

# Pediatric cardiac surgery under the parents view: A qualitative study

*A cirurgia cardíaca pediátrica sob o olhar dos pais: um estudo qualitativo*

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## Abstract

**Introduction:** Congenital heart defects can often be corrected through surgery, providing for parents to expect a normal life, but the hospitalization experience often early, causes more pain, for which surgery is the worst moment.

**Objective:** The aim of this study was to analyze the experience of families of children undergoing cardiac surgery and to identify the coping resources used by the families.

**Methods:** A qualitative approach was the methodology of choice for this study, which took place with six semi-structured interviews and 100 hours of observation. Thematic analysis was used to understand the data.

**Results:** The results were categorized into four themes: feelings and emotions facing the illness of the child; heart disease under the watchful mother, mother and child on the ICU and coping resources. The speech of mothers demonstrated the importance of the heart due to its symbolism that enhances their emotional fragility in the face of illness. Religiosity and a solid social network of support were contributing factors for the maintenance of the adaptive behaviors. The presence of mothers in all stages of the child's treatment contributed to minimizing the suffering generated by hospitalization.

**Conclusion:** The experience of families was characterized by ambivalent feelings such as fear of death, guilt and helplessness against the different stages of treatment. The anguish and anxiety prevailed in the face of unknown situations when information were required before therapeutic procedures, hospital routines and the actual life situation of the families.

**Descriptors:** Adaptation, Psychological. Mothers. Heart Defects, Congenital.

## Resumo

**Introdução:** As cardiopatias congênitas podem muitas vezes ser corrigidas por meio de cirurgia, assegurando para os pais a expectativa de uma vida normal, entretanto, a vivência da hospitalização, muitas vezes precoce, ocasiona maior sofrimento, sendo a operação o pior momento.

**Objetivo:** O objetivo deste estudo foi analisar a vivência de famílias de crianças submetidas à cirurgia cardíaca, identificando os recursos de enfrentamento utilizados pelos familiares.

**Métodos:** A abordagem qualitativa foi a opção metodológica deste estudo, onde realizou-se seis entrevistas semi-estruturadas e 100 horas de observação participante.

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Foi utilizada a análise temática para a compreensão dos dados.

**Resultados:** Os resultados foram categorizados em quatro núcleos temáticos: sentimentos e emoções frente ao adoecimento do filho; a doença do coração sob o olhar materno; mãe e filho na dinâmica da unidade de terapia intensiva e recursos de enfrentamento. A fala das mães demonstrou a importância do coração devido a seu simbolismo que, por sua vez, potencializa sua fragilidade emocional diante do adoecimento. A religiosidade e uma consistente rede social de apoio foram fatores contribuintes para a manutenção de comportamentos adaptativos. A presença da

mãe em todas as etapas do tratamento da criança contribuiu para a minimização do sofrimento gerado pela internação.

**Conclusão:** A vivência das famílias foi caracterizada por sentimentos ambivalentes, como medo da morte, culpa e impotência frente às diferentes etapas do tratamento. A angústia e a ansiedade prevaleceram diante de situações desconhecidas, necessidade de informações frente às condutas terapêuticas, rotinas hospitalares e da própria situação de vida das famílias entrevistadas.

**Descritores:** Cardiopatias Congênitas. Adaptação Psicológica. Mães.

## INTRODUCTION

Although the National Policy of Humanization have been established in most hospitals in the country are still evident situations where families are not seen as an essential part of care [1]. The families are often isolated from the process of care and have limited their participation by hospital rules.

Mitre & Gomes [2] suggest that hospitalization in childhood can be perceived as a potentially traumatic experience because the child away from everyday life and family environment and promotes a confrontation with pain, physical limitation and passivity, emerging feelings of guilt, punishment and fear of death.

Souza et al. [3] described the scene of the hospital as a reality, which deprives the child of his role: being a child. The computerized appliances, lights flashing, the countless numbers of wires, serums, tubes and oxygen masks restrict their movements outside its condition of patient. Added to this the presence of people who work with their white clothes and stereotyped behaviors that help remove children from their clothes and their toys.

