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CONTEXTUAL ASPECTS RELATED TO NURSING CARE MANAGEMENT OF THE CHILD WITH CHRONIC CANCER PAIN[1]

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ABSTRACT

Objective: to discuss the contextual aspects related to nursing care management of hospitalized children with chronic cancer pain.

Method: a qualitative research developed and based on the methodological framework of the Grounded Theory and the Complex Thought theoretical framework of Edgar Morin. Data were collected through a semi-structured interview and non-participant observation. The 21 participants of the research were organized into three sample groups: the first was composed of seven nurses; the second was made up of seven nurse technicians and the third was formed by seven professionals from the multiprofessional health team. The results of the research were validated by five examiners, three of whom were experts in the research method.

Results: the "Unveiling contextual aspects of nursing care management of children with chronic cancer pain" category and subcategories revealed that hospitalization of these children is long and is marked by changes in family dynamics, losses and limitations imposed by the disease and/or treatment. Nursing care management is complex, performed through teamwork and requires planning that values the various needs of the child and the family.

Conclusion: the results show that nursing professionals must contextualize their care relationships, by putting value on the aspects that transcend the biological dimension of hospitalized children with chronic cancer pain.

DESCRIPTORS: Pediatric nursing. Child care. Hospitalized child. Chronic pain. Neoplasms.

ASPECTOS CONTEXTUAIS SOBRE O GERENCIAMENTO DO CUIDADO DE ENFERMAGEM À CRIANÇA COM DOR ONCOLÓGICA CRÔNICA[1]

RESUMO

Objetivo: discutir os aspectos contextuais relacionados ao gerenciamento do cuidado de enfermagem à criança hospitalizada com dor oncológica crônica.

Método: pesquisa de abordagem qualitativa, desenvolvida com base no referencial metodológico da Teoria Fundamentada em Dados e no referencial teórico do Pensamento Complexo, a partir de Edgar Morin. A coleta de dados ocorreu por meio da entrevista semiestruturada e da observação não participante. Os 21 participantes da pesquisa foram organizados em três grupos amostrais: o primeiro foi composto por sete enfermeiros; o segundo foi constituído por sete técnicos de enfermagem e o terceiro foi formado por sete profissionais da equipe multiprofissional de saúde. Os resultados da pesquisa foram validados por cinco examinadores, dos quais três apresentavam expertise no método de pesquisa.

Resultados: a categoria intitulada "Desvelando aspectos contextuais sobre o gerenciamento do cuidado de enfermagem à criança com dor oncológica crônica" revelou por meio de suas subcategorias que a hospitalização dessa criança é longa, marcada por mudanças na dinâmica familiar, perdas e limitações impostas pela doença e/ou tratamento. O gerenciamento do cuidado de enfermagem é complexo, realizado por meio do trabalho em equipe e da demanda um planejamento que valorize as múltiplas necessidades da criança e do familiar.

Conclusão: os resultados apontam para a necessidade do profissional de enfermagem contextualizar suas relações de cuidado, a partir da valorização de aspectos que transcendem a dimensão biológica da criança hospitalizada com dor oncológica crônica.

DESCRITORES: Enfermagem pediátrica. Cuidado da criança. Criança hospitalizada. Dor crônica. Neoplasias.

ASPECTOS CONTEXTUALES SOBRE EL GERENCIAMIENTO DEL CUIDADO DE LA ENFERMERÍA PARA EL NIÑO CON DOLOR ONCOLÓGICO CRÓNICO

RESUMEN

Objetivo: discutir los aspectos contextuales relacionados al gerenciamiento del cuidado de enfermería para el niño hospitalizado con dolor oncológico crónico.

Método: investigación de abordaje cualitativo y desarrollado con base en el referencial metodológico de la Teoría Fundamentada en Datos y en el referente teórico del Pensamiento Complejo a partir de Edgar Morin. La recolección de datos ocurrió por medio de la entrevista semiestructurada y de la observación no participante. Los 21 participantes de la investigación fueron organizados en tres grupos de muestras: el primero fue compuesto por siete enfermeros; el segundo fue constituido por siete técnicos de enfermería y el tercero fue formado por siete profesionales del equipo multiprofesional de salud. Los resultados de la investigación fueron validados por cinco examinadores y tres de ellos mostraron experiencia en el método de investigación.

