

Experiences of family members of children with cystic fibrosis under the light of Callista Roy

Vivências de familiares de crianças com fibrose cística à luz de Callista Roy
Experiencias de familiares de niños con fibrosis cística a la luz de Callista Roy

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ABSTRACT

Objective: To know the experiences of family members of children with cystic fibrosis under the light of the theory of Callista Roy. **Method:** Qualitative research that used the adaptation theoretical framework of Callista Roy for inductive content analysis. Fifteen family members, in a university hospital, between 23 and 63 years old, participated in the study, from September to October 2018. **Results:** Two categories were elaborated: "Evaluation of stimuli" and "Evaluation of behaviors". The first has three subcategories: "focal", "contextual" and "residual". And the second, four subcategories: "physiological domain", "self-concept", "role function" and "interdependence". **Final Considerations:** During the evaluation of stimuli, work overload and stress were identified as focal stimuli. Regarding contextual stimuli, it was noticed that the social life of caregivers was prejudiced. As for residual stimuli, the fear of loss is constant, and it appears that the emotional aspect of family members is the most affected comparing with physical exhaustion. **Descriptors:** Family; Cystic Fibrosis; Pediatric Nursing; Nursing; Nursing Theory.

RESUMO

Objetivo: Conhecer as vivências de familiares de crianças com fibrose cística à luz da teoria de Callista Roy. **Método:** Pesquisa qualitativa que utilizou o referencial teórico de adaptação de Callista Roy e análise de conteúdo indutiva. Participaram do estudo 15 familiares entre 23 a 63 anos, em um hospital universitário, no período de setembro a outubro de 2018. **Resultados:** Elaboraram-se duas categorias: "Avaliação de estímulos" e "Avaliação de comportamentos". A primeira gerou três subcategorias: "focal", "contextual" e "residual". E a segunda, quatro subcategorias: "modo fisiológico", "autoconceito", "função do papel" e "interdependência". **Considerações Finais:** Durante a avaliação de estímulos, foram identificados como estímulos focais a sobrecarga de trabalho e estresse. No tocante aos estímulos contextuais, percebeu-se que a vida social dos cuidadores foi prejudicada. Já quanto aos estímulos residuais, o medo da perda é constante, e infere-se que a parte emocional dos familiares é a mais afetada em comparação ao desgaste físico.

Descritores: Família; Fibrose Cística; Enfermagem Pediátrica; Enfermagem; Teoria de Enfermagem.

RESUMEN

Objetivo: Conocer las experiencias de familiares de niños con *fibrosis* cística a la luz de la teoría de Callista Roy. **Método:** Investigación cualitativa que ha utilizado el referencial teórico de adaptación de Callista Roy y análisis de contenido inductivo. Participaron del estudio 15 familiares entre 23 a 63 años, en un hospital universitario, en el período de septiembre a octubre de 2018. **Resultados:** Se ha elaborado dos categorías: "Evaluación de estímulos" y "Evaluación de comportamientos". La primera generó tres subcategorias: "focal", "contextual" y "residual". Y la segunda, cuatro subcategorias: "modo fisiológico", "autoconcepto", "función del papel" y "interdependencia". **Conclusiones:** Durante la evaluación de estímulos, han sido identificados como estímulos focales la sobrecarga de trabajo y estrés. En el tocante a los estímulos contextuales, se ha percibido que la vida social de los cuidadores ha sido perjudicada. Ya cuanto a los estímulos residuales, el miedo de la pérdida ha sido constante, y se infiere que la parte emocional de los familiares es la más afectada en comparación al desgaste físico.

Descriptor: Familia; Fibrosis Cística; Enfermería Pediátrica; Enfermería; Teoría de Enfermería.

INTRODUCTION

Families are considered to be networks of supportive and protective bonds and are characterized as a group of people with or without any blood ties, experiencing different cycles. The core family has specific functions, and the influence among its components comprises psychological and social dimensions, which involve the learning of health behaviors⁽¹⁾.

