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Social representations elaborated by mothers on the care of the child with congenital heart disease in the hospital

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ABSTRACT
This article discusses part of the results of a multi-method research of Doctoral Thesis.
The study aims to describe the social representations of mothers about the care of their children with congenital heart disease. Descriptive guided by the Theory of Social Representations (SRT), developed in two stages. The first stage had 88 mothers to apply the sociodemographic questionnaire and the Test of Free Association of Words (TALP), which contained as inducing stimuli: heart disease, caring for the child with heart disease and mother-child relationship in the hospital. Eight mothers participated in the second stage for the semi-structured interviews. It was carried out in a reference hospital in the North and Northeast of the country in the treatment of congenital heart disease linked to the Secretary of Health of the State of Ceará. The data collected through TALP were transcribed and processed by the Trideux software, version 5.3. The statements obtained from the interviews were organized based on Bardin's content analysis. The data obtained by both techniques (TALP and interviews) were categorized and substantiated with RRT, emerging the following categories: Social representations of mothers about the moment of diagnosis: apprehension of a new reality; Social representations of mothers about maternal care in the hospital routine and social representations about maternal feelings. The results showed that maternal representations are related to the importance of understanding the child's diagnosis with clear information, that maternal care in the hospital is carried out with feelings of pain, despair, worry, insecurity and difficulties and is overcome through love and faith, which makes it special and that the mother-child relationship is adapting to the new reality in the hospital experience and with the experience of other mothers and health team. Therefore, apprehending the social representations of these mothers about the care of their children with congenital heart disease in the hospital is a path in search of quality care to the mother-child dyad, in which it is necessary to awaken in these mothers the value they have when caring for their children in the hospital. It is important that the health team understands the maternal social representations to plan interventions that can alleviate the suffering and support them in the care throughout the hospitalization.

Keywords: Representations, social psychology, care; mother, heart disease, congenital.

1 INTRODUCTION

The birth of a child is an indescribable moment for mothers, so they devote time and energy preparing this reception: they choose the name of the child and plan the trousseau, gradually building an identity for this child that is still being generated.

However, when this period is accompanied by the discovery that your child has a congenital heart disease, suffering, anguish and fear are inevitable, implying moments of joy, but also of pain and uncertainty, especially the frustrated desire for a perfect pregnancy. The constant fear of the loss of the child, who carries an often-serious disease and who requires hospitalizations for surgical interventions and painful procedures, sometimes for long periods of hospitalization in Intensive Care Units (ICU), which imply limitations in their activities of daily living, disadvantages in their psychomotor development, suffering due to separation from the family and uncertainty about the future.

Upon receiving the diagnosis of congenital heart disease (CHD) from the child, the mother experiences a period of transition that requires decisions and attitudes towards the new situation that is imposed on her. This process brings with it the fact of having in your arms a child with a serious disease and permeated with uncertainties. However, the hospitalization of the child in the ICU causes a strong family impact, contrasting with what was idealized in pregnancy, especially by the mother (Silva, 2019).

Although the arrival of a child, in general, represents great joy, receiving in the arms a child with a serious disease, with a Congenital Cardiac Malformation (CCM), is a great challenge for this woman who is faced with new responsibilities, fears and insecurities of caring for a child with serious health problems.

Congenital heart disease can be defined as any disorder in the structure or function of the cardiocirculatory system and can be identified since embryogenesis or at any stage of life, being one of the most frequent malformations and the one with the highest morbidity and mortality (ROSA *et al*., 2013).

They are anomalies resulting from anatomical defects in the heart or circulatory network that compromise its functions. They are considered as diseases with complex chronic health conditions, due to their common characteristics, such as temporality and continuity of care, symptom control and longitudinality of care, interruption and incorporation of life routines. (MOREIRA *et al*, 2017)

Pinto Júnior *et al.* (2015), highlight an incidence between 8 and 10 cases of congenital heart disease per 1,000 live births in Brazil, a total of 23,834 new cases/year of which: 2,565 cases would be distributed in the North region, 6,669 in the Northeast region, 9,470 in the Southeast region, 3,169 in the South region and 1,962 in the Midwest region.