Resultados: la categoría titulada "Esclareciendo los aspectos contextuales sobre el gerenciamiento del cuidado de la enfermería para el niño con dolor oncológico crónico" rebeló, por medio de sus subcategorías, que la hospitalización de ese niño es larga, marcada por cambios en la dinámica familiar, pérdidas y limitaciones impuestas por la enfermedad y/o tratamiento. El gerenciamiento del cuidado de la enfermería es complejo y realizado por medio del trabajo en equipo y de la demanda de un planeamiento que valorice las múltiples necesidades del niño y del familiar.

Conclusión: los resultados señalan la necesidad del profesional de enfermería de contextualizar sus relaciones de cuidado a partir de la valorización de aspectos que transcienden la dimensión biológica del niño hospitalizado y con dolor oncológico crónico.

DESCRIPTORES: Enfermería pediátrica. Cuidado del niño. Niño hospitalizado. Dolor crónico. Neoplasias.

INTRODUCTION

In Brazil, childhood and adolescent cancer (children and adolescents from 0 to 19 years old) is considered rare when compared to adult tumors, since it accounts for between 2% and 3% of all malignant tumors which is the biggest cause of death in developing countries.[1] The different types of leukemia are the most common cancers in childhood,[2] including lymphoid, non-lymphoid, acute or chronic.

In the national context, it was estimated that 12,600 new cases of cancer occurred in children and adolescents up to the age of 19 in 2016, with the Southeast and Northeast regions having the highest number of new cases, 6,050 and 2,750, respectively.[1] In the United States of America, the annual incidence of cancer in children and adolescents is 186.6 per 1 million children between the ages of 0 and 19 years. In addition, 15,780 new cases of cancer and 1,960 deaths from this disease among children and adolescents aged zero to 19 years was estimated in 2014 in The United States of America.[3]

In the pediatric oncology context, pain stands out as one of the most common and distressing symptoms, as it causes the child and family to suffer, as well as influencing the whole hospitalization process of the child.[4-6] In one study,[4] the pain represented 56% of complaints reported by children with advanced cancer, with pain in head being the most common site, followed by the abdomen, back, legs and feet. According to this result, another study[6] conducted in hospitals in Nigeria, presented pain as one of the main symptoms experienced by the child in cancer treatment. In addition to this condition other symptoms were experienced: nausea, lack of energy, lack of appetite, loss of hair and weight loss.[6]

It is emphasized that in developing countries, where many children have advanced cancer and few have access to effective treatment, that pain is related to the progression of the disease. In developed countries, cancer pain in children is related to the treatment and diagnostic and therapeutic procedures.[7] However, it is accepted that regardless of its cause, cancer pain is always bothers the child, and thus, needs to be evaluated and managed by the nursing professionals in the scope of teamwork, in a correct and immediate way, in order to mitigate its negative impacts on the quality of life of the child.

Cancer pain can manifest itself as acute or chronic. Acute pain arises as a result of a tissue injury and tends to disappear when the wound heals. On the other hand, chronic pain is continuous (persistent) or recurrent (episodic) and persists beyond the normal expected time.[7] While acute pain is usually self-limiting, in some patients pain persists beyond the expected healing time (arbitrarily defined >3-6 months), which is classified as chronic pain.[8]

Literature[7] emphasizes that the presence of chronic pain in children with chronic disease, such as cancer, can adversely affect various aspects of the child's life, including physical activity, school attendance, sleep patterns, social relationships, among others aspects. In this regard, a study[5] identified that children who presented with chronic cancer pain presented difficulties in extracurricular (16.7%), domestic (14.6%), social (12.6%), sleep (12.6%) and academic (12.5%) areas.

