ORIGINAL ARTICLE

CHALLENGES OF NURSES AND CAREGIVERS IN THE CARE OF CHILDREN IN ONCOLOGICAL TREATMENT

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Highlights:

(1) Understanding the complexity and challenges of childhood illness. (2) Understanding the importance of professional support during the illness process. (3) Overcoming challenges and barriers faced by families as caregivers.

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CHALLENGES OF NURSES AND CAREGIVERS IN THE CARE OF CHILDREN IN ONCOLOGICAL TREATMENT

ABSTRACT

The practice of caring in pediatric oncology is challenging, since it requires, in addition to specific material and therapeutic resources, a health team and caregivers attentive to the demands inherent to this universe. Thus, the objective was to analyze the challenges of caring for children with cancer from the perspective of nurses and caregivers. It is a strategic social research, with qualitative approach, which had as participants 18 nurses and caregivers of children in oncological treatment of two public health institutions of the hinterland of Pernambuco. Data collection was carried out by semi-structured interviews, analyzed in the light of the Complexity Paradigm. Thus, from the reports of the research participants, several challenges were identified as a result of cancer treatment emerged as a challenge for nurses and caregivers in the follow-up of the affected child, what required these actors the development of mechanisms to deal with situations of uncertainty and insecurity, in order to provide care without being overwhelmed by the difficulties imposed by the context of the disease. Nurses and caregivers listed relevant aspects about barriers to cancer therapy, revealing strategies used to overcome barriers found and, thus, it was shown that the emotional of the interviewees appeared as a hindrance to treatment, beyond the recognition of the existence of gaps in the training of nurses, limiting their performance. It is concluded, therefore, that the challenges experienced in the care of children with cancer involves a context of significant changes in the routine of the family and the child, as well as difficulties in the logistics of displacement and hospitalization, and the awakening of fears and uncertainties before the treatment brings negative impacts on the experience of this disease process.

Keywords: Child health; Nursing care; Oncological nursing; Neoplasms; Caregivers.

INTRODUCTION

Cancer terminology is used to describe the group of more than a hundred diseases that share as common characteristics, abnormal and uncontrolled cell growth, which can occur in any part of the body, having the ability to spread from one site of the body to others, this process being called metastasis[1]. Neoplasms appear in prominent position in mortality rankings on a global scale, standing out as the second leading cause of death in the world, being responsible for 19 million deaths in the year 2020[2].

In Brazil, a survey conducted by a reference institute on cancer follows the same pattern of worldwide distribution, with an estimate that there will be for the three-year period 2023-2025 the occurrence of 704 thousand new cases of cancer each year in the general Brazilian population[3]. In this context, in the country, childhood cancer assumes epidemiological characteristics similar to those of adults. Over the years, the occurrence of cancer cases was taking uncontrolled proportions, currently configuring it as a public health problem, especially when associated with its degree of morbidity and mortality, in which about 70% of deaths occur in underdeveloped or developing countries, as is the case in Brazil, reflecting signs of possible failures of current health systems, either in screening or treatment effective[2,4].

Therefore, the oncological nursing stands out in that the nurse is an important professional to administer care to the child, observing signs/symptoms suggestive of neoplasms, enabling the identification and establishment of assertive interventions in the process of illness by neoplasia, promoting better prognoses and conditions for a better care to children[5].

Thus, the present study is considered to give visibility to the assistance provided to the cancer patient, understanding the perspectives and strategies adopted about the treatment and its particularities, visualizing the patient in a holistic way, revealing the mechanisms of coping with the disease from the point of view of the nurse, as a professional daily exposed to the feelings unleashed before a child in oncological treatment, as well as the family/caregiver.

The childhood cancer disease brings several impacts on the child’s family relations due to changes in routine, adaptations to the needs of the patient, considering all its particularities, which involve changes in his daily life; the separation of siblings and other family members; distance from school; restriction of games and friends, in addition to the loss of a healthy body. All this makes the treatment process a time of need for comprehensive care not only for the child, but also for his family[4].

