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RESEARCH

Experiences with severe maternal morbidity: a qualitative study on the perception of women

Experiências em morbidade maternal grave: estudo qualitativo sobre a percepção de mulheres

Relatos de morbilidad materna grave: estudio cualitativo sobre la percepción de mujeres

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ABSTRACT

Objective: to know and analyze the experiences of women who developed an episode of Severe Maternal Morbidity. **Method**: this is a qualitative study, in which we interviewed 16 women admitted to a tertiary level hospital, as a result of this morbid state. We used content analysis in data processing. **Results**: two categories were identified: "Understanding maternal morbidity as a negative presence" and "Moving ahead: on constant alert". The interviewees mentioned negative aspects, such as treatment difficulties and hospitalization, feelings of fear, concern for the fetus, frustration with the idealized pregnancy, trauma; and positive aspects, such as learning and the expression of the divine will in the experience of illness. **Conclusion**: effective care during the prenatal period, delivery and postpartum period should provide adequate support for the prevention and assistance in Severe Maternal Morbidity.
Descriptors: Maternal Welfare; Maternal Health; Pregnancy Complications; High Risk Pregnancy; Morbidity.

RESUMO

Objetivo: conhecer e analisar as vivências de mulheres que desenvolveram um episódio de Morbidade Materna Grave. **Método:** trata-se de um estudo qualitativo, no qual foram entrevistadas 16 mulheres internadas em hospital de nível terciário, em decorrência deste estado mórbido. Utilizou-se a análise de conteúdo no tratamento dos dados. **Resultados:** Foram identificadas duas categorias: "Compreendendo a morbidade materna como uma presença negativa" e "Seguir em frente: em alerta constante". Foram mencionados pelas entrevistadas aspectos negativos, como dificuldades do tratamento e hospitalização, sentimentos de medo, preocupação com o feto, frustração da gravidez idealizada, trauma; e aspectos positivos, como aprendizado e expressão da vontade divina na experiência da enfermidade. **Conclusão:** o cuidado efetivo no pré-natal, parto e puerpério deve prover suporte adequado para prevenção e assistência na Morbidade Materna Grave.
Descritores: Bem-Estar Materno; Saúde Materna; Complicações na Gravidez; Gravidez de Alto Risco; Morbidade.

RESUMEN

Objetivo: conocer y evaluar los relatos de mujeres que tuvieron morbilidad materna grave. **Método**: se trata de un estudio cualitativo, en el que se entrevistaron 16 mujeres ingresadas en un hospital de nivel terciario, debido a un estado mórbido. Se empleó el análisis de contenido en el trabajo con los datos. **Resultados**: se clasificaron dos categorías: "Comprendo la morbilidad materna como algo negativo" y "Sigo adelante: en constante alerta". Las entrevistadas relataron aspectos negativos —dificultades en el tratamiento y hospitalización, sentimientos como miedo, preocupaciones con el feto, frustración de un embarazo idealizado, trauma—; y aspectos positivos —aprendizaje y la voluntad divina en la experiencia de la enfermedad. **Conclusión**: el cuidado eficaz en el prenatal, el parto y el puerperio puede promocionar un adecuado suporte en la prevención y atención en la morbilidad materna grave.
Descriptores: Bienestar Materno; Salud Materna; Complicaciones en el Embarazo; Embarazo de Alto Riesgo; Morbilidad.

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INTRODUCTION

Severe Maternal Morbidity is a *continuum* that begins with the occurrence of a complication during pregnancy, delivery or postpartum and the outcome of which can be death, allowing for the recognition of a separate group of extreme gravity known as *near miss*[1]. It represents conditions of extreme gravity or near death[2]. The classification criteria of Severe Maternal Morbidity were standardized by the World Health Organization in 2011[3]; previous studies showed significant variation in the estimates of the event[4-5]. It is estimated that up to 20 cases of severe morbidity occur for each registered maternal death and up to a quarter of the women can suffer severe and permanent sequelae[6].

