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Palliative care at the end of life in pediatric oncology: a nursing perspective

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Cuidados paliativos no fim de vida em oncologia pediátrica: um olhar da enfermagem

Cuidados paliativos al final de la vida en oncología pediátrica: una visión desde la enfermería

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ABSTRACT

Objectives: To identify the knowledge of nursing professionals about palliative care in pediatric oncology and their needs for end-of-life care.

Method: A descriptive study with a qualitative approach, carried out in a federal hospital in Rio de Janeiro specialized in oncology. 29 nursing professionals from the pediatric inpatient sector participated in semi-structured interviews between July and August 2019. Data submitted to textual lexicographic analysis with Iramuteq.

Results: Professionals are aware of the use of comprehensive care, centered on the family, aimed at comfort, and dignified death. They highlighted the need for psychological support for the nursing team, in addition to effective communication with a multidisciplinary team and carrying out actions for professional training in pediatric palliative care.

Final considerations: A study showed care that is consistent with the precepts of palliative care and points out gaps in training, highlighting the need for professional training with a view to quality care.

Keywords: Palliative care. Hospice care. Neoplasms. Nursing. Pediatrics.

RESUMO

Objetivos: Identificar o conhecimento dos profissionais de enfermagem sobre os cuidados paliativos em oncologia pediátrica e suas necessidades para realização dos cuidados no fim de vida.

Método: Estudo descritivo, com abordagem qualitativa, realizado em um hospital federal do Rio de Janeiro especializado em oncologia. Participaram de entrevistas semiestruturadas 29 profissionais de enfermagem do setor de internação pediátrica, entre julho e agosto de 2019. Dados submetidos à análise textual lexicográfica com Iramuteq.

Resultados: Os profissionais têm conhecimento quanto ao emprego de cuidados integrais, centrados na família, direcionados para o conforto e morte digna. Destacaram a necessidade de suporte psicológico para equipe de enfermagem, além de comunicação efetiva com equipe multidisciplinar e realização de ações para capacitação profissional em cuidados paliativos pediátricos.

Considerações finais: Estudo evidenciou cuidados coerentes com os preceitos dos cuidados paliativos e aponta lacunas na formação evidenciando a necessidade de capacitação profissional com vistas a uma assistência de qualidade.

Palavras-chave: Cuidados paliativos. Cuidados paliativos na terminalidade da vida. Neoplasias. Enfermagem. Pediatria.

RESUMEN

Objetivos: Identificar el conocimiento de los profesionales de enfermería sobre los cuidados paliativos en oncología pediátrica y sus necesidades de cuidados al final de la vida.

Método: Estudio descriptivo con abordaje cualitativo, realizado en un hospital federal de Río de Janeiro especializado en oncología. 29 profesionales de enfermería del sector de la hospitalización pediátrica participaron en entrevistas semiestructuradas entre julio y agosto de 2019. Datos sometidos a análisis lexicográfico textual con Iramuteq.

Resultados: Los profesionales son conscientes del uso de la atención integral, centrada en la familia, orientada al confort y la muerte digna. Destacaron la necesidad de apoyo psicológico al equipo de enfermería, además de la comunicación efectiva con un equipo multidisciplinario y la realización de acciones para la formación profesional en cuidados paliativos pediátricos.

Consideraciones finales: Un estudio mostró un cuidado acorde con los preceptos de los cuidados paliativos y señala brechas en la formación, destacando la necesidad de una formación profesional con miras a la calidad asistencial.

Palabras clave: Cuidados paliativos. Cuidados paliativos al final de la vida. Neoplasias. Enfermería. Pediatría.

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INTRODUCTION

Palliative care aims to improve the quality of life of patients and families facing conditions and diseases that threaten the continuity of life. It is based on the prevention and suffering relief, with early identification, adequate assessment and treatment of pain and other physical, psychosocial and spiritual problems(1).

When those who face a condition or illness that threatens the continuity of the child or adolescent's life, pediatric palliative care (PPC) should be used, which is differentiated due to its passage through different stages of development. This comprises a total active care of the patient's body, mind and spirit, which involves supporting the family, and should start in the diagnosis of the disease(1).

