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## Diagnosis of Childhood and Youth Cancer: The Families-Percurrred Path

Diagnóstico do Câncer Infantojuvenil: O Caminho Percorrido Pelas Famílias

Diagnóstico del Cáncer Infantojuvenil: El Camino Recorrido por las Familias

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### ABSTRACT

**Objective:** The study's goal has been to analyze the trajectory of children and adolescents from cancer suspicion to its confirmed diagnosis. **Methods:** It is a descriptive-exploratory research with a qualitative approach, which was performed in 2017 through semi-structured interviews of 19 family caregivers of children and teenagers with cancer diagnosis. The data were subjected to thematic analysis. **Results:** Both children and adolescents' trajectories start from multiple and unspecific clinical and development alterations in the social-family settings, following that they go through countless healthcare services and are subjected to a variety of biomedical procedures. Along this path, there were evidenced barriers of access to healthcare services in the cancer diagnosis pursue. **Conclusion:** It is crucial that the healthcare system go towards attending the necessities of children and adolescents' population in all levels, including the appropriated access to an earlier diagnosis of cancer, and a better qualification of healthcare professionals for cancer detection. Hence, ensuring the right to health care under the care completeness standpoint.

**Descriptors:** Child, Adolescent, Neoplasms, Early diagnosis.

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## RESUMO

**Objetivo:** Analisar a trajetória percorrida pelas crianças e adolescentes da suspeição à confirmação diagnóstica de câncer. **Métodos:** Pesquisa qualitativa, desenvolvida em 2017, com entrevistas semiestruturadas junto a 19 familiares cuidadores de crianças e adolescentes com câncer, cujos dados foram submetidos à análise temática. **Resultados:** A trajetória de crianças e adolescentes é iniciada a partir de múltiplas e inespecíficas alterações clínicas e de desenvolvimento no âmbito sociofamiliar, posteriormente elas percorrem inúmeros serviços de saúde e são submetidas a diversos procedimentos biomédicos. Nesse caminho, barreiras no acesso aos serviços de saúde na busca pelo diagnóstico do câncer foram evidenciadas. **Conclusão:** É imprescindível que o sistema de saúde atenda as necessidades da população infantojuvenil em todos os seus níveis, incluindo o acesso adequado ao diagnóstico precoce do câncer, assim como melhor formação dos profissionais para a detecção. Garantindo, assim, o direito à saúde na perspectiva da integralidade do cuidado.

**Descritores:** Criança, Adolescente, Neoplasia, Diagnóstico Precoce.

## RESUMEN

**Objetivo:** Analizar la trayectoria recorrida por los niños y los adolescentes de sospecha de confirmación diagnóstica del cáncer. **Métodos:** Pesquisa cualitativa, desarrollada en 2017, con entrevistas semiestruturadas junto a diecinueve familiares cuidadores de niños y adolescentes con cáncer, donde los datos han sido sometidos al análisis temática. **Resultados:** La trayectoria de los niños y adolescentes empieza a partir de varias e inespecíficas alteraciones clínicas y del desarrollo en el ámbito sociofamiliar, posteriormente ellas recogen inúmeros servicios de salud y son sometidas a diversos procedimientos biomédicos. En este camino, barreras en el acceso a los servicios de salud en la busca por el diagnóstico del cáncer fueron evidenciadas. **Conclusión:** Es imprevisible que el sistema de salud atienda las necesidades de la población infantojuvenil en todos los niveles, incluyendo el acceso adecuado al diagnóstico precoz del cáncer, así como mejor formación de los profesionales para la detección. Garantizando, así, el derecho a la salud en la perspectiva de la integralidad del cuidado.

