



## To palliate, caring beyond pain: a reflection of health professionals in pediatric oncology

### *Paliar, cuidando além da dor: uma reflexão dos profissionais de saúde na oncologia pediátrica*

### *Paliar, cuidando más allá del dolor: una reflexión de los profesionales de salud en oncología pediátrica*

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#### ABSTRACT

**Objective:** To analyze health professionals' perception when caring for cancer patients in Pediatric Palliative Care (PPC). **Methods:** This is an integrative literature review carried out on LILACS, MEDLINE/PubMed, BNDENF – Nursing, IBECs and SciELO, databases in the period between January 2015 and January 2022 using the terms Palliative Care and Pediatric Oncology. After selection criteria, 14 national articles were analyzed to answer the following question: What is the nursing professionals' perception when caring for cancer patients receiving PPC? **Results:** We found the perception of care – which should be adaptable to the family's social life, values and habits – arises through the palliative care plan to facilitate decision-making. Assistance is related to adaptability, bonding, feeling of gratitude, playing to promote development and communication with the patient. And, the challenges relate to the feeling of powerlessness in the face of death and the difficulty of separating personal life from professional life. **Conclusion:** Health professionals' perception when caring for cancer patients receiving PPC concerns three aspects: care assistance, the perception of nursing care and its inherent challenges in the process.

**Descriptors:** Oncology; Pediatrics; Palliative Care; Nursing.

#### RESUMO

**Objetivo:** Analisar a percepção dos profissionais de saúde ao cuidar de pacientes com câncer em Cuidados Paliativos Pediátricos (CPP's). **Métodos:** Trata-se de revisão integrativa da literatura realizada nas bases de dados: LILACS, MEDLINE/ PubMed, BNDENF – Enfermagem, IBECs e SciELO, no período pesquisado entre janeiro de 2015 e janeiro de 2022 utilizando os termos Cuidados Paliativos e Oncologia Pediátrica. Após critérios de seleção, analisaram-se 14 artigos nacionais para responder à seguinte pergunta: Qual a percepção dos profissionais de enfermagem ao cuidar de pacientes com câncer sob CPP? **Resultados:** Encontrou-se a percepção sobre os cuidados – que devem ser adaptáveis à vida social, valores e hábitos da família –, que surgem por meio do plano de cuidado paliativo para facilitar a tomada de decisão. A assistência relaciona-se à adaptabilidade, ao vínculo, sentimento de gratidão, à brincadeira para promover desenvolvimento e à comunicação com o paciente. E, os desafios dizem respeito ao sentimento de impotência diante da morte e a dificuldade de separar pessoal e profissional. **Conclusão:** A percepção dos profissionais de saúde ao cuidar de pacientes com câncer em CPP's diz respeito a três aspectos: a assistência ao cuidado, a percepção da assistência da enfermagem e seus desafios inerentes ao processo.

**Descritores:** Oncologia; Pediatria; Cuidados Paliativos; Enfermagem.



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## RESUMEN

**Objetivo:** Analizar la percepción de los profesionales de salud al cuidar de pacientes con cáncer en Cuidados Paliativos Pediátricos (CPP's). **Métodos:** Se trata de revisión Integrativa de la literatura realizada en las bases de datos LILACS, MEDLINE/PubMed, BNDENF – Enfermería, IBECs y SciELO, en búsqueda hecha entre enero de 2015 y enero de 2022, utilizando los términos Cuidados Paliativos y Oncología Pediátrica. Pasados criterios de selección, fueron analizados 14 artículos nacionales para responder a la siguiente pregunta: ¿Cuál la percepción de los profesionales de enfermería al cuidar de pacientes con cáncer bajo CPP? **Resultados:** Se encontró la percepción sobre los cuidados – que deben ser adaptables a la vida social, valores y hábitos de la familia –, que surgen por medio del plano de cuidado paliativo para facilitar la toma de decisiones. La asistencia se relaciona a la adaptabilidad, al vínculo, sentimiento de gratitud, al juego para promover desarrollo y a la comunicación con el paciente. Y, los retos se relacionan con los sentimientos de impotencia ante la muerte y la dificultad de separar personal y profesional. **Conclusión:** La percepción de los profesionales de salud al cuidar de pacientes con cáncer en CPP's está relacionada a tres aspectos: la atención al cuidado, la percepción de la atención de la enfermería y sus retos inherente al proceso.

**Descriptor:** Oncología Médica; Pediatría; Cuidados Paliativos; Enfermería.

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## INTRODUCTION

Pediatric Palliative Care (PCC) is defined by the World Health Organization (WHO) as comprehensive and dynamic care of the child's body, mind and spirit. In addition, it provides support to the family, including in the period of mourning<sup>(1)</sup>. The diagnosis of palliation in children is a challenge for professionals because teaching in the health field does not give the necessary attention to the finitude of life and its confrontation<sup>(2,3)</sup>. PCC is defined as a curative treatment option for embracing patients with diseases and whose death will occur before reaching adulthood. Thus, the treatment aims to improve quality of life, prevent and alleviate the suffering caused by pain and other physical, psycho-emotional, social and spiritual symptoms<sup>(3)</sup>.

