Assessment of family grief over the gestational and neonatal loss

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ABSTRACT

Objectives: To evaluate the degree of grief caused by gestational or neonatal loss in parents, associating with sociodemographic variables. Additionally, compare the degree of grief according to the moment of loss. **Methods:** Cross-sectional study conducted with the application of a sociodemographic questionnaire and a validated questionnaire (Perinatal Grief Scale-PGS) in parents who lost their child at any time during pregnancy or in the neonatal period. **Results:** 542 fathers and mothers were able to participate in the study and after invited to respond, 104 (19.1%) were willing to participate. The 104 respondents were divided into two groups: loss in the first gestational trimester (76.9%), and other trimesters added to the neonatal period (23.1%). There was a predominance of maternal responses (89.4%) and a mean age was 29.1±15.58 years. The median PGS score was 90 points, with no difference between the scores according to the moment of loss. First pregnant and women under the age of 25 had higher scores than the others (p=0.042 and p=0.047) respectively. Suicidal ideation was reported by 15.4% and 32.7% of mothers who blame themselves for the death of the baby have significantly higher scores than those without such feelings (p <0.0001). Marital status, education, economic status, religion, prenatal care, ethnicity, and previous miscarriage were not significantly associated with the scores obtained in the PGS. **Conclusion:** Family grief occurred regardless of the moment of loss, being greater in younger women and those with feelings of guilt. Measures must be taken to minimize such suffering.

Keywords: Death; Grief; Gestation.

INTRODUCTION

Every year, three million pregnancies result in fetal death around the world, with several reasons for this outcome1. Among the countries with the highest fetal mortality, rates are those in Sub-Saharan Africa and Asia, with numbers that reach 30 stillbirths for every 1000 births[1]. In developed countries, such rates drop to 2 to 7 per 1000[1]. In Brazil, from 2000 to 2016, the rate of fetal deaths was 5.3 per 1000 live births[2]. Neonatal mortality shares the same circumstances and etiologies with fetal mortality, corresponding to 70% of all infant mortality in Brazil [3]. A systematic review carried out in 2019 on fetal deaths in Brazil between 1996 and 2015 revealed higher fetal mortality in the less favored population and the extremes of reproductive age. Additionally, the authors emphasize the low visibility of the subject even though this is an event that affects a large number of individuals [2]. A series of cases on maternal grief resulting from pregnancy loss carried out between 2006 and 2014 in Paraná and pointed out that there is a feeling of lack of support from health services to families at this time [4]. Muza et al [5] refer that families who suffer from mourning avoid the subject, opting for silence, in an attempt to alleviate suffering. The mourning generated by gestational or neonatal death provides an expected reaction of sadness and a sense of loss. However, such feelings can become abnormal, excessive and even disabling[6]. According to Lee and Slade[7], the occurrence of depressive symptoms in post-abortion women is four times greater than in the general population and such symptoms may still recur after one year of fetal death. The medical profession, especially in the first months of pregnancy, is possibly underestimating the mourning resulting from pregnancy loss when the risk of miscarriages is known to be greater[10].

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The present study aims to assess the degree of grief caused by pregnancy or neonatal loss in mothers and fathers, associating the scores with socio-demographic variables. Additionally, compare the degree of grief according to the gestational age at the time of loss

METHODS

This study was approved by the Ethics and Research Committee of Hospital do Trabalhador under number CAAE 87492418.0.0000.5225. It is noteworthy that psychological counseling was offered to all families that go through the mourning process at the Hospital do Trabalhador. The study had a cross-sectional design and was carried out from April 2018 to March 2019. We used a validated questionnaire (Perinatal Grief Scale - PGS) together with a socio-demographic questionnaire where data were collected such as: if the participant was father/mother, age, race, marital status, the city where he lives, education, employment, economic status, number of children, previous abortion and prenatal care. PGS is the most used instrument to identify bereavement in pregnancy and neonatal loss. It has been translated and validated for use in the Brazilian population[8]. The questionnaire consists of 33 statements divided into 3 categories: active suffering, difficulty in coping and despair. Each statement has 5 answer options that score from 1 to 5 points. According to the score - which can vary from 0 to 165 points - signs and symptoms of mourning are evaluated, such as the adaptation to fetal loss, feelings and thoughts. The first subscale, Active Mourning, deals with sadness and the loss of the baby. The second, Coping Difficulty, addresses difficulties in daily activities and in relationships with other people. The last, Despair, refers to feelings of self-depreciation and discouragement. High PGS scores (above 91 points) are associated with depression, anxiety and post-traumatic stress (PTSD) and relationship problems between couples in subsequent pregnancies [8,9,10]. The patients were seen at the midwifery services and were recently born at the neonatology service at the Hospital do Trabalhador during the studied period. Parents were contacted and invited to participate during hospitalization for curettage, delivery induction or up to 28 days after the procedure or neonatal death of a baby admitted to the neonatal ICU of the Hospital do Trabalhador.

