Original article

Revista de Enfermagem do Centro-Oeste Mineiro
2025; 15/5611
www.ufsj.edu.br/recom

RECOM
Revista de Enfermagem
do Centro-Oeste Mineiro

Cancer in childhood and adolescence: understanding feelings and challenges

Câncer na infância e adolescência: compreendendo sentimentos e desafios

Cáncer en la niñez y la adolescencia: entendiendo los sentimientos y los desafíos

ABSTRACT

Objective: To understand how children and adolescents perceive cancer. **Method:** Exploratory-descriptive study with a qualitative approach. Data were collected through semi-structured interviews with nine children and adolescents aged eight to twenty, accommodated in a Support Home. The sample was selected by convenience, following defined eligibility criteria and psychological follow-up. The interviews were analyzed using Bardin's Content Analysis technique. **Results:** Four categories emerged from the analysis: cancer from the perspective of children and adolescents; feelings and emotions experienced; facilitating and hindering elements in social reintegration; and the child and adolescent's perception of care. Participants reported fear, social stigma, impacts on daily routine and self-image, but also highlighted the role of the support network, play, and active listening as protective factors. **Final remarks:** Children and adolescents express understanding of their illness and wish to be included in care. Clear communication, welcoming attitudes, and individualized care contribute to treatment acceptance and coping with challenges. Nurses, being present in the patients' daily lives, become key figures in care, promoting empathy, emotional support, and articulation with the support network throughout the illness experience.

Descriptors: Oncology nursing; Pediatric nursing; Neoplasms; Child; Adolescent.

RESUMO

Objetivo: Compreender como as crianças e adolescentes percebem o câncer. **Método:** Estudo exploratório-descritivo com abordagem qualitativa. Os dados foram coletados mediante entrevistas semiestruturadas com nove crianças e adolescentes dos oito aos vinte anos de idade em uma Casa de Apoio. A seleção foi por conveniência, com critérios de elegibilidade definidos e acompanhamento psicológico. As entrevistas foram analisadas por meio da técnica de Análise de Conteúdo de Bardin. **Resultados:** Quatro categorias emergiram da análise: o câncer sob a óptica de crianças e adolescentes; sentimentos e emoções vivenciados; elementos facilitadores e dificultadores encontrados na reinserção social e a percepção da criança e do adolescente acerca do cuidado. Os participantes relataram medo, estigmas sociais, impactos na rotina e na autoimagem, mas também destacaram o papel da rede de apoio, das brincadeiras e da escuta ativa como fatores protetivos. **Considerações finais:** Crianças e adolescentes expressam compreensão sobre a doença e desejam ser incluídos no cuidado. A comunicação clara, o acolhimento e o cuidado individualizado contribuem para a aceitação do tratamento e enfrentamento dos desafios. O enfermeiro, ao estar inserido no cotidiano dos pacientes, torna-se referência no cuidado, promovendo acolhimento, empatia, suporte emocional e articulação com a rede de apoio durante o enfrentamento da doença.

Descritores: Enfermagem oncológica; Enfermagem pediátrica; Neoplasias; Criança; Adolescente.

RESUMEN

Objetivo: Comprender cómo perciben el cáncer los niños y adolescentes. **Método:** Estudio exploratorio-descriptivo, con enfoque cualitativo. Los datos se recolectaron mediante entrevistas semiestructuradas con nueve niños y adolescentes de entre ocho y veinte años, acogidos en una Casa de Apoyo. La muestra fue seleccionada por conveniencia, con criterios de elegibilidad definidos y acompañamiento psicológico. Las entrevistas se analizaron mediante la técnica de Análisis de Contenido de Bardin. **Resultados:** Del análisis surgieron cuatro categorías: el cáncer desde la perspectiva de niños y adolescentes; sentimientos y emociones vividas; elementos facilitadores y obstaculizadores en la reinserción social; y la percepción del cuidado por parte de los niños y adolescentes. Los participantes relataron miedo, estigmas sociales, impactos en la rutina y en la autoimagen, pero también destacaron el papel de la red de apoyo, el juego y la escucha activa como factores protectores. **Consideraciones finales:** Los niños y adolescentes expresan comprensión sobre su enfermedad y desean ser incluidos en el cuidado. La comunicación clara, el acogimiento y el cuidado individualizado contribuyen a la aceptación del tratamiento y al afrontamiento de los desafíos. El enfermero, al estar inserto en el día a día de los pacientes, se convierte en referencia del cuidado, promoviendo empatía, apoyo emocional y articulación con la red de apoyo durante el proceso de la enfermedad.

