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ORIGINAL ARTICLE

THE ITINERARY OF FAMILIES TO OBTAIN THE DIAGNOSIS OF THE CHILDREN WITH SPECIAL HEALTHCARE NEEDS

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ABSTRACT

Objective: to know the itinerary taken by the family to obtain the diagnosis of the children with special health needs. **Method:** a qualitative study was carried out in a pediatric inpatient unit in southern Brazil. Grounded Theory was used as a methodological reference. Sixteen (16) family caregivers participated. Data were collected in 2019 through interviews and submitted to open and axial coding. **Results:** the families traveled a long route until receiving the children's diagnosis: they detected changes in their general condition; performed several exams; they were suspicious of the diagnosis because other members of the family had already been diagnosed with the same conditions; received information from health professionals about the necessary care and specialized services for the treatment; showed fear, panic and denial; and they valued faith in God in the hope of improving of the children. **Final considerations:** nurses need to develop an educational process with the family so that they feel prepared and capable of taking care of these children.

Keywords: Children. Technologies. Family. Chronic disease. Nursing.

INTRODUCTION

During pregnancy, families experience beliefs that are established in society for the arrival of healthy, idealized children without disabilities. The birth of a child with special health needs transgresses this idealization and families start to suffer when they realize that something is wrong and is not expected, making this reality difficult to accept[1-2]. Reality becomes uncomfortable and threatening, the dreams and expectations that were planned during pregnancy are undone, emerging the need to adapt to this new reality[3].

Children with Special Healthcare Needs (CSHCN) are characterized by needing specialized and continuous and long-term care, which will ensure the maintenance of their vital status[4]. Special needs arise as a result of chronic conditions, such as prematurity, congenital malformations, genetic abnormalities, trauma, metabolic disorders, cystic fibrosis, and severe neurological sequelae after a hypoxic or infectious event. CSHCN can become Technology Dependent Children (TDC), needing the help of devices that keep their vital functions functioning to avoid death or the worsening of their disability[5-6].

The number of CSHCN has been an important challenge for health systems, since its incidence has been growing considerably, especially in developing countries[7]. In the United States of America, it is estimated that there are about 11.2 million. Brazil does not have records of concrete estimates, but an instrument that allows screening for CSHCN

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has already been validated, which will make it possible to obtain more accurate epidemiological data on the subject[8].

The care demands of these children are incessant and exhausting, emerging the need for the family to reorganize itself and develop strategies that allow for their effective care. Families faced with their children's disabilities, face many obstacles that include problems related to health, search for diagnoses, and professionals from different specialties, hospitalizations, demands for care and technologies, education and social assistance. It was noticed that many families stop seeking health services due to their failures, the delay in reaching a concrete diagnosis or access to consultations, which are often considered short and shallow[9].

Itinerary is the path taken by these families in search of health services to solve the children's needs. During this itinerary, families outline strategies to deal with the disease. It is believed, therefore, that it is important to know the itineraries taken by the families of CSHCN, in addition to having a qualified and humanized nursing team that inserts and helps the family during this journey, since nurses are the main link of the children and are present daily throughout their treatment[10]. A study pointed out that knowledge of this itinerary contributes to improving the quality of care offered to CSHCN by health care networks, strengthening social and support networks, and reducing the risks and vulnerability to which this public is subject[11].

In this way, having professionals trained to mediate and guide families in this complex and frightening process is something of great value. The nursing team needs, in addition to training, to be more sensitive and attentive to recognize the relevance of an intervention aimed at helping the families and the children to face the fears and challenges that this condition provides[12]. In this sense, the professional nurses, being closer to the families, is able to minimize their anguish and also guide the necessary care for these children[11-13].

Knowing the itinerary taken by the families can guide other families to have a path that is less painful. In this perspective, the following question guided this study: what is the therapeutic itinerary of the families until the diagnosis of the children with special health needs? From this, the objective was to know the itinerary taken by the families to obtain the diagnosis of the children with special health needs. It is believed that the knowledge provided in this study will help health professionals to provide quality care aimed at the real needs of this group.

