A presence of the child's family with cancer in the intensive therapy unit

A presença do familiar da criança com câncer na unidade de terapia intensiva

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RESUMO

Objetivou-se descrever a percepção do familiar da criança com câncer quanto a sua chegada e presença na unidade de terapia intensiva pediátrica. Pesquisa descritiva, de natureza qualitativa, realizada na unidade de terapia intensiva pediátrica de um hospital especializado em oncologia, de outubro a novembro de 2014. Participaram de entrevista semiestruturada 10 familiares de crianças. Da análise de conteúdo resultaram as seguintes categorias: o itinerário da criança e seu familiar dos primeiros sinais e sintomas até a chegada à unidade de terapia intensiva pediátrica e a percepção do familiar da criança com câncer quanto a sua presença na unidade de terapia intensiva pediátrica. Conclui-se que a chegada da criança com câncer e do seu familiar é permeada por medo, incertezas e dúvidas, contudo, a presença da família promove à criança proteção, calma, segurança, amor e carinho. Ademais, os familiares passam a compartilhar alguns cuidados com a equipe de enfermagem.

Palavras-chaves: Família, Criança Hospitalizada, Câncer, Unidades de Terapia Intensiva Pediátrica, Enfermagem Oncológica.

ABSTRACT

The objective of this study was to describe the perception of the relative of the child with cancer regarding their arrival and presence in the pediatric intensive care unit. Qualitative descriptive research carried out in the pediatric intensive care unit of a hospital specialized in oncology, from October to November 2014. Ten family members of children participated in a semi-structured interview. Content analysis resulted in the following categories: the itinerary of the child and his / her relative from the first signs and symptoms until arrival at the pediatric intensive care unit and the perception of the relative of the child with cancer regarding their presence in the pediatric intensive care unit. It is concluded that the arrival of the child with cancer and his family is permeated by fear, uncertainties and doubts, however, the presence of the family promotes the child protection, calmness, security, love and affection. In addition, the relatives begin to share some care with the nursing team.

Keywords: Family, Hospitalized Child, Cancer, Pediatric Intensive Care Units, Oncology Nursing.

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INTRODUCTION

In Brazil, over the last few years, the incidence of childhood cancer has been increasing in the age group from 0 to 19 years. This chronic and treatable disease, and in many cases curable, especially when the diagnosis happens early, has significant repercussions on the life of the child and the family(1) .

Despite the increase in the number of cases, childhood and juvenile cancer is still considered rare, accounting for 3% of all malignant tumors. However, it represents the second cause of death among children and adolescents, with an estimate for each year of the 2018-2019 biennium there will be 12,500 new cases of this disease in this population until the age of 19(2).

The diagnosis of cancer triggers shock reactions among family members, which includes intense suffering, especially for the possibility of a child dying. Therefore, this situation is permeated by diverse expectations regarding the diagnosis and treatment itself, and by numerous feelings such as fear, anxiety and guilt(1,3) becoming even more painful when the child needs to be hospitalized in a pediatric intensive care unit (PICU).

The hospitalization in the PICU represents, for the relatives, a rupture associated to the loss of autonomy over the child. In addition, it reflects the possibility of loss and death, as it is a stressful environment, of complex care and generating an emotionally compromised atmosphere, adding to the various negative feelings regarding the diagnosis and treatment of the child with cancer(4).

In view of the above, if, on the one hand, early referral of the child to the PICU provides the necessary technological support for the reestablishment of their clinical condition,(5) on the other hand, the family members experience a whirl of feelings while remaining in this environment. However, in this area, technology-related issues still have priority over humanized assistance(6). In this sense, study(7) on the family of the child with cancer points out that care should also be directed to the accompanying family member, since care for the child should not be disconnected from the family and their needs.

It should be noted that the insertion of the family in the hospital setting is governed by the Statute of the Child and Adolescent, which guarantees the permanence of one of those responsible throughout the hospitalization(8). Therefore, the constant presence of the family member in the hospital promoted, among other aspects, changes in the care of the child in this environment, including in the PICU, in which there is a constant interaction with the nursing team.

