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Meanings assigned by families about children's chronic disease diagnosis

Significados atribuídos por familiares acerca do diagnóstico de doença crônica na criança

Significados de las familias sobre el diagnóstico de enfermedad crónica en los niños

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ABSTRACT

Objectives: to understand the meanings assigned by family caregivers about children's chronic disease diagnosis. **Methods:** qualitative study, which used as theoretical framework the Symbolic Interactionism, and methodological, the Grounded Theory. It was held in a pediatric unit in Southern Brazil, in 2016, through interviews submitted to open and axial analysis, with the participation of 20 family caregivers of hospitalized children. **Results:** relatives, interacting with the nursing/health staff, perceive children's disease at birth. They are diagnosed with chronic disease by the physician and deny it. Subsequently, they accept and seek information on care. **Conclusions:** the results pointed out the stages that relatives experience by assigning meanings to about children's chronic disease diagnosis. These meanings provide subsidies for nurses' actions, which need to be aware of children's and family's needs in order to offer comprehensive and humanized care.

Descriptors: Chronic Disease; Family; Hospitalized Child; Pediatric Nursing; Qualitative Research.

RESUMO

Objetivos: compreender os significados atribuídos por familiares cuidadores acerca do diagnóstico de doença crônica na criança. **Métodos:** estudo qualitativo, que utilizou como referencial teórico o Interacionismo Simbólico, e metodológico, a Teoria Fundamentada nos Dados. Realizou-se em uma unidade pediátrica no Sul do Brasil, em 2016, mediante entrevistas submetidas à análise aberta e axial, com a participação de 20 familiares cuidadores de crianças internadas. **Resultados:** familiares, ao interagirem com a equipe de enfermagem/saúde, percebem a doença da criança ao nascimento. Recebem o diagnóstico de doença crônica pelo médico e o nega. Posteriormente, o aceita e buscam informações para o cuidado. **Conclusões:** os resultados apontaram os estágios que os familiares vivenciam, ao atribuir significados ao diagnóstico de doença crônica na criança. Esses significados fornecem subsídios para a atuação do enfermeiro, que precisa estar atento às necessidades da criança e da família, tendo em vista o oferecimento de uma assistência integral e humanizada.

Descritores: Doença Crônica; Família; Criança Hospitalizada; Enfermagem Pediátrica; Pesquisa Qualitativa.

RESUMEN

Objetivos: comprender los significados atribuidos por los cuidadores familiares sobre el diagnóstico de enfermedades crónicas en los niños. **Métodos:** estudio cualitativo, que utilizó como referencia teórica el interaccionismo simbólico, y metodológico, la Teoría Basada en Datos. Se llevó a cabo en una unidad pediátrica en el sur de Brasil, en 2016, a través de entrevistas sometidas a análisis abiertos y axiales, con la participación de 20 cuidadores familiares de niños hospitalizados. **Resultados:** los miembros de la familia, cuando interactúan con el equipo de enfermería / salud, perciben la enfermedad del niño al nacer. El médico les diagnostica una enfermedad crónica y lo niegan. Más tarde, lo aceptan y buscan información para recibir atención. **Conclusiones:** los resultados señalaron las etapas que experimentan los miembros de la familia, atribuyendo significados al diagnóstico de enfermedades crónicas en los niños. Estos significados brindan subsidios para las acciones de las enfermeras, que deben ser conscientes de las necesidades del niño y la familia, a fin de ofrecer una atención integral y humanizada.

Descriptores: Enfermedad Crónica; Familia; Niño Hospitalizado; Enfermería Pediátrica; Investigación Cualitativa.

INTRODUCTION

Hospitalization in childhood is a period of fear and uncertainty for children and their families, which needs the help of nursing professionals, especially when dealing with a chronic disease[1]. The disease follows the person for a long time, compromising their physical, emotional or mental condition. Often, it prevents children from attending school regularly and/or performing their routine childhood activities[2]. Constant visits to the physician, use of medications and the need for hospitalizations may be common, bringing changes in family routine, as they affect children's development and social relationships[3].