Participants were included according to the following criteria: fathers and mothers over 16 years of age, who had fetal or neonatal death (up to 28 incomplete days after birth) and agreed to participate in the study by signing the consent form. People under anesthetics or other drugs that could alter their cognitive status and questionnaires answered in an incompletely excluded. Fathers and mothers who suffered pregnancy loss due to induced abortion were also excluded.

Frequency tables and contingency tables were created. Statistical analyzes were performed with GraphPad Prism 6.0 statistical program. Continuous variables were expressed as mean ± standard deviation and compared with the Mann-Whitney tests. Categorical variables were expressed as percentages and compared with the chi-square test or Fisher's exact test, as appropriate. P values less than 5% were considered statistically significant.

RESULTS

In total 542 individuals among fathers and mothers were able to participate in the study. After the initial contact and invitation to respond to the survey, only 104 (19.1%) of these people were willing to answer the questionnaire. The included interviewees were divided into two groups:

Group 1: loss occurred in the first quarter; that corresponded to 80/104 (76.9%) of the cases; **Group 2:** loss occurred in the other quarters or the neonatal period and represented 24/104 (23.0%). It should be noted that 8 (7.7%) cases of neonatal loss were studied, all answered by the mother. The clinical and demographic data of the people studied are shown in table 1.

Table 1
Demographic data of the people studied (n=104)

Participant	n	%
Mother	93	89.4
Father	11	10.6
Ethnicity		
White	70	67.3
Yellow	3	2.8
Parda	24	24.2
Black	7	5.7
Civil status		
Single	23	22.1
Married	50	48.2
Stable union	30	28.8
Divorce	1	0.9
Schooling		
Incomplete first level	4	3.8
Primary level complete	15	14.4
Secondary level	63	60.5
Graduation	22	21.3
Number of children		
None	29	27.8
One	48	46.3
Two	20	19.2
Three or more	7	6.7
First pregnancy		
Yes	32	30.7
No	72	69.3
Previous abortion		
None	65	62.5
One	26	25.1
Two	10	9.6
Three or more	3	2.8
Prenatal follow up		
Yes	75	72.1
No	29	27.9

Few paternal responses were obtained, only 10.6% of them were willing to respond to the survey and there was a wide predominance of maternal responses (93/104). The average age was 29.1 ± 15.58 years. Regarding PGS scores, the median was 90 points (IIQ = 64 - 119), with 34.2% of respondents having scores above 120 points. When the groups were compared - first trimester and other moments of loss - (Figure 1a), there was no significant difference concerning the calculated scores, demonstrating a similar degree of grief regardless of the moment of loss (p = 0.18). Table 2 shows the distribution of the scores of the subscales of the PGS and it was found that there was no significant difference in the scores obtained at different times of the loss, according to gestational age.

Table 2
Score distribution according to the subscales of the Perinatal Grief Scale (PGS) questionnaire

	Median (IQR)	p*
Active grief		
Total	40.5 (32 - 47)	
1º Trimester	29 (15 – 35)	
Other periods	42.5 (15 – 37)	0.09
Coping Difficulty		
Total	24 (15 – 35)	
1º Trimester	24 (14 – 35)	
Other periods	24 (31 – 32)	0.49
Desperation		
Total	25 (15 – 37)	
1º Trimester	22,5 (15 – 38)	
Other periods	29,5 (18 – 36)	0.17