Early neonatal mortality is equivalent to about 60% to 70% of infant mortality, with 10% of these deaths resulting from congenital heart disease (AGUIAR *et al*., 2018).

Braga *et. al*, 2017 conducted an observational ecological study, evaluating the trend of mortality from cardiac malformations in Brazil, based on the Mortality Information System (SIM), whose data are managed by the Ministry of Health, and processed by the Unified Health System Information System (DATASUS). In the study, a trend was observed in the reduction of cases of mortality due to

congenital heart disease in Brazil, pointing out as the main cause the probable underreporting and underdiagnosis in the neonatal period.

Due to the complexity of heart disease and its treatment, the family needs to adapt to an arduous routine of care, with frequent visits to medical appointments and recurrent hospitalizations. There are several transformations of this family, especially for the mother, who in the vast majority assumes the demands of care that become part of their daily lives.

The Social Representations (SR) relate new knowledge and ideas that are presented to the subject, and consists of the shared interpretation of a group of mothers about the care of the child with CHD and thus can direct their attitudes, behaviors and conducts in the hospital routine. Social representations are generated in social environments through interpersonal relationships from symbolic exchanges. In this cntexto, Moscovici (2013) considers culture, language and communication, values, ideological and historical context, social insertion of subjects - their position and group affiliation. Thus, these relationships share the construction of this knowledge, which explains the complex human subjectivity.

As for the formative process of SR, there is anchoring and objectification. Anchoring consists of making the unknown or new object familiar from a pre-existing thought system. The objectification corresponds to materialize the abstract, makes concrete the object of SR through a network of meanings and association with reality (JODELET, 2001; MOSCOVICI, 2003).

In this perspective, the mothers' social representations about the care of their child with congenital heart disease can be understood as a collective interpretation of the reality lived and spoken by that social group, directing behaviors and communications. In this way, the collective itself penetrates as a determining factor, within individual thought (MOSCOVICI, 2013). Given this statement, SR can be re-signified, enabling new practices and social knowledge.

With the experience of the researcher in a cardiopediatrics unit, it is believed to be at a time when it is necessary to obtain knowledge of how the mothers there accompanying with their children in Cardiopediatrics Units (ward and ICU), experience this experience, through their own perceptions or constructed from the experiences of other mothers in the hospital. This is possible, since in the social environment of these subjects, through their relationships and communication, beliefs, opinions, feelings about caring for their child with congenital heart disease in the hospital are conveyed.

In this sense, the objective was to apprehend the social representations of mothers who care for their children with congenital heart disease in the hospital. This study becomes relevant since, in possession of these social representations, it will be possible to understand the needs and feelings experienced by these mothers, unveil the meanings of maternal care in the hospital and from then on, be based to re-signify them, and thus provide better care and assistance to the dyad in a cardiology unit.

2 METHODOLOGIES

This is a descriptive study using multimethods, anchored in the Theory of Social Representations (Moscovici, 2013). Data were collected in the cardiopediatric hospitalization units of a public hospital, located in the city of Fortaleza, Ceará, Brazil, from October 2020 to April 2021.

The selection of the mothers, participants of the research, occurred with the support of the team of the pediatric service of the hospital and individually, being clarified, by the researcher, about the objectives, justification and relevance of the study, guaranteeing them the confidentiality and freedom of participation without prejudice to their care in the unit. After the clarification phase, with acceptance and the signing of the Terms of Free Consent Clarification – TCLE, the data collection period began. It is noteworthy that this study included mothers aged 18 years or older, accompanying their children from 0 to 3 years with congenital heart disease, hospitalized in the cardiopediatrics unit and who were in a position (guidance and communication preserved) to participate in the research. The exclusion criteria were the following: babies who were not in clinical conditions, that is, hemodynamically stable for maternal care and mothers who presented some alteration that could make communication unfeasible, such as mental disorders and/or another morbid condition in a way that compromises participation in the research.

In the first part of the sample, a form was used to trace the sociodemographic profile of the mothers and a technique to apprehend the social representations of the participants, with an instrument, called: Test of Free Association of Words (TALP), applied with 88 mothers.

