PEDIATRIC PALLIATIVE CARE: ANALYSIS OF NURSING STUDIES
CUIDADOS PALIATIVOS PEDIÁTRICOS: ANÁLISE DE ESTUDOS DE ENFERMAGEM
CUIDADOS PALIATIVOS PEDIÁTRICOS: ANÁLISIS DE ESTUDIOS DE ENFERMERÍA

Thaís Cristina Flexa Souza¹, Antonio Jorge Silva Correa Júnior², Mary Elizabeth de Santana³, Jacira Nunes Carvalho⁴

ABSTRACT

Objective: to analyze the scientific evidence about pediatric palliative care. **Method:** this is a bibliometric study of Brazilian publications with 23 articles available online, between 2012 and 2016 in the LILACS, MEDLINE and BDNF databases analyzed by simple descriptive statistics in figures and later according to content analysis. **Results:** the articles found are in journals B1 and B2, with publications in 2014. The most studied subjects were nurses and nursing staff and the most indexed descriptors were palliative care, child, oncological nursing, nursing, child health, and neoplasms. All of them referred to the oncology and evidence for humanistic support: caregiver care, oncological pain control, engendering care for recreational activities and maintaining effective communication with staff, children, and family. **Conclusion:** the analysis showed a literature focused on oncology and caregiver care, revealing still low publication of other chronic conditions in pediatrics. The themes that may contribute to the advancement of nursing in later studies are an expansion of care plans for specific symptoms; research on administration and management; typification and content of the communication during hospitalization; and complexity of the hospital and home care network. **Descriptors:** Bibliometrics; Palliative Care; Pediatrics; Pediatric Nursing; Child; Chronic Disease.

RESUMO

Objetivo: analisar as evidências científicas acerca dos cuidados paliativos pediátricos. **Método:** estudo bibliométrico de publicações brasileiras realizado com 23 artigos disponíveis on-line, no período de 2012 a 2016 nas bases de dados LILACS, MEDLINE e BDNF, analisados pela estatística descritiva simples em figuras e posteriormente segundo a análise de conteúdo. **Resultados:** os artigos encontrados estão em revistas B1 e B2 majoritariamente, com publicações no ano de 2014. Os sujeitos mais estudados foram enfermeiros e equipe de enfermagem e os descritores mais indexados: cuidados paliativos, criança, enfermagem oncológica, enfermagem, saúde da criança e neoplasias. A totalidade referiu-se a oncologia e as evidências para o suporte humanístico: assistência ao cuidador, controle da dor oncológica, engendrar cuidados com vista em atividades lúdicas e manter comunicação eficaz com a equipe, criança e família. **Conclusão:** a análise mostrou uma literatura focada na oncologia e assistência ao cuidador, revelando ainda baixa publicação de outras condições crônicas na pediatria. Os temas que podem contribuir para o avanço da enfermagem em estudos posteriores são: ampliações de planos de cuidados para sintomas específicos; pesquisas sobre a administração e gestão; tipificações e o conteúdo da comunicação na internação; e complexidade da rede de atendimento hospitalar e domiciliar. **Descritores:** Bibliometria; Cuidados Paliativos; Pediatria; Enfermagem Pediátrica; Criança; Doença Crônica.

RESUMEN

Objetivo: analizar las evidencias científicas acerca de los cuidados paliativos pediátricos. **Método:** estudio bibliométrico de publicaciones brasileiras realizado con 23 artículos disponibles online, en el período de 2012 a 2016 en las bases de datos LILACS, MEDLINE y BDNF analizados por la estadística descriptiva simple en figuras y posteriormente según análisis de contenido. **Resultados:** los artículos encontrados están en revistas B1 y B2 majoritariamente, con publicaciones en 2014. Los sujetos más estudiados fueron enfermeros y equipo de enfermería y los descriptors más indexados fueron cuidados paliativos, niño, enfermería oncológica, enfermería, salud del niño y neoplasias. La totalidad apuntó la oncología y las evidencias para el soporte humanístico: asistencia al cuidador, control del dolor oncológica, engendrar cuidados para actividades lúdicas y mantener comunicación eficaz con el equipo, niño y familia. **Conclusión:** el análisis mostró una literatura enfocada en la oncología y asistencia al cuidador, revelando aún baja publicación de otras condiciones crónicas en la pediatria. Los temas que pueden contribuir para el avance de la enfermería en estudios posteriores son: ampliaciones de planos de cuidados para síntomas específicos; investigaciones sobre la administración y gestión; tipificaciones y el contenido de la comunicación en la internación; y complejidad de la red de atendimento hospitalario y domiciliario. **Descriptor:** Bibliometría; Cuidados Paliativos; Pediatria; Enfermería Pediátrica; Niño; Enfermedad Crónica.

