

Articles

Experiences of women in gestating and giving birth to anencephalic fetuses: the multiple faces of obstetric violence

Iulia Bicu Fernandes(a) <iulia.bicu.86@gmail.com>

Paulo Alexandre de Souza São Bento(b)

<fiocruzsmiff@gmail.com>

Rozânia Bicego Xavier(c)

<rozania.xavier@iff.fiocruz.br>

- (a) Setor de urgência, Maternidade, Hospital Municipal de Petrópolis Alcides Carneiro. Rua Vigário Correas, 1345, Correas. Petrópolis, RJ, Brasil. 25720-320.
- (b) Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira (IFF), Fundação Oswaldo Cruz (Fiocruz).
- (c) Área da Gestante Clínico-Cirúrgica, IFF, Fiocruz. Rio de Janeiro, RJ, Brasil

Anencephaly - a congenital malformation characterized by total or partial absence of the brain, resulting in incompatibility with the extra uterine life of the fetus and reports of violence suffered by these women are usual. Objectives: Identify the violence suffered by pregnant women with anencephalic fetuses and discuss the violence experienced by women in gestations and births of anencephalic fetuses. Method: Life Narratives, being the study conducted between June and November of 2016 in a maternity in Rio de Janeiro, with 12 women diagnosed with anencephalic fetus. After a comprehensive and comparative analysis of the data, obstetric violence arose predominantly in the form of moral judgment of women's choices; bad assistance; abuses; use of jargon; among others. In these experiences permeated by suffering and loss, obstetric violence increases the vulnerability of women. There is a need for a more in-depth debate.

Keywords: Anencephaly. Violence. Obstetric violence. Women's health. Public health.



Introduction

Motherhood is considered a social construction and, depending on each specific cultural context, the concept of mother and child has a different meaning¹. This is not restricted to the inherent physiological aspects, since a pregnancy also includes a set of feelings and emotions that are intertwined and are anchored in the society in which the woman is inserted; that is, pregnancy involves dynamic changes, be they physical, social and emotional and is considered a healthy life experience in most cases².

However, certain pregnant women have a higher probability of unfavorable evolution; they are called high-risk pregnant women. Therefore, prenatal care and assistance, which will allow a dynamic assessment, early detection and appropriate management of possible risk situations, is of paramount importance in order to prevent an unfavorable outcome². One of these situations is when there is a history of a malformed newborn in previous pregnancies or when there is a fetal congenital anomaly in the current gestation².

Approximately 21% of these malformations involve the central nervous system, denominating them as one of the most frequent congenital defects³. According to the latest data from the Ministry of Health, in 2016 there were 2,857,800 live births across Brazilian territory, of which 4,085 were diagnosed with congenital malformation of the nervous system. The Northeast Region had the highest number of cases, with 1646 live births with this diagnosis, followed by the Southeast Region with 1568 cases, North Region with 365, Central West Region with 267 and South Region with 239 cases⁴. Also called neural tube defects (DFTN), these malformations focus on the initial phase of fetal development, in the fourth week of gestation, covering the primitive structure that will give rise to the brain and the spinal cord, with a failure in the adequate closure of the embryonic neural tube. The causes are crossed by the interaction between genetic and environmental factors, called multifactorial inheritance, with folic acid deficiency being an important risk factor, but the exact mechanism during embryogenesis is unknown³.

With regard to anencephaly - one of the most frequent DFTNs – it is a congenital malformation resulting from failure to close the upper end of the neural tube during the fourth week of embryogenesis, resulting in total or partial absence of the brain and skull, leaving the brain exposed. It is a lethal disease that occurs in one to five cases every 1000 live births, and is more frequent in females. This involvement of the fetus makes it unfeasible, that is, there is an incompatibility with extra uterine life. In more than a half of the cases, the fetuses do not resist gestation and those who reach the time of delivery survive minutes or hours outside the uterus ^{5,6}. As with DFTN, it is estimated that the main agent causing anencephaly is deficiency of vitamins during pregnancy, especially folic acid, in addition to the influence of other teratogenic agents such as radiation, sulfonamides and salicylates ⁷.

