

## CHRONIC ILLNESS IN CHILDHOOD AND ATTENTION FROM HEALTH SERVICES

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### ABSTRACT

The chronicity of a disease interferes particularly with family dynamics. Depending on its complexity and severity, families stay long periods in hospitals, are subjected to several admissions along with the child, go to many health services, share losses, limitations and care actions, have their cycles shaken and go through changes of roles and functions. Therefore, this study aimed to apprehend the perception of caregivers of children with chronic illness about the care provided by health services in the illness trajectory, through a descriptive and exploratory survey of qualitative approach conducted between April and June 2011. Interviews were held with seven mothers of children with a chronic illness at the pediatric unit of a public hospital in João Pessoa, Paraíba. Data were processed through the thematic analysis technique. Two categories were built: "Family caregiver, the trajectory since the child is diagnosed with a chronic disease at health services" and "Diagnostic confirmation and the impact of a child's chronic disease on the family as his or her primary unit of care". It was apprehended that families face a care process path permeated by confrontation, changes, conflicts, impact, concerns, insecurity and fear, with challenges related to the illness and the subjection to health services during the course of diagnosis and treatment. All this highlights the importance of expanding the significance of meeting the needs of children with chronic diseases and their families at health services in order to provide a comprehensive and effective care, having the family as the primary unit of a child's healthcare.

**Keywords:** Family. Care. Hospitalized child. Chronic disease.

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### INTRODUCTION

Throughout history, the family has been the primary social group in which human beings learn and interiorize the foundations of care, especially for children. This relation of interdependence between humans corresponds to an ethics of care. The family has a fundamental role in the wellbeing and health of its members, being capable of reducing disorders caused by hospitalization needs and minimizing aggravations and frequent hospitalizations, as in the situation of treating a child with a chronic illness<sup>(1-2)</sup>.

The chronicity of a child's disease oftentimes makes a family feel responsible for mitigating the effects triggered in this process, seeking to promote his or her development and growth as satisfactorily as possible, thus sharing losses, limitations and care actions, having their cycles shaken and going through changes of roles and functions. In this context, family care is regarded as a resource for professionals to expand the

level of healthcare, taking this perspective as part of their praxis and professional practice. Thus, pediatric care means engaging children and individuals that are significant to them in this care, which is, involving their family, represented by the family caregiver<sup>(1,3-4)</sup>.

In the case of a chronic disease, a family's routine becomes difficult and exhausting, especially when children are hospitalized. To be involved in the care and ensure they are followed-up in the hospital, families experience a deconstruction in their dynamics and have to reformulate their everyday routine so as to care for hospitalized children<sup>(5-6)</sup>, because every phase of the illness process will cause changes in the life of the children and their families and might lead to conflicts and other negative implications<sup>(5)</sup>.

Depending on the complexity and gravity of a chronic disease, families stay in hospitals for long periods, which triggers difficulties related to available structural and emotional conditions, in addition to involvement and exhaustion on the part of families while coping with the disease

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and, oftentimes, with formation of family and social networks of support. In this sense, these families need to share personal feelings and be encouraged in their own ability of caring for their children in order to regain balance<sup>(1,4-7)</sup>.

The entire process following the onset of a chronic disease in children has also been relevant to reflections on a child's healthcare and on implications derived from the search for a solution to health problems<sup>(8)</sup>. Amidst this situation, family caregivers appeal to healthcare networks, whether on a city or state level. They receive the diagnosis and comply with the treatment provided by these health services, which depends on organization, coordination and care continuation, at times considered complex and hard to be incorporated into the routine of the families in which those caregivers will be inserted, oftentimes without a support to the families for the continuation of care.

It should be recognized that care face a chronic disease in children is a reflex of the therapeutic path walked by family caregivers through a healthcare network. The latter, in turn, consists of a range of health services with common goals, without hierarchy between its constituent levels – primary, secondary and tertiary – but with an interconnection between them, in which all are equally important, aiming at providing services that are consonant with available evidence, and a continuous and comprehensive attention.

