

Children with rare diseases: maternal experiences and challenges

Crianças raras: vivências e desafios maternos

Niños con enfermedades poco comunes: experiencias y desafíos de las madres

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Abstract

Objective: To analyze mothers' experiences and challenges when informed about a diagnosis of congenital anomalies. **Methods:** Qualitative, exploratory and descriptive research, developed at Basic Health Units in the municipality of Dormentes, state of Pernambuco, Brazil, through semi-structured interviews with 8 mothers who were informed about the diagnosis of a congenital anomaly during prenatal care or after birth, from 2017 to 2022. A non-probability and intentional sample was used, with closure due to exhaustion. The data collected were analyzed based on the thematic content analysis technique. **Results:** When informed about the diagnosis, the mothers experience fear, sadness and grief. Disclosure of the diagnosis implies adaptations that involve the entire family, in which the challenges posed upon receiving the news evidenced the importance of welcoming and of clarifying the diagnosis and pointed to the search for information and religiousness as strengthening devices. **Conclusion:** The findings revealed the families' adaptive processes, mainly in the mothers, pointing above all to the need for professionals, in particular, from the Nursing area, to rethink their role based on empathy and humanization, seeking to empower families to adapt to the new reality and encouraging them to experience the process.

Descriptors: Congenital Abnormalities; Mother-Child Relations; Nursing.

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Whats is already known on this?

Receiving the news of a congenital malformation exerts psychoemotional impacts on mothers and family members and these impacts are related to losing the idealized pregnancy.

What this study adds?

It contributes in adaptation and reinvention of the family routines, offering subsidies to rethink the professionals' role, based on empathy, humanization, social support and maternal and family empowerment.



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Resumo

Objetivo: Analisar vivências e desafios de mães mediante a revelação do diagnóstico para anomalias congênitas. **Métodos:** Pesquisa qualitativa, exploratória e descritiva, desenvolvida no município de Dormentes, Estado de Pernambuco, Brasil, em Unidades Básicas de Saúde, através da entrevista semiestruturada, com 8 mães que receberam o diagnóstico para anomalia congênita durante o pré-natal ou pós-nascimento, ocorrida entre 2017 e 2022. Utilizou-se uma amostra não probabilística, por intencionalidade, com fechamento amostral por exaustão. Os dados coletados foram analisados a partir da técnica da análise temática de conteúdo. **Resultados:** As mães ao vivenciarem o diagnóstico experimentam medo, tristeza e luto. A revelação do diagnóstico implica em adaptações que envolvem toda a família, na qual, os desafios postos, ao receber a notícia, evidenciaram a importância do acolhimento, do esclarecimento do diagnóstico e apontaram para busca de informações e da religiosidade, como dispositivos de fortalecimento. **Conclusão:** Os achados desvelaram os processos adaptativos das famílias, principalmente das mães, apontando sobretudo para a necessidade de os profissionais, em específico, da enfermagem, repensarem seu papel alicerçado na empatia e na humanização, buscando o empoderamento das famílias para se adaptar ao novo, encorajando-as a vivenciarem o processo.

Descritores: Anormalidades Congênitas; Relação mãe-filho; Enfermagem.

Resumen

Objetivo: Analizar experiencias y desafíos de las madres al ser informadas del diagnóstico de anomalías congénitas. **Métodos:** Investigación cualitativa, exploratoria y descriptiva desarrollada en Unidades Básicas de Salud del municipio de Dormentes, estado de Pernambuco, Brasil, a través de entrevistas semiestructuradas con 8 madres que fueron informadas sobre el diagnóstico de una anomalía congénita durante el período prenatal o luego del nacimiento, entre 2017 y 2022. Se recurrió a una muestra no probabilística y por intencionalidad, con cierre muestral por exhaustividad. Los datos recolectados se analizaron a partir de la técnica de análisis temático de contenido. **Resultados:** Al ser informadas del diagnóstico, las madres sintieron miedo, tristeza y luto. Enterarse del diagnóstico implica adaptaciones que involucraron a toda la familia, donde los desafíos impuestos al recibir la noticia pusieron de manifiesto la importancia de ofrecer amparo y de aclarar el diagnóstico, además de indicar la búsqueda de información y religiosidad como dispositivos de fortalecimiento. **Conclusión:** Los hallazgos revelaron los procesos adaptativos de las familias, principalmente de las madres, señalando especialmente la necesidad de que los profesionales, específica de Enfermería, repiensen su rol sobre la base de empatía y humanización, procurando empoderar a las familias para que puedan adaptarse a la nueva realidad y alentándolas a experimentar el proceso.

