

Repercussions of Near miss and women's perception of care received in the critical care unit*

“Near miss”: repercussões e percepção da assistência recebida por mulheres sobreviventes egressas de uma unidade de terapia intensiva

“Near miss”: repercusiones y percepción de la asistencia recibida por mujeres sobrevivientes egresadas de una unidad de cuidados intensivos

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ABSTRACT

Objective: To report the repercussions of near miss on the life of women who survived that event and the women's perception of the care received during the near miss event in the critical care unit. **Methods:** This was a qualitative study using oral history interviewing. Medical anthropology served as the conceptual framework for the study. Data were collected from 2003 to 2005 through narrative interviews with 13 women who were discharged from a critical care unit and who were residents in Fernandópolis, SP. **Results:** Some of the women reported that the experience of near miss brought suffering and sequelae such as infertility, depressive symptoms, and lack of perspectives in life. Other women were able to adjust and redirect their life. Many women complained of the care received, and the negligence and/or incompetence of health care professionals during the near miss event. **Conclusion:** The study's findings allowed us to understand the experience of this sample of women and suggested they receive a dehumanized care. There is a need for further studies regarding health care professional ethical behaviors.

Keywords: Pregnancy complications; Women's health; Reproductive medicine

RESUMO

Objetivo: Relatar as repercussões do “near miss” para a vida de mulheres sobreviventes e a percepção da assistência recebida. **Métodos:** Trata-se de pesquisa qualitativa fundamentada na história oral. Foram utilizados conceitos da Antropologia Médica como referencial teórico. Para a coleta de dados foram realizadas entrevistas organizadas em narrativas com 13 mulheres egressas de uma UTI, durante o período de 2003 a 2005, residentes em Fernandópolis, SP. **Resultados:** Os resultados mostraram que para algumas mulheres a experiência foi sofrida e deixou marcas, como a perda da fertilidade, sintomas depressivos, resignação ou falta de perspectiva de vida. Outras conseguiram ajustar-se e redirecionar suas vidas. Muitas se queixaram da assistência recebida, da negligência e ou imperícia dos profissionais durante o evento. **Conclusão:** Os resultados permitiram compreender a experiência das mulheres e apontaram para a desumanização do cuidado indicando a necessidade de estudos a respeito de questões éticas relativas às ações dos profissionais.

Descritores: Complicações na gravidez; Saúde da mulher; Medicina reprodutiva

RESUMEN

Objetivo: Relatar las repercusiones del “near miss” para la vida de mujeres sobrevivientes y la percepción de la asistencia recibida. **Métodos:** Se trata de una investigación cualitativa fundamentada en la historia oral. Como referencial teórico fueron utilizados conceptos de la Antropología Médica. Para la recolección de datos se llevaron a cabo entrevistas organizadas en narrativas con 13 mujeres egresadas de una UCI, durante el período del 2003 al 2005, residentes en Fernandópolis, SP. **Resultados:** Los resultados mostraron que para algunas mujeres la experiencia fue de sufrimiento y dejó marcas, como la pérdida de la fertilidad, síntomas depresivos, resignación o falta de perspectiva de vida. Otras consiguieron ajustarse y reorientar sus vidas. Muchas se quejaron de la asistencia recibida, de la negligencia y o inexperiencia de los profesionales durante el evento. **Conclusión:** Los resultados permitieron comprender la experiencia de las mujeres y apuntaron hacia la deshumanización del cuidado indicando la necesidad de estudios respecto a cuestiones éticas relativas a las acciones de los profesionales.

Descritores: complicaciones del embarazo; Salud de la mujer; Medicina reproductiva

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INTRODUCTION

The Brazilian government considered the year 2004 as the International Women's Year, when the 1st National Conference on Women's Policies was held. This conference was organized by the Department of Women's Policies, in the city of Brasília, in July, aiming to contribute with the construction of public gender policies such as "all women's right and government's duty", in the field of health, work, education and citizenship⁽¹⁾.

