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Children and adolescents with cancer: vulnerabilities and implications on the right to health

Crianças e adolescentes com câncer: vulnerabilidades e implicações no direito à saúde

Niños y adolescentes con cáncer: vulnerabilidades e implicaciones en el derecho a la salud

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ABSTRACT

Objective: To know situations of vulnerabilities experienced by children and adolescents with cancer and their implications on health rights.

Method: A qualitative study, developed from 2017 to 2018, in two Santa Catarina hospitals. The interviewees were 11 family members of children/adolescents with cancer, a prevalent chronic disease identified in hospitalizations in 2017. A descriptive and thematic analysis was carried out based on the vulnerability and human rights framework.

Results: Among the chronic diseases, cancer was prevalent. Vulnerability situations were discussed considering the trajectories in the health care network, the challenges facing the care routine and the support networks for the exercise of the right to health.

Final considerations: Chronic diseases such as cancer require timely, decisive and effective responses from the health system with a view to maintaining human rights.

Keywords: Neoplasms. Health vulnerability. Child advocacy. Delivery of health care. Pediatric nursing.

RESUMO

Objetivo: Conhecer as situações de vulnerabilidades vivenciadas por crianças e adolescentes com câncer e suas implicações no direito à saúde.

Método: Estudo qualitativo, desenvolvido de 2017 a 2018, em dois hospitais de Santa Catarina. Foram entrevistados 11 familiares de crianças/adolescentes com câncer, doença crônica prevalente identificada nas internações de 2017. Realizou-se análise descritiva e temática ancorada no referencial da vulnerabilidade e dos direitos humanos.

Resultados: As situações de vulnerabilidades foram discutidas considerando as trajetórias na rede de atenção à saúde, os desafios frente à rotina de cuidado e as redes de apoio para o exercício do direito à saúde.

Considerações finais: Doenças crônicas como o câncer infanto-juvenil exigem respostas pontuais, resolutivas e efetivas pelo sistema de saúde com vistas a mitigar as situações de vulnerabilidades e promover os direitos à saúde.

Palavras-chave: Neoplasias. Vulnerabilidade em saúde. Defesa da criança e do adolescente. Assistência à saúde. Enfermagem pediátrica.

RESUMEN

Objetivo: Conocer las situaciones de vulnerabilidad experimentadas por niños y adolescentes con cáncer y sus implicaciones para el derecho a la salud.

Método: Estudio cuantitativo, desarrollado de 2017 a 2018, en dos hospitales de Santa Catarina. Se entrevistó a 11 familiares de niños/adolescentes con cáncer. Se realizó un análisis descriptivo y temático basado en el marco de vulnerabilidad y derechos humanos.

Resultados: Entre las enfermedades crónicas, hubo prevalencia de cáncer. Se discutieron las situaciones de vulnerabilidad considerando las trayectorias en la red de atención de la salud, los desafíos en la rutina de atención y las redes de apoyo para el ejercicio del derecho a la salud.

Consideraciones finales: Las enfermedades crónicas como el cáncer requieren respuestas oportunas, decisivas y efectivas por parte del sistema de salud con miras a mantener los derechos humanos.

Palabras clave: Neoplasias. Vulnerabilidad en salud. Defensa del niño. Prestación de atención de salud. Enfermería pediátrica.

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INTRODUCTION

Studies on Chronic Diseases (CDs) have intensified in recent years due to their spread in different populations, evidencing CDs as a public health problem(1). Among the CDs, Chronic Noncommunicable Diseases (CNCDs) stand out, with four being the most prevalent: cardiovascular diseases, neoplasms, chronic respiratory diseases, and diabetes mellitus(2). In childhood and adolescence, the incidence of CDs is related to genetic and behavioral factors, such as irregular and unhealthy eating and lack of physical activity(3).

