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# Healthcare to youth with chronic illness

# Cuidado à saúde nas doenças crônicas infanto-juvenis

# Cuidado de la salud en las enfermedades crónicas infantojuveniles

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This study aims to analyze the health care of children and adolescents with chronic illnesses. It is a qualitative research, carried out with ten caregivers of children/adolescents with chronic illnesses, with the aid of a map speaker and an in-depth interview, from March to May 2015. The data were interpreted by the thematic analysis proposed by Minayo. Three categories were elaborated: "*First steps in the search for care*"; "*Factors that influence care*"; and "*Daily care: rearrangements in family routine after the diagnosis of chronic illness*". Family pilgrimage through health services was identified due to limited, non-resolving care and difficulties in accessing primary care; lack of preparation of professionals at different levels of care to deal with chronic childhood and youth illnesses; impaired communication between services; lack of accountability of public agencies in follow-up and supply of inputs. We highlight the welcoming to others who come to their aid, qualified and sensitive listening and the ethics of responsibility as anchoring elements for care in chronic conditions of children and adolescents.

**Descriptors:** Delivery of health care; Chronic disease; Child; Adolescent; Caregivers.

Este estudo tem como objetivo analisar o cuidado à saúde de crianças e adolescentes com doenças crônicas. Trata-se de uma pesquisa qualitativa, realizada com dez cuidadores de crianças/adolescentes com doenças crônicas, por meio de mapa falante e entrevista em profundidade, de março a maio de 2015. Os dados foram interpretados pela análise temática proposta por Minayo. Três categorias foram construídas: "*Primeiros passos na busca pelo cuidado*"; "*Fatores que influenciam o cuidado*"; e "*Cotidiano do cuidado: rearranjos na rotina familiar após o diagnóstico da doença crônica*". Identificou-se peregrinação das famílias pelos serviços de saúde devido a atendimento limitado, não resolutivo e dificuldades de acesso na atenção primária; falta de preparo de profissionais nos diferentes níveis de atenção para lidar com as doenças crônicas infantojuvenis; comunicação prejudicada entre os serviços; desresponsabilização dos órgãos públicos no seguimento e fornecimento de insumos. Destacam-se o acolhimento ao outro que vem a seu encontro, a escuta qualificada e sensível e a ética da responsabilidade como elementos de ancoragem para o cuidado nas condições crônicas infantojuvenis.

**Descritores:** Assistência à saúde; Doença crônica; Criança; Adolescente; Cuidadores.

This study aims to analyze the health care of children and adolescents with chronic illnesses. It is a qualitative research, carried out with ten caregivers of children/adolescents with chronic illnesses, with the aid of a map speaker and an in-depth interview, from March to May 2015. The data were interpreted by the thematic analysis proposed by Minayo. Three categories were elaborated: "*First steps in the search for care*"; "*Factors that influence care*"; and "*Daily care: rearrangements in family routine after the diagnosis of chronic illness*". Family pilgrimage through health services was identified due to limited, non-resolving care and difficulties in accessing primary care; lack of preparation of professionals at different levels of care to deal with chronic childhood and youth illnesses; impaired communication between services; lack of accountability of public agencies in follow-up and supply of inputs. We highlight the welcoming to others who come to their aid, qualified and sensitive listening and the ethics of responsibility as anchoring elements for care in chronic conditions of children and adolescents

**Descriptores:** Prestación de atención de salud; Enfermedad crónica; Niño; Adolescente; Cuidadores.

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## INTRODUCTION

Chronic illnesses deal with several health problems that require long-term treatment and usually demand permanent care, generating the need for comprehensive and systematic ful-time care for the individual, family and society[1]. Among these diseases, non-communicable diseases stand out, such as cerebrovascular, neurological, cardiovascular, diabetes mellitus, neoplasms, asthma, genetic disorders and obstructive respiratory diseases[2].

Children and adolescents who have these diseases have their health demands met at home by family members who often perform complex care without the necessary technical knowledge and technologies available in hospital, as well as without the support of health professionals to manage this home care[3]. These are called informal caregivers, as they take charge of these responsibilities with a view to improving the child's health and quality of life[4], and resorting to formal caregivers from the Health Care Network (HCN) in search of assistance.