Thus, it is evident that the process of caring for a child in cancer treatment is accompanied by a context of hopelessness, impotence, fear, guilt and uncertainties, which has the potential to negatively impact on the well-being of the child, directly affects the way the disease is dealt with and the positivity of the treatment[4]. In the meantime, investigating this reality will allow a greater visibility to the assistance provided to this public by understanding the perspectives and strategies adopted about the treatment and its particularities, revealing the mechanisms of coping with the disease.

Therefore, this study started from the following question: what are the main challenges faced by nurses and caregivers of children in cancer treatment? It aimed to analyze the challenges of care for children with cancer from the perspective of nurses and caregivers.

METHOD

This is strategic-social type research, with a qualitative approach, as it aims to understand the subjects in their own contexts where social phenomena and subjective aspects of social action develop[6].

The principles of Complex Thought that founded the construction of this work are the Dialogic, the Organizational Resource and the Holographic. The dialogic principle claims the conjugation and association of contradictory elements in the analysis of a given phenomenon, relating them at the same time as complementary and antagonistic, producing reorganization and complexity[6-7]. The organizational resource principle conceives, unlike the cause-effect relationship, the nonlinear process in causal relations, which highlights products and effects as causes and producers of what produced them, that is, the individual is product and producer of the interactiones[8]. The Holographic Principle recommends that the study of a phenomenon should provide the distinction between the parts and the observation of the whole, incorporating these parts, so that they dissolve and lose their differences[6-9].

Therefore, the epistemological positioning is based on the Complexity Paradigm, which denies the opposition between complexity and simplicity, and understands as complex what is "woven together" and is in fact the fabric of actions, happenings, events, determinations, interactions and feedbacks, that form our phenomenal world[7-8]. The Paradigm of Complexity emerged in search for the understanding of complex phenomena and consider the contradictions, instability, unpredictability and uncontrollability of these phenomena, understanding them in constant transformation, always in the process of becoming and becoming, dialect, in this way, enables the multidimensional, transdisciplinary, dynamic and contextual approach to reality[8].

Thus, when considering the contradictions and unpredictability, complex thinking enables a multidimensional view and understands the experience of childhood cancer in an interaction and interdependence of its elements, allowing an expanded look and greater degree of understanding and knowledge.

The research was carried out in two institutions that provide oncology care to children, one with outpatient care and the other in the hospital sector that functions as back beds for children's oncology patients, both located in a municipality of the hinterland of Pernambuco. The study population was composed of eighteen participants, being nurses and caregivers of children in cancer treatment. As inclusion criteria, nurses were chosen to be working in the oncology sector for a period equal to or greater than six months; and in the case of caregivers, that was the child's primary caregiver and presented age above 18 years. The exclusion criteria were nurses who were on vacation or leave at the time of data collection, and caregivers who were minors.

The data collection took place between December 2020 and January 2021, through semi-structured interviews in a pre-established place and time, according to the participant's availability, with an average duration of 20 to 33 minutes and were performed with the aid of a portable voice recorder.

The script of the interviews covered guiding and open questions that allowed to obtain a specific view of the participant on the phenomenon under study. The question script to nurses included the following guiding questions: 1. Do you have difficulties in dealing with the oncologic child? 2. How do you describe your emotional state when caring for a child with cancer? 3. What are the challenges identified in treatment in pediatric oncology? 4. What strategies have you adopted to work with children in cancer treatment? 5. Can you describe the feelings unleashed in the face of bad prognoses? 6. How do you feel about the imminent death of a child with cancer?

Already, the script of questions to caregivers included the following guiding questions: 1. What difficulties did you have in dealing with the child's treatment? 2. Did you feel the need to learn more about your child’s illness? 3. Did you need to look for additional information in websites/books to better understand the disease? 4. Can you describe how your emotional state was/is before the care of the child with cancer? 5. What strategies are used to provide better care for the child? 6. How was/is your relationship with the nursing team that attended/cares for children under your care?

To maintain participants' anonymity, the N1 to N7 coding was adopted for nurses and C1 to C11 for caregivers, according to the order in which the interviews were conducted. The recordings with the participants were authorized with the signature of the Informed Consent Form and, subsequently, the recorded speeches were transcribed in full. The number of interviews followed the data saturation criteria, both for nurses and caregivers.