In families, one of the several health-disease situations that stand out is the diagnosis of a chronic illnesses in children, since these disorders can have biological, psychological, and cognitive nuances. The Brazilian reality shows the growth of chronic diseases in this age group, reaching a rate of 9.3% between individuals aged 0 to 14 years. Its minimum duration is one year and they produce social, physical, cognitive / emotional consequences, requiring special multidisciplinary care⁽²⁾.

Generally, family caregivers of children with chronic illnesses show fatigue due to the number of activities performed and time spent on care, in addition to exhaustion for accompanying the child in their fight for life⁽³⁾. It generates communication difficulties between those involved in the care during the treatment of this pathology, specially because of the child's distress and / or age; thus, some parents do not explain to their children the pathology that affects them and even omit information from them. Therefore, the pediatric nurse, working in direct care, has a fundamental role regarding these subjects⁽⁴⁾.

Cystic fibrosis (CF) or mucoviscidosis is a part of this context, since it is a serious hereditary disease determined by an autosomal recessive inheritance pattern, affecting the lungs and pancreas in an obstructive process caused by the increase in the fluid viscosity of the lungs and digestive tract. In the lungs, this increase in viscosity blocks the airways and promotes bacterial proliferation (especially *Pseudomonas* and *Staphylococci*), which leads to chronic infection, lung injury and death due to respiratory dysfunction. In the pancreas, when the ducts are blocked by thick secretion, there is loss of digestive enzymes, leading to malnutrition⁽⁵⁾.

In Brazil, it is estimated that the incidence of CF is 1:7576 live births, but there are regional differences with higher values in the southern region⁽⁶⁾. CF is detectable even in neonatal screening, in the pre-symptomatic stage in all live births, being one of the main chronic lung diseases of childhood. It is estimated that around 70.000 people live with CF worldwide, and in Brazil, data from the Brazilian Registry of CF points to more than 4.000 patients. This number may be higher, as there are still people without a diagnosis⁽⁷⁾.

This condition has an extremely high mortality rate. However, in recent years, the prognosis has improved, with rates of 75% survival until the end of adolescence, and 50% until the third decade of life. Previous studies have shown that only 10% of patients exceed 30 years of age⁽⁵⁾.

Since FC generates significant changes in the adaptation of those involved, Callista Roy's adaptation theory was chosen. This theory sees the person as an adaptive and holistic system and includes the notion of stimuli that interact with people and trigger responses. Due to the need to respond to stimuli, coping mechanisms are activated. The behaviors resulting from these

subsystems are observed from four adaptive domains, namely: physiological, self-concept, role function / performance and interdependence domain⁽⁸⁾.

Theoretical models have contributed for nursing care practice when used as a reference for the organization and systematization of care. With the advancement of nursing science, it was necessary to create a specific, scientific, and systematic method for performing tasks⁽⁹⁾. The Nursing Care Systematization (SAE) is regulated in Brazil as a method that organizes such tasks, enabling the implementation of the Nursing Process (NP), a methodological instrument that guides professional care. This method is organized in five interrelated stages: collection of data, diagnosis, planning, implementation, and evaluation⁽¹⁰⁾.

OBJECTIVE

To know the experiences of family members of children with cystic fibrosis under the light of Callista Roy's theory.

METHOD

Ethical aspects

This study was approved by the Research Ethics Committee of the Universidade Federal do Pará and the João de Barros Barreto University Hospital. The relatives of children with CF were approached personally, received information about the research and its objectives, and were formally invited to participate. The Informed Consent Form (TCLE) was read and signed by all participants before the beginning of each individual interview.

Theoretical framework

With strong inspiration from the behavioral, sociological, and biomedical sciences, Callista Roy believes that the theory of adaptation provides a framework for the union of knowledge between nursing and society. She considers that the improvement of knowledge is essential for the survival of the profession and for innovations in care in the face of increasingly common chronic conditions⁽¹¹⁾. When it comes to the family, the adaptation theory looks for sources of stress and help to meet basic needs. It effectively guides the maintenance of both the self-concept of individuals and family identities before society. The theory is also able to offer an analysis of the stressful effects of the epidemiological transition on individuals and families.

