

## The viewpoint of hospitalized children with regards to oncological treatment

Percepção de crianças hospitalizadas acerca do tratamento oncológico

La percepción de los niños hospitalizados sobre el tratamiento del cáncer

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### ABSTRACT

**Objective:** The study's purpose has been to understand the children's perception concerning the treatment provided in a pediatric oncology unit from *Petrolina* city, *Pernambuco* State. **Methods:** It is a descriptive study with a qualitative approach, which was performed in a philanthropic hospital located in the interior region of the *Pernambuco* State. Five (05) children, within the age group from six to twelve years old, have participated through a semi-structured interview. Data scrutiny was based on the Bardin's Content Analysis. **Results:** The found categories reveal the need for the therapeutic process, alterations of the self-image and the invasive procedures as important sources of suffering for the child and the accompanying family member; the negative and positive aspects from the hospital experience; and also the reasons why children adhered to therapy and coped with the disease. **Conclusion:** Some strategies should be prioritized aiming to establish communication with the children and their family, including aspects such as therapeutic protocol, unit routine, invasive procedures, ambiance modifications, among others; organizing the unit, considering the routine of the child and the accompanying family member; as well as, encouraging them to overcome difficulties and to engage in treatment adherence.

**Descriptors:** Hospitalization, Hospitalized child, Oncology.

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## RESUMO

**Objetivo:** compreender a percepção de crianças, na faixa etária de seis a doze anos, acerca do tratamento em uma unidade oncológica pediátrica de Petrolina/Pernambuco. **Método:** pesquisa descritiva, com abordagem qualitativa, realizada em um hospital público, localizado no interior do estado de Pernambuco. Participaram cinco (05) crianças, na faixa etária de seis a doze anos, por meio da entrevista semiestruturada. A análise ocorreu tendo como referência a análise temática de conteúdo proposta por Bardin. **Resultados:** emergiram categorias que revelam a necessidade do processo terapêutico, as alterações da autoimagem e os procedimentos invasivos como importantes fontes de sofrimento para a criança e o familiar acompanhante; os aspectos negativos e positivos da experiência hospitalar; e os motivos pelos quais as crianças aderiam à terapêutica e enfrentavam a doença. **Conclusão:** estratégias devem ser priorizadas no sentido de estabelecer comunicação com a criança e a família, incluindo aspectos como o protocolo terapêutico, a rotina da unidade, os procedimentos invasivos, as modificações estéticas, dentre outros; organizar a unidade, considerando a rotina da criança e do familiar acompanhante; e os incentivar para a superação de dificuldades e para a adesão ao tratamento.

**Descritores:** Hospitalização, Criança hospitalizada, Oncologia.

## RESUMEN

**Objetivo:** Conocer la percepción de los niños, de seis a doce años de edad, sobre el tratamiento en una unidad de oncología pediátrica de Petrolina/Pernambuco. **Método:** estudio descriptivo con enfoque cualitativo, realizado en un hospital público, situado en el estado de Pernambuco. Con la asistencia de cinco (05) niños, de seis a doce años, a través de entrevistas semi-estructuradas. El análisis se llevó a cabo en relación con el análisis de contenido temático propuesto por Bardin. **Resultados:** categorías emergieron que muestran la necesidad del proceso terapéutico, los cambios en la autoimagen y procedimientos invasivos como una importante fuente de sufrimiento para el niño y el miembro de la familia que acompaña; los aspectos negativos y positivos de la experiencia en el hospital; y las razones por las cuales los niños se adhieren a la terapia y se enfrentaron a la enfermedad. **Conclusión:** Las estrategias deben ser priorizadas para establecer la comunicación con el niño y su familia, incluyendo aspectos tales como el protocolo terapéutico, rutina unidad, procedimientos invasivos, los cambios estéticos, entre otros; organizar la unidad, teniendo en cuenta la rutina de los niños y miembro de la familia que acompaña; y alentarlos a superar las dificultades y la adherencia al tratamiento.