Descriptores: Enfermería oncológica; Enfermería pediátrica; Neoplasias; Niño; Adolescente.

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http://doi.org/10.19175/recom.v15i0.5611

INTRODUCTION

Childhood and adolescent cancer comprises a group of diseases characterized by the uncontrolled proliferation of abnormal cells, which can develop in any part of the body, most often affecting blood-forming cells and supporting tissues. These tumors are predominantly of embryonic origin and consist of undifferentiated cells, a feature that generally favors a better response to current treatments. The most frequent types in this age group are leukemias, tumors of the central nervous system, and lymphomas(1).

In Brazil, it is estimated that between 2023 and 2025, there will be nearly 7,930 new cases of childhood and adolescent cancer annually, with an estimated risk of 134.81 per million children and adolescents. Significant progress in treatment over the past four decades has enabled cure rates of around 80% among children and adolescents diagnosed with the disease, particularly when early diagnosis and treatment are carried out in specialized centers(1).

Despite technological advances, childhood and adolescent cancer and its treatment carry psychosocial consequences that may negatively affect family relationships, educational performance, vocational opportunities, and access to insurance and healthcare. Patients may also face challenges such as distressing changes in body image or experience chronic symptoms, including fatigue and pain, which impact emotional health and quality of life(2,3).

Pediatric oncology nursing care must be holistic, addressing not only the physical needs of children and adolescents but also their psychological and social demands(4). This requires individualized and humanized care that minimizes traumatic effects, actively involves the family throughout the process, provides clear information about the disease and treatment, and prepares the child for necessary procedures. Pain and discomfort relief measures should be implemented, always respecting the decisions of both the family and the child (5).

In this context, an important question arises: How do children and adolescents perceive the diagnosis and treatment of cancer? From the perspective of understanding this perception, identifying the main sources of suffering experienced by young patients coping with oncology and, clarifying the worries they face in carrying out their daily activities, this study aims to understand how children and adolescents perceive cancer.

METHODS

This is an exploratory-descriptive study with a qualitative approach, structured according to the Consolidated Criteria for Reporting Qualitative Research (COREQ)(6). The research was conducted in a nonprofit support facility in Rio Grande do Sul, Brazil, which provides free assistance to individuals diagnosed with cancer and living in vulnerable conditions.

Participants were selected using convenience sampling and included nine children and adolescents aged between eight and twenty years, covering the period of late childhood and adolescence(7). Eligible participants were children and adolescents diagnosed with any malignant neoplasm, who had initiated cancer treatment and were emotionally fit to participate in the study at the time of data collection. he institution's psychologist evaluated all participants to ensure suitability for the study. Individuals deemed by the support center team to be lacking adequate physical or emotional readiness were excluded from participation.

Data were collected in October 2018 through individual semi-structured interviews conducted by the nurse-researcher at the institution, in a private setting, with the institution's psychologist present. The interviews were conducted by one of the authors, an undergraduate nursing student previously trained by the principal investigator. Both researchers had no formal employment at the study site, yet they engaged in preliminary interactions with the institution to gain an understanding of its context.

Although the data were collected in 2018, the topic, as well as its analysis and discussion, remains highly relevant to the current context of nursing. The experiences reported highlight aspects of the illness and treatment process that continue to require skilled attention from healthcare professionals. Moreover, the data were gathered with methodological rigor, supported by an appropriate and up-to-date theoretical framework. Their use at this time is justified by their relevance to the practice of humanized care, as well as the ongoing need for studies exploring children's and adolescents' perspectives on cancer.

The interview was guided by the following questions: 1 What do you know about your illness? 2 How did you feel when you found out you had cancer? 3 What are your daily activities? 4 What do/did you experience during treatment? 5 What is/was it like to be away from family and friends? 6 How were you cared for?