Subsequently, eight of these 88 mothers answered the semi-structured interview with a guiding question: ***How is it for you to take care of your child in the hospital?*** This combination of techniques had the intention that the different methodological perspectives complement each other to integrate and know the consensual universe of the mothers about the care of their child with congenital heart disease, which made it possible to enter into the maternal subjectivity and to know the meaning of their experience in the hospital environment.

The mothers responding to the TALP were selected by intentional criteria from a sample of 88 mothers. For the elaboration of the TALP chose three inducing stimuli: ***heart disease,*** *caring for my child with heart disease and Mother-child relationship* ***in the hospital*** previously defined by the researcher, taking into account the characteristics of the interviewed subjects as well as depending on the object of the SR to be researched. In addition to the opinion variables (inducing stimuli), three fixed variables were chosen, such as: maternal age (IDA), religion (REL) and marital status (SCI). This type of attachment made it possible to establish groups of social actors who have common and non-consensual SR about maternal care for children with CHD in the hospital.

After the application of the test, the evoked words were transcribed in their entirety and organized in a database and processed in *the* Trideux 5.3 software, which allowed an interpretation based on the Correspondence Factor Analysis (CFA). (Cibois, 1998).

The interviews were analyzed from the perspective of qualitative analysis, with the application of the resources of the techniques of thematic content analysis (Bardin, 2011), to the data from the open questions and grounded with the framework of the Theory of Social Representations.

The categories obtained from the analysis of the two techniques received the following names: Social representations of mothers about the moment of diagnosis: apprehension of a new reality; Social representations of mothers about maternal care in the hospital routine and social representations about maternal feelings.

The research was submitted to and approved by the Research Ethics Committee (CEP) of the Hospital de Messejana Dr. Carlos Alberto Studart Gomes, with opinion 4346177 and CAAE 39059920.7.0000.5039 and developed in accordance with Resolution 466 of 2012 of the National Research Ethics Commission that regulates research with human beings (BRASIL, 2012), together with the consent of the institution where the research was conducted.

Anonymity was guaranteed by the alphanumeric identification of the testimonies, whose letter M stands for mothers followed by the numeral (1 to 8) identifying them also by names of precious stones in dedication to the brilliance of these women: M1 Bright, M2 Sapphire, M3 Ruby, M4 Emerald, M5 Turquoise, M6 Amethyst, M7 Tourmaline, M8 Jade.

3 RESULTS AND DISCUSSIONS

3.1 CHARACTERIZATION OF THE STUDY PARTICIPANTS

Regarding the eight mothers interviewed: two had only one child, one mother had two children and the other seven children and four mothers had three children, all started prenatal care, however three of them did not go to all appointments due to the fear of being infected by the new Coronavirus. Five had cesarean section and three had normal deliveries in the hospital.

It is worth mentioning that the Ministry of Health recommends that at least six or more consultations be performed (Correa MD *et. al, 2018) and that studies by BRITO VRS* et al, *2010* highlighted the prevalence in the establishment of fetal diagnosis between 21 and 25 weeks made possible through diagnostic tools fetal echocardiography, Doppler and obstetric ultrasound during prenatal care; allowing to plan therapeutic medications pre and post immediate delivery as well how

Of the eight mothers interviewed, two had children diagnosed with Hypoplasia of the Left Heart, and the children were aged 2 months and 5 months. Two mothers with children with Tetralogy of Fallot aged 1 year and 1 month and 1 year and 5 months, one with Truncus Arterial Type I aged 1 month and 20 days, the other with a child with Arterial Truncus Type II aged 7 months, a child with

Unspecified Malformation of the Heart at 6 months of age, and finally, a child aged 1 year and 5 months with a diagnosis of ventricular septal defect.

Congenital heart disease is a malformation arising from the development in the intrauterine period, that is, the individual is already born with a cardiac dysfunction. In Brazil, it is considered the second leading cause of death in children under one year of age, with 1 case occurring in every 100 live newborns, whose 1/3 of these babies underwent surgery. Technological advancement enabled greater survival, as many were no more than 5 years old (Santos, 2020; Barreto, 2017).