Descritores: Anomalías Congénitas; Relaciones Madre-Hijo; Enfermería.

INTRODUCTION

Pregnancy is a physiological phenomenon that each woman experiences in a unique and singular way. This period involves various biopsychosocial changes in pregnant women's lives and is characterized by hormonal, physical, psychological and social alterations. Also during pregnancy – via prenatal consultations – it is possible to identify signs of eventual malformations and genetic diseases, such as congenital anomalies. The diagnosis can already be disclosed during the gestational period, or after birth on many occasions. This possibility is important for prenatal care, which starts to demand more specialized assistance.⁽¹⁻²⁾

Congenital Anomalies (CAs) are defined as abnormalities that can be structural or functional and which occur during pregnancy, having structural, behavioral, functioning and metabolic disturbances of the fetus as inherent characteristics. They can be of a genetic, infectious, environmental or nutritional origin, although the cause cannot be identified in many cases. According to the World Health Organization (WHO), nearly 8 million newborns in the world have some congenital anomaly each year. This high number warns about the relevance of the theme and the need for a debate on the challenges and experiences faced by the mothers and their family nucleus.⁽³⁾

When a pregnant woman or mother is informed about the diagnosis of a congenital anomaly, the most common reactions are shock, anger and even guilt. Therefore, it is delicate and complex to give this news, considering what is understood as bad news. Adapting to this reality involves various factors that can complicate this process, such as economic problems, insufficient public or private services for specific care and a restricted support network. Each person undergoes this process in an individualized way according to the expectations, culture, maturity of the couple and to the very context involving the anomaly.⁽⁴⁻⁵⁾

That said, between the imaginary of a perfect child and the real confrontation with the diagnosis of a congenital anomaly, taken by the fear of the unpredictable, mothers and their family nucleus are emotionally impacted and different experiences and challenges can emerge. Thus, converging with the assumption addressed, the following research problem emerges: Which are the experiences and challenges faced by mothers when informed about a diagnosis of congenital anomalies?

The study proved to be relevant due to the repercussions on family dynamics, with the possibility of contributing to the adaptation and reinvention process of the family routines, offering subsidies to

rethink the role of professionals, mainly nurses, based on empathy, humanization, social support and maternal and family empowerment, encouraging them to experience the process in a more pleasant way. The theme gained more visibility in 2015 after the explosion in the number of microcephaly cases in the country; thus, research studies on the theme have only intensified in the last decade and, therefore, there are still many biases to be unraveled in the literature. Consequently, the objective was to analyze mothers' experiences and challenges when informed about a diagnosis of congenital anomalies.

METHODS

A qualitative, exploratory and descriptive research study⁽⁶⁻⁷⁾ developed at Basic Health Units (BHUs) in the city of Dormentes, state of Pernambuco, Brazil. The municipality has eight BHUs: four in urban areas and another four in rural settings. According to the Brazilian Institute of Geography and Statistics (*Instituto Brasileiro de Geografia e Estatística*, IBGE), Dormentes has a population of 18,692 inhabitants and is located 738 km from the state capital city, in the region of the Pernambuco *Sertão* and, according to the state's health indicators, the municipality is a regional landmark in prenatal care, making it a locus of interest for research.⁽⁸⁾

The following eligibility criteria were listed: being mothers belonging to any age group; living in rural or urban areas, including adolescents; and having been diagnosed with a congenital anomaly during prenatal or postnatal care from 2017 to 2022, noting that collection took place between January and June 2022. The intended time frame and underage participants were included in the sample to reduce research participation restriction, as the eligibility criterion might limit the number of participants; in addition, also due to the fact that teenage pregnancy, mainly between the ages of 10 and 14, increases the risk of comorbidities during pregnancy.