The palliative diagnosis of children is a challenge for professionals, as this experience can create a long-term psychosocial burden for parents and caregivers<sup>(4)</sup>. For that reason, it is important to acknowledge the patient's suffering and share anguish, fears and pain experienced by those involved in care. Thus, health professionals, together with the support network, will help to minimize symptoms of anxiety and depression and encourage the patient's autonomy<sup>(5)</sup>.

Bereaved parents demonstrated that oncological children who received palliative care experienced less anguish, pain, dyspnea and anxiety at the end of life<sup>(6)</sup>. For this, the standard for pain assessment is self-report, and since not all children can be verbal, the support network is essential to understand the manifestation of pain<sup>(7)</sup>.

The decision-making process involves all individuals who are committed to the well-being of the child/adolescent<sup>(8)</sup>. Thus, when parents need to plan the death of their children, the focus is almost always on the patient's quality of life<sup>(7)</sup>.

That way, the team of health professionals must focus on the real needs of patients and their families and be able to quickly identify them – either verbally or non-verbally. However, this trust depends on the application of established PPC principles, so that the end of the child/adolescent's life is a journey with quality and comfort. Thus, this individual will be able to enjoy their family, play in a playful way and live intensely the moment of their finiteness<sup>(9,10)</sup>.

It is also known that cancer is the leading cause of death in children in Brazil and in developed countries. These are children and adolescents between 1 and 19 years of age, with an estimated cure rate of up to 80% of cases when diagnosed early. In Brazil, cure rates vary 50% in the North region, 60% in the Northeast region, 65% in the Midwest region, 70% in the Southeast region and 75% in the South region<sup>(11)</sup>.

Palliative care promotes health by prioritizing ethical and humane behaviors and protecting life during the process that may (or may not) lead to its finitude. This type of care is delivered through the integration of strategies in the treatment and relief of pain, stress and other needs<sup>(9)</sup> through a process that transits between conventional treatment, transgresses the disease and offers assistance to people with a view to promoting health and quality of life<sup>(12)</sup>.

Health promotion can be seen in the respectful way in which PPC takes place. This can arise through alternative approaches and also in a highly interventionist way when seeking either pharmacological or non-pharmacological proposals for the control of symptoms<sup>(13)</sup>. In addition, PPC is an ethical, legal, humanitarian and social obligation. Therefore, health actions essential to human dignity are promoted<sup>(14)</sup>.

And to deal with the rest of the cases, where cure is no longer an option, palliative care usually brings some comfort. Given that, this research aims to guide professionals, patients and researchers to expand their knowledge about PPC. In particular, with regard to nursing professionals who work with this care through the proposed research problem: What is the perception of nursing professionals when caring for cancer patients receiving PPC?. Thus, the aim of this study was to analyze the perception of health professionals when caring for cancer patients receiving Pediatric Palliative Care (PPC).

## METHODS

This research was conducted through an integrative literature review. Thus, the study was carried out in six stages<sup>(15)</sup>: formulation of the research question, definition of inclusion and exclusion criteria and search in the literature for definitions of the information to be extracted from the selected studies as well as the evaluation of the selected studies, the interpretation of the results and the presentation of the review.

Thus, the research question of the study is: What is the perception of nursing professionals when caring for cancer patients receiving PPC?. To answer that, we used articles selected from the databases available in the virtual health library: Latin American and Caribbean Literature on Health Sciences (LILACS), the USA National Library of Medicine (MEDLINE/PubMed), the Nursing Database (*Base de Dados de Enfermagem – BDENF - Nursing*), the IBECS database – *Índice Bibliográfico Español en Ciencias de la Salud* and the Scientific Electronic Library Online (SciELO).

The search for articles took place in June 2022. As a search strategy, the following Health Sciences Descriptors (*Descritores em Ciências da Saúde – DeCS*) were used: (Palliative Care) and (Pediatric Oncology).

The studies were selected based on the following inclusion criteria: full-text open access Brazilian articles available online in Portuguese, published between January 2015 and January 2022 with title or abstract describing the involvement of a nursing team as an object of study.

The choice of national articles envisaged that palliative care presents itself as a possibility of intervention for physical, psycho-emotional, social and spiritual symptoms<sup>(3)</sup>. And, after considering cultural uniformity and its impacts in relation to social and spiritual aspects, it was decided to keep only Brazilian studies in the analysis. The period of seven years was defined by the observation of the main novelties regarding the practices of the nursing teams relating to PPC.

Exclusion criteria consisted of: studies that did not involve pediatric palliative care, those that addressed only other areas of activity that did not involve nursing and those that were not in an article format.

