REFLEXOS PSICOLÓGICOS DA MALFORMAÇÃO FETAL PARA REDE DE APOIO: PERSPECTIVA DA GESTANTE

PSYCHOLOGICAL IMPACTS OF FETAL MALFORMATION ON THE SUPPORT NETWORK: THE PERSPECTIVE OF THE PREGNANT WOMAN

REPERCUSIONES PSICOLÓGICAS DE LA MALFORMACIÓN FETAL PARA LA RED DE APOYO: PERSPECTIVA DE LA EMBARAZADA

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ABSTRACT

Introduction: Fetal malformation consists of a functional, organic or genetic alteration in the fetus and can be identified before birth, allowing early assistance. Its occurrence generates anguish in the pregnant woman or in the couple and demands family preparation for the arrival of a baby who will need specialized care, often intensive, surgical and, in some cases, palliative. Objective: To analyze, from the perspective of pregnant women, the psychological reflexes that fetal malformation generates in their support network. Methodology: This is a cross-sectional, descriptive study with a qualitative approach developed in a High-Risk Pregnancy Outpatient Clinic and in the ultrasound examination sector of a maternal and child teaching hospital in a city in the interior of the state of São Paulo. The study was conducted with 11 pregnant women being followed up by the Fetal Medicine team for a diagnosis of fetal malformation. The instruments used were: sociodemographic, obstetric and family questionnaire and open structured interview, analyzed by Content Analysis. Results: The results showed the sociodemographic, obstetric and family profile of the participants, as well as five thematic categories elaborated from the analysis of the reports. It was concluded that, in most cases, the support network was able to strengthen the pregnant woman, but in others, fragility was identified. Difficulties in adapting the support network were identified in the face of external/visible malformations and genetic syndromes. The reports showed shared coping strategies such as religiosity, doctor-patient relationship and quality health care. In addition, most of the participants reported playing a fundamental role in reducing distressing fantasies related to fetal malformation, favoring the integration between the idealized baby and the real baby in the family group. Finally, the study emphasizes the importance of the presence of the support network in prenatal consultations and exams, as well as the use of soft technologies in maternal and child health care.

Keywords: Fetal malformation. Support network. Pregnant women.

RESUMO

Introdução: A malformação fetal consiste em uma alteração funcional, orgânica ou genética no feto e pode ser identificada antes do nascimento, permitindo assistência precoce. Sua ocorrência gera angústia na gestante ou no casal e demanda preparo familiar para a chegada de um bebê que necessitará de cuidados especializados, muitas vezes intensivos, cirúrgicos e, em alguns casos, paliativos. Objetivo: Analisar, sob a perspectiva da gestante, os reflexos psicológicos que a malformação fetal gera em sua rede de apoio. Metodologia: Trata-se de um estudo transversal, descritivo, de abordagem qualitativa desenvolvido em ambulatório de Gestação de Alto Risco e em setor de exame ultrassonográfico de um hospital-escola materno infantil de uma cidade do interior do estado de São Paulo. O estudo foi conduzido com 11 gestantes em acompanhamento com equipe de Medicina Fetal por diagnóstico de malformação fetal. Os instrumentos utilizados foram: questionário sociodemográfico, obstétrico e familiar e entrevista estruturada aberta, analisada por Análise de Conteúdo. Resultados: Os resultados evidenciaram o perfil sociodemográfico, obstétrico e familiar das participantes, bem como cinco categorias temáticas elaboradas a partir da análise dos relatos. Concluiu-se que, na maioria dos casos, a rede de apoio foi capaz de fortalecer a gestante, mas em outros, foi identificado fragilidade. Foram identificadas dificuldades de adaptação da rede de apoio diante de malformações externas/visíveis e síndromes genéticas. Os relatos evidenciaram estratégias de enfrentamento compartilhadas como religiosidade, relação médico-paciente e assistência em saúde de qualidade. Além disso, a maioria das participantes relatou ocupar um papel fundamental na redução de fantasias angustiantes relacionadas à malformação fetal, favorecendo a integração entre o bebê idealizado e o bebê real no grupo familiar. Por fim, o estudo ressalta a importância da presença da rede de apoio em consultas e exames do pré-natal, assim como o uso de tecnologias leves na assistência em saúde materno-infantil.

Palavras-chave: Malformação Fetal. Rede de apoio. Gestantes.

