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The awakening of a new pregnancy after the birth of a malformed baby

O despertar de uma nova gestação após o nascimento de um bebê malformado

El despertar de un nuevo embarazo tras el nacimiento de un bebé malformado

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ABSTRACT
Objective: to understand the feelings surrounding a new pregnancy after the birth of a malformed baby. **Method:** in this descriptive, qualitative study, supported by the life narrative method, with 10 women who decided to conceive after a previous experience of congenital malformation, data were collected through interviews in the first half of 2019, at a maternity hospital in Rio de Janeiro, and subjected to the thematic analysis technique, after due approval by the research ethics committee. **Results:** the main feelings expressed were fear, despair, and rejection, but the desire to mother, and not just to gestate and give birth, drove the participants to get pregnant again. **Conclusion:** reproductive planning is essential to demystify negative feelings relating to fetal malformation and raise good expectations for a new pregnancy.
Descriptors: Congenital Abnormalities; Mothers; Pregnancy.

RESUMO
Objetivo: compreender os sentimentos que envolvem uma nova gravidez após o nascimento de um bebê malformado. **Método:** estudo descritivo e qualitativo, apoiado no método narrativa de vida, com dez mulheres que decidiram engravidar após a experiência prévia de malformação congênita. Os dados foram coletados por meio de entrevistas no primeiro semestre de 2019, em uma maternidade do Rio de Janeiro, e submetidos à técnica de análise temática, com a devida aprovação pelo Comitê de Ética em Pesquisa. **Resultados:** os principais sentimentos externados foram medo, desespero e rejeição, mas o desejo de maternar, e não somente gestar e parir, impulsionou as participantes a engravidar novamente. **Conclusão:** o planejamento reprodutivo é fundamental para desmistificar sentimentos negativos relacionados à malformação fetal e trazer boas expectativas para nova gestação.
Descritores: Anormalidades Congênitas; Mães; Gravidez.

RESUMEN
Objetivo: comprender los sentimientos que involucran un nuevo embarazo tras el nacimiento de un bebé con malformaciones. **Método:** estudio descriptivo y cualitativo, basado en el método de narrativa de vida, con 10 mujeres que decidieron quedar embarazadas luego de una experiencia previa de malformación congénita. Se recolectaron los datos a través de entrevistas en el primer semestre de 2019, en una maternidad en Río de Janeiro, y luego se sometieron a la técnica de análisis temático con la debida aprobación por parte del Comité de Ética en Investigación. **Resultados:** Los principales sentimientos expresados fueron el miedo, la desesperación y el rechazo, pero el deseo de maternar, y no solo de quedar embarazada y dar a luz, empujó a las participantes a volver a quedar embarazadas. **Conclusión:** La planificación reproductiva es fundamental para desmitificar los sentimientos negativos relacionados con la malformación fetal y generar buenas expectativas para un nuevo embarazo.
Descriptores: Anomalias Congénitas; Madres; Embarazo.

INTRODUCTION

Pregnancy is a unique and complex phenomenon in a woman's life. Therefore, it is a moment in which the body adapts to shelter the developing fetus, undergoing intense hormonal and emotional changes that affect its physical, psychological and biological aspects. The pregnant woman and the fetus go through unique experiences and, even for those who have already experienced pregnancy more than once, the process is always a novelty because of the uncertainties, fears and anxiety that always seem to be renewed, especially if there were complications in the previous pregnancy[1,2].

Most couples dream of the birth of a perfect child, idealizing a socially expected event. However, given the previous experience of a fetal malformation, there can be certain discontinuity related to the imagery construction of a perfect baby, bringing out negative feelings associated with the possibility of malformation recurrence[3].

Upon diagnosis confirmation, there is confrontation between the imaginary and the real child, where adaptation to the baby with a congenital malformation is a gradual process of acceptance and understanding of the new reality, with intense repercussions in the family scope[3,4].