Data were collected based on the following premises: exploratory reading of all selected material (quick reading that aims to verify if the consulted material is of interest for the work); selective reading (more in-depth reading of the parts that really matter); and recording the information extracted from the sources in specific instruments (information on authors, method, result and conclusion).

The analysis and interpretation of results were made through analytical reading with the purpose of ordering and synthesizing the information contained in the sources in a way that made it possible to obtain answers to the research question.

The initial search on the databases yielded 39 articles. Of these, 17 were on LILACS, 2 on IBCS, 6 on BDENF, 3 on MEDLINE and 11 articles on SciELO. However, with the use of controlled descriptors and after their selection and verification, a second analysis was developed to verify adherence to the research, whose details are shown in Figure 1.

Finally, the articles included are shown in Table 1.

## RESULTS

The final sample comprised 14 articles from national journals. Regarding the year of publication, 21.4% of the analyzed articles were published in 2015 and 2019 and 21.4% in 2016 and 2021.

As for the methodological design of the articles, four (36.36%) are descriptive and exploratory qualitative studies, five articles (35.7%) are qualitative studies, three (27.27%) are integrative review studies and two (14.2%) are quantitative bibliometric studies. All articles are of Brazilian origin, with publications concentrated in the South, Southeast and Northeast regions.

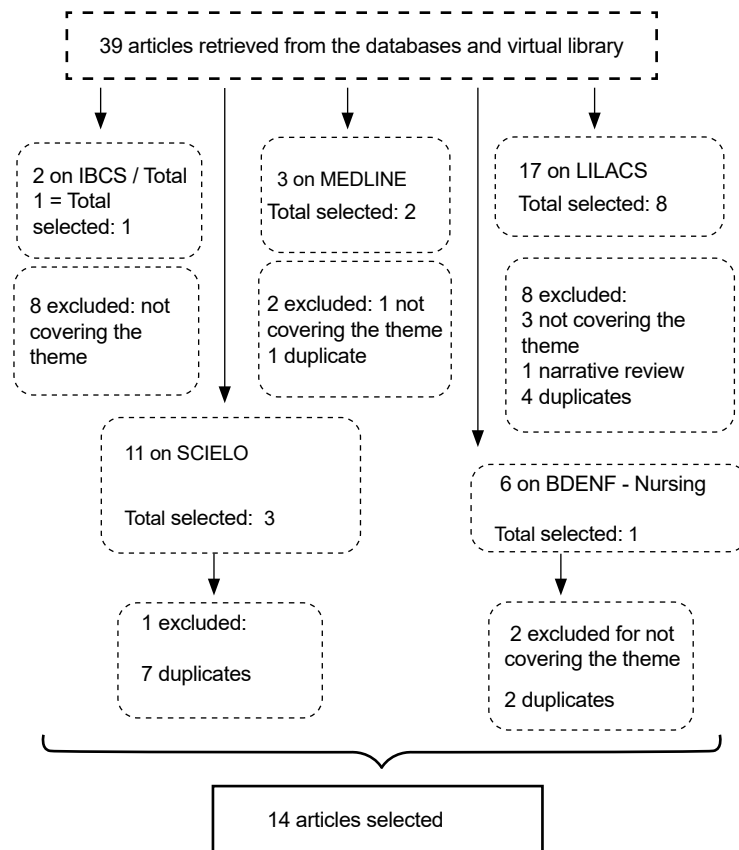


Figure 1 - Description of publications retrieved and selected for the study.

Chart 1 - Number of articles retrieved from the databases dating from 2015 to June 2022.

Database	Articles found	Articles excluded	Articles selected	Duplicates	Total of articles analyzed
LILACS	17	8	7	1	7
IBCS	2	1	1	0	2
BDEFN	6	2	2	2	1
MEDLINE	3	2	1	1	1
SciELO	11	1	3	7	3
TOTAL	39	14	14	11	14

Legend: description of articles found, excluded, selected and duplicated

Regarding the studies with health professionals found in the present review, most of the studies involved professionals from a nursing team (49.9%). And the other studies included health professionals (50.1%). In the development of the analysis, a form was built with the following items: title, authors and year of publication. Thus, the selected data allowed for the construction of Chart 2 for later interpretation of the information.

Chart 2 - Identification of studies included in the integrative review per title, authors, and year of publication.