The number of children living with chronic diseases, seen in hospitals and other health services, is growing, considering the general clinical management and access to these resources in public health services. In Brazil, the rate of chronic diseases is 9.1% in children from zero to five years old, 9.7% from six to 13 years old and 11% of adolescents from 14 to 19 years old[4]. A global epidemiological study, conducted with 500,000 children, aged between six and 14 years, interviewed in 31 countries, ratified the national data. It revealed that fast food consumption contributes to the development of asthma, rhinitis, eczema, overweight, diabetes, and obesity. There is a 39% increase in the risk of severe asthma for adolescents and 27% for children[5].

Chronic diseases in childhood are incurable and cause sequel over time, imposing limitations on children. They require special care skills and competencies from their family caregivers for their rehabilitation, requiring training, supervision and observation of care. It is clear that relatives, when interacting with the nursing staff, seeks to share feelings and perceptions regarding the finitude and fragility of the human condition, which a chronic and severely severe disease imposes[6]. It is considered an interactive sharing when the human being not only reacts to the actions of the other, but understands the context in which he finds himself, which can positively influence healthy ways of living[7].

Relatives suffer when they realize the incurable child's diagnosis, mainly because of having difficulty dealing with this reality. Family caregivers come to live with uncertainty, insecurity, disorder and continuous need for reorganization. Family is the basic unit in the construction and development of its members, values that transmit rules, customs and ideas to generations, as well as models and patterns of behavior[8].

Relatives, when organizing in the hospital, seeks support from the health/nursing staff to promote actions that favor better performance in the control of chronic disease and prevention of complications in children. As it is a dynamic and complex interaction, relatives need to build a relationship of satisfaction that allows them to feel interdependent and cooperative in care, with these professionals to develop a dialogic practice that promotes autonomous care[9]. It is the sharing of actions that favor the experiences among individuals who seek the solution of their problems in the environment where they work[7] .

Nurses should support relatives and contribute to their instrumentalization, encouraging participatory care practices so that they can overcome their fears and anxieties of caring for children with chronic disease. Understanding, compassion, and respect are efficient and effective attributions in interaction with relatives in order to rescue values, enabling moral support. In addition, the interactional process includes sharing information so that relatives can make and act on family choices, professional flexibility, and responsiveness to requests[10].

In Symbolic Interactionism (IS), knowledge is processed through the interaction between the subjects and the environment. Thus, knowledge develops through the action of individuals in relation to things, based on their own meanings. They are meanings resulting from social interaction and modified by the individual interpretation of people who interact and interact socially[7,11].

In this interaction, the nursing staff contributes to the establishment of bonds with family caregivers and children with chronic disease, in the context in which they are inserted, promoting reciprocal care. This shared care between the nursing staff and family caregivers can be a source of support and support to care and treatment for children with chronic diseases in hospitals[12].

During children's hospitalization, there is proximity between the nursing staff and their family caregivers. It becomes the moment when relatives evaluate the nursing care provided[13]. Understanding the meanings assigned by family caregivers about their interactions with nursing professionals in care for children with chronic disease in the hospital contributes to these professionals seeking participatory care focused on care for these children and their families. There is the guiding question of this study: what is the meaning assigned by relatives about children's chronic disease diagnosis?

OBJECTIVES

To understand the meanings assigned by family caregivers about children's chronic disease diagnosis.

METHODS

Ethical aspects

The ethical principles of research involving human beings were respected, according to the recommendations of Resolution 466/12[14]. The research project approved by the Ethics Committee of *Universidade Federal do Rio Grande*/UFRG. Family caregivers of children with chronic diseases agreed to participate in the study by signing the Free and Informed Consent Term.

Theoretical-methodological framework

This research had as theoretical framework the Symbolic Interactionism (SI). The methodological framework used was the Grounded Theory (GT), which allows the generation of theories by describing and interpreting phenomena, enabling the deepening of knowledge, within the multidimensionality of human experience in daily life[15].