Several clinical conditions are eligible for PPC, namely(2): 1- Conditions in which the potentially curative treatment may fail, such as cancer and severe congenital heart disease; 2- Conditions in which long-term intensive treatment can be prolonged but premature death can occur: cystic fibrosis, HIV infection, severe epidermolysis bullosa, kidney failure, severe immunodeficiencies, muscular dystrophy; 3- Progressive conditions in which the treatment is almost exclusively palliative, but can last for many years: neurodegenerative diseases, progressive metabolic diseases, chromosomal abnormalities, severe forms of osteogenesis imperfecta; 4- Non-progressive neurological conditions that result in high susceptibility to complications and premature death: extreme prematurity, important neurological sequelae or infectious diseases, hypoxic brain injuries.

It is important to highlight that these patients, with eligible clinical conditions, can benefit from palliative care from the diagnosis of the disease in association with treatment with a curative proposal; over time, if the patient is no longer able to cure, palliative treatment becomes exclusive; and in the end, with the proximity of death, they continue to be followed up with end-of-life care(3). Thus, palliative care is more comprehensive than only those used in terminality(4).

For the implementation of CPP the performance of a multidisciplinary team is essential(1), as care demands include different specialties and all professionals are important to monitor the patient's trajectory. Within it, there are nursing professionals who need to be familiarized with the philosophy of pediatric palliative care(5), so that they can provide quality care to children, adolescent and their families.

A review study showed that assistance in PPC involves different aspects with psychological and emotional implications for nursing professionals who are inserted in the care process(6).

National and international researches show that these professionals have difficulties working with patients in PPC, especially for end-of-life assistance, and they need better preparation and training to deal with care situations(5–8). In this sense, it is important the development of studies that aim to identify possible gaps in these professionals' knowledge so that strategies can be implemented in the future to better equip them for this assistance.

This research had as a guiding question: what is the knowledge of nursing professionals about palliative care in pediatric oncology and their needs for providing end-of-life care to this population? Thus, the objective was to identify the knowledge of nursing professionals about palliative care in pediatric oncology and their needs to perform care at the end of life.

METHOD

The present study is an excerpt from a master's thesis in nursing(9), configuring itself as an exploratory, descriptive research with a qualitative approach, carried out in a federal hospital, which is a reference in teaching, research and cancer treatment, located in the city of Rio de Janeiro, Brazil.

The data collection scenario was the pediatric inpatient sector that serves patients aged 0-19 years. It has 30 beds, being 12 for onco-hematology, with 4 private beds, and 18 for onco-pediatrics, with 4 private beds. Private beds are initially intended for patients who need isolated rooms, whether due to a contagious disease or contagious infections, they are also used by patients with evolution of the condition for end-of-life palliative care.

Thirty-five nursing professionals, nurses and nursing technicians were eligible for the study. Twenty-nine nursing professionals participated in the research, who met the following inclusion criteria: being a nursing professional and working in the oncology ward with patients in PPC for at least 1 year. Exclusion criteria were professionals who were on medical leave and on vacation during the period of data collection.

For participants recruitment, an invitation was sent to a group of social messaging application (WhatsApp) of nurses and pediatric nursing technicians, of which one of the authors of the article was already a part and acted as a facilitator. Subsequently, face-to-face contact was scheduled to clarify the research objectives. After acceptance for participation, a prior appointment was made for the interview. The criterion for closing the interviews was obtaining the theoretical saturation of data(10) and the utilization rate of the text(11).

Data collection took place from July to August 2019, based on semi-structured interviews. A script with participant characterization data and the following open questions were used: 1) For you, what is palliative care? 2) Talk about the palliative care you use for children and adolescents with cancer at the end of life.

The interviews lasted around 25 minutes and were conducted by only one of the researchers in the study, after discussion and guidance among the authors. All were audio recorded, transcribed in full and identified by alphanumeric code, thus ensuring the anonymity of the participants. Interviewees were sequentially coded as follows: the nurses: Nur.01 to Nur.10; and the nursing technicians: Nur.Tec.11 to Nur.Tec.29. They did not have access to the content of the interviews after they were carried out.

