Repercussions of the diagnosis of fetus malformation under the light of Betty Neuman's theory

Repercussões do diagnóstico de malformação fetal à luz da teoria de Betty Neuman

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Objective: to understand the repercussions of the fetus malformation diagnosis in the life of pregnant women, under the light of Betty Neuman’s theory. Methods: qualitative study, based on Betty Neuman’s theory. The semistructured interview included ten women pregnant with malformed fetuses hospitalized in a maternity hospital specialized in fetal risk. The thematic analysis technique was used, respecting all ethical aspects. Results: the way in which the malformation is communicated, the lack of empathy from professionals, the lack of information, being alone, fearing judgment, and feeling guilty led to emotional alterations and changes in the projects of the pregnant women. The family, specialized care, and religiosity contributed for the balance of the participants. Conclusion: Neuman’s theory allowed us to recognize stressing factors that shook the lines of defense of the pregnant women, leading to fragilities which are overcome by specialized care and by a support network.

Descriptors: Nursing Theory; Congenital Abnormalities; Pregnancy.

RESUMO
Objetivo: compreender as repercussões do diagnóstico de malformação fetal na vida das gestantes, à luz da teoria de Betty Neuman. Métodos: estudo qualitativo, fundamentado na teoria de Betty Neuman. Participaram da entrevista semiestruturada, dez gestantes de fetos malformados que estavam internadas em uma maternidade de referência para risco fetal. Foi realizada a técnica de análise temática, e os aspectos éticos foram respeitados. Resultados: a forma de comunicar a malformação, a falta de empatia do profissional e de informação, estar sozinha, medo do julgamento e sentimento de culpa repercutiram em alterações emocionais e nos projetos das gestantes. A família, o atendimento especializado e a religiosidade contribuíram para o equilíbrio feminino. Conclusão: a Teoria de Neuman permitiu reconhecer fatores estressantes que abalaram as linhas de defesa da gestante, ocasionando fragilidades, as quais são superadas pelo atendimento especializado e rede de apoio.

Descritores: Teoria de Enfermagem; Anormalidades Congênitas; Gravidez.

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**Introduction**

Fetus malformations are structural or functional anomalies found in intrauterine life and at birth. They are caused by one or more genetic, infectious, nutritional, or environmental factors, and in 50% of them, the cause is unknown. Estimates indicate that, around the world, 295 newborns die in the first 28 days after birth per year due to fetal malformations\(^1\).

Although interventions can be carried out in many malformations in different levels of care, they can contribute for long-term disabilities and health issues, causing social stigma and financial impacts for both family and health system, since most of them require high-complexity exams and procedures\(^2\).

In Brazil, fetus malformations are responsible for 11.2% of children’s death, thus being the second most common cause of this outcome. From 2013 to 2017, 121,061 children were born with some type of malformation, an average of 8.2 per thousand born alive. The most common were disabilities in the musculoskeletal, nervous, digestive, and circulatory system, which, together, represented more than 60% of the malformations in the country. The Southeast of the country has the highest percentage of cases (47%), with nearly 4 per thousand born alive having some type of malformation. The Northeast region has 26.5%, followed by the South, with 13.3% and the Midwest, with 6.3%. It should be mentioned that, in Brazil, undernotification is still an issue\(^3\).

Obstetric ultrasonography is an important tool to detect alterations in the structure of the fetus. An early diagnosis of the malformations makes it possible to plan interventions during pregnancy or in the immediate and early postpartum period, reducing perinatal and child morbidity and mortality, in addition to allowing for a multidisciplinary planning of mother-fetus interventions and providing information to the parents\(^4\).

The malformation diagnosis deconstructs the image of the perfect baby from one’s imagination. Dealing with the malformation of a child can manifest in different ways, depending on the expectations, culture, support network, maturity of the couple, personal beliefs, and on the context that involves the malformation. Therefore, for the emotional reorganization of the pregnant women and her connection with her fetus, and later, with her child, it is essential that she receives specialized professional support that can embrace her, listen to her, and clarify her doubts\(^5\).