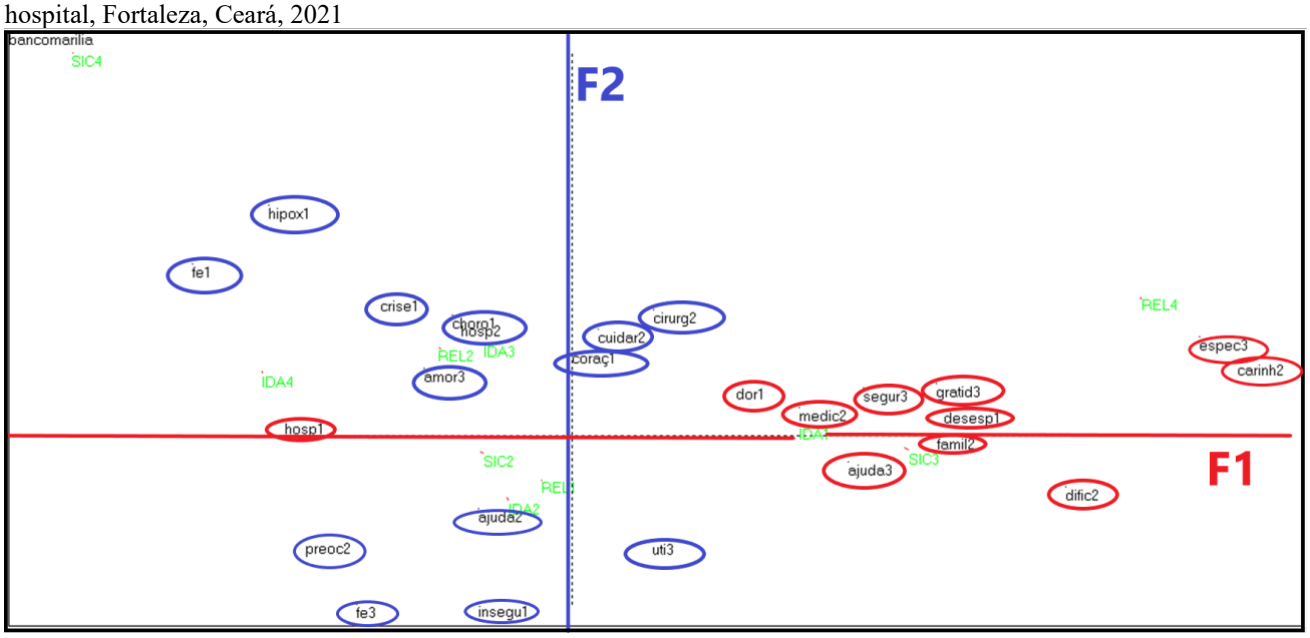
Regarding the sociodemographic data of the caregiver mothers, two of them were from Fortaleza – capital and four came from the interior of Ceará, followed by two from the State of Piauí – Teresina. As for marital status, four married, three in stable union and one single. Regarding schooling, six mothers had incomplete elementary school and two completed high school. Regarding occupation and income, four mothers define their occupation as housewives and have no income, the other four are in the formal labor market: two cleaners, with income below the minimum wage; an elderly caregiver and another pharmacy consultant, both with an income of one minimum wage. On religion, four defined themselves as Catholic and the others as evangelical.

3.1.1 Factorial analysis of correspondence of the evocations issued by the talp of the caring mothers to the child with congenital heart disease

The evocations obtained through the TALP were processed in *the Trideux* 5.3 software and interpreted according to the Correspondence Factor Analysis (CFA). For each inducing stimulus, 384 different words were evoked, totaling 1058 words.

This factor map determines the most frequent and most significant evocations for the three inducing stimuli. Chart 1 represents the two axes, axis F1 (horizontal axis) and axis F2 (vertical axis). Factor 1 is represented by the color red, where the most consensual representations of the social actors of this study are found and explained 24.6% of the variance, while Factor 2, represented by the color blue, highlights the idiosyncrasies of the representations and demonstrated a variance of 17.5% making a total of 42.1% of variance or significance in the total of responses evoked. The fixed variables are represented by the color green, in which IDA refers to maternal age, REL to religion and SIC to marital status. The numbers 1, 2 and 3 that accompany the evocations are equivalent to the corresponding inducing stimulus.