Since it is a recent theme, little is known about the effects of Severe Maternal Morbidity in the long term for the health of these women. The way they adapted, reacted and the meaning of this experience are aspects little studied thus far. We believe that the Severe Maternal Morbidity experience can negatively affect the quality of life of women, their children and their families, reflecting negatively on quality of life and also persisting for a long period after the event.

The scientific literature contains reports of women who felt anguished and anxious by the lack of knowledge and information about their health status at the time of illness and hospitalization due to events of Severe Maternal Morbidity[7-9]. Listening to these women would make it possible to target them more effectively and contribute to better handling the difficulties that arise from the morbid event.

It is also known that Severe Maternal Morbidity goes beyond physiological complications and permeates all aspects of women's lives. The 5th Millennium Development Goal is to improve maternal health and therefore reduce maternal mortality by three quarters between the years of 1990 and 2015. The desired goal is a maximum of 16 maternal deaths per 100,000 live births[10]. Currently, maternal mortality in Brazil is 69/100,000 live births[11]. To achieve this goal, we need to understand precisely the causes and reasons for maternal mortality and possible assertive interventions. We hope the study of social representations of women who were at risk of death during pregnancy and childbirth will be able to offer us elements to understand this experience to broaden the scope of knowledge and performance in the clinical nursing practice.

Given these considerations, this study's objective was to understand the meanings attributed by women to the experience of Severe Maternal Morbidity in their last pregnancy and childbirth cycle.

METHOD

Theoretical and Methodological Framework

This is a descriptive study with a qualitative methodological approach, based on the conceptual aspects of the Theory of Social Representations[12]. Through qualitative research, from the perspective of social representations, it is possible to have access to what women, pregnant women or postpartum women survivors of an episode of Severe Maternal Morbidity know and think, and what are their behaviors regarding getting sick during the pregnancy and childbirth cycle, thus contributing for the development of preventive strategies of maternal mortality and health problems in women during this period.

To substantiate the analysis and discussion of the data, we adopted the theoretical framework of social representation within a cultural perspective.

Methodological Procedures

Study scenario

The survey was conducted in the city of Ribeirão Preto, São Paulo, Brazil, with identification and recruitment of participants occurring within a tertiary level hospital, regional reference for care in obstetrics, including care to Severe Maternal Morbidity, which justifies its choice as study scenario.

Source of data

Women hospitalized due to an episode of Severe Maternal Morbidity were identified and invited to participate in this research. Women diagnosed with organ dysfunction according to the criteria of Severe Maternal Morbidity[3] and residing in Ribeirão Preto were included. Women whose newborns died after birth, were born with severe disabilities or were hospitalized, were excluded, when the selection was performed during the postpartum period. We justified the exclusion by the fact that these situations themselves are already favorable to maternal emotional changes, making it difficult to link them directly to the situation of Severe Maternal Morbidity.

The sample was defined according to the concept of theoretical saturation, when the information became repetitive and the material obtained responded to the proposed objectives.

Data collection and organization

During the data collection period, 35 women met the criteria for participation in the study, and 16 were later added to the sample. To ensure privacy, anonymity and confidentiality of information, the study participants are identified in the speeches by pseudonyms they chose.

The first contact occurred after the certification of the welfare status of the women. In this meeting, the objectives of the research were explained, its purpose, an agreement was signed for their participation in the second meeting, for the interview, and an informed consent form was signed.

Data collection was performed within the first 30 days after hospital discharge, through: (i) psychosocial and sociodemographic questionnaire developed to obtain demographic, social, obstetrical information and as well as information regarding the Severe Maternal Morbidity event; (ii) semi-structured interviews, guided by base questions that permeated the central theme, such as the actions taken with self-care, the experience of living through an episode of Severe Maternal Morbidity, of surviving and what the consequences and expectations are after the morbid event. The interview was operationalized in the home of each woman or another place of their choice, recorded and then transcribed for analysis.