In the scope of nursing care, it can be noticed that, in practice, teams have shortcomings in the care for pregnant women with fetus malformation diagnoses. Professionals do not feel prepared to act as supporters, listeners, or to clarify the doubts of these women, which leads to a reflection about how important it would be to use nursing theories to elaborate science-based care.

This study is justified by the urgent need of subsidizing nursing care based on theoretical concepts that qualify the team for human and holistic care, focused on the specificities that involve women pregnant with malformed fetuses.

The use of nursing theory in reflections about health is relevant because it allows one to direct relations of care and to construct parameters and models of assistance for the performance of the profession, not to mention that it is a reference for the syllabi of nurses and other team members\(^6\).

Betty Neuman’s System’s Model Theory was chosen because it has a holistic perspective in regard to the dynamics of individuals, focusing on the reduction of stress and on the human need for protection. Its use allows for the nurse to see people as belonging to a culture, society, or group, with principles, family, and different levels of education and knowledge; especially, it allows the nurse to see that these individuals have total interaction with the environment, and may be the target of intra/inter/extrapersonal stressing demands\(^7\).

In order to map the object “repercussions of the diagnostic of fetus malformation in the lives of pregnant women”, the following guiding question was elaborated: What are the repercussions of the diag-
nosis of fetus malformation on the lives of pregnant women? The objective was to understand the repercussions of the fetus malformation diagnosis in the life of pregnant women, under the light of Betty Neuman’s theory.

**Methods**

Qualitative study, structured according with the Consolidated Criteria for Reporting Qualitative Studies (COREQ). It was based on Betty Neuman’s System’s Model Theory, which is focused on the well-being of the client in regard to inter/intra/extrapersonal stressors and the reactions to these stressors.

According with this model, the system of the client is protected by three imaginary lines of defense. The flexible line, the most external and active one, protects the individual against external factors, called stressors. It assumes the role of a shield, so the system is not corrupted by stressing factors, which would lead to instability in wellbeing and health. The normal line is the middle one and represents a dynamic state of adaptation, the capacity of maintaining the stability and integrity of the system, also determining any variations in wellbeing. The resistance line, on the other hand, is the most internal one, with internal and external resources that may be known or unknown and sustain the basic line of the individual in the search for protection; it seeks to stabilize the system of the client and promote a return to normal wellbeing.

Participants were selected by convenience, according with the following inclusion criteria: pregnant women, above 18 years old, who received a diagnosis of fetus malformation more than 24 hours ago, whose fetuses were alive and who were hospitalized at the time of the interview. Exclusion criteria: pregnant women who were under strong emotional strain, who tried an abortion during the current pregnancy or previous ones, who went through induced deliveries, whose fetuses were dead, who were receiving treatment for depression, who mentioned some type of personality disorder, severe or moderate psychiatric diagnosis, who had some type of cognitive or speech impairment, and who did not speak Portuguese.

All women were addressed individually and privately at the bedside in the nursing ward for pregnant women of a public maternity hospital specialized in fetal risk, in the city of Rio de Janeiro. The protocols of the coronavirus disease (COVID-19) pandemic were respected. The first three interviews were carried out by a female nurse (MS in sciences) and a male nurse (MS in nursing) to train the obstetric nurse who carried out the other interviews. All interviews were used.

The instrument for the semistructured interview was edited, finding results related with age, educational level, marital status, religion, race, profession, family income, number of pregnancies, deliveries, abortions, alive children, type of malformation, and complications during pregnancy. A script was also used, containing open questions focused on the following one: When was the malformation diagnosis discovered, and how did it affect your life?

The interviews happened from July to September 2020, were recorded in an MP4 device and lasted for a mean of 20 minutes. They were transcribed in full and coded using the letter E (for the Portuguese word for interview, entrevista), followed by a number indicating the order in which the interview was conducted. They were carried out respecting the deadline established by the schedule. In this period, it was possible to invite ten women pregnant with malformed fetuses to participate. There were no refusals, no interview was abandoned, and no interview had to be repeated. The investigation attempted to determine the intensity of the phenomenon, considering its sociocultural dimensions as expressed by behaviors, reactions and values, more than focusing on the repetition of the occurrences.