A non-probability and intentional sample was used, as the individuals were selected based on certain characteristics considered important to conduct the research. Sampling was ended due to exhaustion, where all the eligible participants during the collection period were invited to take part in the study, totaling 8 interviewed mothers.⁽⁹⁾

Semi-structured interviews were employed, following a previously established script. The script included identification questions such as age, marital status, schooling and children. In addition to that, the guiding questions consisted of five open questions, namely: 1. How was it for you to receive the news? (Diagnosis of the congenital anomaly); 2. How did you feel?; 3. Which was the largest challenge?; 4. What helped you at that moment?; 5. How do you think that the health professionals might have contributed?; and 6. What has your life been like since then?

A survey was carried out of the mothers who met the eligibility criteria, through the diverse information collected by the nurses working in the service and passed on to the municipal Primary Care Coordination, which made the previous contacts with the eligible mothers, inviting them and clarifying them about the research proposal. The interviews were conducted after their consent, following all the preventive measures against the Coronavirus (COVID-19).

The interviews were carried out individually with the participants in a private environment chosen by the mothers where they felt comfortable, always maintaining secrecy and ethics and in a way that would not generate harms or costs for them. Among these places, 02 interviews were at the health unit itself, 01 at the Municipal Health Department and 05 at the mothers' own homes. The testimonies were recorded in audio using a smartphone device and in mp3 format, and subsequently fully transcribed. In order to ensure secrecy and confidentiality, the participants were identified in the interview script only as "M1" (Mother 1), and thus, successively, listed in the order in which the instrument was applied.

After transcription, all the empirical material was analyzed based on the thematic content analysis technique, in order to analyze the testimonies and reinterpret the interviewees' messages and perceptions in relation to the phenomenon under study. The content was explored following three stages: pre-analysis, exploration of the material; and treatment of the results (inference and interpretation). In the first phase, Pre-analysis, the initial ideas were systematized. The following stage corresponded to Exploration of the material and consisted in coding, decomposition or enumeration operations, based on previously formulated rules. The last stage, Inference and interpretation, consisted in capturing the evident and latent contents present in the entire material.⁽¹⁰⁾

The research complied with the ethical determinations set forth in resolutions 466/2012, 510/2016 and 580/2018 and was only initiated after due approval by the Ethics Committee of *Faculdade de Integração do Sertão* under opinion No. 5,107,557 issued on November 16th, 2021.

RESULTS

The study had eight participants: three aged from 19 to 29 years old and five between the ages of 30 and 49, with one of them living in the urban area and the others, in rural settings. Three of them had children with Down Syndrome and the other five had offspring with Cleft Palate, Cerebral Palsy, Microcephaly, Physical Disability and an unidentified syndrome, respectively. Two mothers were informed about the diagnosis already during their pregnancy and the other six, after birth.

Only one of the participants was single and the others were married. In relation to the number of children, six women had two, one had three and another one had one. In relation to schooling, one had Complete Elementary School, one had not finished it, four interviewees had Complete high School, one had not finished it, and another one was completing High School in the Education for Youth and Adults (*Educação de Jovens e Adultos*, EJA) special modality.

Three thematic categories emerged from the analysis, namely: "Feelings awakened when informed about the diagnosis"; "Coping strategies when receiving the news"; and "Challenges and changes in family dynamics".

Feelings awakened when informed about the diagnosis

In the women, the diagnosis awakened feeling associated with losing the idealized child. In the testimonies, the participants reported how they felt after receiving the news. When analyzing the interviews, it was possible to perceive that negative feelings such as fear and sadness were mentioned.

I was very afraid [...], fear is really dominating. (M3)

I was very sad, when they told me that it might be microcephaly I said: - Dear God, it's horrible to take care of a sick child, but be it God's will. (M5)

I felt a little sad, but it vanished after a while. I wanted to take care of him, whether he was normal or not, I'd take care of him anyway [...]. (M1)

The sudden breach of expectations also generated conflicting feelings of shock and denial in the face of an unpredictable diagnosis, in which they experienced feelings of grief at the first moment when receiving the news.

It was really shocking, I cried a lot because [...] you never expect your child to come with a problem [...]. I felt anguished, I can't put it into words. (M8)

[...] my son's going to die, I cried and cried, I was in agony. [...] he really is my son, right? They didn't exchange him? (M2)

Coping strategies when receiving the news

This category presents the coping strategies mentioned by the participants. Professional support and clarification of the diagnosis were highlighted as a shelter for them at that moment.