Data analysis

Subsequently, we proceeded to the thematic content analysis, proposed by Bardin[13], with the final content being grouped by thematic similarity, thus resulting in the identification of two categories. I) "Understanding maternal morbidity as a negative presence". II) "Moving ahead: on constant alert".

Ethical aspects

This research project was approved by the Ethics Committee, and all participants signed an informed consent form.

RESULTS

Regarding the socioeconomic and demographic profile of the sample, we have that the age of the 16 participants ranged from 16 to 37 years, with a mean of 25.5 years. Half of the women completed high school, nine women said they were married, eight were currently working, four in the informal market. Most (12 women) reported having black or *pardo* skin color. Most women lived with other family members, with a per capita income within the poverty range. Almost half of the women interviewed declared being financially dependent of their family.

The results of the analysis of obstetrical and clinical variables identified seven currently pregnant, nine were recent mothers, six were close to giving birth and 10 were multiparous. The average number of children was 1.5 children per woman. Regarding the identified morbidity criteria, eight women had hypertensive complications and five had renal complications, one woman had hypertension and renal complications, one woman had septic shock and one had severe asthma. Regarding the form of resolution of pregnancy, among the nine new mothers interviewed, five underwent cesarean section and three had normal deliveries.

The analysis of the interviews allowed us to identify two categories on the experience of Severe Maternal Morbidity: *Understanding maternal morbidity as a negative presence*; and *Moving ahead: on constant alert*.

Understanding maternal morbidity as a negative presence

When approached about their health conditions during their last pregnancy, most women interviewed reported having a difficult pregnancy due to health complications, treatment and imminent risks.

> *Very complicated.* [...] *it was because of the high pressure I had. I spent the pregnancy from beginning to end... suffering. One day I was fine, the other day I was bad.* (Sofia)

> *Because in the early morning I began having pain in my back and stomach. Then I started... it was pain, it was pain so unbearable that I wanted to hit my head on the wall or walk away, so unbearable it was. Then I saw I was no longer well.* (Laura)

The reports show that those interviewed refer characteristic symptoms of severe maternal morbidity linked to cardiovascular and uterine systems dysfunctions[6].

An experience of Severe Maternal Morbidity was also reported as a source of fear:

> *I was traumatized. I was even afraid to die. I had pre-eclampsia. I never thought it would happen to me.* [...] *The doctors said it was a miracle I survived. Gosh, I was kind of traumatized!* (Raquel)

> *Oh, I was mad. I was afraid* [...] *I almost died.* (Rafaela)

Besides being afraid for their own health, during episodes of Severe Maternal Morbidity, there is also concern for the health of the fetus, as evidenced by the following speeches:

> *The doctor said it was risky to keep him in my belly, so he took him out. Thankfully, he didn't have to stay in the incubator, nothing like that. He stayed with me.* [...] *Then, after I was calmed down, I was getting calm, because I saw it was risky for my son.* (Bruna)

> *I was afraid she would be born with some problem. But she had nothing. It was silly of me.* [...] *She took the foot test and had nothing.* (Raquel)

Another representation seized in the context of difficulties of experience, was the perception of being unable to perform daily and work activities:

> *A sick person... it's hard to work, sick people stay in bed...* (Catarina)

> *The disease is one thing that knocks us down. We have to depend on a lot of people.* (Laura)

> *Yeah, I started having a lot of headaches, a lot of dizziness. I even fainted at work twice.* (Laiane)

> *Oh, I try to think that is not interfering. That all is right. But I don't know* [...] *it's unemployment, it's a lot of stuff.* (Marina)

Still within the negativity of the experience, two key aspects were identified that put the experience of Severe Maternal Morbidity into perspective: treatment and hospitalization. When asked about the pregnancy, most women linked it to morbidity through the treatment and hospitalization that resulted from the situation getting worse.

