Experiences of women with sickle cell disease who experienced pregnancy losses

Experiências de mulheres com doença falciforme que vivenciaram perdas gestacionais

Experiencias de mujeres con anemia falciforme que pasaron por pérdidas gestacionales

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Abstract

Objective: To understand the experiences of women with sickle cell disease in the face of pregnancy losses caused by spontaneous and stillborn abortion.

Methods: This is a descriptive, exploratory study with a qualitative approach, developed with 20 women diagnosed with sickle cell disease and treated at a reference clinic in the city of Salvador-BA. Data collection was carried out from July to September 2017, through semi-structured interviews and analysis was performed using the Discourse of the Collective Subject.

Results: The results indicate 4 central axes: *Women's emotional status is altered in the process of spontaneous abortion*; *After everything was prepared for birth, loss came with a stillborn fetus*; *Partner and family support generates strength to support the loss process*; *The absence of a qualified team and institutional racism intensify feelings in the loss process*.

Conclusion: It is concluded that the pain experienced in the experience and the crisis immediately installed in the lives of these women are little welcomed by the health system and felt as not seen by society. They feel the need for someone else who understands their pain and not just those who have had an equal experience.

Resumo

Objetivo: Compreender as experiências das mulheres com doença falciforme diante de perdas gestacionais provocadas por aborto espontâneo e natimorto.

Métodos: Trata-se de estudo descritivo, exploratório, com abordagem qualitativa, desenvolvido com 20 mulheres diagnosticadas com doença falciforme e atendidas em um ambulatório de referência do município de Salvador-BA. A coleta dos dados foi realizada no período de julho a setembro de 2017, através de entrevista semiestruturada e a análise foi realizada utilizando-se o Discurso do Sujeito Coletivo.

Resultados: Os resultados indicam 4 eixos centrais: o estado emocional das mulheres é alterado no processo do abortamento espontâneo; Após tudo preparado para o nascimento, veio a perda com o feto natimorto; O apoio do companheiro e da família, gera forças para suportar o processo de perda; A ausência de equipe qualificada e o racismo institucional intensificam os sentimentos no processo de perda.

Conclusão: Conclui-se que a dor vivida na experiência e a crise imediatamente instalada na vida dessas mulheres são pouco acolhidas pelo sistema de saúde e sentidas como não vistas pela sociedade. Elas sentem a necessidade de que exista mais alguém que compreenda sua dor e não apenas as que tenham passado por uma experiência igual.

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Resumen

Objetivo: Comprender las experiencias de las mujeres con anemia falciforme ante pérdidas gestacionales provocadas por aborto espontáneo y mortinato.

Métodos: Se trata de un estudio descriptivo, exploratorio, con enfoque cualitativo, llevado a cabo con 20 mujeres diagnosticadas con anemia falciforme y atendidas en consultorios externos de referencia del municipio de Salvador, estado de Bahia. La recopilación de datos se realizó en el período de julio a septiembre de 2017 mediante entrevista semiestructurada, y el análisis se realizó utilizando el Discurso del Sujeto Colectivo.

Resultados: Los resultados indican cuatro ejes centrales: El estado emocional de las mujeres se ve alterado en el proceso del aborto espontáneo; Después de tener todo preparado para el nacimiento, ocurrió la pérdida con el feto mortinato; El apoyo del compañero y de la familia genera fuerzas para sobrellevar el proceso de la pérdida; La ausencia de un equipo calificado y el racismo institucional intensifican los sentimientos en el proceso de pérdida.

Conclusión: Se concluye que el dolor vivido durante la experiencia y la crisis inmediatamente instalada en la vida de estas mujeres tienen poca contención por parte del sistema de salud y parece que no son vistos por la sociedad. Ellas sienten la necesidad de que exista alguien más que comprenda su dolor, no solo las personas que pasaron por la misma experiencia.

Introduction

Sickle cell disease (SCD) is a genetic disease that causes different problems in the lives of people who have the disease and their families. In the case of women, interference can be observed throughout their life cycle, from growth and development, sexual maturation, late menarche, changes in the pregnancy-puerperal cycle and maternal-fetal complications.[1]

According to the Brazilian National Neonatal Screening Program (PNTN - *Programa Nacional de Triagem Neonatal*) of the Brazilian Ministry of Health, SCD predominates among black people, each year 3,500 children are born with SCD and 200,000 with sickle cell trait.