The National Policy for Comprehensive Child Health Care in its IV Strategic Axis - Comprehensive Care for Children with Prevalent Diseases in Childhood and Chronic Diseases, also indicates changes in the morbidity and mortality profile of the Brazilian population, evidenced by the reduction of infectious diseases, an increase in CNCDs and, more recently, the increase in cases of congenital anomalies(2). These changes caused new demands on the health system, which needs to adapt to care for children and adolescents with chronic health conditions.

Among the CNCDs that affect children and adolescents, neoplasms stand out. In Brazil, data from the Mortality Information System in 2014 revealed that cancer ranked eighth among the causes of death in children aged zero to four years old, being the main cause of death in the age group of five to 19 years old. In 2016, it represented the leading cause of death (8% of the total) due to illness among children and adolescents aged 1 to 19 years old(4). Globally, there are around 300,000 cases diagnosed annually in this population, demonstrating the substantial burden of the disease, which disproportionately affects populations in environments with limited resources(5).

The occurrence of this condition interferes with the life dynamics of children and adolescents, triggering changes in family life, resulting from the search for the correct diagnosis, acceptance of the health problem, structural and behavioral changes in the family and long-term treatment. However, even with the increased burden, the family remains the main support network for children and/or adolescents(6).

Given this scenario, creating education strategies with these families would help to improve the daily care related to risk factors, complications and lifestyle(1). For this, it is necessary to qualify the care network for care and control of this CD through comprehensive care based on humanized welcoming, multi-professional assistance, articulation and flexibility of the services.

In this perspective, the concept of vulnerability was sought(7), anchored in the human rights framework(8) to help reflect on issues involving children and adolescents with cancer, inserted in the context of the Health Care Networks (*Redes de Atenção à Saúde*, RAS), aiming to favor discussions and clarify issues involving access to health care, agility in diagnosis and health monitoring.

This study was conducted based on the following research question: What situations of vulnerabilities are present in the daily lives of children and adolescents with cancer? Thus, the study aimed to know the situations of vulnerabilities experienced by children and adolescents with cancer and their implications for the right to health.

METHOD

A qualitative study, developed in two hospitals in a city in western Santa Catarina, one of which is a reference for the care of children with cancer and the other is a regional reference for care of the adult population, here including adolescents, with the participation of family members of children and adolescents. In order to characterize the profile of the sample eligible for the study, first the chronic diseases prevalent in children and adolescents hospitalized in clinical sectors were investigated in the medical records of these hospitals (excluding intensive care units). This survey together with the health services, carried out from January to September 2017, made it possible to identify 20 children and 12 adolescents diagnosed with CDs.

From this diverse information, the prevalent chronic condition evidenced was cancer (53.1%). From October 2017 to March 2018, family members of children and adolescents with this pathology were contacted, after hospital discharge, and invited by phone to participate in the study, with the meeting scheduled according to their availability. The individual semi-structured interview took place at the hospital in a private location, preceded by the family member's signature of the Free and Informed Consent Form. 11 family members were interviewed, due to the death of six children, this outcome being considered as the study exclusion criterion. The interviews lasted from 10 to 30 minutes, were audio-recorded and later transcribed.

The analysis of the information was carried out based on thematic analysis(9) anchored in the human rights framework(8) and in the three dimensions of vulnerability(7): Individual – as intersubjectivity, refers to the information that individuals have about their health problem and the ability to act protectively in their favor, recognizing the person as a subject of law; social – as contexts of interaction, related to access to information and the ability to intervene socially and politically to obtain security and protection; programmatic – as institutionalized forms of interaction, that is, relationship with the offer, access, functionality and quality of health programs and services, analysis of how much and how governments protect and promote the right to health(8).

The ethical aspects set forth in Resolution No. 466/2012 of the National Health Council on research involving human beings were respected. The research was approved by two Ethics Committees, under CAAE No. 54517016.6.3002.5530 and CAAE No. 54517016.6.3002.5530, respectively.