The stimulus is understood as everything that triggers a response, the focus of interaction between the human system and the environment. It originates from the external environment (external stimulus) or the internal environment (internal stimulus). Roy's theory determines three types of stimuli that form the person's environment: focal, contextual, and residual. The focal stimulus is the internal or external stimulus that confronts the person the most, it is the object or event that attracts the most attention. The contextual stimulus refers to the environment and society. Residual stimuli are factors that have effects in current situations and are not central. The person may not be aware of the influence of these factors, but they will always affect current

behaviors⁽¹²⁾. In the end, nursing diagnoses and interventions are designed based on the behaviors and stressors found.

Study design

Qualitative study with theoretical support from Callista Roy's adaptation theory.

Study setting

The initial setting for the selection of participants was the Outpatient Clinic of the Cystic Fibrosis Care Program, located at the João de Barros Barreto University Hospital, which has eight doctor's offices, *Hospital Dia* (Day Hospital), a physical therapy and sweat collection room, and reception. The assistance program has a multidisciplinary team formed by nurses, pulmonologists and pediatricians, biomedical doctors, pharmacists, nutritionists, psychologists, physical therapists, and social workers. It aims to diagnose and assist people with CF of any age group. At the moment, in the state of Pará, 200 patients are registered with the disease, and the João de Barros Barreto University Hospital has become the only reference hospital for treatment in public and private assistance.

Data collection

The research team followed the steps of the Consolidated Criteria for Reporting Qualitative Research (COREQ)⁽¹³⁾, based on reflexivity, study design, choice of theoretical frameworks, and collection and analysis procedures, with no software used. The participants were approached at the outpatient clinic of the Cystic Fibrosis Care Program, at a university hospital, during nursing consultations. The research sample was not probabilistic⁽¹⁴⁾, so the selection criteria were: being parents or guardians of children diagnosed with CF, of both sexes, and being willing to answer the instrument in full.

A collection protocol was used to evaluate stimuli and behaviors, as well as to direct statements for each type of stimulus/behavior according to adaptive modes: physiological, self-concept, role function, and interdependence. In the physiological domain, the guiding statement was: "Tell me about your health after starting the child's treatment". After that, there was a question about self-concept: "How do you see yourself after the hospitalization? How have you cared for yourself?" In terms of role function, social life was assessed through the question "Have you received social support?" Regarding interdependence, the participant was asked: "What are the feelings that represent this moment? Talk about the changes that occurred in the period of illness and hospitalization". After this stage, focal, contextual, and residual stimuli were investigated. In the focal stimulus, the orientation was based on the following statements: "Talk about your first impressions regarding the child's illness, feelings experienced during this period, from diagnosis to the present moment. What are your expectations about the child's recovery?" For contextual the stimulus, the following questions were asked: "How is your family structured? Do you know about the child's illness? What are the main changes that have occurred in your daily life and

in your family environment?" Regarding residual stimulus, it was asked: "What are your past experiences with hospitalization? Have you had another experience with a child with cystic fibrosis up close?" The instrument included sociodemographic variables to characterize the participants.

The interviews were scheduled according to the date and time availability of each interviewee. An empathetic posture was prepared in order to allow the interviews to occur naturally; on average the interviews lasted 20 minutes, were recorded in audio and converted into an MP3 file. The collection lasted from August to September 2018.

The number of interviews was not established before the research began. The statements were obtained until saturation occurred and the content was found to be sufficient to allow an in-depth, comprehensive, and diverse understanding of the process of adaptation, in accordance with what is recommended for qualitative research⁽¹⁵⁾. Fifteen interviews were carried out and all of them were considered for analysis.

Data organization and analysis

Regarding the data, a six-step inductive analysis⁽¹⁶⁾ was carried out and coded under the light of the scientific evidence on Callista Roy's Adaptation Model. The first readings were after obtaining the corpus of analysis, seeking to understand the interviews as a whole, in order to apprehend the global meaning of the experiences of the participants. Sequentially, in a second step, new readings were made in order to find interrelated subthemes. They were highlighted and grouped by similarities to compose categories by thematic approximation, considering Roy's theory. In order to guarantee anonymity, the transcripts were identified by the letter F (for "family caregiver") followed by the Arabic number corresponding to the order of the interviews: from F1 to F15.