METHOD

The study was carried out with family members of CSHCN hospitalized in a Pediatrics Unit of a University Hospital in Southern Brazil (UH). This institution was chosen because it is a reference in maternal and child care to the population of the micro and macro region of Rio Grande do Sul, in addition to being involved with teaching, research, outreach and health care. The Pediatrics Unit of the UH has 18 beds for children aged between 0 and 12 years who are hospitalized for clinical and surgical care by the Unified Health System.

As inclusion criteria, we used to be a caregiver responsible for the child at home since his diagnosis, accompanying the child during his care at the health institution and being 18 years of age or older. As an exclusion criterion, being a family member who eventually took care of the child in the hospital.

Data collection and analysis took place in the first half of 2019 simultaneously according to the Grounded Theory, the methodological framework used in this study, which provides the scope of knowledge about the issues related to the studied group, its actions and experiences, this being a field of increasing interest and work in nursing[14]. The qualitative approach of this theory can lead to the understanding of this phenomenon based on the observation of the social scenario. Data collection, coding and analysis were carried out in order to identify the events indicative of categories. Data collection was performed until theoretical saturation occurred, when there was repetition or absence of data[15].

Data collection took place through semi-structured interviews operated by an interview plan. These were individually scheduled, recorded and transcribed for analysis and lasted

approximately 1 hour. The performance took place in the pediatric unit with a previously scheduled date and time. Caregiver families were asked about their itinerary until the children's diagnosis. Data analysis was performed by open and axial coding. In relation to open coding, it should cover the breakdown, analysis, comparison, conceptualization and categorization of research data. In the axial coding, the data are grouped in a new way, with connections between the categories[15].

The ethical principles of research involving human beings were respected according to Resolution 466/12[16]. The favorable opinion of the Research Ethics Committee was 01/2019, CAAE 23116.006431/2013-19. The identification of family members was given by the letter F, followed by the interview number, as a way of guaranteeing his anonymity. Participants signed the Informed Consent Term in two copies.

RESULTS

Sixteen caregivers of CSHCN participated in the study. Two sample groups emerged from the study, the first consisting of eight families of children hospitalized in the Pediatrics Unit who used life support technologies, such as the use of gastrostomy tube, ventilator for mechanical ventilation and central venous access for medication use. Of the eight children, six were male, five had cerebral palsy, one had osteopetrosis and two had congenital clubfoot. Their ages ranged from 1 year and 2 months to 10 years, with mean of 5 years. Through coding, analysis and comparison between the data, this first group made it possible to form the initial codes and categories of analysis. Several memos were prepared, which supported the reflections raised.

The second sample group was formed by eight families of children dependent on technologies to improve their quality of life, such as the use of plastered splints, orthopedic boots for surgical correction of congenital clubfoot, special wheelchair, orthoses for immobilization and support of the upper and lower limbs, glasses and hearing aids. Of the eight children, seven were male, five had cerebral palsy, one had congenital clubfoot, one had hemophilia and one had moderate blindness, deafness and HIV. Their ages ranged from 11 months to 7 years, with mean of 3.75 years. In addition, all children in this group needed rehabilitation treatments, such as physical therapy, speech therapy, horse riding, physical education, etc.

After the analysis, the following category was found:

Going a long way until receiving the child's diagnosis

Detecting changes in the children's general condition, the caregiving families reported that soon after birth they observed that their children did not have the same physical and behavioral development as other children of the same age. They observed that the children had muscle hypotonia, not being able to sustain normal body support. In addition to the children having seizures, body bruises and bleeding, problems related to swallowing, they did not follow the gaze, did not blink and did not smile, as well as physical changes such as clubfoot:

> The part that he doesn't smile. The neurologist said he has facial paralysis, the muscles in his face are unresponsive, and he doesn't blink as often as we do. He also has astigmatism, that's why he wears glasses [...] His musculature is different from ours, he's softer, fluffy, that's why he had a hard time sitting up and supporting his head [...] because his foot is not normal, he has no balance **(F03).**

> When she was three months old, I noticed that she didn't follow our eyes. So I went to see the ophthalmologist to see what was going on. They sent me to Porto Alegre to make exams there, because that's where the exam is done. Moderate blindness was diagnosed **(F10)**.

