

# CUIDADO É FUNDAMENTAL

Escola de Enfermagem Alfredo Pinto – UNIRIO

RESEARCH

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## CHILDHOOD CANCER: CHILD'S PERCEPTIONS OF CHEMOTHERAPY TREATMENT

*Câncer infantil: percepções da criança frente ao tratamento quimioterápico**Cáncer infantil: percepciones del niño frente al tratamiento quimioterápico*Marciele Pinheiro<sup>1</sup> Josiane Lieberknecht Wathier Abaid<sup>2</sup> Suzinara Beatriz Soares de Lima<sup>1</sup> Rosiane Filipin Rangel<sup>2</sup> Giovana Calcagno Gomes<sup>3</sup> Nadiesca Taisa Filippin<sup>2</sup> 

### ABSTRACT

**Objective:** to describe how children perceive chemotherapy treatment and its hospitalization in this period. **Method:** descriptive exploratory study, of qualitative approach, carried out with six children in chemotherapy treatment hospitalized in hemato-oncologic unit of a teaching hospital, located in the central region of Rio Grande do Sul. Individual interviews were conducted, recorded in digital media and transcribed in full. The interviews were submitted to thematic analysis. **Results:** three thematic categories were identified: perceptions of the child regarding chemotherapy treatment; main challenges pointed out during hospitalization by the child in chemotherapy treatment; ludicity as an ally in dealing with hospitalization for chemotherapy in children. **Conclusion:** it is considered that the child hospitalized in chemotherapy treatment is aware of the importance of therapeutics for the cure of the disease. The importance of playfulness and play in hospitalizations were also confirmed in the study, since these are presented as strategies for coping with the process of illness by the child hospitalized in cancer treatment.

**DESCRIPTORS:** Pediatric nursing; Drug therapy; Neoplasms; Child.

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## RESUMO

**Objetivo:** descrever como as crianças percebem o tratamento quimioterápico e sua internação neste período. **Método:** estudo descritivo exploratório, de abordagem qualitativa, realizado com seis crianças em tratamento quimioterápico internadas em unidade hemato-oncológica de um hospital-ensino, localizado na região central do Rio Grande do Sul. Realizaram-se entrevistas individualizadas, gravadas em mídia digital e transcritas na íntegra. As entrevistas foram submetidas à análise temática. **Resultados:** identificaram-se três categorias temáticas: percepções da criança quanto ao tratamento quimioterápico; principais desafios apontados durante a internação pela criança em tratamento quimioterápico; ludicidade como aliada no enfrentamento da internação para quimioterapia em crianças. **Conclusão:** considera-se que a criança internada em tratamento quimioterápico tem conhecimento da importância da terapêutica para a cura da doença. A importância da ludicidade e do brincar nas hospitalizações também foram ratificadas no estudo, visto que estas apresentam-se como estratégias de enfrentamento do processo de adoecimento por parte da criança internada em tratamento oncológico.

**DESCRITORES:** Enfermagem pediátrica; Tratamento farmacológico; Neoplasias; Criança.

## RESUMEN

**Objetivo:** describir cómo los niños perciben el tratamiento quimioterápico y su internación en este período. **Método:** estudio descriptivo exploratorio, de abordaje cualitativo, realizado con seis niños en tratamiento quimioterápico internados en unidad hemato-oncológica de un enseñanza – hospital, ubicado en la región central de Rio Grande do Sul. Se realizaron encuestas individualizadas, grabadas en medios digitales y transcritas en su totalidad. Las entrevistas fueron sometidas al análisis temático. **Resultados:** se identificaron tres categorías temáticas: percepciones del niño en cuanto al tratamiento quimioterápico; principales desafíos señalados durante la internación por el niño en tratamiento quimioterápico; ludicidad como aliada en el enfrentamiento de la internación para quimioterapia en niños. **Conclusión:** se considera que el niño ingresado en tratamiento quimioterápico tiene conocimiento de la importancia de la terapéutica para la cura de la enfermedad. La importancia de la ludicidad y del juego en las hospitalizaciones también fueron ratificadas en el estudio, ya que éstas se presentan como estrategias de enfrentamiento del proceso de enfermedad por parte del niño internado en tratamiento oncológico.