Within this integrated network, primary health care (PHC), is considered as the gateway to health services, acting as a coordinator of care, ordering flows and counter-flows of people, products and information between different components in the network. It is the preferred space for the promotion of a child's health in the sanitary domain, bearing in mind that most preventive and curative interventions in childhood is technologically simple, dispensing with hospital care<sup>(9)</sup>. On the other hand, in cases that need more technologically complex interventions, primary healthcare is the bridge that connects different levels, allowing for the continuation of care by coordinating attention, because the complexity of changes imposed by the chronic condition (physical, emotional, development and behavior) often extrapolates primary household care.

The healthcare network for people with chronic diseases adopts a health model aimed at a coordinated, continuous, organized, proactive and integrated care that is also capable of supporting individuals as their lives change with the requirements of the disease, without disregarding individual desires. This care should be mainly performed by and in primary healthcare. As coordinator of care, PHC must point the way users should take in this network of attention when it comes to chronic patients in order ensure a comprehensive and quality care<sup>(9-17)</sup>.

The way the coordination of care networks is organized, towards ensuring the integration of practices and care continuation, greatly interferes with the way a family takes care of a child, and requires from involved health professionals accountability and search for a comprehensive healthcare, as well as the construction of a work dynamics and care management tools that seek to expand resolution possibilities for this care, having the understanding of the child-family relationship as fundamental pieces of the process of caring<sup>(4)</sup>.

Bearing in mind the singularities presented by the family caregiver of a child with chronic disease, health service professionals need to deepen their understanding about the meanings of human care and health and apprehend how the trajectory of the child-family complex interferes with this illness process. There is a scarce number of studies approaching this theme, but this understanding is of great relevance because, based on it, nursing will be able to reconsider professional care throughout healthcare networks that contemplate a subject's needs as the agent of care in the illness process of children with chronic disease.

Face the abovementioned, this study aimed to apprehend the perception of family caregivers of children with chronic diseases about the attention provided in the illness trajectory from health services.

## METHODOLOGY

This is a descriptive-exploratory study with a qualitative approach conducted from April to June of 2011, at the pediatric unit of a public hospital located in the city of João Pessoa, PB, considered

as reference in Paraíba and other states for the treatment of chronic diseases in children aged from 0 to 18 years old.

The research subjects were family caregivers of children diagnosed with a chronic disease, selected according to the following inclusion criteria: being the family caregiver of a child with chronic disease, regardless of the time of diagnosis, and residing in João Pessoa or in the metropolitan area. The criterion that ended data collection was sufficiency, that is, when the assessment of the empirical material allowed outlining a comprehensive picture of the investigated matter<sup>(10)</sup>. Thus, seven companions/caregivers were included in the study.

Empirical material was collected through the semi-structured interview technique using the recording system, with the following guiding question: "How would you describe the attention from healthcare services since your child has been diagnosed with a chronic disease?"

Empirical data were interpreted according to guidelines on thematic analysis, which consist of: data arrangement; data classification and final analysis<sup>(10)</sup>. This method establishes the organization of data encompassing all collected material, which, in our case, it is the interviews. Thus, the interviews were read and transcribed for a first organization of reports in a certain order, which soon provided a classification and outlining of the horizontal map of the material. Subsequently, considering the proposed objectives, an exhaustive and repeated reading of the texts was carried out, establishing an interrogative relation with them so as to apprehend structures of relevance. This procedure allowed elaborating a classification by means of transversal reading. Then, based on the structures of relevance, the classification was filtered, with the regrouping of the most relevant themes for the final analysis.

The research complied with all ethical observations set forth in Resolution 466/12, particularly regarding the subjects' consent and autonomy, being approved by the Research and Ethics Committee of Lauro Wanderley University Hospital (protocol No 619/10). The subjects signed an informed consent form. In order to preserve the participants' anonymity, they were identified by a capitalized letter "M" to designate the family member, followed by numbers according to the order in which the interviews were conducted.

