

# Nursing Care in the Context of Palliative Care: Integrative Review

Thaís Costa de Oliveira<sup>1</sup>, Brunna Hellen Saraiva Costa<sup>2</sup>, Thainá Karoline Costa Dias<sup>3</sup>,  
Bruno Gonçalo Souza de Araújo<sup>4</sup>, Patrícia Serpa de Souza Batista<sup>5</sup>, Luciane de Araújo Medeiros Braga<sup>6</sup>,  
Jael Rúbia F de Sá França<sup>7</sup>

<sup>1</sup>Universidade Federal da Paraíba, João Pessoa, Paraíba, Brasil  
thaisfds[at]hotmail.com

<sup>2</sup>Universidade Federal da Paraíba, João Pessoa, Paraíba, Brasil  
brunnabruh36[at]hotmail.com

<sup>3</sup>Universidade Federal da Paraíba, João Pessoa, Paraíba, Brasil  
thaiinakaroline[at]gmail.com

<sup>4</sup>Universidade Federal da Paraíba, João Pessoa, Paraíba, Brasil  
brunogsda[at]gmail.com

<sup>5</sup>Universidade Federal da Paraíba, João Pessoa, Paraíba, Brasil  
parriciasarpa[at]gmail.com

<sup>6</sup>Faculdade de Enfermagem São Vicente de Paula, João Pessoa, Paraíba, Brasil  
aimee.leal[at]outlook.com

<sup>7</sup>Universidade Federal da Paraíba, João Pessoa, Paraíba, Brasil  
lucianemedb[at]gmail.com

**Abstract:** ***Objective:** To analyze the scientific production published in online journals on palliative care and children with cancer. **Method:** This is a bibliometric study, carried out with 58 articles, of which 29 are national and 29 international, published between 2006 and 2016 and selected in LILACS, MEDLINE and BDNF databases. **Results:** The years 2013 and 2016 had a greater quantity of publications. 38 dissemination vehicles were identified. The journal *Pediatr Blood Cancer* was the one that published the most on the subject, the United States of America was the country with the largest number of published articles, however most studies were published in Portuguese. Publications produced by researchers in the field of Nursing and authors with the title of doctor predominated. **Conclusion:** The study showed that there is a small number of publications about palliative care and children with cancer, in the national and international scenario. This means that further studies on the subject are needed.*

**Keywords:** Palliative Care, Child, Neoplasm, Bibliometry

## 1. Introduction

In the contemporary world, the advance of science and technology in the field of Health is notorious, especially with regard to the discovery of earlier diagnoses and the search for treatments that prolong the life of patients. This unrestrained technological development and the incessant search for a cure bring suffering and compromise the well-being and quality of life of individuals with incurable diseases, such as some stages of cancer.<sup>1</sup>

Cancer is a disease that can last for many years, and this significantly compromises the lives of individuals affected by it, both in the biological, social and psychological dimensions, and makes life difficult for the patient, especially when it comes to children or of teenager.<sup>2</sup>

With regard to childhood cancer, in Brazil, mortality rates are lower compared to cancer in adults. For 2017, a large number of new cases of the disease per year were estimated, which is already considered the leading cause of death from disease among children and adolescents aged between one

and 19 years. However, if the diagnosis is early, approximately 70% of these people can be cured.<sup>3</sup>

The child affected by cancer undergoes intense changes in daily life, as the disease process causes suffering and requires interventions and care that include family members. In this sense, the promotion of palliative care is of fundamental importance.

Palliative Care is considered an innovative therapeutic approach to care that encompasses the patient and his family. It is a complex care, aimed at the human being in its entirety, in which the physical, social, emotional and spiritual dimensions are worked on. This requires a multi-professional teamwork.<sup>5</sup>

It is important to highlight that palliative care is aimed at patients with an incurable disease and extends to their families, especially when this member is a child. Such assistance is provided by a multidisciplinary team, consisting of a physician, nurse, psychologist, social worker, among other specialists in philosophy and palliative practice.<sup>6</sup>

A published study analyzed the scientific production published from January 1990 to March 2011, regarding the spiritual dimension of children and adolescents with cancer, and concluded that, of the 72 authors involved, 34% were nurses. <sup>7</sup>Another study aimed to characterize publications about playing and children with cancer, disseminated in online journals, and observed that, between 1985 and 2013, 75 different researchers developed studies on the subject. The results showed that Nursing is the most prevalent training area among scholars, with 47%, followed by Psychology, with 20%, and less significantly, by Medicine (5%).<sup>8</sup>

Considering the relevance of palliative care for the promotion of care for children with cancer and the importance of socializing studies published in online journals, it was considered opportune to explore the available knowledge on the subject through a bibliometric study. For this, in this investigation, we sought to answer the following question: What are the bibliometric indicators available in online journals about palliative care and children with cancer? From this perspective, this investigation aims to analyze bibliometric indicators of scientific articles published in online journals on palliative care and children with cancer.

