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Family care in the context of perinatal loss: perceptions of bereaved mothers

Cuidado às famílias no contexto das perdas perinatais: percepções das mães enlutadas

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Abstract

Objective: To develop a theoretical–practical quality care framework for families experiencing perinatal loss, grounded in international guidelines and maternal experience reports. Method: This study derives from the doctoral research "*Gestação Subsequente à Perda Perinatal: Análise dos resultados de um Programa de Pré-Natal Psicológico*" (Pregnancy Following Perinatal Loss: Analysis of the Outcomes of a Psychological Prenatal Care Program), conducted between 2022 and 2023. It included 15 pregnant women, from the 12th week of gestation onward, with an obstetric history of stillbirth. A qualitative method was employed, using open interviews based on the "life history" approach and content analysis to categorize meaningful expressions, drawing an analogy with the Six 'R' Processes of Mourning classification model: Recognizing the loss; Reacting to the separation; Recollecting the loss; Relinquishing the maternal role; Readjusting to the new situation; Reinvesting/Resignifying. Results: The analysis yielded the following categories, recommended for the theoretical–practical framework of care in the context of perinatal loss: Supportive reception and respectful attitude; Clear and comprehensible communication with informed choice; Individualized care adapted to personal needs; Best practices of care across different contexts; Ongoing care and support and Qualification of care. Conclusion: The themes that emerged provide guidance for the implementation of clinical guidelines and practices focused on individualized care, with the

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potential to positively impact the experiences of women and families following perinatal loss. It is concluded that two challenges are particularly relevant in this context: the qualification of care and the provision of sufficient emotional support to health professionals.

Keywords: Bereavement; Humanization of assistance; Mental health; Stillbirth.

Resumo

Objetivo: Desenvolver um referencial teórico-prático para o cuidado de qualidade às famílias na situação de perda perinatal fundamentado em diretrizes internacionais e nos relatos das experiências maternas. Método: Derivado da pesquisa de doutorado "Gestação Subsequente à Perda Perinatal: Análise dos resultados de um Programa de Pré-Natal Psicológico", realizada no período de 2022 a 2023. O presente estudo, incluiu 15 mulheres, gestantes, a partir da 12ª semana de gestação, com histórico obstétrico de natimorto. Utilizou-se o método qualitativo com entrevista aberta utilizando a "história de vida" e a análise de conteúdo para a categorização das expressões significativas por analogia ao modelo da Classificação dos Seis Processos 'R' de luto: Reconhecer a perda; Reagir à separação; Rememorar a perda; Renunciar à maternidade; Reajustar-se à nova situação; Reinvestir/Ressignificar. Resultados: derivou-se da análise as seguintes categorias recomendadas para o referencial teórico-prático do cuidado no contexto da perda perinatal: Acolhimento e atitude respeitosa; Comunicação clara e compreensível com escolha informada; Atendimento individualizado e adaptado às necessidades pessoais; Boas Práticas de atenção nos diferentes contextos; Cuidado e apoio contínuo e Qualificação do Cuidado. Conclusão: Os temas que surgiram oferecem orientação para implementar diretrizes e práticas clínicas com foco no cuidado individualizado podendo ter impacto positivo nas experiências das mulheres e famílias após perdas perinatais. Conclui-se que é relevante ressaltar dois desafios neste contexto: a qualificação do cuidado e o suporte emocional suficiente aos profissionais de saúde.

***Palavras-chave**: Luto materno; Humanização da assistência; Saúde mental; Natimorto.*

For every woman, experiencing pregnancy constitutes a special moment, often representing the realization of a life goal. When the baby is lost, there is an abrupt break in expectations, and the impact can be devastating and persistent in the parents' lives, leaving deep and traumatic scars (Amthauer, 2017).

The loss of a child in the perinatal period has lasting psychological, physical, and social impacts that must be addressed, not only through the prevention of these deaths but also by improving care for bereaved families. This loss is associated with a range of negative psychological symptoms and is a significant risk factor for depression, anxiety, and symptoms of post-traumatic stress disorder (PTSD) (Shakespeare et al., 2019).

According to the report of the United Nations International Children's Emergency Fund (UNICEF, 2020), there were approximately 2 million stillbirths worldwide in 2019. The numbers alone make the issue a global priority, considering its social and economic consequences, such as family crises, occupational difficulties, and the high costs of healthcare (UNICEF, 2020).

Bereaved parents have been identified as a high-risk group for complicated grief, with up to 25% experiencing severe symptoms years after the baby's death (Ellis et al., 2016). In addition, around 50% of women become pregnant within a year of the loss; therefore, negative psychological effects may be prevalent in subsequent pregnancies and in parenting (Mills et al., 2022).

Conversely, the global health agenda remains silent on fetal loss, perhaps in part because the broader impact has not been systematically analyzed or understood, resulting in the absence of public policies aimed at its prevention (Ellis et al., 2016).

The World Health Organization included a clear roadmap for eradicating preventable neonatal deaths and stillbirths by establishing standards of quality care and recording births and deaths in the Every Newborn Action Plan (ENAP). However, the first stillbirth report – A Neglected

Tragedy: The Global Burden of Stillbirths – concluded that many countries will not reach the ENAP target by 2030 unless additional efforts are made (UNICEF, 2020).

In 2019, the campaign Why We Need to Talk About Losing a Baby was launched, with the aim of making miscarriage, stillbirth, and neonatal death visible worldwide, as well as to highlight the need for better practices and qualified professional healthcare (World Health Organization [WHO], 2019).

Other relevant international guidelines have also emphasized the importance of improving healthcare professionals' preparedness to provide effective perinatal bereavement care (Boyle et al., 2020; Qian et al., 2022; Schott et al., 2016).

