

# Meaning of the health-disease process in the perception of children undergoing hospitalized cancer treatment

*Significado do processo saúde-doença na percepção da criança em tratamento oncológico hospitalizada*

*Significado del proceso salud-enfermedad en la percepción del niño hospitalizado en tratamiento oncológico*

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## ABSTRACT

**Objective:** to understand the perception of pediatric patients undergoing cancer treatment and hospitalized regarding the health-disease process. **Method:** participatory qualitative study based on art, using creativity and sensitivity techniques *Free to Create* and *Photovoice*, carried out with ten children aged between seven and twelve years old, hospitalized in the pediatric oncology ward of a university hospital in the state of Rio Grande do Sul. Data generation took place from May to August 2023. For data analysis and interpretation, Minayo's thematic analysis framework was used. **Results:** it is possible to associate children's perception of the health-disease process with the lack of daily routine, social isolation, and also painful procedures. **Final considerations:** it is necessary to give children voice and space to express their perceptions and feelings while experiencing illness, treatment, and the hospital environment. Thus, it is expected to provoke reflections among the healthcare team to expand and improve the quality of care in pediatric oncology.

**Descriptors:** Nursing; Medical Oncology; Pediatrics; Health-Disease Process.

## RESUMO

**Objetivo:** compreender a percepção do paciente pediátrico em tratamento oncológico hospitalizado sobre o processo saúde-doença. **Método:** estudo qualitativo participativo baseado em arte, por meio de técnicas de criatividade e sensibilidade Livre para Criar e *Photovoice*, realizado com dez crianças com idade entre sete e 12 anos, internadas na unidade de internação oncológica pediátrica de um hospital universitário no estado do Rio Grande do Sul. A geração de dados ocorreu no período de maio a agosto de 2023. Para análise e interpretação dos dados utilizou-se o referencial da análise temática de Minayo. **Resultados:** é possível associar a percepção das crianças sobre o processo saúde-doença pela falta da rotina diária, isolamento social e, também, procedimentos dolorosos. **Considerações finais:** é necessário dar voz e espaço às crianças para revelar suas percepções, sentimentos ao vivenciar a doença, tratamento e o mundo do hospital. Assim, espera-se suscitar reflexões na equipe de saúde para ampliar e qualificar o cuidado em oncologia pediátrica.

**Descritores:** Enfermagem; Oncologia; Pediatria; Processo Saúde-Doença.

## RESUMEN

**Objetivo:** comprender la percepción del paciente pediátrico en tratamiento oncológico hospitalizado sobre el proceso salud-enfermedad. **Método:** estudio cualitativo participativo basado en el arte, mediante técnicas de creatividad y sensibilidad *Libre para Crear* y *Photovoice*, realizado con diez niños de entre siete y 12 años, internados en la unidad de hospitalización oncológica pediátrica de un hospital universitario del estado de Rio Grande do Sul. La generación de datos se llevó a cabo entre mayo y agosto de 2023. Para el análisis e interpretación de los datos se utilizó el marco de referencia del análisis temático de Minayo. **Resultados:** es posible asociar la percepción de los niños sobre el proceso salud-enfermedad con la falta de rutina diaria, el aislamiento social y también los procedimientos dolorosos. **Consideraciones finales:** es necesario dar voz y espacio a los niños para revelar sus percepciones y sentimientos al vivir la enfermedad, el tratamiento y el mundo hospitalario. De esa forma, se espera suscitar reflexiones en el equipo de salud para ampliar y cualificar el cuidado en oncología pediátrica.

**Descriptores:** Enfermería; Oncología Médica; Pediatría; Proceso Salud-Enfermedad.

## INTRODUCTION

The health-disease process consists of a binomial with distinct concepts that vary according to the context in which they are embedded. Health and disease reflect the social, cultural, political, and economic environment, and therefore this process is not perceived in the same way by all individuals<sup>1</sup>.

Theories that explain the health-disease process result from scientific elaborations belonging to different periods. As such, one must consider the weight of ideology and other determinants that, within the field of epistemological disputes, end up legitimizing the way of looking at the phenomenon to the detriment of less acceptable approaches. Considering the inherent dimension of human nature, which encompasses the two opposing states of the organism, — health and disease—, both are subject to explanations and theories that date back to classical antiquity<sup>2</sup>.

When addressing this theme in the context of comprehensive child health, greater engagement is required, as attention must be given to all the conditions involved in the health-disease process, such as environment, education, relationships with parents, nutrition, and emotional bonds, among others. Without this favorable environment, the child's development is hindered, which may also affect other stages of their life<sup>3</sup>.

In the case of children hospitalized for cancer treatment, these difficulties are intensified due to the complexity of the treatment experience, which involves the distress of invasive and painful procedures, hospital routines, physical limitations, and also the disruption of school activities<sup>4</sup>.

In this context, it is important to highlight that childhood and adolescent cancer refers to a group of various diseases that share the common characteristic of the uncontrolled proliferation of abnormal cells, which can occur in any part of the body. This type of cancer is predominantly of embryonic origin and usually affects blood system cells and stromal tissues<sup>5</sup>.

For the 2023–2025 triennium<sup>6</sup>, the estimated number of new childhood and adolescent cancer cases in Brazil is 7,930, corresponding to an estimated risk of 134.81 per million children and adolescents. It is worth noting that currently, around 80% of children and adolescents affected by the disease can be cured, provided they are diagnosed early and treated in specialized centers<sup>5</sup>.