Data were processed using the IRAMUTEQ software (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*) 0.7 alpha 2, developed by Pierre Ratinaud, which allows for statistical analysis on textual *corpus* and individual/word tables, enabling different processing and statistical analysis of produced texts. In this research, the Descending Hierarchical Classification (DHC) method was used(11).

From the set of interviews and the corpus preparation, the DHC performed the dimensioning of the elementary context units (ECU) or text segments (TS), classified according to the most frequent words, understood as significant for the qualitative analysis of the data, and higher chi-square values (χ^2) in each class, as they have a greater association between their ECUs and their class(11).

After this step of data processing, the data analysis phase began, which was based on the precepts of qualitative research, guided by six steps(12): step 1 – organization and preparation of data for analysis, step performed by the guidelines for making the *corpus*; step 2 – reading of all data, with re-readings to assess the transcribed content; step 3 – detailed analysis with the coding process, performed in the IRAMUTEQ software, which made the word dictionary; step 4 – use of the coding process to describe the participants and the categories or themes for analysis, with an evaluation of all classes presented in the dendrogram and new readings of the interviews; step 5 – information on how the description and themes are represented in the qualitative narrative, supported by the literature consulted after the analysis of the categories; and step 6 – extraction of the meaning of the data and, after its analysis, presentation of the results by the researcher through his/her personal interpretation, based on scientific literature.

The ethical precepts involving research with human beings were respected and data collection took place after the interviewees signed the Free and Informed Consent Form (FICF). This study was sent to the Brazil platform and approved by the research ethics committee of the proposing institution under opinion number 3.411.284, CAAE 12129519.9.0000.5243 and the co-participating institution where the research was conducted under opinion number 3.471.640, CAAE 12129519.9.3001.5274. All data were handled and analyzed anonymously.

RESULTS AND DISCUSSION

Participated in the research 10 (34%) nurses and 19 (66%) nursing technicians. Most participants, 23 (79%), said they had received some type of training in palliative care, 17 (59%), including nurses and nursing technicians, have a postgraduate degree as the highest level of instruction in nursing. Most nursing technicians 14 (74%) have a degree in nursing and only 05 (26%) have a high school degree and a technical course in nursing, these data indicate that most professionals have nursing qualifications. 14 (48%) work at the institution between 3 and 5 years. Female gender predominated, 27 (93%).

By processing the IRAMUTEQ, through DHC, the textual corpus, which corresponds to the set of texts analyzed, was composed by 29 texts, which are equivalent to the number of participants. In addition,7,315 word occurrences, 210 text segments were identified, with 87.62% success rate and 4 classes. The classes were generated by the software from the analysis of the similarity of their words(11). For this article, the results of classes 1 and 2 that are related to its objectives will be presented.

Class 1 was titled by the researchers as “Knowledge of the nursing team regarding palliative care in pediatric oncology”, with 59 text segments, which represented 32.1% of the textual corpus. Class 2, on the other hand, was named “Needs of the nursing team to work with the end of life”, consisting by 61 text segments, with 33.15% of the corpus.

Table 1 brings the most relevant words/terms, in descending order as generated by the DHC. It represented those with a value greater than χ^2 and $p< 0.0001$. It is noteworthy that the higher the value of χ^2 and the lower the p-value, the greater will be the relationship of the word/term with the class that was allocated, which corroborates the reliability of the results.

Table 1 – Main words/terms of each class of member interviews of the nursing team generated by DHC- Rio de Janeiro – RJ – Brazil – 2019

Classes	Words/Terms
Class 1	care
	comfort
	relieve pain
	no curative treatment
	pain
	when
	adolescent
	quality of life
	analgesia
	pay
	control symptoms
Class 2	important
	find

Source: Research data, 2019.