According to Finkel [4], illness and hospitalization cause on the child intense and complex emotional experiences. At that moment, a new context raises that requires mobilization of internal resources for adaptation condition imposed by the illness. This new condition will cause reactions in children who depend largely on the level of psychic development, degree of family support, the type of disease and the doctor's attitude. To elaborate on this experience, it is necessary that the child can have tools available for his domain and knowledge. The presence of an accompanying person, especially a parent, is essential for coping with the hospitalization, especially in complex situations such as congenital heart disease (CHD).

Congenital heart defects can often be corrected through

surgery, assuring for parents to expect a normal life, though it involves the use of invasive diagnostic and treatment, the hospitalization experience often early causes more suffering, and the surgical repair is the worst moment of this process. [5].

According Rathsam and Francé [6], during hospitalization nobody is able to calm the anxieties of children and their families, and in that sense, it is imperative that the institutions that serve children with congenital heart disease have a humane policy toward offering support the family. That kind of attention helps families in finding resources for coping with the disease situation of their children.

This study aimed to examine the experience of families of children undergoing cardiac surgery in an Intensive Care Unit of Cardiology, identifying coping resources used by families.

## METHODS

### Type of study

We performed a descriptive, exploratory, qualitative, case study, considering the nature of the object being investigated (families).

### Study site

We studied families of children with congenital heart disease undergoing cardiac surgery at a university in the Northeast of Brazil, state reference in Cardiovascular High Complexity whose clientele is composed exclusively by users of the Unified Health System (SUS) and provides assistance to children coming from other services from the capital and cities in the state.

### Research subjects

The study included families of children diagnosed with

congenital heart disease, with up to 10 years old under care during the study period (March 2008 to May 2008). The limit of 10 years aimed to exclude young people considering the particularity of the group that brings the need for specific studies.

### **Data collection**

Six interviews were performed with mothers and another with mothers and father together, the number of interviews was based on the criterion of saturation consisting of the presence of repetition in the data that are collected by setting up a common structure on the phenomenon studied.

We used a structured questionnaire in which sociodemographic data were sought from the child's family searched and a semistructured interview which was sought on the testimonies of the families in order to define the meaning core to the content analysis, and participant observation by two observers independent.

The interviews were taped with the permission of mothers and later transcribed. The interview served the purpose of guiding the establishment of a dialogue between the researcher and the interviewee, allowing it to be kept a direction, in the process of collecting information of qualitative nature.

Participant observation allowed the researcher to direct contact with the context being investigated. The immersion in the field enabled the direct and personal observation of its object of study. Thus, the daily experiences of the subjects were observed and had deciphered their meaning.

The observation was performed following a script previously prepared with questions aimed at understanding the dynamics of the environment of the ICU during the interviews and recording their impressions of the researcher. The observed data were recorded in a diary. The observations occurred on two occasions: in the ICU environment during the visit of the parents and remaining close to the child and during the conduct of medical record information. Were performed in all about 100h of observation during the study period and 22h were from these formal observation.

### **Data analysis**

Data from field work were analyzed using content analysis, which seeks the visible and hidden meanings in the qualitative material, using it for several techniques, among which the thematic analysis.

The thematic analysis occurred in three stages:

#### **Pre-analysis:**

After the transcriptions of the speech (interviews) were transformed into text with units of meaning and significance. An initial reading, and exhaustive questioning of this material was performed to apprehend the central ideas and determination of unit record (key words or

phrases) and the establishment of the corpus. This consists of all material studied, even if it is necessary to increase, but covering all aspects of the script to respond to the proposed objectives. We determined the units of records (keywords) and the context unit that is the understanding of these units of records.