Regarding the treatment period, hospitalization of children with cancer has aggravating characteristics, such as the chronic nature of the disease; physical and psychological trauma resulting from painful, invasive, and often mutilating interventions; changes in self-image; the possibility of a poor prognosis; social exclusion; and family-related problems<sup>7</sup>.

Given the importance of conducting studies that identify the health-disease process from the perspective of the pediatric population itself, and with the aim of contributing to the improvement of care for children undergoing cancer treatment, the following research question was formulated: *What are the perceptions of hospitalized children undergoing cancer treatment regarding their health-disease process?*

This study aimed to understand the perception of pediatric patients undergoing cancer treatment and hospitalization regarding the health-disease process.

## METHOD

This is a qualitative, participatory study based on art, using *Livre para Criar* (Free to Create) and *Photovoice* creativity and sensitivity techniques, inspired by the Creativity and Sensitivity Dynamics (CSD). These methods foster children's playful engagement with their subjectivity through artistic productions, guided by a debate-provoking question<sup>8</sup>.

The study site was the Pediatric Oncology Inpatient Unit of a University Hospital located in the state of Rio Grande do Sul. The facility, considered a High Complexity Oncology Center, has 25 beds and serves patients aged from 28 days to under 18 years old.

The research population consisted of ten children undergoing cancer treatment, hospitalized in the pediatric oncology unit of the aforementioned institution. Participants were intentionally selected through invitation. The children were referred by the unit's nursing team, and data collection continued until theoretical saturation was achieved.

As inclusion criteria: patients hospitalized in the pediatric oncology unit, of school age, between seven and twelve years old, with a confirmed diagnosis of malignant neoplasm at any clinical stage and already undergoing treatment. The child's legal guardian had to agree to sign the Informed Consent Form, and the child also needed to show interest in participating in the study and sign the Informed Assent Form, as a way of respecting their decision-making capacity. The exclusion criteria included: the inability to participate in the study due to disabling physical, cognitive, or psychological conditions unable to comply with study methodology; and children under exclusive palliative care.

Data collection took place between May and August 2023 and was carried out in four stages. In the first stage, contact was made with the team responsible for the unit to coordinate the data collection in a manner that would not compromise the children's wellbeing. In addition, the researcher was present in the research setting for one week to facilitate engagement and build trust with study participants, both parents and children.

In the second stage, the participants indicated by the healthcare professionals in the unit were formally invited to take part in the study. The informed consent/assent forms were administered, as well as the sociodemographic questionnaire, which was completed together with the child's legal guardian.

In the third stage, the first creativity and sensitivity technique, called *Free to Create*, was applied. It is important to note that the techniques were conducted individually, considering the particularities of children hospitalized in the Pediatric Oncology Inpatient Unit. The following guiding question for discussion was used: Can you tell me how you're feeling at the hospital, at home, at school, and with your friends? This technique consisted of offering participants various playful materials (paper, markers, and modeling clay), enabling free artistic creation to produce qualitative data in response to the guiding question<sup>9</sup>. This stage was carried out individually and at different times, since not all participants were hospitalized during the same data collection period. The drawings were produced either in the unit's playroom or in the child's own room. When conducted in the playroom, the activity was scheduled at times when no other children were present, in order to ensure confidentiality and anonymity.

In the fourth stage, *Photovoice* creativity and sensitivity technique was applied, using the same guiding question for discussion. *Photovoice* is a photographic production method that has been increasingly used in social and health research, as it makes participants active agents in data production and in the construction of the research. It allows for an expanded view of the context and possibilities for intervention for both participants and researchers, as it portrays real-life experiences<sup>10</sup>.

In this study, *Photovoice* technique was employed to enhance understanding of children's lived experiences regarding the debate-provoking question. When combined with the *Free to Create* technique, it provided richer analytical frameworks for interpreting children's creative outputs.

Accordingly, it was agreed with the child and their legal guardian that the photographs for this technique would be taken using the parents' cell phone cameras, considering the children's ease of handling the device and the fact that all participants had access to it. Guidance was provided regarding the purpose of the photos, and a return meeting was scheduled with the child and their guardian for the delivery of the images and explanation of the photographs taken by the child. This moment was conducted by the child in the presence of their parents and supervised by a hospital staff member to ensure there was no interference in data production. The images were then sent by the parents to the researcher via digital means—WhatsApp®.

It is important to clarify that the creativity and sensitivity techniques were composed of five stages. In the first stage, the materials were arranged in the environment, aiming to ensure maximum comfort, silence, and privacy. The researcher actively participated in data collection and in guiding the techniques. In the second stage, a formal introduction of the participant and the researcher took place. Afterwards, the technique, its objectives, and the materials available for artistic production were explained. The researcher, assuming the role of cultural facilitator, introduced the guiding question for discussion, reinforcing it whenever necessary. To undertake this role, preparatory training was conducted with a co-researcher experienced in implementing the methodology. The third stage corresponded to the development of individual artistic production. In the fourth stage, the participants presented their material as part of the individual production process. The fifth stage consisted of the individual analysis of the shared production, as well as the validation of the data collected through the technique.

Both creativity and sensitivity techniques applied were recorded using digital media and later fully transcribed, with the authorization of the participants and their legal guardians. Most sessions were conducted in the hospitalization unit's playroom, as it is a familiar and playful space where participants naturally gathered. However, some participants requested that the *Free to Create* technique be carried out in their hospital rooms. All techniques were conducted in a single session, individually, and with respect for the limitations and uniqueness of each participant.

The interviews were conducted individually. The average duration of each interview was 15 minutes, and the presence of the legal guardian was allowed, under the condition of non-interference during the recording. However, most guardians chose to leave the room, allowing the child to express their feelings freely. This occurred with the consent of both the child and their guardian.