Therefore, nursing care management that considers the multidimensionality of chronic cancer pain, child and family suffering, as well as the underlying aspects of the hospitalization process of the child is considered important. In view of this, the referential of complexity in Edgar Morin's perspective could be used as a way to support a more contextualized perception about the reality of the child and their family, as it refers to a way of thinking that values the inseparable relationship between the phenomenon and its context, as well as the interrelations between the intrinsically associated heterogeneous constituents,[9] as is the case with pain.

In this way, although the literature[5,10-13] on chronic cancer pain in children has advanced through scientific research with qualitative and quantitative approaches, little is known about the contextual aspects that permeate the nursing care management of hospitalized children with chronic cancer pain, whereas the focus of researchers is mainly on the issues related to the assessment and management of chronic cancer pain. Thus, the understanding of these aspects, in the perspective of complexity, gains noticeable relevance, given its capacity to influence the assessment and management process of pain, as well as the effectiveness of the treatment of hospitalized children with cancer. Thus, the objective of this study is to discuss the contextual aspects related to nursing care management of hospitalized children with chronic cancer pain in the Complex Thought perspective of Edgar Morin.

METHOD

A qualitative approach study, based on the Grounded Theory methodology and the Complex Thought theoretical framework in the perspective of Edgar Morin. The Grounded Theory method was used by virtue of its ability to produce dense and theorized concepts of a phenomenon,[14] including the underlying processes and dynamics in its respective context.[15] On the contrary, the use of Complex Thought in the perspective of Edgar Morin, is justified by the interest in valuing the multidimensionality of chronic cancer pain and the inherent complexity of the pediatric oncological context.

Data were collected through two techniques: a semi-structured interview and non-participant observation between August 2014 and June 2015. The research scene was the Pediatric Inpatient Unit of a hospital located in the city of Rio de Janeiro, Brazil. This unit consists of 13 beds and the majority of the diagnoses of the hospitalized children are: leukemia, lymphoma and sickle cell disease.

Twenty-one health professionals who fulfilled the following inclusion criteria participated in the research, the criteria were: having at least one year of experience in childhood cancer and pediatric care and the same period of time working in the institution. Health professionals on leave or on vacation were excluded from the study. The research participants were organized into sample groups due to the use of theoretical sampling,[15] whose objective is to find people, places or facts that increase the possibility of discovering variations between concepts and making dense categories with respect to their properties and dimensions. Thus, the first sample group was composed of seven nurses; the second was composed of seven nurse technicians; and the third and last sample group included seven professionals from the multiprofessional health team, two physicians, two physiotherapists, a social worker, a psychologist and a pharmacist.

The questions that guided the interviews with the nurses were: how do you care for a child with chronic cancer pain? How do you perceive the hospitalization of the child with chronic cancer pain? What meanings do you attach to the context of care? The analysis of the statements revealed that the context of care for the child with chronic cancer pain is marked by the need for teamwork, whose objective is to offer the child and his family care in line with their multidimensional needs. In addition, teamwork was understood as an action strategy and an intervening condition in the relationships that permeate nursing care management. Considering the complexity of the exposed phenomenon, it was necessary to expand the data collection to other health professionals.

The guiding questions for the participants of the second and third sample group were: how do you perceive the hospitalization of the child with chronic cancer pain? What meanings do you attach to the context of care? The non-participant observation was performed on five occasions, during the daytime period, after the discourse analysis, and had a total of 54 hours. The contents were recorded in observation notes. It should be emphasized that the finalization of the data collection in each sample group was determined by the theoretical saturation i.e., when the new data collected were no longer changing the consistency or theoretical density of the constructed concepts.[15]

In Grounded Theory, data are collected and analyzed in parallel. The comparative analysis was used, as it is a characteristic of the analyzes conducted by this research method. Data were analyzed by means of the following coding steps: open, axial and selective. In open coding, the data were coded line by line, generating the preliminary codes which, in turn, after being grouped by similarities, gave rise to the conceptual codes. The grouping of conceptual codes by similarities gave rise to categories and subcategories.