Chronic illnesses, as they are often difficult to diagnose, treat and/or rehabilitate, require comings and goings of the individual, social group or family to the HCN services in search of meeting the demands that arise from them, from diagnosis to monitoring/treatment[1].

For the care of people with chronic illnesses within the scope of the Brazilian Unified Health System (*Sistema Único de Saúde - SUS*), HCN recommends articulation of services to guarantee comprehensive care by offering health promotion and protection actions and services, preventing aggravation, diagnosis, treatment, rehabilitation, harm reduction and health maintenance[5]. The expectation of effectiveness of the HCN is that care is expanded and longitudinal, so that assistance levels interact with each other to meet the demands of people with chronic illnesses[6].

However, in the search for care in the HCN, families of children/adolescents with chronic illnesses face challenges and weaknesses, such as: poor communication between services, lack of welcoming by Primary Health Care (PHC), delay in obtaining referrals to specialists, lack of resources or services in the community to support these people, in addition to lack of knowledge of some health professionals on issues related to the chronic condition and its management[7].

These weaknesses are also evident in other countries, such as England, which, despite having achieved improvements in pediatric care, has not yet managed to advance the issue of coordination and access to services to meet the needs of children with chronic illnesses[8]. Thus, the family remains vulnerable to the chronic condition, having to wander through various services in search of resolutive care[6,9].

To be effective, care actions must understand the interactional dimension between individuals, encompassing not only technical and technology application, but welcoming reception and empathy, which are fundamental resources for a line of care in the HCN[10].

Therefore, there is a need for the elaboration of action/interaction strategies by health professionals, through articulation of multiple knowledge and practices, considering the complexity of the child with a chronic condition and their family, being multidimensional beings, to fully meet their needs[11].

It is essential to be sensitive to the singularities of the family, opening spaces to listen to their demands in the certainty that there will be accountability of self (health professional) to the other (child/adolescent/family), in the establishment of a face to face relationship with a view to building the bond between health professionals and users[6].

In this sense, it is highlighted the relevance of this study's proposal to analyze this care as a primordial strategy for understanding their needs, as well as for future social and health interventions in order to improve care for this population.

Given the above, the question was asked: *How is the care of children/adolescents with chronic disease configured in search of care in the HCN?* Thus, the aim of this study was to analyze the health care of children and adolescents with chronic illnesses.

## METHOD

This is a descriptive-exploratory, qualitative study, carried out with families of children and adolescents with chronic illness registered in Family Health Units (FHU), services that integrate Primary Health Care (PHC) of the five Sanitary Districts (SD) (I, II, III, IV and V) of a municipality in the state of Paraíba, Brazil, from March to May of 2015.

Caregivers who met the following inclusion criteria participated in the study: being the main caregiver of the child/adolescent with chronic illness, being over 18 years of age and accompanying the child/adolescent with chronic illness while seeking care at health services, children and adolescents under their care who have been diagnosed with chronic disease for more than six months and aged between 0 and 18 years. The exclusion criteria consisted of a caregiver with communication problems to express the experiences lived by the HCN.

The choice of the FHU was for convenience purposes, and the choice of participants followed indication of health professionals of these services, who provided the families' address and telephone number for contact in order to know their interest in participating in the research and schedule a meeting for data collection, if they so accepted.

As a data collection strategy, the Map Speaker technique[12] was initially used, in which the participant was asked to illustrate on paper the path taken with the child/adolescent by the health services from the beginning of the first signs and symptoms to the present days. This technique allowed the participant to reflect on services performed and contributed to the conduct of the interview conducted later.

The Map Speaker constructed was used as a trigger for the in-depth interview question: "*I would like you to report on the assistance offered by these health services when you sought care for your child/relative with chronic illness, from the beginning of the first signs and symptoms to the present day* ".

The interviews, with an average duration of 40 minutes, were recorded at the interviewees' home, after the consent of the participants, and transcribed in full. Data collection ended with the criterion of data sufficiency[13], that is, when the researcher and an expert on the theme judged that the material produced allowed a thorough understanding of the object under study.