Articles	Authors	Year of publication
Palliative care at the end of life in pediatric oncology: a nursing perspective	Silva T, Silva LF, Cursino EG, Moraes JRMM, Aguiar RCB, Pacheco STA <sup>(16)</sup>	2021
Losing a child at pediatric age: qualitative study of parental grief support	Costa, AR, Almeida, F <sup>(17)</sup>	2021
Palliative care in oncology: nurses' experience when caring for children in the final stage of life	Santos GFATF, Alves DR, Oliveira AMM, Dias KCCO, Costa BHS, Batista PSS <sup>(18)</sup>	2020
Dissertations and theses on palliative care in pediatric oncology: a bibliometric study	Dias KC, Batista PS, Fernandes MA, Zaccara AA, Oliveira TC, Vasconcelos MF, et al <sup>(19)</sup>	2020
Relapse in pediatric oncology from the perspective of professionals	Silva S, Melo C, Magalhães B <sup>(20)</sup>	2019
Palliative care in pediatric oncology: perspectives from health professionals	Guedes AKC, Pedrosa APA, Osório MO, Pedrosa TF <sup>(21)</sup>	2019
Interdisciplinary team's perceptions of palliative care in pediatric oncology	Pacheco CL, Goldim JR <sup>(22)</sup>	2019
Pediatric palliative care: analysis of nursing studies	Souza TCF, Correa Jr. AJS, Santana ME, Carvalho JN <sup>(23)</sup>	2018
Palliative care in pediatric oncology: an integrative review.	Semtchuck ALD, Genovesi S, Santos JL <sup>(24)</sup>	2017
Challenges to comprehensive care in palliative care in pediatric oncology at the José Alencar Gomes da Silva National Cancer Institute	Martins GB, Hora SS <sup>(25)</sup>	2017
Nurses' care for terminally ill cancer patients: an integrative review	Coropes VBAS, Valente GSC, Oliveira ACF, Paula CL, Souza CQS, Camacho ACLF <sup>(26)</sup>	2016
Palliative Care in Pediatric Oncology: Perceptions, Knowledge and Practices from the Perspective of the Multiprofessional Team	Silva, AF, Issi HB, Motta MGC, Botene, DZA <sup>(27)</sup>	2015
Child with cancer in the process of dying and their family: the nursing team's coping	Carmo AS, Oliveira ICS <sup>(28)</sup>	2015
Palliative care in children with cancer: an integrative review	Javorski AR, Bushatsky M, Viaro VD <sup>(29)</sup>	2015

With regard to the objectives of the studies, it was observed that most researchers were concerned with describing or knowing the experiences and perceptions and the meanings of PPC<sup>(16,17,18,23,24,25,27,28)</sup>. The other studies<sup>(19,20,21,22,26,29)</sup> address the interventions and actions involved in the nursing care provided to children and their families.

## DISCUSSION

After successive readings of the studies selected for the present review and the grouping of information, there was the possibility of building three thematic approaches: assistance to palliative care; the nursing team's perception; and challenges listed by the nursing team.

### Assistance to palliative care

The treatment of childhood cancer corresponds to a long period of destabilization in the routine of the parents and especially the child as they will need to spend long periods of hospitalization for the treatment and will be unable to carry out their daily activities, such as going to school and play<sup>(13)</sup>.

In this context, the importance of nurses in the performance of palliative care is perceived. They are responsible for having a holistic view and focusing not only on the care of the disease, but on the child's life as a whole: physical, social, family and spiritual aspects. And, this is possible due to the skills developed throughout their training for the humanization of care for palliative patients who want to maintain coexistence in society and biopsychosocial balance<sup>(17)</sup>.

When providing care to oncological children, professionals help to manage the social aspect of the patient and family in addition to treating suffering with invasive procedures and side effects. Such procedures affect the psychological wellbeing and bring up complaints, fears, doubts and uncertainties about reality and its treatment<sup>(30)</sup>.

It is important to highlight that the patient diagnosed with a terminal illness needs professionals with knowledge of PPC. This is important for providing comprehensive care to children/adolescents and for their social and family

context<sup>(31)</sup>. This is because the family almost always understands the diagnosis of cancer as an incurable disease related to death<sup>(30)</sup>.

These people are, by and large, not wrong, as cancer is a threatening disease. Therefore, care is recommended along with conventional treatment since the diagnosis<sup>(19)</sup>. This must occur in an active and full way, that is, an intense and global care must be provided to patients and their families in order to provide permanent support to all aspects (physical, psychological, social and spiritual) that involve the lives of these children and adolescents<sup>(16)</sup>.

PC for children and adolescents should start soon after the diagnosis and concomitantly with the curative treatment to advocate the relief of pain and suffering and promote the autonomy of the family with the participation of the patient. This approach is important even if the child or adolescent expects to be cured<sup>(16)</sup>.

PC is also discussed as an integral care to strengthen the meaning of life, show an inner look at oneself and the family, remember that smiling can be easy, encourage lightness in life and generate awareness about time and priorities. Above all, palliative care assistance should elicit the perception that there is always something to be done, regardless of the diagnosis, and that we should not hold on to "how long?", but "with what quality?"<sup>(16,20,30)</sup>.

Palliative treatment speaks of special care aimed at providing wellbeing, comfort and support to the patient and their families through the rights they are guaranteed, such as the right to truth, dialog, autonomy, decision, therapy and the benefit<sup>(19)</sup>.