**Descritores:** Hospitalización, Niños hospitalizados, Oncología

## INTRODUCTION

The occurrence of childhood cancer, although not higher than in adulthood, is an important cause of morbidity and mortality in Brazil, with an increasing incidence of approximately 1% per year.<sup>1</sup> On the other hand, its control has advanced a lot in the last decades, then resulting in the increase of the survival of children diagnosed early, since more than 70% of these can be cured.<sup>2</sup>

No matter how effective is the oncopediatric treatment, children are still subject to long periods of hospitalization, successive readmissions, various interventions, the risk of therapeutic complications and death; experiences that are

full of meanings, which in turn impact on the life of the child and his or her family.<sup>3,4</sup>

Authors further describe that the treatment and hospitalization of these children have aggravating characteristics in relation to the others: the chronicity of the disease; physical and psychic trauma resulting from painful, mutilating and invasive interventions; changes in self-image (such as alopecia); the possibility of a poor prognosis; social exclusion; as well as, family issues.<sup>5</sup>

Based on the specificities involved, it is now understood that in order to care for children in the oncology unit, changes are necessary that allow the understanding of their particular worlds, in their evolutionary stages of life, encompassing integral care. This includes considering the other as a participant, growing and assisting in their growth, in order to exchange knowledge to support actions.

Therefore, due to the commitment assumed in favor of the therapeutic quality and well-being of the children and their relatives/accompanying family members, the health professional should favor their expressions during the period of hospitalization in order to better interact with them and offer care more appropriate to the needs presented.<sup>6,7</sup>

The motivation for this study came about during the Residency in Child and Adolescent Health, specifically during the experience in the pediatric oncology unit from a hospital located in *Petrolina* city, *Pernambuco* State. It was possible to observe that children showed fear and insecurity from admission, aspects that intensified during the hospitalization, possibly due to the greater need to express their fears, feelings, and opinions about the disease and treatment. Researchers also reported similar observations, which subsidized studies from the perspective of children in the same situation - hospitalization and cancer experience.<sup>8,7</sup>

This instigated the search for greater theoretical knowledge about child hospitalization in an oncology treatment unit, but from the perspective of the child himself. In this sense, a search was conducted in the Scientific Electronic Library Online (SciELO) and *Literatura Latino-Americana e do Caribe em Ciências da Saúde (LILACS)* [Latin-American and Caribbean Literature in Health Sciences] databases, important indexes of the scientific and technical literature, in order to find related publications indexed in the January 2004 to November 2014 (last ten years). The descriptors used were: hospitalization, hospitalized child, oncology (the same descriptors of this study).

Despite knowing of the existence of works in this sense, only one scientific article,<sup>9</sup> published in December 2004, was found compatible with the mentioned search criteria: the period, the databases and the descriptors. The article, nonetheless, used for data collection a validated method, which included illustrative boards with topics related hospitalization in the pediatric oncology unit, without considering the elaboration of thought, statements and verbal expressions of children.

It is understood that, in Brazil, the scientific production containing the child perspective on the subject is still restricted,

and further studies are needed. Authors<sup>10,8</sup> describe that giving voice to children and adolescents has not yet been common practice in national health care research, and this requires the attention of researchers to carry out further studies. Bearing in mind these thoughts, it was decided to carry out a study based on the children's perception concerning the treatment provided in a pediatric oncology unit.

## OBJECTIVE

Comprehending the perception of children within the age group from six to twelve years old with regards to the treatment provided in a pediatric oncology unit from *Petrolina* city, *Pernambuco* State.

## METHODS

It is a descriptive study with a qualitative approach. The type of study called descriptive shows unknown characteristics of certain phenomena or situations; and the qualitative one makes possible the understanding of the subjects' viewpoint about issues that they experience, based on their own feelings and desires.<sup>11,12</sup>

The project was assessed by the Research Ethics Committee from the *Universidade Federal do Vale do São Francisco*, and approved under the Legal Opinion No. 0017/121212. The Resolution No. 196/96 from the National Health Council, which deals with the ethical issues of research with human beings, was respected throughout the development of this research.<sup>13</sup>

Inclusion criteria were the following: children hospitalized at the pediatric oncology unit; with a history of more than two hospitalizations in the unit, occurring less than a year ago; within the age group from six to twelve years old; who voluntarily agreed to participate in the research, by reading and signing the informed assent agreement; and whose accompanying relatives also agreed to the participation of the respective children, by reading and signing the Free and Informed Consent Term. Exclusion criteria were as follows: children in the isolation or intensive care area; with cancer in the central nervous system; in the terminal stage; with psychiatric problems; hearing impaired; as well as under the effect of neuroleptic drugs.