In axial coding, the categories were related among themselves and between their subcategories in order to determine their properties and dimensions. An analytical tool called the Paradigmatic Model was used at this period of analysis, which enabled the gathering / ordering / integration of the previously elaborated categories, favoring the emergence of the central phenomenon of the study, performed in the selective coding stage. In the last stage, validation of the results was also performed,[15] which took place in September and October 2016 with the participation of five examiners, three nursing researchers with expertise in Grounded Theory and / or research in the nursing management area and two nursing assistants from the first sample group of the present study. It should be noted that the selection of the examiners occurred was done for convenience. In addition to the coding process, memos and diagrams were used to aid the theoretical analysis of the data.

It should be noted that data collection was only initiated after the approval of the study by the Research Ethics Committee of the partner institution, under opinion No. 355/14, as well as by the Research Ethics Committee of the proposing institution, under Number Opinion 816,736 and CAAE 32795514800005238. All participants signed the Informed Consent Form.

Considering the recommendations of Resolution 466/2012 of the National Health Council of the Ministry of Health, the nurses' statements are identified by the letter E, the nurse technicians by the letter T, the physicians' by the letter M, the pharmacist by the letters FC, those of the psychologist by the letter P, the physiotherapists' by the letters FS and the social workers' by the letters AS. All are followed by a number that refers to the order in which the interviews occurred in each sample group (E1, T1, M1).

RESULTS

Only one of the research participants out of the 21 was male and was in the first sample group. In this same group, the amount of professional experience in childhood cancer and pediatric care ranged from one to 13 years. There was a variation between one and two years in the second sample group considering the same item. In the third sample group, the pediatric hematologists had experience ranging from three to five years. On the contrary, the physiotherapists as well as the psychologist had one year and six months of experience in childhood cancer and pediatric care, while the mentioned social worker had two years of experience in the same scenario. The pharmacist who took part in the stated research reported that she did not work directly with the children, due to her responsibility of managing the institution's pharmacy. However, she highlighted that she had been working as part of the team with the health professionals of the Pediatric Inpatient Unit for two years.

The central phenomenon emerged from the data coding process, - Nursing care management of hospitalized children with chronic cancer pain: a multiple inter-action experience which presents the entitled category as a contextual condition: Unveiling contextual aspects about the care management of the child with chronic cancer pain.

This category is composed of four subcategories: Presenting specificities of the health institution; Understanding the hospitalization of the child with chronic cancer pain; Characterizing nursing care for children with chronic cancer pain; and Revealing family distress.

In the category "Presenting specificities of the health institution", the specificity of the scenario of the study is highlighted as it is a hospital that is configured as a State center of excellence for the care of people with hematological diseases. Thus, the provision of training courses is frequent and necessary due to it being a highly specialized care setting.

The people here are trained. It is a center of excellence. Not that we are better than other hospitals, but we have a differentiated notion (T3).

Here, they offer us many refresher courses. They give us a lot of guidance and these courses are very important (T5).

The health professionals have an institutional pain protocol, which was developed to guide the clinical practice of care for the person with chronic pain, whether adult or child, oncological or non-oncologic. In the meantime, given the relevance of a systematized practice, evaluation and reevaluation of pain are part of the medical prescription and are performed regularly.

*Here, we have a pain protocol and we use it for all types of pain, whether oncologic or non-oncolog*ic (E1).

The institution started to put more emphasis on the pain assessment and the prescription as well. Now, we do checks, every 4 hours and they always orientate us to re-evaluate the pain after one hour (T4).

Pediatric oncology presents specificities related to the care of the child with chronic cancer pain, which was meant to be different when compared to the care established with the hospitalized adult.

Health professionals are much more connected to patients because they are children ... When you see a sick child with pain, their vision is different, their care is different (FC3).

In pediatrics, the staff are more on top of things, they are more concerned with things, and this is in any hospital, not only here. So there is always greater care, there are more guidelines (FS4).

The management of the Pediatric Inpatient Unit is performed by the day nurse, a professional who manages the human nursing resources and the material resources. All nurses develop nursing care management, as discussed below.