^{1,2}Master degree students, Post-graduation Program in Nursing/PPGENF. Federal University of Pará/UFPA. Belém (PA), Brazil. E-mail: thaisflexa@gmail.com ORCID iD: <https://orcid.org/0000-0002-7296-0380>; E-mail: juniorjorge_94@hotmail.com ORCID iD: <https://orcid.org/0000-0003-1665-1521>; ^{3,4}Ph.Ds., Federal University of Pará/UFPA. Belém (PA), Brazil. E-mail: betemary@terra.com.br ORCID iD: <https://orcid.org/0000-0002-3629-8932>; E-mail: jacirancarvalho@gmail.com ORCID iD: <https://orcid.org/0000-0002-5464-2434>

INTRODUCTION

The basic components of palliative care include proximity and warmth, dignity and pain relief. In pediatrics neonatal, nurses need to be at the forefront of these contingencies for care.¹ It is considered that in the Brazilian reality among the causes of death maternal there are perinatal factors (prematurity, asphyxia/hypoxia, perinatal infections, respiratory diseases, perinatal cardiovascular disorders and maternal diseases), congenital malformations, child infections, immunopreventable diseases, external causes and malformed causes.²

A child affected by a chronic disease is considered when a disease is diagnosed and treated in the first years of life, comprising durable and non-specific time, having difficulties in the family routine and also, its transition from childhood to adolescence attending health services. The health system and its professionals must adequately visualize the therapeutic possibilities, including the genetic predisposition and the influencing factors preneonatal and postneonatal.³

Pediatric palliative care is categorized into three levels: Basic, whose professionals have a postgraduate degree in pediatrics, identifying children with palliative needs and referencing them quickly to higher levels of care; Generalist, whose professionals are interested in palliative care courses for children and can structure human resources training plans and/or individual plans for interventions in sick children; Specialized, whose professionals have specialized training, passing through the other levels, performing research in the area and providing care in complex cases.⁴

Factors such as leadership are highlighted in nursing work in specialized clinics to guide the team's work during the hospitalization period, depth of clinical knowledge, self-reflection, and awareness about the work.¹ "Make a difference" during their care service encompasses aspects relating to the family, supporting them, and

managing the symptoms of their children individually.⁵

In this study, the term pediatrics is used to denote the age range from 0 to 19 years old, encompassing the concept of adolescence according to WHO, respecting the following respective age groups: neonatal or newborn - 0 to 28 days; infant- 29 days to 12 months; infant - 1 to 3 years old; preschool - 3 to 6 years old; school - 6 to 11 or 12 years old; adolescent - 11 to 19 years old.⁶

OBJECTIVE

- To analyze the scientific evidence on pediatric palliative care.

METHOD

This is a bibliometric study using the quantitative analysis of the publications to give subsidy to the formulation of new scientific research. It is divided into three stages, beginning with two quantitative stages: 1) synopsis of titles and other information 2) display of figures for percentage discussion; and a descriptive stage: 3) discussion based on recurrent themes on pediatric palliative care.⁷

The articles were surveyed by two independent reviewers in the months of June and July of 2017. In the development of the study, a search and review protocol for articles was used: 8 identification of the theme and selection of the research question: **What is the state of the art regarding the production of articles between 2012 to 2016, about palliative care in pediatric nursing in Brazil?**; establishment of criteria for inclusion and exclusion of studies; selection of information to be extracted according to the validated template form, 9 evaluation of the included studies according to the seven levels of evidence,¹⁰ interpretation of the results and the presentation of the synthesis of knowledge.

The search was carried out through a search through Online access in important database systems in the context of Brazilian

Souza TCF, Correa Júnior AJ, Santana ME et al.

Pediatric palliative care: analysis of nursing...

health: Latin American and Caribbean Literature in Health Sciences (LILACS), Medical Literature Analysis and Retrieval System Online (MEDLINE via EBSCO), Nursing Database (BDENF). The inclusion criteria were: Articles only in Portuguese between January 2012 to December 2016 and available in full. The exclusion criteria were: research without nursing subsidy and that did not explicitly address pediatric palliative care.

The Health Sciences Descriptors (DECs) and combinations in a strategy ("cloud of combinations of DECs") were combined: "Palliative Care", "Nursing Care", "Child", "Pediatric Nursing" and "Illness Chronic" linked by the Boolean operator AND, and employees with the appropriate selection in "TITLE, ABSTRACT AND SUBJECT".

The seven levels of evidence for clinical practice explored and typified in this study: level 1 for systematic review or meta-analysis, level 2 for randomized controlled trial, level 3 for controlled trial without randomization, level 4 for case-control studies or cohort studies, level 5 for qualitative meta-synthesis, level 6 for qualitative studies and level 7 for expert opinions.¹⁰

With the final composition of the database, the first analysis was guided by simple descriptive statistics as referential that provides for Tabulation, Refinement,

Construction of graphs; Presentation and interpretation of data and Discussion.¹¹ The second analysis was guided by the technique of Content Analysis to discuss the content of articles.

The authorship of the researched articles was assured using only surnames of the authors to contemplate the ethical aspects. Because it is a type of documentary study whose data are of a public nature, all the ethical precepts involved in relation to the analysis and dissemination of the research data were respected.

RESULTS

There were 177 articles found, and 154 of the articles were about the topic of palliative care and/or did not contribute to nursing. In the case of repetitions of publications between the databases, the LILACS database was chosen. Twenty-three articles relevant to the objectives were selected for analysis.