**Descritores:** Niño, Adolescente, Neoplasias, Diagnóstico precoz.

## INTRODUCTION

According to estimates by the *Instituto Nacional de Câncer (INCA)* [Brazilian National Cancer Institute], 12,600 new cases of cancer can be expected in Brazilian children and adolescents in 2017, which represents close to 1% to 3% of all new cases in the country.<sup>1,2</sup>

Although not very expressive when compared to the same disease in adults, today in Brazil, the cancer is the second cause of death in the population within the age group from 5 to 19 years old. Even though it is still considered a rare event, childhood and youth cancer cannot be observed as a simple disease, since it presents peculiar characteristics varying according to its location, histological origin, gender, age, and tumor extension, and can lead to death or generate continuous and complex special health needs.<sup>2</sup>

Childhood and adult cancer have some similarities, however, these needs to be analyzed separately, since in most cases in children and adolescents this disease mainly affects blood cells and supporting tissues, unlike the adult that

affects, mainly, the epithelial cells lining the body's organs.<sup>3</sup>

The evolution in the treatment of childhood and youth cancer has progressed significantly in the last four decades, allowing a greater chance of cure and survival. It is estimated that around 80% of children and adolescents affected by cancer can be cured if they are diagnosed early and the disease is treated in specialized centers.<sup>1</sup>

This fact reserves a complex and multidimensional set of factors that directly influence the early detection of cancer. These factors include the ability of the medical professional to suspect cancer, adequate conduct to assess suspicion, provision of diagnostic services in the public health network, and the financial resources of the family to ensure the numerous displacements.<sup>4</sup>

It is necessary to train health professionals, as well as guidelines for the general population on the main signs and symptoms of childhood and youth cancers, such as weight loss, fever, bruises, anemia, among others.<sup>3,5</sup>

It should be noted that early diagnosis of childhood and youth cancer is one of the health issues of this population of great magnitude and that studies developed on the subject are still incipient. It is emphasized that among all types of a malignant tumor the cancer of children and adolescents presents high possibilities of cure.

Considering the path taken by families in view of the early diagnosis of childhood and youth cancer as a fertile topic for new approaches, it is important to underline the objective of this work: to analyze the trajectory of children and adolescents from cancer suspicion to its confirmed diagnosis.

## METHODS

It is a descriptive-exploratory study with a qualitative approach<sup>6,7</sup> that was carried out in a Pediatric University Hospital located in the *Rio de Janeiro* city, which has the High Complexity Assistance Units from the Ministry of Health.

The research participants were 19 family caregivers of children and adolescents bearing cancer, being 14 mothers, 4 grandparents, and 1 father. As criteria for inclusion were adopted: family caregiver of children and adolescents with cancer, over 18 years old and who knew the trajectory covered until confirmation of the diagnosis of the disease. And the exclusions were as follows: family members of children or adolescents who needed full-time companions, making it impossible for them to leave the family for the interview and the family caregiver of children or adolescents in palliative care.

The technique used in the study was the semi-structured face-to-face interview, which followed a script used by the interviewer,<sup>6</sup> with questions to characterize the sociodemographic and clinical profile of the child and adolescent, namely: degree of kinship of the participant

family caregiver, gender of the child or adolescent, birthdate of the child or adolescent, type of cancer, municipality of residence, date of suspected disease and date of confirmation of diagnosis. The other part contained the following questions: How was it perceived that there was something different about the health of the child or adolescent? Where the disease was confirmed? How long did it take to confirm the disease? How was the path taken to get the diagnosis of the disease? Talk about the facilities and difficulties encountered along the way.

Data collection took place in September 2017. The interviews were conducted in a reserved room of the chemotherapy outpatient clinic, with the purpose of preserving the participants' privacy, had an average duration of 10 minutes, were recorded on digital media, and later transcribed in full. None of the relatives, during data collection or after, expressed a desire to withdraw from the study, however, two companions refused to participate in the study.

Participants were asked to read along with the researchers the Informed Consent Form (ICF), and to sign it in agreement. In order to preserve the anonymity of the participants, the family members' speeches were identified using alphanumeric codes, in the sequence in which the interviews were performed, using F1, F2, successively, until F19.

The number of participants was delimited by theoretical saturation, when the statements provided the data expected to complete the study ideas,<sup>8</sup> without there being a need to persist in collecting new data.

Data were subjected to the thematic analysis; where in the first phase three floating readings of the material were carried out, the transcriptions read unpretentiously aiming the impregnation of the content. After completing this stage, the categorization of the lines was done by colorimetric marking using the yellow color for the first category, green for the second, and blue for the third. In the last phase, an interpretative synthesis was performed, correlating the conceptual framework with the initial objectives of the research.<sup>8</sup>

In observance of the Resolution No. 466/December 12<sup>th</sup>, 2012, from the National Health Council/Ministry of Health, the interviews were conducted only after approval of the study by the Research Ethics Committee of the institution, study scenario, with the respective Legal Opinion No. 2,220,083 and under the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appreciation] No. 71340817.2.0000.5264.

