EXPERIENCE OF CHILDREN WITH CANCER UNDER PALLIATIVE CARE IN A SUPPORT HOUSE

VIVÊNCIA DE CRIANÇAS COM CÂNCER SOB ASSISTÊNCIA PALIATIVA EM UMA CASA DE APOIO

LA EXPERIENCIA DE NIÑOS CON CÁNCER EN CUIDADOS PALIATIVOS EN UNA CASA DE APOYO

ABSTRACT

The diagnosis of cancer triggers a series of stressful and painful experiences for the child and his/her family as it involves prolonged and painful treatment. In this perspective, living in a support house becomes an option to guarantee and facilitate the access of children to curative and palliative treatment, when their families do not live near the hospital. Thus, this study aimed to understand the experience of children with cancer in palliative care in a support house in the light of Human Caring Theory. A qualitative field study carried out with eleven children, chosen by sufficiency criteria, who were hosted at the Support Center for the Child with Cancer. For the data collection, an adaptation of the technique of the story drawing was used, in which the statements were recorded and later transcribed. The analysis was done through the content analysis technique and in light of Human Caring Theory. From this, two categories emerged. These results allow concluding that play, caress, attention, and dialogue, as well as a welcoming environment, become fundamental tools in coping with the disease by the child, aiding him/her during all the experience in the support house.

Keywords: Palliative Care; Child; Neoplasms.
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RESUMEN
El diagnóstico de cáncer desencadena estrés y mucho sufrimiento para el niño y su familia, pues es un tratamiento prolongado y doloroso. Desde esta perspectiva, vivir en una casa de apoyo es una opción para garantizar y facilitar el acceso de los niños a un tratamiento curativo y paliativo cuando sus familias no viven cerca del hospital. Por lo tanto, el objetivo de este estudio fue comprender la experiencia de niños con cáncer en cuidados paliativos en una casa de apoyo a la luz de la teoría del cuidado humano. Estudio de campo de naturaleza cualitativa con la participación de once niños alojados en un centro de apoyo a niños con cáncer, elegidos por criterio de suficiencia. Para la recogida de datos se utilizó una adaptación de la técnica dibujo – cuento, donde se registraron las entrevistas, posteriormente transcritas. El análisis se realizó utilizando la técnica de análisis de contenido a la luz de la teoría del cuidado humano. A partir de este análisis surgieron dos categorías. Estos resultados permiten concluir que los juegos, el cuidado, la atención y el diálogo, así como el ambiente acogedor, se convierten en herramientas clave en la lucha contra la enfermedad y que ayudan al niño en su experiencia en la casa de apoyo.
Palabras clave: Cuidados Paliativos; Niño; Neoplasias.

INTRODUCTION
Cancer is highlighted among the chronic diseases that threaten the child’s life. In childhood, the most common types of cancer are leukemia, brain tumors, lymphomas, kidney tumors, sarcomas, among others. At this point, childhood cancer represents 1 to 3% of all cancerous tumors in most populations.1

Statistics show that there were 394,450 new cases of cancer in the pediatric age group, in Brazil in 2014, excluding non-melanoma skin tumors. The incidence in Brazil of children and adolescents up to 19 years old with cancer is close to 3% of all cases. Therefore, there will be 11,840 new cases in this population. The Southeast and Northeast regions had the highest number of new cases with 5,600 and 2,790, respectively, followed by the South (1,350), Midwest (1,280) and North (820).2

Like any other serious illness, the diagnosis of cancer leads to a series of stressful and suffering experiences for the child and his family since it involves a prolonged and painful treatment, requiring care and changes, which in turn are not arising only from the progression of the disease, but from the chronic condition, considering the social, emotional, affective, cultural and spiritual aspects, consequently causing problems in the life of the child and his family.3 This becomes more impacting when the child finds out of therapeutic possibilities of cure, as in palliative care.