Nevertheless, until the year 2012, the exclusion of illicit abortion in Brazil did not predict the clinical situation of anencephaly or other malformations incompatible with the life of the fetus, and women were forced to continue their pregnancy or seek judicial authorization for abortion, without the guarantee of obtaining it. Only in 2012 the situation of the anencephaly was contemplated in the Supreme Federal Court and the interruption of the pregnancy in these cases became legal. The purpose of this decision was not to create a new permissive for abortion but to demonstrate that



the clinical situation of anencephaly did not fit into the criminal determination of crime of abortion, since the anencephalic fetus has no extra-uterine life expectancy and therefore it cannot be considered abortion⁸.

In view of this situation, the pregnant woman experiences very negative feelings, in addition to the fact that the anencephalic gestation itself can lead to physical complications, such as polyhydramnios, births with dystocia, hypertensive diseases, severe psychological conditions, among others⁵. There is a rupture with the expectation of the idealized and perfect child, which translates into a moment of intense emotional distress and anguish in most cases and the complex decision to interrupt or not to interrupt the pregnancy becomes real⁹.

As if the experience of gestating an anencephalic fetus does not suffice in the life of the pregnant woman, it is not uncommon the reports of violence suffered by these women during the gestation and birth of the anencephalic babies. This reality is capable of unleashing losses to the mother-child binomial that often becomes irreparable¹⁰.

The Latin American and Caribbean Committee for the Defense of Women's Rights defines violence against women as any act or conduct based on gender, causing death, harm or suffering of a physical, sexual or psychological nature to women, both in the public sphere and private¹¹. This is one of the main forms of violation of human rights, affecting women in their rights to life, health and physical integrity and is manifested by carelessness, social discrimination, verbal violence (gross treatment, threats, reprimand, shouting, intentional humiliation), physical violence (not using analgesic medication when indicated), inappropriate use of technology or unnecessary interventions, even sexual abuse. These violence are manifested in health institutions, which also characterize them as institutional violence^{12,13}.

Violence causes significant impacts on the mental and physical health of women, not being a phenomenon restricted to the domestic sphere but a world public health problem, often veiled¹². In Brazil, it has only recently been evaluated as a serious social and public health problem to be faced, through the denunciations of feminist movements initiated in the sixties and the recognition of women rights as Human Rights¹⁰. It is also seen as one of the expressions of gender violence, specifically targeting women and manifesting themselves on the basis of unequal power relations between men and women in our society¹⁴. It has as central nucleus the patriarchal culture that since its emergence, delimits borders between dominator / dominated, where the second one will be repressed by the first one. Even though relations between people, especially between men and women, change historically and geographically, the ideology of leadership remains strong in many cultures affecting the most diverse forms of conviviality¹⁵.

One of these ways of expressing violence against women, often hidden, is obstetric violence (VO). It occurs at the time of gestation, delivery, birth and / or postpartum, including abortion care and can be classified as institutional, moral, physical, psychological, verbal and sexual violence. These are translated in the lack of access and pilgrimage, in the overvaluation of technology and excessive medicalization, in the disrespect, neglect and maneuver of Kristeller. It is also translated in excessive touches, episiotomy and amniotomy, the use of synthetic oxytocin and denial of analgesia, swearing, shouting and humiliation during obstetric care, among others¹⁶.



According to several authors, about one-quarter of women who experienced the experience of childbirth and half of those who went through an abortion process experienced some type of obstetric violence^{12,17}, indicating that violence has already become naturalized, transforming into a common characteristics of childbirth care¹⁴.

The moment of childbirth is also permeated by institutional violence, committed precisely by those who should be the main caretakers of women in this social event that is maternity. The patient is treated as an object of interventions and voided as a subject of rights, particularly sexual and reproductive rights. This is determined in part by gender violence, which transforms differences from being a woman, as well as a patient, into inequalities. In this way, institutional violence occurs within unequal power relations: on the one hand, due to the gender relations existing in our society and, on the other hand, within the professional relationship of health and patient, where the professional is hierarchically superior and the holder of knowledge and the patient is inferior and the recipient of care^{13,14}.

