

# CUIDADO É FUNDAMENTAL

Escola de Enfermagem Alfredo Pinto – UNIRIO

RESEARCH

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## CHILDHOOD CANCER: KNOWLEDGE OF FAMILIES OF CHILDREN ASSISTED IN PRIMARY HEALTH CARE

*Câncer infantojuvenil: conhecimento de famílias de crianças atendidas na atenção primária à saúde*

*Cáncer infantil: conocimiento de familias de niños atendidos en la atención primaria de salud*

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### ABSTRACT

**Objectives:** to identify the knowledge of the families of children assisted in Primary Health Care about the signs and symptoms of cancer in children. **Method:** descriptive, qualitative study carried out with 14 family members of children and adolescents assisted in Primary Health Care. Data were collected through semi-structured interviews conducted through a simultaneous messaging application and analyzed following the steps recommended by Qualitative Content Analysis. **Results:** it was possible to list two central categories: knowledge and perceptions of families about childhood cancer and information needs about childhood cancer. **Conclusion:** the involvement of families in childcare consultations and the sharing of information by professionals are resources that can facilitate the recognition of warning signs and symptoms for childhood cancer, especially in Primary Health Care.

**KEYWORDS:** Knowledge; Neoplasms; Pediatric nursing; Family; Primary health care.

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## RESUMO

**Objetivos:** identificar o conhecimento das famílias de crianças atendidas na Atenção Primária à Saúde sobre os sinais e sintomas do câncer infantojuvenil. **Método:** estudo descritivo, qualitativo realizado com 14 familiares de crianças atendidas na Atenção Primária à Saúde. Os dados foram coletados por meio de entrevista semiestruturada realizada por intermédio de um aplicativo de mensagens simultâneas e analisados seguindo as etapas preconizadas pela Análise Qualitativa de Conteúdo. **Resultados:** a partir da análise dos dados, foi possível elencar duas categorias analíticas: conhecimentos e percepções das famílias sobre câncer infantojuvenil e necessidades de informações sobre o câncer infantojuvenil. **Conclusão:** o envolvimento das famílias nas consultas de puericultura e o compartilhamento de informações por parte dos profissionais são recursos que podem facilitar o reconhecimento de sinais e sintomas de alerta para o câncer infantojuvenil, principalmente na Atenção Primária à Saúde.

**DESCRITORES:** Conhecimento; Neoplasias; Enfermagem pediátrica; Família; Atenção primária à saúde.

## RESUMEN

**Objetivos:** identificar el conocimiento de las familias de niños atendidos en la Atención Primaria de Salud sobre los signos y síntomas del cáncer en niños. **Método:** estudio descriptivo, cualitativo, realizado con 14 familiares de niños atendidos en la Atención Primaria de Salud. Los datos fueron recolectados a través de entrevistas semiestructuradas realizadas a través de una aplicación de mensajería simultánea y analizados siguiendo los pasos recomendados por el Análisis Cualitativo de Contenido. **Resultados:** fue posible enumerar dos categorías centrales: conocimientos y percepciones de las familias sobre el cáncer infantil y necesidades de información sobre el cáncer infantil. **Conclusión:** la participación de las familias en las consultas de puericultura y el intercambio de información por parte de los profesionales son recursos que pueden facilitar el reconocimiento de signos y síntomas de alarma del cáncer infantil, especialmente en la Atención Primaria de Salud.