Palliative care is understood as an approach offered to the patient out of healing possibilities and to his family, seeking to provide them the best possible quality of life through accurate assessment and effective treatments for pain relief and other symptoms as well as suffering due to their illness, being of a physical, psychosocial and spiritual nature, to promote comprehensive interdisciplinary care, from diagnosis to the mourning phase of the family.4,5

In pediatric care, palliative care involves active and total care, considering the absolute condition of the child, his body, mind, and spirit, and his action must begin at the time of diagnosis of the disease, independently of being accompanied by a curative treatment.6,7 One of the modalities of palliative care is palliative assistance, which is aimed at meeting the patient’s needs in the biopsychosocial spheres, based on humanization.

Thus, care based on empathy, compassion, human interaction, that is, on the Me-Other relationship becomes essential for the effectiveness of palliative assistance in Pediatrics, since it allows the child to be perceived and understood in its entirety.7

In this context, the child is submitted to hospital treatment as part of the therapy. Hence, hospitalization becomes a potentially traumatic experience in the patient’s life, because it distances him from the family environment, promoting confrontation with pain, physical limitation and passivity, feelings of guilt, punishment, and fear of death.4 Thus, accompanied by his relative or caregiver, the child needs to perform the treatment, submitted to chemotherapy and radiotherapy sessions, and the need for periodic medical visits. This experience may become even more distressing when they have to travel from their home city to carry out outpatient treatment, needing to stay in family or supportive homes.

Brazil has philanthropic entities that aim to support cancer patients and their families. Is The Children’s Homes with Cancer an example of a philanthropic entity, which offers the opportunity for specialized treatment when it does not require hospitalization, characterizing an outpatient therapy.8 The opportunity to stay in a support house facilitates access of the child to treatment since in many cases the families do not have the financial conditions for travel and hospitalization. During the life in support houses, the child has the opportunity to build friendships, which can be a support for this phase that he is experiencing.9

It is notorious that when a child gets cancer, his life goes through a rapid and intense transformation, regardless of his age and capacity for cognitive understanding of the reality that surrounds him.8 Thus, from the signs and symptoms, stigma, and limitations, the contact of the child with cancer as well as with the people he meets during the treatment and healing process, greatly influences how he experiences and lives the adversities of becoming ill. To understand how the child experiences these changes, it is important to adopt a theoretical reference, such as the theory of human care. From this theory, it is possible to connect to the subjective, emotional and spiritual world of the child, transcending the dimensions of being.
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through a transpersonal process. This refers to the intersubjective connection that permeates the relationships with oneself, with the other and with the universe in a plan that extrapolates the concrete and the visual in search of the reconstitution of the balance of the human being.10,11

Thus, it is necessary to understand the experience of the child with cancer under the palliative care in nursing homes, to subsidize discussions and strategies applicable to the care of the child and his/her family to alleviate their suffering. Therefore, this study aimed to understand the experience of children with cancer under palliative care, in a support house based on the human care theory.

METHOD

This is a field study of a qualitative nature, based on the theory of human care proposed by Jean Watson. The investigation was carried out in a support house located in João Pessoa - PB, Brazil, considered as a reference in the state of children and adolescents with cancer care, needing or not palliative care, from the interior of Paraíba and neighboring states, who did not have economic conditions to stay in the city during treatment at the state referral hospital.

It should be noted that this institution receives children from a referral hospital in the cancer treatment and palliative care of young infants, following the guidelines recommended by the World Health Organization regarding the care provided to the child outside the therapeutic possibilities of cure.

To have access to the accommodation at the support house, the child must have caregiver person and referral from a hospital presenting his/her diagnosis and treatment, defined by eligibility criteria for palliative care and highlighting the non-adherence to curative therapies and relapse of the disease. This referral is important so when arriving at the hospital to the support house, the children can have a care that meets their physical and psychosocial needs, allowing them a better quality of life.

This institution is a private, non-profit initiative that carries out activities exclusively through donations. Children usually spend weeks in the house while they are being treated at the hospital until they return to their hometowns since many of them reside in the interior of the state.

