

BEING A MOTHER OF CHILD HOSPITALIZED WITH A CHRONIC ILLNESS

SENDO-MÃE DE CRIANÇA HOSPITALIZADA COM DOENÇA CRÔNICA

SER MADRE DE UN NIÑO INTERNADO CON ENFERMEDAD CRÓNICA

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ABSTRACT

This work is a phenomenological study whose objective was to understand mothers of children hospitalized with chronic illnesses. Access to subjects was performed at the Pediatric Nursing Unit in a university hospital in the countryside of the state of Sao Paulo, Brazil. Fourteen mothers in this situation were interviewed by answering the open question: "how is it to be the mother of a child with a chronic illness?" The mothers' answers were recorded and transcribed. The understanding of these discourses was performed by evaluating the mothers' descriptions of the given experiences according to the analysis of the specific phenomenon's structure. Being a mother of a child with a chronic illness involves multiple perspectives and understandings. From the mother's own introspection showing the changes resulting from the child's chronic illness to changes in family dynamics, the mothers traverse winding roads, at times more optimistically, at times powerless when facing the true reality of the disease.

Keywords: Children Hospitalized; Chronic Disease; Family Nursing; Mother-Child Relations; Qualitative Research.

RESUMO

Trata-se de um estudo fenomenológico cujo objetivo foi compreender mães de crianças hospitalizadas com doenças crônicas. O acesso aos sujeitos se deu no serviço de enfermagem pediátrica de um hospital universitário do interior do estado de São Paulo, com 14 mães que estavam vivenciando a experiência, por meio de entrevista aberta com a questão norteadora "como é ser mãe de uma criança com doença crônica". Os discursos foram gravados e transcritos. A compreensão destes se deu pela descrição das experiências de acordo com a análise da estrutura do fenômeno situado. Ser mãe de uma criança com doença crônica envolve múltiplos olhares e compreensões. Do olhar para si própria evidenciando as mudanças advindas da cronicidade da doença do filho às transformações na dinâmica familiar, as mães vão caminhando por sinuosas trilhas, ora com mais otimismo, ora mais impotentes diante da facticidade da doença.

Palavras-chave: Criança Hospitalizada; Doença Crônica; Enfermagem Familiar; Relações Mãe-Filho; Pesquisa Qualitativa.

RESUMEN

Se trata de un estudio fenomenológico llevado a cabo con el objeto de comprender a madres de niños internados con enfermedades crónicas. Se realizaron entrevistas a 14 madres en los servicios de enfermería pediátrica de un hospital universitario. Se les preguntó: "cómo es ser madre de un niño con enfermedad crónica". Los discursos fueron grabados y transcritos. La descripción de las experiencias permitió entender los discursos que se analizaron según la estructura del fenómeno situado. Ser madre de un niño con enfermedad crónica involucra múltiples perspectivas y comprensiones. Desde su propia perspectiva, la madre percibe los cambios causados por la enfermedad crónica de su hijo y las alteraciones en la dinámica familiar. Las madres caminan por senderos sinuosos, algunas veces con más optimismo, otras sintiéndose impotentes ante la realidad de la enfermedad.

Palabras clave: Niño Hospitalizado; Enfermedad Crónica; Enfermería de la Familia; Relaciones Madre-Hijo; Investigación Cualitativa.

INTRODUCTION

For children, the presence of their parents serves as a security blanket, since the process of hospitalization can generate feelings of fear and anxiety, considering that the hospital is seen as a strange place where painful experiences occur.¹

Reflecting on parents and children in situations of hospitalization, Law 8.069, which regulates the Child and Adolescent Statute (ECA in Portuguese), ratified in 1990, determines that "the healthcare establishments must offer conditions for the full-time hospital stay of one of the parents or guardians in cases of hospitalizations of children or adolescents".^{2,48}

The presence of family members during the period of hospitalization lessens the children's suffering, allowing them to maintain their emotional references, which is essential, given that this situation treats a human being in a period of growth and development, whose physical, mental, and social health conditions are directly related to the characteristics of the family and the community in which they live. Hospitalization, as it changes this daily routine, can bring about conflict and disturbances for all involved.¹

Considering the importance of the family for children, the inclusion of family members within children's healthcare requires the nurse to take on an attitude that is both open and attentive to the impacts that hospital experiences can unleash upon both the families and the children during the hospitalization process. Moreover, the nurse needs to understand the singularity of the family dynamics of each child.^{3,4}

Interaction between the family and healthcare professionals within the hospital environment has been a challenge, despite the fact that the latter recognize the difficulties that the families are facing, as well as the importance of the presence of the parents in the child's recovery and their right to stay with their child.

