

Existential experience of children with cancer under palliative care

Experiência existencial de crianças com câncer sob cuidados paliativos

Experiencia existencial de niños con cáncer bajo cuidados paliativos

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ABSTRACT

Objective: To understand the existential experience of children with cancer under Palliative Care from the Humanistic Nursing Theory's point of view. **Method:** This is a field and qualitative research, in which eleven children participated, supported by the Support Centre for Children with Cancer in Paraíba State. To collect data it was used the Story Drawing Procedure. The data were qualitatively analyzed based on Humanistic Nursing Theory. **Results:** From the analysis of the empirical study's subject, the following thematic categories have emerged: children experiencing fear, sadness, anguish and insecurity in the face of their diagnosis and children experiencing fear of their family falling apart because of the possibility of dying. **Conclusion:** It is fundamental the participation of nurses in the Palliative Care to the children with cancer in order to strengthen the trust between the children and the professional to have the relationship of dialogue as central axis.

Descriptors: Children; Nursing; Palliative Care; Cancer; Nursing Theory.

RESUMO

Objetivo: Compreender a experiência existencial de crianças com câncer sob Cuidados Paliativos à luz da Teoria Humanística de Enfermagem. **Método:** Trata-se de uma pesquisa de campo, com abordagem qualitativa, da qual participaram onze crianças acompanhadas pelo Núcleo de Apoio à Criança com Câncer na Paraíba. Para a coleta de dados, utilizou-se a técnica do desenho-estória. Os dados foram analisados qualitativamente com base na Teoria Humanística de Enfermagem. **Resultados:** Da análise do material empírico do estudo, emergiram as seguintes categorias temáticas: crianças vivenciando sentimentos de medo, tristeza, angústia e insegurança diante do seu diagnóstico e crianças vivenciando o temor da separação de suas famílias diante da possibilidade de sua finitude. **Conclusão:** A participação da enfermeira nos Cuidados Paliativos à criança com câncer é fundamental para fortalecer a confiança entre a criança e o profissional, tendo como eixo central a relação dialógica.

Descritores: Criança; Enfermagem; Cuidados Paliativos; Câncer; Teoria de Enfermagem.

RESUMEN

Objetivo: Comprender la experiencia existencial de niños con cáncer bajo Cuidados Paliativos a la luz de la Teoría Humanística de Enfermería. **Método:** Se trata de una investigación de campo, con abordaje cualitativo, en la que participaron once niños acompañados por el Núcleo de Apoyo al Niño con Cáncer en el estado de la Paraíba. Para la recolección de datos se utilizó la técnica del dibujo-historia. Los datos fueron analizados cualitativamente con base en la Teoría Humanística de Enfermería. **Resultados:** En el análisis del material empírico del estudio, surgieron las siguientes categorías temáticas: niños experimentando sentimientos de miedo, tristeza, angustia e inseguridad ante su diagnóstico y niños experimentando el temor de la separación de sus familias ante la posibilidad de su finitud. **Conclusión:** La participación de la enfermera en los cuidados paliativos al niño con cáncer es fundamental para fortalecer la confianza entre el niño y el profesional, teniendo como eje central la relación dialógica.

Descriptorios: Niños; Enfermería; Cuidados Paliativos; Cáncer; Teoría de Enfermería.

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INTRODUCTION

"Cancer" diagnosis affects the way people live, being considered as a very bad experience, causing them physical and emotional changes due to the fear of the unknown, the pain, the disfigurement, the self-esteem loss, among other important changes in their way of living⁽¹⁾. When this diagnosis is discovered in children, this experience provides quick and intense changes as in the children's life as in their family's life.

Child cancer diagnosis, when it is no longer possible to cure, is perceived by the children as a devastating experience, directly impacting on its evolutionary process, which requires deep adaptation to the various changes that affect them in their daily lives⁽²⁾. For the children, childhood is a phase of discoveries and games, which brings with it the expectation of a healthy and happy future. However, it is lost in the uncertainties and anxieties triggered by the impact of the diagnosis of the disease and the treatment affecting the children in their physical, cognitive and psychosocial aspects, according to a study conducted in Sweden in the city of Lund with 15 children with cancer⁽³⁾.