The following categories came from the thematic analysis of data: 1) The trajectory beginning along with the perception of the clinical and developmental alterations; 2) The tortuous path between the places covered and the medical procedures; 3) The barriers found while looking for the cancer diagnosis.

## RESULTS AND DISCUSSION

The reports of family members of children and adolescents bearing cancer conveyed a better understanding of how important this trajectory was for families. With the characterization of the sociodemographic and clinical profile of the child and the adolescent, it was noticed that the majority of the participants were mothers with 73.6%; the male gender prevailed with 63.2%; their age range was from 1 year old to 15 years old; Acute Lymphoid Leukemia (ALL) was predominant with 89.4% of the cases; As for the municipality of residence of the interviewees, *Rio de Janeiro* was the one that stood out the most with 42.1%, nonetheless, had participants from different municipalities, including being a participant from *Santo Antônio* city, *Minas Gerais* State; Another relevant aspect was the time of the diagnosis of these children and adolescents, since eight participants obtained the diagnosis of cancer in less than eight days, however, two cases have drawn attention, among them one who received the diagnosis with ten months and the other with one year after the first signs and symptoms.

The categories that emerged from the data analysis are presented below.

### The trajectory beginning along with the perception of the clinical and developmental alterations

The family members' speeches revealed that clinical alterations such as fever, weight loss, swelling, altered (ganglia) and paralysis on one side of the body were the reasons that triggered the beginning of the trajectory for the diagnosis of cancer, as can be observed in the following statements:

*He had a fever, it only gave him a fever and he lost a lot of weight. (F1)*

*He started to get swollen [...] too much lymph nodes appeared in him. (F2)*

*She began to complain of a little gland in the armpit [...] and felt the fever. (F4)*

*He started to swell his joints, he was hot and red [...] he had a lot of fever [...] my son had this crisis that his right side was not stirring because he was all swollen. (F12)*

In the same circumstance, other alterations, such as fainting, fatigue, night sweats, headaches, joints, arms, and legs were also mentioned by the interviewees:

*He started fainting at school. (F10)*

*She began to get tired [...] in two days she had a night sweats [...] and what caught her attention was her breathing. (F16)*

*He complained of a headache. (F17)*

*Pains in the joints, strong, arms and legs, and the pain only increased. (F18)*

Concerning the skin of children and adolescents, the yellowish color, pallor and purple spot were also warning signs for the participants to start the search for diagnosis:

*He turned yellowish. (F6)*  
*She turned pale, had a purple spot on her skin. (F8)*  
*It made a lot of purple spot on the body. (F10)*  
*She turned yellowish, her eyes half yellow on the inside. (F11)*

Changes in the digestive system have also been reported, including loss of appetite, pain in the belly and distended abdomen. As the following statements show:

*He did not eat so well, he ate little. (F2)*  
*He felt pain in his belly. (F17)*  
*He had a very large belly, had a very distended abdomen. (F19)*

Additionally, other family members also cited changes in behavior and daily activities such as walking, falling, and increased sleep as the factors that led to the suspicion of cancer.

*He stopped walking. (F3)*  
*He was lying flat on the bed. (F7)*  
*She did not walk for a long time, she stayed almost 2 months without walking [...] she had several falls at school. (F8)*  
*He was very weak, he just wanted to know about sleeping, he was sleeping all day. (F19)*

Another relevant issue regarding changes in the development of the child was the decrease in the desire to play, and it was observed in the following statements:

*He was not playing anymore... he started to stop doing the things he did, he was very active, playing ball, running, playing bicycle. (F2)*  
*He was not playing. (F7)*

Bearing in mind those statements, it is clear how the beginning of the trajectory of these children and adolescents was marked by different clinical and developmental changes, reinforcing how the signs and symptoms of childhood and youth cancer are multiple and nonspecific.