The thematic analysis technique, after a minute reading and the use of colorimetry, allowed for the identification of 36 topics, that emerged from the statements of participants and formed the corpus of the analysis. The objective was to answer the ques-
tion: What are the repercussions of the diagnosis of fetus malformation in the lives of pregnant women? The topics were grouped in three thematic units, considering the inter/intra/extrapersonal factors that affect the lines of defense of the organism: the flexible, normal, and resistance lines. The thematic units were later regrouped in two categories, separating the factors that had a negative or positive influence on the pregnant women: Diagnosis of fetus malformation and its impact on the flexible line of defense of pregnant women; and Experiences that strengthened the line of resistance of pregnant women.

All ethical precepts were respected. The research project was approved by the Research Ethics Committee of the Instituto Fernandes Figueira/Fiocruz, under opinion 4,131,445/2020 and Certificate of Submission to Ethical Appraisal number 32348620.8.0000.5269. The acceptance of the participants was confirmed with two signed copies of the Free and Informed Consent Form, one of which remained with the participant.

Results

Regarding the profile of the pregnant women, four of them self-declared as white, three as brown, and three as black. Their age varied from 23 to 44 years old; six were single and four were married; six had one or more children alive; six were evangelical, two had no religion, one was from an African religion, and one was catholic; seven had completed high school, one had incomplete high school studies, and only two had higher education; eight declared to have a family income above R$ 1500.00 while two had a lower income; eight pregnant women lived in cities that were far from the maternity hospital they were in, while two lived in Rio de Janeiro.

Diagnosis of fetus malformation and its impact on the flexible line of defense of pregnant women

In this category, the topics found are related to the thematic units “flexible line” and the reports involve the moment when the fetus malformation diagnosis was discovered: A transvaginal, I didn’t even expect to be pregnant, due to my age [42 years old], I have two grown children already. He said [physician] “You are pregnant, your baby, he has a malformation, the pregnancy can be interrupted. You have to look for this immediately, because he has no nose bone, a shortened arm, an edema in the belly...” and he reported it to me like that. I didn’t expect the information, so it was very bad! I got confused! (E1).

When I did the morphological, the doctor said at first that there was an alteration on the head. I’d went to the morphological to find out what the sex was. The doctor just said that and scheduled again for the other week. For one week, I was terrified! I searched a lot of stuff on the Internet, found a lot of absurd stuff (E3).

In the room, I was alone, my husband was outside, but it was complicated. I started crying, he got nervous, so, until he could explain later, it was hard, kind of rough (E7). The professionals would only tell me nonsense, a lot of nonsense! Oh! They told me that if I decided to continue with the pregnancy, a lot of stuff would happen to me, that I had 42 weeks to abort the child. So, I was traumatized about going to the doctor, because whenever I went there, I heard him speak nonsense, I never heard them say anything good to me (E10). So, the few people that knew, that know to this day, I don’t want to tell everyone, judging, so I don’t have to explain myself to everyone (E9). I thought it was my mistake (E4).

Experiences that strengthened the line of resistance of pregnant women

This category includes the thematic units “normal line” and “resistance line”, addressing aspects that collaborated for the wellbeing of the pregnant women: I can’t complain about a thing in regard to guidance, embracing, and respect. Whatever I was missing in the professionals outside, in private practice, I got here, I was given here (E9). And we are in this pandemic moment as well, but, you know, I did have my support here. The psychologist, she calls me, she contacts me (E1). He [husband] was with me at all times! (E2). Oh, my husband is a 10, he’s with me through thick and thin (E4). Well, the whole family embraced me, right, everyone wishing me well and all (E7). I have to give her attention. I even feel like leaving my job because, whether I want it or not, she’ll need me more. And my husband has to work too (E3). The baby united what was separated, many relatives that didn’t even use
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Discussion

Limitations of this study include dealing with the beginning of the COVID-19 pandemic, which required social distancing measures. This changed the way in which spaces are occupied and affected human interaction, potentially affecting interpersonal, professional, and personal relations.