Acute childhood illnesses, though they do present significant complications, affect the family to a lesser degree, while chronic illnesses, which affect the functions of individuals in their daily routines for more than three months/year, can require hospitalization during one month per year or require the use of special adaptive devices and can definitively disrupt the family, either temporarily or in the future.⁵

Nevertheless, families do not always have adequate support to deal with these situations. They need help from healthcare professionals, especially as regards the needs for healthcare education and collaboration from other people within their community.⁶

The support received from the healthcare team and from other family members who make hospital visits is invaluable in the process of confronting these difficulties, allowing for the strengthening/construction of ties as well as the development of confidence in the healthcare team and in other people, an essential condition needed to overcome adversities.

In this sense, it can be perceived that the nurses play an important role in the lives of families with children who suffer from chronic illnesses through educational interventions, aimed at incrementing the knowledge and comprehension of the children and their family members regarding their illness, while at the same time offer psychosocial support.⁷

Considering the problematic issue of families with children who suffer from chronic illnesses – especially as regards the mother which, in the context of this study, is the most present companion – and the need for the mother's prolonged stay with the child, this study undertakes to understand the experiences of mothers of children hospitalized with chronic illnesses.

METHODOLOGY

METHOD

The present work consists of a qualitative study based on phenomenology as a school of thought – analysis of the specific phenomenon's structure. Phenomenological research is presented as a descriptive, strict, and concrete science which demonstrates and exemplifies concern about the essence of the experience.⁸

Thus, researchers do not begin from a specific problem, but rather conduct their research on the basis of the questioning of a phenomenon which is necessarily being lived by the subject. The search is for the essence of experiences that are free of prejudice, since the true meaning lies within the experience itself.^{9,10}

Through the subjects' experiences, that is, their discourses in response to a guiding question, the researcher organizes the units of meaning and, subsequently, the thematic categories, searching for similarities and differences among them.⁸

In this manner, the phenomenological research is pertinent to Nursing, as it seeks to comprehend the human being in its existential whole, since the answers are provided by people who lived the phenomenon in a given historical and culturally situated environment.¹¹

It is important to emphasize that the units of meaning are not clearly delineated within the subjects' answers, but rather appear through various readings and during the process in which the researcher establishes an empathetic relationship with the situation being lived by the subjects. These moments should be seen not as a sequence, but rather as constituents of the ideographic analysis, which refers to the individual analysis of the discourses.⁸

Thus, it is clear that the comprehension of the phenomenon – being a mother of a child hospitalized with a chronic illness – interconnects with the chosen methodological path.

The present study was carried out at the Pediatric Nursing Unit in a university hospital in the countryside of the state of São Paulo, Brazil.

The subjects of the study included 14 mothers who were living the experience, that is, mothers of children hospitalized with chronic illnesses.

The project was presented to the Board of Directors of the Pediatric Nursing Unit of the aforementioned hospital and later to the Research Ethics Committee of the College of Medical Sciences from Universidade Estadual de Campinas (UNICAMP), under protocol number 53/2010 – CAAE – 0043.0.146.000-10, and was approved at both levels.

The mothers were identified by analyzing the medical records of the child and were invited to participate, at which time they received all pertinent information regarding the study, signed a consent form, and received a copy of the signed form.

The phenomenological interviews were carried out in the healthcare unit itself, from May to July 2010, asking the guiding question: “how is it to be the mother of a child with a chronic illness?” The answers were recorded in digital audio and fully transcribed. Fictitious names have been adopted in the presentation of the discourses.