Prior contact was made by telephone with the parents or legal guardians of the participants to explain the objectives of the study and invite them to take part. Upon acceptance, the date and location of the interview were scheduled, and both the Consent Form (CF) for the legal guardian and the Assent Form for the participant were obtained and signed, ensuring the child's or adolescent's autonomy, as well as permission for audio recording. For participants over 18 years of age, the CF was obtained directly from them.

The interviews were recorded in digital format and fully transcribed into a word processing file *.docx. They were organized sequentially, and the transcripts were standardized for spelling and grammar to facilitate reader comprehension, without altering the original meaning of the content. No participants withdrew from the study. Data collection was concluded when, after continuous analysis, repetition of information and the absence of new relevant elements were observed, thus characterizing theoretical data saturation. Data analysis followed Bardin's Content Analysis framework(8), structured in three stages: (i) pre-analysis – initial, exploratory reading of the transcripts and organization of the material; (ii) material exploration – coding and categorization based on participants' narratives; and (iii) treatment of results and interpretation – development of thematic categories grounded in participants' accounts and supported by the relevant literature.

The project was approved by the Research Ethics Committee of Centro Universitário FSG under protocol number 2,905,687, and authorization was also obtained from the institution where the study was conducted through a Letter of Agreement. All procedures complied with Resolution No. 466/2012 of the Brazilian

National Health Council, which regulates research involving human participants.

In accordance with the General Data Protection Law (Law No. 13,709/2018), data were anonymized during transcription and, participants were identified by the names of characters from Turma da Mônica (Monica's Gang). Audio files and transcripts were stored in a restricted Google Drive folder, accessible only to the researchers responsible for finalizing data publication.

RESULTS AND DISCUSSION

Nine participants aged between eight and twenty years took part in the study, six of whom were female. Regarding age at diagnosis, cases were evenly distributed across early childhood, middle childhood, and adolescence.

Three of the nine participants experienced relapse: two cases of leukemia relapse in Dona Marocas, who had previously been diagnosed with leukemia; a relapse of Ewing's sarcoma in Chico Bento, who had initially been diagnosed with lymphoma; and a relapse of lymphoma in Carminha Frufru, who had also previously been diagnosed with lymphoma.

Content Analysis led to the identification of four thematic categories: (a) cancer from the perspective of children and adolescents; (b) feelings and emotions experienced; (c) facilitating and hindering elements in social reintegration; and (d) patients' perceptions of care.

Cancer from the perspective of children and adolescents

Despite significant technological advances over the past decade, which have enabled more effective cancer treatments with higher success rates, the association of the disease with death and fear remains deeply deep-rooted in society(9–11).

This perception was repeatedly highlighted by study participants, indicating that societal views of the disease are often shaped by cultural trends and ideologies, as reflected in the following statements.

Several people told me that this disease, which many people have and die from because it is so tough, hits children even harder. (Maria Cascuda)

For me, I thought I was going to die, you know? But that's not what happened. (Carminha Frufru)

I only saw it in movies, where everyone died. They died and there was nothing else to do. (Cascão)

The media representation of cancer can significantly influence social perceptions, contributing to the construction of stigmas that affect the lives of these adolescents. Instead of highlighting stories of overcoming and the importance of resilience, the media generally chooses for narratives that emphasize fear and helplessness, which harms not only how society views these patients but also how they see themselves(9).

Once, when I watched a soap opera about a woman who had cancer, I remember that when I went to cut my hair, I recalled that scene and thought: "my God, I never imagined this would happen to me." I remember that when I watched that soap opera, I thought, "wow, poor woman," and then it happened to me. It is very different (Magali).

In addition to media influence, the occurrence of the disease in family members, most often older individuals, is commonly associated with the concept of fragility, which is further intensified by cancer and frequently linked to the process of death.

"I don't really talk much about this either. I know it's in the past, and I just hope it never happens again, because in my grandpa, the one who is outside right now, the cancer came back (Maria Cascuda)."

"My grandma also had cancer, and we lost her at the beginning of the year, in January. By the end of the year, I was diagnosed. So, for us, in the family, it was horrible, you know? Because we keep thinking about so many things (Carminha Frufru)."

