

Experiences of Mothers of Children with Congenital Heart Disease

ORIGINAL

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Abstract

Introduction: This article discusses the experience of mothers during the process of falling ill of their children with congenital heart disease.

Method: This is a descriptive research with qualitative approach conducted with nine mothers who had their babies admitted to a pediatric cardiology unit in a reference center for treatment of congenital heart disease in the North and Northeast regions in Brazil located in Fortaleza, Ceará. Information and reports on the experience of these mothers emerging from the diagnosis process, surgery, treatment and hospitalization were collected in semi-structured individual interviews. After interviews, the testimonies of mothers were transcribed in full-length, identifying the speeches with the codes M1, M2,... M9, thereby ensuring anonymity. We used the thematic analysis technique of Minayo (2012) for treatment of information and design of the content of this article. This article is part of the research project: Breastfeeding babies with heart disease, approved by the Research Ethics Committee of the Messejana Hospital, under Opinion No 1,285,784.

Results: The study demonstrated that infants with congenital heart disease require specific and specialized care and that mothers undertake a long and sometimes painful journey in the search for the healing of their child.

Discussion: Based on the collected speeches, we learned that mothers also need to be assisted by professionals of the health team. They must support the mother's empowerment in the child care and strengthen the relationship of the mother-infant binomial, and help in coping and adapting to the reality in the process of falling ill and healing of their child.

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Introduction

Congenital heart diseases (CHD) are defined as cardiac malformations that occur in the embryonic period, which may be associated with genetic and/or chromosomal changes [1]. They are classified, based on hemodynamic effects, into acyanogenic (when there is no mixture of oxygenated and non-oxygenated fractions in systemic circulation) and cyanogenic (when there is mixture of fractions) [2].

The incidence of CHD in the state of Ceará is 1,159 new cases/year [3] and studies conducted in southern Brazil have shown an incidence of 43.8% among children under 12 years of age [4].

The symptoms of congenital heart diseases are diverse. However, some common manifestations are difficulty to eat, cephalic pole sweating during breastfeeding, prolonged jaundice, cyanosis, respiratory distress, chest pain and syncope, in addition to "murmur" detected in cardiac auscultation, which is the primary reason for referral to cardiology [5].

Congenital heart disease can be diagnosed during prenatal or in the postpartum by the health team or even by the mother who identifies some of the above symptoms. This is a difficult and unique moment. The mother is inserted in the world of illness of her baby, in which a great loss takes place and that idealized baby ceases to exist. A period of mourning for the expected child starts in this moment.

Despite the relevance of heart diseases during infancy and the need for early care, people in poor and/or remote regions still have great difficulties to receive diagnosis and treatment because of the lack of specialized professionals and the difficulties to access to health services [6]. This condition imposes on mothers the need for a pilgrimage in the search for healing of their children.

Thus, in the case of babies diagnosed with heart diseases, due to the peculiarities of these diseases, there is a need for technological support and a spe-

cialized team, prepared to deal not only with the baby but also with the mother who experiences the whole process of illness.

The process of diagnosis, treatment, surgery and hospitalization of babies with heart disease and their mothers is sometimes slow and time-consuming, and causes much stress, doubts and uncertainty. Thus, knowing how these mothers experience the disease in the hospitalization process is an important step towards improving the care provided by health professionals, in order that they become allies in providing care to the child in the inpatient and outpatient treatment. Thus, this study aimed to understand the experience of mothers during the process of falling ill of their children with heart disease.

Methods

This is a study of descriptive nature with qualitative approach carried out in the Pediatric Cardiology Sector of the Hospital Dr. Carlos Alberto Studart Gomes (Messejana Hospital), a reference in the North and Northeast of the country, in treatment of congenital heart disease. The target group consisted of mothers of infants with congenital heart disease admitted to the pediatric unit.

The total number of participants was nine mothers. They were aged ≥ 10 years to < 60 years, according to the definition of the Ministry of Health (2011) [7], and mothers whose babies had comorbidities in addition to the heart disease were excluded. Participants were informed about the purpose and relevance of the study, assured about anonymity, and asked to sign the Informed Consent.

Data collection was conducted through semi-structured interviews during the months from February to April 2016 in the Pediatric Unit. Interviews were recorded. During data collection, hospitalizations were suspended in two periods due to varicella outbreaks, leading to a longer period of contact with mothers.

After interviews, the testimonies of mothers were transcribed in full-length, identifying the speeches with the codes M1, M2,... M9, thereby ensuring anonymity. We used the thematic analysis of Mina-yo (2012) [8] for the treatment of information and design of the content of this article.

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Results

Being a mother of a baby with congenital cardiopathy

The concept of motherhood has changed over time and currently concerns only co-blood relationship. A broader term is given for the affective bond, the care and affection between mother and child; these elements are named mothering [9].

Maternal feelings towards the child can start since pregnancy, a time of physical and emotional changes for women, when idealization and planning of the awaited child happen. Women assume a new role from then on, the role of mothers.

In the case of the birth of babies with a disability such as congenital heart defect, the proposed theme of this research, we can imagine how difficult is for these women having to deal with the disease and all the events resulting from it, what end up destroying everything that was conceived by them.