Thus, in reflecting on the concepts discussed above on fetal malformation, anencephaly and violence, it is understood that violence against women contains several forms of violence, notably: gender violence, obstetric and institutional violence. It is noteworthy, but not infrequently, that many women still experience these types of violence today. In this sense, it is necessary to question some singular aspects: the experience of pregnant women of anencephalic fetuses reveals that situations of violence? What are the effects of violence in the lives of these women? Thus, the objective of this study is violence against women in gestations and births of anencephalic fetuses and the objectives: to identify the violence suffered by pregnant women with anencephalic fetuses and to discuss the violence experienced by women in gestations and deliveries of anencephalic fetuses.

The present study - footwear in a matrix research (Work of Completion of Residence) - reveals and illuminates the need to broaden the debate about the vulnerability of women to the different types of violence in their life contexts. When thinking that gestating an anencephalic fetus is, by itself, something complex regarding the subjectivities of women, they are faced with various types of violence, in a constant, within the Brazilian health institutions. In addition, during pregnancy and after childbirth, there are still symbolic situations of violence, and in this sense, reflections and discussions about the theme will once again recognize this phenomenon and strengthen the recognition of health professionals to think and rethink their conduct.

Methods

It was a study with retrospective, qualitative approach and study method of Life Narratives¹⁸. The field of research was the nursery of pregnant women of a maternity hospital in Rio de Janeiro and the participants were women older than 18 years, diagnosed with anencephalic fetus and who delivered the child at the institution, whether or not they chose to interrupt their pregnancy. Maternity files were used to identify the women who developed anencephalic fetuses and a list of 79 telephone contacts of eligible women was used, and the invitation to participate in the survey was made via telephone. Taking into account the availability of admission and discharge



books, the search was carried out as of 2009. After contact, 55 losses occurred, for the following: missing numbers, mistaken connections and calls not completed or not answered on several occasions. Of those who were contacted, nine women did not agree to participate, two women reported whether it was a diagnosis other than anencephaly and one woman reported living in another city. Thus, a total of 12 women who accepted to participate in the survey were reached. The narrative interview was used to collect the data and the interviews were carried out from June to November of 2016, after signing the Term of Free and Informed Consent.

A single question was asked to guide the interview: "Let's talk about your pregnancies, can you tell me about your pregnancies?". And the Thematic Agenda was used as an auxiliary tool. The interviews were held at a convenient time and place for the participants: two in the maternity ward, two in the women's residence and the rest in public places, ensuring the confidentiality of the narrative. Progressive saturation was achieved in the fifth interview, from the recurrences and the data collection was closed in the twelfth interview, allowing the negative case study^{18,19}. In order to guarantee the anonymity of the participants, they were identified from the alphanumeric system and the interviews were sequentially enumerated according to their performance and the letter E (of interview) was used before each number. In order to provide parallel reading, the interviews were recorded in MP3 and transcribed simultaneously.

A floating and in-depth reading of the material emerged, 18 statements were verified and from these it was possible to perform a comprehensive and comparative analysis of the data, as Bertaux points out¹⁸. In this article, we discussed what was named narrative nucleus, the narratives that evoked the experience of women about violence. The research was approved by the Research Ethics Committee of the hospital and has the Certificate of Presentation for Ethical Appreciation nr 52403915.6.0000.5269. In this way, the norms of Resolution 466/12²⁰ were respected.

Results and discussion

The age range of study participants ranged from 23 to 42 years. Regarding skin color, two-thirds of the women described themselves as brown, two declared themselves black, one white and one yellow. As for schooling, two women reported elementary school: one incomplete and one complete; four - complete high school and one - incomplete high school; two declared to have incomplete higher education and two complete higher education. One woman said she was a graduate student. Regarding the occupation, two thirds of the women reported being formally employed, three of them reported to be house worker and one woman declared herself a student. Concerning the marital situation, seven participants said they were married, two in a stable union and three were single. In terms of income, it ranged from zero to 11 minimum wages.