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According to data from the Brazilian Institute of Geography and Statistics (*Instituto Brasileiro de Geografia e Estatística*, IBGE), the number of births in Brazil was 2,793,935 in 2016, corresponding to a birth rate of 14.3/1,000 inhabitants[5,6]. Among the congenital anomalies identified at birth and duly registered, those related to the musculoskeletal system stand out, with 6,448 cases, followed by those that affect the Central Nervous System, representing 4,085 cases, in addition to those classified as other congenital malformations, totaling 3,257 cases[6].

In the 1980s, malformations occupied the fifth and last position among the main causes of infant mortality, which corresponded to 5% of the total. Currently, they rose to the second place, accounting for 13% of the deaths among children under 1 year of age[4].

Considering that children with congenital malformations require health care and that their families normally experience crisis situations due to emotional wear out and to the need for financial support[4], the following questions emerged: What was it like for a woman to get pregnant after the birth of a malformed infant? What feelings were present in this new pregnancy? To answer these questions, this article aims at understanding the feelings surrounding a new pregnancy after the birth of a malformed infant.

METHOD

A descriptive study with a qualitative approach, supported by the life narrative method. The choice for this methodological design allowed in-depth knowledge of the object, when working with subjectivity, as well as of its values amidst a universe of meanings and feelings that led women, with the previous experience of a malformed infant, to decide getting pregnant again, considering and understanding what was most relevant in the experience of each interviewee[7].

The convenience sample was defined based on the following inclusion criteria: being over 18 years old and having previously given birth to an infant with a malformation. Women in the following situations were excluded: hospitalization in labor or in the immediate postpartum period, as well as those with cognitive deficit or any mental impairment.

The participants were recruited privately, at the bedside, during hospitalization in the pregnant woman's ward and rooming-in at a reference maternity hospital for fetal risk, located in the municipality of Rio de Janeiro. The interviews were carried out by the main researcher, on the days when she was on duty, assuming responsibility for the direct care of those women. This proximity allowed for a period of familiarization, providing the creation of a bond and an atmosphere of trust so that they could express their thoughts during the interview.

Data collection took place from January to May 2019, with conduction of a pilot test, which was not accounted for in the analysis. It is noteworthy that there were no refusals or need to repeat the interviews, reaching a total of ten participants, of which five were pregnant and five were in the puerperium.

The open narrative interviews were based on the following triggering question: "*What was it like to get pregnant after the birth of a malformed infant*", were recorded in MP4 and lasted a mean of 30 minutes. They were transcribed in full and coded with the letter M for woman ("*Mulher*" in Portuguese), followed by a number representing the order in which they were conducted.

The thematic analysis technique was processed after exhaustive reading of the narratives, highlighting the excerpts that approached the study objectives and extraction of the main themes that were categorized and comprised the analysis corpus.

The research was approved by the Research Ethics Committee, all the ethical precepts were safeguarded, and the participants signed a Free and Informed Consent Form, with subsequent reception of a copy by the participant.

RESULTS AND DISCUSSION

Regarding the characterization of the study participants, five self-declared to be white-skinned and another five as brown-skinned, aged between 24 and 38. Most of them are single, Evangelical and have only one child alive. With regard to schooling, four have complete elementary school, four had concluded high school, and two have complete higher education. Regarding family income, the majority stated earning less than two minimum wages.

Feelings of being pregnant after births with malformations

The awakening to a new pregnancy after the birth of a malformed infant was anchored in the women's desire to exercise motherhood. For them, the dream of being mothers was not only about getting pregnant and giving birth, but it involved care, breastfeeding and fulfillment as mothers.

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> *[...] I wanted to know what it was like to have that feeling of being a mother. I wanted to know what it was to be a mother [...] to love as a mother [...] I wanted to know what it was like to breastfeed, care, love, that was the feeling! I always liked children! (M9)*
>
> *[...] it was the dream of being a mother! I wanted so much, but I couldn't… When I knew it could happen, I went after it, even if a special child could come, I would love my child the same way! Love is the same thing, when we really want a dream, we can make it come true... I feel fulfilled to have him, there are times when I still don't believe it's mine! (M2)*

Winnicottian thinking works with motherhood as a way for the mother to take care of her baby in a good and protective manner, with the aim of meeting the physiological needs and investing in desire, love and warmth[8]. This state of primary concern emerges at the end of pregnancy, for many women being a natural instinct that directs a significant part of their attention to their own existence, seeking to devote themselves exclusively to the child in order to, through the child, satisfy it with a set of care actions[9].