Type of study

This is an exploratory-descriptive research with a qualitative approach.

Methodological procedures

Study setting

It was developed in a Pediatric Unit of a University Hospital, located in the extreme south of Brazil, from January to July 2016. It is intended for patient care from zero to twelve incomplete years, being certified as a Child's Friend Hospital and reference in maternal and child care within the Brazilian Unified Health System (*Sistema Único de Saúde*). It consists of 18 beds distributed: an isolation bed, a ward with five beds and four wards with three beds, which operate with joint housing system. It allegedly a favorable environment for the interaction of care and the bond between family caregiver and health/nursing professionals. Emphasis is placed on valuing the meanings derived from the beliefs and cultural values of families, with a view to interrelated health care planning, integrated and aligned with the needs of children and caregivers.

Data source

Participants were defined using the convenience sampling technique. Thus, all relatives of children with chronic diseases who were hospitalized during the data collection period were invited to participate. Inclusion criteria were: being a frequent caregiver of children and providing direct care in the hospital and being 18 or older. Relatives who eventually took care of children in the hospital were excluded. Twenty relatives were interviewed. This total ensured the theoretical saturation of the data content, justified by the lack of new data[15].

Collection and organization of data

Data collection was performed through semi-structured interviews, in which relatives were asked about how they understood children's chronic disease diagnosis. The meetings for data collection were previously scheduled with participants. Interviews lasted an average of 30 minutes and were held in the unit's inpatient room, ensuring the participants' privacy and data confidentiality. They were also recorded in audio through mp3 players and transcribed for later analysis.

Data analysis

Data were analyzed according to Glaser and Strauss[15] substantive coding and theoretical coding. Substantive coding aims at the constitution of concepts. For this, it is subdivided into open coding and selective coding of data[15]. In open coding, a thorough line-by-line analysis of the raw data was performed to explore the impressions, feelings, thoughts and beliefs revealed by participants.

In selective coding, the initial codes, identified through open coding, were grouped into categories, based on the similarities, pattern repetition and relationships that emerged. In order to consolidate the research results and give scientific rigor to the study, the formulated categories were presented individually to each family member. They aim at confirming the obtained data, complementing or modifying the information that represents the investigated reality, validating the study. Participants' statements were identified by the letter F, followed by the interview number.

RESULTS

Data analysis showed the characterization of the families participating in the study and the categories represented, as shown in Figure 1.

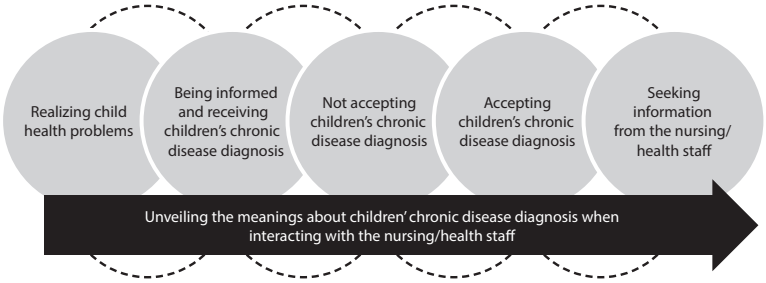

Figure 1 - Representative diagram of the relationships between the categories that make up this study

Characterization of families participating in the study

Twenty relatives of children with chronic diseases participated in the study, being the mother the main caregiver. The participants' ages ranged from 19 to 44 years old. Regarding the level of education, five had not completed elementary school, eight had completed elementary school, six had completed high school and a higher education in progress.

Regarding occupation, 15 participants had never worked outside the home, with children's father being the family income provider. The other five worked outside the home (a clerk, a child care worker, a hairdresser, a seamstress, and a cleaning lady). Household income ranged from 800 to 2,500 *reais* (*reais* is the name of Brazil's currency; 1 *real* is about 4 US dollars), and the minimum wage at the time of data collection was 880 *reais*. Ten mothers who participated in the study shared care for their children with their spouses, five with children's grandparents and five cared for children alone.