> *You have to take medicine. You have to go to the hospital. It's something no one wants. That completely stops people's lives.* (Laura)

> *So, I was more in the hospital than at home with the pregnancy I had.* (Sofia)

The medication was, also, a reason for concern, regarding the repercussions it could have on the fetus, thus becoming another stress factor for some women:

> [...] *you with your concern. Will I have to take medicine, will it pass to my child?* (Valentina)

Not even that I could do, breastfeed. Because of the strong medications. (Raquel)

Treatment was understood by these women as necessary, but also as a source of suffering, insecurities and anxieties. Medications, although a source of insecurity for some women due to fear of complications to the fetus, were mentioned as being necessary to control morbidity.

For me, it was bad. Because I had never had that. So it was those pills all the time. (Raquel)

Every time, medication, medication, medication. They gave me medicine. I left, came here and began to feel ill. (Bruna)

Women also linked the severity of the morbid event to the duration of the hospitalization period. Being hospitalized during the pregnancy and childbirth cycle makes the disease a concrete matter, visible and public.

It was horrible. Changed me completely. I got nervous. Because I have two little ones too. I was stuck. Because all the hospitalizations that I had, I was there for more than five days. And once I stayed for eighteen days. It impacted a lot with my emotions. (Sofia)

The change in their routine and the imposition of routines, in a reverse effect on the treatment of the disease, were set out by one of the participants as a difficulty faced during hospitalization:

They want me to stay in bed, I can't stay lying down. Then I get scared, you know? [...] *And here I have to lie, it's where the pressure goes down.* (Marina)

The experience was not very good. I did not like, no. [...] *I couldn't do anything. Depended on them. I had nurses who had no patience with me.* [...] *Then, oftentimes I also thrashed a lot. They tied me to the bed.* (Raquel)

On the other hand, some participants mentioned positive aspects of the experience of Severe Maternal Morbidity. One of the women saw this experience as a source of learning; the other as a divine purpose. The participant summarizes that, due to their serious health condition, her family became more united and close.

I think like this: God does not make us go through anything without a purpose... what this brought was that it helped us to be closer. The day I got really sick, the girl from the obstetrical center was talking like this: 'it seems that your whole family is there at the door'. [...] *They all came on the day of visit and started fighting because everyone wanted to come up! Everyone got closer, you know?* (Laiane)

Moving ahead: on constant alert

As part of the *corpus*, we also identified the presence of frustration with the idealized pregnancy, trauma and learning.

Then, every hour was one problem after another. Something we don't expect when you're pregnant. We expect to have a healthy pregnancy, a good thing. So, you see a lot of people talking; 'Ah, pregnancy is a time when you... are at your best'. Not me. In my pregnancy, I felt pain from beginning to end. (Mônica)

It was a quiet pregnancy up to seven months. Now, I began having high blood pressure, breathlessness. (Camila)

Complications that characterize Severe Maternal Morbidity can make women feel frustrated for not having an idealized pregnancy.

Oh, I did not regret it [...] *because it was what I wanted for myself, but* [...] *mothers soon went home, breastfed. I couldn't do even that, breastfeed. If I knew it was going to have all these complications, I think I would not have tried getting pregnant.* (Raquel)

Even if at a given moment, they show no symptoms of morbidity during pregnancy and puerperium, the threat of relapse is present, which generates anxiety and insecurity.

But now, I... any little thing I'm afraid of getting sick. But now, thank God, I'm fine. I'm recovering very well. Now I can't be doing any extravagance, right? Now I have to be a little quieter (laughs). (Laura)

Still have that pressure, for those who have high blood pressure problems, no way, right? Even taking the medication, you know that sometimes destabilizing happens. So for me, it's living one day after the other. (Joana)

On the other hand, while still experiencing the morbid event, some participants expressed expectations of improvement and overcoming morbidity after birth.

As a result of an intense emotional experience, some behavioral changes were mentioned by the women, in the form of an increased attention to health.

