







## RESEARCH ARTICLE (ORIGINAL) 8

## Early detection of childhood and adolescent cancer in Primary Health Care: possibilities and limitations

*Deteção precoce do cancro infantojuvenil nos cuidados de saúde primários: possibilidades e limitações*

*Detección precoz del cáncer infantojuvenil en la atención primaria de salud: posibilidades y limitaciones*

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### Abstract

**Background:** The early detection of cancer has a major impact on the lives of children and adolescents because they start treatment in better conditions, thus influencing their prognosis and survival.

**Objective:** To investigate the possibilities and limitations regarding the early detection of childhood and adolescent cancer, based on reports from professionals working in Primary Health Care.

**Methodology:** Exploratory study conducted in 3 basic health units. Eleven health professionals participated in the study. Data were collected through semi-structured interviews. The empirical material was qualitatively analyzed based on the Content Analysis Technique.

**Results:** The possibilities found were contextualization and interpretation of clinical findings, as well as systemized and interdisciplinary care. The limitations found were lack of specificity of the signs and symptoms of childhood and adolescent cancer, non-compliance with the principle of accessibility, and need for training/capacity building.

**Conclusion:** This study will contribute to improving the performance of these professionals regarding the early diagnosis of cancer in children and adolescents receiving care in PHC.

**Keywords:** early diagnosis; neoplasms; pediatrics; primary health care

### Resumo

**Enquadramento:** A deteção precoce do cancro tem grande impacto na vida de crianças e adolescentes, uma vez que estes iniciam o tratamento em melhores condições, influenciando, assim, no seu prognóstico e na sobrevida.

**Objetivo:** Investigar as possibilidades e limitações no que diz respeito à deteção precoce do cancro infantojuvenil, a partir de relatos de profissionais que atuam nos Cuidados de Saúde Primários.

**Metodologia:** Estudo exploratório, desenvolvido em 3 unidades básicas de saúde. Participaram no estudo 11 profissionais de saúde. A colheita de dados foi realizada por meio de entrevista semiestruturada. O material empírico foi analisado qualitativamente, de acordo com a Técnica de Análise de Conteúdo.

**Resultados:** Apresentaram-se como possibilidades – a contextualização e interpretação dos resultados clínicos, além de uma assistência sistematizada e interdisciplinar. Como limitações – a falta de especificidade dos sinais e sintomas do cancro infantojuvenil, não observância do princípio de acessibilidade, assim como a necessidade de formação/capacitação.

**Conclusão:** Sendo assim, constatou-se que este estudo possibilitará uma melhor atuação destes profissionais a respeito do diagnóstico precoce do cancro em crianças e adolescentes assistidos nos CSP.

**Palavras-chave:** diagnóstico precoce; neoplasias; pediatria; atenção primária à saúde

### Resumen

**Marco contextual:** La detección precoz del cáncer tiene un gran impacto en la vida de los niños y adolescentes, ya que estos comienzan el tratamiento en mejores condiciones, lo que influye en el pronóstico y la supervivencia.

**Objetivo:** Investigar las posibilidades y limitaciones respecto a la detección precoz del cáncer infantojuvenil, a partir de informes de profesionales que trabajan en la atención primaria de salud.

**Metodología:** Estudio exploratorio, desarrollado en 3 unidades básicas de salud. Once profesionales de la salud participaron en el estudio. La recopilación de datos se llevó a cabo mediante una entrevista semiestructurada. El material empírico se analizó cualitativamente, de acuerdo con la técnica de análisis de contenido.

**Resultados:** Se presentaron como posibilidades, la contextualización e interpretación de los hallazgos clínicos, así como la asistencia sistemática e interdisciplinaria. Como limitaciones, la falta de especificidad de los signos y síntomas del cáncer infantojuvenil, el incumplimiento del principio de accesibilidad, así como la necesidad de formación/capacitación.

**Conclusión:** Por lo tanto, se constató que este estudio permitirá un mejor desempeño de estos profesionales en cuanto al diagnóstico precoz del cáncer de niños y adolescentes atendidos en los CSP.