Regarding the number of pregnancies, this varied between two and four pregnancies per interviewee. As for the number of deliveries, there was variation between one and three deliveries per participant. Regarding the number of abortions, the variation was between zero and two per woman interviewed. At the time of the interviews, three participants were pregnant. In relation to the gestation of the



anencephalic fetus, a little more than half chose the therapeutic anticipation of the birth, three participants underwent cesarean section, one woman went into preterm labor and one interviewee interrupted the gestation due to the diagnosis of intrauterine fetal death. Regarding the gestational age of the procedure, there was a variation of five and nine months. Concerning the anencephalic gestation, it was the first gestation in half of the cases and the variation occurred between the first and fourth gestation. As for the number of children, two interviewees had no live children at the time of the interview, two thirds had a live child, and one participant reported having two children and one referred to having three children.

The results of this research revealed that from the time of the anencephaly discovery to the period of hospitalization to interrupt the gestation or delivery, the study participants suffered various types of violence. That is, the journey of these women was permeated by this phenomenon, which translated into an even more painful journey. After analysis, this violence were classified as facets of VO and throughout this chapter, they will be brought to discussion.

The identification of the various forms of obstetric violence was not immediately perceived as a sociocultural phenomenon involving inequalities related to gender, race, and institutions. Initially, the scenarios were classified as disrespect to women's choices, poor professional assistance, - among others - becoming important elements, but still dispersed in the narrated experiences.

In this sense, it was important to understand and validate through reading and analysis that these elements generated the hard core of obstetric violence. This reflects the type of prevailing health education, where the professionals training needs are valued above the right to autonomy or bodily integrity of parturient. In addition, health professionals are socialized to believe that their care, even generating situations of violence, is an "aid" to women and tends to ignore the existence of these different types of violence, unless there is a more the subject. Therefore, when parturients perceive and verbalize care as abuse and disrespect, these narratives are viewed with hostility by health professionals²¹.

One of the facets of obstetric violence that most attracted attention was the moral judgment of women's choices. This was manifested by the reproach and disrespect on the part of the health professionals and relatives for the woman's decision regarding her own body, either by deciding to carry on an anencephalic gestation, that from the point of view of those around her, it was useless and it made no sense, either by deciding to interrupt the gestation.

The recrimination and non-acceptance of the choice and decision of the woman is permeated by the unequal relations of power present in the relationship between the health professional and patient, in which medicine holds the power, while legitimate knowledge in our society and the patient is seen as vulnerable. At the top of the hierarchy is the doctor and the power exercised by this practitioner is based on the cultural and moral authority that the medical profession has held in our society. This authority is based not only on certain scientific knowledge and technologies, but also on certain cultural values and beliefs that are shared as socially true, as well as exercising certain mastery over the subjects' moral conduct. Thus, health professionals, namely the medical staff, are based on scientific legitimacy and this is reflected in the doctors' statements of disapproval in relation to the decision of women¹³.



On the other hand, the woman and her body have been seen as machines, where the medical professional is the engineer who has all the knowledge about her and therefore, is in the right to neglect information, emotions, feelings, perceptions and rights of the same way of gestating, giving birth and expressing their feelings and emotions, which is contrary to the National Humanization Policy¹¹. This can be seen in this report: "[...] everywhere I came it was the people [...] so they looked at me crooked, or they thought it was crazy [...] I did not [...] carry a pregnancy so [...] it would be in vain for them, right?" (E5).

Another very evident phenomenon that several interviewees mentioned was the poor assistance and banalization of their complaints, as analgesia was denied even when prescribed and also because of the pain and sensation of the parturient as one (woman) in labor, then she would have to endure the pains in silence, because that would be the social condition accepted by society.

The pains felt by women during labor are culturally recognized as sensitive punishments related to the religious concept of having committed the original sin. The replication of this view in the historical and cultural framework of lay society and health professionals exposes women to obstetric and gender violence and pain becomes inherent in the experience of motherhood¹¹. The woman must endure the pain of childbirth, since she is able to bear biologically, being the price for the supposed pleasure experienced in the sexual act originating from gestation¹³. The following account meets this thought: "Ah, this is labor, you have to be accustomed to it '[...] in fact I was also having a renal crisis and I asked the nurse, she said she would not apply". (E4).

The presence of obstetric violence also appeared as the treatment was coldly refused in the case of the interviewed E4, since it involved gestation of the anencephalic fetus. The interviewee's doctor refused to perform the placement of a catheter because of the kidney problems that the interviewee presented, despite the health risks that she was running and in addition, said that she would die if she did not interrupt the pregnancy as soon as possible. That is, the centrality of the anticipation of childbirth and the constant denial of care were continuously present.

