

## The therapeutic pathway of families of children with cancer: difficulties faced in this journey



*O itinerário terapêutico de famílias de crianças com câncer: dificuldades encontradas neste percurso*

*El trayecto terapéutico de familias de niños con cáncer: dificultades encontradas en este recorrido*

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### ABSTRACT

**Objective:** To know the difficulties faced by families in the therapeutic pathway of children with cancer.

**Method:** Qualitative, descriptive and exploratory research, with a quantitative approach, performed from March to November 2016, through face-to-face semi-structured interviews, with 21 relatives of children undergoing oncological treatment at a federal university hospital in Rio de Janeiro, whose data were submitted to content analysis.

**Results:** The difficulties of these families traverse the identification and investigation by health professionals regarding the signs and symptoms of children as well as the passage of relatives through various health services until diagnostic confirmation.

**Final considerations:** The early diagnosis of childhood cancer depends on actions from health and teaching institutions for the appropriate investigation of the disease by professionals, including the nurse who works with risk classification in emergency departments and in primary care, besides the appropriate operation of the reference and counter-reference system of the health system.

**Keywords:** Neoplasms. Child. Early diagnosis. Delayed diagnosis. Primary health care. Pediatric nursing.

### RESUMO

**Objetivo:** Conhecer as dificuldades encontradas pelas famílias no itinerário terapêutico de crianças com câncer.

**Método:** Pesquisa descritiva e exploratória, de abordagem qualitativa, realizada de março a novembro de 2016, através de entrevistas semiestruturadas, com 21 familiares de crianças em tratamento oncológico em um hospital universitário federal no Rio de Janeiro, cujos dados foram submetido à análise temática.

**Resultados:** As dificuldades das famílias perpassam a identificação e a investigação pelos profissionais de saúde dos sinais e sintomas da criança e a passagem dos familiares por diversos serviços de saúde até a confirmação diagnóstica.

**Considerações finais:** O diagnóstico precoce do câncer infantil depende de ações de instituições de saúde e de ensino para a apropriada investigação da doença pelos profissionais, entre eles o enfermeiro que atua nas classificações de risco das emergências e na atenção básica, além do adequado funcionamento do sistema de referência e contrarreferência do sistema de saúde.

**Palavras-chave:** Neoplasias. Criança. Diagnóstico precoce. Diagnóstico tardio. Atenção primária à saúde. Enfermagem pediátrica.

### RESUMEN

**Objetivo:** conocer las dificultades encontradas por las familias en el trayecto terapéutico de niños con cáncer.

**Método:** investigación cualitativa, descriptiva y exploratoria, con planteamiento cualitativo, efectuada entre marzo y noviembre de 2016, mediante entrevistas semiestructuradas presenciales, con 21 parientes de niños bajo tratamiento oncológico en un hospital universitario federal en Río de Janeiro, cuyos datos se sometieron al análisis de contenido.

**Resultados:** las dificultades de las familias atraviesan la identificación e investigación por los profesionales de salud de los signos y síntomas del niño y el pasaje de los parientes por diversos servicios sanitarios hasta la confirmación diagnóstica.

**Consideraciones finales:** el diagnóstico precoz del cáncer infantil depende de acciones de instituciones de salud y de enseñanza para la apropiada investigación de la enfermedad por los profesionales, incluyendo el enfermeiro que actúa en las clasificaciones de riesgo de las emergencias y en la atención primaria, además del adecuado funcionamiento del sistema de referencia y contrarreferencia del sistema de salud.

**Palabras clave:** Neoplasias. Niño. Diagnóstico precoz. Diagnóstico tardío. Atención primaria de salud. Enfermería pediátrica.

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## ■ INTRODUCTION

Cancer in Brazil was responsible for about 2,800 cases of deaths among children and adolescents from 0 to 19 years old in 2013, ranking second among deaths in this age group, it was only below deaths from external causes. For the biennium 2018-2019, in the Brazilian scenario, it is estimated that 12,500 new cases of this disease appear for this population group<sup>(1)</sup>.

