

MOTHERS' EXPERIENCES OF BEARING-CANCER CHILDREN UNDERGOING PALLIATIVE CARE CONCERNING THE CANCER DIAGNOSIS, ITS TREATMENT AND FAMILY SUPPORT

Vivências de mães de crianças com câncer em cuidados paliativos mediante diagnóstico, tratamento e apoio familiar

Experiencias de madres de niños con cáncer en cuidados paliativos mediante diagnóstico, tratamiento y apoyo familiar

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ABSTRACT

Objective: The study's main purpose has been to investigate the mothers' experiences of bearing-cancer children who were undergoing palliative care concerning the cancer diagnosis, its treatment and family support during hospitalization. **Methods:** It is a field research with a qualitative approach, which was carried out with 10 (ten) mothers of bearing-cancer children who were undergoing palliative care at a hospital in the Paraíba State. Data collection took place through semi-structured interviews, subsequently, being subjected to the content analysis as proposed by Bardin. **Results:** After analyzing the empirical material, the following thematic categories were elaborated: Experiences of mothers facing of the diagnosis and treatment of their cancer children undergoing palliative care; Importance of family support during care provision for hospitalized children bearing cancer. **Conclusion:** Palliative care must be fully integrated with care provision towards cancer children mothers. Furthermore, it is necessary to provide spaces for embracement dialogues by health professionals.

Descriptors: Neoplasms, Child, Mothers, Palliative care, Embracement.

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RESUMO

Objetivo: Investigar a vivência de mães de crianças com câncer em cuidados paliativos acerca do diagnóstico, tratamento e apoio familiar durante a hospitalização. **Métodos:** pesquisa exploratória com abordagem qualitativa, realizada com dez mães de crianças com câncer em cuidados paliativos em um hospital no estado da Paraíba, através de entrevista semiestruturada e submetido a análise de conteúdo proposta por Bardin. **Resultados:** extraíram-se duas categorias: vivência de mães frente ao diagnóstico e tratamento de criança com câncer, destacando a dor, o sofrimento, a angústia perante o diagnóstico do filho; e importância do apoio familiar durante os cuidados à criança hospitalizada com câncer, voltada ao compartilhamento de sentimentos, enfrentamento das condições adversas e tomadas de decisões difíceis. **Conclusão:** os cuidados paliativos precisam ser inseridos integralmente na assistência às mães de crianças com câncer, sendo necessário o desenvolvimento de espaços de diálogos acolhedores pelos profissionais de saúde.

Descritores: Neoplasias, Criança, Mães, Cuidados paliativos, Acolhimento.

RESUMEN

Objetivo: Investigar la vivencia de madres de niños con cáncer en cuidados paliativos en cuanto al diagnóstico, tratamiento y apoyo familiar durante la hospitalización. **Métodos:** investigación exploratoria con abordaje cualitativo, realizada con diez madres de niños con cáncer en cuidados paliativos en un hospital del estado de Paraíba, mediante entrevista semiestructurada y sometida a análisis de contenido propuesto por Bardin. **Resultados:** se extrajeron dos categorías temáticas: la experiencia de las madres respecto al diagnóstico y tratamiento de un niño con cáncer, destacando el dolor, sufrimiento, angustia ante el diagnóstico del niño; y la importancia del apoyo familiar durante el cuidado de los niños hospitalizados con cáncer, orientado a compartir sentimientos, afrontar condiciones adversas y tomar decisiones difíciles. **Conclusión:** los cuidados paliativos deben estar plenamente integrados en la atención a las madres de niños con cáncer, y es necesario desarrollar espacios de diálogo de bienvenida por parte de los profesionales de la salud.

Descriptores: Neoplasia, Niños, Madres, Cuidados paliativos, Acogida.

INTRODUCTION

Childhood cancer has peculiar characteristics, such as embryonic origin and the involvement of blood system cells and supporting tissue, which differentiates it from cancer in adults. Accordingly, leukemias, lymphomas and tumors of the Central Nervous System (CNS) are the most prevalent cancers. In recent years, the treatment of cancer in children and adolescents has made significant progress reaching approximately 80% of cure when diagnosed early and treated by specialists.¹

Nevertheless, childhood cancer is a public health problem representing the leading cause of death from disease among children and adolescents within the age group from 1 to 19 years old. This is largely due to the diagnosis and treatment performed late. Moreover, it should be taken into account that cancer treatment is long-lasting and accurate to the involvement of professionals-patient-families for its efficacy.²

It is emphasized that cancer treatment in children causes a change in the family routine, especially for parents who experience the disease with the child. Many parents

establish relay periods to accompany the child in the hospital, modify their activities and need support from the multidisciplinary team for better treatment support.³

