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RESEARCH

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## MATERNAL FEELINGS IN FACE OF PERINATAL DEATH

Sentimentos maternos frente ao óbito perinatal

Sentimiento maternal frente para muerte perinatal

*Beatriz Gonçalves Lopes<sup>1</sup>, Márcia Regina Carletto<sup>2</sup>, Taís Ivastcheschen<sup>3</sup>, Pollyanna Kássia de Oliveira Borges<sup>4</sup>*

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### ABSTRACT

**Objective:** to understand maternal feelings towards perinatal death. **Method:** qualitative study of an interpretative nature, with 23 women who would experience the loss of a child in the perinatal period in 2015, in the municipality of Ponta Grossa / Paraná. Data analysis was done through Content Analysis from the perspective of Bardin. **Results:** after analyzing the information, two context categories emerged, “Maternal feelings towards death” and “Who sees my pain”. Feelings such as anger, fear, shock, despair and deep sadness were present. Every mother demands time to find meaning in her loss and then restructure life and her role in the family and society. **Conclusion:** it is extremely important to create support networks capable of serving these mothers and helping in this difficult process.

**Descriptors:** Perinatal mortality; Bereavement; Public Health.

### RESUMO

**Objetivo:** compreender os sentimentos maternos frente à morte perinatal. **Método:** estudo qualitativo de natureza interpretativa, com 23 mulheres que vivenciariam a perda de um filho no período perinatal no ano de 2015, no município de Ponta Grossa/ Paraná. A análise dos dados se deu pela Análise de conteúdo na perspectiva de Bardin. **Resultados:** após a análise das informações emergiram duas categorias de contexto, “Sentimentos maternos frente à morte” e “Quem vê minha dor”. Sentimentos como raiva, medo, choque, desespero e tristeza profunda se fizeram presentes. Toda mãe demanda de um tempo para encontrar um significado a sua perda e então reestruturar a vida e o seu papel na família e na sociedade. **Conclusão:** é de extrema importância criar redes de apoio capacitadas para atender essas mães e ajudar nesse processo difícil.

**Descritores:** Mortalidade perinatal; Luto; Saúde pública.

- 1 Enfermeira. Mestre em Ciências da Saúde. Universidade Estadual de Ponta Grossa. Ponta Grossa- Paraná- Brasil. ORCID: <http://orcid.org/0000-0001-8993-2602>
- 2 Bióloga. Doutora em Educação Científica e Tecnológica. Universidade Estadual de Ponta Grossa. Ponta Grossa- Paraná- Brasil. ORCID: <http://orcid.org/0000-0003-3442-5093>
- 3 Enfermeira, Mestranda do Programa de Pós-graduação em Ciências da Saúde. Universidade Estadual de Ponta Grossa. Ponta Grossa- Paraná- Brasil. ORCID: <http://orcid.org/0000-0001-8496-5990>
- 4 Cirurgiã Dentista. Doutora em Saúde Coletiva. Professora associada. Universidade Estadual de Ponta Grossa. Ponta Grossa- Paraná- Brasil. ORCID: <http://orcid.org/0000-0002-9390-0459>

## RESUMEN

**Objetivo:** comprender los sentimientos maternos hacia la muerte perinatal. **Método:** estudio cualitativo de carácter interpretativo, con 23 mujeres que experimentarían la pérdida de un hijo en el período perinatal en 2015, en el municipio de Ponta Grossa / Paraná. El análisis de datos se realizó a través del análisis de contenido desde la perspectiva de Bardin. **Resultados:** después de analizar la información, surgieron dos categorías de contexto, "Sentimientos maternos hacia la muerte" y "Quién ve mi dolor". Sentimientos como ira, miedo, conmoción, desesperación y profunda tristeza estaban presentes. Cada madre exige tiempo para encontrar el significado de su pérdida y luego reestructurar la vida y su papel en la familia y la sociedad. **Conclusión:** es extremadamente importante crear redes de apoyo capaces de servir a estas madres y ayudar en este difícil proceso.

