

Early diagnosis of child cancer: the journey taken by families

O diagnóstico precoce do câncer infantojuvenil: o caminho percorrido pelas famílias

El diagnóstico precoz del cáncer infantil y juvenil: el camino recorrido por las familias

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ABSTRACT

Objective: This study's objective was to describe the path taken by children, adolescents and their families, from the beginning of signs and symptoms up to a definitive cancer diagnosis. **Methods:** This is a descriptive-exploratory study with a qualitative approach. Semi-structured interviews were used to collect empirical data, from which emerged the category "a long journey: from becoming sick to the beginning of treatment." **Results:** Ten families of children and adolescents with cancer undergoing chemotherapy participated in the study. The participants reported their experiences in a detailed and chronological way, describing the first signs and symptoms, the need to go back and forth to health services, and the work of professionals from the primary and specialized health care services. **Conclusion:** Children and adolescents go through a long journey when they face an oncological situation. Difficulties accessing the diagnosis resources were observed. Such difficulties hinder the possibility of reaching an early diagnosis.

Keywords: Child; Adolescent; Oncologic Nursing; Cancer; Early Diagnosis.

RESUMO

Este estudo teve como objetivo descrever o caminho percorrido pela criança, adolescente e suas famílias, desde o início dos sinais e sintomas até a definição do diagnóstico de câncer. **Métodos:** Trata-se de estudo descritivo-exploratório, com abordagem qualitativa. Utilizou-se entrevista semiestruturada como recurso para coleta do material empírico. Estes foram agrupados na categoria "a longa peregrinação: do adoecimento ao início do tratamento". **Resultados:** Participaram do estudo 10 familiares de crianças e adolescentes com diagnóstico de câncer em tratamento quimioterápico. Os sujeitos relataram as experiências de forma detalhada e cronológica, descreveram o início dos sinais e sintomas, as idas e vindas pelos serviços de saúde, e a atuação dos profissionais no setor primário e no especializado. **Conclusão:** Conclui-se que a criança e o adolescente percorrem um longo caminho diante da situação oncológica. Foram evidenciadas as dificuldades relacionadas ao acesso aos recursos diagnósticos, o que compromete as possibilidades de um diagnóstico precoce.

Palavras-chave: Criança; Adolescente; Enfermagem oncológica; Câncer; Diagnóstico precoce.

RESUMEN

Objetivo: Este estudio visa realizar la descripción del camino recorrido por el niño, adolescente y sus familias, desde el comienzo de los signos y síntomas hasta la definición del diagnóstico de cáncer. **Métodos:** Estudio descriptivo exploratorio con abordaje cualitativo. Ha sido utilizada la entrevista semiestructurada como recurso para recolección de material empírico. **Resultados:** Han participado del estudio 10 familiares de niños y adolescentes con diagnóstico de cáncer, en tratamiento quimioterápico. Los sujetos del estudio han relatado las experiencias de forma detallada y cronológica, realizando la descripción del inicio de los signos y los síntomas; las idas y venidas por los servicios de salud; la actuación de los profesionales en el sector primario y en el especializado. **Conclusión:** El niño y adolescente recorren un largo camino delante de la situación oncológica, evidenciando las dificultades relacionadas al acceso a los recursos diagnósticos, lo que compromete las posibilidades de un diagnóstico precoz.

Palabras-clave: Niño; Adolescente; Enfermería Oncológica; Câncer; Diagnóstico Precoz.

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INTRODUCTION

Progress in the treatment of child cancer has been significant in the last four decades, increasing the chances of cure and survival. It is estimated that about 70% of children with cancer can be cured if diagnosed early and the disease is treated in specialized centers. Despite child cancer having a short period of latency, high rates of proliferation and a strongly invasive nature, it responds better to treatment when discovered early¹. When the treatment is successful, patients heal, resume family life and reintegrate into social life².

Early diagnosis of childhood cancer is a challenge because the signs and symptoms are not necessarily specific and for this reason children/adolescents are referred to treatment when the disease is already in an advanced stage. A late diagnosis may occur due to the type of tumor, patient's age, clinical suspicion, severity of the disease, care provided by the parents or their perceptions concerning the disease, parents' level of education, distance from a treatment center, and the healthcare system. Therefore, it is important that health professionals, through technical and scientific knowledge, are able to recognize the disease and its main forms of presentation³.