It should also be pointed out that this study is a pioneer work in the aforementioned support house and the children and their mothers who are there receive the attention of a multi-professional team that develops actions to receive them, in a humanistic approach, as one of the principles of palliative care. This team is trained in the approach to palliative care, specifically in the form of palliative care. Since these children do not clinically present conditions that limit them to the bed, their clinical treatment is at a hospital level.

Considering the qualitative approach of the study, the sample was defined along the research process, according to the sufficiency criterion, that is, when the empirical material analyzed allows to delineate a comprehensive picture of the investigated issue.12 Thus, the study sample consisted of 11 children who were hospitalized in the support house and who met the following inclusion criteria: to be followed up at the support house for more than a year, with a diagnosis of cancer for more than six months that could not be cured; to know their diagnosis; to be older than seven years old, because it is this age that allows better cognitive development so the child reports his experience more clearly.

The exclusion criteria were: children with PS 3 and PS 4 scores, evaluated according to the Eastern Cooperative Oncology Group (ECOG) Performance Status (PS) scale, which establishes the scores from zero to four; zero represents the patient with normal activity and four classifies him as restricted to the bed, that is, those more dependent.13

The study was approved by the Research Ethics Committee of the Federal University of Paraíba, according to protocol 0206/13 and CAAE: 15750313.1.0000.5188. The ethical observances contemplated in Resolution 466/2012, of the National Health Council, were considered, mainly regarding studies involving children, with the application of the consent term for the parent or caregiver and the consent form for the participant.

An adaptation of the technique of drawing-history with the theme was used to obtain the empirical material, which is a combination of expressive motor processes (drawing), dynamic apperceptive processes (thematic verbalizations) and direct associations of the type inquiry (interview). It is a resource through which the child can present his/her history, worldview and his/her own way of seeing and thinking reality.14 This adaptation was taken to consider as material for interpretation only the reports, excluding the drawing because the training of nurses is not directed at their interpretation.

The data collection was carried out from June to September 2014, individually, with each child, in the morning shift, in the toy room of the support house reserved exclusively during this period of collection for the researcher. It was preceded as follows: the child was invited to sit next to a table and the researcher sat down in front of him. As soon as the interaction began, 12 colored pencils and a graphite pencil were placed on the table along with a sheet of paper. The researcher asked the child to make a free drawing and create a story based on the image produced. Clarifications were required for the understanding and interpretation of the design and the story (inquiry phase) to deepen the content addressed by the child. He was asked to draw a child with cancer and tell the story of how he discovered that he had the disease. The investigation stage was followed, using the following guiding questions: “What did this child feel when he learned that he had cancer?” “What changed in the child’s life after the illness?”
As these questions were explored, others were formulated to further deepen the information, such as “Can you explain it better?”, “What do you mean?” The technique was used to understand the child’s perception of the theme through the stimulus of telling the stories. It should be noted that the whole procedure was recorded, after authorization of the responsible person and the child and transcribed in full, soon after its execution, so no details were lost during the research.

The empirical data from the interviews were analyzed using the categorical content analysis technique, which refers to a set of communication analysis techniques, whose purpose is to obtain systematic procedures and objectives of content description and message indicators, which make possible the induction of information on the production categories of these messages, consisting of the following steps: pre-analysis, material exploration, grouping of categories and treatment of results.9

The option of choosing color codenames was offered to the children participating in the study as a way of secrecy and anonymity regarding their identity. The children chose the name of colors: orange, beige, blue, gray, black, brown, green, yellow, violet, pink and red.

The consolidated criteria for Consolidated Criteria for Reporting Qualitative Research (COREQ) were considered as a support tool to allow better understanding of the study design, collection of empirical material, analysis and interpretation of data.15

RESULTS AND DISCUSSION

The study sample consisted of 11 children. Five of them were females and six were males. Their diagnoses were leukemia (6), lymphoma (2), osteosarcoma (1), nephroblastoma or Wilms tumor and ovarian cancer (1).