The distribution by database: LILACS (n=18), BDENF (n=3), MEDLINE (n=2) (Figure 1). Figure 2 was used for the interpretation of the data and synthesis.

Figure 1. Flowchart with search detail. Belém (PA), Brazil, 2017.

Titles and Identification Code	Authors/Source/Year/Level of evidence	Objective	Recommendations/Conclusions
Nursing performance in children with cancer: palliative care/A1	Monteiro; Rodrigues; Pacheco; Pimenta/ LILACS/ 2014/VI	To know the action of caring for the nurse with the child with cancer in palliative care.	Nurses take care of children in palliative care in a unique way, based on understanding, caring and respect for their needs and their family.
The experience of the family of the child and/or adolescent in palliative care: floating between a goal and a hopelessness in a world transformed by the losses	Misko; Santos; Ichikawa; Lima; Bousso/ LILACS/ 2015/VI	To understand the experience of the family of the child and/or adolescent in palliative care and to construct a theoretical model representative of the process experienced by the family.	The parents' stay with the child at home expected the recovery and maintenance of life and removed the feeling of the possibility of the death of the child.
The importance of playing for children with cancer hospitalized in palliative care/A3	Soares; Silva; Santos; Depianti/ BDEFN/ 2016/VI	To identify the importance of playing in the palliative care of hospitalized children with cancer in the perception of the nursing team.	It is important to include playing during nursing care for children with cancer in palliative care, as it helps the child to be happier and promote well-being, in addition to making care more humanized.
The importance of palliative care provided by the nurse to the child with terminal stage cancer/A4	Bernardo; Bernardo; Costa; Silva; Araújo; Spezani / LILACS/ 2014/	To reflect on the importance of the palliative care provided by the nurse to the child with cancer in the terminal stage.	The results of this study are confirmed by the importance of the nurses' performance because the proximity of bonds allows a more effective and conscious nursing practice among all involved.
Child care in palliative care in Brazilian scientific production/A5	Garcia-Schinzari; Santos/ LILACS/ 2014/	To describe publications in Brazilian scientific production regarding child care in palliative care.	There is difficulty in approaching pediatric palliative care. In this way, it is necessary to value this type of care, not only emphasizing the physical aspects but also the psychological, social and spiritual aspects. It is also observed that it is difficult for health professionals to deal with issues related to caring for the family, with children with physical and psychological exhaustion.
A child with Cancer in Dying Process and his Family: Nursing Team Meeting/A6	Carmo; Oliveira/ LILACS/ 2015/VI	To describe the specificities of nursing care to the child with cancer in the process of dying and his/her family and to analyze the performance of the nursing team in front of the child with cancer in the process of dying and his	The nursing team has difficulty coping with the death of the cancer child in the process of dying and supporting their family. These difficulties are related to the lack of knowledge about palliative care.

		/ her family.	
Children and adolescents with cancer in palliative care: family experience/A7	Sanches; Nascimento; Lima/ LILACS/ 2014/VI	To investigate the experience of relatives in caring for children and adolescents with cancer in palliative care, particularly in end-of-life care.	The study was shown to be important for the care of children and adolescents with end-of-life cancer, since the complex, dynamic and comprehensive experiences of families in the care of children and adolescents contribute to the understanding of the care process in the light of the fundamentals of palliative care.
Nursing care for the child who has the advanced oncological disease: being-with in daily care/A8	Mutti; Padoin; Paula; Souza; Terra; Quintana/ LILACS/ 2012/VI	To understand the meaning, for the nursing team, of caring for children who have an oncological disease that no longer responds to curative treatments.	Care in pediatric oncology transcends technical issues and routines, demand and competencies to meet the peculiarities and needs of the child and the family.
Palliative care for children with cancer/A9	França; Costa; Nóbrega; Lopes/ LILACS/2013/VI	To understand the existential experience of nurses in caring for children with cancer without therapeutic possibilities.	Palliative care is an effective tool in caring for the child with cancer to promote authentic communication and a bond between the child and the nurse, who develops a therapeutic process based on universal humanistic values, with benefits for both.
Palliative care in pediatric oncology in the perception of nursing students/A10	Guimarães; Silva; Espírito Santo; Moraes/ LILACS/ 2016/VI	To know the perception of nursing academics about palliative care in pediatric oncology.	The complexity and multiple aspects involved in palliative care require that it be addressed during nurses' graduation.
Palliative care in pediatric oncology: perceptions, knowledge, and practices from the perspective of the multi-professional team/A11	Silva; Issi; Motta; Botene/ MEDLINE/ 2015/VI	To know the perceptions, knowledge, and practices of the multi-professional team in the attention to children in palliative care in a pediatric oncology unit.	The themes revealed that the team suffers, equally, with the death of the child and, similarly to the family, moves towards the construction of coping mechanisms for the elaboration of mourning. Paradoxically, the team shares knowledge to outline the bases of the unique therapeutic project to be implemented and inserts the family in this process so that it can assume the leading role of child care.
Unveiling the experience of mothers of children with cancer/A12	Costa; Agra; Souza Neto; Silva; Braz; Mendonça / BDENF / 2016/VI	To understand the daily life of mothers caring for children with cancer	The research findings made it possible to reveal the various changes in the professional, family and personal life of the mothers caused by the illness and hospitalization of the child, such as abandonment of employment, removal from home and their domestic functions, leaving spouse and other children to own luck, the detachment of their personal desires and needs. These changes contributed to intensifying the physical and emotional exhaustion of these women. Host strategies are proposed through qualified listening.
The spatiality of being-	Mutti; Padoin; Paula/ LILACS/	To understand the meaning	It is pointed out the need for the development of strategies