In childhood, cancer is a highly lethal disease, with several clinical presentations due to differences in origin, risk factors, histological types, anatomical sites and response to treatment. Pediatric tumors, in general, are of embryonic origin and present a short latency period, thus, environmental factors have little or no influence on their occurrence; in addition, they have nonspecific symptomatology and tend to be more aggressive and evolve more rapidly. Therefore, the association of these characteristics makes the diagnosis and timely treatment of childhood cancer difficult, making the early detection imperative for a good prognosis, thus increasing the chance of better results with fewer sequelae<sup>(2)</sup>.

A study carried out in the United Kingdom highlighted that among the main signs and symptoms of warning identified in children in consultation in primary care, three months before the diagnosis of childhood cancer, were headache, lymphadenopathy, hepatosplenomegaly, petechiae and fatigue<sup>(3)</sup>. Thus, from the appearance of the first signs and symptoms of illness to the early or late diagnosis of the disease, there is a trajectory to be followed by the child and their family. This pathway, associated with individual and sociocultural practices, in an attempt to solve children's health problems, is called the therapeutic pathway<sup>(4)</sup>.

Studies on therapeutic pathways of patients looking for health care help the understanding of the behavior in relation to care, as well as the way health services are operated and used. However, the pathways traveled in search of care are often different and do not necessarily coincide with schemes or flows predetermined by the health system. In this way, the inadequately performed route can project a late diagnosis, reducing the chances of cure and increasing the risks of sequelae and death<sup>(4)</sup>.

It is important to highlight that the therapeutic pathway has been the subject of research with relatives of children and adolescents in different situations of illness, such as respiratory disease, diabetes, cancer, among others, allowing the visualization of the trajectory of the child and family by the health system and the social and cultural aspects involved in the process of illness<sup>(5-7)</sup>. However, to better understand these itineraries, it is important to approach the Explanatory Models and subsystems that make up the Health Care System.

The Explanatory Models are the conceptions about the illness and the forms of treatment employed by all those engaged in the clinical process and that will define which sector of the Health Care System will be activated in the care process. Health Care Systems are made up of three sectors (subsystems) that characterize care practices of different natures: the professional, the popular and the familiar<sup>(4)</sup>. In this study, emphasis was placed on the professional subsystem that includes health professionals and the official health care network.

In this context, nurses should know the trajectory of children with cancer and use it as an instrument for nursing care, health promotion, disease prevention and early detection of childhood cancer<sup>(5)</sup>. However, the need for a better understanding of the factors that may delay the diagnosis of childhood cancer is still urgent, in order to help the adoption of governmental, institutional and professional strategies that fill the gaps of this trajectory, so that universality, equity and comprehensiveness are guaranteed.

In view of the above, the guiding question of the study was: What are the difficulties families face in the therapeutic pathway of children with cancer? In order to answer this question, the objective of the study was to know the difficulties faced by families in the therapeutic pathway of children with cancer.

## ■ METHOD

The present study is the result of a completion of course work in nursing graduation<sup>(8)</sup>, being configured as a descriptive and exploratory research, with a qualitative approach, performed at the chemotherapy outpatient clinic of a pediatric university hospital located in the city of Rio de Janeiro.

The research setting is one of the hospitals certified by the Ministry of Health and the Ministry of Education, because in addition to traditional health care activities, it promotes human resources and research training, technological development for the health system, and contributes to the formulation of public policies. In addition, it has the Unacon habilitation, High Complexity Care Units, of the Ministry of Health, because it brings together technical conditions, physical facilities, equipment and human resources adequate to the provision of specialized care of high complexity for the definitive diagnosis and treatment of cancer, in the specific case of children.

And because it is an institution dedicated to the specialized care of childhood health problems, it has been constituted, over time, in a reference hospital to attend to complex and rare clinical conditions. In addition, it receives children from different regions of the state of Rio de Janeiro and other

Brazilian states, also for the treatment of childhood cancer, especially the cases of leukemia and lymphoma.