## RESULTS AND DISCUSSION

The study participants were all mothers, with three coming from nuclear families (father/stepfather mother and children) and four from semi-nuclear families (mother and children). As to children, there were six girls and one boy, all aged between three months and eight years old and suffering from the following chronic diseases: cardiopathy (1), cystic fibrosis (2), nephrotic syndrome (2), mitral insufficiency (1) and pinodysostosis (1).

The perception of family caregivers of children with chronic diseases about the attention from healthcare services is permeated by changes deriving from a new trajectory: coping with the disease daily, implications to the family's capacity to take care of the children, conflicts and difficulties in the search for and confirmation of the diagnosis of chronic disease and, the treatment and impact of chronic diseases on health services.

This new trajectory brings vulnerability to a family's routine for the need to care for and being cared for<sup>(2)</sup>. Vulnerability is the universal expression of the fragility of human condition; condition of suffering, abnormality, incapacities, etc<sup>(11)</sup>.

People are vulnerable to the extent that, given their fragility, they need protection, solicitude and care<sup>(11)</sup>. The situation of vulnerability face the disease puts family caregivers before repercussions in the life of child, as well as difficulties as to access to and resolubility of healthcare. The thematic analysis of this perception of family caregivers provided two categories, which will be presented and discussed below.

### **Family caregiver: course of the diagnosis of chronic disease in children at health services**

Thinking a child might be suffering a chronic disease is distressing for families and this process aggravates when the path towards defining a diagnosis is permeated by the rationality of the organization of health services<sup>(12)</sup>.

The disease constitutes a way that is oftentimes long, tough and unpredictable marked by the search for access to services and resolubility in health actions that define the child's problem. Family caregivers and children start to experience many hospitalizations with a back-and-fourth at different hospitals, in many cities, with different

opinions from health professionals, in addition to a series of exams<sup>(8)</sup>.

[...] I went to hospital A and (the doctor) referred us to hospital B. When I got there, there was no vacancy left, so they referred us to hospital C. After 15 days I got a vacancy here. I came and spent 14 days here (M1);

[...] the first time, she was admitted to this hospital, the second time to another, and the third time to a different one, and only there, in the third hospital, it was found what was her problem; (M2);

[...] you see, it's been eight years of struggle but so far nobody has a complete diagnosis (M4);

[...] she was hospitalized in November, left the hospital in February. In March, I went to the doctor and she asked for a series of exams [...] Around 15 days ago I went to another doctor [...] it was when he saw her exams and said it was cystic fibrosis (M6);

The caregivers manifest the difficulties they face concerning healthcare services towards the definition of the diagnosis of the child's chronic disease. They are difficulties referring to the organization of services, especially due to the existence of a mismatch between the family caregiver's perspective, who looks for a resolute healthcare, and the rationality of the service, which shows contradictions in the coordination of the flow in the attention network and the effectiveness of actions, which causes conflicts and dissatisfaction from users<sup>(8)</sup>.

The form the integrality of SUS health services is structured does not respond adequately to demands imposed on the needs of the clinical handling of chronic conditions: a complex process involving care practices, multiprofessional approaches and guarantee of care continuation<sup>(4)</sup>. This occurs due to a fragmentation of health actions between managers and services and between services and the personnel in charge of diagnostic and therapeutic support, causing a disarticulation in the clinical practices of different professionals in relation to users<sup>(4)</sup>.

When there is no guarantee of care continuation, its longitudinal nature, families go through adverse situations face the children's disease and its repercussions, especially when their act of caring is an attitude, inherent to all human beings, of concern, occupation, accountability and emotional involvement with the individual being cared for<sup>(8,13)</sup>.

Family members and children, faced with the disease, become vulnerable when entering a situation of subjection to hospitalizations in the illness process, seeking a definition for what is going on with the child's health, which configures a routine of admissions and discharges, with situations getting worse or better, in short and sudden periods of time. It is possible to see that family caregivers and children become submissive, that is, are subjected to the sector organization of hospital care and to a resolubility that does not lead to an immediate solution to their existing problem.