The combination of these methods of analysis and subsequent interpretation were guided by the Complexity Paradigme[6-7], following the roadmap with three phases: Classification and organization of the information collected to obtain an overview of the research as a whole and the vision of specific issues related to the totality of the researched. The reports were transcribed in full, listing the most cited points, more relevant and specific to the phenomenon under study; Organization of reference frames with the significant elements of the participants' answers, in order to have an enlarged look at the set of information that makes it possible to categorize them; and, Concentration of reports, understandings, ideas that were discussed and were implied/understood by concepts, to establish relationships between the data through their organization in categories.

The present study followed all the ethical aspects related to Resolution 466/2012, having been approved by the Human Being Research Ethics Committee of the Institute of Integral Medicine Prof. Fernando Figueira, under the number 4.052.022/2020.

RESULTS

Seven nursing professionals and 11 caregivers participated in the study. Among the nursing professionals, four were women, with an average age of 33 years, and most had children. Regarding the profession, most of them had less than five years of training and up to five years of service in oncology.

Regarding the caregivers, there were 11 participants, all women, with an average age of 28 years, and only one had no child. Nine claimed to be mothers of the children they were accompanying, one was the patient’s sister and another grandmother. Regarding the time of treatment, most stated that the child had between one and five years of cancer therapy.

Data analysis unveiled four strategic categories, namely: Challenges of nurses and caregivers during child cancer treatment; Emotional battle of caregivers in the experience of the child with cancer; Limitations of professional performance in pediatric oncology by the deficit in academic training.

Challenges of nurses and caregivers during child cancer treatment

Regarding all the problems involved in oncological illness, when asked about the challenges experienced in the treatment of childhood cancer professionals and caregivers reported that the greatest of them is to observe the experience of painful procedures, Long periods of hospitalization and chemotherapy performed by children, which are seen as a being of greater vulnerability and fragile, who has no understanding of what is happening to her.

> *[...] It's difficult for us to understand why that child is going through all that, right? Because it's not an easy treatment [...] there are painful procedures, hospitalizations, chemotherapy. (N2)*
>
> *[...] Because it's a child [...] we are much more sensitive, the family is much more sensitive, so it's a disease that has many ups and downs [...]. (N6)*
>
> *[...] It's a matter of catching it, getting access, because sometimes we can't get access right away... right, and then [...] we suffer a lot, we suffer with the children, even children, regarding the treatment. (C10)*

Thus, given the particularities that involve the care of the child under oncological treatment, the nurses pointed as another challenge the conquest of trust, as well as the creation of bond between the child and the family, as a way to optimize the performance of necessary procedures involving the prescribed therapy, since many of them are traumatic and painful.

> *Children need to trust you, trust you as a professional. You need to win them over and bring them closer [...] so that the care isn't as traumatic as it already is [...]. When a*

> *child trusts you, they're less afraid. (N1)*
>
> *[...] We can create a bond [...] instill trust that sometimes many of them aren't so open to [...], especially when you're just getting close and gaining the trust of that child to be able to provide care [...]. (N2)*
>
> *[...] There are children who come here completely distressed, and I play around, bothering them [...] until they forget that I'm the guy who's going to prick them, who's going to install the IV, that it's going to hurt. (N3)*

Still on the challenges experienced in the care process of children with cancer, some professionals and caregivers reported the physical structure and lack of a place of reference for hospitalization as a limiting factor to treatment.

> *We don't currently have a quality inpatient oncology service yet. We have a small, well-equipped space at (name of hospital) [...]. (N3)*
>
> *[...] A more adequate physical structure, here we only have two areas (two rooms in the service specifically for children's care), which is too small for the number of children we have. (N4)*
>
> *[...] I believe our region has a service deficiency, as we currently don't have a hospital that accepts these patients outside of here [...]. Many patients we have here need to travel to Recife for treatment, to Salvador, because of this difficulty in the region. (N5)*
>
> *[...] We don't have a dedicated space here, we have a room provided at the hospital. (C3)*

Although in the course of the reports it is noticed that the fields of research acted as complementary to each other in the services provided, the statements of the interviewees discuss a factor that is sometimes suppressed amid the difficulties of treatment, the physical space of hospitalization for children with cancer, where even if humanization measures are adopted, the hospital environment alone annoys the child by taking him out of his routine and placing him in a hostile hospital environment.