**DESCRIPTORES:** Conocimiento; Neoplasias; Enfermería pediátrica; Familia; Atención primaria de salud.

## INTRODUCTION

Child and adolescent cancer accounts for between 1% and 4% of cancer cases in the Brazilian population and is the leading cause of death from diseases between the ages of 0 and 19. It is estimated that there will be 7,930 new cases each year in the three-year period 2023-2025, with a predominance of males. In terms of the most common types in childhood and adolescence, leukemias are in first place, followed by cancers of the central nervous system and lymphomas.<sup>1</sup>

Considering the rapid proliferation and invasive nature of the disease, with the aim of changing this scenario, it is imperative that the approach to cancer in children and adolescents is geared towards early diagnosis. However, the clinical presentation of this type of cancer occurs through non-specific signs and symptoms, common to other diseases prevalent in childhood, which facilitates late diagnosis and has a negative impact on prognosis.<sup>2-4</sup>

On the path from the appearance of the first signs and symptoms to the diagnosis of childhood cancer, there is an interweaving of factors involving: parental screening, i.e. the parents' perception of the symptoms and/or the need to seek a health service; professional screening, in which health professionals need expertise so that procedures can be carried out in a timely manner, as well as access to and resolution of health services.<sup>5-7</sup>

It is known that diagnostic screening for childhood cancer involves a number of factors and the family is a determining factor in the perception of physical and behavioral changes, in the search for evaluation, in negotiating procedures and in ensuring that access to the health system is effective. It's a dynamic and winding path, whose starting point is the child's

parents or social network, who will be the first to identify physical and/or behavioral changes that need to be investigated.<sup>5,7</sup>

Studies on parents' experiences and the diagnostic itinerary for childhood cancer show that, given the lack of knowledge about the disease and its rarity, parents often do not immediately interpret their child's symptoms as being related to some type of cancer, which delays the search for health services.<sup>3,6-7,9</sup> However, once the family realizes that there is something wrong and seeks care, they mobilize for information about their child's clinical condition and are eager to obtain a diagnosis.<sup>7-10</sup>

Therefore, the population has a key role to play in the diagnostic screening of childhood cancer, since knowing about the disease and its warning signs equips them to seek information and care from health services. In this context, health professionals must be able to recognize families' information needs in order to plan educational actions with the population, especially in primary care. In view of the above, the following questions arose: what does the family receiving primary health care know about childhood cancer and its signs and symptoms? What actions do families consider important to disseminate and share information about childhood cancer? The aim of this study was to identify the knowledge of the families of children treated in primary health care about the signs and symptoms of childhood cancer.

## METHOD

This is a descriptive study with a qualitative approach, conducted in a virtual environment. Participants were recruited by convenience, following the Snowball technique, in which the first participant

indicates to the researcher other potential participants for the study. The initial search took place through social media and the WhatsApp® messaging app, due to the social distancing imposed by the COVID-19 pandemic. From the first contacts, other families were indicated and contacted by the first researcher to clarify possible doubts and proceed with the invitation to take part in the research.<sup>11</sup>

Families of children between the ages of one and 11 treated in Primary Health Care (PHC) in the state of São Paulo took part, according to the following inclusion criteria: having attended a PHC appointment no more than one year prior to data collection and being responsible for the child at the time of the appointment, regardless of the degree of kinship. Those with no direct link to the child were excluded from the study. Data collection was scheduled according to the availability of each family, through prior contact with the researcher. Contact prior to data collection facilitates the creation of rapport, i.e. a relationship with the participant, and can increase the perception of safety and comfort in the participants, since they can have access to the data and the researcher's photo.<sup>12</sup>

Semi-structured interviews were conducted between 2021 and 2022 via a simultaneous messaging application, using written and audio messages between the researchers and the interviewees. Each interview was transcribed in full, subject to the participant's consent. All the families received a copy of the Informed Consent Form (ICF), drawn up in accordance with the recommendations for conducting research in a virtual environment during the pandemic.<sup>13</sup>

To guide the interviews, a script was drawn up consisting of sociodemographic information about the child and family member (age, degree of relationship, origin, level of education),

and information related to the frequency of visits to primary health care services. In order to cover the phenomenon studied, two guiding questions were initially asked: "Do you know what childhood cancer is? Do you know any warning signs or symptoms of childhood cancer? If the answers to both questions were positive, the family was asked: "How did you find out about this information?" If the answer was no, the family was asked the following questions: What information would you like to know? How would you like to have this information?