As with other chronic diseases, pregnancy in women living with SCD is considered to be at high risk, with high rates of maternal and neonatal morbidity and mortality. Pregnancy is a moment that requires a woman to adjust her entire life, needing to adapt to physical and psychological changes, changes in self-image. For women with SCD there is an increased risk in this period for pre-eclampsia, preterm delivery and restricted intrauterine growth (RIUG), puerperal infection, premature delivery, pregnancy loss, and stillbirth.[2,3]

Gestational loss is the most common complication of pregnancy, defined as elimination of the embryo or fetus before reaching viability. Psychological aspects related to this event can be enhanced in women with SCD, leading to a high frequency of emotional problems and this is a disorder present in 10 to 33% of cases.[4]

In view of all these aspects, pregnancy loss is a complex process, and it is important to understand aspects of this moment in the life of women with SCD. From these considerations, we realized the need to understand the experiences of women who went through this entire process of loss.

Child loss during pregnancy brings different reactions. There is a devaluation of self-image on the part of the woman, due to the feeling that her body could not function properly during pregnancy, or due to the belief that it was socially and culturally constructed that she is unable to perform her biological and conjugal role.[5,6]

Studies recognize that loss due to abortion, due to fetal or neonatal death, is a traumatic event. Among the reactions to loss are the temporary impediment in carrying out daily functions, social isolation, intrusive thoughts, feelings of longing and sadness, which vary and evolve over time.[6,7]

Despite the risks, the authors emphasize that, for these women, the act of generating a child creates the feeling that it is possible to overcome obstacles such as illness, death and risk, which represents a victory.[8]

Although women with SCD are more likely to be at risk during pregnancy, this is not an obstacle to the desire for motherhood. The desire to have a child often transcends the dimension of the disease. Sexual and reproductive rights guarantee women the power of decision over their bodies and their fertility by including the ethical principles of corporeal integrity, which guarantees rights to the security and control of their bodies,[1] women must to have the right to access, to quality assistance that has an expanded view of their needs, that has an awareness of class and race issues. Thus, having children is an option that, despite giving risks to the woman and the fetus, must be ensured based on quality prenatal care.[1]

Death before birth usually represents a great loss, especially for the mother, considering that it is the woman who experiences a loss that affects her body and all her feelings. It is a process of mourning, of interrupting dreams, hopes, expectations and planning that the couple normally deposits at birth and which are put on hold.[9]

From these considerations, we realized the need to understand aspects of this moment in the life of pregnant women with SCD, in order to improve women's quality of life and health, justifying the pertinence of investigating possible answers to the problem that moves this research, namely: how did women with SCD experience the process of pregnancy loss? The central objective of this article is to understand the experiences of women with SCD in relation to pregnancy losses due to spontaneous and stillborn abortions.

Methods

A qualitative, descriptive and exploratory research was conducted. The research was carried out in the city of Salvador with women who have a diagnosis of SCD and a history of pregnancy losses, followed up at the Municipal Outpatient Clinic for Viral Hepatitis and SCD.

The inclusion criteria were having a confirmed diagnosis of SCD with registration in the outpatient clinic, presenting a history of pregnancy loss regardless of the time of loss, aged over 18 years.

Data collection took place from July to September 2017. The interview with a semi-structured script was used as an instrument for data collection. Also, 20 face-to-face interviews were conducted in a reserved room, at the outpatient clinic, applied by the researcher, using an audio recorder. The interviews were transcribed in full and had an average duration of 30 minutes.

The Discourse of the Collective Subject (DCS) was used for data analysis, which consists of a qualitative way of representing the thought of a collective, which is done by aggregating discourse contents of a similar meaning, emitted by different people in a single speech-synthesis in response to open-ended interview questions.[10]

The verbal material collected was analyzed, extracting from each of the statements the central ideas and anchorages and their corresponding key expressions, which make up one or more synthesis speeches in the singular form of the first person. [10]

It is noteworthy that, in order to allow a better understanding of the study design, collection of empirical material, data analysis and interpretation, the consolidated criteria for reporting qualitative research (COREQ) were considered[11] as a support tool.