Therefore, it is relevant to give voice to the family members so that they express their perception about their arrival and presence in this sector that is surrounded by beliefs and feelings, considering the scarcity of literature correlated to this environment. Thus, the following guiding question was delineated: how does the family member of the child with cancer perceive their arrival and presence in the pediatric intensive care unit? The purpose of this study was to describe the perception of the relative of the child with cancer regarding their arrival and presence in the pediatric oncology intensive care unit.

METHODOLOGY

Descriptive, exploratory research with a qualitative approach that applies to the study of history, relationships, representations, beliefs, perceptions and opinions, products of human interpretations of how they live, build their artifacts and themselves , feel and think(9).

The scenario was the pediatric intensive care unit of a reference hospital in the treatment of cancer of the public health network of the City of Rio de Janeiro.

The research scenario unit consists of boxes with a 1 intensive bed each, which has support equipment such as a monitor, respirator and all the necessary equipment for an intensive unit, as well as a reclining chair to accommodate the accompanying family member. It is worth mentioning that a full-time companion is guaranteed to stay with the child.

Participated in the study 10 family members accompanying children hospitalized at the oncology PICU. It should be noted that there was a low turnover of hospitalizations in the sector during data production, from October to November 2014, which justifies the number of accompanying relatives involved, since the sector has only 6 beds available for hospitalization.

To select the participants, the following inclusion criteria were used: to be familiar to children hospitalized at the pediatric oncology intensive care unit, of both sexes. E, exclusion: family members of children who died, were discharged from hospital and / or were transferred from the sector during the period of data collection.

The production of data occurred through a semi-structured interview with the following questions: 1) Tell us a little about your arrival with the (name of the child) here pediatric intensive care unit; 2) How do you perceive your presence here in the pediatric intensive care unit? The interviews were recorded in digital media, according to the participants' availability, in the morning, afternoon and evening, in a reserved area of the institution, namely the nursery nursing room. The average duration of the interviews was 10 minutes.

To identify the interviewees, an alphanumeric code was used, the letter "F" being a familiar one, followed by arabic numeration according to the order of the interviews.

After transcription of the interviews, the empirical material was completely read and the data were submitted to categorical content analysis following the steps: pre-analysis; exploitation of the material; treatment of results, inference and interpretation(10). Following the steps of pre-analysis and exploration of the material it was possible to organize the research data. Subsequently, the results obtained were processed and interpreted, and after the analysis of the data and identification of the themes that generated the thematic categories.

In order to maintain rigor in the study, the following strategies were used: the interviews were available after transcription, for all the participants, in order to verify if they were represented in the way the data were being analyzed and used if consolidated criteria for Reporting Qualitative Research (COREQ).

The research followed the recommendations of Resolution 466/12 of the National Health Council(11) and was approved by the Ethics and Research Committee of the University Hospital Antônio Pedro (CEP / HUAP / UFF), under the opinion n. 826.222 / 10/2014 and CAAE 30546214.0.3001.5274 and by the Ethics and Research Committee of the Hospital Scenario Study. In this sense, all participants signed a Free and Informed Consent Term (TCLE).

RESULTS

Participated in the study 10 family members of whom, 09 (90%) were mothers and 01 (10%) were parents. Regarding the age group, 03 (30%) were between 20 and 30 years, 04 (40%) between 30 and 40 years and 03 (3%) between 40 and 50 years. As for marital status, all 10 (100%) of the family were married; in relation to the number of children 02 (20%) had 01 (one) child who was hospitalized in the CTIP; 04 (40%) had 02 children, of whom 01 were in the CTIP, 03 (30%) had 03 children, one hospitalized, and 01 (10%) had 05 children, of whom 01 were hospitalized. As for Teaching: 02 (20%) attended the complete Elementary School, 02 (20%) incomplete High School, 04 (40%) High School and 01 (10%) were undergraduate students in Nutrition. As for the profession / occupation: 07 (70%) were from the home, 01 (10%) were undergraduate students in nutrition, 01 (12.5%) were school van drivers and 01 (10%) worked with general services. When asked about the religious option 09 (90%) were evangelicals and 01 (10%) were Catholic.

