DOI 10.18471/rbe.v36.47287

MATERNAL EXPERIENCES AFTER THE DIAGNOSIS OF CONGENITAL INFANT HEART DISEASE IN THE CHILD WITH DOWN SYNDROME

VIVÊNCIAS MATERNAS APÓS O DIAGNÓSTICO DE CARDIOPATIA CONGÊNITA INFANTIL NO FILHO COM SÍNDROME DE DOWN

EXPERIENCIAS MATERNAS DESPUÉS DEL DIAGNÓSTICO DE CARDIOPATÍA INFANTIL CONGÉNITA EN EL NIÑO CON SÍNDROME DE DOWN

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How to cite this article: Souza DM, Sigaud CHS, Toriyama ATM, Borghi CA, Polastrini RTV, Campos FLM. Maternal experiences after the diagnosis of congenital infant heart disease in the child with Down Syndrome. Rev baiana enferm. 2022;36:e47287.

Objective: to understand the experiences of mothers of children with Down Syndrome after the diagnosis of congenital heart disease. Method: exploratory and descriptive, qualitative study, conducted through semi-structured interviews with nine mothers of children with Down Syndrome and Congenital Heart Disease, with data treated by Bardin's thematic content analysis, in the light of the theoretical framework of the Theory of Social Representations. Results: the main category "Maternal experiences after the diagnosis of congenital heart disease in children with Down Syndrome" was composed of four subcategories, which portrayed the challenges faced by mothers, from the communication of the diagnosis, emotional reactions, motherhood and treatment of the condition. Final considerations: the maternal experience with a child with both diagnoses proved challenging, with an accumulated experience of suffering.

Descriptors: Pediatric Nursing. Heart Defects. Congenital. Down Syndrome. Maternal and Child Health. Child Health.

Objetivo: compreender as vivências de mães de crianças com Síndrome de Down após o diagnóstico de Cardiopatia Congênita infantil. Método: estudo exploratório e descritivo, qualitativo, realizado por meio de entrevistas

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semiestruturadas com nove mães de crianças com Síndrome de Down e Cardiopatia Congênita, com dados tratados pela análise temática de conteúdo de Bardin, à luz do referencial teórico da Teoria das Representações Sociais. Resultados: a categoria principal "Vivências maternas após o diagnóstico de cardiopatia congênita no filho com Síndrome de Down" compôs-se de quatro subcategorias, que retrataram os desafios enfrentados pelas mães, desde a comunicação do diagnóstico, às reações emocionais, à maternagem e ao tratamento da condição. Considerações finais: a vivência materna com um filho com ambos os diagnósticos mostrou-se desafiadora, com uma experiência acumulativa de sofrimento.

Descritores: Enfermagem Pediátrica. Cardiopatias Congênitas. Síndrome de Down. Saúde Materno-Infantil. Saúde da Criança.

Objetivo: comprender las experiencias de las madres de niños con Síndrome de Down tras el diagnóstico de cardiopatía congénita. Método: estudio cualitativo exploratorio y descriptivo, realizado a través de entrevistas semiestructuradas a nueve madres de niños con Síndrome de Down y Cardiopatía Congénita, con datos tratados por el análisis de contenido temático de Bardin, a la luz del marco teórico de la Teoría de las Representaciones Sociales. Resultados: la categoría principal "Experiencias maternas tras el diagnóstico de cardiopatía congénita en niños con Síndrome de Down" estuvo compuesta por cuatro subcategorías, que retrataron los retos a los que se enfrentan las madres, desde la comunicación del diagnóstico, las reacciones emocionales, la maternidad y el tratamiento de la afección. Consideraciones finales: la experiencia materna con un niño con ambos diagnósticos resultó desafiante, con una experiencia acumulada de sufrimiento.

Descriptores: Enfermería Pediátrica. Cardiopatías Congénitas. Síndrome de Down. Salud Materno-Infantil. Salud del Niño.

