abortion rights of unwanted pregnancies become more difficult, the involuntary termination of desired pregnancies continues to be treated as a medical case rather than a case of bereavement. This approach is reflected in the legal framework, which does not provide neither maternity protection nor bereavement leave following a miscarriage. Consequently, women are compelled to depend on physicians for medical certificates to obtain sick leave.

Globally, approaches to bereavement leave after a miscarriage vary. New Zealand pioneered in 2021 by introducing specific bereavement leave for miscarriage (Hodson & Jerram, 2023), which sparked an international discussion on the matter (Middlemiss et al., 2024). The establishment of such bereavement leave is acknowledged as a vital and empathetic public health initiative, offering both practical support and a symbolic recognition of the loss. This approach not only aids in alleviating workplace conflicts but also honors the significant emotional toll of the loss by categorizing the time off as bereavement leave rather than merely a medical absence, thus acknowledging the deep emotional impact of such losses.

In Italy, structured support following miscarriages is not legally mandated or financially supported. Our data reveal that while some hospitals may offer services, the availability of these supports is inconsistent across healthcare facilities. Contrasting this with Germany, for instance, where mothers are entitled to free midwifery support, Italy lacks standardized provisions. Our findings emphasize the critical need to expand and enhance postnatal care services after pregnancy losses, ensuring they are freely and readily accessible to all mothers, irrespective of the pregnancy's duration or their financial circumstances. Postnatal care by midwives is beneficial because midwifery may be perceived as less stigmatizing than psychological support, potentially leading to greater acceptance. Additionally, this care is crucial for potential mental and physical health benefits in future pregnancies. Overall, the evolving legal frameworks reflect

advancements in addressing the needs of grieving parents but also highlight the persistent challenges that need attention, such as bereavement and maternity leaves following a loss.

Implications for future research and practice

Although a substantial amount of research has been conducted on the impacts of pregnancy loss, bridging the gap between theoretical knowledge and its practical application continues to pose significant challenges. Recent advancements, such as allowing parents to see their child and create tangible memories through photographs, have been successfully integrated into clinical practices. However, the adoption of these practices is inconsistent and often slow to spread across all healthcare settings. This delay in implementing scientific findings into clinical routines and in shifting societal perspectives on sensitive issues like pregnancy loss stems from several factors. For instance, it often takes time for the medical community to adopt new protocols and integrate them into existing systems. Additionally, many clinical settings may lack the necessary resources or infrastructure to implement new practices effectively.

Thus, there is still considerable work to be done to incorporate existing evidence and recommendations routinely, particularly concerning early losses, the roles of fathers and female partners, and the presentation of all medical options in a non-biased manner. It is also essential to ensure that affected parents are fully informed about their rights and the options available to them following their losses. Overall, while the clinical setting is making efforts to adapt, the need for a more cohesive and comprehensive approach remains evident. This would not only streamline the integration of new insights into practice but also help in sensitizing society to the complexities of pregnancy loss, fostering a more supportive environment for affected families.

Our study highlights the urgent need for continual updates and the broader implementation of existing evidence and recommendations into clinical settings. Parallelly, there is a critical need to enhance societal discourse through improved education, increased awareness, and a deeper understanding of the different contexts of pregnancy loss. Furthermore, the way pregnancy loss is discussed and managed varies widely across different regions, underscoring the necessity for more research to understand these variations and to address the specific gaps in care and knowledge. This research is essential to fostering a more informed and supportive environment for all affected by pregnancy loss.

Strengths and limitations of the study

One of the strengths of this study is the use of qualitative methods, which allows for a nuanced exploration of the personal experiences and perceptions of both parents and healthcare professionals. The snowball sampling technique facilitated access to a population that might otherwise be difficult to reach due to the sensitive nature of the subject. Additionally, the study's focus on integrating research into practical applications addresses a significant gap in current healthcare practices.

However, the study has also limitation. The experiences captured may not represent the diversity of experiences across different cultures and socioeconomic background. Snowball sampling, while useful for accessing specific populations, carries several limitations that can impact research outcomes. Its reliance on participant networks introduces potential biases, including selection bias and the overrepresentation of certain groups, limiting the diversity and representativeness of the sample. Additionally, the retrospective nature of the interviews may be subject to recall bias, and the study relies on self-reported data, which may not capture all dimensions of the experience.