The data were interpreted based on the guidelines of the thematic analysis proposed by Minayo[14]. All empirical material was subjected to exhaustive readings, allowing a first organization and systematization of data. Then, the central thematic units were identified and the final analysis was carried out by means of an interpretative synthesis with inferences based on the relevant literature.

The research was approved by the Research Ethics Committee under Protocol No. 054/2014; CAAE 27102214.6.0000.5188. All participants signed the Free and Informed Consent Form (ICF). As a guarantee of anonymity of the participants, they were identified in the text by the letter F (Family member) accompanied by ordinal numbers (F1, ..., Fn), concerning the order the Map Speaker and respective interview were performed and, for each health institution mentioned by participants, they were replaced by random letters (A, B, C, D, E, F).

## RESULTS

Ten caregivers participated in the study: seven mothers, one father and two aunts, between 19 and 49 years of age; the time of living with the chronic condition ranged from six months to 14 years; monthly family income between one to three minimum wages. One of the aunts (F2) took care of an adolescent during the day in order for the mother to work and the other aunt participating in the study had the adolescent's custody (F4) due to the mother's neglect of his treatment. The participating father (F10) took care of the child during the day in order for the mother to work, as he worked the night shift.

Table 1 shows the characterization of children and adolescents with chronic illness in the families surveyed.

**Table 1.** Children and adolescents with chronic illness of the surveyed families. Paraíba, 2015.

| **Cod** | **Age** | **Chronic Illness(es)** |
|---|---|---|
| F1 | 4 years old | Congenic cardiopathy |
| F2 | 14 years old | Hodgkin's lymphoma |
| F3 | 15 years old | Epilepsy |
| F4 | 13 years old | Type 1 diabetes mellitus; Hypothyroidism; Chronic liver disease |
| F5 | 11 years old | Type 1 diabetes mellitus |
| F6 | 8 years old | Asthma |
| F7 | 15 years old | Congenital Adrenal Hyperplasia - CAH |
| F8 | 4 years old | Type 1 diabetes mellitus |
| F9 | 11 years old | Cerebral palsy |
| F10 | 8 years old | Asthma |

With the analysis, the following thematic categories were constructed: "*First steps in the search for care*"; "*Factors that influence care*"; and "*Daily care: rearrangements in family routine after the diagnosis of chronic illness*".

### *First steps in the search for care*

In view of presentation of the first signs and symptoms of the disease in the child/adolescent, the initial attempts to solve the problem are found in the family subsystem, in the FHU and/or in a specialist physician:

*[...] The lump did not disappear with the medication I gave at home, so I decided to take him to the FHP doctor, who examined him and said that I could not do anything for him and already referred him to hospital A* (F2, aunt).

*She* (mother) *took* (name of the teenager) *at the FHU, but they never tested to see if it was Diabetes, because it was unlikely for a child to have it. When his health worsened and he almost died, his mother took him straight to hospital C* (F4, aunt).

However, when asked about the reasons for not seeking the FHU in order to have access to medications and care of the children/adolescents under study, the caregivers reported lack of credibility in the resolving potential of this service.

*[...] because in the units* (FHU) *it is so difficult to treat his case* (child with asthma). *[...] it doesn't solve anything ... there isn't even a doctor to treat it* (F6, mother).

*Last year ants appeared in her urine and that's when I became desperate. The other day I went for a private exam, suspecting diabetes. He charged a rate of 230 in the blood* (mg/dl) [...]. *First, I did a basic diet at home, everything integral, but it didn't work. Then I bought a glucose device to keep it under control, but I couldn't lower it just with food. So I went to the endocrinologist at Ambulatory B* (F8, mother).

*[...] when we got there* (FHU) *and saw that the service would take a long time,* [...], *we looked for the fastest* (hospital) *and we didn't go after the FHU anymore. It doesn't help me* (F10, father).

