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## FROM DIAGNOSIS TO SURVIVAL OF PEDIATRIC CANCER: CHILDREN'S PERSPECTIVE<sup>1</sup>

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**ABSTRACT:** The study aimed to investigate the process from diagnosis to survival of cancer from the child's perspective. This study is exploratory with qualitative analysis of the data, based on an adaptation of story-board narrative research and use of thematic interpretation. A precocious maturity was revealed, through the children's understanding regarding the diagnosis, of the different phases of the treatment, and coping with the difficulties of co-existing with classmates and re-adapting to school after the end of treatment. The use of strategies to help the children to adopt attitudes which minimize and/or prevent the distress related to cancer is a role of the health team, considering as care not only clinical protocols but also criteria relevant to the existential dimension.

**DESCRIPTORS:** Oncology nursing. Pediatric nursing. Chronic disease. Chil. Drug therapy.

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## DO DIAGNÓSTICO À SOBREVIVÊNCIA DO CÂNCER INFANTIL: PERSPECTIVA DE CRIANÇAS

**RESUMO:** Objetivou-se compreender o processo do diagnóstico à sobrevivência do câncer a partir da perspectiva da criança. Estudo exploratório com análise qualitativa dos dados, com base em uma adaptação da técnica do desenho-estória e utilização da interpretação temática. Revelou-se uma maturidade precoce, por meio da compreensão das crianças acerca do diagnóstico, das diferentes fases do tratamento e enfrentamento das dificuldades de convívio com colegas e readaptação na escola após o término do tratamento. É papel da equipe de saúde usar estratégias para ajudar as crianças a tomar atitudes que minimizem e/ou previnam a aflição relacionada ao câncer, considerando-se para o cuidado não somente protocolos clínicos, mas também critérios referentes à dimensão existencial.

**DESCRIPTORES:** Enfermagem oncológica. Enfermagem pediátrica. Doença crônica. Crianças. Quimioterapia.

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## DEL DIAGNÓSTICO A LA SUPERVIVENCIA DEL CANCER INFANTIL: PERSPECTIVA DE LOS NIÑOS

**RESUMEN:** Se intentó comprender el proceso de diagnóstico a la supervivencia del cáncer a partir de la perspectiva del niño. Un estudio exploratorio utilizando el análisis de datos cualitativos, basado en una adaptación de la técnica del dibujo y la utilización de la interpretación temática. Se reveló una gran madurez precoz, por medio de la comprensión de los niños sobre el diagnóstico, de las diferentes fases del tratamiento y enfrentamiento de las dificultades de convivencia con colegas y readaptación en la escuela después del final del tratamiento. Es papel del equipo de salud usar estrategias para ayudar a los niños a tomar actitudes que minimicen o prevengan la aflicción relacionada con el cáncer, considerándose para el cuidado, no solamente los protocolos clínicos, sino también los criterios relativos a la dimensión existencial.

**DESCRIPTORES:** Enfermería oncológica. Enfermería pediátrica. Enfermedad crónica. Niños. Quimioterapia.

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## INTRODUCTION

The families talk with the children about the various meanings that cancer has, which arise from socio-cultural experiences.<sup>1</sup> Nowadays, in spite of the scientific and technological progress in the diagnosis and treatment of chronic illnesses, cancer's stigma remains, as it is seen as an irreversible process, and is nearly always associated with a death sentence.<sup>2</sup> When cancer affects a child, the feelings of fear and uncertainty are more intense, as she is at the beginning of her life and, perhaps, may not live to see the achievement of her hopes and dreams. These are the meanings which can be transmitted to the children by the families.

Investigating the impact of the disease and the treatment on the cancer patients is essential for planning actions which aim for appropriate attendance to their needs. Some strategies are necessary for treatment objectives, such as: implementation of preventive measures and protection from harm to health; early diagnosis of complications resulting from the treatment; the implementation of efficacious conducts, whether pharmacological or not, to reduce the risk of sequelae; promoting physical, psychological and social means of rehabilitation;<sup>3</sup> and the creation of appropriate conditions for integral care for the child with or without possibility of cure.