This event occurred from the need to prioritize actions aimed at women's health, taking into consideration health indicators that challenge health services and society as a whole. High maternal and neonatal mortality rates represent a violation of women's and children's rights to health, affect the Brazilian regions unequally and prevail in the lower social classes⁽²⁾.

Despite all advancements and achievements obtained by women in the last century, many of them still die or become ill as a result of health problems in the pregnancy and infancy period, others survive the potential maternal death risk.

In the last decades, the theme of maternal mortality has been a reason for concern by researchers, especially in developing or underdeveloped countries. Brazilian researchers' attention has usually turned to local statistical data, causes of maternal mortality, risk factors and strategies to reduce maternal mortality⁽³⁾.

In addition to mortality, there has been a growing interest in maternal morbidity. It is relevant to understand why women are becoming ill, what is causing their illness and what the repercussions for their health are.

In the literature, "near miss event" means an adverse clinical occurrence. It is a term employed by air traffic control to designate an accident that nearly happened, but, for some reason, by chance or as the result of a decision, was not observed. This term has been used by clinical medicine, and it can be employed in several situations. In the case of obstetrics, when thinking about maternal mortality, a near miss is usually an adverse and serious event that caused harm and morbidity to the mother who, somehow, survived⁽⁴⁻⁵⁾.

According to the World Health Organization, there is no universally applicable definition for the term "near miss". For audits or case analyses, one of the main advantages of using near miss cases, instead of maternal deaths, is that obstetric complications occur more frequently than deaths, enabling a broader quantitative analysis⁽⁶⁾.

Near miss events have harmful repercussions for the woman's and her family's physical, mental and social health.

In this sense, some studies on this theme have been performed, seeking to demonstrate conceptual and clinical

issues, but few mention the experience of a surviving woman. Thus, a study was performed, using hospitalization of women with severe obstetric or clinical complications during pregnancy, delivery or post-delivery, in intensive care units, as criterion of severe near miss maternal morbidity, aiming to broaden the view health professionals and all those involved have beyond quantitative issues (reason for maternal morbidity and mortality)⁽⁷⁾.

This study aimed to report the repercussions of near miss for the life of surviving women and also for the perception of health care received.

METHODS

This is a qualitative study that uses basic concepts of Medical Anthropology as theoretical framework and Oral History as methodological framework.

Oral History as methodological framework was used to collect data, because of the need to obtain accounts from women who identify with the experience of having gone through severe morbidity in the pregnancy-infancy period, i.e. they experienced a near loss of life due to serious complications. Thematic Oral History method was the category considered to be most appropriate for this study, as the narratives of women who survived the risk of maternal death form the main content of analysis. The investigation was developed in the countryside of the state of São Paulo, using the city of Fernandópolis as point of reference.

This research project was approved by the Review Board at Escola de Enfermagem da Universidade de São Paulo. The hospital authorized the study to be performed. All participants, after becoming aware of and being informed about the study's proposal, signed an Informed Consent Form, authorizing their participation in the research.

The guiding question was: "Tell me how it was for you to experience this moment of almost death in your life."

Research participants were 13 surviving women cared for in the Intensive Care Unit of a general hospital in the city of Fernandópolis, between 2003 and 2005, who had experienced a serious complication in the pregnancy-infancy cycle process.

The institution cares for users from the *Sistema Único de Saúde* (*SUS* – Single Health System) and other clients also covered by it, reaching 11 smaller neighboring cities. It is a service that provides low- and medium-complexity hospital care, outpatient clinic and emergency services. The hospital has 12 obstetric beds, of which ten are for the *SUS*. In the last three years, the total number of deliveries were 910 (2003); 858 (2004); and 833 (2005). Cesarean delivery rate varies between 50% and 60% (data

from the hospital's *Serviço de Arquivo Médico e Estatística - SAME/ Medical Archives and Statistics Service*)⁽⁷⁾.

Among the criteria defined, 35 transfers of pregnant women or those with infants who had serious complications were found.