Such care in the pediatric field has become increasingly recognized due to services aimed at quality of life throughout the course of the disease and through the search for alternatives to relieve symptoms, discomforts and stress experienced. Thus, the multidisciplinary team is responsible for being a point of reference during the entire treatment and at each decision-making of the patient and their families<sup>(25)</sup>. This does not mean admitting that resources for curing the disease have run out or that there is nothing more to be done. On the contrary, it is a desirable and indispensable conduct in the oncological context<sup>(19)</sup>.

It is essential that nursing can achieve as much comfort as possible for the child. This should be contextualized in the presentation of a palliative care plan with the objective of preserving the child's quality of life, offering time and information for decision-making, seeking effective communication in planning the care desired by the child and their families so that there is calm and common sense in difficult times<sup>(28)</sup>.

Thus, the team, in reducing suffering and generating comfort for the patient, promotes care capable of maintaining human dignity for more years with the best possible quality of life<sup>(29)</sup>. For this, it is important to identify the vulnerabilities of patients and develop a holistic care based on the context of the family and its values and habits. It is also essential for the team to go beyond their daily routine to be willing to do something more for terminally-ill patients<sup>(19)</sup>.

Among the various symptoms that affect the child in the final stages of life, pain is the most reported. This significantly affects the quality of life and its management should be a priority in care planning. On the other hand, non-pharmacological measures do not replace analgesia, but must be used together because pain is much more than a sensation and is influenced by social, psychological and emotional aspects<sup>(20)</sup>.

It is also important to assess the complexity of pain in the implementation of therapeutic measures capable of involving the child and their families. It is understood that playful approaches such as games and stories, for example, elicit the perception of everyday life in the child and make them forget a little about their suffering<sup>(26,28)</sup>. Therefore, PPC in oncology should always consider the three levels of intervention: the physical, referring to signs and symptoms such as nausea and vomiting/pain; the psychosocial to identify their fears and concerns; and spirituality<sup>(29)</sup>.

Thus, the team involved must listen to the child and talk about what they are experiencing, about their fears, insecurities, about separation from loved ones and objects and about the impossibility of not fulfilling their future dreams<sup>(23)</sup>. It is understood, therefore, that nurses play an essential role in a multidisciplinary team since PC is directly linked to their practice, to the art of care, and the support and comfort in the different stages of the lives of patients and families<sup>(29)</sup>.

The nursing team that works in PPC directs the role and autonomy to children, adolescents and their families. When promoting comfort, quality of life, relief from suffering and pain, care should also be made more flexible and more humane actions should be sought for the routine of this family according to their social context. This makes the experience of palliative care less traumatic and increases acceptance by the members included in the care<sup>(22)</sup>.

### **Palliative care: the nursing team's perception**

The nursing team entangles itself with patients and family members by creating bonds due to the care provided and the affinity with patients. Comprehensiveness, in these cases, concerns the love spent and listening to the child's complaints, praises and requests<sup>(20)</sup>.

Caring for children with cancer transcends technical and scientific issues. It is necessary to observe each particularity of the patient and this makes nurses develop their skills according to the needs of the patient and their families<sup>(25)</sup>.

Based on professionals' perception, PPC is the care provided in relation to pain and comfort. These allow professionals to focus on care and the act of caring. At this point, it is no longer about curing but about how to live with quality of life. The professional's role is to rescue the humanization lost in health actions. The reports sought in the articles highlight the feeling of gratitude of professionals when working with children in palliative care, overcoming, as a result, difficulties they face on a daily basis<sup>(32)</sup>.

In addition, professionals want to provide a positive experience with less pain and control of symptoms or discomfort caused by treatment. Care makes nurses protagonists in the art of care; however, they are not the only ones, as the professionals together with the multidisciplinary team must respect the space, desires and beliefs of the child and their families<sup>(17)</sup>.

Through knowledge and sensitivity, teams realize the importance of minimizing physical fatigue and respiratory effort. The objective is to focus on controlling pain and other symptoms and promoting better quality sleep and rest for the child<sup>(23)</sup>.

Professionals also highlight the importance of carrying out activities aimed at the children's universe and emphasize playing as an essential activity for the child to continue emotional, mental and social development. Playing also allows feelings, anxiety and frustrations to be communicated<sup>(28)</sup>. There are, therefore, toys at the bedside to reassure, distract and guide them during procedures, recreation rooms where parents participate as storytellers, and playrooms to familiarize the child with their new living environment<sup>(25)</sup>. However, the teams highlight the difficulty of carrying out activities such as playing, as children are unable to get out of bed and do not feel comfortable and willing to live what PC advocates<sup>(25)</sup>.

The professionals' perception of PC is aimed at increasing a patient's quality of life, reducing pain and symptoms resulting from illness<sup>(24)</sup>. The nurses' work process related to the subject leaves gaps on how to put the theoretical content into practice as professionals understand what PPC is but are unable to develop humanized care due to the lack of preparation for dialog and the use of a holistic view of this patient and their families<sup>(19)</sup>.