Regarding the difficulties listed exclusively by caregivers, it was pointed out the lack of resources to purchase medications when they are not available free of charge, and logistics of travel to reference centers, such as the city of this study, for the child to perform chemotherapy when the municipality of origin does not have the necessary resources to perform this treatment.

> *[...] He needs to take supplements and we can't afford them. (C3)*
>
> *[...] We're not from here, right? That's the issue (of money) because we have to be here every week, right? (C10)*
>
> *[...] This medication cost seven thousand BRL [...], because I wanted to see my son well, and I didn't know how to buy it because it's not just seven thousand BRL and you don't need just one box, you need four boxes [...] and I didn't know what to do. If I sold my house, I wouldn't be able to buy four boxes; it would be enough for three, but he wouldn't need just three. (C11)*

The interviewees' statements highlight the financial dilemmas that families face in order to afford some costs associated with treatment. Although the services in which these children are treated are under the responsibility of the Unified Health System (SUS), a large part of the interviewees were from other municipalities, bringing to these places the costs of travel to perform treatment, In addition to some therapeutic resources are not included in the protocols used by the Ministry of Health, requiring families to take legal action to obtain medication or seek purchase by their own means, due to the judicial delay involved in some cases.

The experience of children with cancer is accompanied by many challenges, and professionals and caregivers needed to adopt strategies so that this process was mitigated and they were able to provide more humanized care. Thus, when nurses were asked to disagree on the strategies adopted to be able to provide good care, they brought that they try to deny their own feelings, read when their therapeutic approaches.

> *[...] Even though it affects us, I don't usually show that I'm so shaken [...] to the family, mainly because I think they're already suffering so much, and seeing the professional who's there to demonstrate trust is shaken isn't very good for them either. (N2)*
>
> *[...] It ends up really affecting both the professional and the family [...] leaving the emotional side aside a little so that it doesn't interfere with the professional side and we can act in the best possible way with that patient. (N6)*
>
> *[...] We don't expect all this suffering, right, to see a child suffering in this situation, but over time, we end up not becoming colder, but becoming stronger because of the*

> *situations we've faced. (N7)*

Considering the speech of some nurses interviewed, it was observed that they are daily exposed to the experience of challenges that put them in situations of extreme joy by patients who receive discharge for healing, even those to whom many efforts have been devoted for months or years, but who unfortunately did not survive, leaving the professional with a sense of frustration.

> *We've had cases here where we take babies [...] and then they grow up, they spend two years here with us. [...] When this child finishes this treatment, we become so attached, we release them after two years, dying of love for them, and then sometimes there is a relapse, recurrence [...]. So when this child comes back with the diagnosis of the disease returning, they come back with a terrible prognosis [...]. It's a pain as if they were really a loved one, a family member of ours. (N4)*

From the point of view of caregivers, on the strategies most used to overcome the challenges of child treatment, there were reports of attempts to offer exclusive care to the child and empower themselves more about the aspects and procedures that involve the disease, in order to provide better care for this child:

> *[...] Time is more for him, right? [...] because he has a lot of pain, sometimes we forget about others and think more about him, [...] the priority is more about himself. (C6)*
>
> *[...] it's total care, it's total dedication. I had to put my job aside and today I'm dedicating myself solely and exclusively to her. (C8)*
>
> *I learned how to give injections, the gralopim, which she takes home, [...] how to apply bandages [...]. Since hers was a tumor, it was pretty bad, so I had to learn how to clean her gums. (C4)*
>
> *[...] I learned how to change diapers, how to apply bandages because she has bedsores, [...] So, I do it, but it's supervised by the nurses here. They explain everything to me thoroughly, they watch, I send photos so they can explain, know what to do, what to use, what not to use. I didn't do any of that before, and I learned. (C9)*

In this context, it is noteworthy that the various ways experienced by caregivers in an attempt to overcome the challenges imposed by the child’s illness shows that the way of experiencing this process varies from person to person. Some have shown to accept and face more positively the disease, with hope that the cure will be achieved, whereas others avoided even speaking the name of the disease and not reporting its aspects as an attempt to deny the problem and minimize the suffering that the treatment and its phases bring to the patient:

> *[...] Dealing with these things that I don't even have the courage to talk about, it's very difficult for us to even talk about [...] because I feel really bad too. (C5)*

Caregivers' emotional struggle as they experience their child with cancer

The emotional state of people who accompany and care daily for a child with cancer was prone to high loads of negative feelings, such as fear, uncertainty, anger and sadness, and respondents showed, through the reports, how they feel in this daily battle before the challenging confrontation of this disease.