RESUMEN

Introducción: La malformación fetal consiste en una alteración funcional, orgánica o genética en el feto y puede identificarse antes del nacimiento, lo que permite una asistencia temprana. Su aparición genera angustia en la gestante o en la pareja y exige que la familia se prepare para la llegada de un bebé que necesitará cuidados especializados, a menudo intensivos, quirúrgicos y, en algunos casos, paliativos. Objetivo: Analizar, desde la perspectiva de la gestante, los reflejos psicológicos que la malformación fetal genera en su red de apoyo. Metodología: Se trata de un estudio transversal, descriptivo, de enfoque cualitativo, desarrollado en el ambulatorio de Embarazo de Alto Riesgo y en el sector de ecografías de un hospital-escuela materno-infantil de una ciudad del interior del estado de São Paulo. El estudio se llevó a cabo con 11 embarazadas en seguimiento con el equipo de Medicina Fetal por diagnóstico de malformación fetal. Los instrumentos utilizados fueron: cuestionario sociodemográfico, obstétrico y familiar, y entrevista estructurada abierta, analizada mediante Análisis de Contenido. Resultados: Los resultados evidenciaron el perfil sociodemográfico, obstétrico y familiar de las participantes, así como cinco categorías temáticas elaboradas a partir del análisis de los relatos. Se concluyó que, en la mayoría de los casos, la red de apoyo fue capaz de fortalecer a la embarazada, pero en otros se identificó fragilidad. Se identificaron dificultades de adaptación de la red de apoyo ante malformaciones externas/visibles y síndromes genéticos. Los relatos evidenciaron estrategias de afrontamiento compartidas como la religiosidad, la relación médico-paciente y la asistencia sanitaria de calidad. Además, la mayoría de las participantes informaron que desempeñaban un papel fundamental en la reducción de las fantasías angustiosas relacionadas con la malformación fetal, favoreciendo la integración entre el bebé idealizado y el bebé real en el grupo familiar. Por último, el estudio destaca la importancia de la presencia de la red de apoyo en las consultas y exámenes prenatales, así como el uso de tecnologías ligeras en la asistencia sanitaria materno-infantil.

Palabras clave: Malformación fetal. Red de apoyo. Embarazadas.

INTRODUCTION

Pregnancy brings out numerous feelings in the family and social circle, as it not only represents the arrival of a new member, but also causes considerable changes in the psychic dynamics of women and their other social relationships (PICCINI et al., 2008). There are several scenarios for the arrival of a baby and the emotional reactions of the individuals involved will manifest themselves according to the particular binding configuration of each scenario (TEODORO, BAPTISTA, 2012). The pregnant woman is at the center of the situation, directly experiencing all the physical and emotional changes resulting from this moment. As stated in the scientific literature, "from fertilization to the birth of a newborn, the pregnant woman and the fetus go through unique psychological, physiological and social experiences" (VASCONCELOS, PETEAN, 2009).

During pregnancy, it is common for parents to idealize a positive experience, associated with the arrival of a perfect and healthy baby (SILVA et al., 2013). However, the diagnosis of a high-risk pregnancy, either due to the risk of prematurity or the presence of fetal malformations, can break these expectations, bringing the family abruptly closer to the real baby (QUAYLE et al., 1996) and arousing feelings of fear and anguish about the future (VASCONCELOS, PETEAN, 2009).

Fetal malformations are significant structural and functional changes that can be detected during pregnancy, being the second leading cause of infant mortality (MINISTRY OF HEALTH, 2022). Fetal Medicine, in turn, is the medical specialty dedicated to the early identification of these conditions and the planning of the necessary care. Their assistance enables not only a better prognosis for the baby, but also the preparation of the family for the arrival of a child that will require specialized health care (QUAYLE et al., 1996). The presence of malformations places the fetus in the position of a patient, intensifying the distance between the idealized baby and the reality imposed by the diagnosis (QUAYLE, 1997). This discrepancy can generate a profound emotional impact, destabilizing parental desires and expectations and significantly affecting family dynamics (GOMES; PICCININI, 2010; COUTO ANTUNES; PATROCÍNIO, 2007).

The scientific literature observes pregnancy as a social and psychological phenomenon, subject to direct influences from the environment and inserted in a broader and more complex system, that of the family (DESSEN; OLIVEIRA, 2012). SLUZKI (1997) defines the support network as the set of relationships that an individual considers significant, highlighting its dynamic character, which changes over time and in response to transformations in people's lives. Although it is related to the support network, social support is a distinct concept, as it adds a qualitative component to the group. It refers to the presence of people, friends or family members, who can be trusted to receive emotional, affective or material support, in addition to providing a sense of belonging and appreciation within the social group (BERKMAN, 1984, cited by GRIEP, 2003). The mother or couple is usually the first person to receive the fetal diagnosis by the medical team. In this way, they are placed as the main interlocutors of the news for their support network, also mediating medical information communicated during consultations and exams about the baby's health status (TAUFER, 2019).