Class 1 – Knowledge of the nursing team regarding palliative care in pediatric oncology

The word "care" was very recurrent in this class, which highlighted the importance of care, which must be comprehensive, centered on the child, adolescent, and their family, as in the reports:

> *Also giving her family a choice, giving her choice of how the treatment will be when she arrives terminally ill. (Nur.01)*
>
> *It is care centered on the family itself, not just on the child and adolescent, because this entire family is sick. (Nur.02)*
>
> *It is comprehensive care, care for dignity, respect for your body, respect for your habits and cultures. (Nur.Tec.17)*

The study results showed that, in the understanding of nursing professionals, it is important to implement comprehensive and family-centered care. A study highlighted that nurses have the opportunity to assess and meet the demands of children and adolescents and their families throughout the process of palliative care, whether in physiological, emotional or psychosocial aspects(13).

The second most recurrent word in this class was "comfort", which was related to the relief of pain and suffering, to promotion of quality of life:

> *You will provide comfort, analgesia for the patient not to feel pain, to have an end of life with quality without suffering. (Nur.06)*
>
> *First place is to provide comfort, to relieve pain, not only for the child, but also for the family. It is providing nursing care focusing on alleviating suffering. (Nur.Tec.18)*

Thus, the participants in this research confirmed that patients and their families need to be cared for and welcomed with a comprehensive approach that focuses on promoting comfort so that they can face together the difficult situations arising from the disease. Another study carried out with nursing professionals confirms these findings(8), indicating the importance of using care aimed at comfort, quality of life, pain and suffering relief, which should be the focus of PC care.

Regarding knowledge related to when PC should be implemented, there were professionals who said that they should be started since the diagnosis:

> *It should be started at the beginning of the treatment even if considering that the curative treatment and over time it would gradually increase, and the patient entering palliative care, which would be the treatment with no possibility of cure, this treatment would be increasingly intensified to care of end of life. (Nur.07)*

In the interviews, few professionals correctly associated the implementation of PC since the beginning of the diagnosis of a disease that threatens the continuity of life. And only two described the transition from PC, that over time, if the patient no longer benefits from the curative therapeutic proposal, he should start palliative treatment exclusively, being followed up until end-of-life care, according to the literature(3).

However, many professionals associated palliative care only with those performed at the end-of-life stage or for children and adolescents with no curative possibility:

> *It is the care at the end of life, for every patient who is out of the possibility, who no longer has any means of cure. (Nur.Tec.17)*
>
> *It is a treatment with a non-curative purpose, precisely to alleviate symptoms and to support those patients who are out of therapeutic possibility. (Nur.Tec.22)*

Similar results to these were found in other studies, which evidenced the mistakes in the association with the implementation of PC(8,14). Due to these misconceptions, the care to be used to patients in PC may not be performed, which will increase the pain and suffering of the patient and family(5).

This brings a reflection on the importance of conducting studies to spread the scope of PC, as the professionals themselves who work with eligible patients with PPC since diagnosis are unaware of its indication.

They showed the knowledge that pain control must be implemented in the end-of-life phase:

> *Sedation also if needed, sedation with morphine and drippings. (Nur.01)*
>
> *Pain control with prescription drugs, analgesia and even nursing care, with a little attention, a warm compress, something you can do so that you can comfort the child in this process of departure. (Nur.Tec.25)*

Regarding the care used in the specific end-of-life phase of children and adolescents with cancer, it can be observed the concern with pain, "relieve pain". In order to understand the complexity of pain approach, care has been mentioned since the administration of analgesics and/or opioids, installation of continuous infusion of opioids, as well as the evolution of this care to palliative sedation, when symptoms are no longer controlled.

Pain in pediatric oncology is very complex, being related to several factors, and cancer patients are also affected with other symptoms that can worsen the painful sensation(7). A study(8) mentions the use of non-pharmacological interventions for pain control in PPC, with the use of similar care to those found in this research, such as the use of compresses, positioning in bed, communication, emotional support, among other precautions for the relief of pain and suffering and the promotion of comfort.