Regarding the profile of children with chronic diseases, ages ranged from one incomplete year to six years of age, 11 males and 9 females. Eleven children had chronic encephalopathy/ paralysis, two had asthmatic bronchitis, two had osteogenesis imperfecta, two had diabetes mellitus, one had cancer, one had short bowel syndrome and one had anal imperfuration.

Regarding care environment of these children, in general, 20 underwent frequent hospitalizations; five attended APAE (the *association of parents and friends* of people with disability) and two attended preschool. The others were cared for exclusively at home. These are children with special needs, 17 users of continuous medications and 15 of care technologies, including nebulizers, colostomy bags, nasal catheters, gastrostomy tube and wheelchair.

Realizing child health problems when interacting with the nursing/health staff

There were several signs identified by some families after contact with the health staff at birth. Some families noticed the small child at birth and dyspnoea due to their prematurity.

> *I thought he was too small; I saw that it was not normal. When I asked, the physician told me it was because he was premature, that it was premature. I was very suspicious.* (F2)

> *He was small to me and had trouble breathing. I was told in the ward that it was prematurity.* (F7)

Other children had neonatal jaundice, cyanosis, coma, tremors and convulsions. These symptoms were identified on medical examination and families were informed of the risk of possible irreversible sequel.

> *I found him very yellow. When he entered the ICU, the physician asked for a blood transfusion and said he would have sequel.* (F20)

> *He is very agitated and turned purple. The neurologist identified by examination that he had seizures due to sequels.* (F15)

> *I fell into despair because she fell into a coma in the hospital. She was short of breath and shivering a lot. After the exams, the pediatrician told me that she could have mental problems that could affect her learning.* (F18)

After children were discharged from the Neo ICU, relatives feared that the baby might not be normal like the other children. The health staff informed them that some health problems could appear.

> *When he left the Neo ICU, I thought he was breastfeeding very little, even with milk in the syringe. They do not use a bottle here. I was worried before we left the unit when the nurse and physician said I had to come to the appointments regularly due to the possibility of neurological problems.* (F2)

> *It was a horror to know before I was discharged from ICU Neo that my son might have trouble moving, talking and learning. I got scared!* (F3)

Being informed and receiving children's chronic disease diagnosis by the nursing/health staff

Most participants were informed of children's chronic disease diagnosis by their physician.

> *When I was diagnosed with cerebral palsy by the physician, I felt very bad. He was rude to give the information. Knowing the seriousness of my daughter's disease and the possibility of her not surviving made me despair of receiving this terrible news.* (F17)

> *The diagnosis of cerebral palsy was given by the pediatrician. He was born with part of the lung only, having to stay in the Neo ICU.* (F1)

Depending on children's pathology, diagnosis was reported by professionals from various specialties, such as pediatrician, neurologist, traumatologist, surgeon and hematologist.

> *My son was born with anus closed and had to have colostomy. Diagnosis was given by the pediatrician.* (F15)

> *Encephalopathy diagnosis was given two days old by the pediatrician and the neurologist.* (F7)

> *He has cerebral palsy since birth. He stayed at Neo ICU when he was born. It was the pediatrician who gave the diagnosis.* (F14)

> *Osteogenesis imperfecta was diagnosed shortly after birth by traumatologist.* (F8)

> *My son had intestinal volvulus and had short bowel syndrome after surgery to remove almost all of his bowel two years ago. Diagnosis was given by the surgeon.* (F12)

They considered it traumatic to know that children have a disease that has no cure, feeling terrified to know that children would not walk or talk, and frightened by the disease's consequences and dealing with children.