The diagnostic process is long and full of uncertainties, as the signs and symptoms resemble those of other common conditions in childhood and adolescence. In addition, barriers to accessing healthcare services and the lack of medical preparedness for accurate diagnosis contribute to these challenges(11,12). Each consultation, examination, and procedure becomes a piece of the puzzle in the quest to resolve the enigma surrounding the clinical presentation.

"I had been undergoing treatment for chronic anemia for a year and a half, but it wasn't getting better. We went for some tests and I felt unwell, I fainted. My mother went to the doctor's office and argued with him, and the doctor said my mother was going crazy, that it was nothing serious, just anemia (Dona Marocas)."

Upon confirmation of a childhood or adolescent cancer diagnosis, families face the dilemma of whether or not to disclose the condition to the child or adolescent, as they are still vulnerable and struggling to comprehend the news(13). The communication process is surrounded by fear, sadness, and uncertainty, influenced by the way the information is conveyed and, consequently, by society's perception of the subject. Initially, families tend to seek a support network among people in their daily lives, sharing the situation and finding in them a source of support to cope with the circumstances(14).

"My mother started talking to her friends and telling them what had happened, and I began to listen. She would say it was a grade IV medulloblastoma. She told others, and I would listen to it (Mônica)."

After the diagnosis, parents may show overprotective behavior in an attempt to reduce suffering. In this context, some choose to hide the diagnosis, remaining silent for as long as possible, which fuels the child's or adolescent's imagination and increases anxiety due to the lack of information(13,15). Only one of the nine interviewees reported having no desire or curiosity to learn more about their condition.

"[...] I didn't even know what I had. While I was still under treatment, I was in Porto Alegre undergoing radiotherapy, and after a long time, I still didn't know I had cancer. I thought it was just a little 'lump'. The doctor told me it was just a little 'lump'. Then one day we were at the hospital, and I came across a sign that said Cancer Institute, and I asked my mother if I had cancer. She told me that I did (Mônica)."

To ensure a better understanding of this process, it is essential to take into account the patient's cognitive maturity and to use clear language. Playful tools, such as cartoons, images, and children's books, may be employed to facilitate comprehension. Information should be repeated as often as necessary to ensure that all questions and concerns are addressed(14,16). The following statement illustrates how an adequate understanding of the situation can provide relief, reduce stress, and foster hope, even in the presence of negative feelings associated with the context.

"I was very little. The doctor explained it to me in a very childlike way, saying that I had red soldiers and blue soldiers. The blue ones were my illness, and they were killing my good soldiers. Then I had to take the orange soldiers, which was the chemo, because chemo is orange, to kill the blue ones. But the consequence was that it would also kill the others. That's how it was. I always understood my tests well; everything was very openly explained, and I was always aware of the seriousness (Dona Marocas)."

"[...] I want to work, but I can't. I'm already 18, and I keep thinking: 'Am I going to stay under my mother's protection forever?' No way! A bird must leave the nest and learn to fly. (Maria Cebolinha)."

Communication, even when modified to each age group, contributes to greater adherence to treatment and to a more effective coping with the overall context, making collaboration in decision-making processes possible(14,16).

"The doctors always tell my mother to tell me everything. They ask her to share everything, not to hide anything, because it's good to tell the whole truth; the more you hide, the worse it is. If not, I can't keep up (Maria Cebolinha)."

Care is entirely focused on the sick individual, sometimes causing delays in skill development, social isolation, and hindering the formation of autonomy. These situations tend to worsen during adolescence(3,17).

Feelings and emotions experienced

The disclosure of a diagnosis reveals a complex blend of emotions. On one hand, the individual and their family experience a sense of relief, as doubts arising from the unknown are clarified. On the other hand, feelings of sadness come, often expressed through tears, as highlighted in several interview excerpts.

"It was somewhat comforting, you know? Because, in a way, we realized that we weren't wrong in feeling the way we did. It was a way of settling that lingering doubt that something was indeed wrong, but we just didn't know what it was, right? [...] Then we went outside and cried, cried, cried, cried, cried (Dona Marocas)."