All participants resided in the masonry house with water and sewage and garbage collection. Of the 10 accompanying relatives, 07 (70%) were natural and living in the State of Rio de Janeiro, 03 (30%) came from the State of Pernambuco, Maranhão and Bahia, but currently resided in the State of Rio de Janeiro for treatment of the hospitalized child in the industry.

It should be noted that family members have a place called the Ronald Mcdonald Institute, popularly known as Ronald's house. This house is home to relatives living in the State of Rio de Janeiro, who live far from the treatment center and who also have relatives from other regions of the country.

After analyzing the answers, the following categories emerged: The itinerary of the child and his relative from the first signs and symptoms to the arrival at the pediatric intensive care unit; The perception of the relative of the child with cancer regarding their presence in the pediatric intensive care unit.

The itinerary of the child and his relative from the first signs and symptoms until arrival at the pediatric intensive care unit

The memories rescued by the relatives of the child associated to the arrival at the PICU were related to the appearance of the first signs and symptoms of the disease still in the socio-familiar environment. According to reports, children initially presented with headache, loss of taste and balance, lump in the abdomen, changes in development and gait, which made them seek a health service.

> *"She (child) began to feel a strong headache, did not taste on one side of the tongue, could not walk because there was no more balance in the body, so we look for the UPA of Teresópolis."* (F1)
>
> *"When he (child) turned 1 year old, I realized that he did not talk and did not walk right, then I went to take the pediatrician to see what could be. She (a pediatrician) advised me to go to a neurologist. The neurologist underwent tomography and then resonance (...). Then he sent for a public hospital with more recourse." (F6)*
>
> *"I think it started with a lump on the side of her belly (child) and had them go to Campos."* (F8)

The deponents also spoke about the path taken by the child and his family until arriving at the treatment center (hospital), the research scenario.

> *"She (child) went to hospitals to diagnose and I come here with her."* (F5)
>
> *"At the Hospital (who was hospitalized) they did the biopsy and discovered the disease, and then they sent us here (Treatment Center)." (F2)*
>
> *"The examination showed a tumor on his head and there he discovered that it was a cancer, he came here (Treatment Center), and here he even discovered that it was a malignant cancer, and he went to do the treatment." (F 10)*

In addition, a relative expressed his nervousness and doubts in the discovery of the cancer of his son and in the arrival to the unit of treatment:

> *"When I found out I was nervous and when I got here I was even more nervous, still because I started asking a lot of questions from doctors and nurses as well."* (F7)

Upon arrival at the PICU, the family members considered the admission of the child and the reasons for the indications for hospitalization of high complexity:

> *"She slept and then did not wake up anymore, so we came here because she was not waking up, and she's sleeping until today." (F 1)*
>
> *"He entered the CTI because he had very high calcium (...). I was on hemodialysis." (F 10)*
>
> *"He has had three cycles of chemotherapy and has already gone down enough to have surgery, he has had surgery and now he is here (PICU)." (F 4)*

The perception of the family member of the child with cancer as to their presence in the pediatric intensive care unit

When asked about their presence in the PICU, the family members answered that they are important because they promote the children's help, because they provide protection, calmness, security, and love and affection.

> *"It's very important to always be together because the child feels more protected." (F 1)*
>
> *"I can contribute by being on his side, giving love and affection." (F 6)*
>
> *"She sees me and I know I'll be helping. She's very close to me." (F 9)*
>
> *"Sometimes he wakes up agitated there I go there, I try to calm him, talking to him, talking to him holding his hand. Sometimes he calms down a little." (F 10)*

Insofar as the role of the family member in this environment is recognized as essential for the children, they remain practically full-time, not taking turns with other possible companions.