RESULTS

Eleven family members of children and adolescents diagnosed with cancer participated in the study (Leukemia, Medulloblastoma, Neuroendocrine carcinoma, Bone tumor, Malignant neoplasm of the sacral and coccygeal region, Hodking's lymphoma). Their ages varied from six to 17 years old. Of these family members, the mother was the main caregiver.

When looking at the data from the perspective of vulnerability and human rights, two thematic categories were elaborated: Situations of vulnerability in the discovery of the disease: trajectory in the health care network and the challenges in relation to the care routine: support networks for the exercise of the right to health.

Situations of vulnerability in the discovery of the disease: trajectory in the health care network

Vulnerability situations and their implications for human rights were present in the family members' statements when recalling the first signs and symptoms before the discovery of the disease. In this sense, they mentioned the use of different points of the HCN, mostly starting in Primary Health Care (PHC), but the diagnosis and continuity of care occurred at the secondary and/or tertiary level.

> *We had been researching for a while, because of his very strong headache daily and he was referred to see if it was something of the sight and kept going, until he lost movement of his legs, then* [...] *they told me* [...] *to see a neurologist and do an MRI scan, then the tumor* [Medulloblastoma] *was discovered.* [...] *He went straight to the hospital, the health center they only take.* (F2).
>
> *She was sleepy, slept a lot and had pain in the back.* [...] *At first she went to the health center, then she went to see the ophthalmologist, there the disease was discovered* [Acute lymphoblastic leukemia], *the doctor asked for a tomography, and already referred him to do the first head surgery.* (F4).

The situations of programmatic vulnerabilities were evident in the face of the pilgrimage of those involved in the care of children and adolescents due to the difficulties encountered in the health services and the delay in making the diagnosis. The family members emphasized the need for greater agility in PHC, referring to the diagnosis and referral to specialist professionals and/or other HCN points, a situation that allows for better future prognosis.

> [...] *the doctors diagnosed it was spine, because she had pain in the back.* [...] *After a year and a half, treating the spine, scoliosis, the pain started to come down to the belly.* [...] *Until one day pimples started to pop on the face, I took her to a dermatologist who said that* [...] *it was a hormonal problem. The gynecologist who noticed that on the ovary she had the wrong thing. That was on a Thursday. On Sunday she started to convulse* [...]. (F3).
>
> *We went to the health center* [...] *She had a lot of pain in her leg and walked with a limp* [...] *I took her three or four times, with the same pain, the doctor said it was a growth phase, that she was growing and the bones hurt. Finally, she started to have a fever and he said it was appendicitis, referred for surgery, they made an ultrasound and saw that it was not* [...] *it was three or four months.* (F7).
>
> *He was treating himself at the clinic* [...] *he had a sore throat, he wasn't eating anymore, he was getting thinner, losing weight so I took him to do the exams* [...] *they thought it was the thyroid, only he had low platelets, low immunity, and the doctor didn't see* [...] *Then he started to get worse and we started looking for private doctors* [specialists] [...] *that's where he discovered the disease.* (F10).
>
> *You need agility* [...] *to make the right diagnosis, so the sooner you can, the better the treatment result. And also that it needs a lot of persistence.* (F11).

Challenges in relation to the care routine: support networks for exercising the right to health

Vulnerability situations, especially individual and social, were identified in the difficulties experienced by the family members throughout the treatment period, especially due to the fact that they often have to stay in the hospital, away from their homes, away from home and from other younger children for a long period. However, they stressed that the support networks available, such as support homes, were essential for them to be able to accompany and remain close to the child and/or adolescent during treatment, contributing to the exercise of the right to health.

> *Our biggest difficulty is staying here* [...] *Only in the hospital, direct.* (F1).
>
> *It was complicated* [...] *I have a small baby too and it was very difficult at first.* [...] *transportation difficulty for his physiotherapy* [...], *until today I couldn't manage.* (F2).
>
> *We had to come and go* [...] *Even a place to stay, because we didn't know about a support house, we didn't know anything, everything was new, we didn't have any knowledge, so we had to pay an inn to stay.* (F6).
>
> *I had to stop working and take care of her, accompany her.* [...] *We practically now live on favor* [...] *as she's a girl and I'm a man sometimes there is a place that is like that impasse* [...] *you have to go into the women's bathroom. But the rest, we face it, we can turn around.* (F8).