Given this framework, there is the figure of the child's mother, who presents a significant representativeness with maternal characteristics that puts her in a scenario that deserves special attention, because it is interconnected to the child since the gestational period, building dreams, perspectives and providing protection to the child undergoing adversities. Many mothers distance themselves from the family to accompany their child in states of reference to cancer treatment, experiencing a whirlwind of feelings that coincide with the fear of loss.⁴

Therefore, the family embracement, especially the figure of the mother, is essential for building bond and trust. Taking into account the need for a holistic look at family follow-up, here, there was emphasized the importance of including palliative care, which can be understood as total and active care that is provided to patients diagnosed with a progressive and advanced disease, in which they contemplate the physical, psychological, social and spiritual aspects of the child and support to the family throughout the disease process, including grief. Palliative care in the child should be initiated soon after diagnosis, integrating it with curative treatment.⁵

Nonetheless, it is emphasized that many institutions still have difficulties to integrate palliative care at the beginning of diagnosis, making palliation a practice already implemented in the terminal phase.⁶ Through this panorama, it becomes more painful and difficult for parents and family members to understand the meaning of palliation.⁴

Many parents, when listening to the professionals that the child has entered a palliation, then relate to the feeling of immediate loss, feel guilty, angry and afraid, so it is necessary that professionals talk to parents from the beginning of the children's diagnosis, always explaining what the palliation represents, providing total care, according to the needs of children and parents.⁵

It is observed that professionals need to provide greater attention to the family and parents who accompany their children in cancer treatment. In this perspective, the problem of the study is included, in which it was observed in the care practice of a Pediatric Oncology Care Service the need to understand the universe of mothers who accompany their children with cancer under palliative care, in order to strengthen the construction of care plans for the real needs of mothers.

Given the relevance that surrounds the theme, it is essential that health professionals be integrated into the care provided to the child, mother and family. By understanding the particularities that permeate the experience of these mothers in the care of their children with cancer under palliative care, one can assist them at this peculiar moment, as recommended by the philosophy of palliative care. In this

perspective, the study contributes to the advancement and dissemination of knowledge about the theme investigated, favoring the quality of care for these mothers who accompany and care for their children who are in palliative cancer treatment in the hospital environment; in addition to expanding the number of publications on palliative care in the area of pediatric oncology.

So, taking into consideration the interconnection of mothers with children and the need to reflect on the experience of mothers during the process of palliation of children with cancer, the following question was elaborated: What are the experiences of mothers during the treatment of their cancer children undergoing palliative care?

Bearing in mind the aforesaid and targeting to answer such question, this work meant to investigate the mothers' experiences of bearing-cancer children who were undergoing palliative care concerning the cancer diagnosis, its treatment and family support during hospitalization.

METHODS

It is a field research with a qualitative approach, which was performed in a philanthropic hospital of high complexity and oncology referral unit, with a daily demand of 800 ambulatory visits per day, located in *João Pessoa* city, Capital of the *Paraíba* State.

The population of this study involved mothers of bearing-cancer children who were undergoing palliative care at the health institution elected for this work. To select the sample, the following inclusion criteria were adopted: mothers over the age of 18 years old, whose child is diagnosed with cancer, who is present during the data collection period and who agrees to participate in the research. As exclusion criteria: mothers who did not show emotional conditions and/or who did not agree to participate.

In the process of defining sampling, research with a qualitative approach is not based on the numerical criterion to ensure its representativeness. The sample of a qualitative research should be linked to the dimension of the object (or question) which, in turn, is articulated with the choice of the group to be interviewed.⁷

Based on this understanding, in relation to the number of participants, the sample was composed of 10 (ten) cancer children mothers.

Data collection took place through semi-structured interviews, using as an instrument a previously elaborated interview script, composed of two parts, the first related to data on the characterization of the participants (age, marital status, education, occupation, family income), and the second, with open questions, aiming at achieving the proposed objective.

With regard to the recording of the empirical material, it was performed from the recording system, through an MPEG Layer 4 (Mp4) device. However, this device was

only used with the prior consent of the study participants. The empirical material obtained was analyzed qualitatively, using the content analysis technique proposed by Bardin,⁸ which is composed of five operational steps, namely: organization of analysis, codification, categorization, inference and data interpretation.

The organization of the analysis is understood by pre-analysis, exploration of the material and the results processing. At this stage, readings of the collected material, called floating readings, are performed in order to apprehend the central ideas and their meanings.

The codification consists of the transformation of the raw data, comprising the following three steps: choice of record and context units, enumeration, classification and aggregation. Herein, there were taken into consideration the record units because it corresponds to the key unit that represents meaning in the content and will serve as the basis for categorization. Thus, phrases from the study participants' discourses were evidenced, which were representative for the analysis. To ensure the anonymity of the participants, they were given a pseudonym of precious stones.

The categorization gathered the record units in order to support the analysis of the empirical material, using the categorical analysis technique.