**Palabras clave:** diagnóstico precoz; neoplasias; pediatria; atención primaria de salud



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## Introduction

Cancer is a life-threatening chronic disease that is characterized by uncontrolled growth of abnormal cells that invade tissues and organs. This disease mainly affects the cells in the blood system, the nervous system, and the supporting tissues, affecting not only adults, but also children and adolescents, which demonstrates the importance of gaining an insight into pediatric oncology, as this disease is feared for posing a life-threatening danger (Ministério da Saúde, 2019).

Studies by the Global Cancer Observatory highlight that the number of new cases and cancer deaths due to 36 types of cancer will continue to increase until 2040. In addition, the incidence of neoplasms will increase by 63% in about 20 years if there is no appropriate management, which is equivalent to 21 million new cases per year. It is known that 3% of all cancers worldwide are in children and adolescents, and 630,000 new cases of cancer are expected to occur in children and adolescents every year (International Agency for Research on Cancer, 2018). In Brazil, cancer is the leading cause of death in children and adolescents, accounting for about 8% of deaths among individuals aged 1-19 years. In 2014, data on childhood and adolescent cancer were recorded and consolidated in Brazil, totaling 2,724 deaths (Ministério da Saúde, 2017a). This survey showed that there are differences in the access to early detection and appropriate treatment for cancer in Brazil.

Thus, in view of the above, the general objective of this study is to investigate the possibilities and limitations regarding the early detection of childhood and adolescent cancer, based on reports from professionals working in primary health care (PHC).

## Background

The early detection of cancer has a major impact on the lives of children and adolescents because they start treatment in better conditions, which influences their prognosis and survival and significantly reduces the mortality rate (Instituto Ronald McDonald, 2018).

Because it is considered a public health issue, the Brazilian Ministry of Health recommends that professionals refer suspected and confirmed cases of childhood and adolescent cancer through a comprehensive line of care, with the definition of paths and actions starting from PHC, with the help of the Protocol for Early Diagnosis of Pediatric Cancer. It should be noted that PHC reaches 46.6% of the Brazilian population, which includes a significant number of children and adolescents (Ministério da Saúde, 2017b).

On the basis of this understanding, PHC should put forward responses that are compatible with the population's health needs, presenting satisfactory solutions. To do this, it should promote interventions that bring positive outcomes regarding the early detection of childhood and adolescent cancer. Conditions should be created to identify clinical signs and symptoms in the initial stage

of the disease, with initiatives to increase the knowledge of health professionals and the community in general about the impact of this disease on the lives of children and adolescents, thus promoting a higher cure rate (Handayani et al., 2016).

Therefore, further studies are needed to discuss childhood and adolescent cancer. This disease involves a set of biological, spiritual, emotional, and social aspects, and it is even more strenuous because it affects children and/or adolescents and imposes limitations to the comprehensive care of this group (Oliveira & Kruse, 2017).

In Brazilian literature, there is a lack of studies on the importance of early detection of childhood and adolescent cancer in PHC. Therefore, studies should be conducted to produce new knowledge about this topic from the perspective of PHC professionals.

## Research question

What are the possibilities and limitations regarding the importance of early detection of childhood and adolescent cancer according to PHC professionals?

## Methodology

This is an exploratory qualitative study. This type of study allows the researcher to start a probing process, whose main objective is to enhance, expand, and clarify concepts, proposing the creation of several hypotheses for the development of future studies (Gil, 2019).

The research was conducted in three Basic Health Units (*Unidades Básicas de Saúde*, UBS) in the municipality of João Pessoa - PB, Sanitary District V of the 1<sup>st</sup> Regional Health Center of Paraíba, after a diagnostic evaluation of these units by the Municipal Health Secretary, upon presentation of the research objectives and purpose.

The research was conducted from October 2019 to November 2019. The sample was composed of 11 PHC professionals working in the UBS selected for the study. This number is justified because it is a qualitative research. The following inclusion criteria were used for sample selection: being a health professional with a higher education degree and working in the UBS selected for the study for more than 1 year. However, participants who worked there but refused to participate in the study were excluded.

Data were collected using the semi-structured interview technique. In this technique, there is not a strict planned order of questions, because it combines both closed-ended and open-ended questions in a flexible way, facilitating the interviewee's understanding (Manzini, 2012).