Studies have demonstrated that, from the perspective of children and adolescents with cancer, some questions are important, such as: loneliness, isolation, loss of a normal childhood, lack of appetite, physical discomfort, incapacity, and changes in self-image, among others, and that these lead to changes with routine. In the context of experiencing cancer, emotional responses such as anger and fear were also identified.<sup>2,4,6</sup> As these youngsters, however, have the perception of how important the phase of treatment is for cure, their concerns are directed not only at the physical conditions, but to the evolution and recovery of their health and their prognosis.<sup>6</sup>

Although the nurses recognize the importance of the various cancer treatments, the priorities must not fall back only on the management of the disease, but must extend to the environment around it. The care must not apply on the biological world of the disease alone, but must also include the world of the person with cancer, in the sociological sense.<sup>7</sup>

In this way the present study's objective was to investigate the process from diagnosis to

survival of cancer from the child's perspective, in search of support for nursing care for children with chronic conditions.

## METHOD

This is an exploratory study with qualitative analysis of the data, undertaken in a public hospital in the city of Rio de Janeiro. It used an adaptation of the story-board narrative research technique for the collection of the empirical material. This technique involves the bringing together of expressive motor processes (the drawing), dynamic nonperceptive processes (thematic verbalizations) and questions about the theme (investigation phase). This is a resource through which the child has the possibility of producing discourses about everything involved in her life, her history and her perception of the world, revealing how she sees and thinks about reality.<sup>8</sup> The adaptation of the technique happened due to its considering only the accounts for interpretation, excluding the drawing, as the nurse's training does not address that. A pilot interview was held for validation of the technique.<sup>9</sup>

The total number of subjects was not stipulated *a priori*; as is usual in qualitative studies, it was defined throughout the research process, according to the sufficiency criteria, that is, when it was judged that the empirical material allowed the understanding of the question investigated.<sup>10</sup> Hence, the study came to include seven children.

The inclusion criteria for the subjects were: children undergoing or who had undergone outpatient chemotherapy; of school age (6-12 years), as at this stage they have the intellectual conditions to understand better their bodies and disease; and to have the physical and emotional conditions (not crying, calm and quiet) to communicate verbally and to draw during the data collection. The physical conditions were evaluated in accordance with the ECOG performance scale (Eastern Cooperative Oncology Group),<sup>11</sup> which allows the security of not including physically incapacitated subjects for carrying out the activities proposed by the researcher.

The collection of the empirical material took place from April to June 2010, individually, during the morning shift, in the chemotherapy unit, known as the Carioca Aquarium, without the presence of the person responsible for the child. First, the child was invited to sit at a table, and the researcher sat in front of her. Colored pencils were

spread on the table along with a sheet of paper. The child was asked to draw freely: "You have a blank sheet, and may draw whatever you want". The researcher waited for the child to finish the first drawing. After the child had finished, the researcher posed the following question: "Looking at your picture, can you make up a story, saying what happened?" Clarification necessary for understanding and interpreting the material produced was requested, regarding both the picture and the story (investigation phase). Following that, the child was requested to produce a drawing resembling the chemotherapy room. When she finished, the researcher asked: "can you tell me the story of a child with cancer?" When the child finished telling the story, the investigation started, using the following guiding question: "could you tell me what happens with this child during the treatment?" As this question was explored, others were formulated so as to further extend the information, such as: "could you explain that better for me?" "How so?" The technique was used with the purpose of understanding the child's experience of the issue through the stimulation to tell stories. The stories started with the child describing what happened to a fictitious child, but in the process, the child spoke about herself.

Thematic interpretation was used for analyzing the statements.<sup>10</sup> After the transcription of the interviews, the first organization of the discourses in a specific order was carried out, thus initiating a classification. In this way, the horizontal mapping of the material was outlined. Later, in the light of the study's objective, exhaustive and repeated reading of the texts was carried out, producing an interrogative relationship with them so as to apprehend the structures of relevancy. The procedure allowed the elaboration of the classification through transversal reading. Next, based on the structures of relevancy, the reduction of the classification was processed, re-grouping the most relevant themes for the final analysis.

Colors were used for identifying the children's statements while guaranteeing their anonymity. The project was approved by the Institution's Research Ethics Committee, under memorandum n. 56/09. The children's legal guardians signed the Terms of Free and Informed Consent.

## RESULTS AND DISCUSSION

Six of the children were male and one female, and their age varied between six and eleven. Regarding their educational level, two were in the

sixth grade, two in the first grade, one was in the fifth grade and another in the third grade, all in primary education, apart from one child who had never studied. The participants' medical diagnoses were: acute lymphoblastic leukemia, Hodgkin's Lymphoma, and neuroblastoma. All the children who participated in the study were classified as being Performance Status - PS 0, according to the ECOG performance scale, that is, completely active and able to carry out all activities as they could before the illness. The children were in an appropriate emotional state (not crying, calm and quiet) for communicating verbally and drawing.