The disease also results in changes in habits, restrictions, isolation, and distancing from routine activities such as playing, recurrent hospitalizations, which cause intense suffering and the most varied feelings, such as fear, sadness, uncertainty, and others⁽³⁾. In addition, it imposes the children to the exhausting need to be in search of care in health services that are unknown and scaring to them⁽⁴⁾.

Notwithstanding, the treatment of child cancer is considered an aggressive therapy with serious side effects for the children, with implications in their daily dynamics in the face of long or frequent periods of hospitalization, causing suffering for the children due to the separation of family members.

Due to the increasing number of children in pediatric services with non-curative sicknesses, the World Health Organization (WHO) and the European Association for Palliative Care (EAPC) have determined that children who have diseases or conditions that threaten or limit their lives have the right to receive palliative care. In this context, Pediatric Palliative Care is defined as care actions aimed at them and their family offered by a multidisciplinary team at all levels of health care, from home to the hospital⁽⁵⁻⁶⁾.

Pediatric Palliative Care should be adopted from diagnosis to the grief stage, when it is present, being concomitant with the curative assistance and covering the physical, mental and spiritual dimensions of the children and their family, guaranteeing their autonomy and dignity.

Palliative Care in Pediatric Oncology should not be limited to performing procedures, especially the emotional component, reciprocity, good communication, dialogue, authentic presence, cognitive aspect of perception, knowledge and even intuition, developing ability to help children and their family to find their potential and recognize their needs related to human well-being and values, helping them to cope with the existential situation experienced⁽⁷⁾.

So, because the nurses are members of the Pediatric Palliative Care team, and spend most of their time in the provision of their care, they must provide the children and their family with care based on a humanistic vision, based on respect for

beliefs and values of the children and their family, in their physical, psychological, spiritual and social aspects.

In this context, it is very important that the professionals seek to support their care to the the children and their family based on a nursing theory, such as the Humanistic Nursing Theory, which is dialogical in its theoretical and practical aspects. This dialogicity involves the encounter, which corresponds to the possibility of waiting for someone to attend (nurse and being cared for); the presence (of the nurse) regarding the quality of being receptive and reciprocal to another person (being cared for); the relationship, in which one goes toward the other, allowing the authentic presence (of the nurse to being cared for); and a call and a response, which are announced in the form of verbal and non-verbal communication, in the caring (from the nurse to the person assisted and from being cared for by the professional)⁽⁸⁾.

To use the theoretical support of this theory, it is necessary to resort to the meanings about the Phenomenological Nursing method, which enables the investigation of the Nursing event itself, that is, of nursing care when being cared for, from the development of the relationship of dialogue between its involved ones (nurses and being cared for). It should be emphasized that this method can be applied to the care, teaching and research in Nursing and can be developed in five stages⁽⁸⁾, which will be explained in the methodology of this study.

In this perspective, the being that cares for and that which is taken care of live in two distinct but related worlds: the inner world - ME - and the external world - YOU - characterized by the ME-YOU relationship (emphasizes the knowledge and respect of the singularity, both of the nurse and of being cared for, in the development of an intuitive relationship, respecting their singularities, through an authentic presence), ME-IT (it is the result of the man's reflection on the relation ME-YOU) and ME-US (provides personal formation through the influence of family, community and society)⁽⁸⁾.

Although Palliative Care in Pediatric Oncology is a practice of extreme care, especially when based on nursing theories, it is reported in the literature, nationally and internationally that there is a small number of studies that address such care to children who need them^(7;9). Such evidence consolidates the importance of new studies that can expand the dissemination and the socialization of knowledge about the addressed subject.

As such, this study started with the following guiding question: how does the existential experience of the child with cancer under palliative care occur?

OBJECTIVE

To understand the existential experience of children with cancer under Palliative Care based on the Humanistic Nursing Theory.