Introduction

Down syndrome (DS) is the most common genetic disorder, with a worldwide incidence of 1/1000 live births(1) and, in Brazil, 1/700(2). Approximately half of the children with the condition are diagnosed with congenital heart disease (CHD). These are anomalies that originate in fetal life and reach the morphology of the vessels and/or heart. They can be corrected spontaneously in the first months or by surgical intervention(3).

Worldwide, more than 1,350,000 children are born with some cardiac abnormality per year(3). CHD have a prevalence between 40% and 63.5% in the population with DS, covering both cyanotic, tetralogy of Fallot, as well as cyanotic, such as Interventricular Communication, Interatrial Communication and Deviation of the Total Atrioventricular Septum(4).

These may impact the experience of families due to hospitalizations, hospitalizations in intensive care units, use of invasive therapies, costs and care needs(5-6). In addition, they are a major cause of mortality, with 50-60% of hospitalizations evolving to death. Children with DS and CHD may die due to factors inherent to or secondary to heart disease, such as infections in the postoperative period(5).

Approximately 80% of newborns with CHD require some surgical procedure during their development(7). In Brazil, of 1,207 children with DS, 50% were diagnosed with CHD; of these, 25% underwent cardiac surgery((8). Surgical intervention reduces the risk of mortality by promoting correction of defects, control of symptoms and improvement of quality of life(9-10).

Several international investigations have been dedicated to the study of the association between DS and CHD, focusing on epidemiological data, seeking to understand the causes, clinic, therapies and outcomes in children's health. However, a look at socio-emotional aspects is necessary, considering that conditions can lead to impacts on maternal and family health. It is known that the diagnosis of DS can cause shock, denial, guilt, anger and rejection(1), and these aspects are similar to cases of CHD(6,11). However, studies addressing the impact of heart diseases on mothers of children with DS are scarce. It is believed to be an accumulative experience, for a condition that limits the child's development throughout life and another that puts his life at risk.

From the above emerged the following concern: "What are the maternal experiences after the diagnosis of CHD in children with DS?" Knowing the phenomenon provides a basis for health professionals to act with support and welcoming, empowering the mother and family in child care, thus laying the foundations for the bridge to full development, with qualified assistance in health services, provided for in the National Policy of Comprehensive Child Health Care(12).

Thus, this study aimed to understand the experiences of mothers of children with DS after the diagnosis of infant CHD.

Method

This is an exploratory and descriptive study with a qualitative approach. For its development, the instrument was used: Consolidated Criteria for Reporting Qualitative Research (COREQ)(13).

The investigation was carried out in a public tertiary level hospital in the city of São Paulo (SP), specialized in cardiology. This service is composed of a division of care for children with CHD, with a pediatric hospitalization unit, two pediatric intensive care units and a neonatal one. Data collection was performed in these units, with mothers of children diagnosed with CHD and DS, who accompanied their children during hospitalization.

Inclusion criteria were: mothers aged 18 years or older, self-declared literate, with preserved cognition and verbal communication, and at least one child diagnosed with CHD and DS up to 6 years of age. Initially, it was established as a exclusion criterion for children over 4 years of age, considering the period of maternal memories about the phenomenon studied, however, during data collection, it was observed that mothers with children above this age group had vivid and rich memories in relation to the diagnosis of CHD. Thus, we chose to reformulate the criterion, addressing mothers of children up to 6 years of age. Thus, the exclusion criteria were adolescent, illiterate and/or with altered cognition and communication.

The researchers visited the inpatient unit and selected children diagnosed with CHD who also had DS. After explanation about the research, the mothers were invited to participate, and all accepted. The Free and Informed Consent Form (TCLE) was signed in two ways, one being given to the participant. The sample was established by convenience, based on the inclusion criteria.