> *Over time, people learn to cope better, right? [...] At first, it's quite complicated. I thought I was having a nightmare, right? I tried to wake up, but I couldn't. (C4)*
>
> *A shock, right? [...] I'm not the same person anymore; we become very sensitive, everything makes our hearts race. (C7)*
>
> *[...] It really shakes me up [...] it's very complicated. I try to stay calm, sometimes I manage it, sometimes I get stressed, sometimes I even end up saying things I shouldn't say. (C9)*
>
> *[...] I'm anxious, I've been suffering a lot, right? A lot of anxiety, many sleepless nights, my emotional state is very shaken, and I'm also experiencing health problems precisely because of her illness [...]. (C10)*

The speeches brought portray how the illness of the child brings with it a burden of suffering for the whole family, which mobilizes and begins to live in function of the sick child. Faced with this process of uncertainty of death or healing, some caregivers cling to faith and spirituality as a way to face these difficult and uncertain moments.

> *[...] We know we have to give him confidence [...] we have to have a lot, ask God for a lot of strength, in reality, it's God who sustains us, you know?! (C1)*
>
> *[...] After almost five years of treatment, of struggle, I have a better understanding of*

> *the situation, God has given me the strength to overcome the difficulties with him [...] he had an early relapse [...], I was convinced that only God is in the cause [...]. I've been in this fight alone and for a long time [...], but through my faith, the Lord helps me overcome the struggles, but it's not easy. (C11)*

Thus, even in the moments of difficulty in treatment, religiosity allows the caregiver to remain firm in the face of the adversities of cancer therapy, and in the moments of loss they cling to this as support elements to overcome grief.

Limitations of professional practice in pediatric oncology due to a deficit in academic training

Considering the importance of scientific knowledge acquired in graduation as a way to favor a qualified nursing care, professionals were asked if they believe they have been prepared during the undergraduate course to act in the assistance to the cancer patient, if they chose this area of activity by free will or vocation, or if they went to work in this field only for a unique opportunity.

> *No! The undergraduate program must have at least one specific course on oncology, because we have some tasks that only nurses can perform and that we aren't trained in [...] we perform procedures on children, practice catheter insertion, we don't do in the program. (N1)*
>
> *[...] Unfortunately, the undergraduate program is very deficient for working in oncology [...]. I studied practically nothing about oncology [...], in the oncology internship, we had, I think, a week of internship, which is very little. Unfortunately, nurses who graduate from the program have to specialize because they have no qualifications to take over the department [...]. (N2)*
>
> *[...] I wasn't prepared to work in oncology, you know? I came because the department was understaffed, so I came and ended up staying. (N4)*

The interviewees emphasized that graduation has deficits in the training process and identify the need for specialization/ training to work in oncology. These findings show that academic training, especially in some more specific areas of the nurse’s curriculum, is deficient, such as oncology.

DISCUSSION

Childhood cancer is a problem that causes several changes in the life not only of the child, but also of all those who live with it[10-11]. By means of the dialogic principle, it is observed the relationship and codependency between the affection directed to the child’s being and the obligation in care. Internal conflicts and instabilities due to living this process alongside the child suffering from the disease have the potential to impact in different ways on the lives of nurses and caretakers[6].

A professional who acts in the assistance of a child with cancer, as well as a family that experiences this process of illness, experience complex moments, with the awakening of extreme feelings, whether they are of joy or sadness, and the closer the bonds with the sick child, the greater the emotional impacts for those who accompany their treatment[4,12].