During the interviews, the mothers were listened to attentively, allowing them to speak freely, without being led to a specific theme. This option to avoid leading the subjects is based on the phenomenological reference, since the researchers do not consider the human being before them to be the object of the research, but rather a subject who possesses a world to be unveiled.¹² The interviews continued until the discourses provided information enough to reveal the phenomenon.^{9-10,12-13}

In an attempt to comprehend the mothers’ discourses, the following steps were taken:

- overall reading of the total content of the descriptions, from beginning to end, attempting to become familiar with that exposed by the mother, seeking to put themselves in the subject’s shoes in such a way that they are not mere spectators, but rather seek to understand the meanings attributed by the subject in the same manner in which the subject attributed them and, therefore, reveal an overall meaning;
- re-reading of the text, attentively, in such a way as to identify the significant affirmations (units of meaning);
- faced with these units of meaning, search for convergences and divergences in an attempt to learn the significance contained within them and, from these, unveil the phenomenon;
- advance to a descriptive synthesis, integrating the significant affirmations that express the meaning attributed by the subject.^{8,11,13}

RESULTS AND DISCUSSION

Being the mother of a child with a chronic illness involves multiple perspectives and understandings, looking inward and outward, looking to those who are nearby and to those who

are distant. Nevertheless, the present study opted to emphasize the perspective of the mother herself and how she behaves when living the experience of changes resulting from her child’s chronic illness. In this context, the maternal discourses allowed for the gathering of aspects that were grouped under a common theme surrounding the guiding question.

BEING A MOTHER OF A CHILD HOSPITALIZED WITH A CHRONIC ILLNESS

Upon introspection when facing the true reality of the child’s illness, mothers feel privileged; they feel they have been chosen by God to be the mother of their children.

[...] to me, being a mother is a privilege. With all the difficulties of not being able to take him home with me, with the problems that he has, which hurts, but we take care of him with such affection, with such love that for me it is a privilege to be by his side, there 24 hours. And he’s happy that I’m there. So I feel really happy and thank God because I’m firm and strong enough to take care of him [...] (Denise).

[...] I feel good today, as incredible as it may seem. It’s strange for people to hear that, but I feel good. That’s how I feel, happy about what God is doing, because, despite it all, we are well, and I feel privileged. It’s like the old saying: God gives us what we need. Since I am his mother, since I am able, you know like, to take care of him, for him to be well-cared for, well-fed, ‘cause there are a lot of restrictions (Marisa).

You know I feel good, I feel very happy to be Júlio’s mother, even though he has this problem, which is a serious problem. Because I think I was chosen by God (Elisa).

Although these discourses illustrate the manner in which the mothers confront their child’s illness and have even refused to give in to it, this behavior is related to the individual characteristics of each mother and to the perception that they possess of their child’s illness.¹⁴ The different answers can be influenced by their network of social support.¹⁵

In this scenario, it is important to recognize the needs of the professional nurse to give incentive to the importance of the mother accepting help from other family members or from social aid networks.^{3,4,16} What can be perceived is that some mothers feel guilty when they leave their children under the care of another person in the hospital other than herself. They do not allow themselves time for leisure or pleasure, not even

with their husbands, isolating themselves from their families. In the following discourse, Maristela demonstrates the importance of the social aid network.

So then, I think sometimes that I am "sort of" quiet because I was a person who whenever my family needed me I was always there, after I had Jonas, everybody found out about Jonas's problem, I had no help from anybody, no one came to see me, only his father. He has been here for seven months and nobody has shown any interest in coming to see him, to find out how he's doing [...] I would rather it be me, but then again, if it was me, who would take care of him? That's what I think, if my family doesn't support me on this, imagine if it was me? (Maristela)

Social aid depends on each mother, on her needs, and on who offers it and, together with the hospital, can promote maternal participation in her family and social life, though it may seem trivial for some mothers of sick children to perceive that the social aid offered is in fact insufficient, particularly when associated with illnesses that generate a high level of healthcare demands.^{15,17}

One study carried out with Chinese women, mothers of children with Cancer, showed that these mothers, when compared to the fathers, presented a high level of anxiety and sought out social aid. The sources of social aid cited in the study included partners, family, friends, maids, hospital teams, and other parents who had experienced the same situation.¹⁸ The aid received from another mother came up in Maristela's discourse:

I only had help from one person, and even so, a person that I met only seven months ago, which was Alice [referring to the other mother], a person that I didn't even know, that I never even dreamed of meeting, the only one that gives me support. I became friends with Alice, when I need her help, she gives it to me, anything whenever I need her, she helps me. She left, but she always came here to see me, she used to bring her daughter for me to see, she would call to know how Jonas was, she would come by to see him. Almost every single day, today I see her as a sister to me (Maristela).