## 2. Methods

This is a bibliometric research, in which quantitative aspects of production in a given area of knowledge, the dissemination and use of scientific information and its results were analyzed. In addition, it guides the elaboration of forecasts and decision-making in the field of science.<sup>9</sup>

Bibliometric research is used to provide the visibility of metric studies of registered information, such as, for example, the chronological development of scientific production and the dissemination of scientific production. It is a very important tool for research on the scientific production of an author, country, journal, institution, among others.<sup>10</sup>

The survey of publications was carried out in May 2017. To select the articles, the Latin American and Caribbean Literature in Health Sciences (LILACS) databases, the Medical Literature Analysis and Retrieval System Online (MEDLINE) databases were consulted) and the Nursing database (BDENF). To contemplate the search, the Boolean operator AND and the descriptors palliative care AND child AND neoplasia were used. These terms are included in Health Science Descriptors (DeCS) and Medical Subject Headings (MeSH).

To select the articles, the following inclusion criteria were adopted: articles published between 2006 and 2016, written in Portuguese, English and Spanish, with abstracts and full texts available online. As for the exclusion criteria, they were: articles related to cancer in adult patients, duplicate articles, which preceded the year 2006 and those that did not directly address the proposed theme. The search resulted in a total of 83 studies, of which 25 were excluded for not meeting the criteria. Therefore, the study sample consisted of 58 works.

To enable the analysis of the selected scientific production, a data collection instrument developed by the research authors was used, containing the following items pertinent to the study: name of the journal, professional training and title of the authors, country where the research was carried out and the respective languages, year of publication of the work, type of publication and the descriptors mentioned in the research. Each variable was registered in an electronic spreadsheet, using the Microsoft Excel Program. The data obtained were presented in tables and graphs, and the results obtained through the keywords were represented in the form of a concept map.

## 3. Results and Discussion

The proposed study consisted of 58 articles that address the theme 'palliative care and children with cancer', disseminated in online journals from 2006 to 2016. To more clearly present the study results, they were presented through the representations graphics, below.

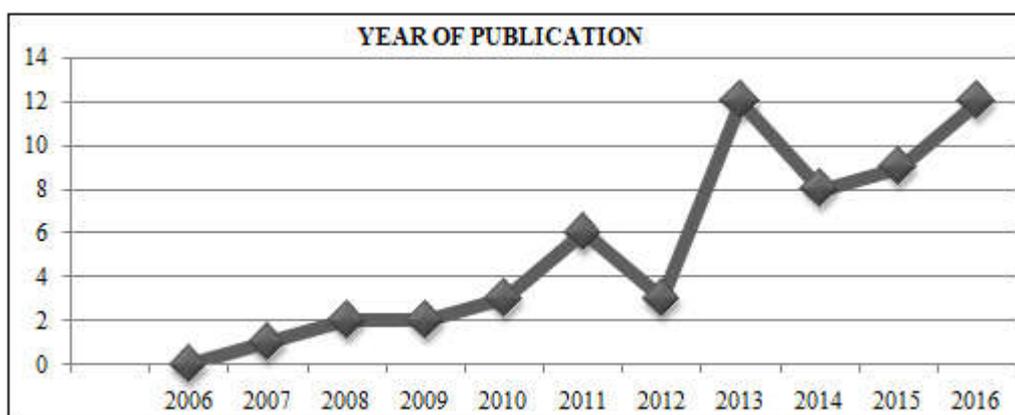


Figure 1: Quantitative distribution of articles referring to the year of publication of the studies (N = 58)

Authors' elaboration

Figure 1, which shows the temporal dynamics of article publications, shows a greater quantity of articles published in the years 2013 and 2016 on palliative care and children

with cancer, with 12 publications (21.0%), followed by the year of 2015, with nine (16.0%). In 2006, no research was found published in the journals selected for the study.

In Brazil, scientific production on children's palliative care has grown a lot, as shown in Figure 1. However, it still lacks in-depth studies and national publications and presents major care and political challenges. A study corroborates this observation and emphasizes that the offer of this type of care is still insufficient, especially regarding the dialogue of public policies that help with dehospitalization. It also notes that, at the National Cancer Institute, pediatric palliative care faces challenges related to the creation of strategies to be used in the varied and complex requirements that palliation covers, such as the difficulties to carry out this care from diagnosis and in the dimension of interdisciplinarity).<sup>11</sup>

**Table 1:** Distribution of online journals that published on the theme 'Palliative care and children with cancer' from 2006 to 2016 (N = 58)