RESULTS

Fourteen women and 1 man participated, with an average age of 42 years. Regarding education, 4 had completed/incomplete college education; 2, complete high school; 3, incomplete high school; and 6, complete/incomplete elementary school. The categories found were: "Evaluation of stimuli", with the subcategories "focal stimulus", "contextual stimulus", and "residual stimulus". The other category found was "Behavioral assessment", which had the subcategories "physiological domain", "self-concept", "role function", and "interdependence". The Callista Roy Adaptation Model brings three types of stimuli that form the person's environment: focal, contextual, and residual stimuli — constantly and simultaneously felt.

Category 1: Evaluation of stimuli

Focal stimulus

Focal stimuli are internal or external stimuli that immediately confront the person. Some parents, due to the lack of knowledge about CF, reach an extreme stage of stress, loneliness, preoccupation, depression, or fear for their child's death.

I was like this, I almost went into a depression, I will not lie to you, you know ... I almost became depressed, I just wanted to cry, cry, I left here crying with him. I only heard the Dr. saying "your son has a problem and there is no cure, there is only a treatment". You know? I just kept crying. (F3)

... the professionals, they do their part, but there's no way, we can't feel alone ... I was here a lot, I cried a lot ... I wore myself a lot, I spent nights awake. (F6)

... When the doctor told me that his life estimate would be five years, I despaired, at the same time she explained to me, and I had never heard of cystic fibrosis, so for me the impact was very strong... (F12)

We immediately think about death, right? They say they will live to be 20, that's all we think about ... I just cried, cried a lot ... (F10)

Analyzed as a focal stimulus, a routine of hygiene and extra care with the child's belongings and food is urgent, adapting the routine and increasing the overload of home care work and abandoning the formal work of caregivers.

... when I had him ... I helped my relatives making flour, when I found out when he was 3 years old, everything changed, I couldn't work anymore, only help at home. (F4)

My house was closed, I lost a lot inside the house due to the house being closed and my life when I came back, I had to readjust to everything again, mainly because of him and then over time, after about 2 years that I started to normalize my life due to the trauma I had, because the whole time was for him, to take care of him ... (F6)

We started to be more careful with her. With her food, her room always has to be tidy, clean, the clothes have been changed, with the medication too. (F9)

For these caregivers to relieve the emotional distress caused by the impact of the disease, they use spiritual support, the religious faith in God, to increase hope.

Yes... We are, I am optimistic, because in recovery we see that he is improving ... and despite the difficulties, always that great care ... that faith that he will be fine. (F2)

I asked God for a lot of strength because you carry a child nine months in your belly, but you never expect him to be born with such a problem, right? (F15)

... I asked God, I just said "God I want my son to grow up soon because I'm tired of seeing his suffering", because when he is small, the organism is still weak, right? So I asked a lot. (F15)

Contextual stimulus

Contextual stimuli are all the other stimuli that contribute to the effect of the focal stimulus, that is, all internal or external environmental factors that present themselves to the person, which can influence the way they react to focal stimuli. For caregivers, it is difficult to maintain an active social life, first due to the care for the child and, secondly, because they feel misunderstood by

some people regarding the specificities of the care provided to the affected person. Feeling apart from society contributes to the likely isolation of children, who stop having fun and playing.