Regarding its contributions, the use of a nursing theory reiterates how important it is for the nurse to use scientific instruments to promote holistic, humanized, multiprofessional, and multidisciplinary attention to women pregnant with malformed fetuses.

Pregnancies after the 35th year of life are more likely to generate malformed fetuses. At this point in their lives, women who did not plan to get pregnant and discover, simultaneously, their surprising pregnancy and the malformation, may suffer irreparable damage if they are not embraced and guided at the time of diagnosis(10). One inadequate word is enough to provoke a negative movement of the flexible line of defense, leading to reduced expectations and suffering for these women, as shown in several investigations(11).

In Spain, a research with 37 obstetric service workers showed that health professionals are not prepared to give difficult news. They highlight that, to improve the communication of difficult and delicate information, such as fetus malformation, there should be training or refresher courses in communicative abilities, specific to the clinical competences of each profession; a comfortable, silent, and private environment; focus on the human and spiritual dimension of health, with especial attention to empathy, authenticity, and listening; adoption of protocols for comprehensive care, based on shared decision making and respect to the grief for the interruption of pregnancy, addressing psychosocial preoccupations(11).

Under the light of the system’s theory, it is essential for women to receive care focused on primary preventive activities during the prenatal, revolving around attentive listening, clarifications, guidance, explanation of doubts about medical discourses that were not understood, and support and encouragement to decision making.

Being pregnant with a malformed baby damages the idealized image of a baby, leading to internal conflicts and questions. The woman must be guided to reflect about their idealizations and realizations, and the real baby must be introduced. The meaning that baby has to the family must be transformed, promoting their inclusion in the group and allowing new forms of love, care, and acceptance in this new day-to-day reality(5,12).

An important interpersonal stressor was the absence of a partner when the diagnosis was discovered. In spite of the COVID-19 pandemic, a communicable respiratory infection that has taken the lives of thousands of people, it would be important to rethink the hospital norms by adapting protective measures, including fetal medicine as a sector that can accept the presence of another with the patient, since there may be diagnoses of malformation or even fetuses incompatible with life.

The physician-patient relation was also identified as an interpersonal stressor, and must be reconsidered, focusing on the humanization of fetal medicine to guarantee respect to the human condition, revise and redefine the rights of users, the care, the clarifications, the support to the anguish and family doubts, as well as the adequate use of interventions and technologies. The relation between physician and patient involves a special process of human interaction that deserves to be discussed from technical, humanistic, ethical, and aesthetic perspectives(11,13).

The interpersonal stressor “fear of social judgment” led pregnant women, especially those above 40 years old, to keep their pregnancies to themselves. Social pressure, shame, fear of malicious comments,
not being certain that colleagues and family will be supportive or wanting to be the target of curiosity, less than respectful statements, the depersonalization of the woman, and a family whose exclusive focus is the malformation of the baby — all of these can generate discomfort, leading women to choose silence as a form of protection\(^{[10]}\).

Regarding intrapersonal factors, guilt was one of the feelings expressed, caused by frustrated expectations, in addition to feelings of anguish, which corroborates data collected in Rio de Janeiro about the experiences of 12 women with anencephalic fetuses. This may happen when they ask too much from themselves, considering themselves accountable for the outcome of the pregnancy and often not including men in this process. This culminates in a search for explanations and justifications that cannot be found\(^{[14]}\).

The psychological follow up of these women is essential for them to continue their plans of motherhood, accepting the fetus and contributing for a humanized outcome, with awareness about the prognosis of the fetus. The normal line of defense was strengthened by eustress factors, that is, positive factors such as embracing and the good care provided by the health care service of specialized in fetal risks.

Being embraced by a health professional can contribute for the moment to be as calm as it needs to be. To this end, some resources are useful, such as: analogies, designs, images, explanatory texts, recurring rates about the present malformation, counseling about the best moment and type of delivery, multidisciplinary teamwork, good environment for the transmission of the information, availability of a well-lighted place with proper wallpaper, pleasant and natural sound, with no sound pollution, simultaneous conversations or the use of phones, showing availability to listen for the anxieties of the couple\(^{[15]}\).