METHOD

Ethical aspects

The study was initiated after approval of the research project by the Health Sciences Center Research Ethics Committee of the Universidade Federal da Paraíba - CEP/CCS. Its

development followed the directives and norms regulating the research with human beings, arranged in the Resolution 466/2012⁽¹⁰⁾ in force in the country. It should be emphasized that, because it is a question of research with children, besides presenting the Free and Clarified Consent Term to those responsible, the child was given the consent term, as recommended by the international guidelines of The Council for International Organizations of Medical Sciences (CIOMS) and the Child and Adolescent Statute, emphasizing that the consent of the child and the adolescent should be obtained for their participation in research⁽¹¹⁾.

Type of study

This is a field and qualitative study based on the Humanistic Nursing Theory.

Study scenario

The research was conducted in a non-governmental institution, located in the city of João Pessoa - PB, considered a reference in this State in the care of children and adolescents with cancer, from zero to nineteen years and their companions, whether or not under Palliative Care.

Data source

The total number of participants was not stipulated a priori; and was therefore defined throughout the research process, according to the sufficiency criterion, that is, when the empirical material analyzed allows us to delineate a comprehensive picture of the investigated question⁽¹²⁾. Thus, there is a sample of the study with eleven children with cancer under Palliative Care.

The inclusion criteria were: children having a diagnosis of any type of cancer without therapeutic possibilities of cure for more than 6 months and was being followed at the institution; being aware of their diagnosis; being in the institution during the period of data collection; have a school age range, between seven and eleven years. The choice for this age group is due to the fact that at this stage they are in the intellectual conditions to better understand their body and their disease; having the physical conditions to participate in the interview and to communicate verbally, to draw and to play.

In order to evaluate the physical conditions of the participating children, the Eastern Cooperative Oncology Group (ECOG)⁽¹³⁾, which establishes the scores from 0 (zero) to 4 (four) (PS 0 to PS 4) was used. with zero representing the patient with normal activity and four classifying it as restricted to the bed⁽¹³⁾. Thus, as exclusion criteria in the selection of participants, we adopted children with PS 3 and PS 4 scores, that is, those who were more dependent; children with visual impairment due to the impossibility of performing the drawing, an essential criterion for the design of the story technique.

Collection and data organization

The procedure for collecting the empirical material was carried out from June to September 2013. It is worth mentioning that the researcher's approach to the children participating in the study occurred two months before the beginning of the collection itself through play activities of a project of in which

the researcher is a part. This project aims to develop playful activities with children with cancer and thus contribute to their growth and physical, social and spiritual development, soothing the situations of pain and suffering in the face of the situation experienced.

For the collection of data, the technique of drawing-history with the theme, which consists of the junction of expressive-motor processes (the drawing), perceptive-dynamic processes (thematic verbalizations) and directed associations of the type inquiry (interview)⁽¹⁴⁾. This is a resource through which the child has the possibility to produce speeches about everything that involves his life, his history, his world view and reveals his own way of seeing and thinking reality⁽¹⁴⁾.

It should be emphasized that the analysis of the stories told by the children was made, since the drawing is established as a triggering cause of the dialogue with the child, and is therefore used in this research as an illustration of their experience. The adaptation of the technique was considered as material for interpretation only the reports, excluding design, since the training of nurses is not directed at their interpretation.

The data collection took place individually, on the morning shift, in the toy library of the institution, exclusively reserved in this collection period to the researcher. It was as follows: when entering the toy room, the researcher warmly welcomed the child, trying to know how the child was; then invited to sit next to a table and sat down in front of the child. As soon as the interaction was initiated, the researcher placed 12 colored pencils and one colored pencil on the table along with a sheet of paper. Next, the child was asked to draw a free drawing. After the conclusion, it was asked: "You, now, looking at the drawing, can create a story, telling what happens." On this occasion, the researcher asked for clarifications necessary to understand and interpret the material that was produced both in drawing and in history, in order to deepen the content addressed by the child.

Later, the child was invited to draw a child with cancer and upon completion, it was asked: "Can you tell the story of a boy who discovered that he had cancer?". After the storytelling phase, the "inquiry" was over. In this, the following guiding questions were used: "What have children felt when they learned that they had cancer? "What has changed in the children's life after the sickness?"

The technique was used in order to understand the children's perception of the theme through the encouragement of telling the stories through the drawings. It should be noted that the whole procedure was recorded and transcribed in full after the child's authorization, as well as the person responsible.

