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Congenital heart disease and maternal perceptions and feelings

Cardiopatia congênita e percepções e sentimentos maternos

Cardiopatías congénitas y percepciones y sentimientos maternos

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Abstract

Introduction: Congenital heart disease (CHD) is a chronic disease, characterized by structural and functional abnormalities in the cardiocirculatory system, which may occur due to genetic factors, mutations, chromosomal alterations, or even have a multifactorial origin. Studies discuss the possibility of CC creating a stressful environment for the child and his family, especially for his mother, as she is the family member who generally takes on the monitoring and execution of care for the child. **Objective:** To identify and describe maternal perceptions and feelings about their child's illness, their difficulties, the impact of the disease on the family's quality of life, and their anxieties about the future. **Method:** Qualitative, cross-sectional, descriptive research, with data collection carried out between December 2022 and February 2023, through semi-structured interviews conducted by telephone, recorded, with 13 mothers of children with CC. The analysis process was guided by thematic content analysis. **Result:** Stress is in the speech of most mothers. These statements bring to the fore the fact that stress is condensed especially in the early stages of the process: discovery of the child's illness, news of the surgery(s), responsibility for prolonged care, and maternal isolation. **Conclusion:** Fear of death, the future and the child's development are ghosts that also circulate in maternal manifestations and express the difficulty in anticipating their children, a basic condition for adequate general development.

Keywords: Heart Defects Congenital; Maternal Stress; Child Development.

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Authors' contributions:
LBG: Study conception; Data collection; Study outline and Critical review.
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Resumo

Introdução: A Cardiopatia Congênita (CC) é uma doença crônica, caracterizada por anormalidades estruturais e funcionais no sistema cardiocirculatório, podendo ocorrer por fatores genéticos, mutações, alterações cromossômicas ou mesmo ter uma origem multifatorial. Estudos discutem sobre a possibilidade da CC criar um ambiente estressor para a criança e sua família, sobretudo para sua mãe, por ser o elemento da família que, geralmente, assume o acompanhamento e a execução dos cuidados com a criança. **Objetivo:** Identificar e descrever a percepção e sentimentos maternos acerca da doença do filho, suas dificuldades, o impacto da doença na qualidade de vida da família e suas angústias diante do futuro. **Método:** Pesquisa qualitativa, transversal, descritiva, com coleta de dados feita entre os meses de Dezembro de 2022 e Fevereiro de 2023, por meio de entrevistas semiestruturadas realizadas por ligação telefônica, gravada, com 13 mães de crianças com CC. O processo de análise foi orientado pela análise de conteúdo do tipo temática. **Resultado**: O estresse está presente na fala da maior parte das mães. Essas falas trazem à cena o fato de que este se condensa especialmente nos períodos iniciais do processo: descoberta da doença do filho, notícia da(s) cirurgia(s), responsabilidade pelos cuidados que se prolongam, isolamento materno. **Conclusão**: O medo da morte, do futuro e do desenvolvimento da criança são fantasmas que também circulam nas manifestações maternas e expressam a dificuldade em antecipar aos seus filhos uma subjetividade, condição de base para o desenvolvimento geral adequado.

Palavras-chave: Cardiopatias Congênitas; Estresse Materno; Desenvolvimento infantil.

Resúmen

Introducción: La cardiopatía congénita (CC) es una enfermedad crónica, caracterizada por anomalías estructurales y funcionales en el sistema cardiocirculatorio, que pueden deberse a factores genéticos, mutaciones, alteraciones cromosómicas o incluso tener un origen multifactorial. Los estudios discuten la posibilidad de que el CC genere un ambiente estresante para el niño y su familia, especialmente para su madre, ya que es ella la que generalmente asume el seguimiento y ejecución del cuidado del niño. **Objetivo:** Identificar y describir las percepciones y sentimientos maternos sobre la enfermedad del hijo, sus dificultades, el impacto de la enfermedad en la calidad de vida de la familia y sus angustias sobre el futuro. **Método:** Investigación cualitativa, transversal, descriptiva, con recolección de datos realizada entre diciembre de 2022 y febrero de 2023, a través de entrevistas semiestructuradas realizadas por teléfono, grabadas, con 13 madres de niños con CC. El proceso de análisis fue guiado por el análisis de contenido temático. **Resultado:** El estrés está presente en el habla de la mayoría de las madres. Estas declaraciones traen a la luz el hecho de que el estrés se condensa especialmente en las primeras etapas del proceso: descubrimiento de la enfermedad del niño, noticia de la(s) cirugía(s), responsabilidad por cuidados prolongados, aislamiento materno. **Conclusión:** El miedo a la muerte, al futuro y al desarrollo del niño son fantasmas que también circulan en las manifestaciones maternas y expresan la dificultad de anticiparse a sus hijos, condición básica para un adecuado desarrollo general.