[...] she just keeps on being hospitalized and taking medication, that's it, she goes to hospital, stays there a while, and then comes back, despite the medication [...](M2).

[...] they said his case required surgery, but they still had to decide if that'd be done in Recife, but there was no vacancy there [...]. Then, with his diagnosis, they asked for us to go to Paraná [another state], they said it was a reference place. (M7).

Health services are responsible for taking care of citizens, meeting the needs of users, who are given assistance to have their problems solved and an efficient result. Different approaches to the resolubility of health services are pointed out by researches and involve aspects relating to demand, accessibility of services, use of technologies in the health sector, existence of a pre-established reference system by level of complexity of primary healthcare, right to health, formation of human resources, the population's health needs, users' compliance with the treatment, cultural and socioeconomic aspects of clients, their satisfaction, and others<sup>(15)</sup>.

This journey through health services starts at the gateway of the system, in primary healthcare on a local level, since the child starts to manifest the most striking signs and symptoms of the disease. The way the family is welcomed in the process of definition of the diagnosis and the explanations they receive have an important impact on how they will cope with the disease<sup>(16)</sup>. Although the confirmation of the diagnosis of a chronic disease is not always effected in PHC (Primary Healthcare), the problems to be faced by the family start to be evidenced. Delayed medical referral in secondary health networks, that is, specialties, goes through the organization of the care network for the definition of the diagnosis, and the choice might be punctual and based on

signs of complications that evidence that the disease requires a differentiated level of complexity aiming at a deepened investigation carried out by health professionals that make referrals to reference hospitals.

The organization of the care network of health services, by failing to provide means for some specific exams in case of suspected chronic diseases within the local care network at hospital level, leads the service provider to a need for referral to other institutions of the health service network towards an assistance that actually solves the problem<sup>(15)</sup>, quick diagnosis, as well as a specific treatment for the disease. This routine reality of referrals that require long trips for services directed to the level of greater complexity triggers in families and children damages, sufferings and difficulties derived from the wait for a definitive diagnosis.

When it comes to a child's health, it must be recognized that the illness process and healthcare refer to a complex reality with multiple causes, which demand, therefore, multiple responses and different perspectives from the Brazilian Unified Health System. Among these different perspectives, health services, especially those of the secondary and tertiary levels, see resolvability as the act of providing children with all medical technology available, prioritizing the definition of the pathological diagnosis and the treatment of each case, in order to approach the individual and collective dimensions of health problems, considering, additionally, a comprehensive approach to these problems<sup>(17)</sup>.

Considering the hospital-level resolvability, the utilization of health technologies becomes a necessity to the obtainment of answers that contribute to the positive effect of health actions from a population's perspective<sup>(17)</sup> and in their classification as a reference in health.

The contradiction of these different forms of perceiving resolvability occurs when secondary and tertiary-level sectors of health networks, responsible for the greatest complexity in health care, do not respond with their actions to what they propose, frustrating a family's expectations. Oftentimes, the response from health services are repeated hospitalizations of children for the definition of a diagnosis adequate treatment. This situation, for family caregivers, is understood as a delay in the specific treatment and the

minimization of problems related to the disease. All this could be mitigated through a dialogical relationship between parties involved in this process. Communication helps with the coping with actions that shake one's emotional aspect when it comes to the family of a child undergoing procedures whose meaning given by the family caregiver interrogates life and the cure<sup>(17)</sup>.

On the other hand, the delay in receiving a definitive diagnosis leads families to walk through a long path in the care network of health services, oftentimes poorly structured and with care processes that barely meet the real needs of families in the children's illness process.