professional-of-nursing in the world of childcare that has cancer/A13	2012/VI	for nursing staff to care for children who have advanced oncologic disease, whose illness no longer responds to curative treatments.	of multi-professional action among the team, considering that this also needs to be taken care of.
Experience in palliative care for children with leukemia: the vision of professionals/A14	Nascimento; Rodrigues; Soares; Rosa; Viegas; Salgado/ LILACS/ 2013/VI	To understand the vision of the multidisciplinary team before the child with leukemia in palliative care.	It was found that professionals have little experience in this area and have difficulty dealing with feelings, feeling sometimes unable to act through the anguish of those involved and death. However, despite the area of action that causes distress and distress to the professional, it is noticed that the multi-professional team identifies with the area what is important for the child and his family to feel safe, respected and welcomed by professionals.
Importance of communication in palliative care in pediatric oncology: focus on Humanistic Nursing Theory/A15	França; Costa; Lopes; Nóbrega; França/ LILACS/ 2013/VI	To investigate and analyze communication in palliative care in pediatric oncology, from the point of view of nurses, based on the Humanistic Nursing Theory.	Communication is an effective element in the care of the child with cancer and is of paramount importance for the promotion of palliative care when based on the Humanistic Nursing Theory.
Decent death of the child: perception of nurses from an oncology unit/A16	Souza; Misko; Silva; Poles; Santos; Bousso/ LILACS/ 2013/VI	To identify the meaning and interventions of nurses who work in pediatric oncology in promoting the worthy death of the child.	This study contributes to broadening the understanding of the care process and allows us to advance in the postulation of a theoretical framework that contemplates the integration of knowledge and actions that constitute an integral care, transcending the needs of only clinical and biological needs.
The nurse and the care of the child with cancer with no possibility of a current cure/A17	Monteiro; Rodrigues; Pacheco/ LILACS/ 2012/VI	To comprehensively analyze the care of the nurse to the hospitalized child with oncologic disease out of the possibility of a current cure.	In the comprehensive analysis, there are two categories: comfort and minimization of pain. From these actions, care is directed towards the family member present, with the purpose of supporting him, providing attitudes of affection, affection, and respect.
The use of play by nursing staff in the palliative care of children with cancer/A18	Soares; Silva; Cursino; Goes/ MEDLINE/ 2014/VI	To describe the ways in which the nursing team uses to play in the palliative care of children with cancer and to analyze the facilities and difficulties of using play in this care.	It is concluded that play gives the child with cancer in palliative care a humanized care, and it is essential to integrate it into the care of these children.
Perception of family members about stressors due to the demands of care of children and	Guerini; Cordeiro; Osta; Ribeiro/ LILACS / 2012/VI	To identify the family perceptions about the stressors due to the demands	It is concluded that, in order to guarantee the achievements made possible by the technological advance, it is necessary to support the family, especially the woman,

adolescents dependent on technologies/A19		of care of children/adolescents dependent on technology.	with policies that allow her to take care of the child/adolescent and to take place in other dimensions.
Relations established by nursing professionals in the care of children with advanced cancer disease/A20	Reis; Cardoso; Potrich; Padoin; Bin; Mutti, et al./ LILACS/ 2014/VI	To understand the relationships established by the professionals of the nursing team in the care of children with the advanced oncologic disease, without therapeutic possibilities.	These relationships were reflected in the difficulties of caring for cancer, intensified by being children since their conception of this disease is associated with suffering and death.
Resilience and death: the nursing professional facing the care of children and adolescents in the process of the finitude of life/A21	Santos; Moreira/ LILACS/ 2014/VI	To analyze the resilience of the nursing team by the process of caring for children and adolescents with chronic illness, which includes dealing with their finitude.	It is observed that health professionals use the following strategies of resilience: in the contact with the process of living and dying with the chronic health situation they bet on their formulations as people, associating technique and affection; they are based on the search for religious reasons; prevent suffering for patients in the dying process; make team changes.
Feelings, acceptance, and humanization in palliative care for children with leukemia/A22	Soares; Rodrigues; Nascimento; Rosa; Viegas; Salgado/ BDENF/ 2013/VI	To understand the vision of the multidisciplinary team before the child with leukemia in palliative care.	It was observed that the professional receives and provides humanized assistance to the child with leukemia in palliative care, providing him with maximum comfort and pain reduction. It was verified that the palliative care performed encompasses not only the patient but also reaches his family. The professional supports welcomes and comforts the entire client's family during the palliative care process.
Experiencing pain: the experience of children and adolescents in palliative care/A23	Borghi; Rossato; Damião; Guedes; Silva; Barbosa et al./ LILACS/ 2014/VI	To know how children and adolescents in palliative care manage pain in their daily lives and how they describe it in intensity and quality.	Although pain is a limiting agent in the lives of children and adolescents, it is found that they faced pain daily and yet had a life beyond pain and disease. In addition, it is important for nurses to understand that effective pain management is essential for a life closer to normality, reducing their suffering.