I think the time of birth will come and the baby will be well. After the baby is born, I won't have this problem anymore. The pressure will lower, will normalize. (Camila)

But then, we have to take more care, right? [...] *so it won't happen all over again.* (Vanessa)

Another consequence was the attention to the diet identified in the speech of some women, such as the reduction in salt intake, among those who had hypertensive complications. The women who had renal complications, on the other hand, said they had to increase their water intake.

Oh, I changed like, I think it was my feeding habits. Having to take care of myself more, drinking more water. Because I had a lot of infection. It impacted the renal part too. (Mônica)

You have to eat food with no salt... a little. Food have no taste. It's bad. But I have to take care of my health. I have to... take care of the health of my children as well. (Rafaela)

In addition, women showed feelings of guilt due to overeating.

> *It was like, a little bit because of me. Because I abused a little bit of what I ate. So I've been a little guilty, now I can see that.* (Leticia)

Another aspect presented in the statements of three of the women interviewed, who said they had "got" tubal ligation with the justification of avoiding complications that may lead to their deaths. Although they are women between 22 and 33 years of age, with at least three children, with one having only one daughter.

> *The lady (don't know if she's a doctor or a nurse) came in to the room and told me that I was getting a tubal ligation, because I could longer get pregnant. No way I could.* (Raquel)

DISCUSSION

We identified various aspects of maternal morbidity referred by women as dificulties. We identified in their discourse, as the core of social representation, pregnancy as a negative event linked to aspects of disease, such as symptoms, treatment and prognosis. Studies on the significance of the experience of Severe Maternal Morbidity also report a strong relationship between pregnancy and the negative experience of morbidity[8,14].

Severe pain, discomfort and malaise, symptoms triggered by cardiovascular and urinary systems dysfunctions, give the pregnant woman the perception of something unusual with the pregnancy. Since women were being or had been accompanied by prenatal consultations, it became evident the inadequate management of their hypertension. Studies show that maternal mortality indicators are sensitive to the obstetric care they receive[15]. Thus, the quality of obstetric care can aid in reducing the occurrence of maternal death[16].

Concerns about the baby's health may be present in a normal pregnancy[17]. However, the real threat to the health and life of woman and baby can intensify emotions, turning pregnancy into a moment of great anguish and suffering, as mentioned by the women interviewed in this and another study performed in Brazil[8,18]. Such emotions should not be ignored, since they can serve as a trigger for the onset of major mental disorders, quite common in women of reproductive age. Thus, it is of utmost importance to improve mental health care of pregnant and postpartum women who experience an episode of Severe Maternal Morbidity.

When thinking about work, we understand the importance of the well-being for women to continue performing their activities. The work outside the home, even if informally, guarantees the survival of the family or even part of it[19]. Complications in the pregnancy and childbirth cycle can put them at risk of losing their jobs, further destabilizing the family income. And, even if women are involved with some kind of self-employment, profit may be compromised with the reduction of productivity in these activities.

Treatment and hospitalization were also mentioned by the women as negative aspects of their experience with Severe Maternal Morbidity. The adaptations regarding time, food and daily rhythm, necessary during treatment, require a great commitment from the patient and can be seen as a downside of the treatment[20].

In addition to limiting the autonomy and activities of the patients, hospitalization, in turn, raises concerns with the children left at home, other family members and home maintenance. The perception that the hospital is a hardship for the patient was also identified in a study conducted in southern Brazil[21].

We noted, in the discourse of the women interviewed, the issue of institutional violence in maternity wards, as recurrent and that, despite government efforts, remains as a discriminatory, punitive and correctional culture directed at women as well as the characteristics of a professional-user relationship: authoritarian, with discriminatory, inhuman or degrading treatment[22]. Fighting this reality stands out as one of the Ministry of Health focal points, with the implementation of the Stork Network (*Rede Cegonha*) and the dissemination of experiences, proposals and strategies to reconcile human rights and good practice in obstetrics[23].

In this context, among the difficulties reported by the women, we have the quality of care in health services, as well as the lack of information and communication by health professionals. The routine work determined by the hospital organization and the professional training in a biomedical model are not conducive to a comprehensive and humanized care[24]. Such factors may result in more feelings of fear and anxiety, increasing also the risks to the health of mother and child[6].