> *"I already wanted someone to come and stay with him, but I was standing behind because mother is a mother. (...). He would take my hand and say, "Mom, do not leave me." I could not even go home." (F 6)*
>
> *"My presence I think is very important to her, I do not get rid of her here no, I do not even change her father." (F 8)*
>
> *"Most of the time I'm here. I only go out when I go to the bathroom to take a shower, to have a meal." (F 10)*

Throughout the hospitalization of the child in said unit, the family members understand that their presence consists in helping the nursing team in the care such as: thermometer use, body hygiene, changing of diapers and bedding, feeding and change of decubitus:

> *"Put the thermometer in general, because there is technique (nursing) that comes to take care of it and accepts help to turn. Sometimes there are few nurses there, I'll help you bathe and brush your teeth." (F 1)*
>
> *"We try to help at bath time, I try to help the nurses, most of who do is they." (F 2)*
>
> *"(...) I ask if there is something I can cooperate to help them (nursing team). I give the food, the soup, clean his mouth, change the diaper, the CTI I help, but in the infirmary I do everything." (F 6)*

For the accompanying family member the need to always be with the child, for fear that some intercurrence happens if he leaves, was identified in the following reports:

> *"Even more CTI, something happens to me far away there stays in that concern, I want to always be on his side. I've seen things I've never seen happening to kids my son's age, I've seen a child die in here, I thought so, my God! I took that shock, that child was in the same situation as my son and I already thought that would happen to mine." (F 3)*
>
> *"At night I do not want anyone else here alone. (...) I'm going to leave here and something happens suddenly and I will not be here." (F 10)*

The results of the research showed that when they spoke about their presence in the PICU, the family felt the need to recover the path of illness from the first signs and symptoms and the conditions that led the child to intensive care.

It was seen that they feel important to calm and give love, thus acting on the child's well-being and that gradually depending on the clinical picture of the child, some activities are shared between the nursing team and the family.

DISCUSSION

The findings of the study showed that the initial signs and symptoms that motivated the family to seek the health service were nonspecific, since often the symptoms of cancer are indistinct and similar to other diseases common to childhood(12). This lack of specificity complicates and delays the suspicion and diagnosis of childhood cancer, since manifestation such as fever, vomiting, weight loss, bleeding, adenomegaly, generalized bone pain and pallor, do not allow the specific localization of the disease(13).

In the course of the participants, in search of the diagnosis, the child went through different health services, being submitted to different biomedical procedures, besides receiving different diagnoses. Thus, the period prior to confirmation of the diagnosis of child and adolescent cancer is often long and difficult, considering that families must resort to several services and resources, which includes different examinations and hospitalizations, until the diagnosis is defined. There are also erroneous medical evaluations, which further delay the correct diagnosis of the disease(12).

It has been reported that the time of diagnosis of cancer is fraught with doubt and nervousness. Therefore, it should be emphasized that family members require competent professionals, both in terms of technical and scientific knowledge, as well as support and attentive listening(7,12). Families can thus benefit from qualified care, in order to clear their doubts and understand the clinical condition of the child and the treatment to be performed.

A study conducted in Turkey shows that parents of children with cancer use doctors and nurses, as well as the internet, friends and parents of other children who stay in the hospital as a source of information about everything that involves their child's illness, which is fundamental to the decision-making process related to child care. Therefore, adequate and systematic guidelines regarding treatment and prognosis should be provided by health professionals throughout the disease process(14).

The data pointed out that different reasons for the child's visit to the PICU are different, since some hospitalizations are due to clinical complications arising from the disease and / or side effects of the treatment, and others due to the need for surgical treatment is in agreement with the indications of hospitalizations in intensive oncological units, described in the literature(4).

A retrospective study in Egypt that analyzed the causes of admission of children with cancer in the intensive care unit identified that systemic infection and respiratory failure were the most common causes, followed by metabolic and neurological disorders, mediastinal syndrome and postoperative monitoring(5).