Conclusions

Our study illuminates the complex interplay between individual experiences, institutional practices, and societal norms surrounding pregnancy loss. It highlights progress in the empathetic handling of miscarriages and stillbirths over recent decades. Former practices often invisibilized these losses; current approaches strive to acknowledge and honor the grieving process. However, evident gaps remain in fully addressing the needs of parents experiencing pregnancy loss.

In the broader societal discourse, progress has been minimal. Despite longstanding awareness, public conversations about early pregnancy losses have seen little change. This stagnation is evident in both legal frameworks and the general lack of health literacy concerning pregnancy loss. Also, public debates often inadequately differentiate between the loss of a wanted pregnancy and other reproductive issues. This early loss, which occurs before the embryo or fetus is widely recognized as having human status and takes

place invisibly within a woman's body, is frequently and inappropriately politicized in debates over abortion rights.

Overall, the transfer of theoretical knowledge to practical implementation demonstrates a clear trend toward improved care and understanding, yet it has not been fully successful. Continued efforts are essential to enhance health literacy and ensure equitable, informed clinical care. Moreover, providing comprehensive psychological support and developing legal frameworks that recognize all forms of pregnancy loss is crucial. Addressing these issues is key to creating a more compassionate and supportive environment for all affected by pregnancy losses.

Acknowledgements

The authors would like to thank the parents who participated in the interviews. We would also like to extend our heartfelt thanks to Dr. Sonia Prader for her invaluable support in this field. Her expertise and commitment to raising awareness of this sensitive topic have been essential. Thanks to dedicated professionals like her, the support for grieving parents continues to improve, and the taboo surrounding early loss is being broken.

Ethical approval and informed consent process

Ethical approval for the study was obtained from the Institutional Review Board (IRB) where the primary investigators were affiliated (Institute of General Practice and Public Health, Claudiana), ensuring compliance with ethical standards for research involving human subjects. Prior to data collection, an informed consent protocol was developed and piloted with a small group of volunteers to refine the explanations of study aims, processes, and participant rights, ensuring that potential participants could make fully informed decisions. Each participant received a detailed consent form outlining the nature of the study, their rights as participants, including the right to withdraw at any time, and measures taken to protect their privacy and data security. Consent forms were verbally explained by the researchers, and participants were encouraged to ask questions to clarify any uncertainties before signing.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

The author(s) reported there is no funding associated with the work featured in this article.

Data availability statement

Requests for data should be directed to the corresponding author.

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Appendix A: Interview topic guide

Interview guide for parents:

1. **Introduction**: Can you describe your experience with pregnancy loss?

2. **Emotional Impact:**
- Could you share your initial thoughts and feelings when you first learned about your pregnancy loss?
- Can you describe how your feelings evolved in the weeks and months following the loss?

3. **Support Systems:**
- What type of emotional and practical support did you receive from healthcare providers after your loss?
- Were there any support groups or community resources that you found helpful?

4. **Medical Interaction:**
- How would you describe your interactions with medical staff during and after the loss?
- Could you specify any particular interactions with medical staff that were particularly helpful or problematic?

5. **Societal Response**:
- How did your friends, family, and wider community react to your loss?
- Can you provide specific examples of how society's response affected you and what changes would you like to see?

6. **Information and Resources**:
- Were you provided with enough information (e.g. about the loss, medical procedures, subsequent pregnancies)?
- What essential information do you feel was missing or inadequately covered during your experience?

Interview guide for experts:

1. **Professional Background:**
- Can you describe your role and experience in dealing with pregnancy loss?

2. **Observations on Emotional Impact:**
- From your professional experience, can you identify any common patterns in how emotional impacts vary among parents experiencing pregnancy loss?

3. **Effectiveness of Support Systems:**
- How effective are the current support systems available for parents experiencing pregnancy loss?
- What gaps have you observed in the support provided to these parents?

4. **Medical and Healthcare Practices:**
- How have medical practices evolved in recent years to better address the different aspects of pregnancy loss? What improvements have you noticed?

5. **Legal and Policy Considerations:**
- How do the current laws and policies support parents dealing with pregnancy loss? What are the most significant gaps in these laws and policies?