Although it is well-known that the child's chronic illness and the hospitalization can cause negative feelings in the mother, some of them develop their own mechanisms to deal with the problem.

[...] I live calmly, I don't get like freaked out, or keep thinking about it too much, I try not to keep thinking about the disease itself, because sometimes if you think about it, it gets worse, because you can't do anything about it; we as mothers, we can only take care of them (Marisa).

[...] so it's that thing we say, he got out of here, he left the hospital. When you return, you go through the entrance door, you know that you are in another environment. Then you suffer less. Because I learned this, I used to take everything with me. I never relaxed. Then I said: man, I gotta stop. Because if I go there [refers to her returning home], I am going to relax, why should I take the whole hospital on my back? So I left this side behind, I learned to live another way. So for me that helped a lot. I never needed a psychologist, I never needed any help at all. So for me this is really good! But there are mothers who want to take everything with them, and they suffer a lot (Denise).

Strategies of how to face a situation are one group of strategies used by people to adapt to adverse or stressful circumstances and are aimed at maintaining one's well-being, seeking to lessen the effects of stressful situations.¹⁹

Gislene uses another means through which to lighten the lived reality – the comparison. She compares her child's illness to that of other children with chronic illnesses, and as her child's is not degenerative, she understands the problem as being acceptable: "my problem is, at least compared to the other mothers, a lot smaller, a lot smaller. But that's OK, everyone has their cross to carry" (Gislene).

Recent national studies about children with chronic illnesses cite the following illnesses: portal hypertension and esophageal varices, Cancer, nephrotic syndrome, sickle-cell anemia, neurofibromatosis, HIV, asthma, among others.²⁰⁻²³ These, sooner or later, will cause some form of limitation in the child's life. On this path, the mother lives her child's suffering caused by the evolution of the disease.

So, I mean, at first I thought it would be easy, even though we did not understand the disease well, he was fine, when he began the treatment, he got a little better. But a little later, uh, in the sixth month of the beginning of the treatment, when he began to take immunoglobulin, he began to show again what he had shown before and even worse things that, actually, he'd caught a CMV [referring to a cytomegalovirus] and he lost his vision, he stopped walking, he stopped moving, so at this stage, you know, it was much harder for me. And it was at this stage that I really began to understand the disease; that I saw that it was really not easy and that it is a thing that we will have to take care of for the rest of his life, you know? (Marisa).

[...] it's not easy either. Because here you see her getting shots all the time. Because the kids, all of them, have bad veins, and they keep getting shots, they stay in the air, in bubbles, on oxygen, there's a ton of medicine, cor-

ticosteroids, they gain so much weight, it's all so difficult. They have to fast when they are tired, then you see the child without eating anything and whatnot, it's complicated, everything you did, this huge job to get him to be able to gain a little weight, then they have to fast, but because they're so tired, they lose weight (Regina).

It's just that it's hard for a mother to see her child this way (Selma).

Children with chronic illnesses, due to the needs that the disease imposes, are commonly hospitalized for long periods of time. It is common for the mother to spend more time in the hospital than at home, and this daily routine can affect the other family members.²⁴

Studies have shown that one of the significant changes is referent to the attention that the mother dedicates to her other children. The brothers and sisters are taken care of by other family members, since the feeling of maternal care is greater and stronger for the ill child. Although the present study's and other authors agree with this difficulty,^{24,25} one of the mothers who participated in this study presented a different behavior toward her ill child: "nothing of the 'poor little thing' just because she's sick, no. For me, she's a normal child, without, without opening any exceptions for her over the other. No child is better than the other. I'm really a *mãe coruja*" (Rosa).

The changes in the daily routine of the family of a child with a chronic illness is not restricted only to the other children. Other essential questions also arise, such as financial responsibilities.