The way the support network perceives the fetal malformation and the social support received has a direct influence on the emotional response of the pregnant woman to the baby's diagnosis (COUTO ANTUNES; PATROCÍNIO, 2007). After the news of the malformation, the baby's family can give opinions, give advice, unite or separate relationships, soften or worsen the scenario (SOUZA, PEREIRA, 2009). In this sense, it is essential to understand how the support network deals with the situation and offers social support, which can provide different forms of support and help parents in the elaboration of grief for the idealized baby (SILVA et al., 2022). In addition to social support, the presence of a multidisciplinary team sensitive to comprehensive care and technically qualified is an essential protective factor, providing adequate support and guidance on the baby's health (DOS SANTOS et al., 2011).

During the bibliographic survey on the theme of support network and pregnancy with fetal malformation, it was possible to identify a low amount of scientific productions aimed at exploring this subject. Thus, the importance of scientific production aimed at understanding this family and social context is highlighted, with the objective of giving visibility to this scenario of maternal and child health, sensitizing health professionals and guiding interventions that favor the integration of the child into their social group. The present study sought to analyze, from the perspective of the pregnant woman, the psychological reflexes that fetal malformation generates in her support network.

METHODOLOGY

STUDY DESIGN AND LOCATION

This is a cross-sectional, descriptive study with a qualitative approach, carried out in prenatal care at a general and specialty outpatient clinic, a reference in high-risk pregnancies, and also in the obstetric and gynecological ultrasonography sector of a maternal and child hospital in the interior of São Paulo. Both services are part of the same complex and serve both users of the Unified Health System (SUS) and supplementary health. The present sample includes only pregnant women from the public health system.

PARTICIPANTS

The sample selection was carried out using the non-probabilistic consecutive sampling technique, which includes in the sample all individuals who meet the inclusion criteria, successively, totaling 11 participants.

INCLUSION AND EXCLUSION CRITERIA

Inclusion Criteria:

Pregnant women whose prenatal care was followed up by the Fetal Medicine team during the data collection period due to the finding of fetal malformation and whose diagnosis was communicated to the pregnant woman at least two consultations together with the specialist team before data collection.

Exclusion Criteria:

Age minority and cognitive or emotional condition that prevented understanding and conducting the research.

INSTRUMENTS

Sociodemographic/Obstetric/Family Questionnaire: Prepared by the researcher herself, in order to identify the characteristics of the sample studied, such as age, city of origin, marital status, monthly family income, whether she practiced religion, whether she had other children, whether she had previous losses, whether she had a support network, who the members were and whether the diagnosis was communicated to her, perception of the risk of the diagnosis and in which gestational period the fetal diagnosis was received.

Open structured interview: Instrument also prepared by the researcher in charge, according to the objectives of the study, consisting of two questions: "How do you feel about your support network knowing about the diagnosis of fetal malformation?" and "How do you perceive that it is being or would it be for them to know that there is a fetal malformation?". The open structured interview was a methodological instrument chosen, as it seeks to understand the subjectivity of the individual. Their reports deal with the way in which that subject observes, experiences and analyzes his historical time, his moment, his social environment, etc. (BAPTISTA et al., 2017). The interviews were recorded using a telephone device and transcribed in full at a later time for analysis of the reports in the light of the Content Analysis proposed by Bardin (2011). Both instruments did not use the names of the patients as a form of identification, being organized and standardized as follows: G1, G2, G3 and so on.

ETHICAL ASPECTS

In compliance with Resolution No. 510/2016 of the National Health Council (CNS, 2016) that governs ethics in research with human beings, data were collected after approval of the Project by the Research Ethics Committee (CEP), under opinion number 6.965.638, CAAE 80525124.0.0000.5415

PROCEDURES

The approach of the patients to participate in the research occurred in one of two moments: after the prenatal consultations at the outpatient clinic, or before the ultrasound examination in the maternal and child hospital sector, concomitantly with the presentation of the research project, the signing of the Free and Informed Consent Record (ICR), after the end of the prenatal consultation and the ultrasound examination, the pregnant women were directed to an individual room in which the application of the instruments individually and confidentially. The open structured interviews were recorded using a cell phone for later transcription in full, with the express authorization of the participants in the ETS. The questionnaire was applied individually, in a self-administered format. At the time of application, reading was offered to the participant, with the aim of avoiding possible embarrassment in participants who did not know how to read. The content of both the interviews and the questionnaires was stored in a confidential and secure place, to ensure the protection of the information. After the research was carried out, all the material produced was properly stored for later disposal.