The "symptom control" and other care were mentioned, as presented in the following reports for the relief of suffering:

> *In the end-of-life phase, first the issue of emotional support for the family, for the child, because we build a bond, because it takes a long time for treatment. Provide oxygen, aspiration and I think more pain control, comfort, oxygenation. (Nur.09)*
>
> *Rescues for pain, SOS of emetic medications, abdominal pain, you make a hot water bottle, you do that too, make the patient in a more comfortable position, to have comfort, even the caregivers themselves, guide them about the care, do something that won't cause so much suffering. (Nur.Tec.15)*
>
> *Put the patient in an isolation room so they can have more privacy, so the family can spend more comfortable time with the patient. (Nur.Tec.24)*

In addition to pain, the control of other symptoms was evidenced in the research, such as respiratory distress, anxiety, emotional suffering, bleeding, loss of appetite, fatigue, among others common in end-of-life patients. For these, several cares were listed, such as medication administration, positioning, communication, support to patient and family.

An integrative review pointed out that it is impossible to provide a dignified death for pediatric patients if they are experiencing physical and/or emotional suffering(6), and nursing professionals, as they are in greater contact with them, need to meet these demands.

As for the comprehensive approach, only one nurse mentioned spiritual care so that a dignified end of life can be offered. This data draws attention to the need to include spiritual support for all PC patients and their families, which points to a gap in the training of professionals.

Since spirituality helps people in the terminal phase to resist pressure and to physical and psychological discomfort in such a way as to promote their well-being until the last moment of their life. Nursing, as a profession that is in direct contact with the patient, is responsible for this holistic look(15).

Due to the peculiarity of the moment, it was cited the importance of reducing invasive care and providing personalized care, respecting individuality and autonomy:

> *It is giving the user a more dignified end of life, free of pain, without invasive procedures, so that he can have a more peaceful end of life. (Nur.Tec.21)*
>
> *I think it's very particular, it depends on how the child is, because each person has a different end of life and there is different care. (Nur.Tec.25)*

For the interviewees, due to the peculiarity of the end of life, invasive care must be reduced and thus avoid futile, obstinate care, giving more space to the patient and family and using individualized care. Thus, these discourses are aligned with the philosophy of palliative care to preservation of comfort(1).

Because this is such a difficult phase for the patient and family, the professionals mentioned the flexibility of conducts as care in this end-of-life phase:

> *If the child is able to eat and wants to eat, I talk to the nutritionist. Sometimes even allowing, authorizing a visit at the time of terminality that arrives outside hours, that lives far away, but that the child loves that person. (Nur.09)*
>
> *Respect for the family's needs, the hours that these are more extended in relation to the procedures. (Nur.Tec.17)*
>
> *Many times, you observe that he needs a greater demand and then we pass it on to the medical team, we have to pay attention to these details he needs. (Nur.Tec.26)*

In relation to the care provision, nursing professionals are recognized as the greatest providers of care in the hospital because they are in greater contact with the patient and family, being able to perceive and request support, when necessary, from other team members to best meet the needs of the patient and their family. Thus, the care with the satisfaction of desires and flexibility of conducts to meet the demands was often mentioned as a peculiarity of care in the end-of-life phase.

Through all these cares mentioned by the interviewees, it was identified the use of care aiming at autonomy, protagonism, satisfaction of desires, comfort, relief from suffering, quality of end of life and, consequently, dignified death, which are precepts of the PPC.

It is highlighted the importance of nursing professionals, as they spend more time in contact with the patient and family, know the phases of the PC so that they can guide, clarify doubts and encourage family adherence to these phases, as well as being a source of information for other team members, which can even avoid greater suffering and anxiety for the patient and family through futile care and false expectations.

Class 2 – Needs of the nursing team to work with the end of life

The text segments and words that characterize this class point out to the needs of professionals to work with children and adolescents with end-of-life cancer and their families.