Regarding the treatment phase, the 11 children were undergoing chemotherapy and four of them were also submitted to radiation therapy. Three were also taken into surgery. All were on monthly follow-up. The shortest diagnostic time was seven months and the longest was two years.

From the analysis of the empirical material, the following categories emerged: playing as a coping strategy for the child with cancer assisted in a support house; the importance of caring, talking and companioning the children with cancer under palliative care in a support house.

PLAYING AS A COPING STRATEGY FOR THE CHILD WITH CANCER ASSISTED IN A SUPPORT HOUSE

Florence Nightingale, in 1859, already emphasized the importance of the healthy environment in the restoration of health. Watson, in his theory, also focuses on the importance of providing a therapeutic environment, but not only a physical structure with mechanism and curative equipment but also a space to live and coexist, to feel and to express.16

Therefore, the support house offers a welcoming environment for the children who are staying and going through an outpatient treatment, hindering to create spaces for playing and games. This reality is poorly understood by the child in the hospital environment, due to several situational factors related to physical structure, playful resources, the clinical condition of the child and availability of professionals for this activity. It is common for children to associate the hospital with a bad environment, where they are away from the family and friends, exposed to innumerable invasive procedures, restricted to an unusual routine of their daily life and with limited possibilities of playing. This reality is implicit in the following discourses:

I think it’s good because there’s no one here to puncture me and I can play with the other guys without taking medicine in my vein and I do not see them crying either [...](Orange)

It’s good here, just not being in the hospital [he silenced and lowered his head]. I play with the other little friends, I get freer, even knowing that I’m in treatment, but it’s different. (Blue)

I think it’s very good, better than the hospital because I can play with the other kids and it makes me stay a bit far from the bad disease. (Beige)

Studies15,19 have shown that activities such as playing and games are important coping strategies because they allow the child to actively communicate and express their feelings, anxieties, and frustrations to alleviate their suffering. Through playing, the child transforms his world and redefines his reality, seeking to soften the suffering of experiencing a life-threatening disease.

Playing allows the child a transpersonal-self, in which he is able to find himself as a developing human being who needs to have his imagination stimulated, his corporal, intellectual and sentimental expressiveness guaranteed, needing of recreation and joy, so he can achieve reflect, associate and understand the situation experienced.16

In Pediatric Oncology, it is imperative that the therapeutic process involves a care that meets the needs of children, with the insertion of play activities. In this context and especially in the face of clinical situations with no more possibilities of cure, playing will enable the minimization of pain, anguish and other negative feelings experienced by the child, as expressed in the speeches below.
When I’m playing, I do not think I’m sick, I just want this playing time not to pass, I could always be playing, it makes me forget the bad disease (cancer). (Grey)

I like it because I have friends, so I remember my little friends from school and from my street that I played. Playing brings me joy, makes me forget my illness more. (Brown)

Childhood is a stage of life with playing as a necessity and main occupation of children. At a time when their lives are tied to traumas such as frequent hospitalizations, treatment-related discomforts, and disease severity, playing is the means by which they rescue the feeling of normalcy, childhood, and the joy of living.

Faced with a frightening reality in which the child is estranged from his or her family and social life, providing a pleasant environment to experience the possibility of interacting and playing with other children can change the way they cope with the disease and interfere in a way in the health-disease process, as some children express:

It’s like a magical tale, when I play I only see a good thing, I do not just think bad things, it makes me very well. (Black)

Playing with us, the games, the video games are really cool. I really like playing cart and that makes me better deal with the treatment. (Green)

It seems that the more I play, the better I get, I cannot even remember that I’m doing the cancer treatment, it’s very good. (Yellow)

I face my illness better here because I play with other friends and the game seems like a magic, when I get sad and start to play, everything is good. (Violet)

In this way, the ludic is a resource that facilitates child care actions under palliative care. It is essential that the multi-professional team recognize and perceive the need to play, seeking ways to achieve it, considering the stage of development of the child to incorporate it in the best way to care.\(^{19,19}\)