The stories began by being referred to a fictitious child, but in the process of collecting data, the person began to speak of themselves, making this movement of the other and of themselves⁽¹⁵⁾. It is noteworthy that the technique of drawing-history, in all its phases with each child, lasted for up to two and thirty minutes at most.

It is important to note that in order to maintain the anonymity of the children enrolled in the study, a coding was adopted from the children's chosen colors: blue, yellow, orange, brown, pink, black, red, green, violet, gray and beige.

Data analysis

The analysis of the empirical material was carried out through the five phases of Phenomenological Nursing, in light of the Humanistic Nursing Theory⁽⁸⁾, elucidated below.

1. Preparation of the cognoscent nurse to come to know - The researcher sought to reflect, from her own point of view, her way of being and acting, both in her personal life and in her professional practice, from reading literary works and that were about the essence of the human being. This phase provided the nurse researcher with a better understanding of her, as well as to recognize the other in her care actions.
2. The nurse intuitively knows the other - Inserted in the field of study, the researcher has dedicated herself to the process of self-knowledge, being aware of the very conception and at the same time open to the points of view of others. In this phase, the technique of drawing-history was used, for which guiding questions were proposed.
3. The nurse knows, scientifically, the other - At this stage, there were several successive readings of the children's stories, searching for their meanings. Next, the corpus is constituted, where repeated readings were made, in a constant coming and going between theory and analysis, in search of understanding its meaning so that possible categories could be identified.

Through this identification, the possible categories were related and interpreted by analyzing the categories that characterized the stories told by the children, with the purpose of adding the knowledge of the experiences experienced in the previous phases, comparing their conformities and distinctions, synthesizing them.

1. The nurse synthesizes the known realities in a complementary way. In this phase, the researcher contrasted and summarized the multiple realities now known, and in comparing the realities found, she synthesized them in a

complementary way to the different revealed truths, broadening her vision about the investigated phenomenon.

2. Succession of the multiple to the paradoxical unit as an internal process of the nurse - The researcher, through reflection and analysis, expanded her own point of view so that she could get a deeper understanding of the investigated phenomenon, also having as a foundation the specific literature for the study.

From the analysis, the following categories emerged: feelings of children with cancer under Palliative Care; importance of the family and the dialogic relationship for children with cancer under Palliative Care.

It is worth mentioning that, in order to allow a better understanding of the study design, collection of empirical material, analysis and interpretation of data, the criteria recommended in the Consolidated Criteria for Reporting Qualitative Research (COREQ) as a support tool⁽¹⁵⁾. These criteria are contemplated in 32 evaluation items in the conduction of qualitative studies.

RESULTS

The study sample consisted of eleven children. Of these, five were females and six males. Their diagnoses were: leukemia (6), lymphoma (2), osteosarcoma (1), nephroblastoma or Wilms tumor and ovarian cancer (1).

Regarding the treatment phase, the eleven children were undergoing chemotherapy and four were also submitted to radiation therapy. Three were also submitted to surgery. All were on monthly follow-up. The shortest diagnostic time was seven months, and the longest was two years. These data are presented below.

To illustrate the presentation of the results, some excerpts from the children's speeches were selected and the following standardization was used: the brackets with ellipses [...] mean suppression in the speeches made by the researcher; the parentheses () are filled with intercalations of the researcher with the intention of contextualizing what was spoken by the children.

Chart 1 – Characterization data of the children participating in the study, João Pessoa, Paraíba State, Brazil, 2014

Name	Age	Gender	Diagnosis	Treatment	Diagnosis Time
Blue	11	M	LLA	QT	January 2012
Yellow	8	M	LLA	QT	February 2013
Orange	11	M	LMC	QT	October 2012
Brown	7	M	LLA	QT	March 2012
Pink	10	F	LLA	QT	January 2012
Black	7	M	LLA	QT	December 2012
Red	11	M	Osteosarcoma	Surgery and CT	December 2012
Green	11	F	Wilms Tumor - nefroblastoma	Surgery, CT and RT	April 2012
Violet	11	F	Hodgkin Lymphoma	CT and RT	May 2011
Gray	10	F	Ovarian Cancer	Surgery CT and RT	February 2012
Beige	7	F	Hodgkin Lymphoma	Chemotherapy and RT	June 2011

Note: Acute Lymphocytic Leukemia: ALL; Chronic Myeloid Leukemia: CML; Chemotherapy QT; Radiotherapy: RT; F: female sex; M: male gender.