Different issues were identified during the analysis of the empirical material, and were organized for a better chronological understanding of the facts which came to light through the children's experiences, namely: the diagnosis, the routine of treatment, the oncological emergency, the process of schooling, and survival after the treatment.

### The diagnosis

In their statements, the children use medical terms appropriately to designate their illness and how the diagnosis came about. They identified the illness they had and the facts related to it, such as the increase in the size of the cervical lymph node, the diagnostic procedures and the treatment: [...] *It was cancer, he had leukemia* (Pink - 10 years old); *I came to have an operation to remove a nodule from my neck. It was a lump here* [points to the cervical area]. *After I was discharged, I came here* [Carioca Aquarium] *to start treatment. I didn't start the treatment there* [the ward]. *I only went to take the nodule out, a biopsy. That's why I had to do chemotherapy* (Green - 11 years old).

A child of school age who has a chronic illness has knowledge about her condition, in line with her ability to understand. How she narrates her history and understands the life-context in which she is inserted results from a process of remembrance of past events, but also of present and future representations. Spending time in close proximity to health professionals during visits to hospital is part of the everyday of children with chronic illnesses,<sup>12</sup> and enriches their vocabulary with medical technical terms. The child's comprehension regarding her illness makes her a possible participant in taking decisions regarding her health/illness process. This fact must be valued and respected by the health team, so as to take into account her personal preferences. The children have the capacity to understand their

illnesses and treatment, and so one must not neglect them, making them into passive subjects in the cancer treatment.

### The everyday of treatment

The children who participated in the study live in poor social conditions (poor = substandard). This fact may be identified in the discourses of the children who have to use public transport, often uncomfortable, and who have to interrupt their sleep to get to hospital, because in large cities such as Rio de Janeiro, traffic jams are common, as are long distances between one part of the city and another: *I get up early, and I come by bus* (Black - 7 years old); *She [the child] comes from home. She comes by bus.* (Orange - 8 years old).

The children always go accompanied by family members, it being most common for them to go with one of their parents, although in some cases both are present: [...] *She comes with her mother* (Orange - 8 years old); *always with my Dad* (Green - 11 years old); *He comes with his Mom and his Dad* (White - 8 years old).

The nursing team needs to know the family structure, its dynamics, and the interactions existing and established in the contexts it passes through, to meet its real needs,<sup>13</sup> seeking to create, strengthen and maintain supportive links to reduce the stress load of the principal carer of the children with cancer.

The children describe the chemotherapy routine with richness of detail. They emphasize that the main advantage of the outpatient treatment is going home after the administration of the medication. It's also possible to identify, in their statements, that they confuse themselves with the characters they invented for telling the story: *the doctor told the Mother: 'this is where you come for the blood test on the 6<sup>th</sup> of June. You have to be here on the 6<sup>th</sup> for the consultation'. They [the child and his mother] come on the 6<sup>th</sup> and give the blood sample. And the Mother says [to the receptionist]: 'I forgot to book the appointment and he has chemotherapy.' She [receptionist] said: 'okay! Just wait while I get his medical notes.' He [character] goes in [to the chemotherapy room], and they punctured the vein and gave him the chemotherapy. Afterwards the doctor came here again and discharged him* (Pink - 10 years old); *when the child comes here [Carioca Aquarium] she stays sitting down in the reception area, waiting. She can watch television or play videogames, then she sees the doctors. [...] the doctor listens to her heart, does the*

*whole consultation, sees everything [clinical, laboratory and radiological examinations]. [...] She has to receive normal saline. As soon as I came in here I had a consultation and received normal saline [...]. When I came in, they put it in the vein. [...] after they took it out [the infusion line and bags of saline]. I went home and began to feel bad* (Blue - 11 years old); *they have to find a vein, put in a rubber tube which stays connected to the normal saline, then put the medication which stays inside a little bag. [...] when it finishes [the infusion of the medications] she [child] can leave* (Green - 11 years old).

Knowing the treatment routines means that the child knows what is going to happen to her. This can create conflicting emotions. On the one hand, knowing, she is prepared to face the situation, and so can develop personal strategies to minimize the stress; on the other, depending on how her body reacts to the medications, she may present ambiguous feelings due to the need to continue with the treatment and the desire not to go through the process of pain and suffering, mainly when the side effects of the treatment are uncomfortable.