Realizing such need requires the caregiver’s sensitivity, attention, dedication, and involvement. Thus, as the child acquires value for the caregiver, it becomes a present being able to develop an authentic care based on the playing and ludic. In this scenario, its presence is paramount in the caring and palliative process, and it is also contemplated in several elements of the theory of human care, presenting intimate relationship to feeling, perceiving and respecting the other.\(^{19}\)

Playing can happen individually or in a group. Individually, the child can use toys or electronic equipment as a form of fun, especially when it is restricted to the bed or has some type of motor limitation. In a group, besides to recreational activity, playing is characterized as an effective form of social interaction, which stimulates the physical, psychic and social development of the child. Thus, playing can be used to "recreate, stimulate, socialize and fulfill the therapeutic function".\(^{19,19}\)

It is recognized that playing has a therapeutic function, especially in Pediatric Oncology, because it promotes joy, tranquility, and safety by establishing a relationship of trust between the child and the health professional. It also requires that it develop empathy to understand the child’s conceptions and identify their real physical, psychosocial and spiritual demands, aiming at a care, whether curative or palliative, based on a care plan that effectively meets the child’s needs in all its individuality.\(^{19,19}\)

It’s good here, I play a lot, I forget something bad [...], I get more cheerful. (Pink)

It is like this, a joy to me that I make this bad treatment to be able to play, I forget more this disease. (Red).

The support house has some volunteers to promote playing and games with the hosted children. Most of these volunteers are students from various areas of health, such as Nursing, Medicine, Nutrition, Occupational Therapy, Physiotherapy, Social Assistance, as well as health professionals linked to an extension project of a federal public educational superior institution, who seek to provide joy and well-being to these children, with the purpose of contributing to the improvement of the quality of life. For children with cancer who are in palliative care, it is imperative that health professionals adopt playing in their daily practice.

In this sense, the support house where this study was developed promotes children’s playing activity, which stands out as an important ally in cancer treatment. However, the reality in hospital institutions is quite different. A study\(^{19}\) carried out in a public hospital in Rio de Janeiro reveals that time is the main obstacle reported by health professionals to promote playing, followed by the physical condition of the child, which imposes limitations and restrictions, causing feelings of sadness, anger and decrease the will to play.

In this context, playing and games meet the elements that underlie the theory of human care, because they provide a healing environment, promote the self and expression of feelings for the child, allow the professional to be present and provide creative care, benevolent and authentic relationship based on the respect, dignity, and needs of the child in an integral way.\(^{19}\)

Based on the above, playing brings aspects consonant to the palliative philosophy and the theory of human care, considering the child in its multidimensionality, able to provide a humanized...
and sensitive care based on empathy, so the child feels welcomed, dignified, human and living. It also enables his family member to take care based on sensitivity, gratitude, and respect.16,20

**The importance of humanized care to the child under palliative care, in coping with cancer in a support house**

Regarding this category, the children demonstrated the satisfaction of being together in a warm and welcoming environment in which feelings of security emerge.

> I think it’s good, very good because here it helps the children, we have friends. We come from another place and can stay here, without paying anything and still receive even help, besides to giving us much love and affection, even support. (Grey)

The humanized attention that contemplates caring, attention and conversation in palliative care becomes a fundamental tool in coping with the disease. According to these reports, it is possible to identify how much this care helps the child during his or her life in a support house and, from this experience, it is notorious how much he/she feels welcomed during the treatment of the disease.

Allowing adequate communication based on dialogue, care and affection are essential for the establishment of therapeutic alliances with the child and his/her family. Communication is a way of forming the bond between the child and the professional, and when it is performed in a sensitive, clear and honest way, the child feels understood, loved and welcomed, favoring his well-being, as well as promoting the satisfaction and confidence in the care provided to the child.23,24

It is possible to see the strong relation of the bond of trust created between the child and the volunteers in the testimonies of the support house studied. This reveals a human conduct capable of developing a social action aimed at the child’s comfort through a relationship of solidarity, as well as promoting resocialization in a creative and recreational space.25

Living in a different environment, with diverse people with different cultures, beliefs and customs, can generate in the child an exhausting situation, considering their emotional fragility due to the diagnosis of childhood cancer, as well as experiencing conflicts, fears and insecurities that, if at least they are exposed and listened to by the multi-professional team, can help her in coping with the disease.9

In the speeches below, the children verbalize how much conversation, understanding, and caring are important to make the environment more comfortable and how much emotional support is indispensable in this moment of fragility.