Falling ill brings about abrupt changes in daily habits and routines, demanding adaptation to the new context imposed by the disease. Despite these challenges, many maintain a positive outlook, acknowledging the importance of resilience in the recovery process. Although faced with restrictions, play is regarded as essential for fostering social interaction, even when adapted to the child's health condition. However, parental concerns, overprotectiveness, and fear, together with the child's own fragility, often hinder such interactions. Conversely, play can facilitate treatment acceptance and mitigate stress levels, underscoring its relevance during this stage of life(3,18).

"I couldn't play. I couldn't go out on the street. I didn't have friends. I had nothing. I didn't go to school, nothing. I wanted to ride a bicycle. I was in treatment when I was seven, eight [years old]. My mother only let me ride a bicycle again when I was ten (Dona Marocas)."

"My mother, she... she... she has always been a warrior, a heroine. She just became more careful, much more careful than she already was" (Maria Cebolinha).

The main feeling at the moment of

diagnosis disclosure was fear, followed by dread, shock, and astonishment. The emotional impacts may stem from factors associated with other dimensions of the patient's experience, with particular emphasis on the physical domain. This latter dimension encompasses signs and symptoms that interfere with quality of life, which, in turn, exerts a significant influence on the individual's mental and psychological well-being.

"When I undergo treatment, I have this problem where my nose becomes very sensitive. My sense of taste becomes sensitive too, and I even feel disgusted by the smell of my own skin, because it gets saturated with medicine. Everything, everything, everything feels like too much (Chico Bento)."

"I used to feel a lot of pain, like, all over my skin, you know? Sometimes I couldn't even put on a sheet, because it hurt too much. Clothes, I had to stay without clothes, because wearing them caused me too much pain (Carminha Frufru)."

Cancer treatment may lead to the development of common psychological reactions in these patients, such as anxiety and depression. These conditions often arise in response to the painful treatment process, which generates feelings of helplessness, fear, and stress, particularly due to uncertainty about the future (17,19).

"The doctor said I was very anxious. I couldn't sleep; I would go two or three days without sleeping. So then she prescribed me Rivotril, because she said I was very anxious (Mrs. Marocas)."

At certain moments, anxiety and the adverse effects resulting from both the illness and its treatment turn into hopelessness, leading patients to feel powerless in the face of the obstacles they encounter. These symptoms can be identified in the following statement:

"Sometimes I thought I wouldn't make it, you know? Because my health kept going like this: down, up, then down, down again, then up, and I just didn't know if I would be able to get through it (Mônica)."

The maternal figure, traditionally associated with protection and family care, seeks to shield her children from life's adversities. As the central pillar of the family, the mother becomes the caregiver in this new reality, facing a profound sense of helplessness in the face of illness and the fear of death(3,18,20). In the following statements, the mother is described as the one the child wishes to protect, establishing a relationship of mutual protection. In only one case was the mother unable to remain by her child's side.

"I felt really sad, but even more so when I saw my mother crying (Cascão)."

"My mother was there through it all, you know? She left her job, left everything to stay with me (Dona Marocas)."

"My mother left the hospital; she didn't want to stay with me (Cebolinha)."

The siblings of the child or adolescent with cancer also become part of the world of illness and take part in the family's reorganization, as parents need to devote more time to the child undergoing treatment(21).

"He [brother] kind of felt rejected. But, like, there was nothing we could do, you know? It was just the four of us. Who else would have stayed with me if not my mother, right? Today our relationship is a bit strained precisely because of that (Dona Marocas)."

This situation may trigger feelings of rejection, fear, jealousy, sadness, and even shame toward the sibling, in addition to forcing them to take on new responsibilities and spend less time with their parents. One way to minimize these effects is to openly share with them what is happening, thereby including them in the process the family is going through(2,21).

"I think my sister felt really lost, really alone. Because before I got sick, I used to help her study and do things around the house. After that, the roles were reversed: she had to take care of me. That's when she became the 'older sister.' My parents even asked her to speak up if they were giving me too much attention, because at that moment I was the priority, you know? They realized they sometimes left her a bit aside (Magali)."

In this process, the family emerges as a vital source of support, offering hope and acting as a safe haven, especially as emotional bonds are reinforced. This support can manifest through words, gestures, presence, and effective communication(3,20).