### **The tortuous path between the places covered and the medical procedures**

The trajectory of the family of the suspicion to the confirmation of the diagnosis of cancer in the child and the adolescent went from the services of assistance in the public system, in the primary, secondary and tertiary levels, to private healthcare services.

Primary care may be noticed in some of the interviewees' statements as the first choice of health service demand.

*I took him to the neighborhood Family Health Program in Santo Antônio (Minas Gerais). (F9)*  
*I took him to a health post. (F11)*

*I took her to the doctor to see, I took her to the post near the house. (F15)*  
*I took him to the station. (F18)*

The search for secondary care was also frequently cited by relatives, highlighting the Emergency Care Units (ECUs), urgency and emergency services, in this case, hospitals, and specialized doctors such as hematologists, orthopedists, and rheumatologists.

*I took him to the Barra's ECU. (F1)*  
*He sent us to a hematologist. (F2)*  
*The pediatrician always passed me to the orthopedist. (F7)*  
*I went to several doctors in the emergency sector of a hospital, where I live in Realengo. (F8)*  
*I went to the appointment [...] with the rheumatologist. (F12)*

Along the way to confirm the diagnosis of cancer, the transfer of children and adolescents to a hospital of high complexity is also observed, in the case of the study scenario, as shown below.

*She was transferred here (study scenario). (F9)*  
*Five days later he was transferred here (study scenario). (F10)*  
*They transferred him here (study scenario). (F13)*  
*Then he transferred me here (study scenario). (F19)*

It is also worth mentioning the demand for private care, such as pediatricians, clinics and hospitals.

*I went [...] to the private clinic. (F8)*  
*I took him to see his pediatrician. (F12)*  
*I took the private hospital in Jacarepaguá. (F16)*  
*I took him to the private hospital in Caxias. (F17)*

During this journey searching for medical care, the childhood and youth population underwent different invasive procedures, such as venous puncture, lumbar and aspiration of bone marrow, imaging, and biopsy, as well as different medications, which can be seen in the following speeches.

*He passed an antibiotic, and him took it for eight days... the examinations [...] made the myelogram. (F3)*  
*He asked for some tests [...] through the puncture we went to the outpatient clinic for the appointment and he had already done other exams on the outside by request of this doctor, bone scintigraphy, blood culture, and several others. (F7)*  
*I did the exam, it gave negative result, she passed several steroids [...] asked for a series of exams... the doctor had done the blood tests, only they could not confirm and went to do the myelogram. (F8)*

*He did the x-ray, then when he returned from the x-ray had a mass of 12 cm in the mediastinum, there was a biopsy. (F16)*

So, it is seen that the path taken by the children and adolescents along with the family was complex. The interviewees' statements emphasize the multiplicity of places traveled and various medical procedures until the final diagnosis of cancer.

### **The barriers found while looking for the cancer diagnosis**

The analysis of the trajectory revealed barriers in the access to health services for the diagnostic confirmation of cancer of children and adolescents. Family members, as soon as they observed something different in the child or adolescent, reported the immediate demand for the health service and in that trajectory different diagnoses were attributed to children and adolescents, possibly related to the non-specificity of signs and symptoms of childhood and youth cancer, as shown the following lines:

*You have to take your child to the hospital several times [...] the doctor comes to you straight and say: your child is taken [...] that was the difficulty. The difficulty for me was the diagnosis. (F7)*

*At the health clinic and at the ECU they had said it was either an intestinal infection or gas. (F15)*

*They suspected of Zika and Chikungunya. (F18)*

*Because of the large abdomen, they said it was gastroenteritis, an intestinal infection. (F19)*

Another difficulty experienced by the interviewees was the journey through innumerable health visits, together with the children or adolescents, without obtaining a definitive diagnosis, being another factor of a deluge for the diagnostic confirmation of cancer.

*I had asked for a routine examination for my daughter and two doctors there (family clinic) who attended, they said that they did not need blood, stool and urine tests, which they simply did not need [...] at the Realengo hospital I went several times, could not take it anymore and did not identify the problem, because the problem was not in the joint, was not visible in the bone was inside. (F8)*

*My son being thrown from side to side like a ball, without a precise diagnosis [...] practically, invisible to the disease, she is very treacherous, masked, quiet, only God can help us. (F18)*

It should be noted that other study participants cited the lack of physical structure in the health service and the absence of specialized physicians as difficulties.