### **Phase of Categorization-investigation of the material**

It consisted of exploring the material in a quest to reach the core of text comprehension. For this, we tried to find meaningful words or phrases around which the talks were organized for the ordering of the categories. These were pre-determined by the theoretical field as a function of the proposed objectives; thereafter was ordained into the core meaning that constituted the analytical categories.

The following analysis categories were extracted:

- Feelings and emotions regarding the child's illness;
- The heart disease under the mother's view;
- The mother and the child on the ICU;
- Coping resources

Importantly, in category "Mother and child on the ICU", there was a need to work with the focus on observations and add with the reports obtained in interviews, unlike other categories, because of the shortage of speech-driven for the subject matter.

### **Analysis and interpretation of results**

After finding the analytical categories described above, interpretations and inferences were performed, interrelating them with the theoretical study, allowing an interface between the studied and found an answer to the proposed objectives. It is important to be placed that during the discussion of the interviews were used to identify the mothers' reports, the names given to Our Lady and the father's speeches, a biblical name, replacing the original names, thus maintaining the ethics of anonymity.

### **Ethical considerations**

This research was submitted to the Ethics Committee in Research (CEP) and its beginning was approved under the protocol 33104-1191/2007 and Opinion No. 456/2007.

Interviewees were duly informed about the objectives and methodology to be used in research, as they were provided free access to their statements and complete privacy on all information provided in any circumstance. They were also guaranteed the right to withdraw from the study according to their convenience and/or anytime it was in their interest.

All interviews were performed after the reading, explanation and signing the written informed consent (WIC) by the interviewees. For ethical reasons, anonymity was protected from all those involved through the use of fictitious names.

## RESULTS

Minayo [7] notes that in a qualitative approach, the criterion of choice of research subjects, to ensure its representative character, is not numeric, since the main feature of this approach is the depth and breadth of understanding of a particular socio-cultural group that is being investigated.

The results were categorized into four themes:

- 1 - Feelings and emotions on the child's illness;
- 2 - Heart disease under the mother's view;
- 3 - The mother and the child on the ICU and
- 4 - Coping resources.

These cores are presented below.

### Feelings and Emotions on Child's Stay in hospital

The fear of losing his son was a sentiment expressed by all interviewed mothers and father. This feeling is particularly linked to the common sense idea of †the occurrence of death during surgical procedures and hospitalization in intensive care units (ICU).

"... I don't know ... I'm so afraid of having an arrest or something..."[Maria das Dores].

"... When we know we have a child in such situation on which we can lose him at any time..."[Maria de Fátima].

"I was very worried because she got tired a lot. Then I wondered go without her, because that's her problem... I felt it was very serious" [Maria das Graças].

Another feeling was the guilt for the child's disease, directly influencing the exercise of the paternal and maternal function, as seen in the speech of João Batista and Maria dos Aflitos.

"The odd thing is that even with all the care she was born seven months, she was born premature, one more to leave us like this: My God what have we done, and it left me - for being a man - a sense of guilt higher... The feeling of guilt is higher, and I was very weak at that time..." [João Batista].

"And here she breathed deeply, and he was real quiet... It's fine now! You can go out there mom ... Let she here because it is on our own, Hail Mary!" [Maria dos Aflitos]."

Another issue that emerged from the speeches was the perception that hospital is not a good place for children. It was observed that in addition to the suffering mother to see his child being played and "caring" for others, without the mothers care, feelings of uncertainty, not knowing what is going on and feelings of powerlessness emerged.

"When he told me to throw it: to put the oxygen, it was too bad! Half a world of a woman holding her, and she slowly dying ... I don't know ... I asked for them: What is it? ... This is killing my child?" [Maria dos Aflitos]

"... Not prepared for that moment, that's the truth. I was very angry when I saw it..." [Maria dos Aflitos].

### The Heart Disease under the Mother's View

The mothers' speeches have shown us that the heart has a duality in its symbolism of life and death. And compared to diseases of other organs, the value is much higher.

"I was very worried, because I think it's a very important organ that we have, you know, the heart, right?" [Maria das Dores].