This study is associated with the research project entitled "Palliative Care in Pediatrics: A look at primary care, hospital care, and support networks" (*Cuidados Paliativos em Pediatria: um olhar no âmbito da atenção básica, hospitalar e redes de apoio*), which was approved by the Research Ethics Committee of the Lauro Wanderley University Hospital (HULW), under Opinion no. 1.268.255 and

CAE no. 48333415.3.0000.5183.

Therefore, this study complied with the ethical principles regarding the development of research involving human beings foreseen in COFEN Resolution No. 564/2017, established in the Code of Ethics of Nursing Professionals (Federal Nursing Council, 2017), in accordance with Article 57 on the duties of compliance with existing legislation for research involving human beings.

The excerpts from the interviews of the participants involved in the research were coded based on their professional category in order to maintain anonymity. Thus, codes were assigned to the participants' statements, for example: nurse "N"; dentist "D"; and physician "P".

In order to highlight the professional responsible for the statement, in addition to the code, the number corresponding to the interview was added. Thus, the first interviewed nurse was coded as "N01", the second as "N02", and so on.

The empirical material was analyzed based on the Content Analysis Technique. The purpose of this technique is to describe the content of messages and obtain quantitative and/or qualitative indicators that make the researcher reanalyze the communication process, thus allowing for an understanding of the concepts through a set of systematic procedures (Bardin, 2017).

Bardin (2017) divides the stages of analysis into pre-analysis, coding, inference, and interpretation of the data. In the pre-analysis, the documents were chosen and the objectives and indicators that sustain the final interpretation were established. It is the phase of the organization itself, consisting of fluctuating reading, choice of documents, and preparation of the material.

In the coding stage, the decisions taken in the pre-analysis stage are implemented. Raw data are organized and aggregated into units, which allow describing the most relevant characteristics in the interviews' excerpts.

The last stage of inference and interpretation consists of the statistical analysis and condensation of the results, in order to highlight the data necessary for the analysis in light of the literature relevant to the topic.

## Results

For a better understanding, data regarding the participants' characteristics will be presented first. Next, the categories resulting from the interview excerpts will be addressed. The age range of the interviewed professionals ranged from 32 to 60 years. With regard to gender, nine were women and two were men. As for their profession, four were nurses, four were dentists, and three were physicians. Regarding their length of service at the unit, three reported 1 to 5 years, two between 6 and 10 years, and six over 10 years.

Thus, after analysis of the interviews, two categories emerged: Systematized care by specialty to children and adolescents in PHC; and Difficulties faced by PHC professionals regarding the early detection of childhood and adolescent cancer.

These categories highlight the technical and scientific

knowledge and skills of PHC professionals, as well as the difficulties faced by them regarding the early detection of childhood and adolescent cancer.

With regard to the first category, data were obtained on the performance of PHC professionals regarding the early detection of childhood and adolescent cancer. The participants' statements showed the contributions and the importance of systematized and continuous care of each professional specialty, either by physicians, nurses or dentists, as revealed in the following excerpts: "The nurse's role is to perform the necessary monitoring, especially in childcare . . . we check in on how the child is doing." (N01; October, 2019); "We observe the child's weaknesses, development and growth, everything regarding childcare, and we see if there's something that is not normal" (N02; October, 2019).

As our work in anamnesis is to look [at the patient] as a whole, then we try to identify the complaint, what is happening to the child and adolescent. . . . it is a process that requires us to pay attention to everything, every complaint, however slight. (N03; October, 2019)

"At the appointments, I always advise mothers to remain vigilant, alert to the signs . . . I talk about the importance of healthy eating, and some signs that the child/adolescent may present if they're ill" (N04; October, 2019); "If a patient arrives, I will evaluate him in the medical consultation, if there are any changes, I ask for a biopsy, I refer him" (P01; October, 2019).