The following step was to search for data on hospitalizations, addresses or telephone numbers and medical diagnoses, with definition of severe obstetric complications, in the *SAME*. Thus, of all the 35 transfers, 32 medical records were found.

Next, women were contacted to request their collaboration for the research to be performed. In this step, the main difficulties were dealt with, as some contacts failed due to change of address or inexistent addresses informed.

The decision to search for women who survived near miss maternal morbidity, in the records of a hospital's Intensive Care Unit in the city of Fernandópolis, was due to the convenience of contacting health team members.

Interviews were treated in three stages, as recommended by Meihy: transcription, textualization, and trans-creation⁽⁸⁾.

Thus, each participant's narratives were initially presented. Next, categories were created from these narratives to obtain an understanding of the group as a whole. These categories were classified, based on the topics reported, and subsequently grouped, thus originating the themes. The resulting themes were: Perception of the problem; Meanings and feelings experienced by the woman in the near miss experience process; Family participation in the woman's perspective; Event repercussions for women's lives.

Narrative analysis had Medical Anthropology as supporting framework, whose guiding foundations were the health-disease process and the experience of the pregnancy-infancy process by women who survived serious complications.

RESULTS

This article deals with themes on event repercussions for women's life and care received during the near miss morbidity process.

Event repercussions for women's lives

This theme comprises maternal morbidity repercussions for women's lives, included in the "health implications", "psychosocial aspects" and "perspectives of a new pregnancy" categories.

In terms of health implications, women reported they recovered from the obstetric complication; however, ambiguity was found in their speech, as they argued they were healthy, but complained about a "birth

experience trauma" and had misgivings about a new pregnancy.

Some women believed they recovered from the complication and their health improved, but their pre-existing diseases, arterial hypertension and diabetes continued:

...If I have to say I'm healthy now, well, I'm really healthy! Sometimes I feel sick, I got chest pains, my pressure goes up, and diabetes strikes... (...) I also smoke. (11)

One of the women reported she recovered from the complication, but, in order to live with the chronic diseases, she had to learn how to care for herself, know the disease, undergo the treatment, always have an activity to do and, above all, have a religion to feel comforted.

...now I take medicine for my pressure, diabetes and circulation. And I go about the rest of my life like this, working, fighting... Diabetes is a factor that comes into our lives and we have to learn to live with this problem! Well... spiritually speaking, I'm fine, thank God! 'Cause one thing leads to another. You got to have a spiritual side to be at peace with your life. (12)

For another woman, recovery was good and the loss of her uterus after the hemorrhagic event solved her problem of menstrual cramps:

...today I think I'm fine about this problem I've had. I feel better, I feel fine for not bleeding every month. It's much better than it used to be, when I had menstrual cramps and suffered. (14)

In terms of psychosocial aspects, the event brought changes for some women that may be classified as negative or positive. For others, the event of complication was resolved and decision making was thus enabled.

Some women pointed out negative health aspects resulting from the complication. They mentioned pains, insomnia, nervousness, feelings such as sadness, and resistance to accept their children's loss. They commented about the ways they found to reduce their discomforts and said they believed they would not recover:

...I have many headaches, almost every day. I also have many backaches where I had the anesthetic. I don't sleep right... I became very nervous too. ...I haven't recovered yet. Even though this is very difficult and I won't accept it anyway, I understand. (11)

Other women considered themselves to be more nervous than before:

...after the birth I got a little of a trauma (...) you may think I'm healthy (...) what really happens is that I'm afraid. I'm afraid of giving birth (...) the problem's the delivery, this is my fear. (12)

Some stories pointed to emotional difficulties that still remain, when they stated they needed to bottle up their feelings to spare the family. The pains, forgetfulness, insomnia, irritability, resentment and fear to leave home revealed the problem:

...I'm not sure if I've recovered, psychologically speaking. I don't think so. It's all bottled up, you know! This harms me, my husband, and my mother, because I involve everyone. It gets messy, so, I bottle up my feelings to avoid this, I pretend it's not about me. I let it all out only when I'm alone (...) And I got this headache here, it feels like I got something spinning in my head. It's something horrible and I forget. (...) I can't sleep well, it's always been like this, I just can't sleep (...) and now it's gotten worse, sometimes, I wake up at night with these things in my head, and it goes on until early in the morning. (I8)