There are chemotherapy protocols which needed to be administered as inpatient treatment, because of the long time taken for infusion, which can sometimes be 24 hours or longer, besides the hyperhydration and continuous replacement of electrolytes. In addition to this, to prevent complications, it can be essential to administer rescue agents, when the chemotherapy drugs are administered in high doses. There are children who receive all their chemotherapy on an outpatient basis, but who, even so, need to be hospitalized for supportive treatment, due to the complications provoked by the chemotherapy toxicities: *I did it once here [outpatient unit] and after, I did it four times on the ward. On those four, I had to be hospitalized* (Green - 11 years old); *I stayed here six days without going home. It was really horrible! I spent the whole time taking medicine. I had an injection in my arm, I stayed receiving normal saline, medicine...* (Blue - 11 years old); *She comes to the Aquarium or to the ward, they puncture a vein and put in the chemotherapy [...] and when she's up there [the ward] the child stays in [remains hospitalized]* (White - 8 years old).

There are chemotherapeutic protocols in which the medications are administered over a number of days consecutively on an outpatient basis. This is what happens with the child in the following account: *after the consultation you go to*

*arrange the next one. [...] someone [auxiliary nurse] will attend her [the child]. [...] She gets a vein. [...] when the medications finish the child goes home. [...] the next day, she comes back here [Carioca Aquarium]. The day after, she comes again. She comes here, they puncture the vein, stick in the medication and I stay sat here [while the medication is infused] (Orange - 8 years old).*

In the previous statement, one can perceive that the child is submitted to consecutive days of chemotherapy, has her veins punctured each day for the infusion of medications, is subjected to the suffering caused by the toxicity of the treatment and her chronic condition, and even so remains calm, seated, waiting for the end of the medication, so as to go home, without rebelling.

One study<sup>14</sup> with 78 children and adolescents with cancer, using the Benefit/Burden Scale for Children (BBSC) as its instrument, identified that the participants with reactions of anger, denial, aggressivity and greater anxiety presented more suffering related to the cancer; while those who presented thoughts of greater acceptance of the condition, such as tranquility, optimism and confidence faced the illness with less stress. The children who got worn out more were those who had a more pessimistic view of life.

The child's strategy of keeping calm and confident can reduce the vulnerability to the suffering, bringing a reduced feeling of malaise, and this contributes to her quality of life and her ability to cope with the chronic condition, seeing as how she has no choice but to receive the medications: *he stayed quiet* (Blue - 11 years old).

The health team should use strategies to help the children to adopt attitudes which minimize and/or prevent the distress related to cancer, this can occur through exploration of the hospital ecology of the Carioca Aquarium,<sup>15</sup> including play as an alternative.

The child needs to face various discomforts during the treatment. In the next statement, the child reports the discomfort of fasting for the lumbar puncture to be carried out: *they're going to do a lumbar puncture, and he has to be hungry [shows dissatisfaction]* (Purple - 6 years old). Lumbar puncture is a medical procedure for administering intrathecal chemotherapy, and also for collecting the cerebrospinal fluid for laboratory analysis, as the majority of the medications do not pass through the blood-brain barrier. The prevention of leukemia in the central nervous system is an essential part of the treatment. It is carried out

under sedation so as to reduce the levels of pain and stress, and requires the child to fast to avoid complications such as bronchoaspiration.<sup>16</sup>

It is necessary for the service's organization to attend a fasting child as fast as possible, so as to avoid the discomfort caused by waiting for the procedure, or even its re-arrangement or its not being done. Lumbar puncture in itself can cause the child fear and distress, so hunger is one more stressing factor which adds to the situation and, consequently, affects the family and nursing team. Depending on the child's age range, she may accept the fast more easily, but even so it is a strain, which is intensified when they present an increase in appetite as a side effect of the corticosteroids.<sup>17</sup>

The phase of oral chemotherapy is generally tolerated better by the children. As it is a non-invasive route for administering the medication, the child's compliance with this phase of treatment is better and, equally, the child does not complain in relation to ingesting the tablets: *now, I'm having oral chemotherapy [animated with the phase of treatment]* (White - 8 years old).