The psychological follow up of the woman pregnant with a malformed fetus must be a part of the specialized health care plan, ensuring she has the opportunity to put her suffering into words. Also, this plan must allow the mother, father, and the family to rebuild the place the baby will have in their lives, detecting potential cases of psychopathy, caring for anguish, anxieties, the symbolic bereavement of the imagined baby, and the possibility of death, also involving the moment when the news about the malformation were received, the delivery, the hospitalization of the puerpera, the discharge and the outpatient follow up\(^{[16]}\).

The participation of a partner was an important interpersonal factor to strengthen the normal line of defense, corroborating that their presence, in addition to being a safe intervention for the woman and having a relative short cost, is a parameter for the care to be provided to the women and to the child. The “Plus one law” requires health services from the public network or that have contracts with the Single Health System to allow for the presence of a companion, chosen by the pregnant woman, during delivery and in the immediate postpartum\(^{[17]}\).

Family and friend support were also mentioned as an important element in the organization of the lines of defense of women, having an essential role for the pregnancy as a whole to be natural and calm. Caring and positive friends, work colleagues, neighbors and relatives have a positive and significant effect on the healthy development of pregnancy\(^{[18]}\).

The line of resistance was associated with changes in the posture of the woman about specific subjects. Assuming the role of main caregiver of the children and letting the man be in charge of paid work was one of the measures mentioned. Nowadays, resistance about the division of labor does not accept the idea that men are connected to the productive aspects of life, while women, to its reproductive aspects. However, a research shows that having a malformed child projects the social role according to which the mother alone must care for the child, especially in regard to health-related care\(^{[19]}\).

The experience of seeing the family coming closer again due to the arrival of the malformed baby was mentioned by a participant as synonymous with union and happiness, contributing for the strengthening of the line of resistance. Going through a pregnancy, even one that is difficult and full of conflict,
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goes beyond usual boundaries, changing people such as siblings, parents, and relatives, who are affected by internal demands and influenced by the environment they live in, and become capable of forgetting previous adversities\(^{(14,17-18)}\).

Tightening religious and spiritual bonds strengthen the resistance of females in regard to the obstacles faced to deal with the finding of the diagnosis. These principles have important aspects in human subjectivity. In the process of coping, religion becomes a sacred instrument in the search for meaning in difficult times. It can provide feelings of belonging, connection, and identification, being related with better mental health and wellbeing indicators\(^{(20)}\).

Not wanting to become pregnant again causes reflections about the role of reproductive planning, not to mention the prenatal and the guidance and preparation of these women. In the prenatal, they must become aware of how to care for a child with different levels of disability, about the potentially limited possibilities of treatment, the potential need for surgical interventions, long treatments, or even for palliative care. Adequate communication is paramount for the pregnant woman to understand and form a critical opinion about reality, and she must receive the adequate support to cope with the diagnosis. It is essential for health professionals to be prepared to aid and give emotional support to the parents, including genetic follow up and reproductive planning for future pregnancies\(^{(10-11)}\).

Conclusion

Betty Neuman’s Systems’ Model Theory allowed us to understand that the diagnosis of fetus malformation causes stressors to appear on the lines of defense of the pregnant woman, leading to emotional weaknesses and changes in the way they project their future. The way in which the diagnosis is communicated, the lack of empathy and information from the professionals, being alone at the time of diagnosis, being afraid of being judged by the age or by the malformation of the child itself, and blaming oneself were stressors that caused fear of social judgment, secrecy about the pregnancy, disbelief on some professionals, plans to abandon work to care for the malformed child, and the desire to not get pregnant again.

Embracing and following up these women in a specialized service, in addition to psychological support, doubt clarification, partner support, and to the integration of family and friends, strengthened their lines of defense, favoring their health.

Authors’ Contribution

Concept, project, analysis, and data interpretation, Writing and relevant critical review of the intellectual content and Final approval of the version to be published: Silva CV, Carvalho TC, Abrão DF, Silva AP, Morais FRC, Carvalho IS.

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