Data were collected from July to September 2019, through semi-structured interviews conducted by the researcher. The interviews were guided by a topic script with participant identification data and questions about the timing of the news and the reactions to the diagnosis of WC in the child: When did you hear about the CHD diagnosis? Do you know what cc was diagnosed in your son? Who or which professional provided you with this information? Was he/she alone or accompanied at the time? If so, accompanied by who? Where were you at the time you were informed? Were you accompanied by someone? If so, who? How was the information presented to you? What was your reaction? How did you feel when you found out? When you were informed that your son had a CHD at the time, did you have any doubts? If so, which ones? Have your questions been clarified? Did you receive any information about the medical treatment of CHD at that time? What were your main concerns? Did you feel supported by the professional? What about your family? Or other people? If so, which ones? Given the information about the diagnosis of CHD, what could you highlight positive in the way it happened? And what would you highlight negative? What and how would you like it to be different at the time of diagnosis? After learning of the two diagnoses (SD and CHD) of your son, how did you feel? At that moment, what did you expect from the child's future?

The interviews were conducted with nine mothers in a private environment, made available by the co-participant institution. They lasted between 30 and 95 minutes, totaling 7 hours and 80 minutes of material. There was no repeated interview. The audios were recorded and transcribed, with the mothers' permission and without later sharing with them. During data collection, the main researchers performed readings of the transcripts together in order to monitor the progress of the collection. For the completion of empirical data collection, the theoretical saturation method of data in qualitative research was used(14).

The data were analyzed through Bardin's thematic content analysis(12), which comprises the transcription of the material, with corpus constitution, and repeated readings (between five and seven times), in order to allow the approximation of the set of documented content. Later, the material was explored with extraction of the nuclei of meaning and codification, giving rise to the theoretical categories. These were grouped according to their similarities and interpreted based on the objective of the study, which resulted in one main category and four subcategories.

In the data analysis, the theoretical framework of the Theory of Social Representations by Serge Moscovici(15) was also used, which allows the expansion of the interpretation of the phenomenon studied with the understanding of material and symbolic content, intrinsically related in the construction of discourses. These discourses, generated by social mediation between the researcher and the mothers of children with CHD and DS, were interpreted through two sociocognitive processes that act dialectically:

a) anchorage, in which the individual integrates new conceptions from his experiences and from the social context to preexisting thoughts, making familiar the unfamiliar;
b) objective, in which abstract notions are realized in the current reality.

Thus, maternal perceptions of the experiences with a child with CHD, a new phenomenon integrated into their social reality, suffer intrinsic influences from the construction of women as a social individual and are expressed in their discourses, allowing the understanding of their beliefs, symbols, knowledge and behavior in relation to the phenomenon.

The research was approved by the Research Ethics Committee and also by the co-participant institution, following the ethical precepts established in Resolution n. 466/12 of the National Health Council. To maintain anonymity in the presentation of the results, an alphanumeric code was used, consisting of the letter M (mothers) followed by a cardinal number corresponding to the order of participation (M1, M2, M3... M9).

Results

Regarding the characterization of the participants, nine mothers of children diagnosed with DS and CHD agreed to participate in the research. Their age ranged from 20 to 43 years; 5 completed high school or higher education; 5 were housewives; and 5 lived with the child's father. The children were between 18 days and 5 years and 8 months; for 8 of them the son was the youngest or only. The main support network mentioned was the family, followed by health services and other mothers of children with the same conditions. The heart diseases diagnosed were: Deviation of the total atrioventricular septum (7 children) and Interventricular communication (2 children).

After analyzing the interviews, a central category was identified – "Maternal experiences after the diagnosis of congenital heart disease in children with Down Syndrome" –, which refers to maternal perceptions regarding the experience of the moment of communication of the diagnosis of CHD, encompassing the emotional experiences of heart disease in particular and added to DS, the experience of motherhood, treatment and future prospects. This category is composed of four subcategories described below.

Experience of communicating the diagnosis of congenital heart disease

In this subcategory, the mothers reported that the communication of the diagnosis of CHD of their children occurred between the pregnancy and the first month of life of the child, mostly performed by the doctor. In two cases, the news was first given to the child's father or maternal grandmother, who then communicated it to he mothers.