Graph 1: Factorial plan of the Social Representations of caregiver mothers to the child with congenital heart disease in the hospital, Fortaleza, Ceará, 2021



Regarding stimulus 1 *heart disease,* in the F1 axis, horizontal, the most representative words and their correspondence by factor (CPF) on the right side were: pain (CPF:28), despair (CPF:52) evoked by mothers with maternal age between 19 and 25 years and on the left side: hospital (CPF:53) evoked by women aged 40 to 46 years and represented by the marital status of stable union.

For the mothers, stimulus 1*, heart disease,* which is confirmed with the diagnosis of congenital heart disease of the child, was anchored to feelings such as pain and despair and was objectified in the hospital, because these feelings were meanings materialized in the experience of hospitalization (objectification). The words pain and despair were revealed as representations at the moment they discovered the heart disease in the child, the moment of diagnosis and the experience of hospitalization.

A study by Menezes et al (2020) obtained similar results and states that the initial reaction to the child's CHD diagnosis as an unexpected event, provoking negative feelings and behaviors, such as fear, worry, isolation and even rejection to the child.

Given the strangeness of the diagnosis, the words mentioned in the F2 axis, vertical, in relation to the same inducing stimulus 1 *heart disease*, the most representative words in the upper pole were: hypoxia (CPF:142), it was associated, still, to this stimulus the words: faith (CPF :45), crying (CPF: 33) and heart (CPF: 25) evoked by women aged 33 to 39 years and with evangelical religion, anchors used in moments of uncertainty in the face of the discovery of heart disease, clinical prognosis, promoted during the hospitalization process and in the lower pole: insecurity (CPF:43) evoked by women with maternal age from 26 to 32 years, married and Catholic.

This axis brings important elements regarding the representation of the child's heart disease, makes it possible to identify and understand the meaning of having in the arms a child with a serious

heart disease, feelings of insecurity are potentiated when the child presents signs in his body that demonstrate how fragile he is and requires care. The word hypoxia as the most evoked by mothers represent the fear of the child having some crisis and dying at any time, these feelings are objectified in crying. However, the experience of caring for the child with CHD succinct feelings of faith, which leads the mother to construct new meanings, to review her expectations in the face of the new reality

Given this, studies reveal that mothers emphasized the heart as a complex organ, essential for survival and, therefore, a cause for greater concern when compared to other diseases. By associating the heart with life, the child's need for cardiovascular surgery puts the mother in contact with the possibility of death, favoring ambivalent feelings between the fear of the loss of the child during surgery and the expectation of cure. (MENEZES, L. T. *et al*, 2020)

Regarding the inducing stimulus 2*, taking care of my child with heart disease,* in the F1 axis on the right side, the most representative words were: affection (CPF: 95) and difficulty (CPF:52) associated with medications (CPF:31) and family (CPF:29) corresponding to maternal age from 26 to 32 years and marital status of stable union.

In the F2 axis, for the same inducing stimulus in the upper quadrant in relation to age between 33-39 years and evangelical religion, the main words were: surgery (CPF:48), hospital (CPF:39) and care (CPF:44) while in the lower quadrant we found the words help (CPF:34) and concern (CPF:25) as more representative.

Schneider; Medeiros, 2012 state that hospitalization changes the way a family lives, since one is in an unknown place, often in a city far from their home, with a sick child who demands special care. However, the care of the child with heart disease is anchored by the family, which although many of them face alone a routine of caring for the child in the hospital, away from their relatives' facing threats of surgery, medication administration, supported by technological structures (accesses, probes, drains, etc.) are objectified by the difficulty and concern, but also by the affection mainly exercised by the team and other mothers from shared experiences as a network of support.

Regarding the inducing stimulus 3*, mother-child relationship in the hospital,* in the axis F1 right pole, the main evocations were: special (CPF: 85) and help (CPF: 74) associated with safety (CPF:32) and gratitude (CPF :36). As for the F2 axis at the upper pole over the same inducing stimulus, the word was evoked: love (CPF:35) and at the lower pole, ICU (CPF: 34) and faith (CPF:44) with greater representativeness.

The term faith and special, besides having been evoked more readily, indicate that there is a connection between the representation of having a child with a serious illness with the spirituality that they experience from their religion, such findings corroborate the understanding of social representations anchored in religious beliefs. In this case, some mothers in possession of their religious

beliefs, believe that caring for a child with congenital heart disease is something special is a gift and love from God.