In addition to the care of the sick child, the Complexity Paradigm refers to the perception that, the fact that the patient in question is the child’s audience, stands out the respect for the phase of life in which the child is, because childhood shows itself as one of the most important phases of living, in which the child begins to establish social and family relationships, build their own image and self-concept, and experience experiences that will have an impact throughout their life. In addition, it is a phase of body maturation, which establishes environmental interactions that help in their recognition as a social being[6,10,13].

Under the lens of organizational resource, it is perceived the existence of a paradox that shows that a child experiencing the changes arising from cancer treatment appears as a great challenge for all involved, given that the disease provides many changes in the routine of the family, taking it from their daily activities of playing, studying, having their social interaction, being these replaced by the need for hospitalizations, performing various painful procedures, medications and also by the side effects of drugs, changing from food to the way it is recognized as a child[11,14].

In this sense, a review study that addressed the readjustment of the routine of caregivers of children with cancer, evidenced that it is common for these subjects to turn all their attention to their sick being, and leave other activities in the background, such as professional assignments, the distance from the home, other children and spouses, which may result in the risk of developing a process of physical and mental illness, requiring the adoption of strategies by caregivers and professionals who work with this public in order to facilitate and humanize attentions[11].

Within the scope listed by the participants, the patient's trust in the professional was shown to be a key piece for assistance, as stated by Paula and colleagues[15], who reiterate the patient's confidence factor as something extremely necessary in the construction of the professional-patient/ caregiver, and that from the establishment of this bond, care happens more quietly, and the assistance ceases to be a moment permeated with distress for both and becomes a moment of exchange and care. All this is essential for this assistance to be effective and more humanized, enabling the patient to develop their autonomy regarding therapies, as well as helping the professional in the exercise of their activities.

In addition to confidence, other studies show that the place where care is administered is also an essential point, because the oncological treatment already presents itself as a tense moment, thus, it is important to understand that children in this modality of treatment need care in places that respect their age, be cheerful, colorful environments and with elements that are part of their world. All this, combined with a humanized approach, has the power to reduce stress before the procedures they need to go through and make the care less traumatic, both for children and their families[14,16].

In this context, a study conducted with nurses who assisted children in palliative cancer treatment reaffirms the importance of an adequate physical structure according to the profile of the patient to whom the service is intended, Understanding that there are many barriers that can limit and compromise the quality of services offered, depending on where this assistance is provided[4].

Also considering the challenges experienced by nurses and caregivers, the latter reported a lack of logistics for the child to have access to the necessary care, where in most cases these patients and their caregivers need to move if urban centers to have access to treatment. This perception corroborates the findings of a study carried out in a children's oncology center in Argentina, which relates the difficulties of access to cancer treatment as a true migration of care, generally experienced by mothers of children with cancer who, the lack of access to adequate diagnosis and treatment in their provinces, need to abandon their routines and start a journey towards large health centers located in capitals so that children can have access to cancer therapy, often without guarantees of access to the requested services[16].

In addition to all the wear and tear that changes bring to patients and caregivers, and of the feelings and meanings attributed, it is noticed that the pediatric oncological treatment entails in professionals working in this sector an emotional as can be demonstrated in two studies, where it was evidenced that the emotional wear of nurses working in children's oncology has become an important factor for triggering mental illness or even abandonment of the sector due to the difficulty these professionals face before cases of childhood cancer, especially those where the therapeutic possibilities have been exhausted and the child is in a terminal state[14,16].

Allied to this, the daily care is directly linked to the patient's comfort during the death process, generating in professionals controversial feelings of impotence and frustration that, although aware that everything possible has been done, the professional ends up dealing with feelings of loss and grief for that patient[12].

Other studies emphasize that the emotional burden placed on the nursing professional in the care of patients at risk of life, especially those with cancer, is very large and puts them in a position of intense exposure by the wear and tear caused by the suffering to which the disease exposes the patient, caregivers and also the professionals themselves, and, in the meantime, the dialogic analysis reveals that all this requires from these agents a greater psychological preparation and above all a greater ability to deal with their own emotions before the situations experienced in the daily life of oncology services, especially in oncopediatrics[14,16-17].