The fieldwork concluded through the process of theoretical saturation, when the researcher observed that participants' responses were becoming repetitive throughout the creativity and sensitivity techniques. In such case<sup>11</sup>, the researcher must be sensitive to realize that further data collection becomes unproductive, as any new information would not significantly alter the research findings. In addition, field notes were taken by the researcher to record impressions and observations made throughout the data collection process.

For data analysis and interpretation, the study used the framework of Thematic Analysis as proposed by Minayo<sup>12</sup>, through the content analysis technique. The thematic analysis was developed in three stages: pre-analysis, material exploration, and processing of obtained results and interpretation. It is important to highlight that the Consolidated Criteria for Reporting Qualitative Research (COREQ)<sup>13</sup> were used to report the method and results.

This study followed Resolution No. 466/2012<sup>14</sup> of the National Health Council of the Ministry of Health, which addresses research involving human subjects. The research protocol was approved by the Research Ethics Committee of the institution where the study was conducted. The Informed Consent Form (ICF) was read and signed by the child's legal guardian or representative and by the researchers, with one copy given to the participant and another retained by the researcher. Additionally, the child agreed to participate in the study by signing the Informed Assent Form (IAF), remaining free to withdraw from participation at any time during data collection. It is worth noting that all participants had their questions answered and that their names were kept confidential. To preserve anonymity, the children's names were replaced with fictitious superhero names.

## RESULTS

The participants included ten hospitalized children from the Pediatric Oncology Unit at Rio Grande do Sul University Hospital, with a mean age of 8.9 years. Data related to the characterization of the participants is presented in Figure 1.

Participant	Sex	Age	Race/ Ethnicity	Diagnosis	Education Level	City of Residence	Household composition
Wonder Woman	F	8 years old	White	B-ALL	3rd grade	Pelotas	Parents
Hulk	M	7 years old	White	B-ALL	1st grade	Garibaldi	Parents
Captain America	M	7 years old	Black	Osteosarcoma	2nd grade	Sapucaia	Parents and sister
Iron Man	M	9 years old	White	B-ALL	3rd grade	Presidente Lucena	Parents and sister
Thor	M	11 years old	Mixed-race	B-ALL	4th grade	Pelotas	Mother and brother
Superman	M	8 years old	White	B-ALL	3rd grade	Pelotas	Parents and brother
Invisible Woman	F	12 years old	White	Osteosarcoma	7th grade	Pântano Grande	Parents
Batman	M	9 years old	White	T-ALL	3rd grade	Camaquã	Parents and sister
Flash	M	7 years old	Mixed-race	Osteosarcoma	Pre-literate	Venezuela	Grand-mother
Black Panther	M	11 years old	White	Non-Hodgkin Lymphoma	6th grade	Porto Alegre	Parents

Figure 1: Participant Characteristics. Porto Alegre, RS, Brazil, 2023.

Children are profoundly shaped by their daily experiences across diverse care and social environments, underscoring the critical role of emotional bonds formed in each of these spaces.

According to Thematic Analysis, the following categories emerged: perception of the health-disease process; what is health; what is disease; and fears experienced during hospitalization. Figures 2 to 6 present the *Photovoice* captures.



Figure 2: The struggle. Porto Alegre, RS, Brazil, 2023.

*Here I wanted to represent a lion, which symbolizes the patients, fighting cancer with the hospital as our ally in this battle. (Black Panther, 11 years old)*

The use of the *Photovoice* creativity and sensitivity technique also highlighted the importance of "mascots" or toys as a means of interaction and motivation for children in the health-disease process.

*I like my teddy bear. He helps me sleep; he's my friend. I always bring him when I come here. It's like my mascot, and this one (the smaller bear) is for playing. (Wonder Woman, 8 years old)*

When the issue of hospitalization for treatment was addressed, the feeling of sadness reported by the children was unanimous. This can be seen in the statements that emerged during the interviews:

*This is the hospital. I feel a little sad, I miss school. (Wonder Woman, 8 years old)*

*And it's a little sad being here right now because I'd rather be at home, but there are still some good moments. [...]" (Captain America, 7 years old)*

*When I have to come here, I feel sad. (Hulk, 7 years old)*

*I feel a little sad because I didn't want to be here, I never wanted to have this cancer [...]" (Black Panther, 11 years old)*

The feeling of sadness was also reported by some participants as one of the negative aspects imposed by their condition during hospitalization.

*When I come here, I think, 'Why do I have to come here?' [...] I come because my immunity is low, things like that. I just know I have to come here then. (Hulk, 7 years old)*

*I like flowers, I have many. Me and my mom. Flowers are nature and I love nature, the feeling of freedom. My dream is to skydive. (Invisible Woman, 12 years old)*

This feeling of freedom described by the Invisible Woman may be further understood through her mother's words. In field notes taken by the researcher, the mother shared that her daughter's dream was to skydive because she wanted to experience the feeling of being free, outside the hospital walls, and to have the "power" to do what she wished, without the restrictions imposed by treatment.

Some children also shared about the beginning of treatment and the feelings and perceptions experienced during that time.