We can infer that the experience of Severe Maternal Morbidity seems to have been felt more deeply than the experience of pregnancy, which raises the question: if overcoming the problem becomes the center of the pregnancy and childbirth cycle, how are the psychological, social and cultural changes caused by a new pregnancy to be handled? To the morbid event, the natural adaptive needs of pregnancy are added, experienced by women in a short period of time. This overload of events should be considered by health services and professionals not only during pregnancy but also after childbirth, thus ensuring that women receive the necessary support to their needs.

In the maternity vision culturally constructed as natural, intrinsically related to the female role and sometimes the only source of fulfillment for women[25], opposes a different experience from that lived by women who had complications during pregnancy, leading them to be frustrated with the idealized pregnancy. However, despite these difficulties, those women interviewed showed themselves committed to overcoming the morbid event despite the constant fear of new complications.

The constant concern with the treatment of morbidity, in chronic cases, and the fear of a relapse may have motivated the changes in eating habits mentioned by the women interviewed.

Although important, behavioral changes cited by the women were isolated events and appear to be motivated by the fear of new episodes, and on itself, may not be sufficient for effective remission and prevention. Noteworthy is the absence or insufficiency of education actions for women's health, aiming for changes through a perspective of completeness and quality of life, which is not restricted solely to changes in how they related to food[6].

Studies performed in Brazil[7-8,18] identified the feeling of guilt suffered due to complications faced by some women who have had an episode of Severe Maternal Morbidity. In this study, the feeling of guilt was linked to their eating habits

which, from the point of view of these women, could have caused the morbid event.

It was possible, therefore, to identify some changes in behavior as a way of coping with Severe Maternal Morbidity. However, tubal ligation was introduced to some women as an important strategy to prevent future morbid events.

In contrast to the only possibility of a definitive procedure, such as tubal ligation, PAHO[6] considers as a strategic area in the Plan of Action to Accelerate the Reduction of Maternal Mortality and Severe Maternal Morbidity, the increase in the coverage of contraceptive methods and the availability of counseling services in family planning for the prevention of unwanted pregnancy and complications resulting therefrom. However, surgical sterilization is not really considered as a contraceptive option, but the solution to concerns about future unwanted pregnancies[26].

The emphasis on health education and appropriate information to different contexts women are present in the literature and in official documents, which aim to reduce maternal mortality and severe maternal morbidity, and to improve women's rights and their autonomy for reproduction and planning their families. Conducting educational groups for pregnant women is an important tool in reducing maternal and neonatal mortality among women living in rural areas, and should be considered in other contexts[27]. In Brazil, however, conducting groups with pregnant women is still an underused strategy.

This article shows the amplitude of the interference of the experience of Severe Maternal Morbidity in women's lives, involving emotional, social, economic and institutional aspects. Reinforcing the need for more effective actions in the care of women with Severe Maternal Morbidity. Since this is a qualitative study, the results are not susceptible to generalizations, which requires additional studies in different sociocultural contexts. Moreover, possible reminiscences of the morbid event were not identified in the women interviewed.

FINAL CONSIDERATIONS

Due to the severity of maternal morbidity in women's lives, we highlight the importance of prevention and control. In this sense, the reports registered here allow us to extrapolate the analysis of the experience itself and point out possible deficiencies or difficulties in controlling and monitoring Severe Maternal Morbidity through the obstetric care that the women participating in this study received. In the reported cases, only after the onset of strong symptoms that pregnant women received proper care for themselves and for others.

It is, therefore, essential to perform studies addressing the experience of women who survived episodes of Severe Maternal Morbidity, both regarding the social relevance of opening qualified listening channels and the knowledge of subjective questions, necessary since such morbid event has not only a physical genesis, its repercussions reach various dimensions of women's lives, their children and their families. Prevention and skilled management of Severe Maternal Morbidity impacted in reducing maternal mortality.

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