*The management of the unit is based on a team with one nurse and four nurs*e *technicians, who are divided into day and night shift. In applying this, we have a nursing assistant who, under our supervision, is responsible for the material* [...] *We have specific materials and we order through a system according to the demands of the unit. We make calendars, manage vacation cover, manage shifts, and we also manage care for the pediatric hematological patient* (E5).

In the category "Understanding the hospitalization of the child with chronic cancer pain" it was highlighted that the treatment of the child with cancer is long and marked by frequent hospitalizations. In this sense, the use of opioids was revealed as an important strategy for the control of chronic cancer pain, however, in the studied context these drugs do not always provide the necessary relief.

The treatment is prolonged and the child always has to be taken to consultations. There are several hospitalizations periods during treatment (E6).

First you start with the medication and then the medication is no longer having an effect. So, you give another medication in the interval period. You give morphine and in a little while, you give dipyrone to help a little but this does not always work (E4).

There are several pharmacological agents. We start with dipyrone and sometimes it does not have the desired effect. So we use ibuprofen which also does not relieve the pain. Then we switch to morphine or Tramal (E5).

Chronic cancer pain was characterized by the nursing professionals as strong, intense and desperate, as it causes the child and the family great suffering.

One very interesting thing is that children with chronic cancer pain *hardly give their pain number 10 on the pain scale. They don't give* 10. *They give 8, 7, 9, because they know their pain can worsen. Many of them know the maximum pain and know that the pain can get worse* (E1).

It's a desperate pain. They have a very intense pain and you notice a very intense suffering, both in the child and in the mother (E5).

The hospitalization of the child with chronic cancer pain is marked by numerous limitations and losses, which are presented by the health professional below.

There are many limitations and losses in hospitalization, such as loss of going to school, loss of friends, freedom that is momentary, coming and going in the hospital, playing (P6).

The limitation of play was also present in nurses' discourses. For this reason, playfulness gains relevance in pediatric care, because it presents itself as a necessity to the child who is threatened by the hospitalization process.

They wait: 'Auntie, I was expecting someone to play with me!' Once the child rang the bell and I ran and asked what had happened and the child told me that there was nothing wrong, she just wanted someone to play with her, because her mother was tired and stressed (E3). *This pain is sometimes the lack of having someone to play with* (E2).

In the oncological context, the cure of the disease is something much desired by the multi-professional health team, by the family, as well as by the child itself, but it is not always possible to achieve this goal.

We know that we can cure many diseases, others not. Sickle cell anemia is chronic and you will never cure it. We can cure some types of leukemia, others we know that we will not be able to cure (M1).

Thus, it is understood in the subcategory "Characterizing the nursing care to the child with chronic cancer pain" that this activity is configured as a complex experience for the nursing professionals, due to the repercussions of care relationships in the emotional dimension of the professional, since the relationship between health-illness and life-death presents symbolic particularities in the context of the child's health.

It is very difficult and I am talking about the emotional part, you see a child suffering with pain. You give palliative medication. You follow that clinical condition day after day. You know there is no cure and it is only a matter of time (T5).

For this reason, the nursing professionals mentioned the need of the health professional to present technical, scientific, and emotional preparation in order to deal with child and family's suffering.

This technical, scientific and emotional preparation is necessary because if you are not prepared, you become lost and everything becomes a novelty (E7). *We have to have a very strong emotional base in care. It's very complicated* [...] *You have to have sensitivity in order to take care of the child* (T5).

Nursing care for hospitalized children with chronic cancer pain was characterized as an exhausting, difficult experience, permeated by professional and personal learning.

It is exhausting because it is a desperate pain and the team has to deal with the mother, with the child and with all the context that this pain causes (E5).

This type of care is very difficult even in the pain evaluation, because of the difficulty that children have in classifying their pain, but you learn a lot (E6).

I've learned that we end up having other ways of caring. You know they are not going to be cured, so your mission is to give support, comfort, and support the family (E4).

We learn to respect human beings more, to listen more, these are the types of learning that I have had (T2).