Neglect, neglect or denial of care are categories of obstetric violence, especially to women who are perceived as very complaining, uncompensated, or demanding. It is the right of women to receive health care in a timely manner and at the highest possible level of health¹⁷, which was not revealed in the study: "In my opinion as a doctor, you would have to put a catheter, but I will not put it ... if it were feasible, I would put it ... I will not put it, I want you to look for the hospital and there you make the interruption [...] if you do not, you will die" (E4).

Two other forms of obstetric violence were physical and verbal abuse and unworthy care, reported by E5, contrary to the right of women to be free from harmful treatment, ill-treatment and care with dignity and respect¹⁷. According to her narrative, when she went to get up after the cesarean section surgery, which should be mediated by qualified care, the professional did not conduct her properly mentioning, even, that her pains were exagerated. As a result of this misconduct, E5 suffered a fall from its own height:



[...] she came very coarse ... very mean ... did not help me up, she held me (pause crying a lot) ... held by one hand and pulled me. When she pulled me I fell to the ground and I was not strapped, nor slashed (crying hard) [...] then I got up alone because she did not help me up. (E5)

There are several authors who describe situations in which the patient and the health professional are equal in the gender, but unequal in the relation of power. This authoritarian discourse and hostile behavior with patients by female health professionals is recurrently reproduced in the interviewees' statements. Inequality often depends on class and ethnicity differences in the technical and scientific knowledge that the professionals hold and also on the ideological naturalization of the exercise of medical power by the hierarchical position they possess¹³.

It was possible to observe that the aforementioned interviewee presented psychological consequences due to the behavior of the professional, manifested by the fear of being alone during the night while hospitalized. She says she feels fear even today, calling the situation traumatizing. This points to the seriousness and seriousness of institutional violence: "As I fell down... I think it hit my emotions ... I was so scared that I could not even sleep, because I was afraid that she would go back there and not have anyone [...] I think this is the only trauma that I have, because I'm afraid to be alone until today" (E5).

The same interviewee also pointed to the use of jargon through speech: "Oh girl, don't be childish... You have to understand that you are already a mother; you don't have to be so... don't you know how to make a baby? Can't be so loose ... everything is Mama, everything is Mama" (E5).

There is disrespect of the parturient in the delivery room and institutional obstetric violence becomes naturalized and banalized in jargon and conduct based on class and gender stereotypes as a practice perpetuated in most Brazilian maternity hospitals. Violence in childbirth translates into the act of shouting or humiliating the patient and subjecting her to embarrassment and poor care is characterized, among others, by the gross treatment marked by professionals' impatience or indifference and by moralistic and disrespectful statements^{12,13}.

It is worth pointing out that the two interviewees (E4 and E5) who were subjected to poor care through the trivialization of complaints, refusal of treatment, physical and verbal abuse and use of jargon were self-declared brown and black respectively. Even though they have not related violence to skin color, discrimination based on certain attributes is a sort of obstetric violence, where differential treatment prevails based on attributes considered positive (married, with planned pregnancy, adult, white skin, more educated, middle class, healthy, etc.), thus depreciating those who have attributes considered negative (poor, not in school, younger, black and those who question medical orders)¹⁷.

Another very present type of violence was the pilgrimage and denial of care, pointed out by the interviewees, since they were in the condition of pregnant women with anencephalic fetuses, which implied the need for a reference center that could accompany this type of gestation. Pilgrimage is still a serious public health problem, implying the lack of organization and quality of obstetric care and the maintenance of maternal mortality rates in Brazil. This on the one hand contributes to noncompliance



with the Millennium Development Goals, which is to improve the quality of obstetric care and, on the other hand, can be considered as obstetric violence, due to the implicit annulment of women's rights²².

In the case of pregnant women with anencephalic fetuses, the pilgrimage until they were attended to was explained by the fact that the pregnant women needed a specialized and referral service, since not all maternity wards could accept a pregnancy of an anencephalic fetus. Thus, the lack of reception created institutional violence, a situation that is present even though there is already jurisdiction over the interruption of gestation by an fetus with anencephaly. The following testimony reveals: "I tried here ... I wanted to do prenatal care here where I live, and none of the hospitals wanted to stay with me here because of my daughter's problem" (E9).