DATA ANALYSIS

For data analysis, Bardin's (2011) Content Analysis technique was chosen, as this technique "seeks to know what is behind the words it focuses on" (FRANCO, 2005, p.10), evidencing its subjective character. The technique is divided into three phases: pre-analysis, the researcher must select the documents to be analyzed, formulate hypotheses and objectives, as well as the elaboration of indicators and the preparation of the material; and, finally, the treatment of the results obtained and the interpretation (BARDIN, 2011).

RESULTS AND DISCUSSION

Data collection took place in a period established according to the execution schedule, totaling a sample of 11 pregnant women diagnosed with fetal malformation. Sociodemographic data and obstetric data with the objective of characterizing the sample of participants will be presented in Table 1 and 2, respectively. While the data on the support network were organized in Table 3. The reports were analyzed in their units of meaning and grouped into five categories: 1 – The support network as an element of strengthening; 2 – When the support network becomes a factor of fragility; 3 - The mother as spokesperson; 4 – The difficulties of the support network in the face of malformation; 5 – Shared coping strategies;

Table 1. Characterization of the participants' sociodemographic data:

	Age	City of origin	Marital status	Household income	Practicing religion
G1	From 36 to 45	Miracéu - SP	Stable union	Up to two minimum wages	Yes
G2	From 26 to 35	José Bonifácio - SP	Married woman	Up to two minimum wages	Yes
G3	From 26 to 35	Orindiúva SP	Married woman	Two or more minimum wages	Yes
G4	From 18 to 25	São José do Rio Preto - SP	Stable union	Two or more minimum wages	No
G5	From 36 to 45	Araçatuba - SP	Married woman	Two or more minimum wages	Yes
G6	From 26 to 35	São José do Rio Preto - SP	Married woman	Two or more minimum wages	Yes
G7	From 36 to 45	Presidente Epitácio-SP	Married woman	Two or more minimum wages	Yes
G8	From 36 to 45	São José do Rio Preto - SP	Married woman	Two or more minimum wages	Yes
G9	From 36 to 45	Jales - SP	Stable union	Up to two minimum wages	No
G10	From 36 to 45	Mirassolândia - SP	Married woman	Up to two minimum wages	Yes
G11	From 18 to 25	Brejo Alegre - SP	Stable union	Two or more minimum wages	No

The age of the participants ranged from 18 to 45 years, with a mean of 34.3 years (standard deviation of 7.40 years); only three lived in the city of the reference services; all were in some kind of relationship with a partner, and seven of them were in a marital relationship; seven had a monthly family income of two or more minimum wages (considering the amount of R$1,412.00, referring to the year 2024) and eight reported having some practicing religion. The sample predominantly did not live in the city of the reference service, demonstrating that Fetal Medicine is still a specialty that is not geographically distributed and is potentially difficult to access. Almost all of them had religion as something present in their lives.

It is important to highlight that in the sample, an advanced maternal age limit was identified, corroborating the fact that extremes of age influence the appearance of fetal malformations. Pregnant women who are in a marital relationship and have a family income greater than two minimum wages per month also prevailed, going against what is commonly addressed in the literature in relation to social vulnerability and the absence of a partner as risk factors for fetal malformation (FREITAS et al., 2021).

Table 2. Characterization of obstetric data of the participants:

	Previous pregnancies	Previous losses	Classification of malformation	Gestational period that received fetal diagnosis	Fetal diagnosis in medical records
G1	Yes	No	I don't know	Q3	Haemolytic disease
G2	No	No	Assessment and follow-up after birth	Q2	Pulmonary sequestration
G3	Yes	Yes	Assessment and follow-up after birth	Q2	Severe hydronephrosis on the right
G4	Yes	Yes	Assessment and follow-up after birth	Q2	Pelvic left kidney
G5	Yes	Yes	Surgical intervention after birth	1st trimester	Atrioventricular septal defect and suspected Trisomy 21
G6	Yes	No	Surgical intervention after birth	Q2	Hypoplasia of the left heart
G7	Yes	No	Surgical intervention after birth	1st trimester	Suspected Ebstein Anomaly
G8	Yes	Yes	Surgical intervention after birth	Q2	Cleft lip and palate
G9	Yes	Yes	Evaluation and monitoring	Q2	Hypoplasia of the left heart
G10	Yes	No	Evaluation and monitoring	Q2	Mesenteric or uracac cyst
G11	Yes	No	Evaluation and monitoring	1st trimester	Ebstein's anomaly