In addition to problems faced at the FHU, occasional and short-term consultations also did not favor early and correct diagnosis, making it difficult to resolve health demands of children/adolescents with chronic disease:

[...] *after six months, he didn't want to take the breast, he cried and I didn't know what it was. I took it to the pediatrician, who said it was normal, a baby thing. After a year he came back from nothing to stand still, he didn't blink, he didn't even want to eat ... I took it to another doctor who said it was a "tantrum". A year went by and the crying went on and on,* [...] *we took him to the hospital, the doctor came, asked for more tests, said it could be beginning of epilepsy and referred me to another doctor who attended by SUS. Tomography, an MRI scan was done, we spent a lot of money, but we discovered the disease* (F3, mother).

[...] *every month I took her* (adolescent) *to childcare* (when I was a child). *The pediatrician said: "her breasts are very big ... I will refer you to the endocrinologist to make an evaluation".* [...] *he looked at her and asked for some ultrasound and blood tests. I came back to show the result, but it didn't explain anything to me, I just said that she was too young to investigate, but when I was about three years old or more I would come back* (F7, mother).

### *Factors that influence care*

Families go through different paths in the HCN in search of care, diagnosis and treatment to solve the problem. Nevertheless, the conflicting relationships experienced reflected in the care offered:

[...] *When I took* (the teenager's name)*, the doctor looked at him, was disgusted and said: "look, what is this"? Because of his belly, she didn't even come close and said she wasn't going to care for him, because he was accompanied by hospital A and that there* (hospital C) *did not attend his case, that it was Calazar. I was disgusted and said a lot to the doctor.* [...] *I took it on my own to hospital C because* (name of the teenager) *was unable to breathe.* [...] *they referred him to hospital A, where doctors discovered that he did not have Calazar, but Diabetes. At hospital A, they monitored his diabetes, gave him medication and he gets the treatment there. The whole team already knows him, I feel more relaxed* (F4, aunt).

In an attempt to obtain timely and resolutive care for the clinical care of children and adolescents, families sought services where family members or other known parents in waiting rooms were successful in therapeutic responses:

*After he went home, about 15 days later he became ill, it was when I went to the Hospital E, which was referred to me by my aunt who had also gotten treatment for her daughter with this doctor* [...]*. She said: "*(name of the child's mother) *go to hospital E, there is a very good cardiologist there". And until this day, thank God, he* (child) *is cared for in that hospital with Dr.* (name of the doctor) (F1, mother).

Unaware of the proper path about bureaucratic procedures and not receiving guidance from health teams, they often traveled wrong and longer paths, triggering physical, mental and emotional stress:

[...] (mother of the child) *I walked a lot and took a lot of wrong paths, because people* (Municipal Health Secretariat/Secretaria Municipal - SMS) *did not know the right place. I started my journey at hospital F* [...] *I was sent to look for the Municipal Health Department* (SMS)*. There I was told that they were unaware that this material* (glucometer tapes, lancets and insulin) *was provided by SMS and sent them to the Civil Forum, where I filed a case and sent me to the State Health Department* (Secretaria Estadual de Sáude - SES)*. I got all the documentation, checked in at SES and that's where I got it. I receive insulin and needles from the state; and in the municipality I receive the tapes* (F5, mother).

*My biggest difficulty is getting things for* (child's name)*. The diaper, his milk, because it is hard for you to go somewhere and someone says: "it's not like that, it's wrong, come back". You know what it is to be stressed, there were two times that I went after his milk in that SMS and they told me: "it's wrong, it's not like that". I came home and then I came back to go to the SMS, I was wrong, I came back again and they sent me to the registry office to authenticate. I spent a lot of money to authenticate it and when I got to SMS they said it wasn't necessary to get it authenticate. Then I said: "are you really making a fool of me?!* [emphasis]". [...] *it is not easy for you to walk from one place to another on foot.* [...] *you depend on these things for free, it's tiring, I only go after it because I need it, if I had conditions, I wouldn't go* (F9, mother).

### *Daily care: rearrangments in family routine after the diagnosis of chronic illness*

From the definition of the diagnosis, the need arises to seek specialized care and the family's interaction with various health services in the HCN:

*When the doctor at hospital D discovered the disease, she said that he* (teenager) *would need chemotherapy every week and it was available only there. On the fourth day he had chemotherapy, from Thursday to Sunday at home* [...]*, on Monday we returned to the appointment and on Tuesday there were exams, X-rays* [...]*. Every week it was this routine, for six months* (F2, aunt).