In Brazil, some important publications on guidelines for care in cases of perinatal loss have been produced (Salgado & Polido, 2018; Salgado et al., 2021). However, it is important to highlight research on complicated grief, which evidenced a prevalence of 35% among Brazilian mothers compared with 12% among mothers living in countries with bereavement support services – a culture still incipient in Brazil (Paris et al., 2022).

In view of the identified gaps, it was deemed timely to identify possible contributions to the understanding of the phenomenon under study in its complexity and subjectivity, with the aim of developing a theoretical–practical framework for quality care for families experiencing perinatal loss, grounded in international guidelines and maternal experience reports.

Method

This study employed a qualitative, exploratory, and descriptive method. To explore the subject and guide the understanding of the phenomenon's complexity, the "life history" approach (Minayo, 2010) was used as a methodological strategy. Derived from the doctoral research "Pregnancy Following Perinatal Loss: Analysis of the Results of a Psychological Prenatal Program", conducted between 2022 and 2023, this mixed-methods study, carried out in two phases, combined quantitative and qualitative approaches to achieve a more comprehensive understanding of the phenomenon under study (Creswell & Clark, 2013). It was characterized by consecutive sampling – recruiting the entire accessible population within the defined timeframe and according to the study's inclusion criteria (Cummings et al., 2015).

The study followed the required ethical procedures: informed consent was obtained through the signing of the Informed Consent Form (ICF), with prior clarifications provided before the start of the study; each participant received a copy of the ICF containing information about the study, as well as the team's contact details and e-mails; the collected data were stored and used exclusively for research purposes. The study did not pose any significant risks to participants.

The research commenced following approval by the *Comitê de Ética em Pesquisa* (CEP, Research Ethics Committee)/*Comissão Nacional de Ética em Pesquisa* (CONEP, National Research Ethics Commission), via the *Plataforma Brasil* database, under Opinion No. 4.492.386.

Participants

For this study, 15 women were included who met the eligibility criteria: pregnant women from the 12th week of gestation onward, with a history of stillbirth occurring from the 22nd week of gestation. The women were between 25 and 39 years of age and came from different Brazilian municipalities. Of these, 93.3% (14) had completed higher education, 60% (9) had no living children,

and they were between five and 45 months past the loss. Subsequently, all mothers gave birth to a living baby and were in a stable relationship with the baby's father.

Instruments

Open or in-depth interviews were conducted without a structured script, with the formulation of only one guiding question, according to the scope of the present study: perception of the care received following the baby's loss (Minayo, 2010). This type of approach is considered ethical and culturally appropriate for this population, as it respects participants' freedom to express their experiences.

Procedures

To increase the sample, participants were recruited with the aid of community organizations that provide support to bereaved parents in the municipalities of Porto Alegre (RS) and Fortaleza (CE), which contributed significantly by disseminating the research through their social media.

Four groups were held, with six to eight pregnant women in each group. The interviews lasted two hours and were conducted by the first author, a psychologist with experience working with pregnant women.

Concerning ethical procedures for interview confidentiality, participants were identified as 'G1, G2...' in the order in which their accounts were presented. The interviews were audio-recorded with participants' consent and were subsequently fully transcribed for analysis. To ensure nationwide reach and provide participants with security, the study was carried out virtually using the Google Meet platform.

Data Handling and Analysis

Content analysis was employed as the data treatment technique, considering its "objective characteristic, so that the content is integrated into the categories chosen, according to the previously established objectives and goals" (Minayo, 2010, p. 308). The analysis consisted of the following phases:

I) Pre-analysis: reading, analysis of the transcripts, and selection of accounts according to the objectives of this study.

II) Analysis: development of impressions, orientations, and directions using Rando's Classification (2012) from the perspective of the Six 'R' Processes of Mourning: 1) Recognizing the loss; 2) Reacting to the separation; 3) Recollecting the loss; 4) Relinquishing the maternal role; 5) Readjusting to the new situation; 6) Reinvesting/Resignifying.

III) Interpretation: categorization of significant expressions by similarity and analogy to the model, considering the evidence that emerged for other subcategories, which in the second stage of analysis contributed to the elaboration of the theoretical–practical framework for quality care in the context of perinatal loss.

The analysis was refined and finalized in meetings between the authors, with discussions and regrouping of the factors analyzed, until full consensus was reached and the results of the significant expressions were described. To ensure methodological rigor and credibility, procedures recommended for the publication of qualitative research in psychology were followed.

The development of the proposal is also grounded in the Canadian Guidelines for Health Care Professionals Supporting Families Experiencing a Perinatal Loss (Canadian Pedriatic Society, 2001) and the British Pregnancy Loss and the Death of a Baby: Guidelines for Professionals (Schott et al., 2016).

Results and Discussion

The results from the first stage of the analysis are presented below, organized into six categories of significant expressions based on similarity and analogy, according to Rando's Six 'R' Processes of Mourning model (Rando, 2012). From these, the categories for the theoretical–practical framework recommended for quality care in the context of perinatal loss were defined.

Analysis of Rando's Six 'R' Processes of Mourning model (Rando, 2012)

Regarding the analysis of the first 'R,' "Recognizing the Loss," a growing body of evidence suggests that, although the impacts of perinatal loss may be as significant as any other loss, the grief from such loss may not be legitimized by healthcare professionals, family, or society. There is an effort to minimize and deny the existing pain. As a result, parents perceive that their baby is seen as replaceable, culturally highlighting the impossibility of acknowledging the baby's death as equivalent to losing a child (Ignácio & Medeiros, 2023; Persson et al., 2023).