> *My husband told me. He came and said, "He has a heart problem, a little hole"* [...] *Then there were five students in the room, one of the other's side, and I in bed, just listening to the doctor say to them, " I can't leave it in any doctor's hand." I felt a lump in my throat, especially since she didn't tell me.* (M5).

Regarding the location, the mothers reported that the communiqué was received in the joint accommodation, nursery, neonatal intensive care unit, outpatient clinic and specialized cardiology service. Many, when receiving the diagnosis of heart disease, were informed of the need for surgical treatment. Four mothers were informed about DS and CHD simultaneously and five were informed of heart disease later.

> *And she* [medical professional] *said, "But he needs to do* [surgery]*, or he's going to die. Heart disease is great." And I said, "But you're going to take him to surgery like that yet?" And she said, "Every surgery has its risk."* (M3).

There was a predominance of positive reports of the communication of the diagnosis, such as the professional's welcoming posture, the clarity of verbal communication, the use of easy-to-understand terminologies and drawings for illustration, preserving privacy, availability and care for the family. In relation to the negative points, the communication made by third parties (maternal grandmother and father of the child), the absence of reception and clarification of the professionals, and the use of technical terms and acronyms were indicated.

> *The way they talk. They are affectionate, speak in a low tone, ask if you understood, they give you attention, give attention to the child. They give a lot to the child and this, for us mothers, is important* [...] *So you saw that it was a care for the human being and not only the patient. You're already away from home, you live in the hospital, so we need understanding people.* (M2).

> *I wanted the doctor to come up to me and talk, and not tell other people, waiting for her to come to me and tell me.* (M1).

Emotional experiences in the face of the communication of the diagnosis of congenital heart disease

In this subcategory, in general, mothers reported sadness, shock, fear, anxiety and denial after knowledge about the diagnosis of CHD and some expressed the hope that the news was a misunderstanding of the medical team.

> *On the day of the diagnosis, my world was over. That day, I cried very, very, very much. You came in at night, and I cried too much.* (M5).
>
> *At that moment, I wish the diagnosis was wrong.* (M6).

As reported in the previous category, some mothers were aware of the diagnosis during the gestational period and each experienced it differently. One claimed to have experienced moments of uncertainty, the other said that the news prevented her from experiencing and enjoying the gestational period the way she had planned.

> *There were times when they could see the hole and there were times that did not* [...] *So in a few moments, I wasn't sure of the heart disease* [...] *"There's a mother", "there's no". We'd stay in this game.* (M4).

> *After I knew, my entire pregnancy was tense* [...] *In pregnancy, I wanted to prepare myself, but you get to read and see a lot* [...] *So I didn't do anything, I didn't do pregnancy photos, diaper tea. I stayed at my recollection.* (M9).

According to the mothers, the overlap of DS with CHD led to an accumulated experience of suffering, since the diagnosis of heart disease had a greater impact, due to the threat to the child's life. One participant said she experienced depressive symptoms after receiving both news.

> *Knowing Down Syndrome was a thud, but knowing congenital heart disease was much worse.* (M3).

> *I thought I had to accept. I couldn't change Down syndrome. And the problem in the heart, is to hope for God to heal* [...] *I was bad after the news, going into depression because of all this.* (M7).

The exposed reactions were consequences of frustration related to the idealized child. The mothers also reported continuous frustrations regarding the pace of the child's development process, which already suffered impacts of DS, enhanced by the functional limitations of CHD.

> *For some time, I wish he didn't have Down Syndrome and Congenital Heart Disease. I didn't wish for a child like that.* (M9).

> *I was worried and was afraid about the issues of walking, talking, playing* [...] *He was underweight, was small, had difficulty developing, because of the syndrome and heart disease.* (M3).

The fragments of the speeches indicated that the course of the experiences over time was responsible for reducing the initial anxieties of the heart disease, producing learnings that demystified the initial mistaken ideas.

> *Time is teaching me. You learn that it is not what you thought* [...] *It's not a seven-headed animal. You can handle it, even with you suffering, crying, by leaps and bounds. You can handle heart disease. You just have to get used to it.* (M8).