This study was approved by the Institutional Review Board of the Nursing School of *Universidade Federal da Bahi*a (EEUFBA), under Opinion 2,170,025 and CAAE 69026717.0.0000.5531, in compliance with the recommendations of Resolution 466/12 of the Brazilian National Health Council (*Conselho Nacional de Saúde*). Before signing the document, the information contained in the Informed Consent Form (ICF) was explained to each participant. Confidentiality about the identity of women was maintained.

Results

The study included 20 women who had a history of pregnancy loss and a confirmed diagnosis of SCD. The most frequent age group was between 35-39 years (30%). In relation to marital status, we found that the highest percentage were women married/in a stable relationship (50%) and a high frequency of women living alone (45%). Most are black (65%), all live in the municipality of Salvador. As for religion, although 15% said they have no religion, 30% are Catholic and 45% are Protestant.

Regarding education, we highlight participants who completed high school, which corresponded to 50%. As for family income, 50% have up to one minimum wage as family income and about 75% live in their own home.

Regarding the obstetric profile, about 70% of participants had more than 02 pregnancies, 65% had live children, 75% had a miscarriage and eight of them were in the first pregnancy and 25% had stillbirths, four of them in the first pregnancy.

In the first central idea of DCS, "Women's emotional status is altered in the process of spontaneous abortion", we identify, at the same time, the desire to be a mother and the disappointment of not having had the experience of maternity. In women with chronic illness, whose consciously desired pregnancy is lost, there is a change in identity, leading to the feeling of personal failure, becoming evident in this speech: "it was very difficult, it was very painful I got into depression, it was very difficult I wanted a lot having children and I didn't have it, it's a loneliness, I thought that when I had a child, I would have a partner for the rest of my life" (DCS1).

Guilt, depression and sadness are signs of psychological wounds suffered by women, indicating how deeply the loss sensitizes them, making them suffer physically and emotionally. "It is a huge sadness to lose a child, I went into depression for months I was locked in a room. At first, guilt came, because I didn't think it was an abortion and I kept putting on strength" (DCS2).

In the second DCS, "After everything was prepared for birth, loss came with a stillborn fetus". In the emotional and psychological field, when a pregnancy is interrupted by late loss, a different grieving process begins to be faced by the mother and the family. The death of a late fetus is also associated with the loss of a life project. Moreover, the fact that pregnancy is often experienced as a moment of fullness can increase the risks for traumatic effects when a loss occurs.

Loss is perceived by women as capable of provoking a grieving process "you know that feeling of grief when you lose a person you love, I felt the same thing, I spent almost a year sad" (DCS3).

The mother did not see her physical presence, but she feels her death as someone who has been by her side and is no longer there. This speech reveals a lot of expectations, plans and ideals: "I already talked to her in my belly, she kicked and moved a lot, she already understood what I was saying, I already imagined what she was going to be like, it was very sad to lose her like this" (DCS4).

In the third DCS, "Partner and family support generates strength to support the loss process", it is clear how important the presence of a partner and family members is in this difficult time. The difference in the emotional state of those receiving family support and those who are alone is visible.

The fact of being with his partner and mother, at this moment, does not dispense with the intervention of different professionals, forming a support network with other possibilities of psychosocial support. "When I learned that my son was dead, thank God my husband and mother were at my side, they held me up because it was hard to handle" (DCS5).

It is observed that despite the fear that the partner had with the possibility of death of both the wife and the child, to calm her down, he uses the argument of a new pregnancy and this is pointed out by women as something positive. "He even said that we should try again, he said that God would bless and provide us with a child" (DCS6). Although the woman received it in a positive way, this statement is very much linked to common sense because this type of speech and statement makes the grieving process difficult and devalues the loss.

The absence of social and professional support aimed at women's mental health results in emotional instability, causing feelings of anguish, conflicts and even depression. "I had no support from anyone at all, I felt alone, then my depression started, it was very hard to face this situation alone" (DCS7).

Finally, in the fourth DCS, "The absence of a qualified team and institutional racism intensify feelings in the loss process". Feelings and reactions to discrimination are indicated by the statements about sadness, malaise, the desire to cry and not wanting to talk about it. "I don't even like to talk about it, there are many women with SCD who think they are nothing in hospitals" (DCS8).