The comings and goings by the services, from the initial investigation of the child's disease to the implementation of a therapeutic routine, triggers changes and the need for rearrangements in family life.

[...] *I worked and had to quit when I had him, because I didn't trust anyone to take care of him* (F3, mother).

[...] *when I go for an appointment with her, I take two buses, I miss work, I have to bring a declaration and the District does not accept a declaration of accompaniment, they really mark me as absent anyway... they accept the declaration if I go to the doctor, but if it is to accompany my underage daughter ... they don't accept it.* (F7, mother)

The difficulties of access experienced in the FHU have repercussions on the family unit and quality of care:

[...] *there was no way to stay traveling* (to another state for follow-up) *or to buy his medication, because it was manipulated and very expensive* [...]*. So, his health became more complicated* [...]*. I say that the financial part weighed heavily on his illness* (F1, mother).

[...] *another difficulty was transportation, because there was only a motorcycle here. So, to bring* (name of teenager), (name of his aunt) *would find a car to bring them, because he was always very tired, sick because of the chemotherapy and the bus was bad for him. These were the difficulties of being in the FHP, in hospitals, in clinics to do these tests. There was a day when we were hungry all day. Also the medication to buy, it was always very difficult to obtain in the FHP, in addition to being very expensive* [...]*. Anyway, we take the money that was supposed to buy the bread, the meat, to pay for tickets. Ten or fifteen reais every day, it was needed in the week* (F2, aunt).

## DISCUSSION

Upon noticing the first signs and symptoms of chronic disease, the family is faced with doubts, uncertainties and despair, looking for ways to solve the problem at home, in the Family Health Unit (FHU) and/or outpatient services, when the person in charge has prior knowledge that makes it possible to decide which medical specialty to look for.

Also, a study[15] with families of children with diabetes identified the influence of the opinion of people close to them on the perception of caregivers about the child's health, reflecting on the decision to seek health services or not, which can delay the diagnosis of chronic illness, in addition to causing complications to the child/adolescent. In this context, they only seek health services when they understand that it is not a condition of simple resolution, when they observe that clinical scenario does not evolve.

The FHU appears as one of the first places that the disease can be identified and treated. However, given the dissatisfaction with the service, the lack of resolution and devaluation of what is reported, families insert other health services in their therapeutic itinerary. Among them, medical specialties or hospital institutions to have their health demands resolved in due course.

This shows the weakness in the welcoming strategy developed by professionals of the FHU team, which should be strengthened in daily health practice, guided by actions of promotion, prevention, rehabilitation and cure. However, it is necessary for professionals to understand its relevance in health care, in order to promote timely access of this public for children and adolescents and their families in the HCN and to guarantee comprehensiveness[16].

Difficulties in access, care, lack of technological apparatus, exams and delays in scheduling appointments with specialist doctors were the problems referred by family members who seek the hospital after initial care attempts at the FHU. A study[7] states that these weaknesses prevent effective functioning of health care for children and adolescents with chronic diseases, with repercussions on the pilgrimage of families through various services in search of care.

International research[8] with the objective of exploring how parents and health professionals see the concept and practice of collaboration in management of long-term conditions of childhood identified that parents' needs regarding support for coordination and or access to care are often not met.

Thus, on the path taken, families face unpreparedness of institutions and professionals to take care of them and meet their health needs. Studies point to gaps in technical-scientific knowledge of health professionals as a cause of this unpreparedness for carrying out an accurate assessment[1,15] and in supporting tests and/or medical procedures to assist in the diagnosis[1].

Beyond this pilgrimage, the resolution of health problems is also affected by the deficiency in distribution and supply of materials, medications and supplies necessary for therapy of the child/adolescent at home, as it results in clinical decompensation[6]. With the presence of worsening chronic illness, the family, once again, mobilizes without support of professionals in search for care in the HCN. This situation generates anguish, insecurity and suffering for the family, increasing uncertainty of the child/adolescent's life prognosis and disorders in the family's daily life.