> It’s a home that helps, unlike a hospital, everyone here is good, just not better than my house, my aunt, but it’s very good, [...]. (Violet)

> It welcomes people who are far away and who came to treat a bad disease. They give a lot of love and attention. (Black)

> I feel it’s good, very good because here it helps the children, we have friends. We come from another place and can stay here, without paying anything and still receive even help, besides to giving us much love and affection, even support. (Grey)

> I feel protected because it is a house that welcomes us, people are very nice, friendly and attentive, take good care of us. I thank also for this house. (Beige)
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Love-centered care is the basis of human care theory. It considers that from simple actions such as touch, the tone of voice and listening to more complex actions such as playing and technical procedures, when performed with love and affection, produce a potent therapeutic effect of the healing process (restoration, care-cure). Thus, benevolence and equanimity expressed through love and caring in the actions of care are configured as a means to reach transpersonal care.16

It is important to emphasize that the communication “goes far beyond words and content, since it contemplates attentive listening, looks, and posture and the adequate use of this resource is a proven therapeutic measure for patients who need it”.23,162 Through verbal and non-verbal communication, the professional can be present and offer authentic care.16

A study conducted in pediatric hospitals in the Midwest of the United States revealed that for 25% of children with cancer who are at risk of death, poor and ineffective communication that does not transmit affection or attempt to understand the child in its entirety, contributes to the reduction of the quality of life of the child.24

The discourse of the children participating in this study allows us to evaluate positively their experience in the support house, considering that, in this institution, the child has the possibility to rescue his childhood, being visualized as a developing being, who needs activities that stimulate and enhance their physical, social, and creative abilities. Also, it allows the detachment of aspects related to the disease and the minimization of feelings of suffering, anguish, anxiety, and worry, without failing to offer care based on the needs of the child, considering their limitations, well-being, and comfort.

FINAL CONSIDERATIONS

The experience of children with cancer under palliative care in a support house is surrounded by feelings of joy and sensitivity. The children’s discourses showed that, in the face of suffering, they seek, through play, to extravasate their emotions and satisfaction by receiving differentiated care focused on the human being and all their biopsychosocial needs, leading them to interact with other children, changing the form of their confrontation with the disease, and interfering in a positive way in the health-disease process.

The children participating in the study demonstrated the satisfaction of living together in a warm and welcoming atmosphere in their speeches in which feelings of security and protection emerge, where the volunteers are fundamentally important when they promote playing and games, welcoming them, understanding and supporting them emotionally, demonstrating a strong relationship of bonding and trust created between children and volunteers.

Playing stimulates and enhances the physical, social, and creative abilities of children. It also allows detachment of the aspects related to the disease and minimization of feelings of suffering, anguish, anxiety, and worry, without failing to offer care based on the needs of the child considering their limitations, well-being, and comfort.

Also, the results showed that a humanized care based on the theory of human care and permeated with care, attention, and dialogue become fundamental tools in coping with the disease by the child, helping him during all his life in the support house. From that experience, it is notorious how much he feels welcomed during his treatment extended to his family.

Also, the child with cancer under palliative care should be careful in his multidimensionality, to minimize the main negative feelings related to the disease and to the treatment, such as pain, suffering, and distress.

The study has some limitations, such as reduced number of participants, which prevents the generalization of the results. Likewise, the incipience of scientific productions that approached the theme hinder the data generated to be compared in more depth.

Thus, this research redesigns a new view of children with cancer under palliative care in nursing homes, so future studies can be developed to raise the knowledge about the topic addressed.

REFERENCES

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