Experience of mothering a child with congenital heart disease

The impacts caused by the news of the CHD followed with the experiences at home, with new challenges associated with the fear of care and death of the child. There were concerns, questions and self-collection regarding maternal capacity to care. The burden due to the need for intensive care, such as polypharmacy, was evident. One mother reported that she had the administration of a wrong medication, and this misunderstanding enhanced her fears and diminished her confidence in care.

> *On a day-to-day note, I wondered, "How are my days going to be?" Will I be able to take care of it? What's different? What do you have to do?* (M5).

> *When we went home, I was scared. I couldn't even sleep. I kept looking at her. I thought she was going to die any minute.* (M8).

> *So I went to give medication, instead of giving 0.4 ml of furosemide, I gave 4 ml. I didn't know about the comma. We ended up in the emergency room* [...] *It was hard, I had to macerated, put it in the food. I had a 6 in 6, 8 in 8, 12 in 12 pill. It was a lot of medicine. I'd part up, so as not to confuse the names. I was scared to death of killing her. She stayed in the serum, just peed, got dehydrated. I felt incompetent, completely useless. But I had to take care of it, because if I didn't, who would?* (M2).

The mothers also reported feeling required, even with the feeling of present fragility. Part of this originated in the social representation of the maternal figure, strong and caring, who needs to be able to meet all the demands of the child without fail.

> *Being a mother is knowing everything, it solves everything. So we have a post, you know? The caregiver, who solves everything. So I was struggling with it. Because if there's anyone who's going to solve it, it's me! Understand, it's me! It's going to be me! So I couldn't despair. I had to fight for her.* (M2).

According to the reports, the family was the main support network for mothers and their children. In addition to the family, they also sought new sources of support within the specialized services they attended, such as with other mothers of children with CHD and/or DS and with the nursing team, for support, reception and clarification of doubts, which provided hope, empowerment and safety.

> *Everyone in the family suffered. In addition to the syndrome and the heart disease, he had surgery.* (M3).

> *Hospitalization made me desolate. I'd come to talk to the mothers and everything was going on, I got up. You see you're not alone, you're not the only one, you get stronger.* (M9).

> *The nursing team, I have nothing to talk about. If all the professionals were like them... They're amazing!* [...] *I felt very welcomed.* (M4).

Experience of treating a child's congenital heart disease

Surgical correction, as the main treatment, provided concerns, with the fluctuation between moments of hope, the expectation that the child would survive, and moments of hopelessness, by the belief that surgery could be a death sentence. The mothers had to wait for the date of the surgery at home.

> *When I heard about the surgery, I thought, "Okay, my daughter's going to die!"* [...] *It's a very strong impact.* (M8).

> *I'm living the today with him, because I don't know how my reaction will be tomorrow, and what can happen tomorrow* [...] *The thing is to accept, to think positive. There's nothing to do.* (M5).

Among the nine, four children had not yet undergone surgery at the time of the research. In these cases, the mothers reported the hope that the procedure would arrive and be successful.

Those who experienced the intervention reported experiencing fear, sadness, anguish, helplessness and hopelessness at the time of the moment it occurred.

> *My fear has always been surgery. In my head, they were going to take him, put him on the table, and I was going to lose him.* (M4).

> *Just yesterday, I was crying. It's hard for you to take your daughter to the operating table. It's a moment you don't know if she's coming back. If you do you are at risk; if you do not, you are at risk* [...] *You think about quitting. It's a very bad feeling! It kills a mother and a father.* (M8).

Among the five children who underwent surgery, one experienced postoperative complications, which prolonged their period of hospitalization and enhanced the mother's feelings of fear and impotence. The other four children recovered and succeeded in correcting the alteration. Thus, the mothers reported that the heart disease was over, that their concern became DS, with hope of proper development, free of surgical interventions and pathologies. Because they experienced the fear of death, the mothers said that they became more caregivers, believing that, in the future, they would treat the child in an overprotective way.