The medical procedure is to request tests, evaluate them, refer to the specialist, make the referral, we also ask that patient to bring the counter-referral from the specialist . . . And another strategy is to ask him to come here every month to be clinically reevaluated. (P02; October, 2019)

"It was in the doctor's appointment, during palpation of the abdomen, I found a strange mass . . . it is based on this initial consultation that we make the final diagnosis." (P03; October, 2019); "I'm always very careful to examine not only the teeth, but the oral cavity in general. The cheeks, the palate, the complete self-examination, I'm very careful with that." (D01; October, 2019); "We are here to provide care, accompany, visit, support the family, provide guidance. We examine, we perform the anamnesis . . . we teach each patient how to do the self-exam and we always have this concern to observe the lesions." (D02; October, 2019); "Our role in dental consultations is to make discoveries. And refer to the relevant sectors. Because we work with prevention." (D04; October, 2019).

The reports of the professionals included in this study show the importance of systematized care as a strategy for early detection of childhood and adolescent cancer, from the physical examination, the follow-up of children and adolescents through periodic evaluation, the request for tests, guidance to those accompanying the patient, to the referral to specialists when necessary. Therefore, these professionals' accounts also revealed the importance of interdisciplinarity, that is, the sharing of knowledge between PHC professionals, in order to effectively promote the early detection

of childhood and adolescent cancer, as can be seen in the following excerpts: “The child always has a nursing consultation, but we also do this rotation with the doctor.” (N01; October, 2019); “When there was a consultation with the dentist or the doctor, in the childcare we do together, we would always pay close attention . . . we already wonder if it’s something different.” (N02; October, 2019).

The one who diagnosed was the doctor on my team . . . So in the nursing consultation, I already try to refer him to where he should go, because sometimes communication with the specialists is difficult. It’s a job where I depend on the doctor, the dentist, the NASF sector, you see? And this link provides a more accurate look from the whole team. (N03; October, 2019)

The team is well prepared in relation to perception, the patients’ complaints. Here in the unit, the team has a lot of groups, waiting rooms, medicine, nursing . . . we usually provide this type of clarification here. (P01; October, 2019)

“When we suspect something, we follow the protocols, we examine the patient, make a home visit, always with someone, we always ask the ACS to go with us, to give us some feedback” (P02; October, 2019); “We even diagnosed it there . . . I found the palpation very strange, then my colleague and I made the diagnosis. . . . meeting on top of another meeting to discuss the welcoming process” (P03; October, 2019); “Together with the professionals on my team, we raise suspicion about the diagnosis, so we refer them” (D01; October, 2019); “We call the team, we talk to the doctors, the dentists, the nurse, the agents, we try to make a unique therapeutic project, we are also responsible for referrals” (D03); “There is a lot of commitment from me and my colleagues. Together we refer all cases to specialized services” (D04; October, 2019). The professionals’ reports highlight the importance of interdisciplinarity because each professional’s contribution based on their specialty is essential for decision-making, both regarding the early detection of childhood and adolescent cancer and the promotion of comprehensive care to children and adolescents with suspected cancer. The following statements from some interviewed professionals regarding the second category reveal the lack of preparation to identify cases of cancer in children and adolescents attending PHC services, as well as the difficulties faced in the referral, when necessary, to specialized services and the lack of communication between the other levels of health care.

This implies that there is a high number of referrals of children and adolescents in a critical condition to the specialists, in which case the possibility of cure is very low (Friestino, Corrêa, & Moreira Filho, 2017), as can be seen in the following accounts: “As it is an atypical situation that we regularly don’t see, we are more focused on what we see on a daily basis” (N01; October, 2019).

A patient was being treated for a sebaceous cyst for some time, but it was actually cancer . . . It would be great if it were actually diagnosed in Primary Care, but that’s not the reality. There is a suspicion of an infection first, then an inflammation and a

delayed treatment, going from doctor to doctor, and only later is the diagnosis . . . we have no experience of a child who has had a quick diagnosis of cancer. (P03; October, 2019)

“She still didn’t have a diagnosis. . . She was fine, you see? Apparently well, we didn’t know. . . . but she was later diagnosed with leukemia” (D03; October, 2019).