Faced with a trajectory marked by innumerable and stressful experiences, there is an urgent need to value the acceptance of the family in the admission of the child. In this process, it stands out that the participation of the nurse is fundamental, since he is responsible for guiding the client and the family, elucidating their doubts about the therapeutic care and resources(15).

The presence of the relative in the PICU maintains the child / family relationship and minimizes the impact of separation, thus providing comprehensive care. Therefore, it is necessary to humanize the hospital environment where the child is present, incorporating the family into the care, since its presence with the child promotes better acceptance and adaptation to hospitalization, besides favoring the formation of the bond with the members of the health team(16).

If, on the one hand, the full-time relative's permanence is beneficial to the child who is in the PICU, on the other hand, physical and mental exhaustion may occur, since confinement in the hospital causes the child to prioritize the care of the sick child, leaving in the background your own care(17).

It was seen that during the period of hospitalization the relative began to perform some care with the carriage. According to the literature, this sharing of care between the nursing team and the family should occur in a dialogical way, in order to contribute to its treatment(17).

Thus, reciprocity in the care of the child between the health team and the family can favor a better identification of the child's needs, allowing the planning of a more holistic and humane care. The exchange of experiences can help the relationship between the professionals, the child and his / her family, possibly minimizing the crisis experienced and the family suffering with illness and hospitalization(18).

The interaction is a negotiation, between the accompanying family member and the nursing team, regarding the care of the child inserted in the hospital environment. During the development of nursing care in the PICU the presence of the family member reduces the anxiety that the child may feel during hospitalization and favors the formation of the bond with the members of the health team, since the exchanges of information make possible the planning a comprehensive and joint care(19).

As also pointed out in another study, the family experiences intense fear of losing the child, facing the stress of the disease, plus the meaning that they have for the hospital and everything the child needs. Parents feel obliged to stay with their child at all times without ever leaving them, not even to feed themselves(20).

Thus, it is important to establish links between the family and the nursing team, from the beginning of hospitalization, in order to attenuate the stress caused by the hospitalization. The emotional support offered to the child hospitalized by the caregiver is a facilitating tool for recovery that, if not well worked out, may imply the creation of a barrier between the nursing and the child(21).

When parents or caregivers realize that their children are being assisted by a "known" person, they begin to trust their competence and feel more secure and open, with a better understanding of their health and treatment status. This sense of security gives them openness to discuss with the nursing staff their feelings about hospitalization, attenuating their anxiety, and helping the child recover(21).

Thus, it is expected that as long as the permanence of the child in the PICU is prolonged, interactions established in the daily coexistence, the fears, insecurities and suspicions of the accompanying family member can be replaced by feelings of trust and respect towards the professionals of nurses who are caring for the sick child.

CONCLUSION

The arrival of the child with cancer and his relative in the PICU is permeated by fear, uncertainties and doubts, because this sector is usually associated with death. After this initial impact, the accompanying family member tends to adapt to the new situation and is organized to offer the child protection, calm, security, and love and affection. At the same time he begins to realize that he needs to share some care with the nursing team.

Therefore, the insertion of the family into the care of the hospitalized child in the PICU represents a challenge for the nursing that needs to recognize it as a co-participant in the development of care.As an interaction between the nursing team and the accompanying family member of the child mediated by the coexistence in the hospital setting is established, caregiving actions are shared.

Sharing child care in the PICU is a process that has been built up through successive negotiations between the family and the nursing team, in order to promote a more effective, holistic, humane and pleasurable care for the child, making the hospitalization less traumatic.

Thus, the realization of this study made it possible to understand that the family plays a fundamental part in the care of children with cancer in the PICU, opening up a range of possibilities for the establishment of more effective interpersonal relationships.

As a limitation of the research, the shortage of publications related to the presence of the relative in a pediatric intensive care unit, exclusively for children undergoing cancer treatment, was notorious for increasing the discussion and comparing this research with others addressing the subject. Therefore, it is suggested that new research be developed.

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