The family members declared that children and adolescents had to leave school due to hospital admissions and their health condition. This situation was overcome with the hiring of a teacher to go to the home, so that they did not miss the school year.

> *Thank God, I got a teacher at home, so she has been following him since last year.* [...] *He can't stop* [studying]. (F2)
>
> *As he can't go the classroom, the State hired a private teacher for him; she comes home.* (F10).
>
> *She had a home teacher, who came home every day. I found that very good, but it's a State thing.* [...] *She managed to follow up, they passed the contents on to her, then she started going to school again.* (F11)

Amid the difficulties, the families revealed the support received from neighbors, family and friends. This help was achieved through moral support, daily activities and financial issues that impacted on the family's life.

> *In general, everybody helps. Neighbor, friend, there was no shortage.* [...] *We are so touched by so many people who came and helped. So much here* [hospital] *also, full support.* (F3)
>
> *We have the health car there, looking for her only, at this point I can't complain that I had difficulty,* [...] *they give her the medicines, if the city does not pay for the SUS.* (F5)
>
> *When the family needs to stay here, they come and stay.* [...] *the city mayor helped us. With health, transportation and money they also helped. A house for us to stay, support house, everything.* [...] [the crutches] *are borrowed. The walker we had to buy.* (F7).
>
> *The family was very supportive, the neighbors, her friends. Moral help, support.* (F9)
>
> *Hospital people, nurses, advising, teaching, helping* [...] *because they knew what we were going through.* (F10)

DISCUSSION

The study revealed that cancer prevailed among the chronic conditions, showing a scenario of difficulties experienced by the family members of children and adolescents affected by this disease. Leukemia, followed by the cancer affecting the central nervous system and the lymphatic system were the types that most affected children and/or adolescents. The study(4) indicates that 80% of the children and adolescents affected by some type of cancer can be cured if diagnosed early and treated in specialized centers, with good quality of life after proper treatment.

With regard to the discovery of the disease, in the relatives' reports, the anguish and suffering due to the delay in diagnosis were evident. Programmatic vulnerability presents itself when they complained about the erroneous conduct of the health professionals and the lack of agility of the services, especially in the context of PHC regarding the clinical condition presented by the child and/or adolescent. They stated that they understand that, the sooner the diagnosis is confirmed, the more effective will the treatment be; however, the data revealed the difficulty and the long waiting period that, in most cases, resulted in the need to access other HCN points, especially, the scope of specialized services for obtaining resolute and qualified care.

Cancer in children and adolescents generally presents with nonspecific symptoms, which leads to delayed diagnosis and late treatment, so the health services need to be qualified with strategies that include surveillance and prevention actions of this pathology based on guidelines and scientific evidence(10).

Unfortunately, many patients are still referred to treatment centers with their diseases in advanced stages. In this sense, early detection of the disease is important, improving the chances of cure, survival and quality of life of the patient/family(5). Thus, health professionals have an essential role in the suspected diagnosis of cancer, and it is essential that family members carry out regular pediatric consultations with their children, aiming at the early identification of the disease, as well as referral to oncological reference centers(4).

However, in some situations there is insufficient preparation in the health professionals when it comes to identifying and investigating more in depth the signs and symptoms presented by the child, a situation that leads the families to long pilgrimages by the various health services until obtaining a precise diagnosis. In this context, the nurse is understood as a professional who can significantly contribute to the early diagnosis of childhood cancer(11).

In view of the above, weaknesses in the health services and the importance of the insertion of permanent education programs for health professionals were verified in order to qualify with knowledge and technologies for the diagnosis and early treatment of chronic diseases, since it is fundamental for the cure prognosis(5). Therefore, material, human resources and health service actions are needed to promote comprehensive care based on an effective and current clinic. It is indispensable that the health professionals, including the nurses who work in emergency risk classifications and PHC, know the signs and symptoms of childhood cancer and use the resources that the health system has in the HCN, as well as recognize the child and adolescent in their entirety(11).