> *She operated, was seed for seven days. The doctors would come* [post-operative hospitalization], *wake up the children, and she'd stay. Until they told me she had an infection, a fever. And I could only stare* [...] *When she was well, my expectation was again stimulated her, and her intelligence, for her to be whatever she wants to be* [...] *I just don't want her inside the hospital.* (M2).

> *Now I imagine it that way. That I'm going to be a much more boring mother than I already was, much more protective than I already was before surgery. The fear of loss is very bad, and I had this fear.* (M9).

Discussion

The birth of a child is a human experience associated with happiness and great expectation of parents to know the child they have idealized so much. However, this joy can be impacted and transformed into anguish, when there are diagnoses of pathologies and/or syndromes, such as CHD and DS(6). Parents are inserted in a new context, with adaptations of parenthood, changes in social and family roles, and restructuring in the face of the transformations required by the uncertain and fold-out nature of diagnosis and treatment(6,16), which begin from the communication of the condition.

The communication of the diagnosis of CHD brings great emotional burden to families, which can be enhanced or mitigated, depending on professional management(11). There is international and national evidence that proposes the best way to approach parents to communicate the diagnosis of the condition(6,16), but impasses are observed for the translation of these evidences in clinical practice, as seen in some maternal accounts of this study. There are reports in the literature of misguided communications, with technical terms that are difficult to understand, confused, insufficient, in an inappropriate place, with lack of privacy, with information without standardization, contributing to doubts and uncertainties(11,16). Although the mothers in this study mention more positive points, there are also some negative points that corroborate those mentioned.

In a qualitative investigation(11), conducted in Spain with health professionals, it was observed that they recognized their limitations at the time of communication of diagnoses, due to the absence of skills, training and institutional protocols. They also recognized that the news of heart disease had a great emotional impact on the family, which had an impact on the provision of limited information to protect the parents. In this case, it is noted that professionals have full knowledge about their lack of preparation and knowledge that affects their practice. However, they do not take any action to change this context.

CHD may manifest during pregnancy from the 8th week onto the prenatal period and be diagnosed in prenatal cardiac screening with fetal echocardiography(17-18). However, even with the development of new technologies, prenatal diagnosis is not accessible to many mothers, as seen in this study. These are often reported late in the postpartum period. In a retrospective study conducted in Morocco, from 2008 to 2014, with 2,156 children with CHD, 40% of them were diagnosed after the 6th month of life(4). The international literature recommends that prenatal diagnosis should occur in more than 78% of mothers(19). However, many of them are unaware of gestational risk factors for CHD and fetal echocardiography is not a priority for prenatal health services.

In a qualitative study(6) conducted in Sweden, with mothers of children with heart disease, there are reports that the information provided about the diagnosis during pregnancy was inconsistent, with visualization of the malformation at some times and in others not, which contributed to doubts and uncertainties, similar to that exposed by a mother in this study. In addition, these mothers were also instructed by health professionals to search for information on Google about the condition and said they did not even imagine what motherhood would be.

When the news of CHD is given during pregnancy, the mother tends not to allow themselves to experience more intense feelings for the child, due to the uncertainty that she may enjoy motherhood. In a qualitative investigation(18), conducted in Korea, after receiving the news about heart disease, mothers moved away from the emotional experiences of pregnancy, due to the difficulty of accepting the diagnosis, culminating in depression and loneliness due to expectations regarding the “imperfect baby”. In this country, there is the possibility of abortion after the discovery of pathologies, and the study reports that mothers experienced doubts about the interruption of pregnancy. They also said that other family members, especially the child’s father, proposed abortion.

In the present study, most mothers received a diagnosis of heart disease simultaneously or after knowledge of DS, which produced an accumulated experience of suffering. It is noteworthy that health professionals who reported the presence of heart disease found a woman previously impacted by DS information.