She is always tired, she needs to eat, rest, she has to have a whole routine, so she cannot receive people at home... she cannot go to where everyone is drinking or smoking, with the barbecue on and the whole house full of smoke. There has to be a right time to eat, to sleep, to take medicine, a right time to do everything. (F5)

There was a family fight. Because he knew the kid couldn't be close to smoke, but even so he didn't change anything, he kept smoking... It only got worse, nothing changed. (F15)

The beach, like, there are times when I can't go because of him, I think it was on the last vacation that we planned to go to the beach and there was an exam result and I was afraid to take him to the beach and see him getting worse. We canceled the trip because of that. (F6)

We are fine as far as possible, but life has changed a lot, it's not the same, it's completely changed, there's no more social life, there's no family anymore. (F5)

Children present themselves as fragile and with reduced immunity. The home environment must be protected from humidity, dust, and excess objects that can accumulate dust, and the medication should be administered at the exactly the right time. Thus, it is necessary for the nurse, during the nursing consultation, to reiterate these guidelines to those responsible for the care.

Be careful with the bed sheets, her room is not to be swept, it is to be clean with a cloth. I'm more careful with her than the others, I don't let her drink anything cold at any time. Everything is room temperature for her, the juice is... I don't give her anything different. (F9)

Look, the expectation is that she will be fine, this is what we want, because she wants to play, she wants to run, to bathe in the igarapé [river], but then I worry about the things that have already happened ... being in the water, she can't, soon she gets the flu and coughs and then there is a fever ... Then it gets complicated. (F9)

It is important that the professional advises on the causes of CF and the importance of adhering to treatment, dealing with the unpreparedness of the caregiver.

The impression I had, from what I heard about the disease, would be that as much as we have faith, they would not survive the disease, because it was a very serious condition, they are very tired all the time. (F2)

So, it was very impactful, because I had no information about ... This disease, the disease that I usually imagined was cancer, then the doctor said "this is not about it, and this is what he was born with, this pathology, it will depend on you, the treatment, the care ", then I began to understand even more, you know ... (F14)

Residual stimulus

Residual stimuli are internal or external environmental factors, whose effects on the situation are not clear enough to be evaluated.

Fear for the loss of the child was shown, as the past experiences of death from CF remained present at some point in life.]

I met a girl here that she came from Marabá, and we did the treatment together and I took her to my house, so she could stay with the baby, but the baby just couldn't resist, her kidney started to stop. (F3)

I am part of the association, so we have to be there supporting the family. Every time I went, it messed me up a lot. We keep thinking "yeah, it could be that one day I'm going through this", so we end up taking that situation for our lives, looking around and asking to not experience a moment like this so soon ... There's no way it doesn't mess with us ... We get scared, right ... The fear of going through that situation. (F12)

I saw a child there, that's when it hit me the most. I saw a child who had fibrosis you know ... he was taking oxygen all the time, swollen ... I was desperate wherever I saw that child. And I thought about my son right away, you know? That child even died, my God! I don't even like to remember. (F15)

Category 2: Behavior assessment

Physiological domain

It is worth mentioning that the changes that occurred in the family due to the treatment lead to preoccupation, anxiety, self-neglect. This generates an increase in blood pressure, overweight, weight loss, insomnia, and even depressive symptoms.

I have a blood pressure problem, then because they get into this situation, the fatigue, we have to be in that rush, the situation of my pressure got a bit worse, due to the concerns, it changed a little. (F2)

Right at the beginning, I was in shock, I was a little bit depressed, but I'm discovering, adapting, we forget about ourselves to take care of him ... Right at the beginning, when I found out, I didn't know what to do. (F3)

I got a little overweight after I adapted to the disease. (F3)

I was always a little negligent about my health ... I gained more weight, I had a cholesterol problem, triglycerides now, I haven't developed high blood pressure yet, but I have a problem with overweight now. (F5)

I lost weight, that emotional shock, after he stabilized, then my health became normal. A bad sleep, not peaceful, but only initially, because then it normalized. (F13)

Self-concept

It is explicitly affected in a negative way. Interviewees lost interest in taking care of themselves. They forget about their own lives, vanities, health, and live exclusively for the child.