The different forms of violence and discrimination, observed through social and individual behaviors, directly impact the experiences of women and their health and shows suffering associated with being a black woman and the fact that they are poor: "look, I think this all happened because I am black and poor, these things make me mad" (DCS9).

It is also possible to perceive in the DCS that the care and treatment received differ when they are accompanied by a man, "look, they took a long

time to see me, because I went with my mother, and my husband was working, he came from work, when my husband got there and complained, I was assisted briefly" (DCS10).

Gender inequality is explicit because care is only given when the man, the husband, positions themselves in an environment where all patients are female. The social invisibility of these women makes their suffering invisible to health professionals and institutions.

Discussion

For many women, the experience of motherhood is a unique moment, with many expectations and feelings, especially when it refers to a state of waiting/uncertainty, as is the pregnancy of women with SCD, for an objective reality of motherhood. In this context, a set of peculiar feelings emerges, which elaborate meanings of being a mother.[12]

The authors[12] define motherhood in their study as a set of ambivalent feelings, which most of the time are lived secretly from the perception of motherhood. In this research, we observed that since the initial period of perception of pregnancy, women felt completely focused on the child, both in the objective aspects of their life, in the organization of space and time and in the subjective aspects, such as feeling the responsibility to take care of themselves, to feed themselves and lead their present and future life, clearly having the constant and dependent presence of a child.[12,13]

SCD can adversely influence the evolution of pregnancy, resulting in losses. Thus, pregnancy is a potentially serious situation, which can leave them even more fragile and insecure, expanding the emotional issues in this process of loss that, in addition to being physical, is emotional. There is a feeling of losing dreams and hopes, a feeling of annoyance, fear, guilt and a lack of emotional support, as they become more sensitive after going through this experience.[14,15]

In women's lives, pregnancy brings physical, behavioral and psychological changes. However, unplanned pregnancies can have significant consequences that influence quality of life.[16]

Spontaneous abortion produces both physical and emotional loss in women. The feelings perceived as most important in their lives were sadness, relief, concern, the desire to have their child alive, because, in addition to the loss, they feel they lose their dreams and hopes. There is also annoyance, fear, guilt and lack of emotional support, as they become more sensitive after going through this experience. The experience of this loss can also trigger disorders such as post-traumatic stress.[17]

Some studies report feelings of intense depression, which evolve to psychiatric conditions, with a frequency four times higher, in this segment, than in the general population.

As well as the report of the women interviewed in this research, the authors mentioned above indicate the depressive state of women who suffered some pregnancy loss, indicate the presence of feelings such as frustration, guilt, sadness, hostility, insecurity, and difficulty in expressing positive feelings.[15,17]

The experience of loss is extremely linked to the suffering and mourning that the event represents. Perinatal loss can exist from spontaneous abortion, fetal death, death related to complications in pregnancy and neonatal death as well as deaths occurring in the first month of life.[17]

As women reorganize themselves in the face of these changes, their identity, their interpersonal relationships and their view of themselves are also reformulated. Thus, pregnancy can be understood not as a period prior to motherhood, but as the first effective experiences in this role.[8]

In this regard, experiences related to pregnancy, especially childbirth, tend to raise positive fantasies to be relived in women's memories later. Corroborating the present study, a study[17] shows that when late fetal loss occurs, especially with pregnancy in a very advanced period, all these fantasies that were forming are replaced by feelings of mourning.

The state of mourning involves not only the understanding of a specific loss, but a positioning in the face of the formation and breaking of bonds. Moreover, it is possible that the death of a loved one also brings secondary losses, as it is not always clear at first glance what was lost in this relationship.[18]

We agree that the loss of a loved one is one of the most intensely painful experiences that human beings can undergo, difficult not only for those who experience it, but also for those who observe it, as they feel powerless to help.

The coping or recovery process takes place due to family support, which is the fundamental pillar for pregnant women's well-being. For those who have participative partners, this support is important because they usually experience psychological sensations similar to that of the woman, and in turn, the fact can have a favorable impact on the couple's relationship.[19]

For the case of subsequent pregnancies, having this support is essential to deal with anxieties related to pregnancy and the loss that previously occurred. In fact, this support network makes a pregnancy safer, making sure women can count on everyone around them.[20]

It is identified in DCS that the family is appointed as a reference of support for women. The support received is a factor that gives them support so that they do not give up taking care of themselves and reinforces that other people care and care about helping them.[20]

DCS showed other problems that these women went through during this experience such as institutional racism and lack of qualified staff to provide assistance.