### **Diagnostic confirmation and implications of a child's chronic disease for the family as the primary unit of care**

The search for confirmation of a disease brings adverse reactions when its chronicity is confirmed. It brings vulnerability as the proof of the fragility, finitude and mortality of all individuals<sup>(11)</sup>. The caregiving family does not expect a child falling ill or a chronic disease. The trajectory that starts with the child falling ill and then continues with the confirmation of the diagnosis of the chronicity of the disease shakes the structure of any family caregiver and leads him to a routine of doubts and fears about the disease having a cure or not and, consequently, about the child's survival chances<sup>(5)</sup>:

[...] because a mother does not expect that, right? I, with four [children] all doing fine, healthy, I didn't expect [...](M1);

[...] because we think we have healthy child but all of a sudden you find out he has chronic disease that has no cure, a lot of things change, we go crazy[...](M5).

[...] like, I still can't believe it, I feel like in a dream [...] I always look it up on the internet and read that is has no cure, no cure. (M6).

The emotional shock a family caregiver goes through with the advent of a chronic disease can be observed in their actions after they received the diagnosis, causing an unbalance<sup>(18)</sup>. This emotional shock surprises caregivers and, at the same time, reveals the absence of a care ethics for professionals to embrace this vulnerability that sets in a meaningful moment, in which needs are made known when one listens, when there is affection, support and trust on the part of the carer and the one being cared for.

When I received the diagnosis I began to laugh, got really agitated, speaking loudly, and asking a bunch of stuff: Is there a treatment? How is that? What am I going to use? Then he looked at me said: 'calm down, calm down, mom' [...]. Like, I still can't believe, I feel like in a dream, I'm not gonna lie[...] (M6)

Feelings of affliction, fear, tension, insecurity, agitation and concern on the part of caregivers are present during the trajectory of a chronic disease in children. The family circumstance of a chronic disease, recurrent hospital admissions, fear of complications and death are responsible for triggering these feelings. This emotional instability that is proper of these moments of crisis has an impact on one's relationship with hospital institutions and hinders re-adaptations and strategies for the coping with the disease, in both personal and family fields of the situation(1,18). A study states that, regardless of the time of diagnosis of their children's disease, some parents keep suffering in other phases of the disease and need encouragement in order to seek support to cope with this<sup>(19)</sup>.

Within this context, doubts about the illness process end up leading families to dilemmas between the cultural immortality and the finitude of the earthly presence of the child being<sup>(11)</sup>. Family caregivers, face this vulnerability and this finitude, can form emotional and trust bonds to minimize afflictions, distress and the fear of death.

[...] the only fear I have is not because he has the disease, because the comments is that this disease doesn't reach 12 [years]. I fear that I'm raising my son, educating my son, to death, you know? I'm so afraid of that. (M5).

[...] the doctor told me that his case is rare, so I can't stop thinking about all this, I get even more afraid of losing him (M7).

[...] as soon as he starts to bloat I run, because I fear that something worse will happen (M3).

The confirmation of the child's chronic disease, by influencing directly the emotional stability of his or her family and main caregiver is described as the causer of a great impact, generating a state of shock, crying spells and even depression crises:

[...] I started crying in the afternoon and by night, I couldn't stop crying. I would work all week crying, I couldn't stay alone that I started crying. Then, on a Sunday, I was home, called her father and said: 'come pick your children that I can't take this

anymore', and cried. He came and I didn't want the kids around me. I didn't want to talk to anybody; I didn't want to eat, so that day they took me to hospital. [...] Then the doctor asked me what was going on. I told her that that had been happening for a long time so I exploded, couldn't handle that all by myself. So I'm taking medication (M2);

[...] I'm taking medication but it's not working because my problems are bigger than me (M4).

The family caregiver finds herself subjected to a heavier load of emotional changes. The prognosis of a chronic disease in children generates situations of stress for most family members<sup>(2,7)</sup>.

The emotional instability experienced by family caregivers does not sets in in an isolated manner but comes from an entire illness process that starts since children develop the first signs and symptoms of the disease, requiring hospitalization, going to many hospitals searching for an answer and consequent solution to their problems, until the delay in receiving a definitive diagnosis of the disease and the outcome of the situation.