The study participants were 21 relatives of children undergoing cancer treatment in this setting. The inclusion criteria of the participants were: to be aged eighteen years old or over; and relatives of children undergoing cancer treatment who were responsible for their direct care from the onset of symptoms. The exclusion criteria were: relatives of children who needed full-time companions, making the temporary absence for the interview impossible; relatives of children in palliative care, because when talking about the pathway traveled, there could be some association between the evolution of the disease and the decisions made in their trajectories, in which case their participation could expose family members to feelings of guilt or sadness.

The data collection was carried out through semi-structured interviews, from March to November 2016, conducted by the first author after training and guidance of the PhD professor, second author, experienced in qualitative research. In order to do so, a script was used with the following questions: What did you notice that was different and that drew your attention to the child's health? Talk about the pathway you went through to search help when you realized there was something different about the child. What were the difficulties you faced along the way until the beginning of treatment?

The relatives who met the inclusion criteria were personally invited and informed about the research and its objectives. After acceptance, the interviews were conducted by the researcher in a private place in the research setting, without the presence of other people. In order to accurately record the participants' testimonials, the interviews were recorded using digital media and transcribed in full afterwards.

The anonymity of the participants was ensured through the use of a code, namely the word "Interview" followed by the Arabic number referring to the sequence of performance (Interview 1, 2, 3 and so on). It is important to emphasize that there were no refusals or withdrawals regarding participation in the study.

The research followed the determinations of Resolution 466/12 of the National Health Council and was submitted to the Research Ethics Committee (REC) of the research setting, being approved with the opinion number 1,392,303 and CAAE No. 51022115.8.0000.5264. All participants signed a Free and Informed Consent Term.

The interviews were analyzed following the three phases of the thematic analysis<sup>(9)</sup>: pre-analysis, with floating reading to know the content of the empirical material generated by the interviews; material exploration phase, when the raw data were transformed into units that represented

meanings and then aggregated into categories; treatment and interpretation of the results phase, when it was possible to make inferences in the light of the scientific literature.

Thus, two thematic categories dealing with the professional subsystem have emerged, covering the health professionals and the service network: the family meeting with the (un)preparation of the professionals for the diagnosis of childhood cancer and the pilgrimage of the family through the different health care levels.

## ■ RESULTS AND DISCUSSION

As for the relatives of the children, of the 21 participants, 17 were mothers; 03 were fathers; and 01 was a grandmother; 05 were between 20-30 years old; 14 were between 30-40 years old; and 02 were over 40 years old. In relation to the 21 children, the age was from 2 to 12 years old; 20 had a diagnosis of Acute Lymphoblastic Leukemia (ALL) and 01 of Acute Myeloid Leukemia (AML). Regarding the time between the beginning of the signs and symptoms until the definition of the diagnosis 02 took 02 days; 01 took 05 days; 02 took 10 days; 01 took 13 days; 01 took 15 days; 03 took 01 month; 03 took 02 months; 04 took 03 months; 02 took 04 months, and 02 took 06 months.

### **The family encounter with the (un)preparation of professionals for the diagnosis of childhood cancer**

On the pathway taken by the family in the search for care, through the perception of something different about the child, there were reports regarding the lack of preparation of health professionals regarding the suspicion and diagnosis of cancer and in the referral to the specialized unit. On the other hand, some relatives reported the contact with professionals who performed the diagnostic confirmation and the appropriate referral to the cancer treatment unit in a timely manner.

In the search for care, from the occurrence of the first signs and symptoms of childhood cancer, such as bruises, difficulty in walking, fever, pain, among others, the relatives stated that children received incorrect diagnosis and treatment, due to the non-association of the condition presented by the child with cancer, in addition to being submitted to different procedures, as well as experiencing countless comings and goings to different health services; which prolonged the time for a definitive confirmation of the disease.