The following statement shows some nursing care developed with the hospitalized child with chronic cancer pain.

We work on the evaluation and the pain medication. We check the vital signs, we do the hygiene of the child, we or the mother give the bath when the child is very small and doesn't know us, we also give information regarding the chemotherapy (T6).

The sub-category "Revealing family suffering" highlights that hospitalization, cancer and chronic pain causes great suffering to the family of the child and cause changes in the dynamics and structure of the family

The pain is too much for the parents. At that time, they often have other children at home and the child that they left at home begins to develop psychosomatic pain and says he has a headache, but in fact, he wants attention. There are several issues, there are changes in the family structure, married life is changed, work. Then, the pain of the disease ends up being multiplied (P6).

When they (family members) receive the cancer diagnoses, they become very fragile and you have to be careful about how you deal with them (AS7).

The nurse, in care relationships, perceives that the family member has affective, emotional and psychological health needs, as can be seen in the following sections:

I observe the psychological state of the mother, how she is in herself, I orient her to take some time if necessary, to ask another family member to stay with the child so that she can get some rest at home (E1).

I realize that they (family) are very desperate, needing support (E3). *I think the family needs a lot of support, because the family is the child's safe house. If family members don't receive support, they cannot support the child* (E4).

At this point, it is important to highlight that the nurse can compose the social and support network of the family of the hospitalized child with chronic cancer pain, in the different health contexts, favoring the continuity of care.

DISCUSSION

In this research, it was understood that the managerial context of care of the hospitalized child with chronic cancer pain was evidenced as a space permeated by objective and subjective aspects, which in a dialogic way,[9] make care a substantially complex experience. In view of the above, the hospital was characterized as a singular care context as it has specific care and management specificities, particularly for users who depend on hematology and hemotherapy services.

The context of care is also marked by the constant supply of professional refresher/ improvement courses, which were characterized by nursing professionals as necessary for quality assistance to the health of the child with a hematological disease. Chronic cancer pain emerges as a contextual condition that challenges health professionals to seek the best evidence for their correct assessment and clinical management.

Health professionals have an institutional protocol which is designed to assist them in pain assessment and management. The use of protocols in the care of children with chronic cancer pain was characterized as essential as it standardizes pharmacological analgesia and confers practicality to the development of care. A study in New Zealand found that 97% of nurses who were members of the College of Emergency Nurses considered it important to have a protocol that guides pain management and characterized the courses aimed at managing this phenomenon as beneficial.[16]

The Pediatric Inpatient Unit is characterized by having children who depend on a permanent multiprofessional approach to maintain quality of life. In the scope of teamwork, the nurse is the professional who manages the Pediatric Inpatient Unit, human nursing resources and material resources. In addition, all nurses manage care for hospitalized children with chronic cancer pain.

From the perspective of nursing care management, an integrative review identified eight nursing actions: manage and lead the nursing team; plan nursing care; educate / train the nursing team; manage material resources; coordinate care; perform the most complex care and / or procedures and evaluate the results of nursing actions.[17]

The treatment of the child with cancer was characterized as long and permeated by frequent hospitalizations. It is a complex, painful experience, marked by frequent medical consultations, chemotherapy, radiation, surgeries, routine exams, withdrawal from school, limitations in performing some activities, loss of opportunities, and changes in appearance and lifestyle.[18-20] In this case, it is necessary to provide support and comfort, especially when the child complains of pain and exhibits behavior of fear and fatigue.[21]

Pharmacological analgesia with opioids is necessary to provide pain relief and to alleviate the suffering of the child and family. In this context, the literature highlights morphine as an opioid that has remained the first choice for the treatment of moderate to severe oncologic pain, for reasons of familiarity, availability, cost and superiority.[22] The medication is chosen by the medical team, who together with the team, evaluates the clinical condition of the child, defines the treatment and prescribes the medications, following the pain protocol defined by the institution.