It should be noted that in the testimonies of the children participating in the study, two categories were presented: 1) children experiencing fear, sadness, anguish, and insecurity about their diagnosis; 2) children experiencing fear of their family falling apart because of the possibility of dying. The aforementioned categories came from the children's reports in the face of their existential experience, where they presented the way they perceive their feelings on the occasion of the discovery of their diagnosis, sometimes identifying themselves as a character in the story, or indirectly through projection, through of the drawing, making mention of a subject-other, referring to the child of the drawing made.

Children experiencing fear, sadness, anguish, and insecurity about their diagnosis

In this thematic category, the subject-children with cancer involuntarily enter a different context, in which through their difficult experience they express their feelings with the advent of the disease, which provoke different reactions, according to their following reports:

She [the child] has a crying black eye. She didn't want to get sick, it's too bad, it was a shock to her. (Red)

I was anxious for what could be worse, still happen [...]. It isn't a good experience [...]. (Blue)

It was really bad, I never thought it would happen to me, but it happened. It's not easy, it's very sad, [...]. (Green)

I felt sadness, a lot of sadness; it's a very difficult experience. (Violet)

[The child felt] a lot of sadness, because I thought I would never have it, this disease [cancer]. I thought it was never going to happen to me. (Grey)

It was difficult, she [the child from the drawing] was sad, she cried a lot. (Beige)

The cancer makes me feel fear and much sadness, anguish [...]. (Black)

It was a shock, right? Sometimes I wonder if it's either a nightmare or not, it's very bad, [...]. (Orange)

She was desperate. It's a bad experience, which seems to have no end, is a lot of suffering. (Brown)

I felt a lot of insecurity, fear too. This disease [cancer] is bad. (Yellow)

I felt fear, insecurity of what is yet to come. I cried a lot, I wanted to scream for help [...]. (Pink)

Children experiencing fear of their family falling apart because of the possibility of dying

Children going through a process of severe and uncertain disease and representing the unknown perceives death itself, in a direct way, which brings fear. This causes them anguish

and suffering, especially for the treatment and separation of their parents and siblings, when hospitalization is necessary, as these reports show:

I felt sadness, fear, I thought I would die and not see my parents and brothers anymore, when I am with them, I feel strong, you know? (Yellow)

I thought I wasn't going to grow up, go on in life, have my family to guide me. I think a lot about my family. (Blue)

I thought I was going to stay away from my family when I went for treatment. With my family close, I feel lighter; it seems that the treatment is shorter. (Black)

I was afraid to die, and not having my mother and father next to me, it is difficult [...]. (Beige)

I was afraid of not having the other day and not seeing my family any longer [...]. (Orange)

She felt fear, [child], fear of not living longer and staying away from her family. (Red)

I was afraid of dying, of not waking up and seeing my family. (Green)

I was very sad, I thought I would die and stay away from my family. (Violet)

I thought I was going to die, I got a sick feeling in my stomach, you know? (Brown)

A bad agony, [I felt] too bad, because I was afraid of not seeing my father and my mother any more. (Grey)

I felt something very bad, it made me very sad, you know? (Pink)

DISCUSSION

The importance of the Humanistic Nursing Theory applied in the practice of palliative care in pediatric oncology lies in the fact that it perfects and guides this nurses practice in an existential way, since this theory is based on the encounter and the authentic dialogue between who cares and who is caution.

A study in southwestern Canada with children with cancer undergoing Palliative Care revealed the frailties resulting from treatment, such as decreased self-esteem, suffering, fear, distress, insecurity and sadness. Being with cancer is for the children and their family to experience daily an overload of negative feelings and emotions, is to have the uncertainty of a future and the certainty of finitude, which every day seems closer. Therefore, the anguish of living in favor of a disease without therapeutic possibilities of cure associated with the suffering resulting from the treatment causes the need for a care that allows the children to feel full again in the face of their limitations, that is, that it has a Palliative Care assistance⁽¹⁶⁾.