> I get angry at people who say, '*don't worry about it, there are people going through worse*'. I believe everyone has their own pain threshold. It's not fair to weigh your pain against someone else's. Everyone knows their own limit to bear. What may be very painful for me may not be at all for someone else, and vice versa. When B. passed away, I felt this way: yes, worse things may exist, losing a child is painful, but losing two is much worse. (G1)

The lack of recognition and support intensifies suffering, and parents experience strong feelings of isolation and disconnection from their social environment (Farrales et al., 2020; Shakespeare et al., 2019), as reinforced by the following accounts:

> (...) Throughout this process, I felt very alone; it seemed that no one understood my pain. Everything people said just made me more irritated – it didn't help, it only made things worse: '*God did what was best', 'After the storm comes the calm', 'You'll get pregnant again soon*'. I even struggle with this term "rainbow baby", because for me, M. will never replace L. It seems like they're always trying to fill the void that someone else left. (G2)

> (...) Not everyone understands the insecurity of a mother who has experienced a loss, and how that fear affects you – it's very complicated. They said, '*You're young; you'll want another baby later*'. (G3)

The second "R" refers to "Reacting to the separation". Given that the maternal role is socially considered a full realization of femininity, women who give birth to a stillborn may question their competence to bear a healthy child, which is perceived as a blow to self-esteem and maternal capacity (Laguna et al., 2021). It is understood that the death of a child goes beyond the loss of an individual and becomes the death of the "we", of all expectations and dreams (Assis et al., 2019). The following accounts illustrate feelings of emptiness and powerlessness, identified by Iaconelli (2007) as a "narcissistic wound", since the loss of the baby evokes the sensation of losing a part of oneself:

> I lost a daughter who was inside me (...) I had a bond with my daughter. She was already moving, responding to me; I would sing to her. There is no greater bond than a baby in your womb. It is a part of

> you. A part of me died with her – a piece of me, an extension of myself. You don't feel this with another human being, only with a son. The feeling that a piece of you has died only happens with a son. (G4)

> (...) During that period, I would say that it wasn't F. who had died. Because F. remained alive in my words, in my love for her, in the dreams I had built for her. The feeling I had was that it was me who had died, not her. It didn't make sense to say that the child was dead – it was her mother who had died. What had died was everything I had dreamed of. (G5)

The third "R" refers to "Recollecting the loss." Persson et al. (2023) categorize "personification" as the parents' need to know their baby as if they were alive, in order to honor them as a family member. It is also a respectful approach in which parents are validated in their grief and recognized as parents, even if their baby was stillborn.

Regardless of the size or condition of the baby, creating memories in accordance with the parents' wishes represents a construction of affection from the pain and can facilitate the grieving process (Persson et al., 2023). The following accounts illustrate the importance of spending time with the baby and creating meaningful memories:

> The moment she came into my arms, I sang to my daughter, I caressed her, I observed every detail of her body. Then my husband came in and held our daughter in his arms, and we had the opportunity to say goodbye. (G5)

> Everything that happened, I always tried to approach with love. I chose an outfit for him, made a little teddy bear. We chose a place to keep his ashes where we had dreamed of taking him to play – a very beautiful place. I will always have good memories of him. I respected my own moments, even regarding his clothes, I waited for the right time to open them and donate them to some people. Everything was difficult, but we took it one step at a time. (G6)

Society's attempt to avoid contact with psychological pain – through denial of reality, by removing the baby's belongings and objects from the environment – frames grief over the baby's death as taboo and unacceptable (Persson et al., 2023).

> (...) When I came home from the maternity hospital without my baby, I was very upset because they had dismantled the crib, hidden his things, and I wanted to see his things in their place. (G1)

It is important that the care team remain attentive and sensitive, respecting each family's individual wishes regarding farewell rituals, whether they want to see or hold the baby, hold funerary rites, or decide the fate of the baby's belongings (Pollock et al., 2020). Each woman experiences the loss uniquely, influenced by her available support network, life history, beliefs, and how the loss unfolded (Teodózio et al., 2020). The following account reflects a mother's wish not to see her baby, which was negotiated with the care team before birth:

> (...) I had arranged with her (the doctor) that I didn't want to see him right after he was born; I wanted them to take him so I could orient myself and then bring him already wrapped (...). So, I turned my back so I wouldn't see him. That was what I wanted at the time; that was what I could handle. (G7)

With professional guidance and family support, it is evident that the mother can gradually engage with reality, as painful as it may be. However, the study found that the need for a sensitive approach can still cause discomfort among healthcare professionals, as illustrated in the following account:

> (...) So, I still had to deal with these conflicts – wanting to see my daughter again, but thinking, 'Which daughter are they going to give me? When a mother loses a child, how long is she allowed to stay with her?' I spent so much time with my daughter in my womb; how much time could I have with

> her in that delivery room? It would have been so good to have more time (...) I think they weren't prepared. I had the impression that my request caused a bit of discomfort: 'What do you mean you want to see your dead daughter?' I think it created some unease. (G5)

"Relinquishing the maternal role" is the fourth 'R'. During pregnancy, a woman invests in a process of constructing representations of her child through idealization of the baby and of her relationship with them. When the loss is confirmed, this entire construction is interrupted, commonly resulting in difficulty accepting the fact, denial, and suffering for both the woman and her family. On the other hand, a woman's reaction to the loss is associated with the emotional significance she attributes to it and depends on the emotional investment she made during her pregnancy (Muza et al., 2013).

A lack of self-recognition is another crucial issue identified in this study. There is an experience of depersonalization, of not recognizing oneself, of a dilution of the woman's identity (Faria-Schützer et al., 2014).