> *She was very sick. Her glucose was very altered. We took her to the physician and got her medication to start treatment. It was a terror to know that she will have to take care of herself all her life.* (F18)

> *When the physician gave the result of encephalopathy, I accepted, though afraid to deal with him for moving little. It was at nine months old that I learned. The physician began to distrust because he hardly moved at all. I criticized myself because I could have forced the physician to order some detailed exams from him. After some tests, I also learned that he had childhood cerebral palsy and epilepsy. That's when he was an hour unconscious.* (F19)

Some families reported crying a lot at children's chronic disease diagnosis, presenting depression soon after birth.

> *When I heard about the diagnosis of diabetes, I cried a lot. I wanted to be in her shoes. The day I was told about diabetes came to me a lot of things in my head. I lost my maternal grandfather because of diabetes. I'm afraid of the consequences of the disease, such as blindness.* (F18)

> *When he was born, I became depressed, I became discouraged. Born six months and went straight to the Neo ICU.* (F9)

Others reported feelings of guilt upon being diagnosed with a child's disease.

> *Everything has changed, I don't count on anyone, I got stuck. I ask God "what did I do?" I feel guilty.* (F3)

> *I put myself in my son's shoes as he suffers. I blame myself for his disease.* (F4)

Not accepting children's chronic disease diagnosis received by the nursing/health staff

Relatives reported that the main difficulty in accepting the disease diagnosis is in relation to its chronicity. The incurability of the disease in children refers to the need for continuous treatment and follow-up and may extend throughout life.

> *I have a hard time accepting that he at six is blind and walks with the walker's help and lives on my lap. The physician does not want you to use a wheelchair, thus preventing him from stopping walking. But it is difficult to accept all this. It's been six years and it's still hard.* (F13)

> *Okay! I know I have to get used to her having diabetes mellitus. I'm not used to her disease yet. Sounds like a lie. She is seven years old and I do not accept that she will not get well, that she has no cure and that her body will develop insulin every day.* (F18)

Some relatives reported being angry at the limitations imposed by children's disease.

> *I am upset that she has a short bowel. It is a syndrome that sometimes makes him hungry. I can't give everything he likes to eat. Feels sick and fills the air and fluid colostomy bag.* (F12)

> *I often feel upset. I seem to be a bad mother, because I can't give her any food to eat. I still don't accept her diagnosis because I see others eating sweets and she can't. Sometimes she gets calm, they offer it to her and she says my sugar is high. When I measure it is at 300 or 400 her sugar. The nurse had already told me that a little of increased blood sugar is emotional.* (F18)

Accepting children's chronic disease diagnosis received by the nursing/health staff

Some time after receiving the diagnosis, some families reported learning to live with this new life situation and accept children's chronicity condition.

> *I have to accept and adapt, so today she's fine, she goes to APAE. I'm not ashamed of her. She has social contact with other children. She has problems, but she has our affection. Dad doesn't pay much attention, but she still loves her Dad.* (F10)

> *He was well accepted in the family. I learned to accept his disease and take care of his needs.* (F11)

> *We are learning every single thing at your time to deal with the disease. I am learning to overcome difficulties with him.* (F4)

Relatives referred to the need to be strong and warlike against their chronically ill children, changing their view of the disease and not being ashamed of their child.

> *As he is special, he usually has difficulty walking, but he does everything on his own. You need to take care of him just so he won't get hurt. It doesn't need so much care, but I'm always with him. I feel stronger seeing him well.* (F6)

> *My daily life has changed a lot. I changed my view of cerebral palsy and epilepsy in a child. I thought I had to be treated alone. Today I realize that no and he can live with people like a normal child. For me it was a life lesson I had. I think I learned more from him than from a normal child.* (F19)

Seeking information from the nursing/health staff about chronic child disease

After acceptance of the diagnosis, families seek information that enables them to care for children.

> *I seek information about her disease, health problems and the need to take medications. I also ask the nurse, severity and the risks of my daughter dying.* (F17)

> *To take care of her, we went to the physician. As she was very weak we left the office with medicines for treatment. The physician explained to us that he would always have to take medication.* (F18)

They sought information about the need for children to be assisted in specialized services such as APAE.