Other statements pointed to the denial of the right to clarification / information, inasmuch as they were not informed of the need to use folic acid, either in the previous gestation or in the gestation of the anencephalic fetus. These reports go against the Technical Norm: Attention to Women with Gestation of Anencéfalos²³, which reinforces the fact that in the act of welcoming the pregnant woman, the transfer of technical information to the woman and / or the family must be done, so that the decision-making is carried out in a conscious and effective manner, leaving no doubt. The health professional must be respectful, listen and inform the pregnant woman, without manifesting discriminatory conduct and making the pertinent guidelines to clarify the doubts. In addition, the professional must present technical-scientific knowledge to make the procedures safe²³. The following report demonstrated such denial: "As soon as I heard about my pregnancy, I told my doctor: look, I'm pregnant and he did not have any vitamin [...]"(E4).

One interviewee in particular (E7) reported intimidation by her gynecologist to perform the cesarean section procedure to interrupt gestation, despite the express manifestation of the interviewee in bringing the gestation to term. According to his narrative, the doctor called several times a week, insisting on the surgery:

We do not want to interrupt [...] and he said "but why not? I don't need to ask for any more tests, so what do I want to know if the baby is well or not? If you're going to die, you don't need it ... we interrupt you soon and in a few months you can get pregnant again. (E7)

This attitude on the part of the doctor is contrary to the one pointed out in the literature. Several authors report that many women can find meaning in the fact that they continue with gestation, even in the face of the infeasibility of the fetus and must be respected in their will to carry on gestation²³. Thus, the decision to interrupt or not interrupt the pregnancy rests exclusively with the pregnant woman and / or the couple and the health professionals have the obligation to respect whatever the decision, which fact did not occur, according to the report of the interviewee E7. On the other hand, although cesarean surgery is recognized as a surgical procedure that safeguards the health of the mother and the newborn, it increases the risk of hemorrhage, puerperal infection, pulmonary embolism and anesthetic complications when it comes to women. In the case of the newborn, there are risks of respiratory problems,



physiological jaundice, iatrogenic prematurity, among others, especially when there is no indication for cesarean section²⁴.

The interviewee E5 pointed to the negligence and coldness in the way of giving the diagnosis of anencephaly by the professional of the ultrasound clinic. The woman and / or the couple are never prepared for the diagnosis of a malformation when they are going to perform a routine ultrasound and thus, at the time of revealing the diagnosis of anencephaly, the professional should do it carefully, offering accurate information, so to avoid that the woman feels guilty by the malformation²³. The diagnosis of anencephaly is always followed by great distress on the part of the patients and the physician must be sufficiently prepared to give the news and guide them safely^{9,23}. Having said this, it is visible through the interviewee's testimony that the way in which the diagnosis of anencephaly was given was contrary to what the literature points to and caused a state of anguish higher than that already expected upon receiving such a diagnosis:

In the morphological [...] she her son does not have the head there I, how thus the child does not have head? [...] This child is going to vegetate, he will not move, he will not talk, he will not walk, you will not have life with this child, this child is practically a dead being inside you [...] I [...] gave me [...] so [...] total panic, I came out of me. (E5)

In the case of the interviewed E4, an experience was pointed out that referred to institutional violence. The interviewee worked as a receptionist in an obstetric clinic that shared the same physical space with a radiological clinic. The violence was translated by the lack of keeping the two clinics in the same space, putting at risk the interviewee, as an employee and pregnant, as well as the pregnant women who were prenatal in the clinic in question.

This fact reveals the direct non-compliance with Regulatory Norm 32²⁵, which refers to the worker who carries out activities in areas where there are sources of ionizing radiation, which should remain in these areas as little time as possible to carry out the procedure and use appropriate personal protective equipment to minimize risks. In the case of all workers with confirmed pregnancy, this should be removed from the activities with ionizing radiation, and should be relocated to activity compatible with their level of training, which did not occur in the case of the interviewee E4: "It was a clinic, it shared a space in the clinic that I worked for, I worked in the obstetrical part and they in the same clinic had the radioactive part [...] people took that radioactive medication and they stayed like that at the reception".