> (...) to this day I still feel somewhat lost; sometimes I think I've lost my identity and I don't know who I am anymore (...). I couldn't accept not being a mother; I want to be a mother. Only after going through this experience of seeing myself with a baby will I see myself beyond being a mother. (G1)

> When I looked at myself, everything reminded me of the baby; I would look in the mirror and see the baby. There was a moment when I wanted to nullify my body because of this. It was truly a process of depression. There was another thing too: my hair grows a lot during pregnancy. It felt like that hair wasn't mine; it was A.'s (angel baby) hair. I had to leave it there because it was the only thing that reminded me of her. One day, in a moment of despair, I cut it all off. As if I were tired, you know? Like, 'I don't want to live this anymore; this hurts me, I don't want it.' So that's what I felt – the issue with breastfeeding, the issue with my body, all of it. It was a very difficult process. After that, I began to process things differently. (G8)

"Readjusting to the new situation" is the fifth 'R' in the analysis. Bereaved parents experience conflicting and paradoxical emotions, which require behaviors they never planned or imagined, in order to develop new meanings and representations of the baby they dreamed of but who is now lost. Grieving the loss of a baby disrupts familiar behavioral references and demands intense psychological work and time for its elaboration (Casellato, 2020).

The following account illustrates the experience of a bereaved mother who held a positive view of childbirth from her own experience and her work as a doula. However, it was a challenge "to surrender oneself and enjoy" a birth that "involved death rather than a life-affirming emotion".

> I didn't want to surrender during the birth (...). I'm a doula, an activist for humanized birth. Despite the pain, childbirth is an experience that brings me something very positive; it is extremely important to me, and at that moment it didn't make sense to surrender. If I were surrendering, it would feel as if I were enjoying the birth in some way. I knew that wouldn't happen; it would be a very different emotion. It wasn't an emotion of life – it involved death... The pain became very intense because, in addition to the oxytocin, there was the pain of the whole experience. I knew I needed to move my body, to sway, and I didn't want to do that either; I couldn't fully surrender to the birth. So, I said to call the anesthesiologist because, 'for me, I'd had enough. The anesthesiologist came, I remained quiet, still, and he came by himself... I was very afraid of that moment, of seeing him dead. (G7)

A stillbirth demands a great deal of energy from the mother, as in addition to physical pain, there is emotional pain. The mother cannot count on the baby's help during the birthing process, and after birth, there is no comfort in holding the baby alive in her arms, which could otherwise help mitigate the physical pain of labor (Teodózio et al., 2020).

> (...) It was very painful, physically and emotionally. Physically, it was very strange, I can't put it into words. I had no strength; my body was very fragile. I had to push by myself because she had no life, so I just wanted it to be over quickly. (G2)

The sixth and final 'R' is "Reinvesting/Resignifying". Successful mourning begins with a reality check: the acknowledgment that a loss has occurred. It is through this acknowledgment that one can become aware that the lost baby no longer exists and, consequently, all vital energy must be detached from the bonds with this object (Teodózio et al., 2020).

The study showed that some participants resignify the death of the baby through resources for the psychic elaboration of this experience, highlighting the subjectivity of this process.

> (...) We had decided to plant a tree with his ashes. I cared for the tree, watched the sprouts, took pictures, saw how the flowers developed – it was really nice to observe and take care of the tree. I couldn't care for him, so I am caring for it. This process is very cool; it brought me a bit of peace. (G7)

> After losing a child, you begin to see life through different lenses. You come to know what pain is, what a problem really is, what despair feels like – what it means to fall into a hole and remain there for years. It is difficult for people to understand. They think you no longer go to the same places because you are depressed, or because you haven't processed your story. And sometimes, it's simply progress. I want to talk about deeper things. I want to be alongside people who knew how to embrace me – with zero judgment, with no one assuming I don't take care of myself, or that I am not giving myself the attention I should. In the end, the hardest part is people thinking everything comes down to depression. (G9)

> I usually like to joke around and say that I kissed madness on the lips –I came face to face with it. What kept me from reaching that point, despite the anger, was God. I formed a very strong bond with this child of mine; there's nothing that explains this mystery that is carrying a child and developing this love. It was a love I had never known before him. M. (my angel baby) taught me motherhood, and I developed a new relationship with God. The same God who took him from me, who allowed this to happen, was also the one who gave me that child and that inexplicable love. Today, having a relationship of deep faith in God is the only thing I hold on to in this pregnancy. (G10)

Construction of the Theoretical–Practical Framework for Quality Care in the context of Perinatal Loss

For the construction of the proposal, the following significant categories were included: 1) Supportive reception and respectful attitude; 2) Clear and comprehensible communication with informed choice; 3) Individualized care adapted to personal needs; 4) Best practices of care across different contexts; 5) Ongoing care and support; and 6) Qualification of care.

1) Supportive reception and respectful attitude

Support from caregivers and respectful guidance from the moment the baby's death is diagnosed are essential for parents, who find themselves in unimaginable chaos (Persson et al., 2023). However, the present study identified negative experiences related to clinical care, and instances of disrespectful treatment:

> (...) The doctor just up and left the room – didn't even say goodbye. He did the ultrasound and walked out, while I was there nervous, crying, worried, and traumatized. For me, it was awful. I understand that he does many ultrasounds, but it was me who was there – a person, an extremely worried mother – and there was no care at all, zero care. And on top of that, I was left alone. (G7)

> (...) How was I supposed to feel in that moment? During the induction, they didn't take care to inform the people coming into the delivery room that my baby was not alive. Many of them said things like: 'Mommy, be happy, soon your baby will be in your arms'. I was like a crazy person, screaming, in pain. Several doctors examined me – every four hours a different doctor did a vaginal exam. It was unbearable! (G3)

These interactions often demonstrated coldness and disregard for the negative emotions triggered by the experience. In the account below, the mother points out that "very few professionals are truly prepared to deal with this and know how to talk to the patient, which is the most important thing" (G2).