Other women stated that the experience of complication left marks that are difficult to be erased, with changes of self-image, and also caused dependence on the husband's presence and depression:

...I had problems in my sexual relationship with my husband. What upset it was that I spent a long time without having sex (...) it was an ugly cut and the sutures were ugly. (I2)

Some women mentioned negative consequences such as: difficulties in their relationship with the husband, discomfort when other people are present and anti-social behavior:

...after the second pregnancy and the loss of the baby, my husband and I went through a very difficult time. This went on for a long time (...) it was very difficult for us to deal with this situation. (I3)

In several parts of the speech, expectation of life improvement was present, showing the woman's hope for the future:

...from now on... Ah! New life, it's gone, it's over. (I1)

For some women, experiencing this near-death process brought about positive consequences, especially in terms of maturity, family relationship and the recognition of the need to be more careful about their health. One woman mentioned God's grace in particular:

...my life's changed a lot, I've really grown. Psychologically speaking, nowadays, I see things in a different way. (...) to tell you the truth, God has given me another chance. (I10)

For one of the participants, the near miss experience brought about a different view of life; if there are days

when the person is "feeling down", they should not give up on life and unexpected experiences leave their marks in one's memory:

...I think like this (...) there are days when we feel blue. Little by little, we keep trying... and it's been a years and 23 days since I left the ICU and I got the impression that it was yesterday... Now, we got a different view. (I8)

The experience of serious complication, in addition to causing women to give up trying to have a child, leads them to make decisions that, perhaps, in a different situation, would not have been made, such as separating from the husband and leaving the mother-in-law's home:

...my life has changed, now I don't try it anymore. I haven't thought of having another child any longer. I don't know what my future is gonna be like, because we split up, but we're sort of... seeing each other. I like him, I think it can still work out, but to go on living with my mother-in-law! No, that just won't do! (I9)

In terms of reproductive life implications, reports show women's perception of the possibility of a new pregnancy.

One participant has good expectations about her future, but while she cannot become pregnant, she will try to live well with her husband and daughter. She was cautioned about the "divine warning" in the perspective of a new pregnancy:

...the only thing I think about is that my husband and I can forget about this problem that happened and give a lot of attention to our daughter, give her all that we can (...) This serious problem represented a lot to me. Even some relatives said something like this, 'D, it worked out this time! You got to thank God because you were saved, you were not supposed to be here now. So, think twice before having another child... What's more, this is the same as a God's warning. (I5)

Another woman's narrative revealed that the change occurred hindered the possibility of maternity even further, causing her to feel sad and resentful. She prefers not to make plans so she will not feel disappointed again:

...my life has changed, I got more bitter and sadder, you know? In a way, I feel calm and would like to have a son. Is it possible? No, it's not. There are so many out there who need a family! I'm gonna wait and try adoption, if this doesn't work out either, well, that's life! (...) I don't know what my future is gonna be like, never thought about it. (I13)

Two women showed insecurity concerning the future and have no plans or perspectives of any type:

...as for my future... I don't know, honestly, I don't know... (crying). (I3)

In the accounts of many women, the power of maternity is evident, even when experiencing serious complications, such as the risk of death and medical prohibition. They would like to be mothers again. Nonetheless, many emphasize their fear of becoming pregnant due to the possibility of going through the same experience. Few of them do not want children anymore, because they do not want to run the risk of dying again:

...I'm afraid to get pregnant again because of this. I wonder, 'Could I have a natural birth?' I always wanted to have a natural birth, but then I think about this question, 'What if it happens again?' And the fact that my uterus has been torn apart, I wonder if it's really closed. I don't know what to do. I think about having another child, but when I remember what happened... it's tough for me! (I2)