Figure 2. Distribution of articles related to palliative nursing care in pediatrics. Belém (PA), Brazil, 2017.

Identification code	Subjects studied
A1, A9, A15, A16, A17 e A20	Nurses
A2, A7 e A19	Family
A3, A6, A8, A13, A18 e A21	Nursing team (technicians and nurses)
A10	Nursing Academics
A11, A14 e A22	Multidisciplinary Team
A12	Caregiver Mothers
A23	Children and adolescents

Figure 3. Subjects of research on palliative nursing care in pediatrics. Belém (PA), Brazil, 2017.

Two of the 23 studies are literature review in databases (A4 and A5). Therefore, remaining 21 original research articles as sample universe/100% is observed according to figure 2 a preference for the choice of nurses (n=6/28, 57%) and the components of the nursing team (n=6/28, 57%) as studied subjects. About the family nucleus and the multi-professional team, three articles were obtained (14.28%); mothers, nursing students, and chronically ill children requiring palliative care, with only one study each (n=1/4, 76%). Of this sample universe/100% (n=21/100%) have a level of evidence VI, that is, all the studies were qualitative and/or descriptive.

Direcionaram-se majoritariamente as publicações para periódicos B1 (n=10/43,47%) e B2 (n=6/26,08%), e o quantitativo em periódicos A1 (n=2/8,69%), A2 (n=4/17,39%) e

B3 (n=1/4,34%) (Figura 4). Sobreleva-se a relevância da publicação do tema em periódicos cujo QUALIS possua algum valor atribuído, atestando a qualidade das pesquisas científicas. Tal sistema valorizado na realidade brasileira oferece uma visão fidedigna da qualidade da produção dos programas de pós-graduação brasileiros.

Most journals were published for journals B1 (n=10/43.47%) and B2 (n=6/26.08%), and quantitative journals A1 (n=2/8.69%), A2 (n=4/17.39%) and B3 (n=1/4.34%) (Figure 4). The relevance of the publication of the subject in papers whose QUALIS has some value attributed, attesting the quality of the scientific research is surpassed. Such a system valued in the Brazilian reality offers a reliable view of the quality of the production of Brazilian graduate programs.

Figure 4. Qualis CAPES (Quadrennium 2013/2016) of the publications. Belém (PA), Brazil, 2017.

Figure 5. Descriptors used in the indexing of publications. Belém (PA), Brazil, 2017.

The articles found are mostly well indexed, judging by the most used descriptors according to the DECS in them: palliative care (n=21), child (n=10) and oncological nursing (n=6), nursing (n=6), (n=6) and neoplasms (n=6) (Figure 5).

The southeastern region has the highest number of studies. The states of Rio de Janeiro (RJ), São Paulo (SP) and Rio Grande do Sul (RS) in the southern region of the country presented the highest number of publications on the subject in question between 2012 and 2016, respectively: 8/34, 78%; 5/21.73%; 4/17.39%.

DISCUSSION

It was observed that all the studies deal with the palliative care of the child in the oncological perspective. As far as pediatric cancer is concerned, it is reported that this is the second cause of death between 0 and 14 years old, only after accidents and although the prospect of a cure is high the infant mortality rate is still very high and stems from unknown causes. Therefore, it is a major public health problem today.

It was observed that it is important not only to turn to the child to direct an accurate look at caregiver, because in palliative care the focus of attention is the patient-family binomial since it constitutes as care provider and receiver. In this context, the main caregiver is inserted, who are most often the parents, who are responsible for the child in a situation of dependency, often giving up their life.¹³⁻⁶

It has also been identified that the scientific productions related to childhood palliative care are centered on the hospital. Historically, when addressing health care in

the terminal stage of any disease, Western culture immediately refers to hospital care. At the same time, this has been demystified due to the newly constructed conception that the home is comfortable, protective, and with a closer relationship between family and friends, making it easier to treat. In this way, the transfer of this patient, when possible, from hospital care to outpatient or home care needs to be carried out.¹⁷

The Brazilian Portuguese scientific literature points out that palliative care for the child is carried out to offering comfort, well-being, safety and quality improvement to a “good death” with measures that alleviate pain and suffering.^{12,14- 8,19-29}

The lack of comfort comes from distressing symptoms and/or anxiety and fear, nursing actions include defining a locus of control, implementing rest measures such as high or low bedside, music, the presence of a particular person or object, among planning long-term actions.³⁰