**Descriptores:** Mortalidad perinatal; Aflicción; Salud Pública.

## INTRODUCTION

Perinatal death is a traumatic event that can bring immeasurable pain to those who experience it. These deaths usually occur unexpectedly, and can cause physical and psychological problems with long-lasting consequences.<sup>1</sup>

The bond between mother and fetus begins from the moment the pregnancy is discovered, as the child develops inside the womb, and the woman is seized by the emotion of being a mother.<sup>1</sup>

Pregnancy is mostly characterized by moments of joy and immense love. However, adverse situations can occur that interrupt and modify the natural course of life, such as perinatal death, and this is a painful experience that brings feelings of failure, anguish, fear, and revolt.<sup>1</sup>

There is also the report of the feeling of invalidity in the eyes of society, because, culturally, a woman would reach feminine fulfillment when she conceives children. By not taking this step, she could feel incapable of being a woman.<sup>2-3</sup>

It emerges from this context that every mother who loses a child needs time and help to re-signify her loss, because the dream of having a child and the expectations about her child growing healthy and developing are shattered along with her identity. At that moment, the mother does not know whether she is still a mother or has ceased to be.<sup>3</sup>

With the support of a well-structured healthcare team and the family, the feelings of anxiety and fear of mothers who have witnessed the loss of a child are gradually reduced. The support offered by a healthcare professional in partnership with the family reduces stressful and depressive factors.<sup>4</sup>

Thus, this study aimed to understand maternal feelings towards perinatal death.

## METHODS

Qualitative study of interpretative nature, included 23 women who experienced the loss of a child in the perinatal period (fetal death >22 gestational weeks or early neonatal death from 0 to 6 days of life), during the year 2015, in the city of Ponta Grossa, Paraná, Brazil.

Initially, information on the total number of perinatal deaths in the year 2015 was collected from the Epidemiological Surveillance of the Municipal Health Department through a documental analysis, where data regarding contact and address of the mothers, causes of death, socio-demographic considerations, and health requirements in the mother-child binomial were acquired, and these data came from the Declarações de Óbito (DO) e Declarações de Nascidos Vivos (DNV) of the deceased child.

In Ponta Grossa, in 2015, 84 resident women experienced perinatal loss. It was not possible to contact 19 of these mothers, due to the absence of location information or change of phone number and address, 24 of them did not agree to participate in the research, 16 initially accepted to participate, but rejected the entry after the second contact for the progress of the study. In short, 25 mothers agreed to cooperate with the research. Of these, two mothers were excluded at the end of the study for lack of validation of the speeches collected, resulting in a final sample of 23 mothers.

The data was collected through a semi-structured interview, which contained three questions with the objective of knowing the history of the death and the feelings experienced at the time of the news, plus three questions with the purpose of understanding how the mothers visualized what the people around them assimilated of what they were living.

The period in which the data collection was carried out occurred in the months of October and November 2016. It was proposed to the mothers, according to the delicacy of the topic, a speech with the possibility of pauses and with freedom to expose their feelings and emotions. The reports were recorded with the agreement and acceptance of the researchers, and then transcribed and validated.

To preserve the identification and confidentiality of the interviewees, their names were replaced by fictitious names of their own choosing. Upon validation of the interviews, the transcripts were sent via e-mail, or delivered in person to each mother, who then had the opportunity to read them, confirm what they had reported, and, if interested, change their speeches.

The descriptions presented were analyzed based on the report of the mothers' feelings in situations experienced during the news of the negative diagnosis and at the time of delivery, as well as upon returning home. The organization and analysis of the qualitative data were performed by means of Content Analysis from Bardin's perspective, based on thematic analysis.<sup>5</sup> This method is applied to the word, allowing a practical and objective observation of what is behind the speeches, to produce inferences from the content obtained in the communication of the investigated population, and can be replicated in its social context.<sup>5</sup>

Those involved in the research were informed about the objectives, risks, and benefits of the research, and their information was collected through spontaneous acceptance and agreement with the Informed Consent Form. The research project was submitted to the Comissão de Ética em Pesquisa

com Seres Humanos (COEP) of the State University of Ponta Grossa, under opinion no. 1,617,353/2016.

## RESULTS AND DISCUSSION

After the analysis of the information, two context categories emerged, “Maternal feelings facing death” and “Who sees my pain”. Among these categories, the following registration units were found, in the first: “Between helplessness and shock”, “The choices”, “The feeling is that your life is no longer in you”, “The farewell” and “Living with other babies”. In the second category “The return to reality” and “It wasn’t with them”.