Faced with these issues, situations of programmatic vulnerabilities were identified, since these families experienced difficulties in obtaining the diagnosis. The offer of diagnostic services, access to them and their functionality appeared to have limitations, considering that there were family members who chose to access the private network, making their own decisions in order to solve their children's health problem. This situation also denotes flaws in the assignment of PHC in acting as coordinator of the health care of the registered users(12). In addition, in order to effectively activate the patient transfer systems between the HCN points, a study(4) recommends that there are defined care flows in order to speed up the diagnosis of chronic diseases, such as cancer.

Chronic conditions require a design of the Unified Health System (*Sistema Único de Saúde*, SUS), ordered, integrated into a network, and focused on the user. The model to be consolidated is that of a strong and qualified PHC, which operates as a network organizer, complemented by specialized outpatient and hospital care that guarantees quality health care for children, adolescents and their families(13).

In this model, it is understood that accessibility, continuous care, trust relationships between users and health professionals, the identification of problems that involve the health/disease process, and the guarantee of early resolution are fundamental for the care of children and/or adolescents with cancer. In other words, it is inferred that, in order to meet the rights of children and adolescents, in terms of health, provided for in the Statute of Children and Adolescents (*Estatuto da Criança e Adolescente*, ECA), it is necessary that these demands be put into practice in an integral and effective way(14).

In this perspective, reflections have been undertaken on how the trajectories of the individual, social and programmatic vulnerability situations are articulated, and their interlocution with human rights. These vulnerability dimensions are understood as susceptibility to the disease to which the person is exposed, and in a related way, the availability of different resources for the protection of their health. In this way, human rights aggregate in order to ensure that people can sue the State when some right is not being protected or promoted, making them less vulnerable to illness(15).

It is emphasized that being vulnerable is part of the human condition, because the person is alive and subjected to the uncertainties of that condition(15). However, it is imperative that a person becomes less vulnerable when he/she knows his/her rights and is able to critically interpret contexts that can put him/her in situations of non-protection and disadvantage. In the same way, the reverse is true, vulnerability situations can intensify if the person is not able to interpret this context and act on it critically(10).

Childhood and adolescence are stages of human development demarcated by civil and political norms and principles that aim to pay attention to the conception of a person with the right to exercise citizenship. The fundamental right to health is a social right implemented through public policies. The experiences reported by the family members in this study refer to the need to debate the rights of children and adolescents as established by the ECA(14). In its Article 11, it states that full access to lines of care aimed at the health of children and adolescents must be ensured through the SUS, observing the principle of equality in access to actions and services for the promotion, protection and recovery of health. The ECA is an instrument that promotes a transformation in the determinants of the health-disease-care process in childhood and adolescence. By means of this legal document, the different social, educational, political and economic segments can build and conduct actions aimed at this population(14).

There are gaps in the implementation of national laws, programs and policies for children and adolescents that ensure the protection and prevention of health problems(16). In the scope of the health services, it is important to expend efforts in strengthening PHC, especially in the Family Health Strategy (FHS), which favors comprehensive care and closer to the community. PHC needs to be an effective and decisive adjunct in the applicability of child and adolescent health rights with a view to consolidating the ECA(14).

With the onset of the disease, there are changes and rearrangements in the family structure, at school and in financial matters since, forcibly, some family members had to leave work and chores to accompany the child during the diagnosis and treatment of the chronic disease. Considering this situation, it is emphasized that some professional categories are guaranteed by law to accompany sick children even for a limited time, while others have no guarantee of maintaining their jobs or income during the children's treatment period, which stands out as an important limit of the current Brazilian social protection policy(17).