**DESCRIPTORES:** Enfermería pediátrica; Quimioterapia; Neoplasias; Niño.

## INTRODUCTION

In Brazil, childhood cancer is the second leading cause of death among children and adolescents between one and nineteen years of age, second only to external causes such as accidents and violence.<sup>1</sup> Approximately 12,000 children and adolescents are diagnosed with this pathology annually, an average of 32 new cases/day.<sup>2</sup> For the triennium 2020-2022, it is estimated that 8,460 new cases of childhood cancer will occur each year.<sup>3</sup>

Despite the advances available for the treatment of oncological diseases in children and adolescents, chemotherapy protocols do not address the care of patients and their families, in order to mitigate the traumatic impact that comes from receiving a diagnosis of cancer.<sup>4</sup>

After the diagnosis of cancer, the first contacts are crucial for an indispensable bond of trust to be established between the team, the patient, and their families. It also prevents parents from seeking alternative treatments that may delay the start of the proposed therapy.<sup>5</sup>

The interaction between the triad health professional-child-family is of great value to understand the child and his needs, seeking a unique therapeutic project and understanding how he sees, feels, and reacts to the adversities of chemotherapy.<sup>6</sup>

The side effects of chemotherapy, such as fatigue, anorexia, nausea, vomiting, diarrhea, pain, mucositis, dysuria, weight loss, and alopecia, appear frequently and are a source of stress

and suffering for children undergoing chemotherapy treatment and their families.<sup>7</sup>

In the search for excellence in treatment, health professionals and teams have been following new paradigms of care, appreciating the patient's basic needs. Thus, knowing how children undergoing cancer treatment perceive the process of chemotherapy and their coping strategies can help in the planning of actions aimed at adequately meeting their needs.

Given the above, the objective of this research was to describe how children perceive chemotherapy treatment and their hospitalization during this period, in order to guide a humanized and integral care, focused on the real needs of the child, thus enabling to fulfill the purpose of a safe and effective assistance that promotes a better quality of life.

## METHODS

This is a qualitative, descriptive and exploratory research. Descriptive research aims to expose the characteristics of the object being analyzed, and from there, to provide a new vision about the existing reality.<sup>8</sup> Exploratory research aims to bring the problem closer, making it clearer and more understandable.<sup>9</sup>

Data collection was carried out between January and May 2020, in a blood cancer unit of a teaching hospital, located in the central region of the state of Rio Grande do Sul, Brazil. The project was approved by the Ethics Committee on Human Research of

the Universidade Franciscana under number 3,742,262 (CAAE: 25170619.4.0000.5306).

The inclusion criteria for research participants were: being between 5 and 12 years old; of both genders; having a medical diagnosis of cancer (including all pediatric malignancies); having received the medical diagnosis more than one month ago (time for the child to have already received at least one cycle of chemotherapy, in order to experience the impact of treatment). The criteria for exclusion of research participants were: children who were not hospitalized for chemotherapy; children in extreme discomfort, without physical, cognitive or emotional conditions to participate in the research (crying, irritability, etc.).

The instrument for data collection was composed of five questions to characterize the participants, with information about sex, age, education, diagnosis and time of treatment in oncology, in addition to the semi-structured interview, with four guiding questions, through which the child was asked about chemotherapy and aspects related to hospitalization during the period of receiving chemotherapy.

Aiming to understand the child's perception about chemotherapy during the period of hospitalization, we asked what the child understands by chemotherapy, what he feels after receiving the treatment, and finally, what he likes and dislikes most when he is in the hospital.

The characterization data of the participants were collected from the patient's medical records. Then, the child was interviewed in a reserved room, and the interview was recorded on digital media. The interviews were transcribed in full and the participants were identified by the letters C (child) followed by a numeral (C1, C2, C3...C6), in order to maintain the participants' confidentiality.

The transcriptions were submitted to thematic analysis. This is divided into chronological stages: pre-analysis; exploration of the material; treatment of the results, and interpretation of the data.<sup>10</sup> The recordings were analyzed several times to extract the essence of the answers, and from that, the thematic categories were created.

## RESULTS

Six children, aged between five and 10 years, participated in the research. All the hospitalized children were accompanied by their mothers, however, they chose to participate in the interview without the presence of the family member, only in the company

of the researcher. Of the children interviewed, only one was in the literacy phase. Table 1 shows the individual characterization of the sample.