The experience of cancer is a long journey for the child or adolescent and the family, with diverse repercussions for their routine, considering both the early and late consequences of treatment. The different therapeutic modalities in the cancer field offer the possibility of a cure for children and adolescents, opening up new prospects of life.

Hence, this study's objective is to describe the path travelled by families from the beginning of the child's or adolescent's signs and symptoms up to the definition of the cancer diagnosis, mainly to contribute to nursing care so it becomes more attentive care, in order to expand the possibilities of early diagnosis for childhood cancer. Therapeutic success is essential to reducing the time between the emergence of signs and symptoms and the definition of the diagnosis, increasing life expectancy.

METHOD

This is a descriptive-exploratory study with a qualitative approach. The field research was conducted in the Oncology Outpatient Clinic at the Joana de Gusmão Child Hospital. This is a university hospital in the South of Brazil, which, among other specialties, is a regional referral center for the care of children and adolescents with onco-hematological disorders.

The study project was approved by the Institutional Review Board (process N^o. 002/2010). The study's participants were invited to participate and signed free and informed consent forms. To ensure confidentiality of the participants' identities, the letter F, which stands for "Family member", was substituted for the participants' real names, followed by a number to differentiate among them, for example F1 (family member 1), F2 (family member 2) and so on.

Eight mothers, one grandmother and one father of children or adolescents with cancer and undergoing chemotherapy participated in the study. Data were collected from March to May 2010 through

semi-structured interviews according to the following questions: How and when did you realize that something was wrong with your child? What were the signs and symptoms your child experienced at the time? What service did you search for? How long did it take to confirm the diagnosis? Tell me how the health professionals can help families during the period the definition of diagnosis is sought.

Interviews were recorded with the consent of those involved and later transcribed. Afterwards, these interviews were repetitively read in order to grasp the individuals' testimonies. The analysis followed the stages recommended by thematic content analysis, that is, pre-analysis, analysis of expressed and latent meanings, development of themes and final analysis⁴. We opted not to analyze the empirical material using statistics, as originally recommended by the technique; instead, we performed a comprehensive analysis.

This process enabled a category to emerge from the empirical material, a long journey: from becoming sick to the beginning of treatment, showing the path travelled by families up to the definition of their children's or adolescents' diagnoses of cancer and the role of professionals in this context.

RESULTS

A long journey: from becoming sick to the beginning of the treatment

The period that precedes the definition of a child cancer diagnosis is often long and difficult. Families realize that something is wrong due to the signs and symptoms their children experience and changes observed in their behavior during routine activities. Most of the time, these changes are mild and ordinary but then suddenly they become worse and, in some cases, the child or the adolescent him/herself warns the parents that something is different:

In February she experienced pain that migrated throughout her body. I thought it was growing pains, then she'd become angry, sad and sleepy. On March 13th she had a temperature at the end of the day (F1).

He showed me. It was small as a pea (F2).

The parents describe in detail the path they travelled in the search to solve their children's health problems, such as the date the signs and symptoms started, when the disease appeared and the search for health services. This information is rich in details, regardless of the time passed, and includes concerns, doubts, and the procedures involved:

On March 12th at midnight he started to feel pain in his leg. He took dypirone the entire afternoon and the fever only got worse (F3).

In March 2009, he was sitting and tried to stand up but felt pain and fell. He couldn't walk anymore. The pain was in the tibia, where the tumor was (F4).

The families begin their journeys with the need to go back and forth to various services, trying various resources until they reached a diagnosis, requiring a search for a family doctor and different specialties, as well as care provided by other professionals and innumerable exams and hospitalizations, as the following testimonies show:

A lump would appear, I'd take her to the masseur and the lump would disappear. Then a lump appeared on the top of her foot, after a massage, instead of reducing it, it got bigger (F5).

One bubo appeared in the groin, I took to the doctor and he said it was normal. One week later there was another one. I called another specialist and he asked for exams and the results were altered. I was referred to an infectologist. (F6).

Another important aspect refers to incorrect medical assessments and inefficient treatment, which most of the time, lead to a delay in correctly diagnosing the disease. Even though there were reports of signs and symptoms, the physicians seemed to be oblivious to the possibility of cancer:

The physician said: "It's normal; it's a childhood disease; it'll hurt another two months then it'll stop. But there had already been two months in which she was feeling pain" (F7).

He diagnosed it as a migraine, gave her medication. We gave the medication for some time and the headache stopped. After a while her eye started to pop out (F8).