### Maternal feelings in the face of death

#### Between powerlessness and shock

When a mother is informed that her pregnancy may be terminated in a negative way with the death of her baby, many reactions can be verified.

*She looked at me very seriously, she said: “Mom, I only have one thing to tell you: your son is not compatible with life! [...] I spent the weekend in shock, in such shock that I didn’t know what to do! (Ana Maria)*

*I don’t even know, I felt fear, only, I felt fear and I tried to put in my head that everything would be all right, right, that I don’t know, I thought like this, if my son dies I think I die with him, right, then my fear was born, that fear, that anxiety, that nervousness, and I did not know what to think, and I could not do anything. (Bruna)*

Upon receiving a negative diagnosis during pregnancy, the first feeling that mothers report is the shock of the news, followed by the feeling of fear. Pregnancy is a time of great joy and planning for mothers, however, when a mother receives the information that her child is not compatible with life, feelings of anguish, sadness, anger, and uncertainty about the future are present.<sup>6-7</sup>

#### The Choices

Many mothers still have to go through moments of decision, in which they must choose whether or not to continue with the pregnancy, or whether to save their own life.

*Then he said “we are going to hospitalize her, she can’t stay at home and you will have to choose between her or the babies”, so it was horrible! I didn’t care about anything else. The only thing I wanted was my daughters! I told my husband that my decision had already been made, that I wasn’t going to give that up. But the doctor talked to me a lot that I had to think about it. (Lilian)*

*I want to, doctor, I assume this risk, but no one will take this child away from me, he will go wherever he goes and I will go with him, wherever I think, wherever God allows*

*David to go, I will go with him and no one will take him away from me, I want him to grow, I want him to have the right to live, no matter what happens! (Ana Maria)*

Although it is a distressing moment, mothers are able to make decisions, but they need to be prepared to receive difficult news. Professionals should use words of solidarity and love, in addition to being clear and honest in their information, offering clarification and support.<sup>8</sup> Giving the right of free will to the parents to choose whether to continue or terminate the pregnancy, when the legislation so allows.<sup>7</sup>

Some reactions such as maintaining secrecy about the health situation of the child and enjoying the pregnancy are present in the maternal reports, but without making future plans with the children. When the expectation was not reached, the mothers felt prepared to say goodbye.

*I had a happy pregnancy, I tried to have a very happy pregnancy, because when people looked in my belly [...], I did not tell people what he had, I told only my family, my husband [...] because I did not want to expose the life of my son, I would not do that to him, and he was, and he is to this day, the greatest love of my life [...] I did what my heart asked me to do, and I did not take my son, I gave him the opportunity to live. And I enjoyed him until God took him away from me. [...] It came at a time of night like this and he was no longer doing well [...], it was the worst moment of my life and the life of my husband [...], my husband looked at me and said “it’s time for us to give him up, it’s time for us to ask God to do what needs to be done,” this was at 11 o’clock at night, we took his hand, we prayed [...]. (Ana Maria)*

Despite the negative diagnosis, parents want their children to be treated with all existing resources and supports. This involves the hope that mothers feel, clinging to the possibility of the chance of survival and the miracle.<sup>7</sup>

On the other hand, it is possible to suppose that the maintenance of secrecy may be a consequence of the denial of the possibility of death, that is, they preferred not to believe in the situation in which they were living to cushion their anguish. Or, they did not feel comfortable to talk about it.

Whatever the main reason for the secrecy, it is reasonable to consider that, when facing human finitude through the death of the neonate, the feeling of fear arises because the awareness of death exacerbates immature aspects of human behavior and also allows reflection on the possibility of death itself.<sup>9</sup>

The diagnosis of early malformation brings anguish, fear, and suffering to parents; however, it brings a period of preparation and acceptance of the situation.<sup>6</sup> Parents prefer to know the news and report that they feel more prepared when the moment of their child’s death arrives.<sup>8</sup>

Thus, the need for training health professionals to deal with these situations is emphasized, especially nurses, because they are the ones who have the most contact with the patients. The lack of scientific instruction and preparation may be negative determinants in the resolution of the grieving process of

mothers who have this feeling.<sup>10</sup> Welcoming, human warmth, support, and empathy are professional attitudes that cooperate to face the situation.