Nursing professionals' perception of PPC appears mainly as the act of caring and providing the child and their family with the necessary comfort without focusing on the perspective of a brief death. And, despite the bond, nursing professionals try not to show their feelings close to the patient and their families<sup>(32)</sup>.

There are reports of nursing professionals wishing to gain the trust of those involved without demonstrating weaknesses. They also emphasize that lies reduce respect and the bond with the professional, as well as the need to separate the home environment from the hospital environment<sup>(23)</sup>. Thus, professionals' perception in the face of PPC is that there is a need for constant learning and preparation to act in the face of the fragility of the patient and their families. Thus, the professional will have enough emotional distance to act ethically and kindly in pain control, in communicating bad news and in coping with the loss as many professionals create an affective bond with patients due to the length of hospitalization and treatment<sup>(22)</sup>.

### **Challenges listed by the nursing team**

Professionals who work with this type of care experience the paradox of dealing with the death of children and disconnecting from work in their spare time. Thus, it was observed that challenges are usually related to feeling powerless in the face of patients' death, feeling of loss, the bond created with patients and family members, the difficulty in dealing with the family's grief and the grief itself due to the loss of children. Most professionals, whether graduates or not, report that dealing with death is not easy because both technical education and nursing graduate education do not specifically address the subject to understand death, the process of death and dying<sup>(21)</sup>.

There are also reports of the feeling of being in constant emotional overcoming, as dealing with the loss of children is more difficult. And, in these moments, professionalism must remain, even if the psychological side of this professional is worn out<sup>(20)</sup>. Despite espousing this point of view, practitioners feel failure to lose a young patient. This becomes even more difficult when social death precedes biological death due to the suffering started before the child dies, since this whole process makes care more difficult, as the deconstruction of the child's social image is understood as something that goes against the common sense of the natural order of the life cycle<sup>(32)</sup>.

The process of diagnosis and death is described by professionals as a moment of intense suffering and negativity. Still, compassion for the family remains and professionals struggle not to show frustration and a sense of failure because even if nursing professionals recognize that this child was receiving PC, there is still hope for an

improvement in the prognosis. In addition, these professionals also experience a constant struggle over their own finitude and limitations<sup>(29)</sup>.

The best way for nurses to face this is through interaction with the child and their family aiming to reduce the fear and insecurity felt by both parties<sup>(23)</sup>. Even so, professionals who work with PPC present with professional exhaustion and inability to separate the personal emotional aspects from the professional emotional aspect due to the difficulty of leaving the assistance while they continue to remember the hospitalized children. This process makes it difficult to create a protection mechanism against the suffering experienced<sup>(25)</sup>.

The feeling of professional shame is also common as a response to the daily life of PC. Thus, one of the greatest difficulties imposed by work is communication with the family given the nature of the news that may need to be given to family members<sup>(13)</sup>. And, although the bonds are beneficial, it is a loss for the professional because most cannot differentiate between personal and professional in relation to love, affection and dedicated time<sup>(31)</sup>. This vulnerability can cause grief, fatigue, burnout syndrome, self-reproach and other disorders associated with non-acceptance of the death process and dying in children and adolescents with terminal cancer<sup>(30)</sup>.

It is often from spirituality that the nursing team is able to carry out work aimed at the comprehensive care of patients and their families. The acceptance of spirituality as part of integrative health care completes professional assistance as time with the patient and family members is valued<sup>(21)</sup>. This is a strategy to deal with the anticipatory grief of family members and their consequent feeling of despair and hopelessness. And for that, specific skills are needed, such as: facilitating postures, sensitivity, and emotional balance and control<sup>(30)</sup>.

The experience of nurses in caring for children and adolescents in palliative care reveals a range of challenges during their journey, and it is common for professionals to accompany their patients in PPC until death. And, despite promoting actions that improve the health of patients and families through listening, relieving physical and emotional pain and honest dialog, it is also the role of these professionals to guarantee the process in the most dignified way possible. After all, promoting health also means stopping treating diseases that have no cure and providing a quality life in the time that still remains<sup>(17)</sup>.

Based on the challenges listed by the nursing team in providing PPC for health promotion, there is the need for training that addresses the philosophy of PPC for a truly comprehensive approach and aimed at promoting the quality of life, protagonism and autonomy of the child/adolescent<sup>(25)</sup>.

It is also evident that the professional who works in palliative care needs psychological and spiritual support to maintain the essence and minimize the traumatic experiences during the performance of care. A practice to take care of professionals and ensure the health promotion of patients and families is to provide permanent health education because if one of those involved in this triad (patient-family-professional) is not emotionally well, health promotion and care can be compromised<sup>(22)</sup>.