*The first time it was even harder, but then I got used to it. I didn't know where I was, the food was bad, I couldn't eat [...] then my stomach stopped, and I couldn't poop anymore. I had a lot of stomach pain and was very hungry. (Iron Man, 9 years old)*

*At the beginning it was harder because I didn't know anything, didn't know anyone, so I got scared. (Batman, 9 years old)*



**Figure 3:** View from the hospital. Porto Alegre, RS, Brazil, 2023.

*Looking at this means I'll be leaving the hospital soon, that I'm going home. (Thor, 11 years old).*

Another notable aspect in some children's accounts concerns infusion therapy. There was a clear association between intravenous fluids, medications, and chemotherapy administration with health improvement expectations, ultimately linking these treatments to hospital discharge and the anticipated return home to daily routines.

*The IV... the bad part is being stuck like this when it's time to sleep. But this is what will make me better and let me go home. (Thor, 11 years old)*

*I have my trailer (IV pole) [he laughs]. It's a tube that connects here to my neck and is hooked up to a pump—is that the name? There, the IV is about to run out. (Superman, 8 years old)*

This statement reveals a clear association between hospitalization and subsequent health improvement. It is worth noting that in his country, Venezuela, he did not have access to treatment and would not have had the possibility of improvement.

*I feel good here because I know I'm going to get better, I'm being well cared for, and back there I didn't have that. (Flash, 7 years old)*





**Figure 4:** The pump. Porto Alegre, RS, Brazil, 2023.

*The pump represents... to make me well, it is happiness. (Captain America, 7 years old)*

*The trailer [name given to the IV pole] is always by my side. (Superman, 8 years old)*

These statements highlight the creativity used by the children to name the infusion pump stand that usually accompanies them during hospitalization. This may be a mechanism to minimize the suffering experienced throughout the days in the hospital or even an attitude of resilience by the child undergoing cancer treatment to follow the therapy as appropriately as possible.

*I take Maria Eugênia [name given to the IV stand] everywhere... at home, it's only for the milk [tube feeding]. The milk is to help me gain weight because I'm not eating much here, only at home. (Iron Man, 9 years old)*

*That doesn't bother me at all [the IV]. The IV is just a liquid and what I need are the medicines. The medicines are to kill the thing I have... my dad said that thing was at 0%, I think that's good. (Hulk, 7 years old)*

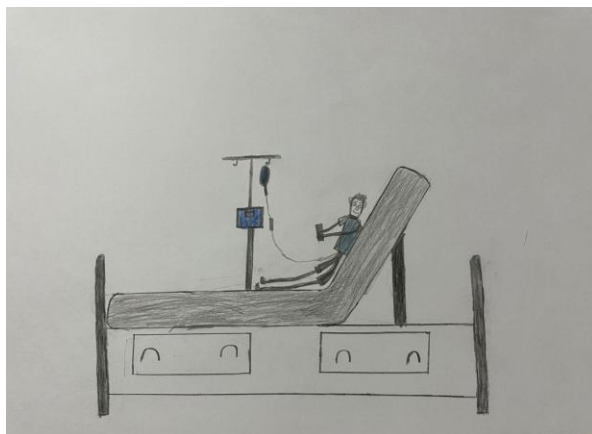
It is important to highlight that, in the children's statements, the IV represents not only continuous intravenous therapy but all infusion procedures they undergo.

Regarding pediatric oncology treatment, this is also addressed and described through its associated adverse effects:

*The treatment makes me very tired, I don't feel like doing much. (Invisible Woman, 12 years old)*  
*After chemo, I felt nauseous, so I ate less. But I don't stop eating, I always eat a little something. (Superman, 8 years old)*

*I was drinking juice that I love... now I stopped for a while because it's kind of acidic and it's hurting here [mucositis]. (Superman, 8 years old)*

#### *Routine changes caused by treatment*



**Figure 5:** The bed. Porto Alegre, RS, Brazil, 2023.

*Here I am, anxious to leave, waiting for discharge. Scrolling through my phone... I always get so antsy to leave. (Thor, 11 years old)*



Figure 6: Representation of reality. Porto Alegre, RS, Brazil, 2023

*I drew myself lying in bed, the pump, the window, the door to go out, the lights, and the bathroom. (Wonder Woman, 8 years old)*

*The bad thing is that the food arrives very early, like lunch at around 11:30 a.m. and dinner at 6:30 p.m. It's early, and that's strange for me. I'm used to having dinner around 8 p.m. and lunch at noon. Here, the schedule is different. (Superman, 8 years old)*

The issue of frequent and often difficult needle insertions is reported in the participants' statements, with some associating this moment with feelings of fear. There are also accounts of fear related to what may be experienced due to the illness itself and the prior trauma endured by the child.

*I'm afraid when they put the needle here, in the port-a-cath. In the procedure room, they squeezed the little ball, and I always get scared because it hurt. (Thor, 11 years old)*

*At first, the needle poke hurt a lot, but not anymore, now I have the port-a-cath. I prefer to do it in the port-a-cath rather than here [points to arm]. (Iron Man, 9 years old)*

*I don't like needle pokes, look at these marks [lifts shirt and shows arm]. But it's already part of my life cycle [laughs]. (Batman, 9 years old)*

*I'm very afraid... I don't like leaving this spot [the bed] because my leg might hurt, I don't like anyone touching here [the bandage]. (Flash, 7 years old)*

*When asked about their understanding of what it means to be healthy, the children gave very similar answers:*

*Health is being well... being really healthy. (Captain America, 7 years old)*

*It's when you're well, when you're taking care of yourself. (Hulk, 7 years old)*

*Being healthy is being well, feeling well. (Batman, 9 years old)*

*It's being well, eating well, and being at home. (Wonder Woman, 8 years old)*

*Being healthy is being well. Not feeling sick, feeling free. (Invisible Woman, 12 years old)*

The children also expressed how they define illness:

*Illness is like a cold. Look at me, you're sitting with a sick person right now. (Batman, 9 years old)*

*It's when a person has microbes in their blood. (Hulk, 7 years old)*

*It's when the person feels bad, could have a cold, a cough, a headache... those things. (Iron Man, 9 years old)*

*It's when your tests are bad, when you're in pain. When you have to keep taking medicine [...]. (Superman, 8 years old)*

*Being sick is when you can't leave the house. Like me, I can't go out much, sometimes I have to come to the hospital.*

*It's a bit boring. (Invisible Woman, 12 years old)*

*It's being in the hospital. I'm not feeling well. (Wonder Woman, 8 years old)*

In the children's view, illness is closely linked to the limitation of not being able to do what they enjoy. This is evident in the following statements:

*There's not much to do here [...] just playing here [in the playground]. (Wonder Woman, 8 years old)*

*Sleeping is boring, I don't like it. At night it's boring because you have to sleep and can't make noise. (Iron Man, 9 years old)*

## DISCUSSION

When discussing the health-disease process, one can perceive that all people are prone to experience both health and illness and may be struck by the unexpected. Consequently, the perception and lived experience of this process demonstrate marked subjectivity, shaped by variable contextual factors.<sup>15</sup>

In a study conducted with 16 children from the fifth grade of a public school, aimed at understanding how the health-disease process relates to life experiences, it was found that children frequently make connections between health-disease phenomena and their daily lives, since they presented a variety of experiences involving the topic. This is because the students face daily situations that can affect their lives, especially due to the sanitary conditions in which they live<sup>16</sup>. In the present study, Children are profoundly shaped by their daily experiences in various care and communal spaces, highlighting the crucial role of affectionate bonds formed in each of these environments.

Toys are highlighted as a vital tool for professionals to create a therapeutic environment where children can express their feelings—distress, fears, anger, and pain, as well as joy, strength, and resilience—that is, their capacity to withstand and cope with the adversities and changes imposed by illness and treatment. It is further understood that playing in the life of a child with cancer is extremely important for coping with the disease. *Through play, children develop holistically, promoting physical and intellectual activity, fulfilling emotional needs, serving as an outlet for emotions, and helping them manage fears, anxieties, and distress.*<sup>17</sup>

The social representation of play in the hospital environment for children is identified as a place for socialization, recovery, and connection to normalcy, where children experience joy, well-being, and the freedom to play. This underscores the critical role of healthcare teams in fostering a welcoming, sensitive environment that integrates play-based approaches. Such initiatives help children adapt to hospitalization and improve their acceptance of the hospital experience<sup>18</sup>.

A study sought to understand the perception of children and adolescents regarding their chronic health conditions. These children and adolescents experience moments of sadness and discouragement upon learning that they have a disease and/or when undergoing treatments<sup>19</sup>. In research with children undergoing cancer treatment, it was shown that play-based approaches contribute positively to the child's treatment. Participants also described a sense of freedom linked to play: for children, not playing felt like being "trapped" or "locked up"<sup>17</sup>.

Consistent with the children's accounts, hospitalized children's narratives reveal their subjective understanding of hospitalization, one intrinsically tied to healing and treatment. This perspective embodies their hope that, after this process, life will return to normal<sup>20</sup>. From a positive psychology lens, 'happiness' can be understood as a relatively enduring emotional state experienced over time, rather than a fleeting or transient feeling<sup>21</sup>.

Furthermore, it is important to emphasize that a particular situation involving suffering, pain, or limitation can represent, for an individual, the path through which they pursue happiness.

Another study conducted with seven children undergoing outpatient cancer treatment highlighted that they were able to narrate the routine of the unit in detail through story-drawings. These children reported that the main advantage of outpatient treatment is going home after the medication administration, "returning to their home." Thus, even in research conducted with children receiving outpatient treatment without the need for hospitalization, there is an association of the infusion of "IV fluids" with returning home<sup>22</sup>.

When analyzing the child's experience of the hospitalization process, it was possible to identify in their statements the subjectivity that the meaning of being hospitalized is linked to cure and treatment, that is, the hope that after this process and discharge, everything will be fine, and they will be able to return to their daily routine<sup>18</sup>.

The child's awareness of upcoming procedures can generate conflicting feelings. On one hand, this knowledge prepares them to cope with the situation, enabling the development of personal stress-reduction strategies. On the other hand, depending on their body's reaction during treatment, they may experience ambivalence between continuing therapy and avoiding further pain, especially when the side effects of treatment are uncomfortable<sup>22</sup>.

Regarding chemotherapy, it was reported that children describe the side effects as exhausting, involving emotions, changes in social dynamics, and even their lifestyle, including the need to travel to a *referral city* for



oncological treatment<sup>23</sup>. Chemotherapy treatment, in addition to causing a series of changes for children and adolescents, such as alterations in their bodies, emotional state, and routine, is mainly remembered for its adverse effects, often followed by suffering. Children and adolescents diagnosed with cancer frequently report fatigue which, Although it lessens over time, it remains present, appearing as a multidimensional experience where psychological distress merges with physical sensation. This is a common, multidimensional, and complex symptom experienced by most cancer patients during treatment. It is usually felt most intensely during the first days after starting a chemotherapy cycle<sup>24</sup>.

The participants' accounts reveal that adverse effects of cancer treatment persist across different phases, significantly impacting children's lives. Most children must adapt their daily routines—whether in eating habits, as expressed by Iron Man and Superman, or in play and daily activities as described by the Invisible Woman.