For this type of study, children from six to twelve years old were chosen because, in this age group, they are in the stage of cognitive development called the concrete operative. In this period of development, thought is so called because the child can think correctly, logically, if the content of his thought is faithfully representing the concrete reality, that is, if the examples or materials that he uses to support his thinking do exist and can be observed.<sup>14</sup>

It is worth noting that the criteria mentioned above were stipulated in order to allow greater reliability to the collected data, through the identification of children with property and conditions to express their perceptions, and the reduction of other factors that may represent a bias. Children in the isolation and intensive care area were not

included because they were a small number; be at risk patients, in a specific situation of hospitalization; and are often unstable for the provision of their testimony. Exclusion criteria for children with psychiatric problems and hearing impairment are not social exclusion/discrimination. They were determined due to the limitation, through the collection of specialized resources that ensure adequate interlocution between researcher-subject.

Data collection was carried out from January to March of 2013, at the Pediatric Oncology Unit of a philanthropic hospital located in *Petrolina* city, *Pernambuco* State, which functions as a support to the outpatient pediatric oncology service of the municipal government. The children who met the study criteria were identified through daily consultation to the Admission Map; communication with members of the nursing team; and access to medical records, under the prior authorization of the Teaching, Research and Extension Board of the hospital.

At the time of collection, only five (05) children met the criteria. Other aspects influenced the reduced number of subjects, since the unit counts on only six beds, in addition to being not only unit of hospitalization, but also of support for the chemotherapy realizations considered ambulatory, since some children, even non-hospitalized, need to be monitored during chemotherapy sessions.

In order to guarantee the confidentiality and privacy of the children involved, their real names have been replaced by randomly assigned children's character names, only the child's gender matches with the character's gender.

It is considered, in this study, that knowledge is only possible from the description of human experience, as it is defined by its own actors.<sup>15</sup> Therefore, the data collection was performed through the semi-structured interview. A script was used to guide the collection, which contained spaces to fill information about the characterization of the child and guiding questions.

The following information was completed in the script: name of the child and his/her responsible person, age, gender, schooling, type of cancer, number of previous hospitalizations, the day of current hospital stay. Its completion was carried out by means of communication with the child and the person in charge, as well as the research in medical records. It is noteworthy that the medical records were consulted only for the confirmation of some information from the script and the interview. The guiding questions were the following: "How has your treatment been in the hospital?" and "How do you feel during your treatment here?"

Data collection was performed in each child's room, which was kept in their bed. It was sought to ensure an environment as calm as possible. The collection took place in the day shift, during periods of less movement, avoiding visiting, feeding and medication schedules. The speech was recorded on a digital voice recorder.

The transcribed lines, as the corpus of the study, were submitted to the Content Analysis as proposed by Laurence

Bardin, aiming the construction of thematic categories. This analysis required the fulfillment of the respective steps: 1) pre-analysis; 2) exploitation of the material; 3) data processing, inference, and interpretation of the data.<sup>16</sup> In their respective categories, the statements were related to referrals about: the care/human care and the child hospitalized undergoing cancer treatment.

## RESULTS AND DISCUSSION

The children who participated in the research had ages from six to twelve years old, with three being female and two male. With regards to education, two did not study and three attended elementary school. Three had Acute Lymphoid Leukemia, Acute Myeloid Leukemia, and another Rhabdomyosarcoma. The day of hospitalization ranged from 5 to 12 days, and the number of previous hospitalizations ranged from 03 to 05. The causes that led to hospitalization during the period of collection were as follows: fever-associated thrombocytopenia, fever associated with dry cough and dyspnea, hydroelectrolytic disturbance, catheter infection.

The following three (03) thematic categories appeared from the interviews: perceiving both the disease and the therapeutic process as suffering sources; identifying both the negative and positive aspects of the hospital experience; and, thinking ahead: reasons for coping with the disease.