"Simple is not it, because when it comes to heart is not simple, there's nothing simple, is always worrying." [Maria dos Aflitos].

The speeches showed the dread of mothers to realize that something was wrong with their children and knowledge of what was causing, allowing for wishful thinking triggers of conflicting feelings and painful; there was also comparison with other child.

"I was scared, I kept hearing a noise." [Maria das Dores].

"When I would bathe her, I realized how in the little breast-side here, the heart was beating so very fast tu tu tu tu, you know? Then I was always so worried. One day I talked with my husband, "You know that my daughter's heart, the heart beats differently from other children?" [Maria de Fátima]

The speech of mothers below showed a differential with regard to child illness. Overprotection shown refers to a time when the lack of information about the heart problem has generated feelings of fear and insecurity.

"I think it's good to avoid being doing much with it. I avoid taking it in place like this, I take, but it's only once in a while, not so steadily." [Maria de Fátima]

"We did not allow him run a lot more, cry or play." [Maria dos Remédios].

"Because he is a special child, I always care. Sometimes I would not let him play certain things, you know, scared." [Maria das Dores].

### The Mother and the Child in the dynamic of ICU

The results obtained directed to this thematic, showed the skills that mothers have to deal with hospital rituals, through adaptive and maladaptive behaviors.

With regard to adaptive behavior, we realize that mothers react more positively to the environment and the dynamics established by it, when her child is not feeling pain, is conscious, able to communicate and is being well taken care of by the team, as evidenced in the statements below.

"He came calmly, I arrived, I spoke with him calmly ... I came and talked to him, he was sitting there, and I said, "My son, give Mommy a kiss. " He gave kisses quietly." [Maria das Dores]

"Then I said, 'Mommy will be here on the outside and

*the door' He: 'Don't go away'. Then I said, 'Ok, I won't.' ' waited for him to sleep so I could leave." [Maria da Conceição].*

"It's insecurity about this space. We feel a little insecure." [Maria de Fátima].

*"The only thing that bothers me is the confusion of the device, because I do not understand, I do not understand about that. So I'm scared. I do not know what time he can feel sick." [Maria da Conceição].*

Moreover it was observed that the difficulty of discharging the function of the mother is a complicating factor of adaptive behaviors to the environment, contributing to the exacerbation of negative emotions and feelings, coupled with the perception of the state of the child by the mother, even without knowing the real medical condition.

### **Coping resources**

The study showed the mother as main caregiver. All children included in the study were accompanied by their mothers and one of them also accompanied by his father. Given the situation of illness of a child and the hospital, it was observed that mothers use as strategies to cope with this experience, the support of the social network, religion, support and care of the health team and her own history life may determine a resilient behavior.

- Religion: *"I trusted in God. I said, "No, but beyond medicine, I know there is a God who can do all things. So there in the passage of the Bible: I can do everything through Christ who strengthens me." [Maria de Fátima].*

- Social network of support: *"She [the mother] was very nervous, could not stay with me during his first surgery. I had the support of my brothers. But now it's great to know that she [the mother] is here." [Maria de Fátima].*

- Support and care of the health team: *"I can not explain. When I saw the nurses and doctors accompanying her I was relieved. I thought the child was alone, the doctors were with other children as they arrived. But the whole team gets together there." [Maria da Graça].*

### **DISCUSSION**

Oliveira [8] states that considering the family as an essential part of human care is something that can not be questioned. The role of family as a host is determining the type of parents' experiences during hospitalization as evidenced in this study.

The feeling of fear of losing his son mixed up with the idea of death in this study, Carvalho [9] states that the process of dying is the horizon and the boundary of the future, making this a mixed resume of past and anticipated future. Temporality is the meaning of life.

In the environment of an Intensive Care Unit (ICU),

families often experience all these feelings simultaneously. Lee & Santa Rosa [10] call this mess of feelings of tragic triad, which consists of the possibility of death, suffering and guilt. The same authors add the importance of transmission security and hosting provided by family presence in the ICU and the suffering experienced by those facing the uncertainty of the patient's clinical condition, prognosis and risk of death.