> [...] Until then he only had seizures. Until four months he was perfect. He did everything a normal child does. After four months, I noticed that he was droopier, which was not normal for his age, so I took him to the pediatrician. She referred for a consultation with the neurologist [...] **(F06)**.

> [...] We saw that he was in pain and we saw that the pain was in his left leg. He was even limping. Until then, we didn't know one hundred percent that he was hemophiliac, but we had that suspicion [...]. He had spontaneous thigh-femoral

bleeding when he was ten months old. [...]. So, we concluded he was hemophiliac [...] **(F09)**.

The mothers also reported that they believed that their children were normal children. They were discharged from hospital and took home normal children. As she grew older, the mothers identified that the children had a problem, thus starting their journey in search of a diagnosis:

[...] he was perfect. He could do everything a normal kid can do. Until I realized he didn't sit down, it was too soft. He had difficulty swallowing, he kept choking [...]. So I went for a diagnosis. **(F16)**.

[...] we went home. She was a normal girl, no problems at all. My mother said she had some problem. That's when the pediatrician told me that she had a little problem with childbirth. He referred me to the neurologist **(F11)**.

[...] He didn't look like a special kid. He was a chubby baby. He started having seizures and I rushed to the emergency. Then I saw that I didn't know what I was dealing with. I needed a real diagnosis to know what I was facing **(F14)**.

The families, after the birth of the children, began the search for the diagnosis of the pathology through examinations. Several tests were performed, including genetic checkup, tests for diagnostic confirmation of hemophilia, in addition to referrals to specialized consultations with a neurologist and others:

[...] he did several exams, when he was hospitalized, to find out what he really had. Then the diagnosis of cerebral palsy and epilepsy came. He also did a genetic checkup with the geneticist to find out if he had genetic problem [...] **(F07)**.

[...] At the pediatrician he was referred to consult with the neurologist. The neurologist said that he was like this because of complications at birth **(F06)**.

[...] We consulted with a geneticist and she said that she had a fifty percent chance of being hemophiliac and fifty percent of not being hemophiliac. When he was born we tried to do tests, we did it in the blood center of Pelotas in Hemopel. They wanted to wait for the exam to work out. The good thing was to dothe test after a year. [...] before a year the result could not be 100% reliable **(F09)**.

[...] by the BEERA exam he has a diagnosis of deafness. Clinical examinations confirmed deafness. He was already two years old when the physicians managed to reach the conclusion that he was really deaf **(F10)**.

Some family caregivers identified the children's diagnosis as having family members in the same situation. One of the interviewees had the disease as a child, the other mother a brother who also had hemophilia and the third reported that her husband had the genetic disease of congenital clubfoot when he was still a kid:

His disease (congenital clubfoot) I had when I was a child and I knew it was corrected and that it was not a more serious disease [...]. I had already gone through this and my sister also had it [...] **(F02)**.

[...] My brother was also a hemophiliac and he died at seventeen. And when I learned that would be a son, we got already apprehensive, because he could be hemophiliac [...] **(F09)**.

[...] We know that it is a genetic disease, because my husband had it as a child, but he was only one foot and my son has both feet [...] **(F08)**

The pathologies reported were congenital clubfoot and the suspicion of Moebius Syndrome through the knowledge of the physicians of the Association of Parents and Friends of the Exceptional (APAE). Only one interviewee reported knowing the precise diagnosis of the child's genetic disease, identified as osteopetrosis:

[...] When the nurse picked up my son, she reported that he had been born with a foot problem. He has congenital feet; his feet are turned inwards **(F01).**

[...] He started going to APAE this year, where they told me that he probably has Moebius Syndrome. They didn't give me a report. That's just a suspicion of them. [...] But due to the characteristics he presents, the physicians think it is this Moebius Syndrome **(F13).**

The disease is rare, osteopetrosis, a disease that attacks the bones, this disease was the diagnosis. Due to this disease, she has an enlarged spleen, her teeth did not all come out [...] **(F04)**.