> *The preparation for his care was done more for me. At first the physician said he should put him in APAE. My husband rejected the suggestion and said he's not crazy to be at APAE. I'm thinking! I think I'll try part of his treatment there.* (F19)

> *Putting him in APAE was a difficult decision. I asked the physician and he said it was the best form of socialization he would have. I believe, but I'm still thinking and talking to mothers who already have their children in the institution. Everyone told me it's worth it.* (F5)

In addition, they sought specialized health professionals, according to the limitations of each chronic disease, to face and deal with them.

> *The physical therapist shows all the movements she can make. Over time, she grows and becomes more prone to hip dislocation. Osteogenesis imperfecta is a disease that limits mobility, but little by little she is learning.* (F8)

> *The neurologist physician said that if we start to let him convulse every day he will start to lose part of the neurons. It ends up hurting the progress we made in his health.* (F19)

DISCUSSION

Relatives assign meanings when discovering children's chronic disease diagnosis by interacting with nursing/health professionals. From this interactive process, they begin to realize children's health problems, even before receiving the definitive clinical diagnosis. When they receive it, they go through the medical diagnosis' denial phase until they can accept the situation and seek help from health professionals to restore children's health balance.

At the symbolic level, they seek to understand and interpret children's health problems. This search gives a meaning related to the perception of a child with health problems, verified from the perception of a baby born premature and that needs advanced technological support in Intensive Care Units. Studies in India[16] and in the United States[17] reveal that the symbolic nature of interactions that ensure meaning for most families is that the discovery of chronic diseases in their child resulted from the birth of a preterm child. This prematurity symbolizes a mismatch between the birth of a baby idealized as healthy and the real baby, that is, born with a chronic disease that unbalances this idealization. It becomes a difficult reality for families to interpret, especially when mothers undergo complete prenatal care and ultrasound examinations to monitor fetal growth. They made a whole symbology of safety for the birth of a child without clinical and chronic imbalances.

With the symbolism of the ideal affected by the birth of a child with chronic disease, relatives, faced with the interactional communicative process, are emotionally shaken and socialize their difficulties in dealing with the unknown, the new and the different. Also when interacting with the nursing/health staff at the Neonatal ICU, where they usually perceive children's health problems. Studies conducted in Brazil[18] and the United States[19] showed that children with chronic disease have a symbolic character. It is mainly due to anatomical and physiological characteristics that predispose it to the development of diseases that, in most cases, are related to chronic disorders of the respiratory or neurological system. Among the main evidences is the infant's tongue being smaller in relation to the oropharynx and the lower mandible. Breathing is usually nasal until the period of four to six months of age. The airways are smaller in diameter and shorter. The infant's epiglottis is longer and flabby. The rib cage is more compliant and alveolar collateral airways are less developed.

Relatives, faced with the need to obtain consensus from the health staff, structure their interactive communicational process, with the self-determined objective of receiving a medical children's chronic disease diagnosis. Studies[7,11,18,20-21] emphasize that relatives are afraid, but aim to receive children's chronic disease diagnosis by the physician or other health professionals, with links in care. This occurs in order to equip themselves for their care and to supply the demands arising from the chronic condition diagnosis. These include food and hygiene care and drug treatment. Also included are adaptation of relatives to the environment in which they live, through an interactional process with children, family and health staff that modifies their relationships in stable social bonds.

As the symbolic character of social relations is not about the transfer of fixed social rules, on the other hand, emotional instability of relatives occurs when receiving the clinical diagnosis of children. Study on the diagnosis of cancer's receipt in children reveals the emotional impact of relatives regarding children's chronic disease's knowledge. Thus, some reported crying, going into shock, not knowing what to do and resistant to the news, but others reported that, due to despair, they were paralyzed and without reaction[22].