The use of oral medications is an advance in cancer treatment; however, for them to be efficacious and efficient, therapeutic compliance is fundamental and it is in this that the nursing care is shown to have a predominant role. The biosocial characteristics of the children and their families must be considered due to the possibility of these influencing compliance with treatment, as well as the carrying out of interventions with the objective of advising on treatment proposals, the anticipated and undesirable effects of the medications; and to adapt the taking of medications to the family's routine activities, and analyze the compliance behavior.<sup>18</sup>

## The oncological emergency

The next account reports the story of a child who was at home and need to seek emergency help. It emphasized the responsibility of the caregiver to take decisions in the face of the complication which occurred: *Nemo [the character created] was at home feeling ill and was under treatment. His mom got him and brought him here. He [the child] goes to the emergency room, then he gives a blood sample, if it's bad he goes to the ward, if it's not he goes home. If the exam's bad, it means he's got a temperature. If he's got a temperature, he has to come here [hospital], because he can't stay home with a temperature. Now, if the mom were laid-back... [the child becomes pensive and*

concludes her thought] *If it were a laid-back mom, she'd leave the child at home.* (Pink – 10 years old).

Oncological emergencies include a wide variety of conditions which can occur during the course of the illness, including complications caused by the cancer itself or by side effects of the therapy. Many of these emergencies pose an imminent risk to life and can strike patients with curable or incurable illnesses. The early recognition and treatment of these conditions can lead to a marked improvement in quality and length of life.<sup>19</sup>

The child considers that a mother who fails to comply with medical advice is not caring correctly for the sick child. The child appropriated the information given by the institution's health team on the importance of seeking the emergency services in the event of any complication taking place at home. It may be inferred that the child hopes that the mothers may have attitudes regarding their children's cancer which resemble those reported by the subjects of a different study,<sup>19</sup> such as: a sense of responsibility, allowing the best care to the child, along with the health team; being alert to the signs that indicate that a new crisis may be approaching; knowing the effects of the treatment, so as to identify what or how to monitor, recognizing all the symptoms which may be manifested; being ready to act at any moment, should it be necessary and that they should be essential throughout the entire process of the illness.

Inpatient treatment is recognized by the child as necessary for the treatment and control of complications related to the illness and the chemotherapy, and as a result they choose to go to the hospital whenever necessary, even though this visit may have the consequence of hospitalization, because under the care of the health team, the child feels safer. At the same time that the children and their relatives are instrumentalized to identify the need to seek help in the hospital, they feel impotent to avoid these situations at home: [...] *I prefer coming here to be treated than staying home. Staying home doing nothing, even if I'm ill. So anyway the doctor had to hospitalize him [the character] [...]* (Pink – 10 years old).

For the mothers, the treatment is seen as extremely aggressive, leading to additional clinical complications for the child, which lead them to seek help from the Emergency Room. At the same time, it is seen as a necessary means of achieving a cure.<sup>19</sup> The hospital is understood as an undesired place, acceptable only when there is no other possibility for improving the situation.<sup>6</sup>

The account below highlights the meaning of health and illness in the perception of the children. During the phases of the illness's exacerbation, or the appearance of the toxicities of the treatment, the child sees herself as ill. This means that she does not always feel ill, even receiving chemotherapy: [...] *when she's ill, she comes by ambulance* (White – 8 years old).

These findings corroborate other results<sup>12</sup> that show that for the child in a chronic condition, the illness or process of falling ill is linked to pain or some symptom which brings discomfort and inconvenience. The person in a chronic condition learns to live with it and accept it; it means accepting what is given, what is limited and painful, but the human side consists in always remaining open to the future and accepting new possibilities. In the face of this, the chronic condition becomes part of the person's life, whether for a long period or an undetermined period,<sup>20</sup> being faced naturally, that is, in a state of health. The daily life of restrictions comes to be experienced with acceptance and coped with well and, after the adaptation to the diagnosis, the illness ceases to be experienced as something involving great pain and suffering, and comes to be considered a routine situation.

### The process of attending school

Some children manage to continue attending school during the treatment for cancer, which is important for their development. This fact is shown in the account below, as the child feels satisfied to be able to read and attend school on a daily basis. She speaks with pride about her ability to draw, and, because of this, calling attention in the classroom: *I can write because I study. I go to school every day. I do this at school, I draw. My teacher says I draw well. I did a very beautiful drawing and the teacher put it on the board. I'm doing the literacy course* (Purple – 6 years old).

One of the striking characteristics of the school age is the development of a sense of industriousness, productivity, a stage of realization, acquired mainly through formal education, and because of this the children value school and make an effort not to miss it, even though they have a chronic illness. The child obtains great satisfaction from independent behavior, in manipulating her environment, developing the skills necessary to become a useful member of, and a contributor to, her social community.<sup>21</sup>

This is not the reality for all the children who receive oncology treatment; many need to stop attending school due to their low attendance as a result of the inpatient treatment and the toxicity of the chemotherapy. Nevertheless, the children desire to return to school. The return to studying after the treatment ends is represented by obstacles for accompanying the course, and conflicts mark school life, above all in the relationship with the classmates, which can be difficult and lead to demotivation and discouragement, leading to failure to adapt, followed by being held back a year. An example: *I didn't go to class, I spent a year without studying and had to repeat a grade. I'm still behind. I should be in the seventh grade, but I'm in the fifth grade. [...] It was very difficult because I couldn't find a group of friends, I spent too long without studying, it was difficult to fit in with the other children there. But afterwards, everything went back to normal. [...] I made friends with everyone, I already know everyone [...]. When I finished [the treatment], I waited a bit, and the school year started, and I entered school* (Blue - 11 years old).