Another feeling was also observed in families of this study and that can join the tragic triad is the impotence, which is the real feeling found in situations where the performance limit of the family does not coincide with the boundaries of professional practice and the technological-threshold human existence [11].

The child's hospitalization is a potentially stressful event for the family, as it inserts it in an environment that often threatens its sense of security and competence, engendering feelings of powerlessness and helplessness [12,13].

The perception of the family, especially the mother on the child's illness is fundamental to understand the functioning of the mother-child and plan the appropriate therapeutic actions.

Helman [14] states that the meaning of an illness is determined mostly by socio-cultural factors, which in turn emit their own language of distress related to the subjectivity of their experiences. It is through socio-cultural factors that humans determine which signs and symptoms are perceived as abnormal and normal, as reported by mothers in this study, when they recognize the changes caused by congenital heart disease.

The importance of the relationship of the healthcare team with the family is essential for planning a more effective and humane care. The dialogue is clear and simple and listening to mothers avoid stressful situations and reduces non-adaptive behavior. For families, receiving attention is a sign that the professionals are concerned and they understand their feelings and needing at that moment. The interviews showed that when the guidelines and explanations are received by their families at crucial moments, their uncertainties and anxieties are minimized [15].

The family tries to adapt effectively to changes caused by illness and hospitalization, by finding positive meaning favoring the process of coping and adapting to the demands added to its daily life. [15].

Moreover it was observed that the difficulty of performing the function of the mother is a complicating factor of adaptive behaviors to the environment, contributing to the exacerbation of negative emotions and feelings, coupled with the perceived status of the child by the mother, even without knowing that the real medical condition. Braga [16] indicates that for the mother, being in ICU with her child, while she should be taking ownership

of his care at his home, makes her feel losing her role of motherhood, having difficulty in recognizing as mother, because there is a team that appropriates the care that should be hers. Mello et al. [17] argue that parents should be encouraged to participate actively in the care of his child, and was initially accompanied by professional nursing staff, becoming progressively to implement care and hygiene, comfort and nutrition.

Recognition of mother as the subject participating in the care, present in this study gained ground in the setting of care in relation to child health, since the emergence of Mother Program Participant, which includes the family in planning the child's care, respecting also his views. This aim, however, still faces obstacles related to the structural condition and understanding of professionals working in the area. To provide a professional and effective care consistent with the needs of the child and family is essential to consider the characteristics and peculiarities of each individual care, having sensitivity and empathy with family members and feel able and motivated to performing a difficult job in everyday practice. The daily field observation of this study showed that the team - despite not having the program Mother-participant - is motivated and has shown itself willing, in many instances, to divide the care.

One of the coping styles used by mothers in this study was the social support network in which the family is understood as a primary care, and social space where members interact, exchange information, support one another, seek to mediate and efforts to minimize or solve problems. Accordingly, many patients and families end up developing in the hospital so-called "intranets" for the purpose of mutual aid and reducing feelings of loneliness and helplessness [18].

Religiosity, according Fongaro and Sebastiani [19], was always there, trying to explain the unknown or giving meaning to human concerns. And the role of religion is essential in providing support and comfort, as noted in the speech of mothers in this study.

## CONCLUSIONS

The results of this study showed that:

1 - The admission of a child with congenital heart disease to perform surgery is a time of crisis for the family system of mixed feelings, but also represents a perspective of healing and improved quality of life;

2 - The main feelings encountered during this time of crisis have been fear of death by heart disease, surgery and anesthesia, guilt and powerlessness in the face of the different stages of treatment from an appointment with the surgeon until discharge from Intensive Care Unit;

3 - Regarding the observed emotions, anguish and anxiety prevailed in the face of unknown situations, need for information on therapeutic procedures, hospital routines and the actual life situation of families. Because of this, initiatives of the health team were identified focused on minimizing the suffering of parents.

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