Sis, I don't even have time to take care of myself, because of him. But it's for him, my time is more for him than for me. (F1)

I have to have time too, in addition to helping their mother, I also have to have time to go to the doctor and for me too, to take care of my spine. (F2)

So let's say that my vanity, buying perfume, moisturizer, going to a doctor, my priorities have completely changed. (F5)

I'm taking care of myself normally ... Ah, now, my health, now it has become difficult, when I see that the consultation is for me and the trip is scheduled ... It's difficult. (F11)

I haven't been to the doctor for a long time, it's more lack of interest, because you can walk, you can spend an afternoon there, put on a sneaker and walk, so it's more lack of interest. (F12)

Role function

In this context, the family is the only social institution that is a source of emotional and financial support; the other spheres seen as parts of the social role are totally compromised: jobs, academic activities, and even friendships and love interests.

It's kind of ... I don't even know ... a little low, right, because I can't, because I almost don't have time, right? For fun, to go out. (F2)

I do, from my sisters I have support, from my family, when I can't be there, they are with me all the time, I have support from his father ... I have support. (F3)

So I gave up friends, work, studying, so I could be able to keep up. (F5)

So it is possible to do it inside our house and not in the house of others, so you end up walking away, because this is not to be done once a week, it is every day. "It's very annoying this thing with your daughter", it is difficult to say that they understand, I think they accept and accepting it is different than understanding it. (F5)

I can't have a love life. (F5)

Interdependence

Feelings are narrated and described as sadness, anguish, anger, and burnout. These emotions are understandable, since it is known that it is difficult to deal with the routine that the treatment requires, especially with the lack of expectations of improvement.

Of sadness ... because this is a disease that has no cure, only treatment. (F1)

For me it's sad, especially when it happens to be two children. (F3)

Sadness. When I found out, they said he wasn't going to get to be a teenager. (F11)

I'm already used to it, I think it's normal ... To say that I have anguish or something, no, I think that it happens even to the best of families. (F7)

I didn't want him, you know, I was angry, very angry, I didn't want him with me, when he came I already knew he had Down syndrome and he came to me with pneumonia, with injuries on his body, 1 month old. I didn't want him, because I knew he was going to give me trouble, because I already took care of others, I raised other people's children, but they were not as much of a problem as this one, but now it's here. (F14)

Once he was admitted here at Barros Barreto last year and I spent about 10 days directly with him, it was very exhausting, it was just me here. (F15)

After the analysis of the statements, it was possible to create a chart (Chart 1) with nursing diagnoses and interventions, completing a stage recommended by Callista Roy.

Chart 1 - Nursing diagnoses and interventions for family caregivers of children with cystic fibrosis

NURSING DIAGNOSES	NURSING INTERVENTIONS
Physiological domain	
<ul style="list-style-type: none"> Anxiety characterized by concerns about changing life events related to stressors Insomnia characterized by difficulty in maintaining sleep and non-restorative sleep patterns related to anxiety and stressors 	<ul style="list-style-type: none"> Recommend a psychologist Offer emotional support to the family of the caregiver Maintain an environment with minimum noise when sleeping
<ul style="list-style-type: none"> Impaired resilience characterized by depression linked to insufficient social support and multiple coexisting adverse situations Self-neglect related to lack of adherence to health activities due to stressors 	<ul style="list-style-type: none"> Talking with family and friends about the stressful situation and ask for help in childcare Request social worker if necessary Set aside time for self-care Refer to occupational therapist
<ul style="list-style-type: none"> Obesity characterized by body mass index > 30kg / m² and overweight characterized by BMI > 25kg / m², related to disorganized eating behaviors 	<ul style="list-style-type: none"> Orientate the search for a nutritionist Eat meals in small quantities slowly Increase water intake and consumption of fruits and vegetables with restricted carbohydrates and sugars intake
<ul style="list-style-type: none"> Imbalanced nutrition: less than body needs, characterized by insufficient interest in food related to insufficient food intake 	<ul style="list-style-type: none"> Direct the search for a nutritionist Increase the nutritional quality of food eaten
<ul style="list-style-type: none"> Fatigue characterized by tiredness related to stressors 	<ul style="list-style-type: none"> Advise to rest for at least eight hours a night Advise on how to eat healthily
Self-concept	
<ul style="list-style-type: none"> Risk-prone health behavior characterized by a lack of preventive action on health problems associated with insufficient social support Ineffective health maintenance characterized by insufficient social support related to ineffective coping strategies 	<ul style="list-style-type: none"> Advise the primary caregiver to ask for help from other people in their social network to provide care for the child
<ul style="list-style-type: none"> Sedentary lifestyle characterized by average daily physical activity below the recommended for age and sex, related to lack of interest and insufficient motivation 	<ul style="list-style-type: none"> Advise on the importance of physical activity Advise to go on walks at least three times a week
Role function	
<ul style="list-style-type: none"> Impaired social interaction characterized by dysfunctional interaction with other people, related to the communication barrier 	<ul style="list-style-type: none"> Encourage the strengthening of the social network through physical or virtual means