Chronic cancer pain was characterized by nursing professionals as strong, intense and desperate. The hospitalization of this child is marked by losses and by the acquisition of new limitations. Thus, a study revealed that the hospitalization of the child in a chronic condition is extensive, complex and marked by several transformations. The child's body is invaded by devices that reveal their limitations and their new care needs.[23]

A study[24] showed that the child saw hospitalization as a necessary process for their treatment and for the control of complications related to the disease and the chemotherapy, and for that reason, accepted to go to the hospital whenever necessary, even if this results in their hospitalization. In their hospitalization, their dreams and projects are broken and replaced with feelings of loss.[25] It is stressed that continued losses can trigger anxiety and depression in the child with cancer.[26]

The literature emphasizes that in addition to bearing the stigma of cancer, the child fails to experience situations that are important for their human development, such as social interaction with friends and teachers at school.[27] In addition, cancer is a chronic health condition which has repercussions on childhood which can limit the practice of some childhood games.[28]

In the same context, a study[29] noted that long periods of hospitalization may lead to changes in the involvement of the child with cancer in play activities. For this reason, it is emphasized that even when hospitalized because of the disease, the child continues to develop as a human being and needs to be stimulated to play, study, question and accomplish everything that a healthy child is encouraged to do.[27]

Their treatment has repercussions within the family, often causing changes in the dynamics, structure and functionality of the family. Regarding functionality, a study highlighted that families of children with chronic pain have family malfunctions, have more conflicts and less cohesion when compared to the families of healthy children.[30] In connection to the above, a study revealed that the diagnosis of cancer in the children had negative impacts on the quality of life of the parents, 61% reported poorer eating habits, 69.9% reported doing less exercise, 81% reduced their sleep time, and 82.9% reported less time to do past-time activities.[31]

In addition to the mentioned disorders, the hospitalization of the child with cancer leads to the occurrence of family suffering, which begins with the diagnosis of the disease. This circumstance inspires the attention of the multiprofessional health team to the possibility of offering support, both emotional and social, necessary to face the disease and the treatment. On this basis, a study conducted in two hospitals in Turkey identified that all mothers of children undergoing cancer treatment reported the need for social support, but only 73.9% received the necessary support. Most social support received was emotional (76.9%) and informative (49.2%), and 54.5% of the mothers reported expecting social support from the nurses.[32]

In addition, it is noted that, in the family environment, siblings of children hospitalized with cancer cry out for parental attention and may develop psychosomatic pain in order to have them by their side. In view of this, a study[33] revealed the importance of siblings of oncological children being supported and involved in the care plan at the time of diagnosis of the disease. In this same study,[33] it was identified that they presented needs for attention, information, to have their fear/concern managed by the team, to want to help and to have a normal routine. In line with this result, a study[34] reinforces the importance of siblings of children with cancer not being neglected by the nurse, given their greater vulnerability to psychological distress.

The treatment of the child with cancer aims to cure the disease, and when this is not possible, it is managed to provide comfort and control pain. In this context, oncologic palliative care is emphasized and emerges as an approach that also aims to promote the child's quality of life and provide support to the family at this difficult time. It is understood that palliative care in childhood is directed at the body, mind and spirit, and involves the provision of support to the child's family.[35] Thus, it is an approach that values life and living with quality, even in the dying process.

In this regard, a study revealed that the daily life of the child in palliative care is greatly affected by pain, which was highlighted as causing suffering, especially when poorly managed by the healthcare team.[36] It is understood that pain in children in palliative care may be related to the disease itself, medical interventions or to treatment.[37]

Nursing care management for children with chronic pain in oncologic palliative care requires thinking about the concept of "total pain". From this concept, it is possible to understand that pain in patients with advanced disease is qualitatively different from acute pain, because it is multifactorial / multidimensional / complex. In this perspective, "total pain" is conceived when it transcends its physical aspect and begins to involve the spiritual, psychological and social dimension of the person, threatening their integrity.