> (...) On Sunday night, a doctor came in, and we were very shaken by his attitude. He compared my loss to something that just happens in life. He said his wife lost one of their babies and they don't even remember it anymore. He spoke as if I had already lost her, and yet I still had hope.... (G2)

Studies reinforce that healthcare teams often lack the skills to deal with parents' suffering and distance themselves emotionally, as they feel unprepared and powerless in the face of the situation (Ignácio & Medeiros, 2023; Pollock et al., 2020). The following account reveals the stigma surrounding the experience of losing a baby, compounded by multiple additional losses, while also highlighting the profound sense of loneliness and vulnerability in such circumstances. According to the participant, the experience of neglect, lack of care, and absence of information about her rights worsened her situation:

> (...) I will never forget this; it was very traumatic for me. We went in for a C-section, and the only person who showed empathy toward me in that operating room was the anesthesiologist. My husband asked if he could come in, and the doctor said: 'No, you don't need to go through this.' And so, I was left alone in the operating room. They cleaned him, put a little cap on him, wrapped him in a blanket. The nurse showed him to me, and I had about 30 seconds – so little time. All I could do was look because I was strapped down. He was so pale, with red lips, as if he were sleeping. He was perfect. I didn't touch him, I didn't hold him, no one guided me. They took him to my husband, but again no one told him he could hold the baby, no one placed our son in our arms. When I started to recover from the anesthesia, I said: *'I really want to see my son, I had so little time with him, is there any way to bring him?'* She said it wasn't possible, because the "bag" had already been sealed, and my son was going to autopsy. I had no choice but to agree. It is very difficult – what I went through in terms of neglect and lack of care, made my situation much worse. On top of grief, I felt utterly abandoned. I suffered for a very long time. It's true he died, but couldn't I at least have kissed him? What if I had smelled his scent? (G10)

Their identities are confronted, and feelings of shame and guilt are common (Pollock et al., 2020). In this context, guilt is generally associated with the psychological need to make sense of the causes of the event, given that the psyche becomes even more fragile when faced with the "obscure mental labyrinth" (Faria-Schützer et al., 2014). Some mothers reported experiences in which the healthcare team reinforced their sense of guilt, blaming them for the loss of the baby.

> The doctor went to check for a heartbeat and couldn't find it, then went on to do an ultrasound. There was total silence, and I could already sense it: 'That's it, H. isn't here anymore'. I started screaming, I called my godmother, and she ran to hold me. The nurse technician said: 'When we feel something, we should go straight to the hospital'. But how could I, if I wasn't having contractions, wasn't losing fluid? She wanted to put the blame on me – that my baby had died because I didn't go to the doctor right away. But I know it wasn't my fault. (G11)

> (...) It was very intense. We tried to have an autopsy done to find out what was happening, but they said that, because of the pandemic, it could not be carried out. By then, the pandemic was already over, yet they still refused to analyze what had happened to her. There was no report, and we were

> left not knowing what had happened. One moment everything was fine – perfect – she was growing; and then, out of nowhere... It was very hard for me to go through labor knowing my daughter would not be alive – my first daughter. I wasn't prepared, I didn't know what it was going to be like. I had to undergo a curettage unnecessarily, and I was left with sequelae. I didn't even know what the best method was; I just did whatever they told me to do. I don't know how the sequence of events unfolded – it was traumatic, and to this day I'm still trying to process what happened. (G3)

These poor practices reflect an attempt by professionals to avoid engaging with suffering – in other words, they mirror the difficulties faced by the team in providing appropriate care, which in turn triggers profound psychological distress (Persson et al., 2023). One participant reported successive experiences of disrespect and deprivation of rights during the stillbirth of her baby:

> (...) When I arrived, they put me in a room they called the "pre-labor" room and simply left me there, abandoned. They didn't allow a companion in, and no one from the hospital staff stayed with me. I stayed there, my pain getting stronger, pacing back and forth, doing whatever was within my reach, because I wanted my son to be born in the best way possible. I had no medication, no monitoring, nothing. I had to remain still, in pain, alone, with no one to support me (...). (G12)

She also reported verbal and physical aggression – experiences that clearly constitute obstetric violence:

> (...) at a certain point, they came and said: 'Get up and grab the baby's clothes, we're going to the other room.' I couldn't take it anymore, I had no strength left. I said: 'I won't be able to get up'. She said: 'Yes, you will'. I picked up the bag and walked to the other room. When I got there, I still had to climb onto the bed without help, lie down, and assume the position. The whole time, they kept saying: 'That's not pushing. If you keep this up, your son won't be born'. It was psychological torture. I remember closing my legs a little, and she just hit my leg. Before his little head came out, I kept feeling her touch my genitals, saying: 'His head is right here, but with this kind of pushing, he won't be born'. That's when I gave that final push, and he came out – but I didn't hear him cry. She threw him on top of me and said: 'Breathe to give him oxygen'. Soon after, she took him back and dropped him on a nearby table. I immediately panicked, while they tried to resuscitate him. One of them ran to call the doctor. When he arrived, he tried, but there was nothing more to do. He just looked at me, shook his head, and said: 'I'm sorry'. Then one of them looked at me and said: 'See what you did?' She said it was my fault, because I didn't cooperate. I don't have memories – I only have trauma from his birth. (G12).