The primary maternal concern is the woman's ability to become intensely involved with the issues of motherhood, devoting herself entirely to this experience[8]. It is a spontaneous process that demands care and welcoming, so that the woman can exercise the maternal role favorably to the bond under construction, particularly in special situations such as congenital malformations[8].

Motherhood is always a choice for caring and devoting oneself with love to the new being, and it is this feeling, this devotion, this affection, that some interviewees reported feeling the need to experience[9].

It was the desire to be a mother that overcame the fear of trying again, of once again experiencing neonatal death or the birth of an infant requiring special care. The search for full motherhood drove the awakening to a new beginning, although this desire was veiled for most of the participants who reported not wanting to become pregnant in the near future.

> *[...] neither of the two was planned. (M7)*
>
> *[...] the doctor told me to do the [reproductive] planning. It turned out that I didn't do it, after a year I went there and got pregnant. (M4)*

In the search for motherhood, anxieties, fears, apprehensions and concerns are common feelings among pregnant women, but they are enhanced in the case of women with a previous experience of congenital malformation. Anxiety is an emotional state that has physiological and psychological components, including sensations of fear and insecurity associated with pessimistic thoughts of catastrophe or personal incompetence[10].

> *Every time, every ultra [ultrasound], I was shaking, the whole body! The nervous system, it was shaking too much! (M9)*
>
> *I was feeling anxious about doing the nuchal translucency! Until reaching the morphological scan, I… But according to the exams that they did here, it made me feel calmer because the other [referring to the previous pregnancy] since the beginning of the translucency it was already showing something... (M5)*

In the study, higher stress levels and psychological symptoms were observed among women who received the malformation diagnosis before birth, that is, in the gestational period[10]. The high levels of misinformation about the health of the fetus and the maternal difficulties in elaborating and dealing with the changes inherent to the gestational period and the infant malformation interfere with mental health and favor states of stress, anxiety and depression. Although most of them had not planned their pregnancies, it is noticed that the women nurture a desire to become pregnant with the outcome of a healthy baby:

> *I didn't want to get pregnant, but it was fast! I... loved it! [...] I got scared! [...] deep down, I wanted to get pregnant again, because I had just lost a baby [...] (M10)*
>
> *I was so looking forward to being a mother again, but I was afraid to try because it was too complicated for me… Knowing that your child is and is not there at the same time [...] (M2)*

The testimonies show that there is no adherence to reproductive planning and that, despite the fear of trying a new pregnancy, the women want to become pregnant again. This failure of reproductive planning in welcoming and meeting the specific demands of women with previous pregnancies of infants with malformations generates insecurities in the face of a new pregnancy:

> *It was good, but at the same time scary. Only those who went through the pain of losing a child know how it is… Fear that it happens again! I take it one day at a time, one week after the other [...] (M1)*
>
> *I was always afraid. The whole pregnancy I was afraid! I was getting pregnant and then I was always losing it […] I was always afraid of getting attached and that the same thing happened again. So I didn't enjoy my pregnancy! Him, I didn't enjoy him! I was afraid! (M9)*
>
> *At the beginning, I was afraid to buy clothes, to create expectations, that it could go the other way [...] (M2)*

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Despite human beings' adaptive ability, fear related to the previous experience of a malformed infant is a feeling that culminates in a state of emotional frailty in the face of an encounter with something unknown and the possibility of recurrence in the new pregnancy[11].

Among the women who are pregnant of infants with congenital malformations, it is noticed that the fear of losing the fetus interferes with the bond[12]. This is a common defense mechanism in the face of unpleasant news, which is characterized by an abrupt interruption in the normal psychological process of pregnancy, causing many women to leave their involvement in abeyance, avoiding common actions inherent to pregnant women, such as caressing the belly and preparing the trousseau, exerting a negative repercussion on the family relationships.