The illness process in children also comprehends difficulties related to care, limitations imposed by the disease and fear of death. Therefore, it is important that health professionals do not ignore emotional needs of the family nucleus, since, in this illness process, families become vulnerable.

By learning about a child's disease, families will be better equipped to care for this human being meet the needs derived from the chronic condition<sup>(20)</sup>. Thus, family caregivers need to be provided clear information as a form of support from health professionals and have their doubts clarified, after the confirmation of the chronicity of the child's disease, in a dialogical relationship in which care presupposes the existence of emotional bonds and execution of tasks to meet emotional needs and strengthen the family group in the sense of emphasizing capabilities and improving human conditions in the living and dying process<sup>(2)</sup>.

The counterpoint between living and coping with the disease and its uncertainties, between aggravation, improvements and cure, generates conflicts in the family core; conflicts regarding the role of the family as a caregiver face the subjection to decisions imposed in the path to be walked, in the access to the health system as a fact of one's everyday life for an uncertain period.

In the emotional domain, family caregivers reveal the implications that the confirmed diagnosis of a chronic disease in childhood brings to a family because, in addition to encompassing body or organic changes in children, restricting relatively their physical capacity and elaboration of situations of psychological, cognitive and emotional order, the chronicity of the disease causes social changes in all members of the family group, when they are assigned duties and/or responsibilities as to the coordination of the care to be provided<sup>(6)</sup>.

Thus, it is believed that health services have a fundamental role in the care for children with chronic diseases and their families by taking on a humanized healthcare, to the detriment of changes in the life of family members, especially mothers, who are culturally the main caregivers from a gender perspective<sup>(2)</sup>. The understanding of the experienced situation reveals that the relation of family interdependence consists of a system of living relations spanned by moments of balance and unbalance, which need care as a basis to survive and develop as people from a family<sup>(2,7)</sup>.

## FINAL CONSIDERATIONS

The journey marked by the search for access to services and solutions through health actions to children with chronic diseases and subjection to hospitalizations when situations becomes worse, in short, sudden or long periods of time, under the organization of the healthcare network, structured and with care processes that do not meet a family's real needs, represents the trajectory of a family in the illness process, as elucidated in the reports of the children's caregivers.

This trajectory discourages the understanding of care provided in health services as a comprehensive care targeting the needs of the child user who is dependent of a family, as preconized by policies on child's health of the Brazilian Unified Health System.

Families experience, with the confirmation of the chronicity of the disease, a deconstruction in their dynamics, reformulating their routine so as to take care of children coping with their diseases.

The impact of a child's chronic disease influences a family's emotional instability, making the latter vulnerable.

Apprehending the perception of families of children with chronic diseases about the care provided at health services leads to discussions on healthcare in the pediatric context, which, despite having broadened concepts about the characteristics and singularities of each family nucleus, needs to be incorporated into the praxis of health professionals. This is a gap that remains throughout discussions on the need for transforming a child's healthcare, but its relevance can promote a reflection by social actors that are part of the network of health services, whether managers or professionals. This reflection instigates one to re-think what changes can be implemented in healthcare actions with the aim of providing children with chronic diseases and their family caregivers new work and attention dynamics, which is vital to expand possibilities of resolution to this type of care. For this reason, the incorporation of the child-family relation needs to be understood as fundamental in the process of caring, breaking with the fragment view that the ethics of care is not part of healthcare.

Face all human conditions of fragility, humanized actions and initiatives should be promoted so as to reach vulnerable human beings, actions to be established in care relations, bringing confidence and dialogue as a means to a type of care that goes beyond the health sector to be transformed into an ethics of care for human action.

At the same time, it is worth highlighting the importance of healthcare networks reflecting on the impacts of their own fragilities in terms of how the health system is organized, especially when it comes to the coordination of care networks, aiming at incorporating and expanding the meaning of the needs of system users, expanding the network of social support that works as a foundation to this process marked by the child's chronic disease, and the understanding of how to act face demands necessary to keep the family's stability as part of the healthcare context.