It was evident in the interviews the perception of the child regarding the therapy, the ways of facing the hospitalizations for chemotherapy and playfulness as essential in pediatric hospitalizations. Therefore, from the data obtained in the research, based on the speeches of the participants, three thematic categories emerged: children's perceptions of the chemotherapy treatment; main challenges pointed out during the hospitalization of children in chemotherapy treatment; playfulness as an ally in facing the hospitalization for chemotherapy in children.

### Children's perceptions of chemotherapy treatment

The children, when asked what chemotherapy is, answered that it is a source of healing, a medicine that relieves what they are feeling and allows them to return to their homes. It is observed from the answers that the children have discernment according to their capacity of understanding.

*Chemotherapy makes the marrow get better!* (C4 – 8 years old)

*It is a medicine.* (C2 – 6 years old)

*It lets us go home, and makes us better.* (C6 – 8 years)

They still perceive chemotherapy as a cure for cancer, a medicine that helps them feel good, they can explain in their perception and what is the objective of chemotherapeutic treatment, as evidenced below:

*I think there are several mixed medicines that they give to people and that make us feel good.* (C1 – 9 years old)

*To get cured! Yes, I know!* (C3 – 5 years old)

*As far as I know it is a medicine that cures cancer. Well, they (the doctors) took it away, I had surgery to remove the tumor from my foot, and now I am doing fourteen cycles of chemo, I have already done four, I will do the fifth! And we do this so that the tumor does not come back!* (C5 – 10 years old)

About the side effects, the following were mentioned: nausea, vomit, headache, pain in the lower limbs, lack of appetite, change in taste.

**Table 1** – Characterization of the sample. Santa Maria, RS, Brazil, 2020

Variables	C1	C2	C3	C4	C5	C6
Gender	Female	Male	Female	Male	Male	Female
Age	9 years old	6 years old	5 years old	8 years old	10 years old	8 years old
Schooling	3rd grade	Kindergarten	Does not attend	3rd grade	5th grade	2nd grade
Diagnosis	ALL	Neuroblastoma	ALL	ALL	Ewing's tumor	ALL
Oncology treatment time	7 months	1 year and 12 months	1 year and 4 months	1 month and 5 days	4 months	1 month e 10 days Recurrence

**Legend:** ALL= Acute Lymphocytic Leukemia

*Yes... nausea, headache, dizziness, sometimes I feel pain in my leg, and... bad taste in the mouth, bitter taste, and sometimes I lose my hunger completely. (C5 – 10 years)*

It is noteworthy that the participants of the study classify nausea and vomiting as the most unpleasant of all symptoms. They are seen as the main manifestation, the most incident and the one that causes the greatest discomfort in the chemotherapy process. It is important to highlight that in the statements it can be observed that the child has the perception that these symptoms may or may not occur.

*Sometimes I feel a little nausea, but otherwise it is normal (C1 – 9 years old)*

*I feel, sometimes I feel craving, and sometimes I don't. (C4 – 8 years old)*

*Vômito... Anxiety! (C3 – 5 years)*

Also, emotions felt after the administration of the drugs were listed, as can be seen in the speech of C6, when asked about what she feels after receiving chemotherapy

*I feel... sometimes I feel joy and sometimes sadness! (C6 – 8 years)*

C5's speech elucidates how much the side effects caused by chemotherapy have repercussions on the child's daily activities, bringing, in addition to discomfort, pain, and changes in routines. In this speech, the child tells how he would like his treatment to be, or what he would change about it:

*What is different about the treatment? I wish chemo didn't give any reaction! (C5 – 10 years old)*

It is important to emphasize that alopecia did not appear in the answers of the study as a stressful or discomforting factor for the children. During data collection, we did not observe the use of any accessories such as caps and scarves. One girl wore a tiara, and all the other participants were without hair and with their scalps exposed.

### **Main challenges during the hospitalization of children undergoing chemotherapy**

When asked about what they dislike about being hospitalized during chemotherapy, they mentioned several moments arising from the hospitalization, such as venipuncture, blood collection, as well as the fact that they need to stay in a hospital environment.

*I think the dressing on the PICC which is the catheter. And taking blood. (C5 – 10 years old)*

*Staying in the room... get stung! (C3 – 5 years)*

*Hum... being in the hospital! ... I think until May 4, a month without going home! (C4-8 years)*

Some participants of the study mentioned that they don't like hospital food. Even the food was cited as one of the main changes that should happen for the improvement of the hospitalization during chemotherapy treatment.