For most of the participants in this study, fear was present from discovery of the new pregnancy until performance of the morphological obstetric ultrasound, around weeks 24 and 28, when it is possible to see the fetus with better resolution. On the other hand, even after this diagnostic exam, some women reported that this feeling lasted until the moment of birth, that is, in which eye contact and verification of good vitality in the newborn without malformations materialized the much-desired healthy motherhood.

> *[...] my concern… I needed to see him! He in my belly, it made me very anxious! [...] That gave me great agony [...] I was always asking in the prenatal: "Aren't you going to do an ultra? [...] I need to know how this child is doing!" (M3)*
>
> *The first morphological scan, the doctor said that everything was fine, perfect, I said: "Wow! I can't believe everything worked out! [...] It was just happiness! From that, I started to enjoy the pregnancy! (M9)*

Both at the time of the ultrasound scan during pregnancy and at birth, identification of complications and communication of bad news are not situations that the family is prepared to bear. These moments can cause trauma and psychological disorganization, especially in the face of fetal malformation or death[13].

Another feeling that emerges from the discovery of a new pregnancy after the birth of a malformed infant is despair:

> *[...] I think that I was not prepared because when you're pregnant you're very sensitive, so everything despairs you. The fear of people's prejudice, how to deal with a special child… It was very difficult for me! (M2)*
>
> *[...] I went into despair! Because she's under medical monitoring [first daughter]! Having another baby? (M4)*

Associated with the fear that the new being might present the same malformation as the previous child, despair adds the sense of work overload, amidst the hormonal condition inherent to pregnancy, with fear of judgments and a possible social demand due to the new pregnancy. Sharing the pregnancy news is not always synonymous of ensured support. Women are often faced with expressions of curiosity and disrespectful approaches from friends and acquaintances. Depersonalization of women in this context and the focus on the possibility of the infant's malformation can be motivating elements for pregnant women to redefine their actions and adopt silence as a protection strategy[14].

The parents' reaction and the degree of attachment to the newborn depends, in part, on the type of malformation: whether it is visible, whether it is correctable, whether it affects the central nervous system or the genitalia, or whether it is hereditary. These characteristics presuppose the future problems they will face; however, regardless of the prognosis of the fetal malformation and the child's appearance, the pregnant women showed a high level of attachment to their fetuses[15].

> *[...] He had type II Arnold-Chiari, but he doesn't appear to have this malformation. Thank God! But he corrected myelo [myelomeningocele] and hydrocephalus. (M7)*
>
> *[...] really had some of that [...] Fear of discovering something in the baby, like other diseases! Down Syndrome, other things… Whether or not it was coming with a little problem [...] because the concern was also for it to come with Down Syndrome. (M8)*

The location of the abnormalities presented by the newborn exerts a direct influence on the parents' degree of anxiety regarding the concern for the child's future. In fact, the smallest abnormality located in the neonate's head exerts greater repercussion in terms of parental concern when compared to a disorder in any other part of the body[16]. Perhaps this explanation is justified by the conception that the face characterizes the most expressive part of the body.

> *[...] it was difficult for me in the first days because I already have two children and they're normal, they don't have any physical disabilities, and this one she had […] Now, I'm getting used to it… She undergoes treatment. I treat her the same as the other two. (M10)*
>
> *[...] I was waiting for that day to come… Doing the ultra morphological scan to see this baby of mine! He didn't come with a disability, with a malformation, like his 4-year-old brother who came with a physical disability. After I did the ultra morphological scan, it gave me a relief, tranquility! (M6)*

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> *[...] I was just waiting for her to arrive. It ended as I wanted! I was dying to see her face! To see how she was going to be born! (M7)*

When engendering a child with a malformation, many parents feel guilty about the outcome and interpret it as a social exposure of their mistakes and decisions. Such perception accentuates feelings of impotence, anguish and failure[3]. On the other hand, despite the feeling of frustration, women want to live the dream of being a mother with the birth of a healthy infant.