Thus, the challenges in relation to the care routines and the need for knowledge of the available support networks allow recognizing the presence of situations of social and programmatic vulnerabilities, which can have an impact on the exercise of the right to health. Among the support networks, the help received from neighbors and friends stands out. A study(18) emphasizes that they are important, however, family members are indispensable in care, with mothers being the main members of this social support network for children and adolescents with chronic illness. The data found in the present study corroborate this statement, since the mother presented herself as the main caregiver; however, her family, social and work routine was modified causing changes in the socioeconomic issues, considering that most of them had to leave work, configuring a social vulnerability of the family.

Resuming the role of the Brazilian State to give concreteness to health promotion and protection, public policies in the area of cancer care were instituted, due to the high severity and lethality of the disease and to the increased incidence in the population(19), as the National Policy for the Prevention and Control of Cancer in the Health Care Network of People with Chronic Diseases. In spite of this, there is still a demand for more comprehensive public policies and with less inflexible criteria, which enable the necessary conditions for the treatment and care to be exercised, such as legislation that guarantee the transportation for the patients to move from their home to the health unit, the maintenance of the Out-of-Home Treatment routine and free public transportation, since these are important mechanisms for guaranteeing cancer treatment(17).

Another point to be discussed is that many families receive government benefits that are directly related to school attendance, which can be compromised due to prolonged cancer treatment(17). Despite this, it is noteworthy that there is a way to go for the fulfillment of the rights of students in complex health situations, mainly to avoid harms in their schooling process, as the educational service ends up not being offered as provided and guaranteed by law, either at home or at the hospital level(20).

The importance of guidelines in the area of education and also in health that regulate and operationalize the organization of this service is reiterated, as a way to guarantee the continuity of the schooling process through collaborative actions mediated by the family, teachers and health professionals, in an articulated and consistent relationship, of collective construction and comprehensive care.

FINAL CONSIDERATIONS

The study brought reflections and subsidies on the vulnerability situations and human rights in the context of chronic diseases, especially in the oncological universe of children and adolescents, corroborating the constitution of actions and movements that need to be incorporated by managers and health professionals so that they can deploy and implement the actions foreseen by the Care Network for People with Chronic Diseases.

It revealed that cancer in childhood and adolescence brings specific care demands, requiring timely responses by the health system, many of which have not yet been effectively implemented. This challenge is amplified by the association of economic, educational and social inequalities that still persist and that need to be faced in the country.

Among the dimensions of the vulnerabilities, the programmatic vulnerabilities were highlighted, in view of the pilgrimage of the families in the health care network, from the beginning of the first symptoms to the final diagnosis. This situation revealed the poor preparation of the health services, especially in PHC, which sometimes does not offer an adequate and integrated approach to health promotion and disease prevention, since the discovery of the disease occurred, in most cases, at a specialized and tertiary level, a fact that leads these families to not having a reference point in PHC to be followed.

This situation, in addition to generating financial impacts for the system, makes it difficult to form a bond between the health service and the users, revealing the non-guarantee of their rights provided for in Laws and in national public policies. However, in the dimension of the programmatic vulnerabilities, some support networks were identified, coming from the family, social, hospital and municipal public authorities that enter the scene and assist in the care routine and in the maintenance of health and school monitoring.

The need for efforts to be continually added to overcome the challenges regarding the right to comprehensive health of children and adolescents is understood as urgent, especially in the scope of PHC, with a view to developing training courses for the health professionals so they can promote concrete and effective interventions targeted promotion and prevention in health in the child-youth population. In addition to that, seeking to articulate movements with other social segments, especially the school, so that they can also be health promoters and assistants in the care of children and adolescents.

Other views are recommended that may explore aspects that are still incipient in the research studies, such as the difficulties that the health professionals have in the early diagnosis of cancer, or even how they perform the PHC monitoring of children and adolescents living with cancer.

The main limitation of this study is the difficulty in accessing children with chronic diseases in PHC, being limited to the hospital environment, due to the monitoring of the health services in a fragmented manner.

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