Being with a life-threatening sickness, since its discovery, is portrayed in the speeches of the participating children in a

unique and shocking way. The discourse of the association of cancer with negative feelings of grief, distress, sadness, fear, anguish and despair. They still bring in their speeches emphatically the uncertainties and insecurity of being in an unknown world where pain and suffering arise in their lives in an unexpected way and without an end perspective.

In the meantime, it is necessary for the children to always have as a *presence*, someone who accepts, supports and comforts them, since "a person is free to be and to become, to control and to plan his own destiny, according to his potential at a particular moment and in a particular situation"⁽⁸⁾.

In this sense, from the establishment of a trust relationship between ME-YOU and ME-IT, which happens at the same time and permeates every care process, the nurse can become the presence that the children need, either when it is requested by this through the *call* or in situations where the professional or the family member deems important. For the development of this study, such a relationship was established, through the *encounter* and the genuine *presence* between the researcher (nurse) and the participating children.

The *presence* and the *encounter* also permeate the relationship between ME-US, that is, the relationship of care between the child and the health team. Such care is characterized in the Humanistic Theory of Nursing as a mediation that occurs among its peers, that is, among the microsomes of their communities that would be the children, relatives and health professionals, especially the nurse⁽⁸⁾. Thus, both the ME-YOU relationship and the ME-US relationship are represented by the commitment of all caregivers to provide a true therapeutic encounter for the children's well-being.

This is an international study based on clinical evidence on Pediatric Palliative Care, with nurse practitioners in Palliative Care, presented in its results that once the child experiences this care, it should be accompanied by people who allow full care, respect their uniqueness and preserve their value⁽¹⁷⁾. This evidence reinforces the importance of nurses' humanistic care. This finding was ratified by a study on the Humanistic Nursing Theory, since its care in the care of the child is surrounded by inter-related, shared, strengthened and experienced feelings among caregiving patients⁽⁹⁾.

International studies with 43 pediatric patients at a large university medical center in the southern United States highlighted the psychological factor among the many factors experienced by children with cancer as having a strong impact and causing emotional traumas and feelings of sadness, anguish, sadness, fear and insecurity, which will be significant in their life⁽¹⁸⁾. These factors are related to their cognitive development, past experiences and level of knowledge, permeated by uniqueness, when perceiving the dimension that the disease has in their life and the way it is lived, which corroborates the findings of this study.

In the Humanistic Nursing Theory, it is understood that the palliative approach involves the establishment of an intersubjective transaction embodied in an existential encounter between caregivers and caregivers, allowing the individual beyond therapeutic possibilities - in this case, the child - to share their feelings, afflictions, pain and frailty. In this sense, a

study on Humanistic Nursing Theory reveals that the essence of this theory is the valuation of the existential experience of the human being⁽⁹⁾. Therefore, this approach to care should be considered a priority in Pediatric Oncology services.

The experience of being diagnosed with a disease, such as cancer, which has an uncertain pathway and prolonged treatment, is expressed in children's discourses from the social representation attributed to the disease in the sociocultural context where the child is inserted. Children still express their families' longing, including father, mother and siblings, as well as fear and sadness about the uncertain future.

A study carried out with children with cancer undergoing palliative care in a large university center in the southern United States revealed that they have a significant impairment of their quality of life, associated with negative psychosocial consequences, related to the feelings that are shown by them in the fear of death and that come to the encounter of the rupture of future before the interruption of life trajectory. Another study developed in the United States shows that the physical, psychological, social and emotional aspects as well as the school performance are strongly compromised in these children, resulting from the bad and painful experiences they face during and their sickness process, in a space of a short vital time, but which for them is painfully prolonged in the face of suffering. Thus, the child with cancer with no therapeutic possibilities of cure becomes the possessor of a short past, a painful present and an uncertain future marked by plans and dreams left behind, which at the moment have been totally or partially destroyed⁽¹⁸⁻¹⁹⁾.