Regarding obstetric history, 10 participants had previous pregnancies, and six had no history of previous loss. Regarding the diagnosis, six pregnant women understood that the baby's prognosis would be outpatient follow-up, and seven pregnant women discovered the fetal malformation in the second trimester. The risk classification was answered by the participants according to their understanding of the baby's prognosis. Regarding obstetric history, most of them have other children, just over half have no history of previous losses, but five of them stated that they have a history of previous losses, which may be in agreement with the findings that relate multiparity and miscarriages as risk factors for fetal malformation (FREITAS et al., 2021).

> Regarding the diagnosis, most of them discovered the diagnosis in the second trimester, allowing a time of psychological, physical and material preparation for the baby's arrival and most believed that the prognosis would be outpatient follow-up, even in cases of high complexity. It is important to emphasize that, although not provided for in the initial methodology, the information about the baby's medical diagnosis was extracted from the electronic medical record, as investigated by the Fetal Medicine team in conjunction with other medical specialties, based on tests and procedures performed. Of the fetal diagnoses, seven have an uncertain prognosis of high complexity.

Table 3. Characterization of data related to the support network:

	Support network	Support Network Members	Communication of fetal diagnosis to support network
G1	Yes	Husband and in-laws	Yes
G2	Yes	In-laws, parents, grandparents and uncles	Yes
G3	Yes	Husband, in-laws, mother to friends	Yes
G4	Yes	Mother, sister, in-laws and aunts	Yes
G5	Yes	Parents, friends, cousins, in-laws and grandparents	Yes
G6	Yes	Mother-in-law, grandmother, siblings, nieces and friends	Yes
G7	Yes	In-laws, parents, uncles, cousins, grandparents, friends	Yes
G8	Yes	Husband, father and siblings	Yes
G9	Yes	Children, uncles, sister-in-law	Yes
G10	Yes	In-laws and parents	Yes
G11	Yes	In-laws, son. Husband and boss	Yes

According to Table 3, all participants reported having a support network. Parents-in-law were mentioned by nine pregnant women, the pregnant woman's parents were mentioned by seven pregnant women, grandparents, uncles, husband and friends were mentioned by four pregnant women, siblings were mentioned by three pregnant women, children of the pregnant woman and cousins were mentioned by two pregnant women, and brothers-in-law, nephews and boss were mentioned by one pregnant woman. All of them communicated their support network about the fetal diagnosis.

It is important to emphasize that all the participants of this research have a support network and all of them decided to communicate the members of this network about the baby's malformation, demonstrating that despite the emotional difficulties related to the moment, sharing the news with their social group is fundamental. The representativeness of the in-laws as members of the support network most mentioned in the reports should also be brought to light, corroborating the idea that these family members can offer significant support to pregnant women. Other scientific productions have stated that in fact, during the birth of a child, the partner, the pregnant woman's parents and the in-laws are the closest members of the mother. Being able to provide emotional and material support, assisting in daily tasks, caring for the baby and providing financial assistance (OLIVEIRA 2009).

Another relevant aspect to be highlighted is that some pregnant women mentioned their husbands as part of the support network, evidencing the understanding that the parent is part of this support, not necessarily sharing the same roles as the mother in relation to the baby. Some studies corroborate this perspective, pointing out that the male role of providing prevails as a material support to mothers and their babies, thus distancing them from a close contact with the dyad, as a result of professional work (RAPOPORT, PICCINI, 2006). In addition, the presence of an informal support network composed of extended family members and co-workers was also highlighted.

The methodological process followed the three steps proposed by the Content Analysis technique. After exploring and coding the units of meaning of the reports, it was possible to identify five main thematic categories: the support network as a strengthening factor, the support network as a weakening factor, the mother as a spokesperson, the difficulties of the support network in the face of the malformation and the shared coping strategies.