This desire is understood as the future of the parental lineage, which emerges when a previous pregnancy engendered a malformed infant and the desire to get pregnant again remains latent, as a compensatory mechanism for the previous outcome that is experienced in a veiled manner[13]. In these cases, when a new pregnancy is confirmed, fear is a very present feeling that can be transformed into happiness, by means of tests that show fetal normality, or trigger rejection.

With important impacts on the parents' bonding with the new child, this rejection process is common, especially among helpless and overburdened women due to the demands related to other healthy children or to those living with some malformation, who lack recurrent health monitoring.

Currently, we still face gender inequalities, which dictate the stereotype that it is up to women to take care of their children, especially for those with differentiated health needs. Although many women have paid jobs, they are also responsible for taking care of the home and of their offspring, generating an exhausting routine and a feeling of helplessness[14].

> *[...] I didn't want any more children at all! I didn't want more work because she [previous daughter] already gives me plenty of work […] She [previous daughter] is a child who needs you to keep an eye on her 24 hours a day. Imagine with two children!! (M6)*

> *[...] I thought: "This child will come with a limitation!" Her father [first partner] doesn't accept her [previous daughter with a malformation]. Now, he [current partner] won't accept the son either [if he comes with a malformation]… I'm going to raise two special children! [...] I fell into depression! (M3)*

It is observed that the care of children with malformations is essentially female-centered, developed by the mother herself or, when she has an employment contract, by another woman hired to assume responsibility. This configuration presents traces of the sexual division of labor and reveals gender inequalities, given men's absence or little participation and involvement in this process[17].

In addition to these issues, it is important to highlight the feeling of guilt, expressed by the woman herself or through the male discourse of blaming the mother for the malformation:

> *[...] I thought it was my fault! Something, [...] So I rambled a lot on that in my head [...] (M5)*

> *[...] he got it into his head that my daughter had the syndrome because of me! Because her syndrome, mostly genetic, comes from the mother's genetic load. […] Only that I had already done the exam! [...] And found out that I don't have it. It was by mutation! It was one in a million and she was born! (M2)*

Generally speaking, in the search for the malformation origins, women search in themselves a justification or explanation for the emergence of the problem. The new pregnancy, in addition to not converging with the initial dreams, renews the traumas and previous discontents experienced with the malformation diagnosis in the previous pregnancy[12].

Thus, it is common for the parents to feel guilty and responsible for the situation, and the psychological shock of having a child with a disability can affect the female ability to be a mother. There is also the maternal feeling of guilt that comes from the idea of allowing the birth of a child with a congenital malformation, as if she had control over the situation[13].

Blaming for what happened is due to self-demands, as well as in the obvious relationship with the man, since she "carries the baby" raising her status of greater propensity to consider herself responsible for the outcome of the pregnancy[18].

It is to be noted that the feelings experienced by the participants could be alleviated through access to sexual and reproductive health services, based on humanization of care and on the rights of women to decide, or not, for a new pregnancy after experiencing a congenital malformation. Becoming pregnant not by chance but by choice, and with qualified professional monitoring to support them in the safe experience full development of motherhood.

Study limitations

The sample is highlighted as a study limitation, as well as its regionalization, which does not allow data generalization.

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CONCLUSION

The feelings that involved a new pregnancy after the birth of a malformed infant were mainly fear, despair, guilt and rejection. Although the women's discourse expresses unwillingness of a new pregnancy, they do not adopt protective measures to avoid it, since the desire to experience pregnancy and the birth of a healthy child, as well as to develop motherhood, remains latent, despite the previous experience with the congenital malformation and the possibility of its recurrence.

Welcoming the demands of women with a previous pregnancy of a child with a malformation is still a challenge to be overcome by reproductive planning, especially in reference units that offer specialized services. Guidance and information are fundamental rights to ensure sexual and reproductive health, with conscious conception and contraception, based on the couple's choice and recognition of their specificities.

New studies are needed exploring the feelings and perspectives of women with previous pregnancies of malformed fetuses, in order to confer visibility to the needs of this group and, thus, drive changes in reproductive planning from the perspective of the female diversities.

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