Even after experiencing two high-risk pregnancies and the difficulties resulting from a pre-existing disease or one caused by pregnancy, a woman still wants to have children. However, she recognized that this will not happen, because the doctor decided to perform tubal ligation:

...if they hadn't operated on me, ah! In five or six years probably, I'd like another child. The need's still there, but it's not possible now. The doctor operated on me in my last pregnancy. (I10)

In addition, she recognized the possibilities of a pregnancy occurring via insemination. However, her wish to be a mother is great, but her fear seems to be greater:

...it's insemination, it may not work out the first time, it'll be another disappointment, all that expectation, you may get depressed. (I13)

There is the narrative of a participant who revealed her wish to have more children, though not at this moment, in view of the still present fear of situations previously experienced:

...I don't wanna have other children at this moment. I'm afraid to suffer when I'm given the anesthetic... (crying)... I'm afraid of pain. (I3)

Perception of obstetric care given in the near miss morbidity process

This theme groups all the narratives concerning care received. During all the period of near miss event care given by professionals, women realized what was

happening around them and the care difficulties. They complained about the quality of care in terms of delay in service, and lack of clarification and guidance about the treatment and care observed:

...we'd been waiting for a bed for two hours and none could be found, and I lying in the stretcher there, losing blood... The doctor said I was gonna be sent to Rio Preto. (I3)

The narrative of a participant reveals clear and upsetting proof of failure in care and its implications, which touch on ethical issues. She states that the delivery was "forced" and the placenta was removed by the doctor. After delivery, her complaints about severe abdominal pain followed by vaginal hemorrhage were not considered by either the nurse or the husband:

...they (nurse and husband) pushed my belly and I began to go out of breath. (...) He (doctor) said, 'You got to push. The team's helping you...' They pushed a lot and then said they could see the baby's little head. But only after they pushed a lot (...) and my ribs got hurt. It was very painful for a long time. (I2)

Due to excessive vaginal hemorrhage resulting from the perineal trauma and hypovolemic shock, she was subsequently transferred to a hospital of higher complexity care. There, she overheard comments about the state of her perineum:

...she (doctor) asked, 'Who did this to you?' Then, I said it was doctor so-and-so and she replied, 'No wonder!'... I heard her say, 'It's the episiotomy which is bleeding.' And the other one said, 'she won't be able to have normal birth again, what has he done?' (I2)

The doctor's clarifications about her situation point to a professional ethical issue and lack of commitment with quality of care:

...I asked, 'Did he do something wrong?' And she said, 'he did all wrong, my dear! But because of medical ethics we try not to comment much. Your womb has been torn apart, the cut was very deep and I had to suture it with a thick needle... (I2)

In addition, her "case" became public and distorted:

...Wow, so, it was her! Then, everybody knew about it, they'd learned about what happened. But what they tell others is, 'Ah, it's normal to have a postpartum hemorrhage... (I2)

DISCUSSION

Perception of serious complication by women showed both positive and negative aspects. Among the positive aspects found in the narratives, family support

and concern about the repercussions of morbidity on women's life stand out. Some accounts showed that family members came closer together, causing emotional bonds to be stronger and thus helping them to face and overcome difficulties resulting from the experience they have gone through.

Some women, with pre-existing diseases, believe that their health has improved; however, they need to adapt continually or are experiencing their recovery and adaptation to new survival conditions. They describe personal growth, greater value of self-care and self-esteem boost to make decisions as factors that help them learn to live with chronic diseases and reaffirm their faith.

Others considered that they recovered from what happened, despite their emotional and physical complaints. They believe they overcame this moment in their lives by reaffirming their religious faith and will to live in order to follow their children's growth. One of them reported that after the event she managed to overcome a chronic physical problem and, as a result, she felt better.

Different participants commented that the experience of the adverse event in their lives was "a thing of the past" and caused practically no changes.

For some participants, the implications were negative, because they were afflicted by diseases, suffering and fears that did not exist previously. In this way, some need psychological follow-up due to their complaints about sadness, depression and fear to interact with other people. In the women's view, the experience was important and painful for the family.