CATEGORY 1: THE SUPPORT NETWORK AS AN ELEMENT OF STRENGTHENING

In this category, it was possible to observe through the reports that despite the impact caused by the diagnosis of fetal malformation, the support network may be able to reorganize itself in the face of the situation, according to its psychic resources, and offer social support, shelter and continence to the pregnant woman. Having a solid support network that offers continence can favor the beginning of the grieving process in front of the imagined baby, as it is in the family that the mother finds the first point of listening and attention, and they are also the first to offer help and support in coping (ZAMPOLI et al., 2022).

G4: "Sometimes, as much as the doctor says "oh, don't worry", it doesn't happen that we are so calm. I got home the first thing I said was "mom, Valentina doesn't have a kidney" and then she talked to me, talked about it".

The literature indicates that the diagnosis causes a process similar to grief, with phases of shock, denial, sadness and adaptation (DROTAR et. al., 1975). Each subject experiences these phases with different time and intensities, but social support was pointed out as a fundamental factor in the transition from phases to adaptation (GOMES, PICCINI, 2010). This social and emotional support allows pregnant women or the couple to become active in the face of the diagnosis and therapeutic planning of their baby (COUTO ANTUNES, PATROCÍNIO 2007) The participants demonstrated a positive bond with their support network, signaling through the reports the importance of sharing the news with the subjects involved and thus easing the pain of receiving the diagnosis by sharing this experience.

G7: "When I found out about the diagnosis, I was already calling everyone, even crying, they all went home, you know?... So my reaction was to call so that everyone knew as soon as possible so that we could have this support, right?".

High-risk prenatal care can cause physical stress in pregnant women, considering the need for more frequent medical follow-up, submission to painful procedures/exams, and sometimes the need to travel to other cities (ZAMPOLI et. al., 2022; QUAYLE, 1997; AMORIM; MAGALHÃES, 2016). Of the 11 participants in the research, only three live in the same city as the reference services, while five live in municipalities far from the region, evidencing the need to travel between cities. In addition, most participants have other children who need to be in the care of others during the mother's visits to the reference services, usually the father or someone from the support network. In this sense, the support network, in addition to creating a solid basis for the pregnant woman to elaborate her anxieties regarding the baby, also plays an important role in encouraging treatment adherence.

G11: "Oh, I feel welcomed because when I found out, they supported me to go after it, not to give up... They said that whatever it takes, they would help me and today they are really helping me, so it's good."

CATEGORY 2: WHEN THE SUPPORT NETWORK BECOMES A FACTOR OF FRAGILITY

On the other hand, some reports also demonstrated the perception of a support network that faces difficulties in reorganizing itself in the face of the diagnosis and consequently offering shelter and continence to the pregnant woman. This category showed that social support, as previously mentioned, adds a qualitative character to the support network, that is, not all support networks offer adequate social support. It is worth looking at the experience of this type of group functioning, as high-risk pregnant women with weakened social support can experience limiting situations, expressed by sadness, discouragement, guilt, and insecurity (SILVA et al., 2022).

G5: "It's as if I didn't want to, I had a difficulty getting in touch with this possibility and I realize that this can be a barrier even to welcome... I feel a little uncomfortable with that, with this network and I try to do this so as not to distress myself."

In addition, the reports in this category demonstrate the mother's concern about the baby's place in her support network. Despite the significant number of fetal diagnoses with potential lethality of the sample, the difficulty of the support network was greater in diagnoses of genetic syndromes and external/visible alterations. Diseases can be seen as "crisis" situations and the individuals involved can experience both constructive growth and personal and interpersonal difficulties (CARDOSO, 2001). The arrival of a child with disabilities can impact family dynamics, being experienced in a unique way by each member. This event can generate adjustments in the routine, in addition to frustrating or postponing personal and family plans (PIMENTEL SÁ, RABINOVITCH 2006).

CATEGORY 3: THE DIFFICULTIES OF THE SUPPORT NETWORK IN THE FACE OF MALFORMATION

As mentioned earlier, the malformed baby's physical characteristics, as well as possible motor/cognitive limitations, often force parents to deal with the prejudice of others, as well as their own. The mother or the couple may have difficulties in dialogue with the support network regarding the diagnosis, due to fear about the reaction of the family and society, especially if there is an alteration in external/visible characteristics, as in the case of genetic syndromes, limb and facial alterations (PÁDUA, JUNQUEIRO-MARINHO, 2021). The lack of dialogue between the couple and their support network can represent a hindrance in the integration of this child in their family and social environment, causing harm to all involved.