Thus, it has become clear that health practices are oriented in a banalizing and naturalizing direction of violence and their professional agents accept different types of violence, including obstetrics, as acts "necessary for care" and thus consider them "good" practices¹³. The banalization of violence can be due to the individual and collective defense strategies of the professionals, to deal with the suffering of others, as in the cases of pregnant women with anencephalic fetuses, as a reflection of a phenomenon of trivialization of social injustice present throughout the society¹².



Final considerations

The study exposed the various forms of violence present in the trajectory of gestating and giving birth to an anencephalic son, with the emergence of obstetric violence. These situations were not identified as such at the first reading of the narratives. The denial of the rights of these women in several aspects, especially the denial and moral judgment of the choices to interrupt or not to interrupt the gestation, the denial of the proper care and treatment, negligence and verbal and physical abuses practiced against the interviewees, was emphasized.

Obstetric violence is present in the daily practices of health professionals and more than that, it is trivialized and consented. Although they were assisted in a reference maternity to attend to pregnant women presenting with fetal risk and experiencing an already fragile condition, these women were subjected to obstetric violence in several dimensions. That is, even when experiencing gestations of severely malformed children, which increases the risk of affecting the mental and emotional health of the woman and her family, these women experienced some type of violence, with a focus on obstetric violence. This phenomenon reminds us of the need for a more in-depth debate about health care and vulnerability situations in this group.

As a gap in the study, the difficulty of accessing these women is indicated, either by the unavailability of complete information in the maternity files, or by refusal to participate in a research that referred to sensitive memories.

It is suggested the elaboration of other studies within this theme, in order to awaken discussions within the academy and the services and to promote in this way reflections about the teaching and assistance provided in the daily life of the training and health organizations.

Authors' contributions

All authors participated actively in all stages of preparation of the manuscript.

Copyright

This article is distributed under the terms of the Creative Commons Attribution 4.0 International License, BY type (https://creativecommons.org/licenses/by/4.0/deed.en).





References

- 1. Gradvohl SMO, Osis MJD, Makuch MY. Maternidade e formas de maternagem desde a idade média à atualidade. Pensando Fam. 2014; 18(1):55-62.
- 2. Brasil. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. Gestação de alto risco manual técnico [Internet]. 5a ed. Brasília: Ministério da Saúde; 2012 [citado 15 Mar 2016]. (Série A. Normas e Manuais Técnicos). Disponível em: http://bvsms.saude.gov.br/bvs/publicacoes/gestacao_alto_ risco.pdf
- 3. Simoni RZ, Couto E, Barini R, Heinrich-Moçouçah J, Bragança WO, Couto ER, et al. Malformações do sistema nervoso central e a presença da mutação C677T-MTHFR no sangue fetal. Rev Bras Ginecol Obstet. 2013; 35(10):436-41.
- Brasil. Departamento de Informática do SUS. Informações de saúde, demográficas e socioeconômicas [Internet]. Brasília: Ministério da Saúde; 2013 [citado 16 Mar 2016]; Disponível em: http://tabnet.datasus.gov.br/cgi/tabcgi.exe?sinasc/cnv/nvuf.def
- 5. Gazzola LPL, Melo FHC. Anencefalia e anomalias congênitas: contribuição do patologista ao Poder Judiciário. Rev Bioet. 2015; 23(3):495-504.
- 6. Diniz D, Vélez ACG. Aborto na Suprema Corte: o caso da anencefalia no Brasil. Estud Fem. 2008; 16(2):440.
- 7. Silva MH, Rodrigues MFS, Amaral WN. Aspectos médicos e psicológicos de grávidas portadoras de feto anencefálico. Femina. 2011; 39(10):493-8.
- 8. Diniz D, Penalva J, Fagúndes A, Rosas C. A magnitude do aborto por anencefalia: um estudo com médicos. Cienc Saude Colet. 2009; 14(1):1619-24.
- Cunha ACB, Pereira Junior JP, Caldeira CLV, Carneiro VMSP. Diagnóstico de malformações congênitas: impactos sobre a saúde mental de gestantes. Estud Psicol. 2016; 33(4):601-11.
- Santos SMAB, Oliveira ZM, Coqueiro RS, Santos VC, Dos Anjos KF, Casotti CA. Prevalência e perfil de mulheres grávidas que sofreram violência física. J Res Fundam Care. 2017; 9(2):401-7.
- 11. Andrade BP, Aggio CM. Violência obstétrica: a dor que cala [Internet]. In: Anais do 30 Simpósio Gênero e Políticas Públicas; 2014; Londrina. Londrina: UEL; 2014 [citado 10 Nov 2016]. Disponível em: http://www.uel.br/eventos/gpp/pages/arquivos/GT3_Briena%20Padilha%20Andrade.pdf
- 12. Strapasson MR, Nedel MNB. A institucionalização da violência contra a mulher no processo de nascimento: revisão integrativa. J Nurs UFPE. 2013; 7 Spe:6663-70.
- 13. Aguiar JM, D'Oliveira AFPL. Violência institucional em maternidades públicas sob a ótica das usuárias. Interface (Botucatu). 2011; 15(36):79-91.
- 14. Aguiar JM, D'Oliveira AFPL, Schraiber LB. Violência institucional, autoridade médica e poder nas maternidades sob a ótica dos profissionais de saúde. Cad Saude Publica. 2013; 29(11):2287-96.
- Silva RLV, Lucena KDT, Deininger LSC, Martins VS, Monteiro ACC, Moura RMA. Violência obstétrica sob o olhar das usuárias. Rev Enferm UFPE. 2016; 10(12):4474-80.
- Martins AC, Barros GM. Parirás na dor? Revisão integrativa da violência obstétrica em unidades públicas brasileiras. Rev Dor (São Paulo). 2016; 17(3):215-8.