After the initial questions, eight situations of children showing warning signs and symptoms of childhood cancer were described, using clear language adapted to the family's understanding, and they were asked about their perception and behavior in the face of the situation. The situations described were: (1) Child with a white spot in the eye visible after flash photography; (2) Child with an increase in volume or presence of a mass (swelling) in the abdominal region (belly) or other regions; (3) Child with fever for more than 2 weeks, weight loss, pallor, fatigue, purple spots on the body; (4) Child with recent onset strabismus, visual loss, bruising or swelling around the eyes; (5) Child with lumps or bumps, which do not hurt and without fever or other signs of infection; (6) Child with persistent headaches or vomiting mainly in the morning or worsening over days; (7) Child with pain in the bones, joints, back, fractures or swelling without trauma or signs of infection; (8) Child with dizziness, loss of balance or coordination or speech impairment.<sup>14</sup>

Data analysis followed the steps recommended by Qualitative Content Analysis.<sup>15</sup> To ensure the anonymity of the participants,

**Chart 1-** Characterization of research participants. Campinas, São Paulo, Brazil, 2022.

Participant	Age	Relationship with the child	Education	Origin	Child's age (in years)
E1	27	mother	HS incomplete	Campinas-SP	3
E2	29	mother	HE incomplete	São Paulo-SP	3
E3	24	mother	HE complete	São Paulo-SP	1
E4	26	mother	HS complete	São Paulo-SP	10
E5	24	mother	HE incomplete	Pirassununga-SP	1
E6	32	mother	HS incomplete	Cotia-SP	11
E7	28	mother	ES complete	Campinas-SP	11
E8	28	mother	HE complete	São Paulo-SP	9
E9	33	mother	HE complete	Campinas-SP	8
E10	21	mother	HS complete	São Paulo-SP	2
E11	33	mother	HS complete	Campinas-SP	6
E12	28	mother	HS complete	Cotia-SP	3
E13	27	mother	HS complete	São Paulo-SP	4
E14	26	mother	undeclared	São Paulo-SP	1

**Legend:** ES (elementary school), HS (high school), HE (higher education)

the name was replaced by the letter E (interviewee) followed by a number in relation to their order of participation, for example, the first interviewee was identified as (E1). The research followed the recommendations of Resolution 466/2012 and was approved by the Research Ethics Committee of the proposing institution on July 20, 2020 (Opinion 4.131.107).

## RESULTS

Fourteen mothers of children treated at Basic Health Units in the state of São Paulo took part in this study. The participants' ages ranged from 21 to 33 and most had completed high school. The children's ages ranged from one to 11 years, with a predominance of school-age children. All the mothers lived in the state of São Paulo.

Data analysis identified two analytical categories: users' knowledge and perceptions about childhood cancer and information needs about childhood cancer. A análise dos dados permitiu identificar duas categorias analíticas: conhecimentos e percepções dos usuários sobre câncer infantojuvenil e necessidades de informações sobre o câncer infantojuvenil.

### Families' knowledge and perceptions of childhood cancer

When asked about their knowledge of childhood cancer, most of the mothers interviewed reported that they did not know about the disease or that they knew very little about it, bringing leukemia as a reference for the group of diseases. Leukemia is referred to by the families as the main known cancer, most likely because it is the most widespread on social media and not all the symptoms are known, only the most representative ones such as bleeding and spots on the body.

*To be honest, I don't know, I've heard of cancer, but I've never heard the term 'childhood cancer'.* (E2)

*I know very little, I've heard more about leukemia, as far as I can remember it's spots or bleeding from the body. I think it's like any other cancer, we're all subject to it.* (E3)

*I know there's leukemia (...) which is in the blood."* (E6)

*I've never heard of it, I don't know anything about it.* (E10)

The interviewees' narratives show that the population confuses the signs and symptoms with the effects of treatment, relating hair loss as a consequence of the disease, revealing stereotyped ideas about cancer. What's more, their knowledge of the disease comes from their imagination, and there were no mentions of information received during treatment.