Palabras clave: Cardiopatías Congénitas; Estrés Materno; Desarrollo Infantil.

Introduction

Congenital heart disease (CHD) is a condition characterized by structural and functional abnormalities in the cardiovascular system, which may be a result from genetic, environmental, or multifactorial factors. These abnormalities can have an acyanotic or cyanotic nature and can be detected during the prenatal period, shortly after birth, during childhood, or in adulthood[1].

In many cases, this condition requires repeated surgical interventions from birth, leading to frequent hospitalizations. Moreover, due to its chronic nature, it can create delicate situations for the child and their family, including developmental obstacles for the child and fatigue from continuous and special care, as well as anxiety and distress about the future for the family[2].

The literature shows that there may be more or less subtle delays in the language, motor, socio-emotional, and learning development of children with chronic diseases, such as those with heart conditions[3,4,5].

Despite indications of potential problems reported by various studies, the development of children with heart disease generally tends to resemble typical development, with issues that appear to be circumstantial and have an indirect relationship between heart disease and overall development, except in cases of dual pathogenesis[6], when significant alterations stand out.

Many studies discuss the possibility that pediatric heart disease creates a stressful environment for the child and their family, especially for the mother, who is often the family member responsible for monitoring and carrying out initial care, which, however, may become prolonged. Furthermore, the fear of the child's death and the uncertainty about their future may lead to a condition of anguish and depression that psychologically weakens the caregiver[7,8].

Stress is inherent in life and can be defined as a process in which an individual perceives and responds to challenging, threatening, or harmful events, leading to physiological and psychological changes, including nausea, vomiting, muscle pain, hypertension, anger, physical and mental illnesses, among others[9]. It should be noted that it is required for normal human functioning as it alerts the individual to threatening events, triggering physical and psychological signs that guide them towards seeking defense mechanisms and necessary adaptation[10]. However, when stress loses its positive aspect, it ceases to be a defense mechanism and becomes a threatening condition itself. In this context, this seems to be the case for mothers of children with heart disease. Research shows that the level of familial and social support received by mothers directly influences their stress levels and, consequently, their relationship with the child[11]. Therefore, higher levels of support are associated with lower levels of stress, and the complexity of the child's condition also influences maternal stress levels.

However, these studies are not conclusive, as there are conflicting results[12], suggesting that each case is unique. In other words, the level of stress experienced by mothers, ranging from mild to severe, depends on various factors beyond the child's chronic illness, as it may be associated with the mother's emotional state, cultural background, and other aspects[13].

This study aimed to identify and describe maternal perceptions and feelings regarding their child's illness, the difficulties they face, the impact of the illness on the family's quality of life, and specifically, the anxieties they experience regarding the future. Understanding maternal experiences can assist clinicians in making therapeutic decisions and improving the effectiveness of treatment for children with CHD.

Thus, this study contributes to the discussion on the topic of stress experienced by mothers of children with heart disease, its relationship with multiple factors, and the diversity in its manifestation or even its absence.

Method

This is a cross-sectional and descriptive study with a qualitative approach, approved by the Decision of the Research Ethics Committee under the No. 61117522.6.0000.5482, which included a signed informed consent forms (ICFs) from all participants.

Thirteen (13) mothers of children with congenital heart disease participated in the study, being selected through convenience sampling as follows: 1) A search was conducted in a database of twenty (20) mothers of children up to 5 years old, of both sexes, with any type of congenital heart disease; 2) A brief explanatory text on the study, including the nature and purpose of the informed consent form, was sent via email, along with a request for voluntary participation in the study and the signing of the ICF; 3) Individual interviews were conducted. Only mothers who completed the entire proposed procedure were considered, resulting in the exclusion of 7 mothers who either agreed but did not complete the interview or discontinued the interview for any reason. Therefore, the sample consisted of thirteen (13) mothers. Their names were omitted to ensure anonymity, and they were identified as M1, M2, and so on.