Time and effort were needed for the child to reintegrate in school. The impossibility of attending school affects school results badly.<sup>6</sup> This context can result in a feeling of inferiority, perpetuated in adult life, affecting self-esteem, with consequences for professional performance and even routine activities.<sup>21</sup> This being so, it is important for the nursing team to consider the child's care in a comprehensive way, concerning themselves with meeting the developmental needs and the child's return to her social environment. Bearing in mind the difficulties found in attending school and coexisting with classmates, as revealed in this study, a closer relationship between health professionals and educational professionals is recommended, so as to ensure the maintenance of formal education and beneficial social coexistence.

Hospital classes are one strategy to avoid breaking the continuity of the teaching-learning process of the chronically-ill child. This environment provides education for hospitalized children and youngsters who need specialized education during this period, or even in the circumstance of their being attended in the day-hospital and at home, this having been obligatory since 2002. In line with the legislation,<sup>22</sup> the child in a situation which stops her attending school has the right to be educated in the period of hospitalization and home education. In the institution where this study was undertaken, there is a well-established school

class; however, it attends only those children who are hospitalized, excluding those who receive outpatient treatment, and there are significant losses, especially for those coping with the more intense adverse effects of chemotherapy.

### Survival after the treatment

There can be uncertainty, insecurity and fear when the treatment is concluded, as the child and her family cease attending hospital and become distant from the people and the health team, who were present during the treatment and who, in a certain way, made them feel safe. The follow-up phase is undertaken through spaced appointments for monitoring the child's clinical condition and as time passes, the interval between appointments increases: [...] *after, you go through reviews to see how the illness is* (Blue - 11 years old).

It is important that the nursing care should not cease along with the treatment. Even after it stops, the child and family need the team's attention.<sup>23</sup> Some physical and psychological sequelae can continue, and, therefore, need attention just as they did before, for the social reinsertion of the child and her family, seeking to overcome possible limitations resulting from the previous illness. Surviving the treatment is related to coping with and adapting to how the child coexists with the chronic condition, her concerns with recuperating health and her prognosis and how they seek to get back her routine and plan the future.<sup>2,6</sup>

### FINAL CONSIDERATIONS

This study revealed the trajectory travelled by the children, according to their own statements, on their routine of oncological treatment from the period of diagnosis until after the end of treatment, as cancer survivors. A precocious maturity was shown which is a characteristic of the chronic condition, through the children's comprehension of the different phases of the treatment and coping with the difficulties of coexisting with classmates after the end of the treatment.

The children, in narrating the story of a child with cancer, brought to light their experience during the treatment, their perception of the world, the universe and the everyday which they experienced as cancer patients. They showed different issues, content and schemes which were or are part of their route in the fight against the cancer, in the quest to be cured, to overcome the illness and the side effects of the treatment, and to

achieve reinsertion into society. It was ascertained that they create a character and that the stories are initially narrated in the third person – and that as the facts progress, the story shifts to be narrated in the first person. There are moments of confusion between the ‘I’ and the characters created in their stories. The material produced establishes a direct relationship between the history experienced and the story created. This study’s development made it possible to understand the children’s experience, each one bringing the world as she experienced it as a person with cancer.

Because of this, caring for the child with cancer means dealing with a human being and her family in a situation of great fragility and physical, emotional and social vulnerability. In addition to the technical and scientific competence needed to act and to understand the physiopathology of the illness and its treatment, this demands of nursing a competence in interpersonal relationships and in the spiritual sphere, with sensitivity to perceive the individualities and specific characteristics of each being, in the face of what seems to be equal and systematized – the cancer treatment. The nursing care for this population is not limited to the clinical protocols. It is the role of the nurse to assess how much the child and her family are affected by the impact of the diagnosis, the aggressive therapy, and the return to normal life after the treatment finishes, identifying their ability to cope with the difficulties, and supporting them in the discovery of new ways of leading their lives in this process.

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