*It's a disease that children get, right? I'm very scared, it makes their hair fall out, they get weak, but I don't really understand how it's caught... knowing how it's caught is good because we pay more attention to things."* (E7)

*What I know is very little (...) I imagine something on my head, because I remember the girl I used to see, her head*

*shaved with a scarf, I think she had a tumor on her head.* (E12)

*I know what's on TV, about the children in hospital and suffering, which makes you cry, I've only heard about it, I know there are liver and blood tumors, but I don't know anything else and I don't know people close to me, it's rare, right?* (E13)

Although most of the participants reported not knowing anything about childhood cancer, when asked about some warning signs and symptoms, they were able to identify those that would prompt them to seek health services immediately.

*Swelling in the abdominal area I would observe, if it didn't improve I would go to the doctor... headaches or vomiting I would go to the doctor or the nurse and I would want to know what was going on.* (E1)

*Knowing his routine, I know that persistent headaches or vomiting aren't normal, it could be something to do with his stomach and I'd try to control it at home for up to two days, after which going to the doctor would really be the alternative until I found out the reason and the cure.* (E5)

*The first three days of fever aren't good, are they? It could be a urinary tract infection, a throat infection or something more serious, two weeks is too long (...) it's not just the fever that we should pay attention to, because there are people who have lumps and no fever, it could also be cancer or something else.* (E6)

However, when asked about leukocoria as a specific warning sign of retinoblastoma, mothers faced with the situation "child with a white spot in the eye visible after flash photography" were not so concerned about seeking health care, a worrying finding given that delayed diagnosis of retinoblastoma can lead to early loss of vision.

*I'd suspect a vision problem, I don't know if I'd take it straight away, but I'd make an appointment to see an ophthalmologist.* (E2)

*I would think it was something in the photo itself, I wouldn't have enough knowledge to imagine anything related to any illness.* (E5)

*I don't think it's something serious to go to the doctor about.* (E12)

### Information needs on childhood cancer

In this category, there was a disparity between what families have to say about childhood cancer and what they would like to know, highlighting the importance of effective communication with health professionals during childcare appointments. When the mothers were asked about the subject during consultations, campaigns or when they received printed or audiovisual material, all of them said that they had never talked about it in the health units.

*It was never discussed. I've never received [information material].* (E4)

*At no time did [receive professional information].* (E5)

*I've never received any material.* (E12)

*No, never [talked to a professional].* (E16)

The mothers showed a desire and considered it important to know more about childhood cancer, especially the signs and symptoms that would alert them to seek a health service, thus contributing to an early diagnosis. In addition, they validate that there is a shortage of information about the disease and that existing campaigns are aimed more at the adult population. The lack of information delays the search for medical care.

*It's very important [to know about the signs and symptoms] because the more we know about the subject, the better we can identify the disease and help our children.* (E4)

*It would be essential if more information were provided, as with breast cancer... what parents should try to understand about it, how it happens, what they should notice and what is different in the child's daily life (...) there is little information, sometimes there is inattention to some signs.* (E6)

*I think it's important to know things. If we knew what the real signs of cancer are in children, families would certainly seek medical help as quickly as possible.* (E12)

In addition, some emphasized the importance of professionals talking about the signs and symptoms of childhood cancer, pointing out that the more people know about them, the quicker they will seek health services and that information is also a form of prevention.

*During consultations, they should comment a little, like, look, be careful if this or that comes up, I don't know, or something for us to think about, I think something that's said is always good because it gets into our heads more: be careful, you know.* (E1)

*From my point of view, it would be easier if a doctor explained to us what can happen and what the symptoms of childhood cancer are.* (E12)

As for how the family would like this information to be conveyed, mothers would like to receive it through reading and audiovisual materials, lectures and health professionals at childcare appointments, in simple language, which would facilitate access and understanding.