Institutional violence in public maternity hospitals has been a recent topic of study in several countries. Research shows that, in addition to the economic and structural difficulties that public health services face, ill-treatment experienced by patients, socio-cultural aspects related to a discriminatory practice regarding gender, social class and race/ethnicity are underlying.[21,22]

This violence is expressed from neglect of care, social discrimination, verbal violence (rude treatment, threats, reprimands, screams, intentional humiliation) and physical violence (including non-use of analgesic medication when technically indicated), to abuse sexual.[22]

Therefore, in line with gender studies, institutional violence in public maternity hospitals in Brazil is determined, in part, by gender-based violence. In this context, the historical permanence of an ideology that naturalizes the physical and moral inferiority of women and their condition as biological reproducers underlies the determinant of their social role, allowing their bodies and their sexuality to be objects of medical control.[22,23]

Racial discrimination, which is present, means any kind of distinction, exclusion, restriction or preference based on race, color, descent or racial or ethnic origin, and can be repeated, imperceptibly, through the way people around them around are treated.[24,25]

This lack of perception of racial discrimination is part of the ideological construction about the myth of racial democracy, which hides the expression of racism, showing that Brazil is a country where relations between racial groups are harmonious and, therefore, racism is non-existent, it is also an instrument for the reproduction of unequal race relations.[25]

When these healthcare professionals see a black woman with SCD in front of them, the image that is formed is of the values historically attributed to this woman. Thus, "granting meaning to the other is a process that occurs due to the elimination of the resistance that the other can represent and operate".[26]

This social construction of what it means to be a woman and what it means to be a man is related to the patriarchal system, here understood as a system of male domination, with historical constitution and foundation, in which the man mainly organizes and directs social life.[26] It was evident in the DCS that women were only heard and assisted in the presence of a male figure, making gender prejudice and inequality visible in an environment that is mostly female users.

Prejudice and discrimination, based on the aforementioned axes, produce harmful effects on women. Furthermore, racial and gender discrimination are also produced in the relationships that are established in health services, resulting in different forms of violence such as obstetrics, which primarily affects black women.

Considering quality of care, these attitudes meet the most holistic and humanized care, in a way of looking at and meeting the needs of each subject

in their specificity, life history, but also of looking at them as subjects of a collective, subjects of the history of many lives.[27]

As a limitation of this research, the scarcity of materials on pregnancy losses in women with SCD stand out, impairing or even limiting the discussion on the subject in a more up-to-date way.

Conclusion

The loss of a child before birth certainly has a great emotional impact on the woman and her family. Regardless of the gestational period and whether they were primiparous or not, participants showed a lot of sadness, guilt, suffering, pain, anguish, fear, depression and grief in the face of the loss, seeking explanations to try to justify and explain such an unexpected situation, which is not always possible. Often, family and/or partner support can be a protective factor for women with SCD. In this case, the family can promote individual resilience, favoring the coping with the loss and complications of the disease. Racial discrimination, which is constantly present in women's lives also because of SCD, is reflected through an inadequate assistance that contributes to racial inequalities in health. Based on the analyzed DCS, we point out that women are inserted in a space where discrimination practices based on race/color, class and gender are present, producing simultaneous and varied, but harmful processes. This study is relevant, as it provides subsidies for health professionals, especially nurses, to organize their guidance practices for self-care for pregnant women with SCD and assistance to alleviate the emotional problems of both the patients and their family. It shows the need for change in care relationships and the importance of determinants of health for developing care strategies and organizing services.

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Collaborations

Silva UB conceived and designed the study, carried out the research, collected, analyzed and interpreted data, drafted the article, critically reviewed intellectual content and finally approved the version to be published. Ferreira SL contributed to the study conception and design, writing of the article, relevant critical review of intellectual content and final approval of the version to be published. Cordeiro RC, Almeida LCG and Santos EA contributed to the writing of the article, relevant critical review of intellectual content and final approval of the version to be published.

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