### Perceiving both the disease and the therapeutic process as suffering sources

The children in the study demonstrated signs and symptoms that preceded their respective hospitalizations. Suffering for hospitalization, for the necessary procedures and for the consequences of treatment is manifested in the dialogues:

*I was with diarrhea... It was diarrhea... Then I came here to do CT [chemotherapy] and I cried a lot because it hurts. (Strawberry Shortcake)*

*I came because I had a pain here [points to the knee] and my belly has grown a lot. Then I came to take some medicine... And I have a fever... If you have a fever, the doctor leaves me here a lot during the day [expression of discouragement]. (Nutty Boy)*

*Oh... It's bad... The worst part is to throw up... You throw up what you do not have! The worst is to vomit without eating... (Sleeping Beauty).*

Conditions imposed by cancer require frequent and prolonged hospitalizations, either for the treatment or the necessary care, when there is an intercurrent.<sup>17</sup> Considering the impact of diagnosis and treatment, these trigger negative feelings - related to pain, nausea and vomiting, loneliness, hopelessness, revolt, and even fear of death.<sup>3</sup>

Children may perceive the finitude of life as a concrete possibility and treatment as the only means of clashing with leukemia and death, as is clearly apparent in Tarzan's speech:

*And I need to take chemo. Leukemia only goes away with chemo. I already thought bad things, things of death. Because "everyone" dies [referring to occurrences of the death of other patients]. (Tarzan)*

It was noted that death was referenced by her as a direct consequence of not performing treatment, and, therefore, conditions her life to hospitalization and medications used. Therefore, cancer brings to the patient the awareness of the possibility of death. This idea is accompanied by anguish and fears that are part of the course of treatment.

As she processes her affective and emotional development, the child experiences actual deaths from people around her, trying to understand what is going on with her.<sup>18</sup> But often the adults who co-exist with her have the misconception that the child does not understand death, and the issues surrounding it, which favors inappropriate attitudes, such as avoiding the subject and saving the child using euphemisms and lies that often confuse it.

By not speaking, the adult believes he is protecting the child, as if this protection would relieve pain and magically change reality. What happens is that the child feels confused and helpless, with no one to talk to.<sup>18</sup> Children, in turn, perceive the hidden facts and, although they do not express them verbally, manifest through their own language: drawings, games, and stories.

The child should talk about death, but this requires, in addition to sensitivity on the part of the adult, the use of words and experiences that are understood by them. It is of real importance to bring the theme of death to a dimension that can be assimilated by the child according to their level of cognitive development.<sup>19</sup>

Hence, in addition to physical treatment, the child and his/her family need psychological and social support in order to feel safe to deal with illness and treatment, as well as to understand the finitude of life.

Alopecia has also been reported - hair loss caused by the influence of chemo in the hair follicles. This is one of the side effects that most concern patients diagnosed with cancer, because it strongly alters the perception of body self-image and reveals, for others, the condition of the patient. This can be clearly seen in the child's speech, where alopecia is perceived as a threat to his self-image and the way others see it, leading to negative emotional reactions and social isolation:

*The hair? [She runs her hand through the hair]. It fell all over... I got depressed. I was ugly. Bald... I did not go to school. It took me to go to school. (Sleeping Beauty)*

Alopecia can lead to emotional reactions such as anxiety, anger, guilt or depression. Furthermore, as far as behavioral aspects are concerned, the child may still be isolated, have

his or her school performance impaired or no longer wish to attend school.

Self-image is an important topic to be worked on with the child, since its aesthetic characteristics inevitably undergo modifications during treatment. The way the child understands and behaves in the face of these changes is fundamental to the reduction of other resulting implications, which undermine his life and consequently his development process.<sup>20</sup>

Cancer treatment is complex and therapy depends on invasive procedures that cause discomfort and suffering. Pain experiences, mainly related to invasive procedures, were highlighted in the children's speech. Puncture is one of the main sources of pain and fear. Regarding the procedures involving puncture, the children reported:

*Had a test that hurt a lot. I had a needle and I cried a lot. (Strawberry Shortcake)*

*The time it starts [puncture] hurts and I cry. (Nutty Boy)*

*Oh my God... I hate the needles. Why cannot the medicine be in the mouth? I prefer the bad taste than the stuck in the arm and the butt. (Strawberry Shortcake)*

*The punctures! Every time there's a needle in my arm... I told you! No one punctures me today! (Tarzan)*

Children undergoing cancer treatment undergo several invasive procedures, which become part of their lives. Among them, the puncture is one of the diagnostic and therapeutic procedures that most cause pain to hospitalized children.<sup>21,22</sup>