In Humanistic Nursing, the nurse must be willing to *be with* and *be there for* the children with cancer without therapeutic possibilities, which allows him to properly appreciate the situation lived to promote alternatives to their well-being and to develop their being better⁽⁸⁾.

A research⁽⁷⁾ points out that care should be centered on the relationship between children and their family, since the children's perception of their well-being and health is strongly influenced by the feelings of their family members. In addition, it is in the family intimate that children find strength and perseverance to continue with the treatment, being able, thus, to feel safe during all the weather caused by the disease and its treatment.

Therefore, the importance of the family nucleus is evident, especially in stressful situations like living with cancer. This fact is exposed in a study⁽¹⁸⁾, which affirms that the family is fundamental for the child in facing the disease, since this happens to have more confidence in parents, faced with difficult situations arising from incurable disease, because these inspire you with love and protection, and this minimizes the fear of the unknown.

In the highlighted testimonies, it is evident that from the absence of treatment that allows the reversal of the pathological picture of a person, in this case, the child, Humanistic Nursing suggests that the nurse should promote a genuine encounter with the patient, and provide a environment of reception, listening and understanding of their emotions, which can be present in a differentiated way in each child, establishing a relationship with this one based on authentic care⁽⁸⁾.

The emotional story of the children, who pronounce to miss their family, is plunged into emotion and feelings inter-related, shared, strengthened and experienced between the nurse and children during the encounter experience, from an intersubjective relationship.

The impact of the disease on experience brings anxiety in children and thus the feeling of impotence and not being prepared for what will come becomes stronger from the moment the children expresses their sensitivity⁽¹⁶⁾. As a result, it is essential that palliative care be extended to parents and their families throughout the care process, even after the child's death and more intensely⁽³⁾.

It is observed, therefore, in the two analyzed categories, that the presuppositions of Humanistic Theory are in line with those of the philosophy of Palliative Care, since they recognize each being as a singular existence in their illness situation, so that the patient, in this case, the child apprehends the meaning of this circumstance in the development of the illness process, and includes his family in the relationship of care, based on the dialogical relationship, that can directly interfere in his health-disease process, as evidenced by a research with nurses on care for children with cancer, based on Palliative Care⁽⁷⁾.

Study limitations

The study presents limitations, such as the data related to a specific experience, and can not be generalized, and the incipience of national and international empirical data suggests the carrying out of new investigations, aiming to raise the knowledge on the subject so that new elements can emerge in order to support the practice of Palliative Care based on the Humanistic Theory of Nursing to the child with cancer.

Contributions to the Nursing

The study contributes to the improvement of the scientific knowledge of Nursing in order to reduce the existing gap in the national and international literature regarding the topic of

Palliative Care directed at children with cancer in the light of the Humanistic Nursing Theory. In addition, it also contributes to support the practice of this care based on Nursing Theories to the child with cancer.

Thus, this study makes it possible to open spaces for discussion among care nurses, who deal directly with the child with cancer, and the teaching nurses, linked to higher education institutions, in a proposal to articulate theory and practice, in the perspective of find new ways of thinking and acting in the care of children with cancer under Palliative Care.

Such articulation is necessary in view of the fact that this dialogue facilitates the confrontation of knowledge among those involved, contributing greatly to the growth of Nursing as a science and, consequently, opening new horizons in the field of nursing care and teaching, with the purpose of to provide this clientele with a humanistic care, emphasizing Nursing as an existential experience that respects the uniqueness and limitations of each care being, in an authentic way.

FINAL CONSIDERATIONS

Nursing is a lived dialogue, through which the nurses' care with their patient occur from the experience of the encounter, the presence, the relationship of dialogical exchanges, the call and the response. The evidences of this dialogue appeared in the discussion of the categories through the affirmations of authentic care, which is based on the demonstration of respect, attention, zeal, affection and sensitivity in being genuinely with the other, that is, the nurse and with cancer.

The results of the study pointed out that Palliative Care for children may occur among all those involved in the process. Directly or indirectly, they constitute effective care for the children and their family who experience the process of being with a limiting illness of their life, and are therefore fundamental for the promotion of Humanistic Nursing care.

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