I had (professional support). Nothing but to thank (the professionals) because they helped me a lot, talking, explaining, they taught me what it was. [...] a first-time mother never understands, or knows. (M1)

They explained exactly how it could be [...]. That was what helped me. (M4)

On the other hand, when the health professionals fail to clarify the situation and welcome the mothers, they feel even more afraid, as stated in the following testimony:

If they had explained more, I would've already learned more, already knowing what it was going to happen. [...] I got that fright, I didn't understand well. It was only after a while that I gradually understood. I also saw things on television [...]. (M2)

During the reports, it was also mentioned that the mothers themselves sought to know more about the subject matter, as a strategy they used to better understand the diagnosis. Religiousness as a coping

element was also observed in the testimonies, in addition to highlighting the importance of the support network at that moment.

It was very difficult when I learned about it, but then I did some research and saw that it has a treatment, then I gradually calmed down. Then, when he started to undergo the treatment and the first surgery, then, that comforted me more. (M8)

First and foremost, God gives me strength. And, thank God, I had a lot of support from my mother, my mother-in-law, my family and we are there. (M7)

Challenges and changes in family dynamics

The CA diagnosis causes changes in family dynamics, ranging from alterations in the routine to emotional repercussions, and each family faces adaptation according to individual characteristics and skills. These repercussions can be recognized in the participants' reports:

Ah, it changed a little, it always changes. You always have to pay attention to him. (I go out) very little. Very little, this moment (of rest) is very complicated. (M1)

Attention for him is really doubled and, sometimes, he's very stressed out, you have to be patient, because he kept wanting to throw himself, he throws himself on the ground, he throws his head against the wall and if anyone tries to scream, complain, it gets worse. Then, we try to adjust him for him to gradually control himself. (M6)

It wasn't easy for the family to adapt... to this day I don't think they understand, they talk a lot about parties, going out and there's no way. Because it's not about them going, I'm afraid of catching something, not feeling anything and even passing it on to him. (M3)

In view of the reports, it is noticed that the attention devoted to the children prevents them from working and even from enjoying leisure time.

I used to work in the fields, picking beans, but now, with him, I don't work, I have to take care of him, because he walks around a lot, there could be some danger, I have to keep an eye on him at home. You have to be careful, because he needs a lot of attention. (M2)

I used to work and had to resign, because I couldn't do it anymore. The question even of his benefit, because I could only do it if I left work. Now I don't work anymore, I only stay with him. (M6)

It changed everything, the routine changed everything. There's no way you can dedicate yourself to a job, for leisure, for parties, for nothing... there's no way for you to live at ease, as it used to be, everything changes. The thing about going out is that I'm afraid of catching anything, any health problem. (M3)

In addition to that, the different etiologies of the malformations, different degrees of visible alterations, varied prognoses and clinical implications demand specific care that requires a routine of consultations, tests, monitoring visits that oftentimes overload the family, generating physical and mental discomforts and also economic expenses.

Living in one city and going for treatment to another hinders and makes it difficult, because you don't always have transportation to go, it's complicated. (M3)

The biggest challenge is struggling with him, traveling for tests and consultations. (M5)

It changes (the routine), because that way, care is greater. The doctor's routine that I didn't have with the other (children) is now a must. (M4)

It is known that there are various challenges in a maternity hospital and that being the mother of a child with a rare disease can lead to even greater difficulties, mainly when talking about single mothers, as

mentioned by interviewee M5. This is because, when a mother lacks support from the child's father, she starts to assume responsibilities that should be shared and the physical-emotional burden is accentuated.

I was stressed out, I was nervous to take care of him, because I live alone, only with him, a 6-year-old. A child with a problem is difficult for me to take care of on my own. (M5)

The reports show the proportions of CA diagnoses in several dimensions – emotional, social, financial – and, at the same time, confirming the importance of welcoming and encouraging the coping process.