The research project approved by a Research Ethics Committee from the *Universidade Federal da Paraíba (UFPB)*, under the *Certificado de Apresentação para Apreciação Ética (CAAE)* [Certificate of Presentation for Ethical Appreciation] No. 113894194.00005188, was based on guidelines and regulatory standards for research with human beings, as addressed by the Resolution No. 466/2012 from the National Health Council.⁹

RESULTS AND DISCUSSION

Participants' characterization

The study sample consisted of 10 (ten) mothers of bearing-cancer children who were undergoing palliative care, of which six were married, two were single, one was divorced, and one was a widow. Concerning the education, five have completed elementary school, three incomplete elementary school, one complete high school and one have incomplete high school. The majority did not have an employment relationship at that moment, self-determining "housewife". Considering the family income, one receives 03 minimum wages, two receive 02 minimum wages, four 01 minimum wage and three survive on less than 01 minimum wage.

After analyzing the empirical material of the proposed study, the following thematic categories were elaborated: Experiences of mothers facing of the diagnosis and treatment of their cancer children undergoing palliative care; Importance of family support during care provision for hospitalized children bearing cancer.

Category 1 - Experiences of Mothers Facing the Diagnosis and Treatment of Their Cancer Children Undergoing Palliative Care

[...] When I found out that my son had this disease, I was desperate, I thought he would die soon, but then the physician explained to me that this disease has treatment and that he was going to live a long time yet, but that he was not going to be good, normal, that he would always be needing care. (Jade)

[...] It was a shock when I heard she was sick. (Emerald)

[...] I cry every day seeing my son's suffering. (Amethyst)

[...] Now that I know everything that might happen, I'm too afraid of losing my son, it's the second time this disease has come back. God help me, please. I ask Him to stay strong all the time to help my son. (Pearl)

[...] One and a half years ago the disease came back... I was emotionally destroyed, more than the first time, that I was in the dark and now I know everything that might happen, that he can die. (Tourmaline)

[...] I see he's getting worse; nobody has to tell me, I know. (Diamond)

[...] My sister-in-law told me his health condition got worse and could die at any moment, so they brought him to the Intensive Care Unit. The physician said he was getting worse and I should prepare for the worst. (Spinel)

[...] The physician told me my son was sick. She said it was very serious and that he was going to do a difficult and time-consuming treatment. (Malachite)

[...] Ever since I heard she was sick, the physician warned me it was very serious. There was the physician, the social worker and her nurse at the time, and I was with my mother, we cried a lot. (Tanzanite)

[...] I was left emotionally destroyed when I heard that the disease had come back, it was all right for us to travel to do the transplant, now I have to wait for him to improve and pray. There were the physician and the nurse at the time I got the news. (Crystal)

The reports presented in the Category 1 show emphatic pain, suffering and anguish of the mothers participating in the study when learning about the diagnosis of the child's disease and painful treatment, besides the feeling of fear in the face of the possibility of premature death of the child.

Category 2 – Importance of Family Support During Care Provision for Hospitalized Children Bearing Cancer

I stopped working to fully dedicate to my daughter, but everyone in the family helps me take care of her, including her brothers. My parents and my in-laws too. Everyone loves my daughter so much. (Cubic Zirconia)

My mom comes to visit us every week, but she works and cannot stay here with me. Also, we are allowed to have only one companion at a time, and I don't have the courage to go out and leave my son with someone else. My sister comes here as well, but she cries a lot, and my son is sad when he sees her crying. (Sapphire)

My husband comes to stay in my place, so I can go home and do the laundry and organize things over the weekend, because he works all week in the farm. I'd help him too, but I left for now to take care of my son. When I get home, the brothers keep asking about him. (Turquoise)

My family supports me, my mother comes to stay with her, so I can come home and see my youngest, moreover, her father stays with her too sometimes. My family is very close. My father, my brother, everyone helps when they need to. (Agate)

We need a lot of help and we have to count on the family [...]. The fight is overwhelming, and the family support is crucial. (Ruby)

My husband comes every day and sometimes stays here, so I can rest. My sister-in-law is helping me a lot. My mother-in-law always comes here as well, and my mother stays here with him. The brothers are small, and I don't want them to see their brother like that. (Brilliant)

Category 2 includes reports from mothers included in the study on the importance of supporting family members to collaborate in child care during their absences or to have a little rest. It is also counted with affective support, since this is fundamental to help them in the difficult journey of caring for a child with cancer in the hospital environment.