Many children, regardless of their age, may react negatively to the procedure and experience elevated levels of anxiety, which may impair acceptance of therapy and generate more or less severe and long-lasting sequelae. Each child has an individual way of reacting to certain procedures, but there are also peculiar characteristics of the stage of development that need to be considered in order to support the planning of the preparation and actions of the health team involved.<sup>23,24</sup>

Professionals should respect the feelings expressed by the child and demonstrate an understanding of their stage of growth and development, since some reactions are expected, especially during hospitalization. Likewise, professionals must establish a communication, prior to the procedure, using the therapeutic toy or other strategies, in order to prepare the child and offer them opportunities for expression and clarification, for the appropriate relief of tensions and effective therapeutic continuity.

During the course of treatment, experiences of hospitalized children also cause distress and insecurity for their family, mainly due to the therapeutic care to be performed by health professionals.<sup>25</sup> The children reported:

*She cried a lot. I said "cry not mom... It does not hurt...". She always cries... I feel sad when she cries because she is sad too. Sometimes I stay and I do not cry... Then my mom is happy. And I eat too. (Sleeping Beauty)*

*Then I stay quiet and my mom is happy. (Nutty Boy)*

Throughout the lines, it is understood that the satisfaction of the needs of the hospitalized child also implies the involvement of the mother in the care provided, demanding strategies to ward off fear, as to generate security and tranquility.<sup>26,27</sup>

Regarding the family, healthcare professionals should offer care that includes communication and emotional support, so that the family can face the implications of the illness and the hospitalization situation in the best possible way. The family also suffers from the experiences of illness and hospitalization with the child, especially the mother who, in general, takes responsibility for care for the sick child.<sup>20,28</sup>

Targeting to reduce the suffering and anxiety of the child and the accompanying family member during the hospitalization period, they need to know that they can actively participate in care and that health professionals, such as nursing professionals, are all available to help them.<sup>3</sup>

So, it is a benefit for the accompanying family member to have the opportunity to reduce their anxiety by talking about their fears and anxieties, clarifying fantasies and receiving the necessary support.<sup>20</sup> When the accompanying family member expresses himself and has his doubts adequately clarified, he may feel safer and, consequently, help the child to feel the same way, helping her to recover better and suffer less. Bearing this in mind, when the health professional considers the family in the care given to the child, it benefits not only the family, but also the child. The calmer the accompanying family member, the more tranquility will be transmitted to the child.<sup>29</sup>

### Identifying both the negative and positive aspects of the hospital experience

*Negative aspects related to the fulfillment of a hospital routine and to behaviors that interrupt the child's individuality and sleep schedule were perceived in some speeches:*

*I do not like [the hospitalization environment]. I do not like waking up early to weigh... (Tarzan)*

Authors affirm that school-age children who choose their activity schedules are more satisfied and happy, as well as being more collaborative during the treatment since they feel useful and participative.<sup>30</sup>

In this sense, they suggest a technique that can minimize negative aspects related to the rupture of the hospitalized

child's daily life, which was called "time structuring". This behavior is more appropriate for the scholar and adolescent who are not critically ill and who dominate the concept of time. It involves the schematization of the day of the child when hospitalized, in order to include and make possible, according to negotiation, all activities that are important for her and her family, as well as for health professionals: be the technical procedures, the time limit for weight measurement, bathing, school work, recreational activities, etc.

The use of this technique can be discussed by professionals in order to put it into practice in the unit. Since children with cancer may be hospitalized several times, negotiation of time structuring should preferably occur from the start of treatment. This structure can be recorded in the child's chart, being open to adaptation in the course of the child's evolution and readmissions.