G8: "So, in general, it's sad, right? I wouldn't like to give this news, it's news that makes me sad... I realize that deep down, I think it's not easy for anyone, something that goes out of the routine, from what is normal, from what is healthy, ends up scaring a little".

The following report belongs to a pregnant woman whose fetal diagnosis pointed to a complex congenital heart disease and suspected Down Syndrome. In it, the mother expresses herself about a difficulty of the support network in accepting Down Syndrome, despite the congenital heart disease, whose complexity could mean greater risk to the baby's life. It is expected that initially, the family will feel difficulties in dealing with the child's disability, and may activate defense mechanisms such as avoidance and denial. However, it is important that, within their possibilities, they can develop appropriate coping strategies to restructure themselves and receive the baby.

According to Sá & Rabinovitch (2006) "some families - or even some family member - can become fixated on the initial phases of denial and revolt, and the possibility of belonging is lost by the child, hindering his development and subsequent socialization" (p.82). The family may feel stigmatized by the arrival of a new member with a congenital malformation, and an initial destructuring and subsequent restructuring are common, depending on the support between the subjects involved. The value of the presence of the support network in prenatal care is reiterated with the objective of favoring dialogue between pregnant women, support network and medical team about fetal malformation and consequently preparing everyone for the baby's arrival.

G8: "I still have some in my network who still deny it, right? Who say "oh no, but she's going to be born perfect, right"? God will work a miracle, she won't have that... But I feel as if the syndrome was denied even more than the malformation in the heart, because the baby is going to undergo surgery, right. And then the issue of malformation, so we accept the heart, she will undergo surgery and come back to life, but not the syndrome, it does not exist".

CATEGORY 4: THE MOTHER AS SPOKESPERSON

Frequent contact with the medical team put the pregnant woman or couple in the place of interlocutors of information about the baby's health status, bridging the gap between the diagnosis and the support network, when the latter cannot be present in consultations and prenatal exams. This was an aspect observed in other scientific productions (ZAMPOLI et al., 2022). This category shows that, contrary to what is more commonly addressed in the literature, the mother is not only favored with the support of the support network, but can also offer support and continence to them. The participants associated the attenuation of suffering and better adaptation to reality with access to information about the baby's prognosis, both through research and communication with the medical team.

G2: "For them it's being, like, more complicated than for me."

G7: "Some even seem to be more worried than us, they are astonished by our tranquility."

G4: "My mother-in-law and father-in-law didn't study, so they get much more worried like "and now, how will it be? And then I have to explain that no, there's no problem."

G3: "As I come to the doctor a lot, it's more comfortable for me to know than for him, you know? And my mother-in-law, my father-in-law, my mother has the information I pass on, so I think I calm them down a lot."

The way parents understand the diagnosis will influence family acceptance and the restructuring process, because from an adequate understanding parents can attribute new meaning to the baby's arrival (PIMENTEL SÁ, RABINOVITCH, 2006). One participant stood out when she burst into the negative reactions of her support network, starting to work together with her partner in order to favor the acceptance of the diagnosis and guarantee a place for her baby in the family. According to the scientific literature. "belonging to the family makes the child assume an active role in the family environment, influencing it and being influenced by it, establishing a dialectical relationship" (SILVA, 2000).

G5: "I know that my husband and I will have a journey, a very long process with them. So it's not only with our baby, but also with this network of transforming thought, consciousness. So sometimes I send them some videos for them to see, but I already realize 'no, right? but it's not going to be no'. So okay, but what if it is? We have to work with the what if it is?".

From another perspective, it was possible to observe the difficult nature of the task of intermediating information between the medical team and the support network in cases with a potential for lethality. Women may have difficulties in sharing news due to social pressures, shame, fear of mean comments, and uncertainty of support, leading to silence as a form of protection, in some cases (SILVA et. al., 2022). Despite perceiving adequate social support, two pregnant women verbalized difficulty in establishing an open dialogue about the baby with their support network. When the baby's prognosis is uncertain, the use of light technologies such as the support of a welcoming and ethical multiprofessional team can be fundamental, providing continence and support, regardless of the future scenario (NUNES, ABRAHÃO, 2016).

G11: "I'm more closed about not wanting to comment too much on the subject because for me it's very delicate... But I try to keep them informed as much as possible."