Based on the above, in the context of oncologic palliative care, the care of the child with chronic pain is revealed as an invitation to a paradigmatic break, in search of a thought that considers the dialogical relationship between order / disorder and life / death. The dialogic principle, in the view of complexity, is what implies the idea of a union between two notions that should be mutually exclusive, but at the same time complementary and antagonistic.[9]

Through this perspective, caring for a child with chronic pain in oncology palliative care means giving him a dignified life in during the dying process and respecting human finitude in the infinity of life. The dialogical relationship of death / life is interpreted in the literature as a paradox of the human condition, since death is considered a part of life and life as part of death.[39] Thus, every human being shares the threat of death, while it is integral part of life.[40]

Care management has been characterized as difficult by nursing professionals as it requires scientific, technical, sensitivity and emotional preparation in order to deal with the suffering of the child and the family. The literature reveals that the emotional unpreparedness and the difficulty in dealing with the death of the child and the suffering of their family members constitute important causes of professional stress,[41] which, when neglected, can cause anxiety disorder, depression and absenteeism.

In this line of thinking, a study[42] characterized the care of the child with cancer as a challenging practice, since cancer is one of the diseases that has the highest incidence of pain, suffering, fear, anxiety and stress, both for the patient and for the relatives and health professionals.

In addition to being difficult, caring for hospitalized children with chronic cancer pain was also characterized by nursing professionals as exhausting, since it involves an entire context marked by the death / life dialogic ,child and family suffering, as well as by the challenge of evaluating and managing chronic cancer pain. Corroborating this result, a study[43] from the perspective of nursing professionals revealed that caring for children with cancer is an exhausting and sad experience. In this case, participants in the aforementioned study[43] reported that the most difficult part is the becoming emotional involved with the suffering of the children and the parents.

Caring for hospitalized children with chronic cancer pain was characterized by nursing professionals as an experience permeated by learning, since there are discoveries about new modalities of care and human values. From this perspective, literature[44] states that nursing professionals who work in a pediatric oncology unit learn to give new meaning to life, family / professional relationships, illness and death due to their experiences of caring.[44]

Nursing care developed for hospitalized children with chronic cancer pain includes: medication administration, vital signs verification, hygiene, pain assessment and management, and giving information about treatment. Corroborating this result, the literature[45-46] reveals that the hospitalized child with cancer needs multiple types of care, such as: medication administration, hygiene, peripheral venipuncture, vital signs verification, chemotherapy administration, blood transfusion, training with the family to perform care, comfort, family support, pain assessment and management pain.

The results of this study present limitations in the criterion of theoretical generalization, since they reveal contextual aspects referring to a single institution in the city of Rio de Janeiro.

However, it is possible that it presents a certain proximity to other realities of care for hospitalized children with chronic cancer pain. Thus, it is recommended to develop new research on the subject in order to give more density to the produced content.

CONCLUSION

Based on the results presented, it was understood that the context of caring for hospitalized children with chronic cancer pain is complex, since in addition to asking health professionals for technical, scientific, sensitivity and emotional preparation, the death / life dialogic presents itself as a condition that challenges them to recognize and deal with the finitude of life. The experience of caring for a suffering child, caused more by chronic cancer pain, reveals itself as difficult and exhausting, but is permeated by personal and professional learning.

The hospitalization of the child with chronic cancer pain is long, marked by losses, limitations, and changes in family dynamics. Its impacts may also affect family structure and functionality, which may make coping with the disease an experience of order or disorder for the family. In this context, it is important to emphasize that chronic cancer pain was characterized by the health professionals as strong, intense and desperate, requiring adequate pharmacological treatment based on opioids.

In the oncological context, palliative care emerges as a way to promote comfort, control pain and support the family as a means to preserve the integrity of the child and to offer the multidimensional support that the family needs. In this context, it is important that nursing care management be performed in a manner consistent with the multifactorial nature of pain, as well as with the multidimensional needs of the child and family.

Emphasis is placed on the nurse's role in the pediatric oncology context, whose needs are related to the management of the pediatric inpatient unit, management of human and material resources, as well as the management of direct care to the children. Therefore, the provision of pain protocols and participation in training courses for adequate assessment and clinical management appear as contextual aspects necessary for the effectiveness of care management.

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