- 17. Tesser CD, Knobel R, Andrezzo HFA, Diniz SG. Violência obstétrica e prevenção quaternária: o que é e o que fazer. Rev Bras Med Fam Comunidade. 2015; 10(35):1-12.
- 18. Bertaux D. Narrativas de vida: a pesquisa e seus métodos. São Paulo, Natal: EDUFRN, Paulus; 2010.
- 19. Fontanella BJB, Luchesi BM, Saidel MGB, Ricas J, Turato ER, Melo DG. Amostragem em pesquisas qualitativas: proposta de procedimentos para constatar saturação teórica. Cad Saude Publica. 2011; 27(2):389-94.
- 20. Brasil. Ministério da Saúde. Resolução nº 466, de 12 de Dezembro de 2012. Brasília, DF: Conselho Nacional de Saúde; 2012.
- 21. Diniz CSG, Niy DY, Andrezzo HFA, Carvalho PCA, Salgado HO. A vagina-escola: seminário interdisciplinar sobre violência contra a mulher no ensino das profissões de saúde. Interface (Botucatu). 2016; 20(56):253-9.
- 22. Rodrigues DP, Alves VH, Penna LHG, Pereira AV, Branco MBLR, Da Silva LA. A peregrinação no período reprodutivo: uma violência no campo obstétrico. Esc Anna Nery. 2015; 19(4):614-20.
- 23. Brasil. Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. Atenção às mulheres com gestação de anencéfalos [Internet]. Brasília: Ministério da Saúde; 2014 [citado 22 Mar 2016]. (Norma Técnica. Série Direitos Sexuais e Direitos Reprodutivos Caderno nº 11). Disponível em: http://bvsms. saude.gov.br/bvs/publicacoes/atencao_mulheres_gestacao_anencefalos.pdf
- 24. Anjos CS, Westphal F, Goldman RE. Cesárea desnecessária no Brasil: revisão integrativa. Enferm Obstet. 2014; 1(3):86-94.
- 25. Brasil. Ministério do Trabalho e Emprego. Portaria nº 485, de 11 de Novembro de 2005. Norma Regulamentadora nº 32 (Segurança e saúde no trabalho em estabelecimentos de saúde). Diário Oficial da República Federativa do Brasil [Internet]; 2016 [citado 06 Dez 2016]. Disponível em: http://www.guiatrabalhista.com.br/legislacao/nr/nr32.htm



Translator: Afonso Salles

Submitted on 10/19/17. Approved on 06/06/19.