Data collection took place from December 2022 to February 2023 through semi-structured interviews conducted via recorded telephone calls, lasting approximately 30 minutes, at a prearranged date and time agreed upon with the mothers. The guiding questions were as follows: 1) When did you discover your child's congenital heart disease?; 2) Did you have any prior knowledge about congenital heart disease?; 3) What were your initial feelings? Did these feelings change over time?; 4) How were you informed about the treatment that should be followed?; 5) What difficulties did you face in the daily care of your child?; 6) Did you experience significant stress at the beginning? What did you feel? Who provided you with the most support?; 7) Do you believe your child's overall development has been/ is normal?; 8) What are the main challenges of being a mother of a child with congenital heart disease?; 9) What are your plans for your child's future?

All collected material was transcribed in its entirety, and the analysis process followed a thematic content analysis approach, which aimed to: "identify the core meanings that compose a communication, where their presence or frequency means something for the targeted analytical object"[14]. Operationally, the analysis was conducted in three stages: (1) Pre-analysis: A preliminary reading of all communications; (2) Exploration of the material: Classification of content was carried out to reach a core understanding of the text, resulting in thematic categories; (3) Treatment of results and interpretation: This step allowed the extraction and interpretation of information according to the study's objective.

Results and Discussion

The collected material was analyzed, and two major categories were identified, each with its own subcategories: 1) **Maternal stress:** Impact (of the discovery); Isolation (due to hospitalization) and ongoing initial care; 2) **Maternal perspective:** The real (the child now) and the ideal (the child's future).

Maternal stress

The impact of the discovery: The birth of stress

The discovery of a congenital disease, whether during gestation, as experienced by some of the studied mothers (5), or after birth, as in the case of 8 mothers, results in an irreversible disruption in these women's motherhood journey, as the envisioned child is deconstructed by the reality that imposes itself, leading to shattered expectations[15]. In the case of heart conditions, there is an aggravating factor because the heart is considered the vital organ for survival and, therefore, holds significant symbolic value, causing feelings of *fear* of death, *anguish* over the uncertainty of the future, and *guilt* over the loss of the imagined and real child to be part of these mothers[16]. The reports of the mothers precisely reflect these feelings:

> **M2:** *"I **felt completely devastated**, I was afraid";* **M9:** *"My world crumbled when I found out. I felt devastated, really **devastated**";* **M13:** "*I was **really bad**, as I had done all the prenatal exams that were necessary and the results were within the normal parameters, so when I found out she had a heart condition, it was quite frustrating. **At that moment, it was frustrating and infuriating, and I kept thinking, 'Why?!'**"*.

Congenital diseases can be detected early nowadays through prenatal follow-up exams called morphological ultrasounds (usually done around 25 weeks of gestation), which, in itself, is a highly stressful situation for mothers as it aims to identify genetic disorders and malformations[17].

The literature highlights the necessary conditions for the success of this exam: proper timing of the examination, accurate instruments, and highly specialized medical image readers[18]. However, the reports of the mothers show a problematic aspect of the exam, as, despite having undergone the examination, it did not indicate any problems in some cases, and the malformation was only detected after birth.

> **M1:** "*I had three morphological ultrasounds, including a 3D one, and* ***none of them found the problem****"; **M2:** "I had a fetal echocardiogram, and it* ***didn't show anything at all. I only found out about the heart condition when she was one month old****"; **M5:** "The morphological ultrasound indicated that my baby was small for gestational age (SGA),* ***but it found no heart problem****".* There was stress in these cases due to the expectation of a result that was not confirmed, as the child was born with a congenital anomaly.