*I would take her to the emergency room, but it was helpless, because they said it was a virus. [...] I kept taking her*

*to the hospital and nothing. Only after it was discovered, but only because she stopped walking and before they had said it was leptospirosis. (Interview 12)*

*Before I got to the orthopedist that made the rheumatic test, he went to emergency rooms many times, and they always said it was transient synovitis in the hip and that it would pass. They said he could have fallen down or something like that. (Interview 14)*

*He had shoulder pain and we took him to a normal [routine] consultation. They said it was luxation. I took him to the orthopedist, who performed an x-ray and also did not give him anything, and then the fever started and the doctors thought it was a virus, something like dengue. [...] The third time I took him to the emergency room, the doctor decided to hospitalize him because she saw that his condition was getting worse and hospitalized him as pneumonia. (Interview 6)*

*The pediatrician said he had bruises because he was beating himself too much, he was hurting himself. [...] A month later, he had a fever, a low fever, I took him to the pediatrician again, and then she said it was an allergic crisis. Then, in addition to the fever, he presented some purple balls inside his mouth, several bruises. And I took him and she said that he could be allergic to the spray of bronchitis because he has asthma. (Interview 17)*

The fact that cancer in children presents vague and nonspecific symptoms, sometimes misinterpreted, by simulating common and harmless childhood conditions, may increase the interval between the onset of the symptoms and the diagnosis<sup>(10)</sup>, as evidenced in the study. Thus, as long as the child does not present a more serious condition of the disease, obtaining the diagnosis becomes more difficult.

Therefore, the findings show that the care that some children received, with the lack of recognition of the symptomatology suggestive of cancer, is in conflict with what the literature recommends. It is necessary to consider that the current emphasis on childhood cancer requires that the process of suspicion and investigation to be precocious, so that this patient benefits from a treatment with all the necessary potential and efficacy, aiming, therefore, at good rates of cure and reduction of disease sequelae<sup>(2)</sup>. Therefore, adequate, timely and informative referral from primary to secondary care is a nodal condition<sup>(10)</sup>, which was not prevalent in the testimonial of the relatives the study.

A study carried out in the United Kingdom showed that children with cancer were treated in the primary care, before the diagnosis, more frequently than the children

in general<sup>(3)</sup>. Therefore, health professionals, including the nurse, need to be aware to the presence of warning signs and symptoms and the frequent search of children for health services, as these are factors associated with a higher probability of childhood cancer.

One of the children presented recurrence of the disease, and although previously submitted to cancer treatment, there was also delay in the diagnosis of relapse.

*When he had it for the second time [relapse of leukemia], it was in the testicle and I was a month and something caring as if it were mumps. We went to the UPA there [Macaé] and to an urologist. He did tests, ultrasound, and he said it was due to the mumps. Then I showed the tests to a doctor from Rio [...]. At the moment he looked at it, he said, No, it is not mumps, that is his leukemia there! (Interview 20)*

Once success in the therapeutic treatment of childhood cancer can be achieved, it is known that the early diagnosis and treatment in reference units are fundamental for achieving cure and quality of life. However, in Brazil, cancer cases with potential for cure are still identified in advanced stages, which has a negative impact on mortality<sup>(2)</sup>.

Thus, the need for detailed records is imperative, through a good data collection and thorough physical examination, particularly in cases involving children with vague and persistent symptoms, which may in fact help in ensuring the diagnosis in a timely manner<sup>(10-11)</sup>.

Therefore, in this context, the nurse has the ability to provide effective care, through the nursing process, identifying health problems in the child, favoring, even, the early diagnosis of childhood cancer. It is known that the therapeutic pathway is involved by the planning and strategies that seek to solve the problems involving the patients' health, being essential the nursing performance in this process<sup>(12)</sup>.

The persistence of the signs and symptoms and the non-resolution of the problem made the families persistent, taking their children to different health services so that an adequate diagnostic investigation was performed. In addition, there were reports that consultations that were completed without the request for complementary tests.

*I began to take him to the emergency room, the doctors asked him to lower his pants and they said it was a bruise and they prescribed a medicine. They never touched my son to examine him, they never asked for a blood test [...]. If they had examined him, it would be possible to see. (Interview 2)*

*We took him to the emergency room. The pediatrician saw him, but he did not make any examination the first time.*

*He said that he was in very good health and that he had nothing. (Interview 8)*

It is important to emphasize that the detailed history provides adequate diagnoses and assertive therapies, in addition to enabling a humanized relationship between the professional and the patient. When the anamnesis is not performed, when it occurs very quickly, or when the patient's complaints are not attentively listened to, there may be impairment in the quality of the treatment, due, also, to the delay in the diagnostic confirmation<sup>(11)</sup>.