Families dependent both on the health system and on the distribution of supplies and materials necessary for assisting the child/adolescent, express frustration in addition to constraints when seeking such services, when they should offer them in an organized and continuous manner. Lack of resoluteness and slowness of public health agencies in making these supplies available show the carelessness with the health of this population and greatly affect the daily lives of families, especially those with low income and who cannot afford to acquire them.

The family members also highlighted the lack of information from workers in the sector regarding services responsible for distribution of medicines, supplies, and which documents are necessary to be entitled to the benefit, placing family caregivers in situations of embarrassment, suffering and helplessness for depending on this inefficient and precarious system.

These findings are similar to the results of an investigation[17] carried out in the Southeastern region of Brazil, which found, in addition to the difficulty of care, a discontinuity of care for children with chronic illness when there is a lack of essential materials and supplies for their daily care. It is necessary to understand that demands of children/adolescents with chronic diseases are different from those of children/adolescents with acute health problems, which do not require special food, expensive medications and special instruments to control the disease. The former have longitudinal and continuous demands that cannot be interrupted, therefore, the State cannot lose sight of its responsibility to accept and resolve these demands, a principle based on the ethics of otherness.

With the improvement of the training process of health professionals, as well as the realization of dialogical reception and sensitive listening, with the valuation of complaints, signs and symptoms, an adequate evaluation is carried out, as well as quick access to exams as essential conditions to avoid misdiagnosis, and ensure effective care in a timely manner[1].

The results of this study corroborate this assertion, when the first embarrassing contact of F4 with the service was experienced with inappropriate attitude of the professional, denial of medical care and, also, difficulty in establishing the correct diagnosis, interfered negatively in the evaluation of the service for the family. Notwithstanding, the welcoming and the resoluteness experienced later on in another service, favored the establishment of a strong bond with the family, often becoming a preferred source of care. In the cases of these families in the study, the service that provided welcoming and resolving demands was the reference hospital for the care of children and adolescents with chronic disease in the state of Paraíba.

Because they do not feel welcomed by other HNC services, families are linked to only one health service. This interferes with the network work recommended by Ordinance no. 483 of April 2014[5], which redefines the HCN of people with chronic disease and establishes guidelines for the organization of lines of care in order to ensure comprehensiveness. The restriction to a single service compromises extended care. This care would promote, in addition to clinical stability, better quality of life and well-being for those involved with the chronic condition.

Although health policies advocate integrality of health care, in chronic conditions of childhood and youth, it is evident the punctual care centered on the complaint-conduct and focusing on medical specialties, the result of gaps in the organization of services, in public policies, and/or resource management.

Also, there are also gaps in implementation of multi and interdisciplinary care, as well as in the singular therapeutic approach recommended for care in chronic diseases. Such aspects make it impossible to provide comprehensive health care to children and adolescents with chronic diseases, as it makes health care more difficult for their unique needs.

To achieve comprehensive care, changes are required in the work processes of health teams, so that strategies are created for the construction of unique therapeutic projects by professionals. This construction, by articulating the diverse knowledge of the team's professionals in their interdisciplinarity, enhances actions in the care of children and adolescents with chronic disease[5].

Given the above, it is apprehended in the results of this study as factors that positively interfere in the care the indication of other people who sought some health service and had successful experience in therapy. As factors that interfere negatively are: punctual and short-term care; the failure to value complaints, signs and symptoms reported by the child/adolescent/family; the lack of responsibility for monitoring cases; inappropriate attitudes of professionals with the family that seeks care; the lack of support from professionals to guide it on the path to go through the HCN to obtain materials, medications and supplies necessary for therapy at home; and the delay of public health agencies in making these supplies available.

The factors that negatively interfere are the result of a mismatch between the family and the services/professionals of the HNC, in which the relationship established did not result in co-responsibility for resolving the needs presented directly or indirectly, which would emphasize the focus of the instituted and focused care in the disease. In this relational process, the challenge for professionals, who are often unaware of services that make up the HNC, and health services is, in addition to knowing and taking ownership of the functioning and flow in the HNC, to implement family-centered care as a strategy for action planning.