DISCUSSION

Birth of a child is a crucial moment in the life of a family and the wait period involves expectations and planning, which makes it very common to have the imaginary construction of this child in relation to its physical, psychological and behavioral characteristics. When reality imposes different conditions, psychoemotional impacts demanding an acceptance and adaptation process are generated. In general, mothers idealize a healthy and perfect child but, when faced with another reality, it is possible that family distress prevails, given the possibility of facing a chronic illness condition.⁽¹¹⁻¹²⁾

In this regard, it is important to state that the feelings and confrontations experienced by the mothers in this study are part of a constant grieving process, although it is not merely part of a medical diagnosis. It can be present in other life situations, at moments marked by losses or changes, such as at the end of a love relationship, dismissal from a job, change of address or death of a close person. Each situation is experienced in different ways and with varied intensity levels, making it necessary for them to adapt to and accept the new reality.

In this way, grief is established when a mother receives the news that her child has a congenital malformation, in which feelings of anguish, shock, fear and sadness are present, with denial of the facts and the need for truthfulness in the information being very common, as was the case in the research. This grief is not finite; it is perpetuated with each new discovery, need for procedures and even prejudices suffered. A study carried out by Medeiros *et al.* (2021) obtained similar results and the feelings mentioned by the participants were analogous to the research in question, in which they also mention sadness and fear.⁽¹³⁾

The feelings revealed were very similar to the initial grief of the families when informed about the diagnosis. Concomitantly with this finding, a study showed that when a mother is informed about the CA diagnosis, she undergoes a process marked by clinical signs related to losing the idealized pregnancy. In this sense, it is important to note that these reactions should not be neglected by the professionals assisting these women, as they are signs of impacts on mental health.⁽¹⁴⁾

Therefore, receiving the news about the congenital malformation and the way of dealing with it in the daily care of the child can prove to be a negative indicator of the families' well-being, mainly the mothers', in whom it is already known the extent to which female anxiety and depression cases are prevalent in these situations.⁽¹⁵⁾

From the testimonies, it is inferred that the mothers feel more confident and sheltered when they are clarified about the diagnosis and have their doubts solved by the health professionals. This communication between health professionals and the family is fundamental to favor psychosocial support and seek coping strategies.^(14,16)

Corroborating this assertion, a number of studies point to the importance of these health professionals' preparedness to assist the mothers and their family nucleus in the face of a CA diagnosis. Another study showed that when the mothers relate to professionals who provide support and clarification, they feel more prepared to take on comprehensive care, as the professionals' empathy and welcoming strengthen them. In addition to that, the way in which the news is communicated also exerts a significant influence on the emotional impact, in which it can be noticed that when it is given in a welcoming, clear and efficient way and with objective and accessible information, the impact of the diagnosis can be minimized.⁽¹⁷⁻¹⁹⁾

In view of this, it is important that services adopt training options that promote improvements in the communication skills of the professionals in charge of the care provided, as the way in which the news is passed on influences understanding and acceptance of the diagnosis. In this same direction, it is worth reflecting on the female role in today's society, where the tasks considered to be household and family care

still belong to the female universe, in a cultural logic with roots in patriarchy. Thus, this scenario contributes to a significant burden on mothers, making it indispensable to promote support, comfort and well-being by offering psychological support and other therapeutic practices targeted at the mental health of these women.

Coping is the combination of cognitive and behavioral strategies used by individuals to overcome external and internal demands assessed as a burden. These strategies are resorted to in order to minimize the physical, emotional and psychological pressure caused by stressors.^(12,20-21) Therefore, in relation to coping measures, attachment to religion was one of the elements mentioned by the participants. According to Faria and Seidl (2005), religiousness triggers psychoaffective resources that significantly contribute to coping with adversities. The interviewees reported attachment to faith to deal with their child's condition, as resorting to religious strategies favors a positive adaptive result because it stimulates social integration and well-being, and it is important for the health team to recognize spirituality as one of those strategies.^(12,20-21) As a protection factor against emotional burden, religion contributes in psychological elaboration and in stress management. The fact that spirituality is very present in the Brazilian culture favors this attachment to religion to be one of the most used coping methods by mothers and family members.⁽²²⁾