*Over there (State hospital located in the city of Rio de Janeiro) had no structure. He was going to stay there taking*

*dipyrrone, he had no rheumatologist, he had no hematologist, none of that, he only had a pediatrician. (F12)*

*But in the city where I live there is no hematologist, so he transferred me here (research scenario). (F19)*

Therefore, it was observed that the barriers found along this path were not few, which made difficult the process for the diagnosis of childhood and youth cancer.

The research comprised the path taken by relatives of children and adolescents with cancer from the suspicion to confirmation of the disease. Besides characterizing briefly the sociodemographic and clinical profile of these children and adolescents, in order to know the target audience of the study. Participants were attentive to children and adolescents from the onset of the disease to the confirmation of cancer, observing the appearance of clinical and developmental changes. They also recounted the search for health services to identify the disease and during that search they found obstacles in the way to identify cancer.

Mothers who care for children with cancer experience different stages of the process to diagnose the disease, from the first signs and symptoms to the beginning of treatment.<sup>9</sup> For the mother, she is the best person to be present, offering security and protection,<sup>10</sup> and this justifies the majority of the participants being mothers.

Considering the gender, the most affected was the male, similar to two studies performed in the North and Northeast, and in *Piauí*, respectively.<sup>11-2</sup> The literature does not explain the association of childhood and youth cancer with the prevalence of sex rates male. Epidemiological studies only point out that this sex is the most common in children and adolescents with cancer.<sup>13</sup>

In the younger population, leukemias have a higher incidence, accounting for about 26%, followed by lymphomas with 14% and tumors of the central nervous system with 13%.<sup>2</sup> Acute Lymphoid Leukemia (ALL) is the neoplasm that affects children the most and adolescents, having a short latency period and the rapid onset of symptoms. In addition, there are some factors that may change the time from signs and symptoms to diagnosis of the disease in the childhood and youth population, namely: tumor type, tumor location, patient age, clinical suspicion, extent of disease, parents' level of education, distance from the treatment center, and health care system.<sup>4</sup>

In one study, it was possible to evidence the relevance of the correct diagnosis from the respondents' reports that they reported erroneous medical evaluations and treatments with no success, which in large part determined the delay in the correct identification of the disease. Moreover, it also pointed to the symptoms presented by children or adolescents and the search for medical care, nonetheless, for physicians these changes appeared to be invisible and irrelevant from their viewpoint.<sup>14</sup>

The suspicion of childhood and youth cancer is mainly impaired by the fact that clinical alterations are similar to other recurrent childhood and adolescent pathologies such as a headache, abdominal pain, osteoarticular pain, bone pain, fever, weight loss, pallor and ecchymosis,<sup>15</sup> as evidenced in the research findings.

In the same perspective of signs and symptoms, the parents of another study also pointed out that when they observed the health of their children, they detected changes in behavior and daily activities, among them: hypersomnia, difficulty in locomotion and lack of desire to play,<sup>16</sup> being observed changes in the findings of this study.

It should be noted that the stage of childhood is marked by active play such as running, cycling and playing ball. On the other hand, cancer sickness causes changes in the child's organism, becoming weak and weakened to play.<sup>17</sup> The act of playing causes the child to have autonomy, curiosity and stimulates memory, thinking and concentration, contributing to the integral development of them.<sup>18</sup> Furthermore, the Childhood and Youth Statute accentuates the importance of playing, making available that it provides freedom for the child, being a right of the child.<sup>19</sup>

This fact makes evident the magnitude of the difficulty of the health professionals to suspect the neoplasm since the signs and symptoms presented by the infant-juvenile patients have ambiguity with diseases frequent in the phases of childhood and adolescence. Faced with this aspect, families seek different health services, health professionals, different medical specialties and perform several tests, all with the purpose of getting the disease diagnosis.

Studies corroborate our findings addressing that parents immediately went to a healthcare service, such as Basic Health Units, Emergency Care services, and private services when they noticed something wrong in the health of their child.<sup>16,20</sup>

A study carried out in Londrina city shows that the diagnosis of cancer in children did not happen in the first health care, making the family members permeate the three levels of health, and in some cases the private service as well, which resulted in an exhaustive and tortuous pilgrimage of the families.<sup>21</sup> It was also evidenced by this research.