After the news, there is the experience of a period of denial concomitant with hope. This is a human resource used as a coping strategy and defense mechanism, in order to remove the idea of the risk and limitations imposed by the pathology on the child, with the mother experiencing, even momentarily, her idealized, healthy and fully developed child. Often, this denial is a consequence of the fact that, regardless of its efforts, it is unable to reverse heart disease(20).

Surgical intervention is the main approach to the treatment of CHD(6). In Brazil, of 28,900 children with heart diseases born per year, about 80% (23,800) are submitted to cardiac surgery(7). This, however, is not performed soon after birth, due to the possibility of morphological correction with development(6). In addition, children may experience other associated clinical conditions. In the Morocco study, of the 2,156 children with heart diseases, 5.9% had DS; of these, 43.7% had multiple cardiac lesions and 53.1% had pulmonary hypertension, which has an even greater impact on child development. Multiple hospitalizations, surgeries, invasive therapies and high-tech devices may occur(6). There is also the experience of delay in childhood development phases, due to the symptomatology of heart disease, such as hypoxia to efforts, and DS(1,11). These experiences enhance the impacts and are configured as new sources of stress for mothers.

In the period before surgery, there are difficulties of mothers in performing basic activities related to child care, mainly due to fear of death. The difficulty results in collection, with self-questioning about their ability to care, and overload that can affect their health and quality of life, with physical, social, psychological and spiritual costs, and also with risk of depression and parenteral stress(11). The use of antidepressants, as a resource used to help and manage tensions in the daily care of children with DS, is also reported in the literature(21), and the number of family members with mental health problems may be even higher. There is a need for further research focusing on this phenomenon.

The full dedication to the child hinders the maternal entry into professional life, often determining the loss or abandonment of work, which restricts the family’s financial resources. Thus, the father assumes the social role of income provider, and the mother, a born caregiver(11,22), being forced to renounce professional practice, as observed in part of the population studied.

In a Brazilian cross-sectional study(22), conducted with 254 mothers of children with heart disease, 54.3% did not perform work activities and 56.7% did not perform leisure activities. The need for financial reorganization, with reduced expenses and increased working hours, in order to guarantee the income necessary for the child's demands, was observed in parents of children with DS(23). In the present study, this demand for financial resources was even greater when there was an association with CHD, considering the accumulation of health requirements.

There is maternal collection related to the other social roles she exercises, as a mother of other children, besides that with heart disease, daughter, granddaughter, wife and friend, which may occur unsatisfactory, in the opinion of members of her social circle(16). This is seen in the marital relationship, which can be lost by the collections and culminate in the separation(5). In this study, four mothers were divorced, but there was no information on the effect produced by heart disease in the decision.

It is extremely important that women are involved in support networks in the process of living with their child, since they influence the way they deal with and face adversity(20). The child's father tends to react with distancing and concerns about the future, assuming the figure of the strong element, even when weakened by experiencing various feelings. Other family members may react with acceptance and support, or enhance the impacts on parents by the child's removal and rejection(11).

When mothers cannot find spaces to find shelters, they may feel overwhelmed and lonely in their battles(20). The frequency of health services offers the possibility of building new networks with people who live similar experiences, such as other mothers, constituting the potential for strengthening in coping with this process(6,11,16). In a mixed method study(15), conducted in Australia, with 154 parents of children with hospitalized heart disease, 77.9% reported that the relationships built in the institution became sources of strengthening in coping, through the exchange of information, availability, emotional support and care. Of these, 72% mentioned health professionals and 42% mentioned other parents of children with the same condition. The large number of parents who identified productive relationships with professionals demonstrates the importance of this interaction in health services, such as those established with nurses.

In surgery, there is an experience of a decisive moment, with tension, feeling of helplessness, fear of death and stress due to decision-making, but also hope of resolving the malformation(3,6). In an investigation with eight mothers and two fathers of children with heart disease, it was observed that they were aware that surgery was essential for the child's life, but fear produced resistance, due to the belief that they would not see it again(6). In Brazil, of 254 children with heart disease, 48.5% underwent surgeries, but only 57.9% were corrective(22), indicating that the emotional reactions faced at the time of the operation can occur multiple times. In addition to surgery, the anguish permeates the postoperative period and the discharge process.