Together, professionals, family members, and children can then plan a daily schedule with written schedules and activities that will be posted in the child's room at each rehospitalization. When specific changes occur, they can be added. A wall clock, positioned in the bedroom, will help the child and the accompanying family member to comply with pre-set times. This can help maintain the organization of the unit and respect the routine of the child and accompanying family member.<sup>30</sup>

Tarzan described another negative perception, referring to the frequency that it is interrupted by health professionals, when the purpose of the interruption is repetitive:

*I do not like every time someone [the health team] asks how I am doing... I'm fine! (Tarzan)*

Inadequate communication between staff members or lack of verification of records in the medical record can lead to repetitions of questions with the child and the family member. Asking children questions about their health can lead to anxiety and discomfort, by interrupting rest periods, sleep, or even other activities such as playing. Therefore, even if it is necessary to ask questions and certain procedures, this does not mean that the child can be interrupted constantly. In many situations, it is possible to avoid and prioritize what is most important to it.<sup>31</sup>

During the rest period, the nursing professionals must control environmental stimuli that can harm it, such as: light; heat; avoiding knocking doors when entering or leaving the room and controlling the volume of the voice itself.<sup>8</sup>

Childhood is a period of great importance in the development of the human being, as much in the biological aspects as psychosocial and cognitive. Child development and growth depend not only on biological maturation but also on the conditions offered by people and the environment in which they are inserted.<sup>32</sup>

Cinderella also reported dissatisfaction with being restricted in personal activities, once common in her daily life, causing her discomfort and making the hospitalization experience even more difficult:

*I do not like it here... Too bad... Today is my birthday; I want to eat chocolate cake. The time never goes by in here. (Cinderella)*

Illness and hospitalization can cause trauma, as well as delay or even hindrances to the process of growth and development of the child with cancer. Therefore, this refers to a reflection about a set of factors that, in a more or less direct way, will exert influence in his life.<sup>33,34</sup>

At school (six to twelve years), children have a high level of physical and mental activity. Nevertheless, when hospitalized, they suffer due to some limitations, such as the impossibility of carrying out activities common to their daily lives (including food and special celebrations), leaving the hospital or even the bed. Often, they find it difficult to find suitable opportunities in the hospital environment to develop activities they would like. In this context, feelings of loneliness, boredom, isolation, and depression are common.<sup>30</sup>

At the beginning of the cancer treatment, the daily universe of the child undergoes profound changes, but it does not stop being a child and, when entering the hospital, will bring with it, besides the sick body, a life full of needs that, before the illness, developed in a unique and peculiar way.<sup>34</sup>

Therefore, the hospital environment should also be adapted according to the needs of the children and their families, as well as the possibilities offered by the institution, so that they feel as little as possible away from home, even through a proximity to objects that are familiar and that make the environment minimally pleasant.<sup>20</sup>

One positive aspect, mentioned by the children, was the contact with people present in the hospital environment, then developing a pleasant relationship. Among these people, nursing professionals were mentioned:

*But sometimes it's nice [oncology unit]. There are nice people here. (Tarzan)*

*I took a lot of blood in my vein. Because I had leukemia in my blood, so the nurse said I was supposed to stay strong. When I cry, they [the nursing professionals] tell me not to cry because I'm going to get well. Then they play with me. (Cinderella)*

The hospital is an unknown and mythic place, which often increases anxiety and hinders the therapeutic process. It is understood that nursing professionals should favor the adaptation of children, combining efforts to help them overcome their fears and uncertainties. For this, they must establish a relationship, communicating effectively from the beginning to the end of treatment.

The limitation of listening time and attention to the patient makes the interpersonal relationship unsatisfactory and loses the therapeutic opportunity it offers. Important aspects such

as trust, adherence to treatment, negotiation, and participation in decision-making are hampered.<sup>35</sup>

In this sense, the professional must ally the technical-scientific competence to human sensitivity to communicate with the patient, since communication is part of the care and the conversation with the patient, even when without a specific purpose, can promote therapeutic effect, reassuring and offering subsidies for care.<sup>36</sup>

Another positive aspect, highlighted in children's discourses, refers to the understanding that nursing professionals are readily available, performing an adequate therapeutic care when necessary, which guarantees, therefore, the continuity of the treatment:

*If I feel a fever, the nurse brings the medicine. If I have a fever I cannot take the blood in the vein, if I vomit a lot, they [the nursing professionals] put the serum. (Nutty Boy)*

*I was low blood. Then the nurse called the place where the blood is. Since I had no blood, a woman gave me her blood. (Cinderella)*

It is known that, during hospitalization, the child, especially in the oncological unit, is submitted to a series of necessary care for the evaluation of his physical condition, determination of diagnoses or, also, to carry out the therapeutic process itself.<sup>37</sup>

The testimonies showed that the children perceived the treatment not as negative but as positive. Probably because they have received necessary and appropriate information for clarification and encouragement since the beginning of the process. In a particular research, the author<sup>8</sup> understands that children when knowing that certain care such as the administration of serum, medication, chemotherapy, and hemotherapy are essential for the success of the treatment, and that they receive them in a satisfactory way, they feel safer and optimistic for healing. These feelings may facilitate the collaboration of the child and family members during treatment.