To be continued

Chart 1 (concluded)

NURSING DIAGNOSES	NURSING INTERVENTIONS
Role function	
<ul style="list-style-type: none"> Risk of tension in the role of the caregiver related to insufficient recreation 	<ul style="list-style-type: none"> Maintain leisure activities together with the child Search other forms of leisure
Interdependence	
<ul style="list-style-type: none"> Chronic sadness characterized by a sensation that interferes with well-being, associated with the crisis in controlling the disease Feelings of helplessness characterized by a sense of insufficient control, related to the role of caregiver 	<ul style="list-style-type: none"> Offer emotional support to the caregiver
<ul style="list-style-type: none"> Tension in the role of the caregiver, characterized by the lack of time to meet personal needs related to the change in the nature of care activities 	<ul style="list-style-type: none"> Advise the caregiver to divide the time between him and for the child, and, when that is not possible, to seek help from an occupational therapist

Source: Elaborated from the NANDA taxonomy⁽¹⁷⁾.

It is inferred that nursing diagnoses aimed at the caregiver are mostly in the physiological domain; with these interventions, it will be possible for the nurse to guide the family caregiver in a more targeted way, according to their personal needs and to achieve adaptation.

DISCUSSION

Family caregivers try to adapt to the new condition of life they will face, seeking strategies according to the complexity of each case. This process happens slowly, as it is not an easy task to perceive the child's new perspective on life⁽¹⁸⁾. Thus, the physiological domain concentrated most of the diagnoses related to the nurse's support, guidance, and collaborative diagnoses with the multidisciplinary team, especially when taking into account the stress and anxiety burden of caregivers, which inadvertently became self-neglect. The health status generates tension in the family because of the uncertainties of the outcome, the need to assume care, and inadequate information from the health team⁽¹⁹⁾.

It is known that the task of caring for someone does not directly lead to symptoms of depression, health problems, or social isolation for the caregiver. An alternative to the desired rest and psycho-emotional health care would be the help of family members to take turns in healthcare tasks, and the training of the health team on how to deal with specific aspects of the pathology and the degree of dependence of the patient⁽²⁰⁾.

From what has been identified, the self-concept is strongly affected, with a lack of health behaviors in the sense of preventive action as well as ineffective health maintenance and sedentary lifestyle. Family caregivers have difficulties managing their own time and a higher risk of developing disorders of physical health and psychological well-being, in addition to suffering anguish, expectations, and feeling pressured as they see their child as a dependent person. In general, mothers spend more time with their children and are primarily responsible for care activities, which, when exercised for a long time, become a continuous source of stress⁽²¹⁾.

Financial overload is a factor that generates stress and physical exhaustion. The role function is affected not only for the caregiver,

but for the whole family, since the caregivers usually have problems with the job when abandoning or reducing the work load, leaving early or even dedicating themselves exclusively to care activities⁽³⁾. The risk for tension related to the role function is increased, and the social interaction itself is impaired, since society considers work as something that gives meaning to life in many cases, and the tasks of care are not valued as such according to the interviewees. Consequently, loneliness and isolation express the person's dissatisfaction with these social contacts, who do not understand the conceptual universe and tasks regarding the care of a person with CF. This circumstance results from the discrepancy between what is expected from a supportive social relationship and reality⁽²²⁾.