In order to speed up the diagnosis and already fearing something more serious, families resorted to various other means to solve the problem faster, even seeking private services:

We paid for the first exams. We'd have to wait for five months to take the MRI if it was through SUS. I paid for the MRI and the ultrasound [...]. I live in a small town. I had to travel in order to take the exams. You have to schedule, there is a waiting period. If it wasn't for the delay, it wouldn't have gone to the ovaries, to the right lung, to the rib (F5).

Some reports make the fragility of the health services organization apparent, since, in addition to the delay in accessing the services, the needs of children and adolescents who seek quality service with problem-solving capacity are not met:

If SUS couldn't afford a CT scan they should have called the parents and asked: can you pay for it? For eight months they prescribed sinus medication (F9).

One of the parents who had a different experience stated that the Unified Health Service (SUS) met all the child's needs for care and treatment:

Every procedure was done through the SUS, including the exams. It was pretty fast. The physicians, nurses, everyone always provided me good service (F10).

Each case required two to five professionals, on average, to reach the correct diagnosis. The specialties most frequently sought were related to the signs and symptoms the child or adolescent experienced. Pediatricians were the professionals most frequently sought followed by rheumatologists, ophthalmologists and orthopedists.

This context shows that health professionals need to identify the warning signs of child cancer to reach an early diagnosis. The health staff's training, at different levels of complexity, needs to be constantly updated to expand the knowledge necessary to identify appropriate procedures so these professionals are able to identify cancer, ask for more detailed exams and, if necessary, refer the child to a specialist.

Considering that most of the interviewees did not live in the city where the child received treatment, difficulties related to a lack of preparedness on the part of the professionals practicing in the patients' places of residence emerge as something that struck them during the process of moving from becoming sick to their treatment. This experience is shown in the following testimony:

The doctor said: you daughter has no cure, I'll refer her to Florianopolis for a treatment in order to prolong life. He gave me no hope. The physicians here are not used to dealing with this type of thing happening to parents, to a child, and said: it depends on the treatment, the patient's desire, a lot of things (F3).

The time the diagnosis is disclosed is closely linked to feelings such as despair, fear, sadness, and concern over the child's future. In this phase, families require competent professionals both in terms of technical-scientific knowledge and in terms of being able to provide support and attentive listening. Given this context, we verify that some experience integral care while others receive mechanical care.

When I saw the orthopedist, he asked: What do you want? You've seen four physicians already. When you ask too many people for advice, you end up with none (F7).

A very insensitive social worker talked to me. She said lots of things at the same time. She talked about money, unemployment. I said: "I don't understand." And she said: "You're stressed." I'll need a psychologist (F2).

The health professionals are wonderful people and helped me, they took my son in their arms and treated him with the utmost care and dedication (F4).

DISCUSSION

The confirmation of a cancer diagnosis intensifies one's experience in the universe of severe diseases even more. The long periods of treatment that require invasive and aggressive procedures require emotional involvement, sometimes more than one can bear. It is however, after the diagnosis and beginning of treatment that the child or adolescent and family, although plunged into a period of restructuring and uncertainty⁵, learn how to deal with cancer, with the hospital environment and therapeutic procedures, and adapt their lives to the reality of the disease.

We observe that, in the beginning, the similarities that signs and symptoms of cancer share with other more common childhood diseases hinder the confirmation of the diagnosis. As a consequence, families seek various services and resources until they reach a diagnosis. Various physicians and non-physicians are consulted, and countless exams and potential hospitalizations are required^{6,7}.

According to the current service network available in Brazil, the first physician to be sought is a pediatrician or a family doctor, who is usually linked to the Family Health Strategy, one of the main forms of reorganization of the health service and its entry door to the population through primary health care. In their entire career, these professionals witness few cases of malign neoplasia compared to what they see in terms of common child diseases. As a consequence, cancer is not the first hypothesis they consider, which often leads to a late diagnosis, to the progression of the disease, a worse prognosis, more aggressive treatment and even greater sequelae from the treatment⁸.

Currently, 70% of cancer diagnoses are identified by non-oncological physicians, which shows their importance in the control of the disease⁹. There is also the role other health professionals, especially nurses, play in the investigation and definition of cancer diagnosis. A more comprehensive assessment would gather information such as the set of signs and symptoms, results of physical and laboratorial exams, aspects related to gender, religion, and family history, among other variables that do not establish the diagnosis *per se*, but help to establish differences among potential diseases. Therefore, before a diagnosis is defined, differential aspects should be thoroughly studied, not only by the physician, but by all those involved in healthcare delivery.