It is important to highlight that the child's illness process often results in hospitalization, and being admitted to an environment unfamiliar to them can bring implications such as disruption of their usual environment and, consequently, changes in habits, self-care capacity, and emotional state, all potential developmental risk factors<sup>18</sup>.

During hospitalization, the child undergoes various changes, including alterations in routine and habits related to their home context, so that hospitalization can be understood as an insertion into a “new world” whose organization, dynamics, and logic differ from their everyday life. Transforming this unfamiliar setting into a more familiar and less threatening context requires effort from the child, involving the appropriation and negotiation of social meanings within their existing framework of everyday categories<sup>25</sup>.

Oncological treatment is complex, and the therapy involves invasive procedures that can cause discomfort and distress. Pain experiences, especially related to invasive procedures such as venipuncture, are considered one of the main sources of pain and fear in children undergoing cancer treatment<sup>26</sup>.

Given this, healthcare professionals must prioritize respecting children's expressed emotions while demonstrating developmental awareness as certain reactions are expected, particularly during hospitalization. Therefore, it is important for professionals to establish effective communication prior to the procedure, using strategies such as therapeutic play, aiming to prepare the child and provide opportunities for expression and clarification, thus promoting proper tension relief and effective therapeutic continuity<sup>26</sup>.

This perspective is based on the idea that the awareness children develop about the hospital occurs within the context of intersubjectivity, as they necessarily face a pre-structured social environment where norms, representations, and scenarios organize the social interactions in which children participate. This approach assumes that historically constructed and socially instituted meanings, such as social representations, can influence the process by which children make sense of healthcare, being internalized through their interaction with subjects and cultural artifacts present in the hospital spaces, understanding the hospitalized child as an active and creative interpreter of reality<sup>25</sup>.

When asked about their understanding of what health means, the children's responses were very similar. Hospitalized children undergoing cancer treatment associate the word health with well-being, free from possible adverse effects caused by oncological treatment, as well as all related issues such as laboratory tests, daily weight monitoring, and adequate nutrition.

Authors reported that most children expressed, through drawings, the idea of being healthy as linked to leisure—playing— and self-care, such as hygiene and healthy eating, which ultimately provides well-being to the individual. They also highlighted that in all children's drawings, playing was the most frequently mentioned activity, and that the children's understanding of how they feel when healthy was based on their own experiences<sup>16</sup>.

In another study investigating how children undergoing chemotherapy understood and perceived their disease and treatment, it was found that these children differentiated cancer from other diseases and perceived cancer as a serious illness that caused significant harm to their health and daily routine<sup>27</sup>.

When asked about their perception of what disease is, it is possible to see that the children develop their answers based on their own experiences throughout their therapeutic journey and the various hospitalizations they have undergone during treatment.

The representations of illness by children undergoing chemotherapy resemble the statements found in this study. The children perceived their illness when the first symptoms appeared, such as fever, pain, paleness, and vomiting<sup>27</sup>.

Consistent with these accounts, authors point out that the limitations caused by illness, as well as by the treatment, impose modifications on the child's usual activities. In the children's perception, illness is intrinsically associated with activity restriction, specifically the inability to engage in preferred occupations<sup>4</sup>. Moreover, the *Photovoice* creative sensitivity technique provided deeper insight into children's perceptions of health-illness continuum, revealing through their own narratives the tangible impacts of disrupted routines.

Children and adolescents with chronic illnesses particularly highlighted changes in eating habits, describing this adaptation as one of the most challenging aspects of hospital life. While they understand the necessity of dietary modifications, they report significant difficulty adjusting, including coping with altered food quantities<sup>19</sup>.

A study with children and adolescents revealed that, for these participants, the illness process signifies disruptions to both individual routines and family dynamics, compounded by the challenge of enduring painful and exhausting treatment regimens. This trajectory further leads to social withdrawal or diminished peer interactions<sup>28</sup>.

Beyond verbal accounts, the *Photovoice* creative sensitivity technique enabled participating children to visually document their hospital routines and the broader hospitalization experience through photographs.

From the child's perspective, illness is closely associated with sadness and the inability to carry out routine activities such as eating, playing, and interacting with other children and family members<sup>16</sup>. In drawing, the child begins with meaning: "This means that my graphic construction is not fixed, just as the lines they arbitrarily add to their artwork, which constantly subvert its meaning (it's a house! No, it's a boat! No, it's an old man)"<sup>29</sup>. Moreover, the drawing becomes a narrative that extends beyond what the child verbalizes upon completion. Every element on the page carries traces of their lived experiences<sup>30</sup>.

### Study Limitations

As limitations of this study, we highlight the characteristics of the hospitalized children during the data collection period, taking into account their treatment phase - that is, each child was experiencing a distinct moment in the health-disease process, and no comparison was made between their different perceptions. Furthermore, all children who participated in this study had more than one hospitalization during the data collection.

### FINAL CONSIDERATIONS

Understanding the health-disease process from the child's perspective is paramount. It reinforces why we must actively involve them as participants and ensure they are informed, within their cognitive limitations, about every step of their oncological treatment journey. Considering that these children will often require hospitalization, whether for treatment or oncological emergencies, it was found that the use of play-based approach in the Pediatric Oncology Unit proved essential, as children need to preserve their daily routine and activities as much as possible, while respecting their fluctuating capacity and willingness at each stage of treatment.

Play-based interventions in hospital settings serve a clear purpose: they help children cope by providing distraction and meaningful engagement. The unit's dedicated communal space is widely used by many children, fostering social interaction and peer connection during hospitalization.