Participants in this study were willing to share their experiences of having a baby with congenital heart disease. They exposed quietly and spontaneously the journey from diagnosis to treatment of the disease.

The diagnosis itself is a unique and, most often, painful moment in which the mother is inserted into the child's illness. The diagnosis can be defined during pregnancy or immediately after birth, or only during the development of the baby.

The mother passes, then, to live within an unknown universe. These are situations, terms and words with which they are not familiar. They have to face such situation often without adequate guidance or professional support.

Symptoms of congenital heart disease are variable, depending on the change and impact of the disease in each baby. This can trigger in mothers feelings of confusion and anguish of noticing that something is wrong with their babies, although sometimes they do not have a clue that this can be a serious condition, as we see in a some lines:

[...] he was very tired and bit purple [...].

M5.

It was because a snore that she had[...] one rattling she has in the throat, we went to investigate what was that [...].

M6.

[...] I called the doctor and asked her to see him because I found it very strange [...].

M9.

To define exactly the type, treatment and prognosis of the heart problem, there is need for a thorough evaluation that may include clinical signs, laboratory tests, chest x-rays, electrocardiograms (ECG) and echocardiography (ECHO) [10].

These are not always available in the original municipalities of the patients, leading mothers to start a journey in the search for the healing of their children, often far from home, from the husband, the family and far from the emotional support needed for the situation they are going through.

Women in this situation end up taking on the role of caregivers. They are the ones who most often interact with the professional team and stay more time with the baby, which helps directly to the relationship between them [11].

Cardiac involvement, therefore, brings with it a number of needs for specialized care that mothers

and their babies will have to live. This includes administering medications, hospitalizations and surgeries, changing daily life and care of this mother with the baby, in the expectations of recovery of the child.

Hospitalization itself may already cause real suffering to the patients and their families, considering that the hospital space is most often associated with suffering and sorrow. In the case of mothers of babies who need to remain hospitalized, a significant loss in the mother-infant binomial may take place due to all matters that hospitalization involves such as change in family routine, an environment far from home, physical distance and maternal care imposed by the disease.

[...] then, she took him to the nursery, connected him on the machines and said he had a heart problem[...]he was immediately intubated and went to the ICU there [...].

M9.

This distance between mother and baby is often motivated by clinical requirements imposed by the disease. However, such situations can interfere with the connection of the dyad established since pregnancy, and can trigger emotional reactions of guilt and fear on the part of the mother, altering the quality of the relationship that is so important to the development of the baby [12]. Such feelings have been reported by some mothers as we can see below:

[...] am separated from her for some time [...] and I don't feel close because I cannot give my best [...].

M6.

[...] It is complicated...he has to be separated from me... stay in the ICU, he cannot be with me [...].

M8.

This feeling of mothers' guilt comes not just from the physical separation caused by hospitalization, but also from the absence of the role of caregiver, which they considered to be exclusively theirs. The treatment of the babies passes on to the responsibility of the health professionals, depriving mother from their role, from mothering. Thus, mothers cease to perform their function with their children in the way they considered ideal. Mother, then, develop troubled feelings of anxiety, sadness, guilt and fear.

Mothers proved to be able to recognize the vulnerability of their babies and the need for technology and specialized care. However, experiencing hospitalization, separation, procedures and surgeries necessary for their babies interfere in the emotional balance of mothers and trigger high levels of stress and anxiety, followed by doubts and questions that include fear of exhausting the healing options, as we can see in some speeches:

[...] we get a little sad, because we did not expect any of this [...].

M1.

[...] it is going to be complicated...he'll have to stay in the ICU, I cannot be with him [...] I do not know how he will be fed[...]as he takes only breast milk [...].

M8.

These troubled feelings can affect the emotional state of the mothers and their experience of motherhood, besides damaging the bond and bringing risks to the psychomotor development of the baby, as well as delays in the acquisition of speech and language [13].

Thus, in this period of illness of children, it is up to health professionals to provide technical and emotional support to these mothers, besides caring for the babies. This means promoting humanized care, listening and clear and simple dialogue, in order to reduce stress, anxiety and inadequate behaviors.

Discussion

We could note that the disease and hospitalization of children promote intense emotional destabilization in the life of mothers. Considering that in the case of congenital heart diseases, prolonged and continuous monitoring and multiple interventions and surgeries are needed, the situation worsens.

Difficulties of mothers relate to the painful journey undertaken in the search for diagnosis and treatment, encountering barriers to access health services, to access the team, specialized technology and places to assist congenital heart diseases, all factors that demand much time until achieve the long-awaited cure for the child.

Conclusion

This study highlighted that these mothers suffer discomforts, anguish and uncertainty in the process of falling ill and hospitalization of their children. This is explained by the physical separation required by the disease itself and the whole technological apparatus that their babies need, with negative consequences for the recognition, autonomy and self-esteem of these women.

We consider that the context of congenital heart disease requires adaptability, strength and resilience in child care. Therefore, there is a need for assistance and support from institutions and professionals in order to restore health, quality of life and physical and emotional well-being of the mother-infant dyad.

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