It is extremely important to address the role of nursing in the child in palliative care that requires pain management and control of other symptoms since pain is one of the signs and symptoms that the cancer patient presents and reports the most. Support for the family, since the diagnosis of cancer, causes a shock perceived by the despair of parents who believe it to be an incurable disease by relating it to death. The treatment is currently based on the analgesic scale of the World Health Organization, promoting adaptation of analgesia interventions and pain levels. It is up to the nurse to assess and measure the complexity of oncologic pain, implementing the therapy considering the family in this context since the child is

suffering from fatigue, nausea, vomiting, dyspnea, constipation, anorexia, convulsions, anxiety, depression, agitation and confusion.^{12,14-5,19-28,31-2}

In the case of chronic pain, the nursing priorities translate into the evaluation of the etiology and triggering factors, determining the response to pain through behaviors or mismatches, helping the patient to deal with pain through dynamics, pharmacological or complementary therapy and promoting well-being through the sense of inner control.³⁰ More Brazilian studies that detect adjustments of nursing interventions for pain control and their distressing symptoms in the pediatric palliative patient are desirable to identify factors of relief and worsening of the clinical condition.

It is also the range of symptoms with complementary therapies, medications or interventions such as positioning, relaxation, massage and other measures to maintain the quality of life, since using a single therapeutic resource has not been shown to be efficient for pain control, mainly of the chronic type. The importance of the association of pharmacological therapy and pain relief with play, art, reading, music and recreational activities, as well as reception and listening by the professional are shown in studies of children and adolescents.³³

Also, activities appropriate to the children's universe are offered as a game characterized as an essential activity for their motor, emotional, mental and social development and the way in which their feelings, anxieties and frustrations are actively communicated and expressed. It is noticed that care in pediatric oncology brings challenges to the team, their material resources, preparation to attend to the particularities of the children's universe.²⁶

There is other evidence in the studies that confirms that communication is an instrument that facilitates health work among the team, and between the child and the family, and the nurse is responsible for the interaction, giving the participants information about the clinical picture and support. Although difficulties are encountered in establishing an effective communicative process, it is important to point out that nurses who work with patients with no prognosis of cure consider communication to be an important and effective therapeutic resource, being a humanizing link and facilitating the emotional balance between the child and his family in the face of this intricate moment.^{12,15,19, 20-1,25-6,32,34-8}

This study is limited by using only the production of Brazilian literature in Portuguese.

CONCLUSION

There was a literature focused on oncology and caregiver care, also revealing a low publication of other chronic conditions in pediatrics. The themes that may contribute to the advancement of nursing in later studies are expansion of care plans for specific symptoms; research on nursing administration and management; typifications and the content of the communication in the internment both between the team and with the family; and exploring the complexity of the hospital and home care network.

FINANCIING

CAPES (Coordenação de Aperfeiçoamento de Pessoal de Nível Superior).

REFERENCES

1. Kilcullen M, Ireland S. Palliative care in the neonatal unit: neonatal nursing staff perceptions of facilitators and barriers in a regional tertiary nursery. *BMC Palliat care*. 2017 May; 16(1):32. Doi: [10.1186/s12904-017-0202-3](https://doi.org/10.1186/s12904-017-0202-3)
2. Ministério da Saúde (BR), Secretaria de Vigilância em Saúde, Departamento de Vigilância de Doenças e Agravos não Transmissíveis e Promoção da Saúde. Saúde Brasil 2014: uma análise da situação de saúde e das causas externas [Internet]. Brasília: Ministério Saúde; 2015 [cited 2017 Nov 15]. Available from: http://bvsms.saude.gov.br/bvs/publicacoes/saude_brasil_2014_analise_situacao.pdf
3. Moreira MCN, Gomes R, Sá MRC. Chronic diseases in children and adolescents: a review of the literature. *Ciênc Saúde Coletiva*. 2014 July; 19(7):2083-94. Doi: <http://dx.doi.org/10.1590/1413-81232014197.20122013>
4. Associação Portuguesa de Cuidados Paliativos. Relatório do Grupo de Trabalho para os Cuidados Paliativos Pediátricos (despachos de 8286-A/2014 e 8956/2014) [Internet]. Porto: APCC; 2014 [cited 2017 Nov 23]. Available from: <http://www.apcp.com.pt/uploads/Relato-rio-do-GdT-de-CPP.pdf>
5. McConnell T, Porter S. The experience of providing end of life care at a children's hospice: a qualitative study. *BMC Palliat Care*. 2017 Feb;16(1):15. Doi: [10.1186/s12904-017-0189-9](https://doi.org/10.1186/s12904-017-0189-9)
6. Pinto JP, Fernandes MG. Crescimento e desenvolvimento infantil. In: Fonseca AS,

organizadora. Enfermagem pediátrica. São Paulo: Martinari; 2013. p. 4-5

7. Costa T, Lopes S, Fernandes-Llimós F, Amante MJ, Lopes PF. A bibliometria e a avaliação da produção científica: indicadores e ferramentas. Actas Congresso Nacional BAD [Internet]. 2012 [cited 2017 Dec 23];11:1-7. Available from:

<http://www.bad.pt/publicacoes/index.php/congressosbad/article/view/429/pdf>

8. Mendes KDS, Silveira RCCP, Galvão CM. Integrative literature review: a research method to incorporate evidence in health care and nursing. Texto contexto-enferm. 2008 Oct/Dec; 17(4):758-64. Doi:

<http://dx.doi.org/10.1590/S0104-07072008000400018>

9. Ursi ES, Galvão CM. Perioperative prevention of skin injury: an integrative literature review. Rev Latino-Am Enfermagem. 2006 Jan/Feb; 14(1):124-31. Doi: <http://dx.doi.org/10.1590/S0104-11692006000100017>

10. Melnyk BM, Fineout-Overholt E, Stillwell S, Williamson KM. Evidence-based in practice: step by step. Am J Nurs. 2010; 110(5): 41-7. Doi: 10.1097/01.NAJ.0000366056.06605.d2

11. Oliveira AAS, Lima CGS, Morais KKC. Bibliometrics and metasynthesis of studies on work published in the Journal Psicologia & Sociedade. Psicol soc (online). 2016 Sept/Dec; 28(3):572-81. Doi:

<http://dx.doi.org/10.1590/1807-03102016v28n3p572>

12. Bernardo CM, Bernardo DM, Costa IA, Silva LR, Araújo WGP, Spezani RS. The importance of palliative care provided by the nurse for children with cancer in terminal phase. J Res Fundam Care (online). 2013 July/Sept; 6(3):1221-30. Doi: 10.9789/2175-5361.2014v6n3p1221

13. Meneguim S, Ribeiro R. Difficulties of caregivers providing palliative care to patients covered by the family health strategy. Texto contexto-enferm. 2016 Mar; 25(1): e3360014. Doi: <http://dx.doi.org/10.1590/0104-0707201500003360014>

14. Carmo SA, Oliveira ICS. Children with Cancer in the Process of Dying and their Families: Confrontation of Nursing Team. Rev Bras Cancerol [Internet]. 2015 [cited 2017 Dec 23]; 61(2): 131-8. Available from: http://www1.inca.gov.br/rbc/n_61/v02/pdf/07-artigo-crianca-com-cancer-em-processo-de-morrer-e-sua-familia-enfrentamento-da-equipe-de-enfermagem.pdf

15. Misko MD, Santos MR, Ichikawa CR, Lima RA, Bousso RS. The family's experience of the child and/or teenager in palliative care:

fluctuating between hope and hopelessness in a world changed by losses. Rev Latino-Am Enfermagem. 2015 May/June; 23(3):560-7. Doi: 10.1590/0104-1169.0468.2588

16. Guerini IC, Cordeiro PKS, Osta SZ, Ribeiro EM. Relatives' perception regarding the stressors resulting from the care demands of technology-dependent children and adolescents. Texto contexto-enferm. 2012 Apr/June; 21(2):348-55. Doi:

<http://dx.doi.org/10.1590/S0104-07072012000200012>

17. Ribeiro LL, Silva LE, França AMB. Cuidados paliativos à criança portadora de doença oncológica. Ciênc Biol Saúde [Internet]. 2016 Nov [cited 2017 Dec 23]; 3(3):151-64. Available from:

<https://periodicos.set.edu.br/index.php/fitsb/iosaude/article/view/3416/2018>

18. Soares VA, Silva LF, Santos PM, Depianti JRB. The importance of playing for hospitalized children with cancer in palliative care. J Nurs UFPE on line [Internet]. 2016 Mar [cited 2017 Oct 12]; 10(3):1047-53. Available from:

<http://pesquisa.bvsalud.org/portal/resource/pt/bde-29622>

19. Sanches MVP, Nascimento LC, Lima RAG. Children and adolescents with cancer under palliative care: experience of family members. Rev Bras Enferm. 2014 Jan/Feb; 67(1):28-35. Doi:

<http://dx.doi.org/10.5935/0034-7167.20140003>

20. Guimarães TM, Silva LF, Espírito Santo FH, Moraes JRMM. Palliative care in pediatric oncology in nursing students' perception. Esc Anna Nery Rev Enferm. 2016 Apr/June; 20(2):261-7. Doi:

<http://dx.doi.org/10.5935/1414-8145.20160035>

21. Silva AF, Issi HB, Motta MGC, Botene DZA. Palliative care in paediatric oncology: perceptions, expertise and practices from the perspective of the multidisciplinary team. Rev Gaúcha Enferm. 2015 Apr/June; 36(2):56-62. Doi: <http://dx.doi.org/10.1590/1983-1447.2015.02.46299>

22. Mutti CF, Padoim SMM, Paula CC, Souza IEO, Terra MG, Quintana AM. Nursing care to children who has an advanced oncologic disease: being-with on daily assistance. Ciênc Cuid Saúde. 2012 Jan/Mar; 11(1):113-20. Doi: <http://dx.doi.org/10.4025/ciencucuidsaude.v11i1.18867>

23. Souza LF, Misko MD, Silva L, Poles K, Santos MR, Bousso RS. Dignified death for children: perceptions of nurses from an oncology unit. Rev Esc Enferm USP. 2013 Feb;

Souza TCF, Correa Júnior AJS, Santana ME et al.

Pediatric palliative care: analysis of nursing...