Some mothers mentioned that they were informed by the physician about the care they would have to have with the child, what treatment should be performed and where to seek specialized care. One of the interviewees reported that the physician and the nurse

informed about the pathology presented by the child and the places where she could receive specialized assistance:

> The first professional was the nurse, who told us that he had been born with a congenital clubfoot problem. The physician only came later and talked about the disease and, also, what care we would have to take with him. [...] he explained everything to me [...] **(F02)**.

> [...] I consulted with a private physician. He told me that it was no use worrying about his foot, because we didn't really know what disease he had to know if he was going to walk or not. We should pay attention to the other more serious problems he had [...] **(F03)**.

> [...] What the physician explained to me: It was due to lack of oxygenation. He ended up with these sequels: he would not walk, talk, and he would be a vegetative child, and that I would have to stimulate him. So, the physician referred me to the APAE. The nurse guided me in daily care: bathing, aspiration, feeding through the catheter. The physical therapist told me about equine therapy and a physiotherapy clinic specializing in children like my son. Then I went to the fight **(F07)**.

Receiving the child's diagnosis can generate feelings such as panic and fear of performing the care and procedures demanded by the CSHCN, for example, airway aspiration and feeding the child by tube. After the child's diagnosis, the search for families with CSHCN began for greater knowledge about the child's disease, as well as for health services that would help them in the treatment:

> [...] And then our whole fight started. It was the neonatal ICU nursing who gave us this support. They taught us what I had to do, how to feed by the probe [...]. The physical therapists used to talk to me. They made me lose the fear of aspiration, because I had panic, I was afraid, I said that was very difficult [...] I spent the nights crying and to sleep I had to take drugs **(F01).**

Some family caregivers even after receiving the diagnosis of the children's pathology denied their disease. They stated that the children did not have deafness, that their neurological state had not been affected by cerebral anoxia, that children did not have poorly developed muscles and that they did not know what really happened after the children's birth. Due to the visible delay in the development of these children, a process of denial of their real condition was identified;

> [...] So far, ten years later, we don't really know what happened. She underwent the vision test and the anoxia did not affect the cornea, it affected anything, normal hearing as well. She only does not talk because of the brain damage and the motor part all impaired. Her development and learning are normal **(F05).**

> [...] The physician talked to me and said he was deaf. I told you he wasn't. I thought, at first, he was deaf, but now I don't think so. At first I did a test at home with a pan lid on his side and he didn't move or care. When he put on his glasses, I noticed that he started having reactions, reacting to the sounds [...]. I said to the physician: He is not deaf, he only listens to what he really wants to hear, the sound he knows. Then, the physicians scheduled a behavioral evaluation exam [...] **(F15).**

During the search for diagnosis and specialized treatment for the children, the family values faith in God, in the hope that everything will go well after the knowledge and that, with care, the children will improve:

> There are people who say: - How do you do it? That's a burden you have to carry! But I don't think it's a burden! If God gave him to me in this condition it is because I can! Everything will be alright. He will get better **(F06).**

> I accept, if God thinks he should stay like this [...], but, God willing, nothing will happen [...] **(F07).**

DISCUSSION

The study showed that families go a long way towards obtaining the diagnosis of CSHCN. In this context, it was noticed that the diagnosis reflects the first obstacle experienced by families. Many of them only became aware of the diagnosis of CSHCN after the birth. Some managed to get it right away. Others, however, took a long time to receive it, often due to the weaknesses found in the health services, in the system of counter-referral to the health unit used by the family, which shows the disarticulation between the levels of the care network[17].