Therefore, social integration strengthens the support networks comprised by family members, friends and even health professionals who are able to promote biopsychosocial assistance, being indispensable during coping. Therefore, the support network is also an important resource in this confrontation and, to exemplify, the literature points out that assembling groups of individuals who go through similar difficulties becomes an effective therapeutic space since, as the different distress dimensions emerge, people lean on each other, either by sharing experiences or with words of support and advice.⁽²³⁾

When asked about what helped them in the process, the mothers revealed the importance of family members and, most of the times, it is primarily to this network that mothers confide the diagnosis, which, consequently, is the basis for overcoming this moment, as it is common for them to offer comfort and be available to collaborate.⁽¹⁴⁻¹⁵⁾ Consequently, religious and/or social support provides less impactful experiences, as it offers shelter for coping with the problem.^(14-15,23)

Regarding the challenges, the testimonies refer to physical burden situations, as the demands are quite different from those of a normal child. Caring for a person that is totally dependent on aid and excessively needs specific or additional care ends up generating an emotional burden as well. And in this case, it is worth noting that, given the precepts imposed by society, women are seen as the main caregivers of their children, leaving their professional and personal achievements in the background as a consequence of the intense child care routine.⁽¹⁶⁾

Concomitant with the dedication time and, consequently, the reduction of social contacts, the family oftentimes has its social interaction and leisure moments with friends and family members impaired due to some particularities related to their children's limitations, such as poor immunity or unadapted environments that become daily challenges when it comes to accessibility and inclusion. In addition, social stances and even those of the family itself, as presented in the study, can be reflected in empowering attitudes when the child's limitations are not understood.

Financial difficulties represent another condition that hinders the care process, as it is very common for parents to end up bearing part of the treatment cost or personal expenses generated due to commuting and food, mainly when this treatment is in another city, as mentioned by the participants. In addition, due to the high cost and lack of resources, it is not uncommon for proper monitoring to be interrupted or nonexistent. It is worth noting that financial problems are stressful factors that potentiate the parents' physical and emotional exhaustion. Consequently, it can be pointed out that lower incomes and, therefore, shortage of resources and materials, exacerbate vulnerability against a fetal malformation diagnosis.^(5,18,21)

Given the above, it is understood that being the mother of a child with a CA is a challenging task that involves acceptance and adaptation. In this coping process, it becomes necessary to welcome these families and resolutely embrace their needs given the emotional impact, the deprivations and the burden experienced. Health professionals are important allies during this process, mainly nurses who perform their activities to promote human health, taking into account its integrality in all its dimensions.

As a limiting factor of the study, the fact that it is restricted to mothers of children with CA living in a single municipality stands out, which did not allow knowing the experience of mothers from other municipalities to understand other realities, suggesting a clipping by classes to compare the realities.

CONCLUSION

The research in question reveals the experiences of mothers who have children diagnosed with CAs and evidences the impacts and challenges that need to be faced by them and the family nucleus, such as the attention required, psychoemotional impacts, changes in routines and financial impacts in view of the needs that arise, among others. Given the results, the particularities of motherhood in the face of a CA are understood, as well as the importance of developing actions targeted at welcoming these families in health services.

Validating these particularities allows recognizing the repercussions of the adaptive process and, therefore, non-preparedness of health services and professionals to welcome and meet the needs of this population segment, aiming at services based on empathy and on care integrality. It is noted that there is a need for a discussion on the subject matter since the professionals' training process, even in undergraduate studies.

It is worth emphasizing that actions in the community, such as Non-Governmental Organizations (NGOs), are also potential strategies, as they allow interaction, exchange of experiences between the mothers and, mainly, social support and mutual help. The importance of welcoming and favoring understanding of grief so that the family can find ways of coping and empowerment in the face of their children's additional needs also stands out.

In this way, this research contributes to the context of adapting to the new, with ways of reinventing family routines that may offer subsidies to rethink the role of professionals, mainly nurses, based on empathy, humanization, social support and the affirmation process, both of mothers and families, encouraging them to experience the process.

CONTRIBUTIONS

Study conception or design: Souza ICC, Melo MCP. Data collection: Souza ICC. Data analysis and interpretation: Souza ICC, Melo MCP. Writing of the article or critical review: Souza ICC, Melo MCP, Santos ADB, Morais RJL. Final approval of the version to be published: Melo MCP.

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