A relative also reported an inadequate approach during care at a health facility.

*A doctor who saw us in the emergency room asked to see it and began to argue with me, saying that it was not an emergency and that I was disturbing her service. (Interview 2)*

Based on this testimonial, it is possible to observe that inefficient communication or an inadequate approach can lead to a series of conflicts, insecurities and even interfere in the early diagnosis of childhood cancer. Thus, communication, mediated by attentive listening, is an important practice of humanized care regarding the contact established with the relatives of the children.

In an attempt to effectively address the child's health problem, the relatives became protagonists on the pathway, pursuing other health services or threatening to sue them, since they believed that the child's treatment was not appropriate.

*My granddaughter was hospitalized and left without a diagnosis. I threatened to go to the forum, open a judicial injunction for them to do something. [...] (Interview 1)*

*He stopped walking, could not even stand. Then I went crazy, I ran to a big hospital to save my son. I was hospitalized with him there for a month and they did not find out anything either. Then they took a look at his belly and saw that his spleen was altered. (Interview 21)*

Data from another research have shown that sometimes several health services have organized their work processes with a focus on the procedure rather than on the patient, leaving aside the qualified listening and prioritizing the performance of tests. The fulfillment of the health needs, when it is not effective, reflects in new actions, since families and the patient are led to seek other ways and services that can offer them access to the care they demand<sup>(12)</sup>.

On the other hand, there were cases in which the families found more qualified professionals, since during the

physical examination or evaluation of the tests they suspected the possibility of a cancer.

*A pediatrician [first consultation in a private hospital] saw us and it was not detected immediately, the test showed that everything was fine. What caught the attention of the doctor was that the liver was increased, he was hospitalized and 4 days later he had a diagnosis of leukemia. (Interview 3)*

*The doctor [first consulted in the emergency room] examined him and saw that his spleen was large and his blood test was all altered. Then they talked to me and found a vacancy here [treatment center]. Here they made the blade, the examination of the spinal cord, and diagnosed that he had leukemia. (Interview 9)*

*They performed the blood test [at the UPA] and transferred him to another hospital. There they told me that he had leptospirosis, but they suspected that it could also be leukemia [...]. They transferred me here where I had the diagnosis. (Interview 18)*

The data indicate that for an early diagnosis of childhood cancer and a good prognosis of the disease, it is essential that health professionals, including doctors and nurses, should be prepared for the first care of a possible child in this situation, since most of the time the first care is not performed by a specialist. Therefore, it is fundamental that health and education institutions train the health professional based on the health needs of individuals and populations at the various levels of health care, aiming at the construction of comprehensive care<sup>(13)</sup>.

Regarding nursing, the National Curricular Guidelines (NCG) advocate the formation of a generalist and humanist nurse who acts on the social reality and meets the needs of the population with commitment to the comprehensive health of the human being and responsibility. Thus, the expected profile has the capacity to recognize and intervene on the different problems and situations of the health-disease process<sup>(14)</sup>.

Thus, the nurse, at the different levels of health care, from primary to tertiary care, including the embracement with risk classification in the emergency services, must be able to care for the children and their families and promote comprehensive care. Their efficient performance should include the ability to recognize the signs and symptoms suggestive of childhood cancer, thus contributing to the early suspicion, with the proper referral of the child to the specialist doctor who will perform the diagnostic confirmation.

## The pilgrimage of the family through the different levels of health care

When the first signs and symptoms of cancer in the child are observed by the family, an often arduous journey begins through different health services, which represents a pilgrimage in the search for diagnosis and treatment.

A family started its trajectory in Basic Health Units (BHU), as recommended by the Unified Health System (SUS – “Sistema Único de Saúde”), however, because it did not solve the problem, the family looked for other care levels.

*We took him to some health units in Caxias, some said it was just a strong anemia, others said it was nothing. Then we took him twice the same day to the emergency room, and the second time he took a test and the doctor referred us here [treatment center] to have a complete diagnosis (Interview 8).*

The relative's report 8 indicates that even looking for the primary care as the first care source, the child did not receive the diagnosis nor was referred to a specialized health unit. With the maintenance of the symptoms, the child was taken to the second level of care, which includes emergencies, and then referred to the third level to receive the diagnosis and due treatment.