*The food, very bad! (C5 – 10 years)*

*I don't like the beans. (C2 – 6 years)*

*The food. (C1 – 9 years old)*

It is noteworthy here the speech of C5 that when asked about what could be done differently, or what he would bring as food for himself and for the other patients if he could change something in the hospital routine, shows the importance of the bonds of affection. One can consider that in the food made by the mother the children find an approximation with the home environment, an affective memory, even in the hospital space, something that reminds them of their daily life.

*I would ask my mother to make the food! (C5 – 10 years old)*

### **Playfulness as an ally in facing the hospitalization for chemotherapy in children**

When asked what they most like to do during hospitalization to receive chemotherapy, the children replied that it is to play and socialize with others, as evidenced in the speeches:

*I like to play, I like toys, I like to play games right?!?! (C2 – 6 years old)*

Most children reported that when they are hospitalized what they most like to do is play with friends.

*Hm... I like to play with the kids that we have here and also to play with them... (C5 – 10 years old)*

*Sometimes I play on the computer, and sometimes I play. (C4 – 8 years old)*

The playroom was also mentioned in the speeches as a favorite place for children in the hospitalization unit.

*I like to meet new people, make friends, the nurses and the playroom. (C1 – 9 years old)*

*The little room! (C6 – 8 years old)*

*It is a small room with toys for the children to entertain themselves. (C1 – 9 years old)*

## **DISCUSSION**

The children interviewed showed an understanding of their disease and the importance of chemotherapeutic treatment to cure the disease. It was observed that this perception, sometimes more concrete, sometimes more subjective, is given according to

the maturity of the child interviewed, the experiences lived and the time of treatment and not necessarily the chronological age of the patient. One can also perceive in the statements different interpretations, sometimes with answers focused on the physical/biological and other times, on the emotional aspects.

Studies have shown that children affected by cancer need to be aware of their disease and the intended treatment. They elucidate the importance of the child being a participant in decision making, as well as in all the orientations that involve the therapy.<sup>11,12</sup> The active participation of the child confirms a better understanding of the need for treatment, as well as the development of strategies for better acceptance, adaptation, and coping with their new life condition.<sup>11,12</sup>

The adverse effects caused by chemotherapeutic drugs provoke in the child the perception of being really sick, requiring strategies to face this new condition.<sup>13</sup>

A study conducted to understand the strategies used by adolescents to cope with cancer confirmed that their focus is on solving the cancer disease, counseling with family members, seeking self-control and tranquility, seeking distraction, talking, forgetting the problem, and thinking about good things.<sup>14</sup>

In the present study, nausea and vomiting were the main adverse effects of chemotherapy. However, it is important to note that one participant demonstrated ambivalent feelings and when asked about how he felt after receiving chemotherapy, the child reported oscillating between joy and sadness. It is believed that the child has the perception of its importance and sees it as a source of healing and also as an indispensable path to the end of the treatment, however, the side effects and the several hours connected to infusion pumps to receive the medication may discourage him/her and cause controversial feelings.

All people experience ambivalent feelings, and these experiences make them learn to deal effectively with their emotions.<sup>15</sup> Recognizing feelings is essential to the search for what makes us happiest. Therefore, according to the authors, the dilemma is not in feeling anger, fear, sadness, or anguish, but in recognizing and accepting these emotions, and being able to move forward despite them.<sup>15</sup>

The chemotherapeutic treatment will always be a duality between pain, anguish, idleness, and the opportunity for cure.<sup>11</sup> The side effects are sometimes seen as responsible for demonstrating the success of the therapy on the disease, and thus stimulating the continuity of the treatment, and sometimes as discouraging, given the intense suffering that they caused.<sup>12</sup>

The care must begin by listening to those who receive it, performing an analysis of their vision, because the patient is the one who most recognizes their needs, related to well-being and their values.<sup>16</sup> The family members must be recognized as important resources for coping with adversities related to the disease, as well as the therapy.<sup>16</sup>

Another issue cautiously discussed among professionals is how much chemotherapy interferes with the acceptance of food and nutritional intake of children receiving treatment. In the

study, besides nausea and emesis, taste alteration and inappetence resulting from the therapy were cited.