*Simple language, perhaps an animation or even a folder with brief but important information.* (E3)

*I think someone explaining it would be best, there could even be some paper that they sometimes give out, but then the person explaining it, right?*

*When you go to the pediatrician, have more pamphlets that report cases that have happened to children.* (E11)

## DISCUSSION

Children's families need to be alert to signs and symptoms suggestive of childhood cancer, as they are the best observers of the child's state of health, capable of noticing changes in the child's behavior and daily activities.<sup>4,15</sup>

The literature is already clear on the importance of the family and the health team in the early diagnosis of childhood cancer, recognizing the influence of parents in recognizing signs and symptoms. Thus, it is important to provide information and materials that promote knowledge about childhood cancer.<sup>16</sup> However, in this study, none of the participants had received any material or participated in any campaign about childhood cancer, showing a deficit in the dissemination of information by professionals.

To highlight the importance of educational materials and sharing information, a study carried out in Nigeria, which aimed to describe the pre-diagnostic symptomatic intervals and the factors that influence delays in diagnosis, concluded that educating parents and caregivers about recognizing early signs is important for early diagnosis and that the longer time taken to make the diagnosis was due to late referral and socio-economic difficulties.<sup>17</sup>

Despite the importance of parents knowing the signs and symptoms and the attitudes needed to signal early diagnosis, it is important to emphasize the responsibility of health professionals in this scenario, highlighting the importance of professionals working with families, following the attributes of Primary Health Care: family orientation, which considers the family as the subject of care according to their physical, socioeconomic and cultural context.<sup>18-19</sup>

The actions of health professionals should be anchored in the precepts of the Patient and Family Centered Care (PFCC) model, which recommends establishing good communication between the health team and the family, taking into account the families' prior knowledge, involving them in care planning and encouraging them to participate in decision-making regarding the child's health.<sup>20</sup>

Effective communication in this relational process can be a key factor. Meeting the family's demand for information helps them make decisions, manage uncertainty, reduce stress and anxiety and care for the child. Providing educational materials is also a strategy to strengthen communication with the family, since the information can be consulted at any time, allowing the caregiver time to grasp its content. Armed with information, families become partners in early diagnosis, as they are able to disseminate knowledge about childhood cancer among their peers and in the community.<sup>21-22</sup>

Health care must therefore focus on the family, which means that the multi-professional team needs to know the family as a whole. Thus, in order to promote quality care, centered on the needs of the child-family binomial, a good relationship between the family and health professionals is essential. One of the foundations for establishing this good relationship is maintaining effective communication, based on active listening and welcoming the family's demands for information.<sup>18-20,23</sup>

It should be added that this study has limitations, especially with regard to online data collection, making it difficult to interact more closely with mothers in order to obtain more in-depth answers. However, even in the midst of the pandemic situation experienced during the data collection period, it was possible to identify important aspects regarding knowledge and information about childhood cancer in primary health care.

## FINAL CONSIDERATIONS

The knowledge of families of children cared for in Primary Health Care about childhood cancer is still little explored, also exposing their weaknesses in recognizing the signs and symptoms that can be a warning sign of the disease.

Promoting health literacy in the field of pediatric oncology should be part of the educational processes of the multi-professional team working in PHC. In this way, the findings of this study reinforce the need to expand attention to the early diagnosis of childhood cancer, and information materials and other technologies can be developed to be applied, for example, in the health education of families of children followed up at childcare appointments.

Considering the countless opportunities that professionals have for contact with children and their families, especially during consultations in the first two years of life in PHC, it is essential to share information about childhood cancer, because although it is rare, it is the leading cause of death from diseases in the pediatric population.

Furthermore, the family unit is the first nucleus that produces health and disease and the involvement of health professionals in sharing information is a resource that strengthens the family to recognize the warning signs and symptoms of childhood cancer. The use of information materials, prepared in simple language and according to the needs of families, should be encouraged by PHC, contributing to the construction of comprehensive care for this population.

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