The participants also reported that the insufficient knowledge about the topic is justified by the lack of contact with cases of children and adolescents with cancer or the lack of continuing education, turning into a difficulty in their work routine:

When a child with suspected cancer arrived, we still didn’t have any training . . . I have my perspective, the doctor has theirs, the dentist has theirs, but if we had continuing education, we would have a targeted look at it and know what to do. There should be continuing education for the whole team. (N03; October, 2019)

“As it is an atypical situation that we regularly don’t see, we are more focused on what we see on a daily basis, we end up not being able to know when there’s a case because we didn’t have that training” (D02; October, 2019).

These interview excerpts show that the early detection of childhood and adolescent cancer may not be performed adequately due to the need for training and capacity building among the health professionals who provide care to children and adolescents in PHC.

In addition, another difficulty faced by the participants is the lack of articulation between PHC and the specialized services, which is aggravated by the poor communication among these services regarding referral and counter-referral, resulting in the discontinuity of health interventions for the patients and their families, as can be observed in the excerpts below:

We face a lot of difficulties. From referral, the moment of diagnosis, to getting that first appointment to that child who is asymptomatic, there is that difficulty, from the moment of diagnosis to getting a first consultation in the specialized sector. (N01; October, 2019)

Before there was no need for a referral to go to the hospital of reference, through the National Regulatory System, now there is, then it slows things down a little bit, because the demand increases . . . as we have about 4,000 inhabitants, we don’t get to see this whole population. (N02; October, 2019)

“One of the most common difficulties in Primary Care, there are only a few professionals who send the counter-referral.” (P02; October, 2019); “there are always some obstacles, some limitations that are inherent to the lack of integrated work and dialogue regarding referral and counter-referral. It turns out everything else gets complicated.” (D03; October, 2019).

## Discussion

In the last 20 years, early detection of childhood and adolescent cancer has increased by 13%. A study developed

in a hospital specialized in pediatric oncology in Minas Gerais revealed the importance of the intervention of the health professionals who are responsible for promoting early detection activities, from the first signs and symptoms. Thus, the identification of the disease at early stages increases the probability of a hopeful prognosis when combined with an adequate treatment, since cancer can be cured in 80% of the cases (Silva et al., 2016).

Corroborating the previous statement, a study emphasized that each professional must be aware of the importance of the necessary competencies and skills regarding the implications and steps of their work process, thus applying their technical, scientific, and human skills, as well the field of epidemiology, of the signs, symptoms, and risk factors inherent to childhood and adolescent cancer, with the purpose of promoting continuous and humanized care (Lima, 2018).

It should be noted that a combination between the technical-scientific knowledge and the more accurate perspective from the professionals integrated in the multidisciplinary PHC team contribute to a more efficient and quick identification of clinical findings, promoting the investigation and possible early detection of childhood and adolescent cancer, with proper referral to a specialist, in order to confirm or rule out the diagnostic hypothesis. In case of cancer, early detection contributes to a more effective treatment, which increases the chances of cure (Lima, 2018).

Thus, a PHC team with adequate technical-scientific competencies will contribute to a significant reduction in the number of malignant neoplasms among children and adolescents, since this level of care is important because it is the gateway for children and adolescents in the UBS (Mutti et al., 2018).

According to the National Institute for Health and Clinical Excellence, there are key recommendations for cases of diagnostic hypothesis or suspected cases found in PHC, such as: active/qualified listening by the professionals; assertive and enlightening guidelines to clarify all of the doubts that the accompanying person may have; scheduling of revaluations in short time; and dialogue with the members of the UBS multiprofessional team to clarify the stage of diagnosis (Van Boven, Koen, Eline, & Els, 2017).

PHC aim to ensure a closer link between health services and users and between the professionals and the population, as well as increased access to the healthcare network. Another aspect in PHC is the increase in the number of common health problems that are solved, as well as making the continuity of care possible (Mutti et al., 2018).

Thus, these accounts make it clear that the performance by these professionals regarding the implementation of health activities, either individual or collective, aims to ensure the comprehensiveness and problem-solving capacity recommended by PHC regarding childhood and adolescent cancer (Handayani et al., 2016).