"My family, they supported me a lot. Because when you're in that situation, what you need most is family, right? (Carminha Frufru)."

Despite the difficulties and vulnerabilities faced throughout the process, it is highly valuable that, alongside medical treatment and disease management, children and adolescents are encouraged to maintain their routine activities. These activities should be considered in light of the patient's limitations and restrictions, and, whenever possible, they should be encouraged to seek ways to stimulate their potential and development, as well as their social interaction, which serve as sources of energy and vitality during the process (3,18). These activities are seen by study participants as a way to distance themselves from the 'world of cancer,' allowing them to talk about topics other than the illness.

"I would go to school when my immunity was good, one or two days a week. When they told me I could go, oh, I would be leaping with joy. I missed it, because it took me out of my world of just cancer, just cancer (Magali)."

Facilitating and hindering elements in social reintegration

Illness often distances patients from their social environments. At the age of the participants in this study, school is the primary setting for social interaction. By the time social reintegration occurs, certain side effects of the disease and its treatment remain evident, setting them apart from the rest of the school population(3,18).

Law No. 9,394 of December 20, 1996(22), establishes the provision of educational services in hospital settings to enable children and adolescents to continue their studies. This approach, known as the hospital class, aims to prevent academic delay during hospitalization, foster moments of socialization and emotional support, and allow the hospitalized child or adolescent to maintain experiences similar to those of their routine prior to hospitalization(23). However, successful implementation requires coordinated efforts among the school, family, and hospital.

"I was sick for a year, undergoing treatment. A whole year, and then I lost the school year because I couldn't manage to do the homework anymore. The teacher would send the assignments from school, but I couldn't really understand them, you know? So I wasn't able to do them, and in the end, I lost the school year (Mônica)."

There are numerous benefits associated with school reintegration; however, several obstacles remain throughout the oncological journey. Among these are the lack of preparedness and knowledge about cancer on the part of both school staff and peers in welcoming the child or adolescent, which often results in prejudice and rejection(3,24).

"I was embarrassed about having short hair, and I used to wear those little hats, you know? Those things. One day, I went back to school [...] and there was a new teacher who didn't know me. Nobody had told her anything, and it was art class. Then she told everyone to take their hats off in her classroom, and I was too embarrassed, so I didn't take mine off. And then she, well, she started... she started yelling at me in class because I wouldn't take the hat off [...]. Then this boy, the one I liked, defended me, saying that I didn't have to take off my hat, that I didn't need to (Dona Marocas)."

Despite all the significant changes that may result from cancer, all participants in this study reported alopecia as one of the most striking factors throughout the health-disease process, as a consequence of chemotherapy. It is noteworthy that the emphasis on alopecia is not merely aesthetic, but is directly linked to social isolation(19,24).

"[...] I would feel embarrassed to show up in front of people I knew, without hair, because then they would start thinking I was strange. They would start asking, 'What is that? What happened?' You know? And, like, they would start avoiding me, right? I knew they would avoid me when they saw me like that (Mônica)."

"At school, they used to call me 'roll-on.' At first I cared, but later I would joke along and rub my head in their armpits (Cascão)."

In situations like these, the participants tend to withdraw from others, as illustrated in the following statements:

"At school, I isolated myself from everyone; I never spoke to anyone again (Cascão)."

"[...] children aren't going to stop what they're doing to remember that they had a sick friend and come see me. And even when I saw someone from school, on the street, I would almost hide, because I didn't want anyone to see me the way I was (Dona Marocas)."

However, there are also those who are part of the support network and, together with family members, provide physical and emotional support, facilitating school and social reintegration in the best possible way. They interact in a manner that treats these individuals as integral members of the group, avoiding any differentiation.

"Wow, everyone [classmates and teachers] treated me really well. [...] I was out of school for a while. When I went back, all my classmates already knew and treated me wonderfully. Not, like... not excluded, you know? They treated me normally, as if nothing had happened, and that was really good for me (Magali)."