Thus, we see a mother seeking recognition for the loss of a beloved child, while those around her fail to understand or to act with sensitivity toward her suffering. The mother feels doubly abandoned – by her baby and by her surroundings. There is no way to inscribe this loss in the psyche, as it is systematically invalidated by others (Iaconelli, 2007).

2) Clear and comprehensible communication with informed choice

It is essential to ensure clear and comprehensible communication with parents and among the different health professionals. This includes: attentive and qualified listening; recording preferences and decisions so that the mother is not forced to repeat her situation; and the use of inclusive and adapted language, avoiding technical terms or, when they are used, explaining them clearly.

Delivering a negative diagnosis in a sensitive manner may not lessen the parents' pain, but it can affect the way they perceive the team's care, directly influencing how grief will be experienced (Setubal et al., 2018). The following account illustrates the experience of receiving bad news in a

sensitive and compassionate way. The professional acknowledged and validated the suffering caused by the child's death and provided dignified and respectful care:

> (...) At that moment, I was speechless. I looked at my husband, he lowered his head and began to cry. I just stood still, unable to say a word. The doctor was very attentive to me; in the middle of the pandemic, when everyone was so afraid, he gave me a glass of water and hugged me. He told me to wait for the test results in the room, so no one would see me crying outside. (G1)

3) Individualized care adapted to personal needs

The healthcare team can show sensitivity and empathy, acknowledge how parents feel, provide clear information, and understand that parents may need specific support to cope with their loss. Providing human rights – based care that is relevant, respectful, and dignified is a requirement for competent maternal and neonatal care (WHO, 2019).

In the following case, after the diagnosis of her baby's death, the participant recounts her experience of choosing the type of delivery together with her obstetrician, who provided all the necessary information, enabling an informed decision that took into account both clinical aspects and her own wishes:

> (...) After the ultrasound, the doctor said she didn't see any reason to perform a cesarean section. She said: 'You can wait; there's no risk for you. Induction will also be difficult – you'll be nervous, and you're not well.' For me, his passing was so overwhelming that I just wanted to go home and wait for him to be born. That was the feeling I had. And the doctor said: 'Go home and think it over, and after a week, we'll do exams to make sure it's safe for you to keep him in your womb'. For me, that was very good. Many people are baffled when I say I went home with my dead son still inside me. But for me, he was my son, you know? (G7).

There can be positive effects on parents' emotional well-being when they have confidence in the healthcare team and feel supported in the decision-making process after the baby's death (Redshaw et al., 2014).

4) Best practices of care across different contexts

Care plans should be formulated in consultation with the parents so that the support provided is based on individualized and holistic care – care that acknowledges the nuances of each family, recognizes their culture, and responds sensitively to their diverse preferences (Qian et al., 2022). The following account highlights the importance of humanized and ethical care in childbirth, not only for a live birth but also for a stillbirth:

> (...) They were very careful with us. The labor lasted two and a half hours. The pain grew very strong, I was exhausted. I stayed in the shower for a long time and the pain wouldn't pass. I usually say that I turned into a wild animal, because I took off my clothes – and I had always been very shy about undressing. I didn't care anymore. My hair was wild, like a lion. They respected the position I wanted for the birth. When she was born, all I felt was the relief of her being born, of the pain ending. I wasn't reasoning about what was happening. In the first five minutes, I wasn't really understanding what was going on. R. (my husband) began crying a lot because he still had the expectation that she might be alive. I was completely out of it. They did the entire process in front of us – measuring, weighing, called the hospital photographer, asked us to play whatever playlist we wanted, and let us spend as much time as we wished with her. I can't say exactly how long I was there for, but I held her in my arms for a long time. I examined every detail, her little legs, her little arms – I remember the feeling of touching her; it was something very important to me. She was fully formed. Despite everything,

> it was beautiful being able to experience this, being able to feel, to be with her, to sense her scent, to cradle her – even though she wasn't completely there, it's an incredible thing our minds can do, to cradle. It made all the difference for me to have that moment with her. It was a very difficult time, but at the same time, it gave me something to hold onto, a way to materialize my daughter's life. That was amazing! My heart breaks when I hear about mothers who didn't have this opportunity, because it was one of the things that helped me. It allows us to look back and say we did everything we could. She was there in front of me – it was very important for me. It was a miracle, exactly as it had to be, God's way. There is no strength; the strength comes from God. (G2)

5) Ongoing care and support

Support is an essential part of care and should be provided by the multidisciplinary team from the moment the loss is diagnosed until the parents return to the community after hospital discharge. In addition to strong social and emotional support, women must receive all necessary physical care.

Women who are pregnant after a previous stillbirth represent a small group, and therefore may benefit from specialized, individualized care – both for their physical and emotional health – which could address many of the gaps identified in existing services (Wojcieszek et al., 2018).

> (...) After that first ultrasound, the doctor asked me to retake it in 15 days to check that everything was fine. I think he realized that I was anxious and wanted to see it all the time. I couldn't get an appointment, and the doctor saw me on a holiday, so that was very comforting for me. (G13)

An important aspect identified among mothers in post-loss pregnancies was the need to share the previous pregnancy loss with the healthcare team in order to receive specialized and attentive care.

> My doctor, unlike in my previous traumatic experience, was very supportive. When I entered the delivery room, all the doctors already knew my history; she had taken the care to inform them beforehand. Everyone was very respectful regarding this. The anesthesiologist explained every step to me, everything he was going to do. When it was time for the anesthesia, he held my hand, and when they were going to remove D., my husband was already in the room with me. (G14)

6) Qualification of care

The literature suggests that healthcare professionals are deeply affected when caring for families whose babies are stillborn, and thus require ongoing education and support (Qian et al., 2022).