In a study carried out with families of children with rheumatoid arthritis, the financial changes in the family budget are commonly cited as a parental concern, which interferes in the quality of the healthcare provided to the child.²⁶

The frequent hospitalizations of the child can also cause the parent to lose his or her job, although some parents decide to quit their jobs to be able to dedicate themselves exclusively to the healthcare and treatment of their child.^{27,28}

As amazing as it may seem to talk about the situation today, our financial situation is not so bad, that I made the triple of what I pay for Lucas's room today, my husband made double, but today we make only 40% of what we used to make, and we live well with the money, our expenses are covered by the government (Marisa).

It is uncommon for mothers of children with chronic illnesses to be in the working market today. Marta is an exception to the rule, although she needs to make a few arrangements to work and take care of her child at the same time: "I also work, I work near home, but I'm always calling, I go home to give him his medicine" (Marta).

Thus, by making a few adjustments and, at times, living stressful moments that trigger a number of fears, the mothers try to understand the problem that involves having a child with a chronic illness, and they do it by approaching the disease as a lesson of life.

[...] I've learned here, because I hadn't learned this out there, I learned it here. Because I didn't accept it either, I didn't understand, I never knew what it was like to stay in a hospital more than weeks at a time. And now I see that this taught me a lot. To change the way that we think, the way that we live, to understand. That's the way it is, it has to be like that. [...] I learned to make friendships, to get to know everybody, a problem for one is a problem for us all, it's "bigger", so you learn to deal with it. And I learned a lot here! I hope to learn even more. I know that there is still a lot to come for us to learn (Denise).

I think that her will to live overcomes everything [...] Hard! Hard because she's a twin. I have to bend over backwards to take care of them both, you know? And at the same time it's great, you know? That I end up learning so many things with them, you know? (Lurdes).

I think that everything in life we take as an example and take advantage of it. So if we are going through this, we have to take something good from it. If it's changing our behavior, our way of thinking, if it's changing the way to be with other people, you understand? It's changing our lives, because in reality it changes life, changes family, changes everything. [...] So I get sad because we don't want this, but I think it was necessary. It's something bad that was necessary for us to make a change in life, I hope that this changes now, that with this transplant we can go home and continue with the same feelings at heart, feelings about the family, of solidarity with others, because we, when we don't have any problems, we couldn't care less about others; it's when we have a problem that we think about the other people's reality too, we don't only think about ourselves. So we totally change our concept of life (Marisa).

From the maternal discourses, even if the chronicity involves the mother and the other family members in a significant problem – the birth of a child – the feeling of becoming the mother of a child with a chronic illness emerges as something positive.

In this conjuncture, the mothers, some supported by others, some confronting the problem alone, 'live' ways of dealing with their child's chronic illness, ways that allow them to traverse this difficult journey.

FINAL CONSIDERATIONS

Upon entering the world of childhood chronic illnesses, through maternal discourses, it could be observed that the mother of a child who suffers from a chronic illness is affected both by the illness and by the hospitalization, and their reactions can be quite diverse.

From the feeling of privilege of being the mother of a special child to confronting the problem through their own mechanisms, from the distancing of themselves from their homes and other family members to the importance of social aid, from the observation of the suffering of the child to the changes in the family dynamics, the mother traverses winding roads, sometimes optimistically, sometimes powerless when faced with the true reality of the disease.

It is important to note that the scenario of this study offers social aid only from the governmental social services as regards certain financial needs – bus fare, guidance regarding governmental requirements for necessary provisions to keep the children at home. There are no mental healthcare services for the mothers and the children; there are no support groups in which stories from other mothers can serve as encouragement and hope. Even so, the mothers find support, even if informally, in some professionals within the healthcare team – educators, occupational therapists, and physical therapists.

Building this research opened the door to a new perspective of the importance of the role of the nurse as a professional and as a human being. In addition, being with the mothers, listening to them, illustrated the dimension of maternal love and the courage with which they take on this journey alongside their children.

This kind of study answers some questions, but also unveils others. How can these mothers deal with the possibility of the death of their children? What is the role of the father during this journey through their child's chronic illness? Could the social aid reported by some mothers as being essential have come from the nursing team? These and other questions should provide the impetus for future studies.

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