In this case, religion is understood as an organized system of beliefs, practices, rituals and symbols created to provide an approximation of the subject with a divine being; and spirituality as a personal search for answers about the meaning of life and the relationship with the sacred (KOENIG, 2001).

In this study, the social representations point to the forms of interpretation of reality according to the experiences and knowledge of the common sense of the mothers in relation to the care of the child with CHD in the hospital context, especially in the ICU. The stress and fear of taking care of the child in the ICU are perceived in a significant way by the mothers.

3.1.2 Thematic content analysis

From these evocations from the TALP and processed in *the* Trideux software, combined with the answers of the interviewed mothers, three categories emerged: Social Representations of mothers about the moment of diagnosis: the apprehension of a new reality; Social Representations of mothers about maternal care in the hospital routine and Social Representations of mothers about maternal care in the hospital routine.

3.2 SOCIAL REPRESENTATIONS OF MOTHERS ABOUT THE MOMENT OF DIAGNOSIS: THE APPREHENSION OF A NEW REALITY

In the first category, it was evidenced that the moment of diagnosis of the child's heart disease is the moment of apprehension of a new reality and changes in a relevant way the life of this mother, to which it will assume a different meaning, a situation that presents itself in a complex way and that requires adaptations, considering that the child's heart disease often brings a slow and reserved prognosis. The process of discontinuity of the dreamed baby, of the perfect child, begins, and then it is realized that they are facing the unknown;

It was difficult to receive this diagnosis from my daughter, when she was born, she was referred to the hospital of Messejana, when I was told that it was cyanosis of the extremity and her disease was tetralogy of Fallot. From there began my suffering with her. I came to take an exam and I didn't go out anymore. After a few days she went for surgery. He had the surgery at 8 months, spent 15 days in the ICU. And I've been told she's going to have to have other surgeries. M3 Ruby

Receiving the news that my daughter had heart problems was difficult, I went into shock, I cried a lot. She has the diagnosis of Hypoplasia of the Left Heart Because I soon thought that she would not resist. M5 Turquoise

The discourses apprehended were significant in their content to the extent that the apprehension of this new reality was verified in the discovery of the diagnosis and in the course of the hospital experience. Faced with the unknown, mothers begin to seek an understanding for the new, the one that needs to be known (heart disease), and thus use the available resources to access them.

This category brings important elements regarding the representation of the child's heart disease. It makes it possible to identify and understand the meaning of having in your arms a child with a serious heart disease, as well as feelings of insecurity potentiated when the child presents signs in his body that demonstrate how fragile he is and requires care. The word hypoxia as the most evoked is anchor represented by mothers as to the fear, they have of the child having some crisis and dying at any time, these feelings are objectified in crying.

However, the experience of caring for the child with heart disease succinct with feelings of faith, which leads the mother to construct new meanings, to review her expectations in the face of the new reality. It is prudent to note, however, that some statements bring in their content these representations:

The moment I received this news (diagnosis) I was floored because I had never heard about this disease, Tetralogy of fallot. The doctors explain, but there's a lot of complicated stuff that I don't understand. I know it's a disease that needs to fix the heart with surgeries. He had seizures (hypoxia) and turns purple. I have faith that we're going to get through this. M8 Jade

Then they were referred to the messejana and the diagnosis was large VSD. It was one scare after another. I knew he had heart disease, but I didn't imagine he would have to stay in hospital for so long, have surgery. It was hard for me, but for him it's been worse. These were days of crying, fear and insecurity. I was looking at him all the time, I think I spent a couple of days without sleep, afraid of him feeling bad and dying. Having a seizure (hypoxia) Because a child with a heart problem is said to die in his sleep. My faith and hope grow every day. M6 Amethyst

3.3 SOCIAL REPRESENTATIONS OF MOTHERS ABOUT MATERNAL CARE IN THE HOSPITAL ROUTINE

In the most complex cases of the disease, hospitalization of the child in a Cardiopediatric Therapy Unit (PICU) is common. Studies by Azevedo, Hemesath & Oliveira (2019), demonstrate, that

the hospitalization of the child in the Pediatric ICU is a frightening experience, marked by several feelings, for having to deal with unknown and unexpected situation, beliefs associated with the possibility of death of the child

Hospitalization brings a different dynamic to the mother, with a sick child who demands special care, in an unknown place, often in a city far from her home, family, friends and work.