> (...) It was very intense, very sad; I wouldn't wish this experience on my worst enemy. I gave birth with a humanized birth team, well-known in Brazil and recognized as a reference in birth humanization. Yet, when such an outcome occurs, even within this humanized approach, it is so difficult that people become disoriented. I was left alone in the hospital room, screaming: 'Where is my son?'– this context was very hard. (G15)

Therefore, it is essential for the healthcare team to be sensitive to physical, emotional, and social needs, thereby providing comprehensive, humanized, and empathetic care in the obstetric context (Qian et al., 2022).

Study Limitations

The results of this study reflect the experiences of the women interviewed. While some details about the actions of healthcare professionals were reported, the professionals' own

perspectives were not directly explored. Therefore, future studies should consider the needs and experiences of healthcare professionals to expand the current understanding of the importance of care and support in the context of perinatal loss. They could also include larger, more representative samples and quantitative outcomes.

Conclusion

Obtaining the collaboration of the mothers through their narratives was essential for identifying the challenges and difficulties related to the care received during the experience of losing a baby. Some of these accounts reveal that stigma and fatalism remain prevalent in interactions with healthcare professionals, and that a sensitive approach toward parents and a stillborn baby can still provoke discomfort.

Particularly noteworthy is the vast number of opportunities lost through insensitive interactions between the team and parents, and the irreversibility of decisions made within the brief timeframe surrounding the loss. According to the literature, such experiences may trigger long-lasting trauma symptoms with ongoing effects on interpersonal relationships, potentially extending into subsequent pregnancies and parenting.

Similarly, it is important to recognize that caring for bereaved parents places additional stress on healthcare professionals, especially in the absence of specific institutional protocols. All healthcare providers should have opportunities to develop and update their knowledge and skills in this area. They should also receive supervision for continuous learning and emotional support, given the potential for emotional overload. Thus, two key challenges in the context of perinatal loss are highlighted: ensuring qualified care and providing adequate emotional support for healthcare professionals.

The themes that emerged offer guidance for the implementation of clinical guidelines and practices focused on individualized care, with the potential to positively impact the experiences of women and families following perinatal loss.

It is hoped that this study will inspire further research on this topic, which remains scarce in the Brazilian scientific literature, highlighting the limited academic space for discussing death in the obstetric context. The findings of this study aim to inform the development of care guidelines for families experiencing perinatal loss within maternal and child health reference services in the State of Ceará, Brazil.

References

Amthauer, C. (2017). Vivências e impressões de profissionais de saúde acerca de possíveis causas de uma perda fetal. *Revista de Enfermagem UFPE on line, 11*(Supl. 1), 334-340. https://doi.org/10.5205/reuol.7995-69931-4-SM.1101sup2017

Assis, G. A. P., Motta, H. L., & Soares, R. V. (2019). Falando sobre presenças-ausentes: vivências de sofrimento no luto materno. *Revista do Nufen, 11*(1), 39-54. https://doi.org/10.26823/RevistadoNUFEN.vol11.nº01artigo44

Boyle, F. M., Horey, D., Middleton, P. F., & Flenady, V. (2020). Clinical practice guidelines for perinatal bereavement care: an overview. *Women and Birth: Journal of the Australian College of Midwives, 33*(2), 107-110. https://doi.org/10.1016/j.wombi.2019.01.008

Canadian Pedriatic Society. (2001). Guidelines for health care professionals supporting families experiencing a perinatal loss. *Paediatrics & Child Health, 6*(7), 469-477. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2807762/

Casellato, G. (Org.). (2020). *Luto por perdas não legitimadas na atualidade*. Summus Editorial.

Creswell, J. W., & Plano Clark, V. L (2013). *Pesquisa de métodos mistos* (2nd ed.). Penso.

Cummings, S. R., Grady, D., & Hulley, S. B. (2015). Delineando um ensaio clínico randomizado cego. In S. B. Hulley, S. R. Cummings, W. S., Browner, D. G., Grady, & T. B. Newman. *Delineando a pesquisa clínica*. Artmed.

Ellis, A., Chebsey, C., Storey, C., Bradley, S., Jackson, S., Flenady, V., Heazell, A., & Siassakos, D. (2016). Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences. *BMC Pregnancy and Childbirth, 16*, 16. https://doi.org/10.1186/s12884-016-0806-2

Faria-Schützer, D. B., Neto, G. L., Duarte, C. A. M., Vieira, C. M., & Turato, E. R. (2014). Fica um grande vazio: relatos de mulheres que experienciaram morte fetal durante a gestação. *Estudos Interdisciplinares em Psicologia, 5*(2), 113-132. https://doi.org/10.5433/2236-6407.2014v5n2p113

Farrales, L. L., Cacciatore, J., Jonas-Simpson, C., Dharamsi, S., Ascher, J., & Klein, M. C. (2020). What bereaved parents want health care providers to know when their babies are stillborn: a community-based participatory study. *BMC Psychology, 8*(1), 18. https://doi.org/10.1186/s40359-020-0385-x

Iaconelli, V. (2007). Luto insólito, desmentido e trauma: clínica psicanalítica com mães de bebês. *Revista Latinoamericana de Psicopatologia Fundamental, 10*(4), 614-623. https://doi.org/10.1590/S1415-47142007000400004

Ignacio, E. S., & Medeiros, A. P. (2023). Nascimento e morte: o apagamento do luto durante a perinatalidade. *ID on Line, Revista de Psicologia, 17*(66), 253-272. https://doi.org/10.14295/idonline.v17i66.3743

Laguna, T. F. S., Lemos, A. P. S., Ferreira, L., & Gonçalves, C. S. (2021). Neonatal grief and the role of psychology in this context. *Research, Society and Development, 10*(6), e5210615347. https://doi.org/10.33448/rsd-v10i6.15347

Mills, T. A., Roberts, S. A., Camacho, E., Heazell, A. E. P., Massey, R. N., Melvin, C., Newport, R., Smith, D. M., Storey, C. O., Taylor, W., & Lavender T. (2022). Better maternity care pathways in pregnancies after stillbirth or neonatal death: a feasibility study. *BMC Pregnancy Childbirth, 22*(1), 634. https://doi.org/10.1186/s12884-022-04925-3

Minayo, M. C. (2010). *O desafio do conhecimento*: *pesquisa qualitativa em saúde*. Hucitec.