The theoretical contribution is evidenced through the knowledge about palliative care assistance, the nursing team's perception and the challenges listed in recent years. These address the difficulties of dealing with the loss of a patient – who in society's view could not die –, the difficulty of giving bad news and the psychological preparation to be able to separate professional from personal life. Given that, further research is needed in order to define the best evidence in the development of palliative care to meet physical, psychological, social and spiritual needs. This is a limitation and also a suggestion for future research.

## CONCLUSION

The health professionals' perception when caring for cancer patients in Pediatric Palliative Care concerns three aspects: care assistance, the perception of nursing care and its challenges.

Care assistance should advocate balance between social life and disease care. This should be done through the palliative care plan to establish intervention levels at critical times.

The assistance of the nursing team in Pediatric Palliative Care is perceived by the professionals' feeling of gratitude, the personalization of care and the need for technical and emotional improvement.

The challenges relate to the feeling of powerlessness and lack of preparation in the face of the constant feeling of overcoming, failure, shame and weariness due to the difficulty of separating personal life and professional life. In addition, constant experiences of grief, fatigue and burnout syndrome are observed.

## CONFLICTS OF INTEREST

There are no conflicts of interest.



## CONTRIBUTION

All authors contributed equally to the conception and design of the study; the acquisition, analysis and interpretation of data; and writing and/or reviewing the manuscript. All authors approved the final version of the manuscript and are responsible for its content and integrity.

## REFERENCES

1. Ministério da Saúde (BR). Resolução nº 41, de 31 de outubro de 2018. Dispõe sobre as diretrizes para a organização dos cuidados paliativos, à luz dos cuidados continuados integrados, no âmbito Sistema Único de Saúde (SUS). Diário Oficial da União [Internet]. 2018 nov 23 [Accessed on 2022 Aug 08]; 225(1): p. 276. Available from: [https://www.in.gov.br/materia/-/asset\\_publisher/Kujrw0TZC2Mb/content/id/51520746/do1-2018-11-23-resolucao-n-41-de-31-de-outubro-de-2018-51520710](https://www.in.gov.br/materia/-/asset_publisher/Kujrw0TZC2Mb/content/id/51520746/do1-2018-11-23-resolucao-n-41-de-31-de-outubro-de-2018-51520710).
2. Costa TNM, Caldato MCF, Furlaneto IP. Percepção de formandos de medicina sobre a terminalidade da vida. *Rev Bioet.* 2019;27(4):661-673.
3. Tirado-Perez IS, Zarate-Vergara AC. Application of the Association for Children's Palliative Care (ACT) criteria at a pediatric reference institution in the Colombian Caribbean. *Rev Salud Publica (Bogota)*. 2018;20(3):378-383.
4. Streuli JC, Widger K, Medeiros C, Zuniga-Villanueva G, Trenholm M. Impact of specialized pediatric palliative care programs on communication and decision making. *Patient Educ Couns.* 2019;102(8):1404-1412.
5. Campos VF, Silva JM, Silva JJ. Comunicação em cuidados paliativos: equipe, paciente e família. *Rev. Bioét.* 2019;27(4):711-718.
6. Friedrichsdorf SJ, Remke S, Hauser J, Foster L, Postier A, Kolste A, et al. Development of a Pediatric Palliative Care Curriculum and Dissemination Model: Education in Palliative and End-of-Life Care (EPEC) Pediatrics. *J Pain Symptom Manage.* 2019;58(4):707-723.
7. Norris S, Minkowitz S, Scharbach K. Pediatric Palliative Care. *Prim Care.* 2019;46(3):461-473.
8. Iglesias SB, Zoolner ACR, Constantino CF. Cuidados paliativos pediátricos. *Ver Res Pediatr.* 2016;6(1):46-54.
9. Heredia CR. ¿Cómo es el dolor? Indagaciones médicas, registros y etiologías del dolor en cuidados paliativos pediátricos. *Cuad Antropol Coc.* 2019; 49:147-162.
10. Franco HCP, Stigar R, Souza SJQ, Burci LM. Papel da enfermagem na equipe de cuidados paliativos: a humanização no processo da morte e morrer. *Rev. Gestão e Saúde.* 2017;17(2):48-61.
11. Akard TF, Hendricks-Ferguson VL, Gilmer MJ. Pediatric palliative care nursing. *Ann Palliat Med [Internet]*. 2019 [accessed on 2022 June 21];8(1):39-48. Available from: <https://doi.org/10.21037/apm.2018.06.01>.
12. Mendes KDS, Silveira RCCP, Galvão CM. Revisão integrativa: método de pesquisa para a incorporação de evidências na saúde e na enfermagem. *Texto & Contexto Enfermagem.* 2008;17(4):758-764.
13. Burlá C, Py L. Cuidados paliativos: ciência e proteção ao fim da vida. *Cad Saúde Pública.* 2014; 30(6):1139-1141.
14. Lo DS, Hein N, Bulgareli JV. Pediatric palliative care and end-of-life: a systematic review of economic health analyses. *Rev Paul Pediatr. [Internet]*. 2022 [accessed on 2022 June 21];40:e2021002. Available from: <https://www.scielo.br/j/rpp/a/yx3xhgXxQP4cRNxZWzBr74r/>.
15. Botelho LLR, Cunha CCA, Macedo M. O método da revisão integrativa nos estudos organizacionais. *Gestão e Sociedade.* 2011;5(11):121-136.
16. Silva T, Silva LF, Cursino EG, Moraes JRMM, Aguiar RCB, Pacheco STA. Palliative care at the end of life in pediatric oncology: a nursing perspective. *Revista Gaúcha de Enfermagem [Internet]*. 2021 [accessed on 2022 June 21]; 42: e20200350. Available from: <https://www.scielo.br/j/rngenf/a/RD5dDjLzFzLcgFDDjp8TbSj/?format=pdf&lang=pt>.
17. Costa AR, Almeida F. Perder um filho em idade pediátrica: estudo qualitativo do apoio ao luto parental. *Rev Port Med Geral Fam.* 2021;37(6):516-33.