Regarding the caregiver's interdependence, chronic sadness, feelings of helplessness and role function tensions are other diagnoses that are easily listed. The imminence of the death of the child is connected with the symbolism of: death of the plans, dreams and projects for that child. This situation generates an overprotection from the parents or, paradoxically, an impulse to emotionally withdraw from the child⁽²³⁾.

Resources used by the participants, and that, according to Roy, are adaptive processes in the form of behaviors, are: faith, spirituality, and religious practices. These resources are effective ways of coping with overload, stress and depression. In addition, the acceptance of spirituality, religion, and beliefs in a superior being, not only help minimizing difficulties, but also give meaning to life and to the dependence^(8,24).

As it was shown, death, despite being a natural event, continues to be seen with fear. For them, it is a lonely, mechanical, and inhuman event. Death is considered as a residual stimulus for caregivers, since they experience it in other children, so that they end up reverberating fear and anguish to themselves unconsciously, affecting current behaviors⁽⁸⁾. As a result, the knowledge of the health team about the possible manifestations is of great importance to optimize patient and family care. The team can understand the reactions presented and intervene according to the needs and demands of the individual at each stage of the illness⁽²⁵⁾.

The nurse must pay special attention to pulmonary symptoms and needs to advise the patient or family member about the risk factors associated with respiratory infections, in order to avoid or reduce complications. Teaching about signs and symptoms of the disease regarding the respiratory and gastrointestinal tracts, as well as stimulating the need for adequate water and nutritional intake, are duties of the nurse⁽¹⁸⁾. Explaining any and all procedures is essential in order to reduce the caregiver's anxiety and surprises with regards to the new situation. This is needed to develop new knowledge to care for and advise about needs and expectations⁽²⁶⁾.

Even in the face of negative findings, caregivers expressed concern that they were not taking proper care of their own health and reported difficulties in reconciling their activities as caregivers and self-care. This difficulty in self-care takes place mainly due to the lack of family support and social and health support networks⁽²⁷⁾.

Study limitations

As limitations of the study, it stands out it was carried out with a specific group of family caregivers of children with CF,

attended in a single health service. This may have contributed to the emergence of similar results and experiences. It is possible that if a similar study is carried out in other places of assistance, other manifestations will be found.

Contributions to the fields of Nursing

The study brings contributions that will foment more humanized assistance to caregivers and children affected by CF, demonstrating that adaptation is a continuous process marked by numerous stressors. Through the diagnoses listed and the knowledge of what these stressors are, this research hopes to make the implementation of nursing interventions easier for users with the same profile as those in the sample.

FINAL CONSIDERATIONS

During the evaluation of the stimuli, the focal stimulus experienced by these family caregivers was stressful, mainly due to the fear of the death of the child. The organization of a new routine influences the labor relations of the caregivers, since they abandon their jobs and professional careers in favor of caring for the health of the child. In this context, as a focal stimulus, religious practices were observed for the relief of suffering. As for contextual stimuli, social life is the first to be affected, due to the routine of household chores that inevitably increases, and because attention is totally focused on the child. Regarding residual stimuli, it was noted that the fear of loss is constant because of previous contacts with death.

After assessing the behavior of these family members according to the Callista Roy theory, it appears that the most affected aspect of caregivers is the emotional one, due to work overload and high levels of stress. However, in the physiological domain, the following changes occurred: increased blood pressure, obesity, overweight, insomnia and sudden weight loss. It was also found that their self-concept is impaired, since the children always take priority over them. Regarding the role function, the support node is the family unit, with whom they share and face emotional and financial problems. Feelings of sadness, anger, and preoccupation are often observed regarding interdependence; behind the CF setting, hides a family caregiver who needs emotional and family support.

The nurses welcome this family member and child into the health system, identify stressors, offer a frank dialogue about the situation with other family members, and take feasible measures, such as referrals to psychology, social assistance, and others, according to each case. Therefore, decisions and recommendations made by the nurse can be taken to improve the caregiver's quality of life, and may include: referrals to the psychology service or occupational therapist; assistance in the division of time in the family of the caregiver; and, mainly, offering sensitive listening and emotional support during nursing consultations.

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