Muza, J. C., Sousa, E. N., Arrais, A. R., & Iaconelli, V. (2013). Quando a morte visita a maternidade: atenção psicológica durante a perda perinatal. *Revista Psicologia: Teoria e Prática, 15*(3), 34-48.

Paris, G. F., Montigny, F., & Pelloso, S. M. (2022). Equivalência da escala de luto perinatal para escala de luto parental após a perda de um filho. *Ciência, Cuidado e Saúde, 21*(1), 1-8. https://doi.org/10.4025/ciencuidsaude.v21i0.59136

Persson, M., Hildingsson, I., Hultcrantz, M., Kärrman Fredriksson, M., Peira, N., Silverstein, R. A., Sveen, J., & Berterö, C. (2023). Care and support when a baby is stillborn: a systematic review and an interpretive meta-synthesis of qualitative studies in high-income countries. *PloS One, 18*(8), e0289617. https://doi.org/10.1371/journal.pone.0289617

Pollock, D., Ziaian, T., Pearson, E., Cooper, M., & Warland, J. (2020). Understanding stillbirth stigma: a scoping literature review. *Women and Birth*: *Journal of the Australian College of Midwives, 33*(3), 207-218. https://doi.org/10.1016/j.wombi.2019.05.004

Qian, J., Sun, S., Wang, M., Liu, L., & Yu, X. (2022). Effectiveness of the implementation of a perinatal bereavement care training programme on nurses and midwives: protocol for a mixed-method study. *BMJ Open, 12*(8), e059660. https://doi.org/10.1136/bmjopen-2021-059660

Rando, T. A. (2012). A perspective on loss, grief and mourning. In T. A. Rando (Ed.), *Contact with the baby*: *illness, crisis & loss* (pp. 295-298). Sage.

Redshaw, M., Rowe, R., & Henderson, J. (2014). *Listening to parents after stillbirth or the death of their baby after birth*. *University of Oxford*. https://s3.eu-west-2.amazonaws.com/sr-bliss/documents/Listening-to-Parents-Report.pdf

Salgado, H. O, Andreucci, C. B, Gomes, A. C. R., Souza, J. P. (2021). Projeto de luto perinatal: desenvolvimento e avaliação de diretrizes de apoio para famílias que vivenciam natimortos e óbitos neonatais no Sudeste do Brasil: um estudo quase experimental do tipo antes e depois. *Reproductive Health, 18*(1), 5. https://doi.org/10.1186/s12978-020-01040-4

Salgado, H. O., & Polido, C. A. (2018). *Como lidar: luto perinatal: acolhimento em situações de perda gestacional e neonatal*. Ema Livros.

Schott, J., Henley, A., & Kohner, N. (2016). *Pregnancy loss and the death of a baby: guidelines for professionals*. Tantamount on Behalf of Sands, the Stillbirth & Neonatal Death Charity.

Setubal, M. S. V., Antonio, M. Â. R. G. M., Amaral, E. M., & Boulet, J. (2018). Improving perinatology residents' skills in breaking bad news: a randomized intervention study. *Revista Brasileira de Ginecologia e Obstetrícia, 40*(3), 137-146. https://doi.org/10.1055/s-0037-1621741

Shakespeare, C., Merriel, A., Bakhbakhi, D., Baneszova, R., Barnard, K., Lynch, M., Storey, C., Blencowe, H., Boyle, F., Flenady, V., Gold, K., Horey, D., Mills, T., & Siassakos, D. (2019). Parents' and healthcare professionals' experiences of care after stillbirth in low- and middle-income countries: a systematic review and meta-summary. *BJOG, 126*(1), 12-21. https://doi.org/10.1111/1471-0528.15430

Teodózio, A. M., Barth, M. C., Wendland, J., & Levandowski, D. C. (2020). Particularidades do luto materno decorrente de perda gestacional: estudo qualitativo. *Revista Subjetividades, 20*(2), 1-14. https://doi.org/10.5020/23590777.rs.v20i2.e9834

United Nations International Children's Emergency Fund. (2020). *A Neglected tragedy: the global burden of stillbirths*. WHO. https://www.who.int/publications/m/item/a-neglected-tragedy-the-global-burden-of-stillbirths

Wojcieszek, A. M., Shepherd, E., Middleton, P., Lassi, Z. S., Wilson, T., Murphy, M. M., Heazell, A. E., Ellwood, D. A., Silver, R. M., & Flenady, V. (2018). Care prior to and during subsequent pregnancies following stillbirth for improving outcomes. *The Cochrane Database of Systematic Reviews, 12*(12), CD012203. https://doi.org/10.1002/14651858.CD012203.pub2

World Health Organization. (2019). *Why we need to talk about losing a baby*. WHO. https://www.who.int/news-room/spotlight/why-we-need-to-talk-about-losing-a-baby

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