The feeding of children undergoing chemotherapy requires greater care because their nutritional status interferes widely in worsening side effects, in the risk of infection, and has significant interference in the therapy.<sup>17</sup>

We highlight the speech of a child who, when asked about what he would change in his hospitalization while receiving chemotherapy, stated that he would like to receive food made by his mother. To minimize the risks of infection/contamination, in the inpatient unit where the research was carried out, the child must eat only the hospital diet and is not allowed to bring food from home and processed foods. It is believed that the request for food prepared by the mother is linked to homesickness, the routines at home and, mainly, by the possibility that this food refers to affection, care and family. Still, it is believed that complaining about hospital food is a way for the child to protest his current condition, which can be healthy, because it acts as a motivational factor to perform the proposed treatment and soon return to family life.

It is important to note that food is a habit established from birth and is closely related to the upbringing, customs, and culture of each person and his environment.<sup>18</sup> However, in chemotherapeutic treatment these habits are altered, especially in the face of adverse effects.<sup>18</sup>

A study conducted in Australia reported as a hospital practice to encourage healthy eating during chemotherapy, the preparation of meals by the child's parents at the hospital and the possibility of bringing food prepared at home to feed the child, as well as release for shopping for healthy foods and those of desire to improve food acceptance in this period.<sup>19</sup>

The pleasure in eating was discussed in a study as one of the coping strategies by the child to chemotherapy, but it points out a great resistance by the pediatric patient regarding the ingestion of the hospital diet.<sup>11</sup> Thus, health professionals, by knowing the coping strategies of chemotherapy therapy by the child, strengthen their strategies to make the treatment less traumatic.<sup>11</sup>

The pain caused by punctures, the numerous blood draws, and the algia itself triggered by chemotherapy treatment were also indicated as a source of dissatisfaction by the child during hospitalization.

Pain is a source of displeasure and demotivation, and ends up limiting and restricting the child's play.<sup>20</sup> Physical, emotional, and behavioral aspects of children undergoing oncologic treatment are affected by pain and discomfort, and may lead to anxiety, impairing their general condition or accentuating the algia.<sup>20</sup>

The use of playfulness for the venipuncture procedure with the use of puppets can be an important ally of the nursing team in distracting the child, able to promote cooperation and minimize rejection to the technique.<sup>21</sup>

Another aspect evidenced in the children's speech is the importance of playing and toys during hospitalization. Hospitalization is always very difficult and exhausting during oncologic treatment, because they are long and very restrictive periods. The

chemotherapy treatment often requires the child to stay connected to chemotherapy drug infusion pumps for several days.

In order to facilitate the child's adaptation to the new reality experienced, hospital playrooms need to provide objects and toys that resemble utensils and tools used by the health team during treatment.

A limiting factor of the study was the small number of participants in the research. In addition, children in different moments of oncologic treatment were included. During the collection period, few hospitalizations to receive chemotherapy were observed; this reduction may be related to the expansion of outpatient chemotherapy infusions due to the ongoing pandemic.

## FINAL CONSIDERATIONS

It is considered that children hospitalized for chemotherapy are aware of the importance of the therapy to cure the disease. Despite the side effects, children see chemotherapy as indispensable and a source of survival.

The importance of playfulness and playing during prolonged hospital stays was also evidenced in the study, since it eases traumas, minimizes fears, and favors the development of strategies for the child to face the process of getting sick.

This study contributed significantly to understanding the perception of this sample of hospitalized children undergoing chemotherapy, from the elucidation of their anxieties and demands, so that some interventions can be proposed to guide a quality care focused on the real needs of the patient.

It was evident in the research that due to the long periods of hospitalization and the side effects of chemotherapy, the hospitalized child has little acceptance of food. In order to minimize aggravation and maximize adherence to treatment, it would be important to allow the receipt of healthy food from home or even the creation of a space in which caregivers could prepare the child's food.

It is important that the health team that works in pediatric oncology is able to work using playfulness, also identified in the research. The application of playfulness in the setting of children expands and enhances understanding and adherence to treatment.

It is suggested that new studies, especially longitudinal and with triangulation of data (including the perception of the caregiver), be conducted in order to expand knowledge and understanding about the perceptions of children hospitalized in chemotherapy treatment and their strategies for coping with the disease and therapy, to meet and accommodate their needs that go far beyond biological care.

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