* Mann-Whitney test comparing both groups.
IQR = Interquartile range

The number of pregnancies affected the grieving scores, where the primiparous women presented significantly higher scores than the multiparous women (p = 0.042, figure 1b). In relation to age, women under the age of 25 years obtained a median of 94 points (IIQ = 76-119) while the median of participants over the age of 35 years was 74 points (IIQ = 54-116) (p = 0.047; figure 2a). About suicidal thinking, 16 (15.4%) participants presented this type of ideation. Comparing those who thought about suicide and those who claimed to have adapted

well to loss, we obtained medians of 145 (IIQ = 125-149 points) and 75 (IIQ = 60 - 112 points) respectively (p <0.0001), suggesting that PGS can help detect potential suicide risk patients. In addition, 32.7% of mothers blame themselves for the child's death and that they have significantly higher PLA than those who do not have such a feeling (p <0.0001; figure 2b). Marital status (p = 0.33), education (p = 0.89), employment status (p = 0.11), economic status (p = 0.31), religion (p = 0.95), prenatal care (p = 0.37), ethnicity (p = 0.86) and previous abortion (p = 0.47) did not present a significant association with the scores obtained in the PGS.

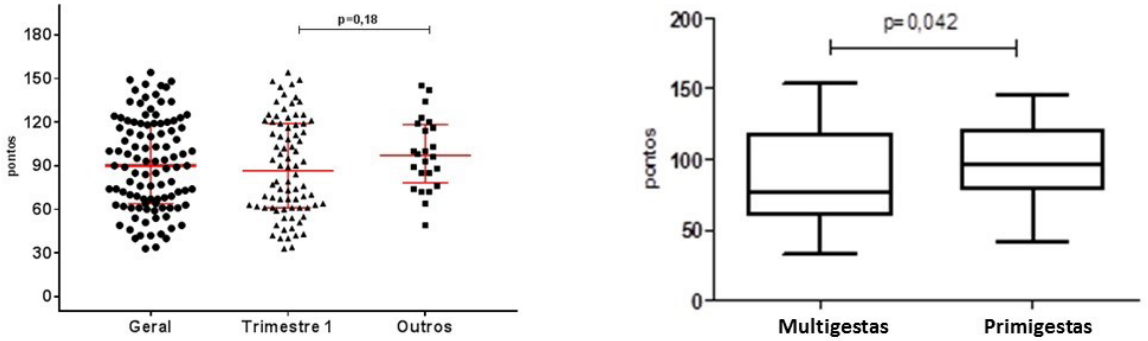

Figure 1a: Comparison between the scores on the perinatal grief scale between women in the first trimester and the other moments of loss.
Figure 1b: Comparison between scores on the perinatal grief scale between multigravid and primigravid women.

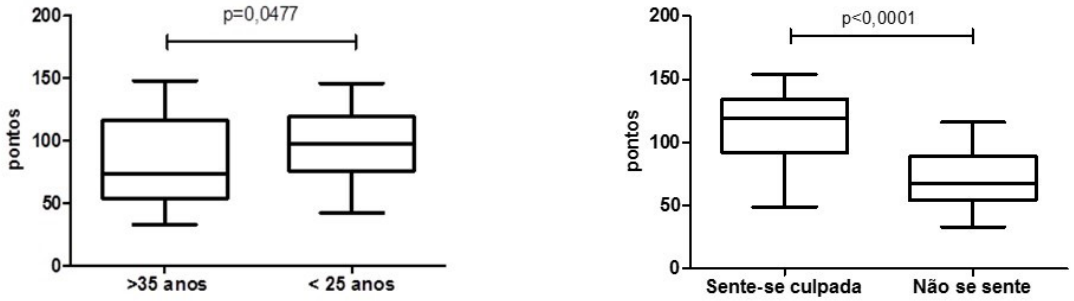

Figure 2a: Comparison between scores on the perinatal grief scale among women studied at different ages at the time of loss.
Figure 2b: Comparison between the scores on the perinatal grief scale between detected women who feel guilty about fetal loss and those with good acceptance.

DISCUSSION

This study presents the quantification and comparison of the mourning generated by the gestational and neonatal loss of mothers and fathers at different times in a Hospital and Maternity in Curitiba-PR through the PGS application. Toedter et al [10] analyzed 22 studies conducted in four countries that used the same questionnaire validated with 2,485 participants after perinatal loss and determined that a score greater than 91 points on the PGS would reflect a high degree of sadness in the parents. This same study states that the results of PGS are comparable in different samples and countries. According to the authors, although most women experience "normal" grieving reactions in response to perinatal loss, about 25% to 30% may have significant, prolonged, highly intense and complicated grieving reactions. This attitude