When families are diagnosed with a child's chronic disease, they usually do not interpret it as a long-term or incurable disease. Feelings of struggle, battle, sacrifice, and guilt can be present in family expositions, characterizing the way they perceive the moment they live. Thus, children's chronic disease diagnosis can bring significant changes in family behavior, changing family relationships and their own structure[23].

During the process of receiving children's chronic disease diagnosis, some families do not accept or feeling angry. A study about children with chronic disease revealed that relatives do not accept and deny their child's chronic disease because they face a reality signified as outside normal health standards[24]. There is a break in the projection of dreams and expectations of a healthy child in relatives. There is a possibility of change in family and child daily life, as it may require several medications and may often be subjected to hospitalizations for exams and treatment, handling of colostomy bags, administration of insulin, probes, oxygen catheters. Children may also face physical, psychic and social limitations, not even symbolized by relatives[25].

However, families, trying to reorganize and integrate them, adapt to care for the sick child and accept their diagnosis. Gradually, families accept and learn, live with children's chronic condition and resign themselves, continuing life. Feelings that seemed dormant emerge, such as joy, courage and strength to live and care[26]. The experience of the facts by families serves as a source of meanings that will be manipulated, modified and accepted, based on an interpretive process that guides their care actions in the environment in which they find themselves, according to children's needs[7].

For some relatives, the search for information about children's disease becomes a necessary resource to know the type of disease of children, enabling them to care for them. Italian study about children with chronic kidney disease emphasizes that relatives, having knowledge of children's pathology, its manifestations and implications, can develop quality care and autonomy, preventing child's relapses and health problems. In this sense, it was stressed the importance of health professionals and specialized care services as reinforcement of family understanding about children's health status, its limitations, the treatment adopted, specific care and its importance in the process of caring in an instrumental way[27].

Study limitations

A limitation of the discussion was the fact that it was a chronic disease of children in general, without considering the great diversity of diseases and/or associated comorbidities. The uniqueness of each disease presented by children participating in the study was reduced to a single and general category, "chronic disease", without problematizing the peculiarities of each one. It is emphasized the impossibility of generalizing the data due to the study being conducted in the hospital context. This made it difficult to deepen the theme in the family context, especially involving gender issues, because care was performed by women, predominantly centered on the mother figure.

Contributions to nursing

As subsidies for nursing practice, we consider the need for interaction between nursing/health professionals and family in prenatal care, especially with obstetric risk in order to minimize the risks to the newborn. Many of these children, after birth, are admitted to the Neonatal ICU, and family support is important for this period. Nurses can play an important role in assisting relatives in managing the therapeutic regime of these children, in effectively participating in the process of transition to home and subsequent follow-up. They give priority attention to children by providing complex therapeutic regimen, especially the medicated.

CONCLUSIONS

The study aimed to understand the meanings assigned by family caregivers about the diagnosis of chronic disease in children. When interacting with the nursing/health staff, relatives often perceives the existence of a disease in children, when born prematurely, or presents sequelae at birth, needing to be admitted to

the Neonatal ICU. Relatives are diagnosed with children's chronic disease by the physician. They feel unprepared, distressed, and guilty about the incurable disease of children, not accepting it. However, from diagnosis acceptance, they begin to seek information about the disease and to organize themselves for child care.

Children's diagnosis should be given to relatives by a qualified professional. Professionals aim to offer support in view of the impact of the news to the family member, contributing to their instrumentalization for care and transmitting information about the disease, as well as emotional support in the preparation of daily coping. The provision of information about the disease, care and treatment should be carried out between nurses and family clearly, according to their understanding, in the environment in which they live and interact.

It was concluded that family interaction with the nursing/health staff contributes to meanings assigned by relatives to children's chronic disease diagnosis. Nursing care planning for children and families allows them to go beyond meeting their health needs. Assistance expands towards the conquest of mutual trust, based on the effective search for the desired therapeutic success. For this matter, nurses need to be aware of children's and family's needs in order to offer comprehensive and humanized care, aiming to positively impact family care process.

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