We observe that when a child becomes sick, the health staff and/or the parents seldom consider something complex, or even a chronic disease, such as cancer.

Even though the signs and symptoms justify greater attention, the parents usually believe that such symptoms are a reflex of "growing pains" or are associated with an easily-solved problem. Hence, the definition of a diagnosis is hindered while the child does not experience severe limitations due to the disease^{10,11}. In this context, families keep their responsibilities, functions, and daily activities while the child's cancer remains confounded with a common childhood disease.

Health professionals often postpone the diagnosis because they do not consider the possible existence of cancer in a child

even when there is evidence of the disease. The difficult task of appropriately dealing with the concern of parents, correctly assessing the main non-specific symptoms, and rapidly accessing diagnostic exams, are the most important steps toward an early diagnosis. Physicians should become accustomed to carefully assess the disease's most common signs and symptoms and those that are more statistically relevant^{10,11}.

Even though childhood cancer is not common, establishing a diagnosis that is not consistent with the child's or adolescent's actual health problem may lead to severe consequences. In some cases, inappropriate treatment may reduce or even mask the signs and symptoms experienced by the child or adolescent. This situation increases the period between the onset of the disease and its proper treatment, which impacts the disease progress.

In line with a late diagnosis of cancer during childhood, we emphasize that parents frequently complain about the need to be persistent with physicians so that they make deeper and more thorough investigations because physicians seldom ask for complementary exams and do not heed the parents' complaints¹².

We conclude that patients, parents, physicians, the child's biological behavior or even socioeconomic factors (public or private health system) may account for a late diagnosis^{7,12}. The main factors leading to a late diagnosis may be related to the child's age at the time of diagnosis, to the parents' level of education, type of cancer, how the signs/symptoms manifest, the site of the tumor, its stage, and medical specialty that was consulted in the first instance. The search for a pediatrician in the first consultation is more frequently associated with an early diagnosis than when a family doctor or other specialties are sought³.

It is relevant to note the weaknesses in and failures of SUS' structure, the difficulties parents experienced to get complementary exams through the SUS, the lack of medication, and the disorganization of public services. It amounts to saying that in some cases, the SUS' principles of decentralization, accessibility and problem-solving capacity have not been implemented, jeopardizing the health of the population^{8,12,13}.

The SUS ensures integral care to any cancer patient. There are more than 300 health facilities in Brazil that are designated by the public system for oncological care of high complexity. These treatment networks are spread out through 26 states and 128 different cities. Even though this support is ensured by the State policy, there is a need to ensure the problem-solving capacity of services. It is believed that the more qualified those involved with care delivery are, the better the use of resources and tools available¹.

The rich details with which the disease signs and symptoms are described in the parents' search for a diagnosis and treatment drew our attention. Unfortunately, these stories are full of difficulties, barriers and limited understanding on the part of the health professionals. This aspect should lead to more serious reflection concerning the role each should play in the process because the health staff working in the pediatric field requires broad technical-

-scientific knowledge. Parents experience situations that are permeated by doubts and questions and need to trust the knowledge of the professional providing care to their children.

Considering that the health staff's technical knowledge directly impacts the quality of care provided, children and adolescents need to be cared for considering them in their entirety, valuing their complaints and also performing appropriate anamnesis, always considering the possibility of cancer. Appropriate assessment is essential for an accurate diagnosis, since the longer the delay, the more advanced the disease can be, the lower the chances of attaining a cure and the greater the sequelae accruing from more aggressive treatments.

Currently, it is the responsibility of the pediatrician to identify suspected cases, initiate further investigation and refer the child or adolescent to a referral service. These procedures should be undertaken early and characterized by skill, which is decisive for this population to receive the most efficacious treatment and the most benefit. Hence, the objective is to achieve higher indexes of cure and reduced sequelae, enabling more successful treatment, since survival is significantly higher and functional results are better when the disease has not spread².

Therefore, the health professional in the primary health care service can already have a diagnostic suspicion, acquired through the various stages, during which s/he should proceed to a more careful analysis based mainly on knowledge of the case and of the disease, always considering the patient in his/her psychosocial aspects. In this process, one makes decisions, which right or wrong, will impact the patient's life and quality of life.