Patients' perceptions of care

Even while investigating signs and symptoms, the hospital environment is abruptly introduced into the life of the child or adolescent. Hospitalizations become routine and lengthy, generating complex experiences due to the disruption of social interactions, habits, routines, and familiar activities. Instead, patients are confronted with a new environment, characterized by limitations and different routines, in which even the simplest tasks, such as taking a shower, are altered. They are also constantly subjected to procedures and devices that provoke fear and pain, in addition to being exposed at all times to incomprehensible terms(3,18).

“If you had to take a shower, like, you had to put a little bag over the IV so no water would get in. Taking a shower like that was awful (Cebolinha).”

The nursing team is intrinsically part of this new world in which hospitalized children and adolescents find themselves. Within this context, nurses must devote attention not only to the patient but also to the family, in order to provide care that goes beyond scientific procedures and engages with the sensitivities of the particular circumstances, aiming to offer high-quality, humanized care(5,16). Empathy is highlighted as central in care, as illustrated in the following statement:

“If they [the nursing team] put themselves in the patients’ place to try to understand what they are feeling, then when the patients are afraid of something, they can speak to them and calm them down. Being like a relative or family member, to gradually help the patient feel calm (Mônica).”

It is essential for professionals to learn to manage patients facing difficult situations, avoiding judgment of behaviors and observing their particularities. Rather than considering certain reactions as failures, it is important to seek to understand the underlying causes of these behaviors(4,16).

“The nurses wanted all the patients to be ‘joking around’ when they arrived in the room. So, since I wasn’t feeling well, I never smiled at people. And then, one day, a nurse came into the room and asked my mother, ‘Why isn’t she smiling? Everyone smiles, only your daughter is different.’ So I wrote a letter to them explaining why I didn’t smile, what I was feeling (Mônica).”

The research participants express dissatisfaction when the nursing staff does not communicate or provide guidance and explanations regarding the procedures being performed. This reveals that simple actions are often lost within hospital routines, as care is provided through automatic mechanisms.

“I was the one who had to say good morning, but that’s okay (Cascão).”

“Some would just come in, say nothing, grab my arm, and insert the IV (Mônica).”

In contrast to these statements, enthusiasm is evident in the accounts of those who were actively involved in their care, had their autonomy respected, and perceived cordiality and affection through the team’s actions, which often becomes almost like a second family for the patient.

“The last time I was hospitalized, they explained things to me. Like, I was going to get an injection in my stomach, and they asked me to choose the spot—whether I preferred my arm or my stomach. I chose my stomach because I was already used to it. [...] I really like a nurse there who calls us ‘flower’ and asks if we’re okay and everything (Maria Cebolinha).”

The healthcare team must be attentive to the needs of each patient, seeking ways to minimize the negative feelings associated with hospitalization and procedures. In contrast, some professionals may appear imposing and indifferent to the feelings of others(5).

“The woman shoved the needle into my arm, all the way into my artery, but, like, she didn’t even bother to check, you know?

If it hurt, if it didn't hurt, if I was weak or not. My arm was purple for two weeks (Dona Marocas)."

By undergoing procedures routinely, patients understand about them and the appropriate technical terms to describe these experiences. In this way, they begin to compare professionals' techniques, expressing a preference for those who provide more humanized care.

"Once, when they gave me the IV access here, they were supposed to put a little tape underneath, right? But they didn't. When the nurse went to infuse a medication by syringe, he started pressing there. I screamed and yelled in pain. I told him to stop, and he didn't. After they removed it, they realized there was a cut up there. Another time, I had a fully implanted catheter, so they could have used it, but no, they poked the catheter, then an arm, then the other arm, and I was there until the afternoon. Then, in the afternoon, another nurse came and said, 'No, she didn't need all of that since she has a catheter.' So she removed everything except the catheter. But they treated me well overall, only sometimes they got confused (Mônica)."

In addition to these factors, and due to the pathology, olfactory and taste disturbances are common, yet they do not receive adequate attention from the healthcare team(10,25). Throughout the interviews, numerous statements related to this issue were reported, often associated with the well-known 'hospital smell.' As a consequence, nausea and loss of appetite are frequently exacerbated.

"My only complaint: the hospital food! That's it. [...] I hated that hospital soup. For someone already feeling unwell, who can't taste anything, eating food that has no flavor just doesn't work, right? Like, even the smell of broccoli still makes me nauseous today. It's really disgusting (Dona Marocas)."