Regarding the main complaints presented by the families, the delay in reaching an accurate diagnosis was noted. For them, the search for a diagnosis occurs through the performance of

several tests. Genetic tests can bring several meanings when the family is able to perform them. For symptomatic children, these serve to legitimize the diagnosis. For those who did not present symptoms, the test would exclude the expectation of suffering and anguish of a possible confirmation of the disease, as well as enabling early treatment [18].

Some families distrust the diagnosis because they have already had other family members in the same situation. Corroborating, it was evidenced that the discovery of the diagnosis and the existence of the hereditary component were already expected, since many relatives had/presented the characteristics and symptoms demonstrated by CSHCN, which already evidenced a problem present in the family. However, receiving the diagnosis was important, since it made it possible to give a name to the condition, as well as the cause and how would be the care provided to the pathology[18].

With the constant technological development in the areas of pediatrics and neonatology, which has provided survival and quality of life for these children, it is important that professionals, especially nurses, are prepared to support welcoming and humanization in the reception and preparation of children and families for the process of adaptation and living with a new universe. Proper preparation can minimize physical and emotional damage to CSHCN and their families[19].

Family members of children hospitalized in a pediatric unit of a public hospital in João Pessoa (Paraíba) revealed that from the first signs and symptoms evidenced by the family about the children's disease begins the pilgrimage in the search for access to services and resoluteness of health actions. Hospitalizations and visits to various hospital institutions were constant, with different professionals, in search of answers and expectations of resolving the problem. The delay of a definitive diagnosis and the outcome of the situation generate emotional instability in the family[20].

It can be understood that the diagnosis of a serious pathology impacts the life of the family. It's like a grief that runs from denial of disease to acceptance. The children do not correspond to the imagined/idealized, causing the disruption of future projects, including everything that refer to their growth and development, as well as other children, requiring a rearrangement of family dynamics [21].

CSHCN require comprehensive care. Many are totally dependent on care for their daily activities. They need care related to food, hygiene, transportation, medicines and equipment that involve or not technologies. In addition to rehabilitation treatment to promote better living conditions, neuropsychomotor development, through stimulation, provides visible improvements in the children. However, families show difficulties in performing the procedures, adapting home care and understanding the guidelines[17].

The nursing team acts as a facilitator in the construction of relationships of care, communication, empathy and trust in the relationship with the children's families. In addition to taking care of the health conditions of their patients, it also starts to see the members of this nucleus as a whole, revealing a family-centered care regarding the management of chronic care[22].

After receiving the diagnosis of CSHCN, the family may present fear and panic when performing its specific care. The literature indicates that, initially, families react with shock and feelings of helplessness and fear. The way the families are supported and welcomed at the time of receiving the diagnosis and the explanations they receive from health professionals have an important impact on how they will face this unknown and new situation. It is noteworthy that professionals need to be trained to be part of the moment of disclosure of the diagnosis. The news should be transmitted by those who have scientific technical knowledge, with language easily understood by family members. Therefore, nurses are the professionals who knows the stages of mourning and who are usually closer to the families, being able to help them and prepare them to experience this situation[21].

It was found that some families are denied a reality they cannot deal with. Many family caregivers cannot have a realistic view of what the child presents and the disease, as well as understand its meaning, the consequences and possible treatments that may be part of this new reality[23].

Denial of the disease and the children's health is one of the feelings that may arise after receiving the diagnosis. Families feel fragile and deny the children's disease in view of the diagnosis obtained as a way to preserve themselves, often starting to doubt the exams and the competence of the health team. They can present doubtful feelings with feelings of anger, which can negatively interfere in the process of adaptation and learning with the health team [24]. The literature reveals that families go through difficult moments and different feelings at the time of the discovery of the child's condition emerge, such as denial, doubt, fear, despair, concern, hurt, sadness and indignation[17,24].

The performance of the nursing team is important for these families to be able to adapt and deal with the diagnosis of chronicity of the children. In this sense, it is up to the nurses to work in health education with these family members in order to know their reality and identify the educational demands, as well as establish a space for listening, learning and exchange of experiences with this group[25]. Thus, the family will have the chance to go through this moment in order to be prepared to deal with daily adversities.