The methodology employed in this study proved particularly valuable by enabling close engagement with child participants and fostering their willingness to participate. The creativity and sensitivity techniques provided essential data that not only addressed the research questions but also contributed to improving care quality for hospitalized pediatric oncology patients.

It is recommended that the healthcare team, in the care process for children undergoing cancer treatment, ensure the child's right to participation, that is, to "have a voice" in decisions regarding their care, taking into account their limitations such as age and cognitive development. Additionally, incorporating play-based approaches helps mitigate suffering during the therapeutic process.

Thus, "giving voice" to the child—allowing them to participate in their care within the hospital context—represents an innovative approach to healthcare in pediatrics. This is, therefore, a model grounded in ethical and aesthetic values, as well as compassion—being empathetic towards others—which should be integrated into the daily practice of pediatric nursing.

## REFERENCES

1. Faria FG, Siqueira Batista R. Perspectives on the health care of homeless people. *Rev Bras Med Fam Comunidade*. 2022 [cited 2024 Aug 7]; 17(44):2548. DOI: [https://doi.org/10.5712/rbmfc17\(44\)2548](https://doi.org/10.5712/rbmfc17(44)2548).
2. Quiroga FL, Paolucci BA. Educação física como estratégia biopolítica da ideologia higienista e seus vínculos epistemológicos com as teorias do processo saúde-doença. *Rco*. 2023 [cited 2024 Aug 7]; 2:365-78. DOI: <https://doi.org/10.25112/rco.v2.3052>.
3. Souza AIJ, et al. (orgs.). *Atenção integral à saúde da criança: medicina*. 2. ed. Florianópolis: Universidade Federal de Santa Catarina; 2016.
4. Ferreira EDS, Pessoa ACRG. Hospital pedagogical support to children with câncer in the literacy process. *Educ rev*. 2023 [cited 2024 Aug 7]; 39:e37031. DOI: <https://doi.org/10.1590/0102-469837031>.
5. Instituto Nacional de Câncer (Br). *Câncer infantojuvenil*. Rio de Janeiro (RJ): Instituto Nacional de Câncer; 2022 [cited 2024 Aug 7]. Available from: <https://www.gov.br/inca/pt-br/assuntos/cancer/tipos/infantojuvenil>.
6. Instituto Nacional do Câncer (Br). *Estimativa 2023: incidência de câncer no Brasil*. Rio de Janeiro (RJ): Instituto Nacional de Câncer; 2023 [cited 2024 Aug 7]. Available from: <https://www.inca.gov.br/sites/ufu.sti.inca.local/files/media/document/estimativa-2023.pdf>.
7. Lima RAG, Scochi CGS, Kamada I, Rocha SMM. Assistência à criança com câncer: análise do processo de trabalho. *Rev esc enfermagem USP*. 1996 [cited 2024 Aug 7]; 30(1):14-24. DOI: <https://doi.org/10.1590/S0080-62341996000100002>.
8. Soratto J, Pires DEP de, Cabral IE, Lazzari DD, Witt RR, Sipriano CA de S. A maneira criativa e sensível de pesquisar. *Rev Bras Enferm*. 2014 [cited 2024 Aug 7]; 67(6):994-9. DOI: <https://doi.org/10.1590/0034-7167.2014670619>.
9. Kinalski DDF, Antunes BS, Motta M da GC da. Children and adolescents living with HIV: participatory health care proposal. *Rev Gaúcha Enferm*. 2023 [cited 2024 Aug 7]; 44:e20220190. DOI: <https://doi.org/10.1590/1983-1447.2023.20220190.en>.
10. Leal CCG, Gomes-Sponholz FA, Mamede FV, Silva MAI, Oliveira NTB, Leite AM. Photovoice: method experiment research with adolescent mothers. *Esc Anna Nery*. 2018 [cited 2024 Aug 7]; 22(3):e20170322. DOI: <https://doi.org/10.1590/2177-9465-EAN-2017-0322>.
11. Falqueto JMZ, Hoffmann VE, Farias JS. Saturação teórica em pesquisas qualitativas: relato de uma experiência de aplicação em estudo na área de administração. *RCA - on-line*. 2018 [cited 2024 Aug 7]; 20(52):40-53. DOI: <https://doi.org/10.5007/2175-8077.2018V20n52p40>.
12. Minayo MCS. *O desafio do Conhecimento: pesquisa qualitativa em saúde*. 14. ed. São Paulo: Hucitec; 2014.
13. Souza VR, Marziale MH, Silva GT, Nascimento PL. Translation and validation Brazilian Portuguese and assessment of the COREQ checklist. *Acta Paul Enferm*. 2021 [cited 2024 Aug 7]; 34:eAPE02631. DOI: <http://dx.doi.org/10.37689/acta-ape/2021ao02631>.
14. Brasil. Resolução n.º 466, de 12 de dezembro de 2012. Brasília (DF): Conselho Nacional de Saúde; 2012 [cited 2023 Dec 23]. Available from: [http://www.conselho.saude.gov.br/web\\_comissoes/conep/index.html](http://www.conselho.saude.gov.br/web_comissoes/conep/index.html).
15. Alves G da S, Viana JA, Souza MFS. Psico-oncologia: uma aliada no tratamento de câncer. *Rev. Pret*. 2018 [cited 2023 Dec 16]; 3(5):520-37. Available from: <https://periodicos.pucminas.br/index.php/pretextos/article/view/15992>.
16. Beltrão GGB, Aguiar JVS, Silva AM. Relação saúde-doença a partir das experiências de vida das crianças. *Revista Exitus*. 2021 [cited 2024 Aug 7]; 11:e020148-8. DOI: <https://doi.org/10.24065/2237-9460.2021v11n1id1560>.
17. Lopes NCB, Viana ACG, Félix ZC, Santana JS, Lima PT, Cabral ALM. Playful approaches and coping with childhood cancer treatment. *Rev enferm UERJ*. 2020 [cited 2024 Aug 7]; 28:e53040. DOI: <http://dx.doi.org/10.12957/reuerj.2020.53040>.
18. Costa TS, Morais AC. Child hospitalization: child living from graphical representations. *Rev Enferm UFPE on line*. 2017 [cited 2024 Aug 7]; 11(1):358-67. Available from: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/view/11916/14406>.
19. Gabatzl RIB, Marten VM, Bório TC, Specht AL, Bazzan JS, Motta MGC. Difficulties and facilitating interactions in chronic health conditions: perceptions of children and adolescents. *Rev Atenção Saúde*. 2021 [cited 2024 Aug 7]; 19(70):73-186. Available from: [https://seer.uscs.edu.br/index.php/revista\\_ciencias\\_saude/article/download/8086/3603](https://seer.uscs.edu.br/index.php/revista_ciencias_saude/article/download/8086/3603).
20. Farias D, Bärtschi-Gabatz RI, Milbrath VM, Schwartz E, Freitag VL. Child perception about the need for hospitalization to reestablish health. *Rev. Enferm. Atual In Derme*. 2019 [cited 2024 Aug 7]; 87(25):1-8. Available from: <https://www.revistaenfermagematual.com.br/index.php/revista/article/download/186/347/1166>.
21. Chakhssi F, Kraiss JT, Sommers-Spijkerman M, Bohlmeijer ET. The effect of positive psychology interventions on well-being and distress in clinical samples with psychiatric or somatic disorders: a systematic review and meta-analysis. *BMC Psychiatry*. 2018 [cited 2024 Aug 7]; 18(1):211. DOI: <https://doi.org/10.1186/s12888-018-1739-2>.
22. Gomes IP, Lima KA, Rodrigues LV, Lima RAG, Collet N. From diagnosis to survival of pediatric cancer: children's perspective. *Texto contexto – enferm*. 2013 [cited 2024 Aug 7]; 22(3):671-9. DOI: <https://doi.org/10.1590/S0104-07072013000300013>.
23. Marcon SS, Lino IGT, Paschoalotto IG, Marquete VF, Batista VC, Ichisato SMT. Mudanças ocorridas após diagnóstico e tratamento do câncer na perspectiva da criança. *Rev. Soc. Bras. Enferm. Ped*. 2020 [cited 2024 Aug 7]; 20(1):22-30. DOI: <https://doi.org/10.31508/1676-3793202000004>.
24. Roganovic J. Late effects of the treatment of childhood cancer. *World J Clin Cases*. 2025 Mar 6;13(7):98000. DOI: <https://doi.org/10.12998/wjcc.v13.i7.98000>.
25. Teibel ENH, Andrade, DBSF. Contação de história e brincadeiras no hospital: significações e vivências de crianças acerca do cuidado em saúde. *Humanidades & Inovação*. 2022 [cited 2023 Dec 16]; 8(68). Available from: <https://revista.unitins.br/index.php/humanidadeseinovacao/article/view/7037>.
26. Emidio SCD, Morais RJL, Oliveira PNM, Bezerra RS. The viewpoint of hospitalized children with regards to oncological treatment. *Rev Fun Care Online*. 2018 [cited 2024 Aug 7]; 10(4):1141-9. DOI: <http://dx.doi.org/10.9789/2175-5361.2018.v10i4.1141-1149>.
27. Perosa GB, Padovani FHP, Lopes GC. Children with cancer's understanding of illness and chemotherapy. *Interface (Botucatu)*. 2023 [cited 2024 Aug 7]; 27:e230028. DOI: <https://doi.org/10.1590/interface.230028>.