Given all these aspects, we realize that there is much to be done so that the health staff acknowledges their responsibility in the prevention and control of child cancer, as well as the early achievement of a diagnosis. Diagnostic and therapeutic conduct is needed, as well as greater agility in how cases are referred.

In addition to poor technical-scientific knowledge concerning child cancer, there is a complaint that health professionals only "see" the sick person and do not provide care to the companion, as well¹⁴. Hence, we perceive that the relationships among those involved in the process is fragile and shows that professionals are focused on the technical intervention at the expense of the family's psychological desires.

The parents experience a feeling of oppression given the quantity of technical information they receive and the fact they have to simultaneously face fear and anxiety while making decisions concerning treatment. Many parents report difficulties in dealing with their own feelings and, therefore, do not have the emotional resources to appropriately prepare their children for the emotional "roller coaster" they will experience during their cancer journey. The parents who experience difficulty expressing their feelings tend to internalize negative emotions, which usually manifest as somatic complaints and a feeling of being overloaded in the emotional experience of their children's disease¹⁵.

It is necessary for health professionals to have a keener sensitivity toward the system's users considering the health and disease continuum. It is crucial that nurses, together with

their teams, develop or strengthen the pleasure of working with these users so that such pleasure is reflected in the quality of care delivery.

To fully achieve the objective of supporting and positively influencing care, effective interpersonal communication is essential through the exchange of easy to understand verbal and non-verbal messages, marked by sincere and flexible behavior, with information coherent with the needs and potential of each family. In this sense, nursing guidance allied with interdisciplinary work is essential to promoting improved quality of life both for the child or adolescent with cancer and their families¹⁶.

It is worth noting that family members do not always verbalize the difficulties they experience and it is important that health professionals, especially nursing professionals, have the tools to help them identify the types of support that can benefit this clientele in order to contribute to the journey cancer imposes on them, planning appropriate services and care based on the needs that emerge in each phase of the disease. Professionals from the oncological field deal with multiple complications that accrue from the treatment and side effects, psychosocial and religious problems, and family conflicts. Given the magnitude and complexity involved in the trajectory of cancer, it is not enough that professionals become concerned with the use of technological resources or with the improvement of techniques. It is also necessary that they improve their skills, abilities, and competencies to provide more comprehensive care focused on the specificities of each child/adolescent and their families.

An early diagnosis of cancer enables minimizing the treatment and maximizing quality of life. The professionals working in the oncological field, especially in pediatrics, face the challenge of reducing the consequences of aggressive treatment, directing care to improve the quality of life of survivors, as well as reintegrating patients into society in a non-discriminating way so they can fully exercise their citizenship. A regimen of cancer treatment affects the lives of patients at various levels and is not restricted to the biological aspect, also affecting the social and emotional spheres. Hence, surviving cancer encompasses time of survival, life conditions, and the limitations imposed by the disease and treatment, which requires improved quality of life during the period of survival¹⁷.

GENERAL CONSIDERATIONS

The path travelled by the families in this study shows, once more, the strength and hope with which they move forward in the search for a diagnosis and treatment for their children, confirming the willpower and desire to enforce their rights, even if others or they, themselves, are not fully aware of such rights. The arduous path, the long journey the families describe in their struggle for life, provides a picture of this context to professionals, who can build more supportive healthcare paths that are increasingly grounded in technical-scientific knowledge.

We also verify that for reaching an early diagnosis of childhood cancer and, consequently, improving the chances of reaching a cure and an appropriate quality of life, actions with the

cooperation of health organizations and institutions that provide education to professionals are required in order to promote integral care, since the principles of accessibility, integrality and problem-solving capacity have been compromised. It is crucial for the SUS to meet the needs of the population at all levels, enabling access to all care modalities and different types of technology, as well as better qualified human resources. Professionals need to know the signs and symptoms of child cancer and use the resources available at the same time in which they care for human beings in their uniqueness, based on the principles of humanized care. It is believed that this will favor the resolution of individuals' health problems.

Health professionals should practice teamwork to provide information and continuous support to families, to help them cope with stressful situations, so they can collaborate and actively participate in their child's or adolescent's treatment. In this way, all those involved in the treatment will get the comfort they need, clarifying questions that permeate the follow-up of a cancer patient.

This study shows the breadth and importance of an early diagnosis of child cancer and contributes to the field of knowledge. It is expected that in the future the term "early diagnosis" will no longer be used as a goal to be achieved but as a fact already experienced in the different contexts and throughout the experiences of health and disease that a child or adolescent may have.

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