### Thinking ahead: reasons for coping with the disease

It was eminent that children contribute to the treatment in the hope of healing by their greater desire to return to the daily routine, as exposed in the speeches:

*I do the CT [chemotherapy] because I want to get well and go to my house. (Strawberry Shortcake)*

*But then I know that you have to take all the medicine to go home. [...] I'm going to take just one more medicine and it's over. And I'll go home soon. (Nutty Boy)*

Cancer interrupts the life that, until the diagnosis, followed in normality, and causes doubts as to the future and

even to the present. In contrast, over time, the therapeutic process, including chemotherapy, leads individuals to value life more. Then, knowing the disease and facing it, getting involved in the whole process, playing, having family around and, above all, believing in recovery are strategies to be used and stimulated during chemotherapy, since even being a therapeutics suffered and restrictive, is responsible for the cure.<sup>33</sup>

The desire for victory and a satisfactory resolution of the disease becomes an important goal for the child and his family, all expectations are often focused on the treatment.<sup>38</sup> Even with a difficult routine, the child wants a future permeated by good moments, as in the following statements:

*I want to go home... My hair will grow too. (Nutty Boy)*

*I want to never have leukemia and never get sick again. I want to go to school and want my hair big! I want flowers and butterflies, just like that drawing [points to an image on the cover of the notebook]. (Sleeping Beauty)*

Children's speeches reveal the importance of reinforcing feelings that strengthen them during therapy. Authors affirm that the bearing-cancer child, even experiencing daily painful situations, has an idea about the future. The child can maintain the desire and the trust in better days, being the support of the family and the health professionals essential for this positive behavior. A child who trusts on the treatment faces with more courage the therapeutic trajectory.

## CONCLUSIONS

The results of this study showed that children can contribute significantly to their care, through their own perceptions about the treatment to which they are submitted in the oncological unit.

They revealed that the necessity of the therapeutic process in the face of the diagnosis, the alterations of the self-image and the invasive procedures represent important sources of suffering for the hospitalized child and for his/her family. It is understood that health professionals should establish adequate communication with the child and family throughout the therapeutic experience, aggregating information about the therapeutic protocol, routine unit, invasive procedures, aesthetic modifications, among other side effects, and other needs.

They highlighted negative and positive aspects experienced during the hospitalization period. The negative aspects mentioned are related to the following: the accomplishment of a routine that interrupts moments of rest of the child, repetitive questions asked by health professionals and restrictions on personal activities. This presupposes that the unit and health team must follow strategies that maintain the organization of the unit, and respect and seek adaptations according to the routine of the child and the accompanying family member.

The positive aspects mentioned were, as follows: contacting people, including nursing professionals, which made the hospital experience more pleasant; and the commitment of these professionals to the continuity of treatment. Positive perceptions can reinforce feelings of security and optimism, essential for strengthening the therapeutic process.

They have indicated that they contribute to the treatment, from the perspective of coping with the disease to the return to the natural daily life. This desire for a future in which health and other possibilities are part of their lives show the importance of children and their families being constantly encouraged to overcome difficulties and adhere to treatment. Therefore, helping to maintain faith, focus, and hope is part of care.

Therefore, the important information derived from their speeches shows that caring in pediatric oncology unit demands the specificity of the health team. This should develop a practice that not only aggregates technical-scientific knowledge and skill, but also attention and respect for the child's growth and development, availability of time, communication capacity and affective relationship, attention to the family member, among others.

It is believed that many difficulties faced by children, and even by their family members, can be avoided when they are heard, understood and accepted, and therefore considered and respected in their opinions, complaints, and needs.

Pediatric oncology is a specialty considered contemporary and still has its body of knowledge and practice in the construction process. This research aims both to contribute to the scientific production of the area and to support the care of hospitalized child by the health professionals, especially, children bearing cancer.

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