28. Mendes MVC, Góes ACF, Brain, FRM. Children and adolescents in cancer treatment: an analysis of the vision of postponing the beginning or interruption of school education. Rev Bras Cancerol. 2018 [cited 2024 Aug 7]; 64(3):301-9. DOI: <https://doi.org/10.32635/2176-9745.RBC.2018v64n3.27>.
29. Merleau-Ponty M. Fenomenologia da percepção. 5. ed. São Paulo: Editora WMF Martins Fontes; 2018.
30. Santos HCC, Nacarato AM. Narratives of children of the 1<sup>st</sup> year of elementary school about skin color. Rev. Educ. PUC-Camp. 2022 [cited 2024 Aug 7]; 27:1-14. DOI: <https://doi.org/10.24220/2318-0870v27e2022a5384>.

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Conceptualization, C.N.S. and M.G.C.M.; methodology, C.N.S. and M.G.C.M.; validation, C.N.S. and M.G.C.M.; formal analysis, C.N.S. and M.G.C.M.; resources, C.N.S. and M.G.C.M.; investigation, C.N.S. and M.G.C.M.; data curation, C.N.S. and M.G.C.M.; manuscript writing, C.N.S., M.N. and M.G.C.M.; review and editing, C.N.S., M.N. and M.G.C.M.; visualization, C.N.S., M.N. and M.G.C.M.; supervision, M.G.C.M.; project administration, C.N.S. and M.G.C.M. All authors read and agreed with the published version of the manuscript.

#### Use of artificial intelligence tools

Authors declare that no artificial intelligence tools were used in the composition of the manuscript "*Meaning of the health-disease process in the perception of children undergoing hospitalized cancer treatment*".