It is known that the BHU is the main gateway and center of communication with the entire health care network. In this sense, when the family perceives something wrong with the child, it is often in this type of unit that the investigation of the clinical condition begins. However, these families can go a long way until finding a specialized unit of treatment<sup>(15)</sup>. A research that studied the therapeutic pathway of families of children with respiratory diseases also identified deficiencies in the BHU that led to hospitalizations for conditions that could have been prevented<sup>(6,15)</sup>.

From this perspective, nurses who work in primary care must be qualified, and in the nursing consultation, they should carry out the history and the physical examination with attentive and sensitive listening in order to identify warning signs and symptoms, so that there is the early referral of the child with suspected illness<sup>(16)</sup>.

Reports have indicated that families sought different public and private services and, even using a variety of resources, the diagnosis of childhood cancer was also delayed.

*In the beginning I paid for a consultation at a clinic, but it did not solve it [...]. I went to many [public] hospitals, to emergency rooms, to the UPA and nobody solved it [...]. One day I took him to the UPA, on the coast, and a doctor*

*told me that it was a very serious thing and that I should take him to a large hospital, because on the coast it would not be possible to solve it. Until I took him to a hospital in the south side [municipal hospital], which discovered it and sent him here. (Interview 2)*

*At the time we had health insurance, [...]. Everything was done in a private clinic [...]. We went to the emergency room, a couple of times, at the end, but they could not diagnose it. There in the clinic, a doctor, after having done all the tests, went for a deeper examination, it was when it was found. On the same day we were taken to this place [treatment center] and he has been hospitalized. (Interview 10)*

The pathways are based on the choices of the routes of treatment traveled, based on the world views and choices made by the patients, especially in relation to the health services and care received. However, the difficulties of access to the specialized service make the relatives define new pathways in the search for care and diagnostic clarification<sup>(4,6-7)</sup>, as evidenced in the study findings.

This same reality was observed in the voices of relatives of adolescents with diabetes who also sought care in private practices, health insurances and services of the Unified Health System, characterizing a network of different pathways and guidelines. Demonstrating that the difficulties faced by users of the health services are not limited to childhood cancer<sup>(7)</sup>.

Therefore, the family does not always choose SUS initially to look for the child's diagnosis. Three families initially sought care at the private outpatient clinic, but prior to their arrival at the treatment center, the children went to public health units. In these cases, the pathway to the diagnosis was not delayed.

*First I went to a private practice that sent me to a municipal hospital here in Rio. He was hospitalized for one day, the other day in the morning they brought me here, they got a vacancy here. (Interview 13)*

*I took him to a private pediatrician and then I took him to an UPA in Botafogo, where the pediatrician suspected cancer. Then they arranged a transfer here. He stayed one day hospitalized at the UPA and the next day he came here. (Interview 15)*

*I took him to the pediatrician of his health insurance. Then to the health unit, they sent him to a large hospital. He went to a municipal hospital and then they transferred me here. (Interview 21)*

Currently, the private network offers a range of resources, services and varied medical specialties. However, in the results of this research, the families that sought the private health services did not obtain the treatment in these services, but in the public health services. These facts show the problems and weaknesses of both the private service and the public system<sup>(17)</sup>.

Part of the families sought the first service in emergency services, whether in emergency care units or public or private hospitals. Sometimes without a quick resolution, and in others the diagnosis and referral to a reference unit occurred more quickly:

*I took him to an emergency room [Private Hospital], we stayed 4 days there and we were transferred to a [Private Hospital] to do a myelogram, in 24h they had already given the result. (Interview 3)*

*I took him to an UPA and a hospital. When I took her the last time, she was admitted to the UPA, from there she was sent to another hospital [public], where she stayed for a month and two weeks, and from there she came here [treatment center]. (Interview 12)*

*We took him to the UPA and the next day he was here [hospital, research setting]. It was a very quick process, because this UPA doctor from Cabo Frio, by coincidence, was a doctor here. (Interview 20)*

It is also known that the diagnosis of cancer in a child is a rare event, so a general practitioner may have difficulties in recognizing childhood cancer<sup>(18)</sup>. The same can happen to nurses who work in the emergency risk classification and also care for these children, since they generally, identify emergencies and give priority to more serious cases<sup>(19)</sup>.