Studies by Silva (2019), reaffirm that the most reported feelings were sadness, impotence and fear of death, all of these noted at the beginning of hospitalization, which tended to be replaced by feelings of satisfaction and joy when perceiving the development of the child, returning to be seen the negative feelings with the verification of the temporal extension of hospitalization.

However, the care of the child with heart disease is anchored by the family, which although many of these mothers face alone a routine of caring for the child in the hospital, far from their relatives facing threats of surgeries, medication administration, supported by technological structures (accesses, probes, drains, etc.) are objectified by the difficulty and concern, but also by the affection mainly exercised by the team and other mothers from shared experiences as a support network, presented in the following statements:

A new challenge, learning to care and live one day at a time. Everything is different, the worry is constant. The simplest thing becomes complicated. The bath, the diaper change, eating through her mouth, until her breathing I watch, I take care of her so she doesn't cry, doesn't get angry and doesn't get tired. There are the medications. She managed to run out of oxygen. Every day a victory. M5 Turquoise

At first, I didn't want to do anything, take care of it, you know? But the professionals were helping me, guiding me. How to bathe, how to hold on his lap, how to change the diaper, put on the clothes, put on the correct way for him to sleep. Each one comes and helps me, corrects me. Because he wasn't like the other children, he has a developmental delay, he's 6 months old, but he looks like a 1-month-old baby. So, for me like he was born the day he came into my lap, we were getting to know each other. M4 Emerald

Studies conducted by Siqueira and Dias (2011) regarding the maternal perception about the experience and learning of the care of a premature baby, bring the reflection of mothers on the importance of being trained during the period that their children were hospitalized and how important these teachings were about care also in the home environment.

In the following discourse, the mother reveals the importance of receiving support and guidance on how to care for the child with CHD in the hospital and at the same time the fear and suffering of

taking their children home and performing the care without the supervision of the multidisciplinary team, as mentioned in the discourses:

I didn't want to take her home now; I'm confused and I don't think I'll be able to take care of her like I have to. There are the medications. She's a special kid, I'm still learning and getting to know my daughter. It's only been 20 days since I've been with her, I'd take a professional of yours away with me. My family will help me, but for them it will also be difficult. M7 Tourmaline

Medina *et al*. (2018), state that the lack of protagonism in relation to decision-making about the care provided to the child without the consent of health professionals can, in some cases, make them feel excluded from the care process.

Even though I stayed with him in the ICU, I was distressed because I knew he was under my responsibility. Even so, the team helped me in the early days. I was nervous about his discharge. I was afraid he would pass out, throw up, cry. I was afraid to bathe, to take him out of bed, I was afraid to change his position and hurt his heart. It was distressing, but he was discharged from the first surgery and we went home. M6 Amethyst

Deepening the knowledge about the Social Representations of mothers about maternal care in the hospital routine, made it possible to understand how groups and human beings think and relate to this phenomenon in its complexity, (JODELET, 2001), as a model that allows the possible mediation between the participants, who relate from a certain logic of conducts. It is in the movement of interpreting the meanings of this experience of how mothers take care of their children, understanding it as feedback between mother and team.

However, as they passed through the course of hospitalization, they adapted to the hospital routine, the routine of caring for the child and overcoming fear and insecurity. This daily experience of care brought the mother-child bond closer together and strengthened.

The team helps a lot. I wouldn't make it without the pros. But I feel very alone, I'm very afraid to take care of her, to do something that might hurt her, afraid of losing the probe, the accesses, the oxygen, fear of everything. The team goes by and guides me, reassures me, I know that if she feels bad, she has the doctors to help. I'm learning how to take care of her. M7 Tourmaline

I'm looking forward to this moment, the high. I've learned a lot from the professionals. Because the care of such a child is different from a normal child. It's very delicate. He's not doing things from a kid

his age; he has a developmental delay. He looks more like a newborn. But I'm still more relaxed. When he takes home, he will meet his brothers and the whole family. I learned here to respect God's timing!! M2 Sapphire

It is noticed in this study that mothers find difficulties in caring for their child with CHD in the hospital, often attributed to the devices that remain in the child, such as the orogastric tube, accesses, the nasal catheter, drains, electrodes, mainly related to their feelings and their limitations; however, they manage to overcome them, because they demonstrate above all faith and courage to overcome the obstacles encountered.