### The feeling is that your life is no longer in you

When the moment of death occurs, the mothers' feelings are antagonistic, regardless of their previous knowledge of the outcome. At the moment of the news, mothers are nervous, indignant, and in shock. In addition, feelings such as sadness, anger, guilt, disappointment, and discouragement are exposed in the reports.

*At the time I cried, at the time the feeling is that your life is no longer in you! (Luana)*

*When I received the news, it was the worst pain [...] the world had ended at that time [...] I couldn't speak, I couldn't, I lacked air, you know, I just thought "my God in heaven, why me? Why?" [...] It's a pain that you can't imagine you know, it's a pain that doesn't heal! (Amanda)*

*We feel incapable of everything, incapable of living, incapable of breathing, incapable of really loving again, it is very bad, it is horrible! (Carla)*

*My crying didn't come out, my voice, nothing, and so, at the time I didn't know what to think. (Geruza)*

*And so, you know, you lose your ground, you lose your reason for living. Your sky falls apart [...] your ground opens up and you disappear. For me, at that moment, I no longer existed, I no longer had a life.*

*Wow, I felt a very big revolt, very, very big, not so much with the doctors because there was nothing they could do, but you think "why us? (Crislaine)*

*At that moment I didn't cry, I didn't do anything, I remember that I was in a state of shock [...] I feel guilty of being a woman who could not give birth. The feeling that I have is that I am no good as a woman [...] You know, it is something, it is a conflict with myself. (Ana Maria)*

*At that moment I felt like a failure. (Barbara)*

During pregnancy, a woman goes through changes and alterations in her body, idealizes dreams, and plans the future with her child. When this connection is interrupted in a negative way, feelings of deep sadness, invalidity, or inferiority before society as a whole come to the surface. The mother feels that she has disappointed the expectations of the people

around her, feeling guilty for not bearing a child full of function and vitality.<sup>11</sup>

The pain of losing a child is one of the worst pains that a human being can experience, justified by the bond created between mother and child. This pain does not depend on the age of the children, whether it was fetal or early neonatal death, nor on the reason, the pain is caused by the loss.<sup>1</sup>

Parents have different ways of acting; some experience the moment immediately and feel great sadness, while others can be in shock for hours or days before feeling the mourning. This situation changes according to the individuality of each person, along with their beliefs and culture.<sup>12</sup>

### The Farewell

Although the news of the baby's death promotes so many feelings, at this point the grieving process has just begun and mothers face other difficulties.

*At the funeral I felt despair, the child was in that little coffin there, with a little cap like this, you know, and then they tied it. Gee, I felt despair for that little piece of people, it was bad, it was bad. (Joelma)*

*In fact I don't like to show my feelings, I'm more closed in these parts [...] I like to cry alone, so at the time I stopped myself, but when he arrived at the cemetery I couldn't stand it, I collapsed in tears. (Joana)*

*I didn't want to see, I didn't have the courage, because I would have a very bad image, I didn't want to have a bad image, because I wanted to have an image of him as well, you know, not bad. (Crislaine)*

Farewell rituals are important ways for parents to recognize the short life of the baby and accept the event.<sup>12</sup> There is great discussion in the international literature about the contact with the stillborn, some are in favor, claiming that mothers who hold their babies have fewer depressive symptoms and have an easier time resigning the death of their child. On the other hand, others claim that mothers may keep a sad image of their child and this would make the mourning process more difficult.<sup>13</sup>

However, it is necessary to ask the mother about her wishes. And, hospital units, where most perinatal deaths occur today, need to review the rules about the possibility of contact between mother and fetus/newborn, and even the mother's departure from the hospital for the child's burial. Many would like to participate in the moment of farewell, however, this right is denied to them for reasons that disregard the humanization of relations in health services and take into account only the norms.

When the mother has the right to see, touch, and hold her child, it is understood that she will find it easier to see the short life of her child, but this moment must be supported by the health team.<sup>2</sup> Thus, the health professional should be responsible for supporting the bereaved mother, helping



her to face the physical and psychological pain, and offering options for choices about the farewell ritual..

### Living with other babies

Another difficulty that mothers report is the contact with other babies, either in the maternity ward or after returning home. Feelings of failure, invalidity, and sadness mark this moment. The envy of mothers who have a healthy child can be a feeling that arises in these post-baby moments, and that should not be a reason for simplistic judgments, but should be understood within the context and as expected reactions within the different stages of grief.