It is worth mentioning the report of one mother (**M3**) who, during the ultrasound examination, initially felt relieved by the absence of genetic disorders but then faced the impact of discovering the cardiac morbidity:

> ***"At first, I felt relieved because there was no syndrome, right?*** *I even had a genetic test.* ***So it was a relief because it's something that can be treated, so to speak. But at the same time, the doubts came... What kind of heart condition? Until then, we didn't know what type of heart condition it was and the extent of the problem. We only knew it was a problem in the heart****".* **M12:** ***"Initially, I was terrified, the way the information was delivered, the doctor questioned me, and it created a sense of guilt like, 'You didn't know?', 'Why didn't you say anything?', 'We could have tested him.', 'We barely made it.'****, it was a shock for everyone. After they did everything possible, everything turned out fine, and they also referred me to the post-operative follow-up, and he still goes for check-ups every six months."*

The testimony of this mother (M3) demonstrates this distressing unfolding, minimized by the temporary and imagined possibility of treatment that congenital heart disease offers, unlike other syndromes that can profoundly and permanently affect the child's overall development. The possibility that the heart disease could be treated (and eliminated?) is merely imaginary, as congenital heart disease is potentially a chronic condition that can have lifelong repercussions[19]. Additionally, there are heart conditions for which only palliative actions can be taken given their severity.

The birth often leads to disillusionment. The baby, who is the product of an illusion, becomes a disillusionment upon birth because the child the parents are confronted with does not correspond to the expectations developed during pregnancy. In cases of congenital abnormalities, this confrontation takes on greater magnitude[18,20], as a void opens up deepening the void created by the initial rupture caused by birth, and thus, anguish, despair, and powerlessness overwhelm these mothers.

> **M1:** "*I was* ***desperate****, but then I talked to the doctor and put my emotions aside a bit and used reason to understand and take action to help her"; **M2:** "I* ***felt completely devastated****, I was afraid, but at the same time, I trusted the medical team taking care of her. But it was that feeling of "'my God, what am I going to do with my life now?'"***M8:** *"****First, I felt powerless*** *because I couldn't do anything at that moment";* **M9:** *"My world crumbled when I found out. I felt devastated, really* ***devastated****."*

Following this, fear engulfs these mothers, as the possibility of the real baby dying is imminent.

> **M8:** "*I was* ***afraid*** *because I thought my daughter was going to die";* **M9:** *"I felt completely devastated, I was afraid, really afraid, and I had a sense of* ***death****, that she was going to die."* Feelings of fear, despair, and powerlessness are potent stressors that seem to emerge at this moment.

Hospitalization: Nourishing stress

The discovery of the heart disease is often accompanied by the announcement of surgeries, creating conflicting feelings between the joy of a potential cure and the fear of death, which is reaffirmed. Furthermore, the surgeries will require hospital stays, causing a kind of confinement that initially separates the mother and baby as the child will be under the care of nurses. This is a second involuntary and unpredictable rupture, following the birth and the discovery of the disease. As such, it carries all the investment necessary for the (re) union of the mother-baby pair[19,20].

Moreover, hospitalization will isolate the mother from family and social interactions, *changing the family structure and triggering subjective feelings and emotions based on each individual's life stories*[16]. In addition, when the child is discharged from the ICU, the hospitalization places the mother in the role of the child's *natural* caregiver, as observed in some traditional family arrangements, in a role that carries significant responsibility and expectations[21]. Other feelings are revealed: sadness, loneliness, fatigue, and depression.

During this time, mothers begin to experience grief as they search for diverse strategies to cope with both the loss of the imagined child and the involuntary arrival of a real child who may die at any moment, which could be another loss. They may develop strategies to adapt to adverse and stressful circumstances, whether through deepening their religious beliefs or relying heavily on technical expertise, almost authorizing the medical professionals, therapists, and even mother support groups to take charge of the case[22], as evidenced by the reports of the mothers:

> **M1:** *"I can say that I matured. Each person has their own way of coping, but* ***I sought to deepen my understanding and research, read scientific articles****, talk to physiotherapists and speech-language pathologists to truly understand my child's heart condition and what I could do to improve her quality of life";* **M2:** "***I started researching a lot, reading articles*** *, and I didn't find much information about children,* ***so I started to follow various accounts****, especially on Instagram, that talk about this on social media.* ***I'm in a group of mothers of children with heart conditions. So, I sought more information, studied****, to feel more secure and make the best decisions for my daughter*"; **M5: "***I sought information* ***from doctors and geneticists****".*

The new feelings triggered by the news of hospitalization and subsequent maternal isolation, such as fear, sadness, loneliness, and depression, further fuel the stress, demanding specific coping strategies that prove to be ongoing[22].