In addition, it was found that many doubts, uncertainties and feelings such as anxiety emerge during the adaptation, knowledge and handling by families of the technologies used by their CSHCN. Another aspect observed is that during their journey in search of diagnosis, the family values faith in God in the hope of the child's improvement. Support based on spirituality and religiosity in the face of the illness of a family member is beneficial.

The limitations of the study were the fact that it was conducted in a single pediatric hospital setting. Studies in other scenarios are recommended in order to show a broader look at the subject, increasingly subsidizing the nurses' practice with the families of the CSHCN, making their therapeutic itinerary less suffering.

FINAL CONSIDERATIONS

The study aimed to know the path taken by the families to obtain the diagnosis of CSHCN. It was found that this is a long way: they detected changes in the general condition of the children; they underwent several tests; they distrusted the diagnosis because they had already had others with it in the family; they received information from health professionals about the necessary care and specialized services for the treatment; they showed fear and panic when performing care and denial before a reality with which they cannot deal. In this trajectory, they value faith in God in the hope of the child's improvement.

It was concluded that nursesshould seek to assist the families in aspects related to the communication of the diagnosis, evaluation of their needs for referral to exams and specialized services, support and assistance in coping with everyday situations related to home care. Thus, it is important that nurses develop an educational process with the family so that they feel prepared and able to meet the demands of the CSHCN.

ITINERÁRIO DA FAMÍLIA PARA OBTER O DIAGNÓSTICO DA CRIANÇA COM NECESSIDADES ESPECIAIS DE SAÚDE

RESUMO

Objetivo: conhecer o itinerário percorrido pela família para a obtenção do diagnóstico da criança com necessidades especiais de saúde. **Método:** realizou-se estudo qualitativo em uma unidade de internação pediátrica do sul do Brasil. Utilizou-se como referencial metodológico a *Grounded Theory*. Participaram 16 familiares cuidadores. Os dados foram coletados em 2019 por entrevistas e submetidos à codificação aberta e axial. **Resultados:** as famílias percorreram um longo itinerário até o recebimento do diagnóstico da criança: detectaram alterações no seu estado geral, realizaram diversos exames, desconfiaram o diagnóstico por já ter outros com o mesmo na família, receberam informações dos profissionais da saúde acerca dos cuidados necessários e dos serviços especializados para o seu tratamento, apresentaram medo, pânico, negação e valorizaram a fé em Deus na esperança da melhora da criança. **Considerações finais:** o enfermeiro necessita desenvolver um processo educativo junto à família para que ela se sinta preparada e capaz de cuidar dessas crianças.

Palavras-chave: Crianças. Tecnologias. Família. Doença crônica. Enfermagem.

ITINERARIO DE LA FAMILIA PARA OBTENER EL DIAGNÓSTICO DEL NIÑO CON NECESIDADES ESPECIALES DE SALUD

RESUMEN

Objetivo: conocer el itinerario recorrido por la familia para la obtención del diagnóstico del niño con necesidades especiales de salud. **Método**: se realizó estudio cualitativo en una unidad de hospitalización pediátrica del sur de Brasil. Se utilizó como referencial metodológico la *GroundedTheory*. Participaron 16 familiares cuidadores. Los datos fueron recolectados en 2019 por entrevistas y sometidos a la codificación abierta y axial. **Resultados**: las familias recorrieron un largo itinerario hasta la recepción del diagnóstico del niño: detectaron alteraciones en su estado general; realizaron diversos exámenes; desconfiaron del diagnóstico por tener ya otros con el mismo en la familia; recibieron informaciones de los profesionales de la salud acerca de los cuidados necesarios y de los servicios especializados para su tratamiento; presentaron miedo, pánico y negación; y valoraron la fe en Dios en la esperanza de la mejora del niño. **Consideraciones finales**: el enfermero necesita desarrollar un proceso educativo con la familia para que ella se sienta preparada y capaz de cuidar a esos niños.

Palabras clave: Niños. Tecnologías. Familia. Enfermedad Crónica. Enfermería.

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