18. Santos GFATF, Alves DR, Oliveira AMM, Dias KCCO, Costa BHS, Batista PSS. Palliative Care in Oncology: Nurses' Experience in Caring for Children in The Final Stages of Life. *Rev Fun Care*. [Internet]. 2020 [accessed on 2022 June 21];12:689-95. Available from: <http://dx.doi.org/10.9789/2175-5361.rpcfo.v12.9463>.
19. Dias KCCO, Batista PSS, Fernandes MA, Zaccara AA, Oliveira TC, Vasconcelos MF, et al. Dissertações e teses sobre cuidados paliativos em oncologia pediátrica: estudo bibliométrico. *Acta Paulista de Enfermagem* [Internet]. 2020 [accessed on 2022 June 21]; 33:eAPE20190264. Available from: <https://www.scielo.br/j/ape/a/tn7RwYbpTHM4PMkgyFWdjTk/?format=pdf&lang=pt>.
20. Silva S, Melo CFM, Magalhaes B. A Recidiva em Oncologia Pediátrica a Partir da Perspectiva dos Profissionais. *Rev Psicologia, saúde & doenças*. 2019; 20(2):542-555.
21. Guedes AKC, Pedrosa APA, Osório MO, Pedrosa TF. Cuidados paliativos em oncologia pediátrica: perspectivas de profissionais de saúde. *Rev SBPH*. 2019;22(2):128-148.
22. Pacheco CL, Goldin JR. Percepções da equipe interdisciplinar sobre cuidados paliativos em oncologia pediátrica. *Rev Bioet*. 2019;27(1):67-75.
23. Souza T, Correa-Júnior A, Santana M, Carvalho J. Cuidados paliativos pediátricos: análise de estudos de enfermagem. *Revista de Enfermagem UFPE*. 2018;12(5):1409-1421.
24. Semtchuck ALD, Genovesi F, Santos JL. Cuidados paliativos em oncologia pediátrica: revisão integrativa. *Rev Urug Enferm*. 2017;12(1):87-101.
25. Martins GB, Hora SS. Desafios à Integralidade da Assistência em Cuidados Paliativos na Pediatria Oncológica do Instituto Nacional de Câncer José Alencar Gomes da Silva. *Rev Bras Cancerol*. 2017;63(1):29-37.
26. Coropes V, Valente G, Oliveira A, Paula C, Souza C, Camacho A. A assistência dos enfermeiros aos pacientes com câncer em fase terminal: revisão integrativa. *Revista de Enfermagem UFPE*. 2016;10(6):4920-4926.
27. Silva AF, Issi HB, Botene DZA, Motta MGC. Cuidados paliativos em oncologia pediátrica: percepções, saberes e práticas na perspectiva da equipe multiprofissional. *Rev Gaúcha Enferm*. 2015;36(2):56-62.
28. Carmo SA, Oliveira ICS. Criança com Câncer em Processo de Morrer e sua Família: Enfrentamento da Equipe de Enfermagem. *Rev Bras Cancer*. 2015;61(2):131-8.
29. Javorski AR, Bushatsky M, Viaro VD. Cuidados paliativos em crianças com câncer: revisão integrativa. *Revista de Enfermagem UFPE*. 2015;9(2):718-730.
30. Arantes ACQ. A morte é um dia que vale a pena viver. Rio de Janeiro: Sextante; 2019.
31. Freitas BEC, Guimarães TB, Maia MLFB, Monteiro-Ângelo GC, Oliveira JS. Cuidados paliativos em pacientes pediátricos oncológicos terminais. *CBioS*. 2020;6(2):177.
32. World Health Organization. Cancer: palliative care is an essential part of cancer control. [Internet]. [accessed on 2022 June 21]. Available from: <https://www.who.int/health-topics/palliative-care>

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