The theme involving future pregnancies had different impacts for each of them. For some, it represented an obstacle to fulfill the dream of being a mother as a result of physical conditions.

For distinct participants, even though pregnancy was a disturbing and painful experience, the perspective of a new pregnancy represents a difficulty to be overcome. Few would not like to have another child, despite the opposing doctor's recommendation. This shows beliefs and values that they have regarding the human reproductive role of a woman and the impact maternity has on their life choices.

Women's speech shows lack of knowledge about questions involving their body during the reproductive process, which contributed to their experiencing these extreme events in their lives. Those that had pre-existing diseases mentioned difficulties in caring for their health, especially about knowledge of the disease, recognition of signs and symptoms of complications, forms of treatment, and care required. Those that experienced complications resulting from the pregnancy mentioned questions and lack of knowledge about risk factors and forms of treatment and control of diseases, as well as

about care for discomforts inherent in pregnancy. In these accounts, professionals' and especially doctors' lack of information became evident.

In this regard, two authors⁽⁹⁾ suggest changes that lead to reflection on the humanization of medicine, particularly the doctor-patient relationship, to recognize the need for higher sensitivity to women's suffering and needs, such as knowing their realities, listening to their complaints and finding strategies that facilitate adaptations to the life style often required by the disease.

Other authors present similar results and emphasize that the medical team sometimes provides the patient and the family with unsatisfactory information about a complication or uses technical terms that they are not familiar with or that are misunderstood.

It is relevant to mention that participants in this study had a pre-natal follow-up, starting in the first trimester of their pregnancy, and performed by doctors or nurses, as recommended by the Ministry of Health⁽¹¹⁾.

However, some did not mention or realize that they should have received specialized pre-natal care, due to their personal and obstetric health histories of chronic diseases, acquired during pregnancy and/or previous complications.

Furthermore, findings reveal the inadequate care women are provided, especially in the immediate postpartum. More than ten years ago, a researcher⁽¹²⁾ pointed out the obstetric team members' lack of consideration for care given during the postpartum period, because, the obstetrician's work, as a rule, ends when birth injuries are sutured and the prescription is given. However, the fourth pregnancy period is considered to be essential for the mother who has just given birth; it is the time when there is higher risk of abnormal events, especially vaginal hemorrhage, as occurred with some women.

Two authors⁽¹³⁾ criticize the biomedical model, which, in addition to its mechanical and reductionist view of the human body, fail to recognize the conceptual autonomy and representations people have about their own health conditions.

Women perceived and assessed care provided by health professionals. According to their accounts, they mentioned the quality of care was well below their expectations. They also pointed out the lack of respect, understanding and consideration for their need to speak about signs and symptoms observed, and the delay in service and transfer to other health services. They observed the health team's lack of care and qualification when receiving the women in the emergency service, and pre-natal, delivery and post-natal follow-up. Almost all the histories of reproductive life of these women suggest inadequate obstetric care, because they were often exposed to unnecessary harmful risks.

CONCLUSIONS

Severe near miss maternal morbidity is identified as a complex process of interpretation, through which women, in their historical and biographical contingencies, attribute a unique meaning.

In health care, it is important not only to consider the complaints about physical and emotional afflictions, but also to try to understand forms of interpretation, values and beliefs associated with problems presented by the women, seeking to grasp the world view of those cared for.

In this study, it could be observed that, in several situations, communication between the health professional and the woman or family and also between the team and the family is ineffective. In addition, there were accounts revealing that professionals, especially doctors, do not provide either the woman or the family

information about what happened.

The study identified a “naturalization” of some signs and symptoms inherent in the pregnancy-infancy period, such as the several types of “obstetric pain”, drowsiness and vaginal bleedings of different intensities.

Accounts revealed the inadequacy of care women receive, especially in the immediate postpartum period. Moreover, they showed that the situation of abandonment of these women after they are discharged. In the narratives, there is no mention of professional follow-up for them, especially for those suffering from chronic diseases and those emotionally afflicted.

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