*When a mother can't hold her child in her arms after the birth, she doesn't want to see or hear other mothers who are with their babies, she wants to go home as soon as possible, she wants silence and privacy, she wants to be comforted by people who can give her affection. (Luana)*

One mother pointed out how much better she felt being placed in a room by herself, not having to share the room with mothers who were with their live babies.

*I stayed in a room by myself, so in this part I give a score of 10, you know, because I was well treated in this part, by the nurses, of not having contact with other mothers, because I think that touched me, because hearing the babies crying from the other room, you know, really affected me, so in this part of the nurses, the nursing staff, after the birth, a score of 10! (Carla)*

Therefore, human empathy is necessary in this difficult moment. These are simple details, such as leaving the grieving mother separate from the mothers celebrating the newborn's life, which in the routine of professional work often go unnoticed, but, if recognized, can reduce people's anguish and minimize suffering.

### Who sees my pain!

#### The return to reality

The return home is also a delicate moment, the return to the routine without your baby is frustrating. Mothers also feel the lack of empathy from the people around them by using phrases that are not always understood as comforting.

*I kind of got into a depression, I didn't want to live, I didn't want to leave the room, I didn't want to eat, I didn't want anything, nothing, I just cried.*

*Then when I went back home it was the most difficult time, because I looked at my house and saw an emptiness inside my house like this, my house is the place I most love to stay and suddenly I wanted to run away from my house, I no longer wanted to stay in my house, because I looked at things, I looked at the clothes, I looked at everything, I said "it makes no sense! (Ana Maria)*

*Then they say things like "you're new and so on", but we don't want to, it's something that we can't accept. (Joelma)*

Social groups want to help, but this help is not always appropriate, phrases such as "you are young", "soon you will have another", and "you should forget and move on" often create pressure on mothers, and as a consequence can increase the mourning period.

That said, the importance of health professionals from the basic health units to support mothers and their families after the loss of the child is noted. Considering that these professionals are the closest to the family, they have better possibilities to accompany the entire grieving process, diagnosing behaviors that may indicate the need for referral to one specialty or another.<sup>14-15</sup>

It is also in the basic health units that popular movements can emerge, under professional guidance and encouragement, in favor of collective actions such as conversation circles, community therapy, mothers' groups, and others, which facilitate and provide moments of exposure of maternal feelings and identification with other subjects who also experienced the death.

#### It was not with them!

When they return home many mothers feel lonely and believe that no one is able to understand them, only mothers who have gone through the same situation. This way they can't express what they feel because of the judgment of those around them..

*People talk as if it was easy, it wasn't with them! They say "it's over", but they didn't feel it, right? They want to comfort us and end up hurting us. Only those who have been through it understand what we [mothers] went through. (Julia)*

*People sometimes even avoid talking about the subject, avoid talking about pregnancy around me. [...] There is no way you can measure a loss of life, there is no way she lost with so many weeks [...] this business of wanting to talk to us, wanting to give us an excuse, is a boring situation, one does not replace the other! (Leticia)*

A situation already posed in another study, in which mothers claimed to go through grief alone.<sup>16</sup> Perinatal death is considered an invisible death in the eyes of society. Believing that parents who go through a fetal death situation suffer little, social groups tend to measure the parents' pain by comparing the baby's death to the death of an older child.<sup>14</sup>

In this context, neonatal death is an unspoken issue. Thus, bereaved mothers go through a period of silence because they may feel unable to show their feelings in public, and this situation can lead parents to isolation from social life.

However, although mothers believe that only another mother who has experienced the loss of a child can understand them, help and support is the responsibility of the health services. Thus, a support network should be offered to these mothers and their families.

## CONCLUDING REMARKS

With this study it was possible to understand the maternal feelings facing perinatal death, such as shock, sadness, guilt, pain, and fear. Therefore, it is of utmost importance to create support networks capable of assisting these mothers and helping in this difficult process.

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### Corresponding author

Taís Ivastcheschen

Address: Rua Daily Luiz Wambier, nº3012

Ponta Grossa/PR, Brazil

Zip code: 84.015-010

Email address: [taiiivastcheschen@gmail.com](mailto:taiiivastcheschen@gmail.com)

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