In the postoperative period, there is initially joy to review the child, but there is also the fear of seeing them sedated, in polypharmacy, with invasive devices, altered general condition and the possibility of surgical reapproach(6). In addition to this aspect, there is also the possibility of experiencing complications, such as infections, experienced by a mother in this study. In a Brazilian retrospective investigation, with 300 operated children, 22% experienced complications in the immediate postoperative period, such as severe pain, bleeding, acidosis, heart failure and cardiorespiratory arrest(10). In the case of complications, there is an increase in hospitalization time and the risk of death(3), which provide new concerns.

When surgical intervention is successful, mothers experience a readaptation, in which the focus becomes DS, with the child's stimulus for full development(11), and heart disease is in the background. However, the impacts of DS can increase, such as the experience of uncertainties about development, victimizations and prejudices(1,20). Time becomes the main responsible for alleviate anguish, with the strengthening of family strategies of mutual support and resilience(21).

There is also the possibility of death. CHD represent the third cause of death in the first days of life and the second leading cause of death of children under one year of age(7), with mortality in 14.1% of children with this condition(4). The incidence of deaths due to CHD is 81 per 100,000 live births, with cardiogenic shock as the main cause in 41.1% of cases(7). In an investigation with 300 children submitted to cardiac surgery, 70% of them had cyanotic heart diseases, the same as in this study, and 17.3% died(9). Death may also occur after surgical correction of the pathology, as occurred, for example, in an American, retrospective cohort, between 1982 and 2003, in which, of 3,571 patients with DS who underwent CHD correction, 3,376 survived the procedure, but in longitudinal follow-up, 386 died, with deaths associated with pulmonary hypertension ($p=0.02$)(23). In these cases, mothers relearn to live, in a context in which their children accompany them only in memories(18). Even the mothers of this study not experiencing death, the fear of its occurrence was impacting, which could lead to overprotection, as observed in the results.

Overprotection occurs since the beginning of motherhood, in which the mother is fully dedicated to the care of heart disease and, later, to correction and DS(1,15). This dedication is associated with the maternal perception that they are the only ones capable of identifying and meeting the needs of the child, and it is unacceptable to give up responsibilities for their own benefit(22). It is noteworthy that this type of protection, consequent to the perception of vulnerability and inability to do activities alone, is harmful to the child. Moreover, it is consistent with the maternal social representation present in this study, seen as a figure of sacrifice, which demonstrates unconditional love and total availability, showing strong in the exercise of the maternal role(1,24).

As in other qualitative studies, this investigation had as main limitation the maternal experiences were not representative of the entire population, because a small group of mothers was approached.

As a contribution of the study, it is expected, with the description of the phenomenon, that health professionals can rethink their care practices, taking into account the maternal representations about events, which, for professionals, are routine, but are unique for mothers, impacting and transforming a whole context of life.

Final Considerations

The study provided the perception that the diagnoses of CHD and DS bring cumulative impacts to the mother. The experience is marked by two conditions that were not desired and lead to coping with atypical situations, especially heart disease, which is experienced as a threat to the child's life. The challenges begin in the communication of the diagnosis and permeate the daily life of motherhood, representing a context of uncertainties, fears, impotence and low self-esteem, plus hope for surgical intervention. The correction of heart disease brings positive expectations, but DS persists, representing other impacts.

In this context, the importance of the nursing professional, especially remembered by the mothers of this study, for their welcoming performance, providing support, active listening and clarification of doubts is noted. The actions of this professional, in the different health services, can mitigate the intrinsic impacts of the conditions of CHD and DS, and should be extended to the whole family, also weakened by the condition. The care provided by the nurse lays the foundation for the full development of the child and enables resilience within the context marked by losses, uncertainties and fears.

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Received: December 8, 2021

Approved: March 13, 2022

Published: April 20, 2022