"It's just that the smell of the food there made me feel like vomiting (Maria Cebolinha)."

Due to the adverse effects of treatment, nutrition is one of the most challenging aspects within the hospital. Providing food according to the patient's preferences, whenever possible, is among the most important aspects of care, considering that patients experience taste alterations and symptoms throughout the day.

"I would eat the lunch, but I had a menu of what I ate at noon. And in the evening, they made pasta for me (Dona Marocas)."

"They always allowed my family to bring food because the hospital food is terrible, right? So they always let my mother bring a fruit or something for me to eat (Carminha Frufru)."

During the interviews, the need for and importance of leisure activities were also observed, corroborating other studies showing that play and therapeutic recreation help children and adolescents temporarily escape their world of illness and support patient development during treatment, minimizing feelings associated with disease and hospitalization(18).

"There were the 'Joy Clowns'. They came to the rooms to do makeup. I think this part excites children the most and even young people like me (Magali)."

"I wish there was more to do inside the room, you know? Not just things for them to do to us, you know? Like, there should be something for us to do, you know? When we were there (Maria Cascuda)."

Playful activities, besides bringing positive feelings to the patient, when combined with nursing care, foster the development of an even greater level of trust among the family, patient, and healthcare team, facilitating care and strengthening bonds. Through this bond, it is evident that humanized care occurs naturally, and the patient's adaptation to the new environment becomes less traumatic, considering that the team effectively becomes part of the family(5).

"I follow all the people who were with me during treatment in the hospital and labs. I have all of them on my Facebook; like, I carried them into my life, because, whether I wanted to or not, they became my family. It was nearly four years in the hospital, so it was inevitable not to have a bond, right? So today, wow, I treat them even better than some relatives I don't see. I have more interaction, more connection. You can't deny it, there's so much care, so much affection (Dona Marocas)."

It is through the nurse's attention to gestures, attitudes, and glances that communication and bonding can be genuinely expressed in care. These expressions often speak louder than words, especially for patients of this age(3,5).

FINAL CONSIDERATIONS

The present study highlights the need to involve children and adolescents in their own care, keeping their autonomy and allowing them to clearly and accurately understand what is happening, as well as to comprehend the changes that will occur following the diagnosis. The support network, including family, friends, and the healthcare team, is of great importance in facilitating treatment acceptance and in reducing the negative feelings associated with oncology patients.

The participants emphasize the importance of individualized and humanized care, personalized to the particular needs of each patient. Through this differentiated care, greater trust is established, reducing the stress caused by routinely performed invasive procedures. It is evident that the nurse is closely involved in care and, by being part of the patients' and families' daily lives, serves as a point of reference for the patients, sharing moments of both sadness and joy, and acting as a basis for coping with the disease.

A limitation of this study is that some participants had completed treatment several years prior, which may result in a perspective different from that of patients currently experiencing this reality. It is hoped that the findings of this research will encourage other investigators to give voice to children and adolescents still undergoing oncology treatment, thereby contributing to the development of qualified and holistic care.

Therefore, the results of this study may help nurses reconsider their approach to care, aiming to foster empathy and provide comprehensive care, perceiving the patient beyond their pathology and taking into account the unique characteristics of each child and adolescent.

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Authors' contribution:
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Data acquisition:LF, ÂCS
Data analysis and interpretation: LF, ÂCS, FMM, SH
Manuscript writing: LF, ÂCS, FMM, LMS, LJRS, SH
Critical review of the manuscript regarding its intellectual content:ÂCS, FMM, LMS, LJRS, SH

Responsible editors:
Patrícia Pinto Braga – Editor-in-chief
Kellen Rosa Coelho Sbampato –Scientific editor

Note:
There was no funding from a development agency.

Received on:: 14/11/ 2024
Approved in:01/08/ 2025

How to cite this article:
Fernandes L, Susin ÂC, Marini FM, et al. Cancer in childhood and adolescence: understanding feelings and challenges. Revista de Enfermagem do Centro-Oeste Mineiro. 2025;15:e5611. [Access______]; Available in:_______. DOI: http://doi.org/10.19175/recom.v15i0.5611