Initial Care (that doesn't end): personal strategies and support networks to mitigate the violence of stress

Regardless of medical explanations and guidance, mothers of children with heart conditions cannot remove the possibility of death or the immense suffering, including physical pain, that afflicts their children from their perspectives. Thus, they tend to become overprotective, hoping to reduce both risks. On the other hand, research shows that a mother's presence with the child, particularly in carrying out routine care, creates a favorable situation for treatment, justifying the encouragement for mothers to assume this commitment[23].

However, these care responsibilities bring about exhaustion, and the main symptoms that manifest are constant fatigue, muscle tension, hair loss, and memory problems, which can pose considerable challenges for those who experience them, given that memorization activities are intrinsic to the demands of the caregiving role. During this phase, symptoms of the psychosocial aspect also emerge, such as anxiety, fear, social isolation, fluctuation in appetite, sexual impotence, and others[24]. As shown below:

> **M7:** "*I was extremely* ***stressed****! Losing hair, nails... I cried all day long,*" or **M9:** *I can tell you that our challenge as mothers is* ***fear*** *and worry, and it's more tiring than taking care of her. Today, I'm undergoing psychiatric treatment,* ***taking medication to sleep, I take anxiolytics. I experienced a sudden and significant hair loss****. So, now I'm paying the price for everything I went through with my daughter, you know?.*

Regarding psychological symptoms, excessive irritability, excessive fatigue, daily anguish/anxiety, constant preoccupation with a single subject, and irritability without apparent cause stand out as the most prevalent psychological symptoms: excessive emotional sensitivity and the desire to escape from everything[24].

> **M9:** *"****I can tell you that our challenge as mothers is fear and worry****, and it's more tiring than taking care of her. Today, I'm undergoing psychiatric treatment, taking medication to sleep, I take anxiolytics. I experienced a sudden and significant hair loss. So, now I'm paying the price for everything I went through with my daughter, you know?*"; **M3:** "*"I became really* ***stressed****, really, and we had other issues regarding the health insurance, which didn't cover the reference hospitals. The surgery was therefore very stressful from the beginning of the pregnancy*"; **M4:** "***"I still feel fear, a lot.*** *Sometimes I'm afraid that she'll collapse right in front of me. Since it's related to the heart, we never know what to expect, right? I was very* ***stressed****, even during pregnancy."*

Some statements show the mother on the verge of finding some coping mechanisms while feeling helpless, unable to fight against the stressor.

> **M5:** "*It wasn't a planned pregnancy, and I felt really bad at the beginning. I had no appetite, no motivation to get up, I was very depressed, you know? I had no plans of having more children, a baby, especially after such a long time. We were in a tight financial situation, so it was a shock, and it took me... and to add to that, my father passed away three months ago, and I was going through the grieving process. Everything just piled up, and I was really unwell. At first, I was very* ***stressed****,* ***irritable, and in a bad mood****";* **M6:** "*I understand the heart condition, I understand the risks, but I do have some* ***fear****, because, whether we like it or not, it's a disease. Even though it's congenital, it can accompany her for the rest of her life or* ***present complications along the way, leading to other problems***"; **M8:** *I couldn't sleep properly. If she took a little longer to wake*

> *up, I would already be there, you know? Watching her breathing, listening if her heart was beating.* ***It made me neurotic for a while****. It started to* ***affect me****, you know?* ***Who can handle living under that pressure for an entire year, right?***

The situation of mothers faced with the impact of the diagnosis, the announcement of surgeries, and the beginning of the child's hospitalization is highly vulnerable. Physical and psychological damages accumulate, and mothers who have support networks experience more effective coping mechanisms[25]. Support networks can take various forms: the medical and nursing staff providing clarification about the case and assisting with special procedures, the multidisciplinary team providing psychological support, social structures, and family members alternating in routine care and sharing responsibilities and decisions[24]. The reports of the mothers highlight the importance of the cardiologist's opinion in finding solutions to cope with the situation, even though it can sometimes increase distress and stress and, in some cases, the suggestions may not be perceived as effective.