For the child or adolescent to have a good prognosis of the cancer is necessary the early diagnosis, thus, the professional that initially attends the children and adolescents needs to have a different look for the signs and symptoms presented, sometimes nonspecific, post that in general the first care is performed by a general practitioner or family doctor, and not by a specialized physician.<sup>16</sup>

The difficulty of the definitive diagnosis impels the familiar caregiver to resort to numerous consultations when the first one provides treatments that do not bring results. In this perspective, one of the greatest barriers presented for the detection of the problem is the lack of resolution.<sup>22</sup> However, it is stressed that the early detection of cancer should occur at all levels of health care, from primary to tertiary, a connection between them.<sup>23</sup>

Delayed diagnosis creates anxiety and tension in the family caregiver because the child or adolescent undergoes different invasive procedures.<sup>24</sup>

Although cancer in children and adolescents is considered a rare event, making a misdiagnosis can have significant impacts on their lives. In some cases, the use of inadequate medications mask some signs and symptoms, helping to increase the time between the onset of the disease and its treatment after cancer is revealed.<sup>14</sup>

Bearing in mind the aforesaid, a primary strategy is for the health professional to give value to the complaints referred by the infant-juvenile patient and to carry out the complete anamnesis and physical examination, paying attention to the chance of being a disease like cancer.

Adequate care is a crucial condition for the identification of neoplasm, since going to different health services prolongs the delay in diagnosis, allowing the evolution of the disease and, consequently, decreasing the chances of cure and quality of life of the child or the adolescent.<sup>4,14</sup>

Hence, the different diagnoses prior to the confirmation of cancer in children or adolescents are justified by the similarity of the symptomatology with common pathologies in this phase of life, and also by the health professional witnessing few cases of neoplasm in this population. Therefore, the qualification of primary care teams can make all the difference for the early identification of cancer and referral to specialized professionals.<sup>23</sup>

It is also worth mentioning the Decree No. 7.508/2011, which regulates Law No. 8,080/90, which provides for the organization of the *Sistema Único de Saúde (SUS)* [Brazilian Unified Health System], elucidating universal, equal and orderly access to the health service network that starts at the door of the *SUS*.<sup>25</sup>

Among the obligations and responsibilities of Health Care Networks, health care places should guarantee adequate and qualified professionals for each region and appropriate technologies, which includes a satisfactory physical structure for assistance. Specialized Care in Oncology Care should complement the primary care services during the diagnostic investigation of cancer and emergency services, guaranteeing the integrality of care.<sup>26</sup>

## CONCLUSIONS

The findings of the study revealed that the trajectory of children and adolescents is initiated based on multiple and nonspecific clinical and developmental changes in the social-family framework. Subsequently, those people travel through innumerable healthcare services; also several biomedical procedures are performed in the search for the disease diagnosis, the cancer. Furthermore, different diagnoses were attributed, possibly related to the non-specificity of signs and symptoms of childhood and youth cancer.

This trajectory has been permeated by access barriers to public healthcare services where the diagnostic confirmation

of cancer takes place. Considering this perspective, the health system must meet the needs of the childhood and youth population at all levels, including adequate access to early diagnosis of cancer, as well as better training of professionals for detection. This guarantees the right to health from the perspective of integral care. Given this reality, it is understood that for the early diagnosis of childhood and youth cancer, in fact, it is necessary that health professionals and managers take a different look and promote different strategies for this population. Thus, reflecting on the practice of care provided with existing public policies becomes essential to improve health practices.

It is hoped that the study may contribute to improving assistance towards the child and adolescent undergoing the process of cancer examination, including the early disease diagnosis as a determinant factor for a good prognosis. Collaborating to reinforce the importance of the suspicion of childhood and youth cancer in the face of difficulties faced by families during the path taken to diagnose the disease.

It should be noted that the study was conducted at a health service in the *Rio de Janeiro* city, consequently, only one source of data was used, interviews with the family caregivers of children and adolescents bearing cancer, which makes it impossible to generalize the findings. This fact points to the need of developing new investigations on this topic, which includes children, adolescents, and their families, as well as other health professionals.

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