Professionals see psychological support, for themselves, as one of the necessary pillars for them to be able to develop and continue the work with end-of-life PPC:

> *Maybe we have support for the employee because it really destabilizes. I've seen several employees after a death feel very bad and sometimes even go into a process of depression for getting too involved at that time and sometimes even getting frustrated. (Nur.07)*
>
> *It is also important to look at the professionals who work with the end of life, which I really miss, because I don't see anyone worrying about who takes care of them, and with that we end up getting sick. (Nur.Tec.18)*

Due to all the technical and emotional care complexity, the text segments from the interviews reveal the need for psychological support for the nursing team. It was possible to highlight the emotional demands to which nursing professionals are exposed when working with PPC, which points to the need to promote a healthier work environment.

These data are in line with another study that showed that most professionals express frustration and impotence in the face of limitations and losses. They also highlighted several emotional stressors, such as anguish, exposure to suffering, difficulties in answering hard questions for patients and families, repeated deaths(8). These stressors were also identified in this study.

It was observed that professionals see the priority of offering emotional assistance to the family, however they have difficulties, which reflects the need to learn about coping strategies to strengthen themselves:

> *I think that the team, despite dealing a lot with end-of-life situations, still has a lot of difficulty in coping with this moment. A better support for the family, sometimes he/she avoids, withdraws because doesn't know how to deal or faces them and then doesn't have emotional support for him/herself, I think it's important to address the issue of facing death, of dying to these employees. (Nur.07)*

Learning about personal and emotional coping strategies, such as adopting spiritual and social practices, engaging in recreational activities of interest, is a good tactic, as is the adoption of strategies by the service management, such as participatory management, continuing education and/or permanent, group meetings, carrying out practices and training to solve individual difficulties, allows for changes in behavior and in the work environment and, consequently, the modification of the stressor element(16).

Another need those professionals pointed out for work with end-of-life care was communication. They reported that they lack more effective communication in the unit, which generates difficulties in the relationship nursing/ patient-family and nursing/other professionals.

> *There are some failures, sometimes the doctor gives some information because the nursing has a lot of contact with the child and the mother ends up questioning and we are not very prepared to be able to conduct that dialogue. (Nur.07)*
>
> *When everything is happening, when all the symptoms are already appearing, the conversation comes, the explanation comes, I think that if this was done before, we would greatly minimize the suffering of both mothers and children. (Nur.Tec.25)*

In this sense, the lack of preparation of professionals for communication and emotional support to patients generates silences, false promises of cure or abrupt communications of adverse prognoses, with serious damages to the therapeutic relationship(17).

When this communication is ineffective, it can generate doubts about the therapeutic plan that will be adopted. This fact was observed in the speech of the participants when they expressed doubts about what has already been said to the family, whether or not they should perform certain procedures. Although it is important to know how to communicate, the topic is still scarcely included in higher education in health and in the continuing education programs of many hospital institutions(17). It is clear that learning about communication, despite being essential for care, represents a big gap in the education and training of professionals of the health team.

Another issue that emerged from the participants was the need for a multidisciplinary team, which needs to be present and integrated:

> *To what extent each professional does so that the other can act. The nurse will do this thing and then the doctor comes and says no, how good is this for the patient, for the companion and for us. (Nur.Tec.12)*
>
> *It's the team, it's not just the nursing team, end-of-life care... everyone is related, it's not enough for the nursing team to be present. (Nur.Tec.13)*

In this context, healthy interpersonal relationships between team members contribute to a more peaceful and harmonious environment, which increases people's ability to be more available to the other (18).

Professionals addressed doubts and difficulties related to implementing or not nursing procedures and care. They pointed out several procedures, such as the provision of oxygen therapy, catheterizations, analgesia, among others. It can be seen from the speeches, once again, that ineffective communication between team members and limited knowledge about end-of-life care are sources of difficulty for care, generating doubts in care:

> *Installing macronebulization is not installing, it is placing vesical catheterization, it is not placing. (Nur.04)*
>
> *Sometimes even this issue of this diet is a difficulty, a barrier for the employee because sometimes even he does not understand the real need to suspend a diet, to suspend an antibiotic, to suspend a very bulky hydration. (Nur.07)*
>
> *The pain control issue, the practical issues, knowing what to do. (Nur.Tec.22)*

With regard to the procedures, in their speeches, it was found that most of the doubts are not from technical order, but the lack of knowledge of when the procedures should or should not be performed in order to avoid obstinate care, futile and not comforting. This data highlights gaps in training regarding knowledge about end-of-life care, which highlights the need for better training of professionals for this assistance.