There are profound changes in family life with the need to reorganize their routine to include the child's health needs after the diagnosis of chronic disease. Among the changes introduced in the routine after the diagnosis are drug treatment and frequent trips to health institutions, requiring financial expenditure, which the family is not always prepared to afford, becoming one of the obstacles in the construction of the therapeutic itinerary for care. Even in the face of few resources, these family members dedicated themselves to comply with medical prescriptions and achieve resolution to the needs of their children, in an attempt to provide them with a comfortable life, within the limitations and peculiarities of chronic disease.

The child is dependent on the family in several aspects and, therefore, when thinking about public policies for this population with chronic disease, attention should be paid to the need to integrate intersectoral areas to provide the necessary support to both. Based on this perspective and in view of the reports found here, it is important to develop actions in order to guarantee the maintenance of formal employment for parents, in view of the costs of treatment, and even the right to accompany the child without losses at work.

Brazilian labor law is restrictive in making working hours more flexible and does not recognize the specificities of the working woman who cares for children and adolescents with chronic illness, with regard to specific leave to accompanying the child during consultations and hospitalization. This situation makes it impossible to remain in the labor market, as it is unable to reconcile employment and child care due to lack of support[18].

Other social and health support actions are also important, such as support for travel to treatment sites, as well as effective communication between the various services of the HCN. The absence of such supports, in addition to hindering the daily lives of family members of children/adolescents with chronic diseases, interferes with their living and working conditions, placing these individuals in a context of vulnerabilities.

Another study[19] corroborates these findings, stating that the health actions implemented in daily practice touch the SUS political-institutional guidelines resulting from weakened work processes, which make care management unfeasible, pointing out the intersubjective relationships between the team and the community as initial step towards the solution of structural and operational limitations for health care.

It is also necessary to plan health care actions that envision these needs as part of the care to support these families and their children and adolescents. In this perspective, the imaginary about caring, solidarity around care and availability to be with others, also become part of life maintenance actions[20].

The families of children/adolescents with chronic illness, in their context of vulnerability, make a call to health professionals and society in general in relation to the conscious and disinterested responsibility of launching themselves to the other, dialoguing with the other, being attentive to their appeal, their needs, to be responsible for the other they trusted and longed to have their unique demands accepted.

However, the reality shows a context of individualism and non-accountability of health professionals and other sectors of society, generating constant pilgrimage of families to health services, consultations and competent professionals without obtaining, however, the desired care.

This relentless pursuit is the rearrangements made by the family to have access to continuous and specific care for the child/adolescent's clinical condition, in order to make everyday life less arduous and minimize suffering[21]. Thus, the family has remained alone to seek, produce and manage the care of children with chronic illness, without social support and health teams, assuming the central role in the therapeutic project.

## CONCLUSION

It was evidenced that, in general, families of children/adolescents with chronic illness start the search for care in the FHU looking for guidance and clarification as to the signs and symptoms presented and conduct to be taken. However, the weaknesses in the clinical evaluation, the lack of technological resources for early diagnosis of the disease, the delay in care and the lack of resolvability generated dissatisfaction and despair that culminated in the modification of paths to be taken for the construction of the therapeutic itinerary, weakening the therapeutic project and the care offered at the primary level of health care. Thus, hospital care started to be recognized as the first choice in the HNC.

Impaired communication between services, the lack of flows and counterflows in the health system, the lack of accountability by public agencies, incoherent information regarding distribution of supplies, materials and medications had a negative impact on care and family routine. Such aspects wear down the family, impair treatment and affect the quality of care for children/adolescents, which is dependent on therapeutic intervention.

In this sense, the qualified and sensitive listening, the welcoming of the other, ethics of responsibility and compassion as anchoring elements for care in the chronic conditions of children and adolescents stand out. There is a need for a shared and responsible work among the various professionals/services of the HNC, in order to rethink the care that has been offered to transform health practices seeking improvements in the care of children/adolescents with chronic illness.

Despite bringing relevant findings for the care of children/adolescents with chronic disease, the study's limitation is the fact that it was carried out in a single Brazilian state, with a limited number of participants, thus making generalizations impossible. It is noteworthy, however, that, in view of challenges and problems evidenced in the singular reality investigated, further studies are necessary to discover new contexts connected to the care of children/adolescents with chronic disease and to deepen the knowledge produced on the subject.

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