can negatively affect their psychological well-being.[10] In our study, the median was 90 points and about 1/3 of the women had scores above 120 points, showing a high frequency of intense grief in our sample. The degree of grief can be influenced by several factors, mainly related to cultural, socioeconomic and religious aspects [11,12], justifying the differences between the populations studied. In the present study, we felt difficulties in the participation of fathers and mothers, given that less than 20% answered the questionnaire, probably due to the moment of stress and discouragement they were in. In addition, Quintans[13] reports that the way of experiencing grief is shaped since childhood, when society influences the form of emotional expression between boys and girls, making the male sex less likely to demonstrate their emotions. In our study, only 10% of fathers participated in the study, what may suggest that they could avoid such feelings or thoughts by not answering the questionnaires.

Barros et al [3] describes increasing numbers of gestational deaths in the third trimester of pregnancy between 1996 and 2015 in Brazil, except for the Southern region of Brazil, which presented stable values. In our study, there was a predominance of losses in the first trimester (76.9%) and a small number of respondents who had losses in the neonatal period. It is noteworthy that there was no difference between the mourning scores at different times of gestational or neonatal age. Such a result is recurrent in the scarce literature on the subject. [14] In general, health professionals tend to minimize grief when the loss occurs in the first trimester of pregnancy, not giving due importance to this situation. In our cases, some women with fetal loss in the first trimester had high PGS scores and reported having a depressive condition, including suicidal ideation. Likewise, the subscales present in the PGS did not show significant differences between the moments of loss, although active mourning is more frequent in the losses that did not occur in the first quarter.

In relation to parity, our study showed that primiparous women obtained a higher total score in PGS than multiparous, probably due to the higher expectation in relation to the first child. Likewise, in relation to the age group, our study found that participants under the age of 25 obtained a median significantly higher than those over 35. PGS proved to be an instrument capable of detecting participants with potential suicide risk, since the analysis of the data obtained reveals that mothers who thought about suicide obtained very high scores compared to those who claimed to have adapted well to loss ($p<0.0001$). Hutti et al [15] described an increase in suicide rates after any type of perinatal loss. It was also observed that one-third of the mothers felt guilty about the child's death and that they developed a significantly higher degree of mourning than those who did not have this feeling. In a review of grief and perinatal loss [11], the authors found in the literature only two factors that were consistently associated with severe or complicated grief after pregnancy loss. The first, insufficient social support, given that high levels of social support from family, friends and others appear to be protective and associated with low scores. The second, a previous history of a mental health disorder, such as depression, has been associated with more intense grief [11]. Regarding common sociodemographic variables, such as age, race, marital status, some authors have found that occupation, income and religion are not associated with the presence of mourning. [11,16] On the other hand, a study comparing 26 Brazilian women and 8 Canadians using the ELP showed that Brazilian women who did not use a professional support group, did not have marital satisfaction, did not practice religion and had less schooling had greater grief [17]. Hutti et al [9] pointed out that the lack of professional support proved to be the most important predictor in the development of psychological complications, since mothers who went through the process of pregnancy and / or neonatal loss and did not receive necessary care after the event, experienced results negative and prolonged psychological problems. Primary health care interventions and a strong family and social support network are invaluable for parents and families at the time of the loss. However, due to the lack of high-quality randomized studies on this topic, the real benefits of current interventions are still unclear18. The sensitive nature of this topic and studies with small sample sizes make it difficult to expand knowledge on the subject [18].

This study has some limitations due to the cross-sectional design and the small sample size, especially in the second and third trimester of pregnancy and in the neonatal period. We deal with the difficulty of accessing fathers and mothers at this delicate moment in their lives, and the consequent refusal to participate in the research because they are stressed and do not wish to address the subject at the moment. Due to the importance of the theme and the few studies carried out in our country, further research is needed to bring a better approach to families that suffer with losses during pregnancy and neonatal period. In addition, it encourages the need for medical education for adequate care for such a group of patients in order to minimize the suffering generated by the loss.

CONCLUSION

A high frequency of intense grief was observed in the participants and this event occurred regardless of the moment of pregnancy loss, that is, it was no different in the first trimester or at another time of pregnancy or even in the neonatal period. Primiparity, age below 25 years and feeling of guilt were the variables that significantly increased the degree of grief. Factors such as marital status, ethnicity, education, employment status, economic status, religion, prenatal care and previous abortion did not influence coping with grief.

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