- 47(1):30-7. Doi: <http://dx.doi.org/10.1590/S0080-62342013000100004>
24. Monteiro ACM, Rodrigues BMRD, Pacheco STA, Pimenta LS. Nurses' work with children with cancer: palliative care. *Rev Enferm UERJ*. 2014 Nov/Dec; 22(6):778-3. Doi: <http://dx.doi.org/10.12957/reuerj.2014.15665>
25. Reis TLR, Paula CC, Potrich T, Padoin SMM, Bin A, Mutti CF, et al. Relationships Established by Nursing Professionals When Caring for Children with Advanced Cancer. *Aquichán*. 2014 Oct/Dec; 14(4):496-508. Doi: <http://dx.doi.org/10.5294/aqui.2014.14.4.5>.
26. Soares MR, Rodrigues TG, Nascimento DM, Rosa MLS, Viegas SMF, Salgado PO. Feelings, reception and humanization in palliative care to children with leukemia. *J Res Fundam Care Online*. 2013 July/Sept; 5(3):354-63. Doi: 10.9789/2175-5361.2013v5n3p354
27. Borghi CA, Rossato LM, Damião EBC, Guedes DMB, Silva EMR, Barbosa SMM, Polastrini RT. Living with pain: the experience of children and adolescents in palliative care. *Rev Esc Enferm USP*. 2014; 48(Spe):68-74. Doi: 10.1590/S0080-623420140000600010
28. Nascimento DM, Rodrigues TG, Soares MR, Rosa MLS, Viegas SMF, Salgado PO. Experience in palliative care for children with leukemia: the professionals' viewpoint. *Ciênc Saúde Coletiva*. 2013 Sept; 18(9):2721-8. Doi: <http://dx.doi.org/10.1590/S1413-81232013000900027>
29. Garcia-Schinzari NR, Santos FS. Assistance to children in palliative care in the Brazilian scientific literature. *Rev Paul Pediatr*. 2014 Mar; 32(1):99-106. Doi: <http://dx.doi.org/10.1590/S0103-05822014000100016>
30. Doenges ME, Moorhouse MF, Murr AC. *Diagnóstico de enfermagem: intervenções, prioridades e fundamentos*. Rio de Janeiro: Guanabara Koogan; 2016.
31. Santos RA, Moreira MCN. Resilience and death: the nursing professional in the care of children and adolescents with life-limiting illnesses. *Ciênc Saúde Coletiva*. 2014; 19(12):4869-78. Doi: 10.1590/1413-812320141912.18862013
32. Soares VA, Silva LF, Cursino EG, Goes FGB. The use of playing by the nursing staff on palliative care for children with câncer. *Rev Gaúcha Enferm*. 2014 Sept; 35(3):111-6. Doi: <http://dx.doi.org/10.1590/1983-1447.2014.03.43224>
33. Chotolli MR, Luize PB. Non-pharmacological approaches to control pediatric cancer pain: nursing team view. *Rev*

- Dor*. 2015 Apr/June; 16(2):109-13. Doi: <http://dx.doi.org/10.5935/1806-0013.20150021>
34. Costa MADJ, Agra G, Souza Neto VL, Silva BCO, Braz LCSB, Mendonça AEO. Unveiling the children of mothers of experience with cancer. *Rev Enferm Cent O Min*. 2016 Jan/Apr; 6(1):2052-65. Doi: <http://dx.doi.org/10.19175/recom.v0i0.965>
35. França JRFS, Costa SFG, Nóbrega MML, Lopes MEL. Palliative care to child with cancer. *Rev Enferm UERJ* [Internet]. 2013 Dec [cited 2017 Oct 21]; 21(Spe 2):779-84. Available from: <http://www.facenf.uerj.br/v21esp2/v21e2a14.pdf>
36. França JRFS, Costa SFG, Lopes MEL, Nóbrega MML, França ISX. The importance of communication in pediatric oncology palliative care: focus on Humanistic Nursing Theory. *Rev Latino-Am Enfermagem*. 2013 June; 21(3):780-6. Doi: <http://dx.doi.org/10.1590/S0104-11692013000300018>
37. Monteiro ACM, Rodrigues, BMRD, Pacheco STA. The nurse and the care provided for child with cancer without the possibility of cure at the moment. *Esc Anna Nery Rev Enferm*. 2012 Dec;16(4):741-6. Doi: <http://dx.doi.org/10.1590/S1414-81452012000400014>.
38. Mutti CF, Padoin SMM, Paula CC. Spaciality of being-nursing-professional in the world of caring to children who has cancer. *Esc Anna Nery Rev Enferm*. 2012 Sep; 16(3):493-9. Doi: <http://dx.doi.org/10.1590/S1414-81452012000300010>.

Submission: 2017/12/31

Accepted: 2018/03/17

Publishing: 2018/05/01

Corresponding Address

Thaís Cristina Flexa Souza
 Programa de Pós Graduação em Enfermagem
 Av. Augusto Corrêa, 01, Faculdade de
 Enfermagem- Cidade Universitária
 Bairro Cidade Universitária
 CEP: 66075-110 – Belém (PA), Brazil