Another highlight in this research is the family acceptance of the diagnosis, which also presents itself as one of the main causes of impacts to treatment. Authors emphasize that family acceptance and coping with the disease often depend on the stage of the illness process, and the post-diagnosis period is more complex for both children and their relatives, in view of the fact that the confirmation of cancer exposes those involved to a wide spectrum of changes through which the family will pass with the advancement of treatment. And, despite the tiredness of the experienced situations, many caregivers try to better understand the process and accept the conduction of situations[11,18].

In this perspective, authors reinforce the negative view of the disease for these subjects, because linked to the cancer name arise in relatives the feeling of fear of death of the loved one, in addition to the limitations that treatment imposes on patients and caregivers. Thus, it is necessary that health promotion actions, especially through dialogue with the caregiver, be implemented so that the experience of cancer in the family is less burdened with stigmas and less traumatic, favoring a better coping with the disease[13].

Faced with the experience of cancer, the feeling that most causes suffering to caregivers and nurses is the fear of death, understanding that this is able to emerge negative emotions attributed to the fear of separating from the loved one[19]. Thus, studies affirm that faith and spirituality emerge as pillars that ultimately provide spiritual comfort to caregivers during the entire process involving cancer therapy, emphasizing that, in addition to these, a sensitive approach by the health professional has great importance in the resignification of care for children with cancer, which can transform it into moments of empathy and integral care[12,19].

By the logic of the holographic principle, it is observed that dealing with feelings of loss requires a lot from the caregiver, as well as the professional, who will be before patients in different degrees of involvement by the neoplasia, Balancing the feelings of hope and positivity together with the moments of insecurity and anguish experienced daily, in order to provide care without being overwhelmed by the difficulties imposed by the disease[11,16-17].

Another limiting factor raised by professionals was the deficiency in the academic training of the professional to act in oncology, what corroborates with other studies that show that most of the time the professional only has awareness of the complexity that involves oncology and the inherent emotional wear of this, when they assume this area assistance[16-17]. Oliveira and collaboratores[17] also emphasize that, although it seems complicated to insert oncology disciplines in undergraduate courses, given its specificity, this becomes an increasingly evident need, as well as the innovation of care techniques and protocols that enable more and more professionals to deal with these patients.

Therefore, considering that nursing is a profession loaded with responsibilities, when the professional, by choice or need, assumes sectors that have a higher level of complexity of care, such as oncology, training and constant updating make it if inherent in this sector[20]. In addition, the academic training of these professionals requires a good knowledge base that allows the professional to appropriate the specificities that are inserted in oncology. Therefore, it is understood that this study brings practical implications to the theme that can be transformed into actions with these professionals, considering the aspects addressed by them in this study and analyzed in the light of the Complex Paradigm.

The research presented some limitations related to the difficulty of access to professionals, due to the demands of work, which was evidenced by the difficulty of reconciling dates, short time for interviews and willingness to participate in the collection. As for caregivers, the difficulties existed considering the Covid-19 pandemic, which limited access to them for fear of contamination.

CONCLUSION

The study showed the challenges experienced by nurses and caregivers in the oncological child care process involves elements ranging from the physical structure, difficulty of access to some therapeutic resources, to the perception and acceptance of cancer diagnosis, which are closely linked and have positive and negative impacts on these experiences.

It was evidenced that the emotional battle of caregivers is permeated by difficulties and changes imposed by therapy, changes through which not only the child passes, but his entire social and family circle. All this is evidenced by the perception of the risks that the disease brings, including the finitude of the loved one’s life, especially for caregivers who need to learn how to deal with the physical and emotional needs of the patient, and in return with their own feelings experienced during the therapy.

For nursing professionals, however skilled they are, acting in oncology is an arduous task that requires a lot of emotional control to be able to perform their functions, having as aggravating factor the emotional wear inherent in exercising the profession, which causes the occurrence of negative outcomes, these professionals experience a whirlwind of feelings. And, coupled with this, the limitations associated with the knowledge deficit, as a result of gaps in academic training, impose greater limits to the good performance of oncological child care.

The Paradigm of Complexity contributed in an essential way to the search for the development of an integral view on the subject, providing greater clarity on the elements that make up the phenomenon and, especially, on the interdependence and interconnectivity between them, in an articulated and contextualized way. New studies that address specificities related to the care of children in cancer treatment and perspectives of other social actors are recommended.

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