> **M2:** "***The medical team was wonderful****, so she underwent surgery at Beneficência Portuguesa (Hospital) and her team is from Ecokids.* ***They explained what she would need to do, what treatments she would require, they were great****. Of course, I tried not to blindly rely on their information and did some research on my own, drawing from my own strength, but they were great*"; **M3:** *"I was actually the one who always sought out information.* ***The doctors themselves were quite vague, in fact, I think they tried to console me more than they tried to explain****";* **M4:** "*As soon as she was born, they explained to me.* ***The doctor explained to me****, especially because I only saw her after the surgery in Londrina*"; **M5:** "*"It was in the hospital, but I wasn't prepared to understand all that information. I only truly understood my daughter's heart condition later on*"; **M6:** "***"I was well-guided, but in reality, they instilled a lot of fear in me. We practically lived in isolation for a year of our lives because his pediatric cardiologist said, 'he will die if he gets COVID'"; M7: ""They (the doctors) provided me with great guidance****. It was at Incor (Heart Institute) and they provided me with excellent guidance when he was discharged. Actually, they didn't want to discharge me (laughs), but I insisted, and then they discharged me*"; **M8:** "*When they called me, it was actually the day of my discharge, and they called the father to talk about the surgery and her condition. Prior to that, I had a conversation with the neonatologist, and* ***she explained her heart condition to me****";* **M9:** *""****The cardiologist who specializes in her condition was the one who always reassured and provided me with a better understanding of the disease****. The other professionals are not prepared and are not even aware of the high risk I faced*"; **M10:** *"At the beginning, I didn't feel any stress.* ***I received great support at the hospital from psychologists, social workers*** *when I came to the hospital before he was born, I already had assistance. They showed me where he would stay after birth, the ICU where he would be, how everything was*"; **M11:** ***"Through the doctors, through the team she went through, they explained everything to me correctly"****.*

The family support network emerges as being very relevant, especially in providing emotional support. The child's care is rarely shared, reinforcing the idea that the mother has a *natural capacity* for caregiving, given the child's vulnerability due to the illness. Studies show that family support is essential for maternal adherence to treatment and medication routines, and when these care practices are well executed, they prevent or delay relapses, thereby reducing stress and creating a positive cycle[8].

The maternal perspective

The child now

The literature indicates possible delays in the development of children with heart disease, particularly in motor skills, but there are also studies that discuss language-related issues[4,5]. There are statements that point in this direction.

> **M5:** *"I asked the pediatrician why my child wasn't sitting at 8 months, and I requested a referral for physical therapy. The same goes for speech, shouldn't she be talking by now?* ***She is just starting speech-language pathology care, but I am aware and I observe it, especially comparing her to children at daycare*** *[...] The earlier the stimulation occurs, the better. I'm not sure if it's time for her to speak more or not. I'll wait another month and then we'll see if we should seek a speech-language pathologist or not*"; **M9:** *""****Now she has caught up with other children. Until then, my daughter's development was quite delayed compared to other children her age.*** *She had physiotherapy three times a week, which we started when she was 1 year old. At 1 year and 1 month, she sat up, then at 1 year and 2 months, she crawled, and at 1 year and 6 months, she started walking."*

The heart condition serves as an indirect source of problems, thus a condition that determines the interaction between mother and child, leading to overprotection, which could interfere with child development[5]. It is noteworthy that when asked about her child's development, she reports on the organic process, indicating her fundamental concern for the child's survival, ensured by physical health.

> **M1:** *"**Regarding the first surgery, she is doing great now**. Her growth is normal, even the doctor says, 'What are you giving to this child?' She has grown a lot and gained a considerable amount of weight. She is like a different child now, and I am able to strictly follow the medication and meals. I do everything in my power, and she is like a different child*"; **M2:** *"I think it's going **well**";* **M3:** *"I don't see **any changes or delays in him**... In terms of speech, everyone tells me that boys usually take longer, right? Because my daughter was already speaking more at his age... But everyone says that girls are more talkative*"; **M4:** "*Her teeth took a long time to come in, but other than that, everything is **normal**;* **M8:** "*She is very lively, and her development is **more than normal***"; **M10:** *"**Normal**, there's no difference. In fact, he is even more energetic and restless. No one would believe he has a heart condition."*

In the case of children with syndromes, there is a different narrative, as the genetic condition triggers a series of problems.