3.4 SOCIAL REPRESENTATIONS OF MATERNAL FEELINGS

The representation is not limited to a simple opinion, but constitutes a structured thought that serves as the basis for what one thinks. It is the product of a group, which gives it its social character. These representations guide the behavior and understanding of the daily life of the world in which we live. They function as organizers of the attitudes and practices of the groups that originate them and organize the expectations of the subjects about the object in order to meet them (JODELET, 2001).

For the mothers in the study, having faith is an essential requirement to face the difficulties of their child's disease, the hospitalization process itself, the ICU, the surgeries, in short, all the mishaps faced.

She's everything to me, I'm proud of her being such a strong child to survive heart surgery. She showed me what it's like to love a real person. I love my daughter so much; she is special and I have faith that God will heal her. I believe it!! M3 Ruby

He (my son) taught me that I need to have more faith and believe in God. I have gratitude to God for my son M4 Esmeralda

The term faith and special, readily evoked by the mothers, indicate that there is a link between the representation of having a child with a serious illness with the spirituality that they experience from their religion, such findings corroborate the understanding of social representations anchored in religious beliefs.

The expressions of the mothers in the word's faith, gratitude, special and love refer in their speeches to the confrontation and the possibility of healing the child's problem, as daily anchors, as emotional support and strength to face reality and find meaning in everything.

4 CONCLUSIONS

From the beginning, there was the intention to approach these mothers and apprehend the SR, which made it possible to reveal important aspects in which they were recorded not only in the interviews, but that went beyond the verbal, from the sharing of an arduous routine and allowed the researcher to recognize maternal care in her daily life in the hospital.

From the results presented, it was possible to perceive how mothers represent the care of a child with heart disease in the hospital. Thus, the construction of networks of meanings that are created and shared in the hospital scenario is noted.

Therefore, the representations apprehended here are re-elaborated productions from the experience that each mother has when caring for her child with congenital heart disease in the hospital, that is, her a priori knowledge of this social object, which is acquired through the group to which she belongs is transformed and receives new clothing as a result of this experience.

In this study, it made it possible to enter the subjective world, the world of social representations that pointed to the forms of interpretation of reality according to the experiences and knowledge of the common sense of the mothers in relation to the care of their child with CHD in the hospital context.

Thus, it is stated that, in general, when representing heart disease (stimulus 1), caring for the child in the hospital (stimulus 2) and mother-child relationship in the hospital (stimulus 3), the mothers highlight the importance of facing the diagnosis of CHD as the first step to understand and apprehend this new reality, either through information, which is often based on a technical language. And even if inserted in the daily life of this child in the hospital with which he has no familiarity, a limitation to his understanding is sometimes accentuated, prevailing a superficial relationship with the medical and multidisciplinary team.

It is perceived that initially, the team assumes the care of the child, due to his clinical condition, the need for technological instrumentalization for intensive support, causes a distance between the dyad, limiting the approach of the mothers to the care of their child.

Understanding the SR elaborated by the mothers is an important step to support them in the care of this child in the hospital, respecting their initial feelings; pain and despair. The importance of help from health professionals in search of quality care to the mother-child dyad is highlighted, in which it is necessary to awaken in these mothers to the value they have when caring for their children in the hospital, a process of (re)signification in the face of the adversity faced (surgeries/hospitalization).

It is evident that the orientations by the team become adequate and effective when the professional, in possession of these SR, interacts with the mothers and develops orientations based on maternal experiences during hospitalization.

However, it is recognized the significant maternal role in the care of the child in the hospital, with actions rich in creativity and affectivity, relevant aspects for development, in which they act directly on the emotion, love, affection, solidarity that will in turn mobilize numerous bodily and emotional processes contributing to an increasingly harmonious mother-child relationship, important aspects for the development of a child.

EMPLOYEES

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