Hence, family support to mothers during the child's hospitalization process is necessary for sharing feelings, coping with adverse conditions and making difficult decisions. Mothers who have family support can better deal with situations arising from the child's illness.^{10,11}

Studies underline that among the feelings generated in mothers, the fear of losing their child to cancer is one of the most experienced. They deal daily with this fear and, so, it is of fundamental importance to support health professionals to maintain a link of trust in order to be able to follow their path more safely.^{12,13}

In this regard, health professionals need to insert mothers into daily care, integrating palliative care for the child and family. It was found that patients receiving

palliative care during treatment have better indicators of quality of life when compared to those who did not receive it during curative treatment.¹⁴ Children who require palliative care require it in a complete, individual and humanized way, strengthening the care provided to the mother-child binomial.

Therefore, when palliative care is inserted early into the treatment of the child, they offer more advantages, since it is possible to prevent, identify and treat symptoms triggered by the process of illness of the child and family, thus providing an improvement in quality of life.⁵

So, it is necessary that health professionals build and implement strategies that can relieve the anguish of mothers when experiencing moments of suffering of the child during invasive procedures. For instance, one can use playful activities to bring the child closer to his universe.¹⁵

Recreational activities are essential for coping with the disease, since they bring children closer to their universe. Furthermore, they allow the expression of feelings through play, relieving the suffering, fear and anguish generated by the hospitalization process. However, it is necessary that children are made available to toys that are part of their daily lives. Thus, the multidisciplinary team should integrate play into their actions, meeting the real needs of children.¹⁶

A study with children in palliative care found that they emphasized the importance of playing, conversation and caring to make the environment cozier.¹⁷ From this perspective, humanized care must be present in the daily lives of professionals who assist children in palliation, welcoming their demands and making the hospital environment a place that is aimed at being a child.

In this respect, the nursing professional stands out, in particular the registered nurse, who establishes a bond of trust with the mothers and seeks to provide effective communication with them, clarifying doubts and reaffirming the care of the child, given he/she is involved in direct childcare processes.^{4,18}

It is worth noting that communication is an instrument of fundamental importance to strengthen the bond between health professionals and mothers of children with cancer undergoing palliative care.

Therefore, it is necessary in the environment of children's oncology to communicate in order to meet the real questions of the mothers, transmitting complete information to help in understanding and future decisions regarding the health condition of their child.¹⁹

Although communication is an indispensable strategy in the context of palliative care, particularly in pediatric oncology, a study draws attention that many health professionals still have difficulties in inserting the philosophy of palliative care into their routine. Barriers such as the absence of theoretical knowledge compromise the understanding of palliation, hindering communication with family members and patients.¹⁷ Another striking

barrier is the difficulties in dealing with the child's terminality and the pain of family members.¹⁸

Given this reality, it is pressing to provide training for health professionals on palliative care that can support more adequate care for mothers of children with cancer undergoing palliative care, with emphasis on humanized care so that they can minimize suffering in the face of both diagnosis and treatment of the child.

It is observed through the reports that some mothers give up work, studies and daily life to take care of their children. This is in line with the findings of the study,¹³ showing the abandonment of the parents of their activities to accompany their children in consultations and hospitalizations. Moreover, mothers exercise the main figure of caregiver even receiving support from their spouse and family members.

Considering this framework, research underlines that cancer children mothers modify their routines to meet the demands of cancer treatment and experience moments of uncertainty, anger and hopelessness during the child's illness process. These mothers start to live according to the child's needs and, in most cases, become overwhelmed and tired with constant thoughts focused on the health-disease process of the child.⁴

It is emphasized that the mothers' feelings are intensified due to the fact that they perform two functions: being a mother and companion. This issue increases the challenges experienced by mothers, since they try to reconcile their daily routine with that of the hospital, most of the time, they spend nights without sleeping with the hospitalized child and need the support of family, friends and health professionals.¹¹

The experience of caring for a child with cancer in the hospital environment is unique for each mother, but regardless of the support she receives from the family, it is necessary that the health team seek to promote targeted support actions to minimize their suffering during the hospitalization of their child.

CONCLUSIONS

The categories presented portray the difficult experience of mothers of children with cancer expressed from their reports, which reveal the painful process of coping with the diagnosis of the disease and treatment of their child and highlight the importance of the support of family members as support during the hospitalization of the child.

It was observed that palliative care must be fully inserted in pediatric oncology care, given the difficult experience of mothers in coping with the diagnosis and treatment of their child. It is necessary that health professionals create spaces for embracement dialogues for active listening of mothers, in which it is possible to share experiences and minimize suffering.

Care provision for children with cancer undergoing

palliative care must be extended to mothers who are involved in the painful process of caring for their child in the hospital environment, so that they can have the necessary monitoring and support of health professionals in coping with the disease of their children.

Further studies addressing this topic are needed aiming to give greater visibility to the need to integrate palliative care into the mother-child binomial in health institutions that provide assistance in the area of pediatric oncology.

As a limitation of the study, it is important to underscore the particularity that distinguishes the experience of each mother. Hence, the results obtained in this research cannot be generalized to all mothers of children affected by cancer, who are hospitalized for treatment.

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