It is important that professionals have a clear understanding of the fundamentals of palliative and end-of-life care so that pediatric cancer patients receive the best care possible(5).

There must be attention in the performance of care so that they do not only cause pain and discomfort for the patient. It is necessary that the nurse, when prescribing the care to be performed, must have the sensitivity and competence to indicate them, aiming at the safety, comfort, and quality of patient care in accordance with the palliative philosophy.

A professional adds that hypodermoclysis, even being performed at the institution, is a source of interest to (re) learn about this topic:

> *Some therapies such as the subcutaneous one, I also think it's super important, although we've seen a lot here, people don't know. (Nur.07)*

As for the technical approach to procedures, participants were interested in learning about hypodermoclysis. In a study, were evidenced the benefits of hypodermoclysis in clinical practice and the need for greater depth in the knowledge and management of this health technology by nursing professionals(19). This highlights the importance of training professionals to use this technique.

Thus, based on the doubts, difficulties and learning interests pointed out by the professionals, they signaled as necessary training and/or updating to better prepare them for working with children and adolescents in end-of-life care:

> *For me everything would be important because I don't have specialization and I wasn't trained. (Nur.01)*
>
> *Knowing about legal issues, I think things get too loose here, you don't know what you can and what you can't. (Nur.Tec.13)*
>
> *Because we do not have this training to deal with end-of-life palliative care. What are our functions, what should we do, how to act, not only emotionally but technically as well. (Nur.Tec.14)*

To learn about ethical precepts was also emphasized. A review study pointed out that the ethical issues involving PPC are related to suffering and a variety of emotions for nursing professionals(6), which highlights the importance of the theme from the professional's training so that they are better prepared to working with PPC until the end of life.

In view of all the complexity of end-of-life PPC, the need for vast technical knowledge and the development of intrinsic skills to promote comprehensive care, participants reported that they need to be better prepared. This data corroborates with studies that conclude that the training of professionals for assistance in PPC is essential(8,14,18), highlighting the importance of developing permanent education activities by institutions.

FINAL CONSIDERATIONS

From the reports of the nursing team, it was possible to identify knowledge inherent to the precepts and philosophy of the PPC. Professionals point out the need for comprehensive care aimed at the protagonism and autonomy of the child, adolescent, and family, to promote comfort, quality of life, relief from pain and suffering, for this they employ care such as analgesia, symptom control, emotional support, flexibilization of conducts, satisfaction of desires in order to achieve a dignified death for the patient and less traumatic for everyone.

In the statements of the interviewees there were divergences about the moment to start palliative care and its eligibility, the majority associated PC only for patients with no curative possibilities or at the end of life, which breaks with PC principles. Another aspect that drew attention was the need for professionals to receive psychological support from the institution and to have a multidisciplinary team present and integrated, a more effective communication between the teams and the patient/family.

Through the indicated needs and the emerging recognition of training, gaps for learning were evidenced, and the participants pointed out topics of interest for learning, such as the scope of PC, communication of bad news, coping strategies, ethical aspects, hypodermoclysis and pain control.

Thus, the results of this study show the need for both technical and psychological training of professionals who provide care to children and adolescents with cancer at the end of life and their families. Demands highlighted by the nursing team make themes/contents emerge from the care practice that can be a subsidy for the development of continuing education in health, aiming to promote more qualified care and a healthier work environment for professionals.

As a limitation, it is highlighted that the study outcomes reflect the experience of professionals who exclusively care for cancer patients, however PPC should be adopted in other chronic diseases and special health needs. It is suggested the development of new research with an approach to the theme of other chronic diseases in order to understand the needs of nursing professionals and, in the future to implement educational strategies to improve care in end-of-life palliative care in pediatrics.

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