The Content Analysis technique emphasizes the importance of sensitivity to latent contents (pauses, silences, gestures, reactions), as these elements complement the understanding of the message as a whole (CAMPOS, 2004). Thus, a pattern similar to the previous report was also observed in another participant, whose fetal diagnosis also has an uncertain prognosis of potential lethality, in which difficulties in expressing her feelings to the support network are verbalized even though she receives adequate social support. Both participants answered in the questionnaire that after birth the baby will be evaluated and followed up on an outpatient basis, even though both diagnoses - left heart hypoplasia and Ebstein's anomaly - usually require surgical interventions and present high mortality rates in the neonatal period (ATIK, 2011; DE ALMEIDA CARVALHO, 2021).

G9: "Look, to tell you the truth, I don't know what to say about this (about how the support network feels). Because it's complicated, right? I'm glad I have his (husband's) support, my children's support and it's been a support like that even good for me, right? I don't even like to talk too much... (participant starts crying)"

3.5 CATEGORY 5: SHARED COPING STRATEGIES

In the face of a crisis situation, research has shown a movement of family rapprochement, in which the support network develops, together, coping strategies to live this experience. Each family will develop different types of coping strategies, and may also combine them with each other. These modes of coping vary according to culturally installed beliefs and the supply and availability of socio-sanitary resources (PIMENTEL SÁ, RABINOVITCH 2006).

G6: "We are in a chain of prayer all the time and this makes our faith increase every day, not only mine, but everyone's... if God does it, he is God, if he does not do it, he remains God."

G1: "So praying, some praying, each one in their own way, right? They are supporting me thank God, giving the greatest strength"

The sample is composed of a religious majority and the reports showed the value of religiosity in maintaining the feeling of hope and offering continence among all those involved (SILVA et. al., 2022). As previously discussed, assertive communication and open dialogue between the pregnant woman and the medical team also evidenced an important coping strategy, because in this way the family can resolve doubts about the diagnosis and prognosis, avoiding distorted thoughts about the baby. In addition to communication with the medical team, research on data and information from reliable sources has also proven to be an important coping strategy.

G3: "We thought it was a very serious thing, but thank God the doctors relieve us a lot and we are well prepared for when she is born"

G4: "Everyone has started researching what a child is who is born with a kidney or who has a kidney that can be breech. And then today it is already a super calm matter, we have seen that there is no risk at all".

Socio-health resources also favor the construction of ways of coping in the health and disease process. Access to quality health care whose approach includes biopsychosocial aspects was perceived by pregnant women as a strengthening factor in coping with them and their support network in crisis situations, because in many cases early diagnosis and planning of care appropriate to the specific needs of the baby can be a determinant for their living process.

G1: "They say that these things happen, it's not normal, right? But they say it's to be patient, to have strength that everything will work out, right? Thank God, we got help here, right? People are working, they're doing the treatment"

CONCLUSION

The support network was mostly perceived as a strengthening factor, but in some cases as a weakening factor. It was possible to observe that the support network presented emotional difficulties in dealing with pregnancy in cases of genetic syndromes and external/visible alterations, which generated a feeling of sadness in the pregnant woman and consequent concern about her baby's place in the social group. Pregnant women presented emotional difficulties in relation to their support network in cases with uncertain prognosis and potential lethality. Both scenarios show a fundamental need to think about strategies with pregnant women to include members of the support network in prenatal consultations and exams, encouraging their presence whenever possible and providing guidance on the possibilities according to the health service. In this way, the pregnant woman's need to mediate diagnosis information for the support network is alleviated and ensures that members have access to information about the baby and thus can better adapt to its arrival. The reports highlighted shared coping strategies, such as religiosity, access to safe information, doctor-patient relationship, and quality health care. This demonstrates that investment in soft technologies in maternal and child care influences the way the support network perceives the disease in its context.

The results made it possible to understand the pregnant woman's point of view about the psychological reflexes that the diagnosis generates in the support network and also what influence this represents in the experience of the mother of a malformed baby. In addition to the previously established objectives, in general, the important role of the pregnant woman and the couple in attenuating distressing fantasies related to fetal malformation in the support network was evidenced, favoring the integration between the idealized baby and the real baby for the family group. The discussion about the baby with malformation in the family is fundamental, as the child depends on the family bond to develop. She needs specific care with her health, food and learning. However, none of this is possible without a social environment of welcome and affection. The present study enables a new look at the health team that assists pregnant women inserted in this context, in order to favor the best use of soft technologies and the promotion of effective interventions directed to the specific needs of pregnant women or couples and their support network, enabling a scenario of reception and care for the arrival of this baby.

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