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## DOENÇA CRÔNICA NA INFÂNCIA E A ATENÇÃO DOS SERVIÇOS DE SAÚDE

### RESUMO

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A cronicidade da doença interfere sobremaneira na dinâmica familiar da criança. Dependendo da complexidade e da gravidade da doença crônica, as famílias permanecem longos períodos no hospital, são submetidas a várias internações junto com a criança, passando pelos diferentes serviços de saúde e compartilhando perdas, limitações e cuidados, sofrendo abalos em seu ciclo, mudança de papéis e funções. Sendo assim, objetivou-se apreender a percepção do cuidador familiar de crianças com doença crônica acerca da atenção prestada na trajetória do adoecimento pelos serviços de saúde, por meio de estudo descritivo-exploratório de abordagem qualitativa, desenvolvido entre abril e junho de 2011. Realizaram-se entrevistas com sete mães de crianças com doença crônica em uma unidade de pediatria de um hospital público em João Pessoa (Paraíba). Os dados foram interpretados mediante a técnica de análise temática. Foram construídas duas categorias: "Cuidador familiar, a trajetória do diagnóstico de doença crônica da criança nos serviços de saúde" e "Confirmação diagnóstica e as repercussões da doença crônica da criança na família como unidade primária do cuidado". Apreendeu-se que a família enfrenta um processo de cuidado permeado por uma trajetória de enfrentamentos, mudanças, conflitos, impacto, preocupações, insegurança e medo, surgindo desafios inerentes ao adoecimento e ao assujeitamento aos serviços de saúde durante o trajeto do diagnóstico e tratamento. Evidencia-se a importância de ampliar o significado de atender as necessidades da criança com doença crônica e sua família nos serviços de saúde a fim de prestar cuidado integral e resolutivo, apreendendo a família como unidade primária do cuidado à criança.

**Palavras-chave:** Família. Cuidado. Criança hospitalizada. Doença crônica.

## ENFERMEDAD CRÓNICA EN LA INFANCIA Y LA ATENCIÓN DE LOS SERVICIOS DE SALUD

### RESUMEN

La cronicidad de la enfermedad interfiere muchísimo en la dinámica familiar del niño. Dependiendo de la complejidad y gravedad de la enfermedad crónica, las familias permanecen largos períodos en el hospital, son sometidas a varias internaciones junto al niño, pasando por los diferentes servicios de salud y compartiendo pérdidas, limitaciones y cuidados, sufriendo cambios en su ciclo, mudanza de roles y funciones. Así siendo, el objetivo fue comprender la percepción del cuidador familiar de niños con enfermedad crónica acerca de la atención prestada en la trayectoria de enfermedad por los servicios de salud, por medio de estudio descriptivo-exploratorio de abordaje cualitativo, desarrollado entre abril y junio de 2011. Se realizaron entrevistas con siete madres de niños con enfermedad crónica en una unidad de pediatría de un hospital público en João Pessoa (Paraíba-Brasil). Los datos fueron interpretados mediante la técnica de análisis temático. Fueron construidas dos categorías: "Cuidador familiar, la trayectoria del diagnóstico de enfermedad crónica del niño en los servicios de salud" y "Confirmación diagnóstica y las repercusiones de la enfermedad crónica del niño en la familia como unidad primaria del cuidado". Se comprendió que la familia enfrenta un proceso de cuidado permeado por una trayectoria de enfrentamientos, cambios, conflictos, impacto, preocupaciones, inseguridades y miedo, surgiendo retos inherentes a la enfermedad y al sometimiento a los servicios de salud durante el trayecto del diagnóstico y tratamiento. Se evidencia la importancia de ampliar el significado de atender las necesidades del niño con enfermedad crónica y a su familia en los servicios de salud a fin de prestar cuidado integral y resolutivo, comprendiendo a la familia como unidad primaria del cuidado al niño.

**Palabras clave:** Familia. Cuidado. Niño hospitalizado. Enfermedad crónica.

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