However, health teams need to overcome some limitations, especially in PHC, related to the difficulties in identifying the signs and symptoms of neoplasms, the obstacles to ensure access to continuous care, going through all levels

of the Unified Health System (Sistema Único de Saúde, SUS), as well as indices that point to late screening and treatment (Miranda, Melaragno, & Pina-Oliveira, 2018). A study conducted in the health districts of Campinas is in line with a review conducted by a Canadian university, which draws attention to one of the greatest difficulties in the early detection of pediatric cancer cases, which is characterized by the set of clinical manifestations that are similar to other benign diseases common in this age group, as well as the presentation of general signs and symptoms of unspecified location, which can hinder and delay the diagnosis of a potential neoplasm (Mutti et al., 2018; Friestino et al., 2017). Therefore, it is of utmost importance that these professionals receive training for the early detection of childhood and adolescent cancer. In this way, health professionals should interpret the clinical findings by contextualizing them based on: age group, gender, correlation of signs and symptoms, period of time over which the disease evolves, and, if necessary, investigate other complementary data, thus enabling a more accurate and timely diagnosis and a systematized assistance (Mutti et al., 2018).

Therefore, although the cases of childhood and adolescent cancer are not a routine demand in PHC, the professionals' lack of information is a weakness in care delivery, since they have several responsibilities in caring for pediatric cancer patients. This situation contributes to an increase in the period of time between disease onset and treatment initiation, with a direct impact on disease evolution (Paixão, Farias, Rosas, & Coropes, 2018).

A dialogue is needed between professionals of specialized services and PHC professionals, giving the feedback about what will be performed with the patient, the stage of the disease, and the specialized team's recommendations for care delivery in the UBS and at home. This dialogue between PHC professionals and specialized services is essential for the continuity of an effective and efficient care delivery (Huesca, Vargas, & Cruz, 2018).

Therefore, it is essential to restructure policies focusing on intersectoral management, providing a flow of care within an operational logistics based on the premise of referral and counter-referral for suspected cases or potential diagnosis of cancer. Thus, the joint efforts of the PHC team and the specialized team will make a difference in reducing mortality and increasing the cure rates, through shared assistance in these services, thus avoiding fragmented and disjointed care (Oliveira & Kruse, 2017). Given the complexity of the procedures in health services, from the investigation process to the final diagnosis and the referral to a specialist/treatment, it is imperative that PHC professionals get more training and qualifications and improve their performance regarding childhood and adolescent cancer at different levels of health care. In this way, they will have a more accurate look during the consultation, through detailed anamnesis and physical examination, a careful evaluation, reevaluation within a short period of time, requests for more targeted tests, while using their technical-scientific skills to reach a diagnostic hypothesis for malignant neoplasms in children and adolescents (Paixão et al., 2018).

From this perspective, the professionals and PHC are responsible for the mission of assisting children and adolescents with cancer, thus transforming the current delivery of care to these individuals, aiming at the early detection of childhood and adolescent cancer no longer as an objective to be achieved, but as an intrinsic process at this level of care (Huesca et al., 2018).

However, this study has limitations because it is a qualitative research with a small number of participants. In view of this, the results cannot be generalized.

## Conclusion

This study brings relevant contributions about the possibilities and limitations regarding the early detection of childhood and adolescent cancer based on the reports of health professionals working in PHC.

With regard to the possibilities, the health professionals included in this study reported the importance of the adoption of strategies in PHC, for example the contextualization and interpretation of clinical findings, as well as a systematized and interdisciplinary care. These strategies demonstrate their concern regarding the early detection of childhood and adolescent cancer in PHC. Regarding the limitations, the health professionals mentioned the lack of specificity of the signs and symptoms of childhood and adolescent cancer combined with the need for training and capacity building, as well as the non-compliance with the principle of accessibility recommended by the SUS, due to poor communication regarding the referral and counter-referral of suspected cases of cancer in children and adolescents of the PHC. Thus, there is a need to provide continuing education and training to health professionals working in PHC that allow early detection of childhood cancer. This intervention will improve the qualifications and the performance of these professionals regarding the early diagnosis of cancer in children and adolescents attending PHC.

In view of the above, this work is expected to contribute to the development of new studies that can have an impact on the performance of health professionals working in PHC, with an emphasis on the early detection of childhood and adolescent cancer. It is also expected to promote a reflection of the best strategies for overcoming the difficulties related to the early detection of cancer in children and adolescents receiving care in PHC.

## Author contributions

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