Thus, the importance of investing in professional training is reinforced, since a large proportion of cancer patients are diagnosed after the onset of life-threatening manifestations because the cancer has not been diagnosed early<sup>(2)</sup>.

Only one of relative has mentioned that they used the on-line regulation system as a scheduling mechanism, as follows:

*Then I paid a doctor who asked me to look for a child rheumatologist. I had a hard time finding a child rheumatologist. I had to register for SISREG, because I could not find it. (Interview 1)*

The referral of the patient in SUS to the various specialties and levels of care depends on a referral and counter-referral system that has an articulated flow. Being a reference

the referral to the levels of higher degree or complexity and counter-referral the return of the patient from a greater complexity to a lower level of complexity, thus, the patient continues to be accompanied by the primary care<sup>(16)</sup>.

From the statements of the relatives, it was verified that this referral and counter-referral flow does not happen properly.

*Then I took him to the orthopedist and it did not show anything. He got worse and I took him to PAM, three times. The third time the doctor decided to admit him, but it did not get better. Then he came here, to be attended by the rheumatologist who soon sent him to the pediatric emergency room [...]. (Interview 6)*

*I took him to several hospitals, nobody knew what he had, he did x-rays and nobody knew what it was. Then I went to the health unit, it was at the unit that I was told to take him to a large hospital. (Interview 21)*

This finding, which points out the inadequacy of the attendance flow, indicates that pathways studies support the evaluation of the effectiveness of services in guaranteeing access and meeting the needs of the population. Thus, they subsidize the development of educative actions in health, professional qualification and adequacy of flows<sup>(4)</sup>.

There is also the invisibility of the Family Health Strategy (FHS) in the relatives' reports, as a public health resource sought by the family or as a service to accompany the child and their family.

The FHS ensures the approximation of professionals and family health centers to the community, increasing the resolving capacity of the most common health problems through the continuity of care, which implies improving the quality of life. In addition, it should be the first place the family seeks when there is a suspicion that something is wrong with the child, being fundamental a professional training so that it is possible to capture the suspicions of childhood cancer and the quick referral to the treatment center<sup>(20)</sup>.

Thus, in the context of the FHS, the nurse should seek to favor an attentive look and qualified listening for children with signs and symptoms suggestive of cancer, thus favoring the early diagnosis of this disease.

## ■ FINAL CONSIDERATIONS

This study allowed us to recover the pathways traveled by children with cancer, from the first signs and symptoms to the diagnosis and referral to the specialized treatment unit.

It was evident that the greatest difficulties were the lack of preparation of medical professionals to identify and inves-

tigate more deeply the signs and symptoms that the child presented. In addition to the need for pilgrimage through the different health services until finding the diagnosis.

The relatives did not make specific references to the nurse, however, their performance in the different health services can contribute significantly to the early diagnosis of childhood cancer. Therefore, it is recognized the need for public policies, permanent education and effective actions that are able to train health professionals at the different levels of SUS and in the private network in order to reduce the time from the symptomatology to the diagnosis of the disease.

It is concluded that for the early diagnosis of childhood cancer and consequently greater chances of cure, actions of the health services, of the institutions that form the professionals, are necessary, seeking to promote comprehensive care, since it was possible to perceive a compromise of this principle. Professionals, among them nurses who work in emergency risk classifications and in primary care, must know the signs and symptoms of childhood cancer and use the resources available in the health system, not forgetting to look at the individual in its entirety. In addition to the need for an adequate functioning of the referral and counter-referral systems of SUS, including a better performance of the Family Health Strategy.

As a limitation of the research, it is pointed out that this portrays the reality of children attended at an institution in Rio de Janeiro, thus, it is suggested to carry out new studies in other regions of the country to broaden the discussion and compare these results with others.

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