> **M6:** "*A normal child, someone who sees him would say, 'He doesn't have what you're talking about, you're crazy.' But he is a child who truly has had limited contact and interaction. He doesn't respond when called by name, and he has some characteristics of autism. However, we have to take into consideration the numerous hospitalizations and invasive tests."* (this child has Edwards syndrome); **M7:** *"So, the only issue now is speech, right? He was diagnosed with DiGeorge Syndrome, and he has physical therapy, speech-language pathology care, and occupational therapy sessions once a week*"; **M11:** "*It's going well, thank God she developed very well even after the surgery she underwent at 9 months old. She has transformed into another child. The only difficulty she still has due to all of this is with feeding*" (this child has Down Syndrome); **M13:** *"She was being monitored at the APAE [Association of Parents and Friends of Exceptional Children] - speech-language pathology, occupational therapy, and physical therapy. It wasn't related to the heart condition, but rather the syndrome itself. She has difficulty with speech, but it has improved significantly with speech-language pathology care. Her overall development is normal, aside from speech. She hasn't had any difficulties in school so far*." (this child has Noonan Syndrome)

The child's future

Anticipation is a fundamental symbolic operation that guides the mother-child relationship from the beginning, marking a time that, although only imagined, serves as the guiding thread for the relationships that unfold over time In this operation, the mother projects her desires onto the child and constructs a fictional subject, anticipating it[26].

Interestingly, mothers of children with heart conditions may deny this operation as a form of self-protection.

> **M3:** "***I live in the present**, I want to protect myself*"; **M6:** *""**I want to live in the moment**, what I planned didn't happen*". They project their desires related to the child's physical health, *hoping for normalcy:* **M1:** *"That she has **normal** growth"; **M2:** "**That she is strong and healthy**";* **M4:** *"That she is not **different**";* **M5:** *"That she develops and **has a life like her siblings***"; **M8:** *"To see if the heart condition **improves**"*. They put themselves in a waiting period to anticipate: **M3:** *"I will live in the **present**";* **M4:** "*Let's see if **everything works out** with the surgery"*. They wish happiness for the child as a future aspiration: **M2:** *"I want her to be **happy**";* **M9:** "*I want her to be **happy**"*. They transfer the role of projecting the future to God: **M10:** *"**I want my plans to align with God's plans**"*.

In other words, mothers of children with heart conditions rarely engage in effective anticipation, but this operation is not always absent[27], and it is pertinent to discuss the issue of death, an imminent possibility that is not rejected. Some of them even outline a plan, even if it is immediate:

> **M13:** "*I hope for her to grow up, study, graduate";* **M12:** "*Start the first year, take music lessons";* **M7:** "*Study, go to college";* **M8:** "*Go to daycare";* **M9:** "*Have a good quality of life, I don't want her to work on the factory floor*."

Final Considerations

Stress is present in the report of the majority of mothers, which is in line with those reported in other studies. These statements bring to light the fact that stress is particularly concentrated in the initial stages of the process: the discovery of the child's illness, news of the surgery(ies), responsibility for the initial complex and prolonged care, and maternal isolation. It should be noted that these phases of the process impose fundamental psychological operations: mourning for the imagined child, disappointment with the real child and subsequent narcissistic injury, guilt, and responsibility for appropriate care, seen as a natural and inherent assignment of the feminine nature. These contingencies contribute to varying degrees of stress, with unique manifestations that should be emphasized in all therapeutic interventions.

Moreover, the fear of death, the future, and the child's development are elements always included in maternal expressions, reflecting their difficulty in anticipating subjectivity to their children, which is a fundamental condition for their overall proper development. Concerns and anxieties escalate when comorbidities are present, such as in cases of syndromic cardiac conditions, but the specific alterations referred to should be highlighted.

The support of healthcare professionals, as well as family members and support networks, becomes increasingly important, as these conditions seem to alleviate the suffering of mothers to some extent.

Finally, research on the perceptions and feelings of mothers of children with cardiac conditions is of great importance and should be expanded to obtain relevant information that will inform clinical decisions in the care of these children.

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