Name of the Journal	Number	%
Acta Paediatr	1	3,0%
American Journal of Preventive Medicine	1	3,0%
American Society of Hematology	1	3,0%
Ann Palliat Med	1	3,0%
BMC Palliative Care	1	3,0%
British Journal of Cancer	1	3,0%
Canadian Medical Association or its licensors- CMAJ	1	3,0%
Cancer	1	3,0%
CHÍA, COLOMBIA	2	5,0%
Cienc Cuid Saude	2	5,0%
Ciência & Saúde Coletiva	3	8,0%
Ciências Biológicas e da Saúde	1	3,0%
Esc Anna Nery	4	11,0%
Eur J Cancer	1	3,0%
J Clin Oncol	1	3,0%
J Nurs UFPE	1	3,0%
Journal of Pain and Symptom Management	3	8,0%
Journal of Palliative Medicine	3	8,0%
Journal of Research Fundamental Care On Line	2	5,0%
Nat Rev Clin Oncol	2	5,0%
Online Brazilian Journal of Nursing	2	5,0%
Paediatr Anaesth	1	3,0%
Palliat Med	1	3,0%
Pediatr Blood Cancer	4	11,0%
Rev Bras Enferm	1	3,0%
Rev enferm UERJ	2	5,0%
Rev Esc Enferm USP	1	3,0%
Rev Gaúcha Enferm	3	8,0%
Revista Brasileira de Cancerologia	1	3,0%
Revista Brasileira de Hematologia e Hemoterapia	1	3,0%
Revista Cubana de Enfermería	1	3,0%
Revista CUIDARTE	1	3,0%
Revista de Psicologia	1	3,0%
Revista El Dolor	1	3,0%
Revista Latino-Americana de Enfermagem	1	3,0%
Revista Pediatría Electrónica	1	3,0%
Singapore Med J	1	3,0%
Texto Contexto Enferm	1	3,0%

Authors' elaboration.

Regarding the journals (Table 1), it is observed that most articles were published in journals in the areas of Medicine and Nursing, especially Esc Anna Nery (11.0% ) and Pediatr Blood Cancer (11.0%) , followed by the Journal of Palliative Medicine (8.0%), Rev Gaúcha Enferm (8.0%), Ciência &

Saúde Coletiva (8.0%) and Journal of Pain and Symptom Management (8.0%)

Escola Anna Nery Revista de Enfermagem is a national nursing publication maintained by the Anna Nery School of Nursing, Federal University of Rio de Janeiro, since 1997. Its main focus is the original manuscripts in the field of Nursing and other areas with interfaces in the Health Sciences and Nursing.<sup>12</sup> Pediatric Blood and Cancer is an international publication covering basic and clinical investigations of childhood blood disorders and malignancies, including diagnosis, treatment, epidemiology, etiology, molecular and clinical biology and genetics of these diseases and how they affect children, adolescents and young adults.<sup>13</sup>

Regarding the type of publication, original articles (65%) prevailed, followed by review (31%) and reflection (4%). The original studies show themes that can include case, descriptive, intervention studies, among others. This type of investigation is an unprecedented research, which must contain the primary data of a study.<sup>14</sup>

Despite the relevance of the original studies, reviews are also important, both to update knowledge about a subject and to spread information about children with cancer, as it is a subject that is little debated on the national and international scene. Every study begins with a tireless review of what is intended to work.<sup>15</sup>

As for reflection articles, they appeared with less representation. The scope of these reflection studies is to show the author's idea of what he will research. He will reflect on what he longs for and present his point of view.<sup>16</sup>

**Table 2:** Distribution of authors of studies selected for research regarding professional training and titles.

Professional Qualification	Number	%
Nursing	33	57,0%
Phsioterapy	1	2,0%
Medicine	19	33,0%
Psychology	4	7,0%
Occupational therapy	1	2,0%
<b>TITRATION</b>	<b>NUMBER</b>	<b>%</b>
Doctorate	19	33,0%
Specialization	3	5,0%
PHD	21	36,0%
Master's	15	26,0%

Authors' elaboration.

Table 2 demonstrates the academic background and qualifications of researchers, in addition to the different areas of knowledge. Of the authors trained in the field of Health, professionals from the fields of Nursing (57.0%) and Medicine (33.0%) stood out. It is worth mentioning that 7.0% of the publications were developed by psychologists, therefore from the field of Human Sciences, and 2.0%, from the areas of Physiotherapy and Occupational Therapy. This denotes the interest of researchers from other areas in producing studies on care palliatives and the child with cancer.

It is noteworthy that, for the exercise of this care, the interdisciplinary team must provide the client and the family

with comprehensive care so that they can face the illnesses without therapeutic possibilities of cure.

A study highlights that no specialty can, in isolation, encompass the complexity of human existence, so the work of a multidisciplinary team is essential to deal with all this complexity and the ways of caring, with a view to minimizing pain and improving the lives of patients and their families.<sup>17</sup>

The aforementioned table also highlights the titles of the authors of the articles selected for the study, with the following result: 36.0% of the authors had PHD; 33.0%, PhD; 15%, Master; and 3% Specialization. These data show the link between the productions of stricto sensu graduate courses. The largest number of doctors is justified because of the large investments in the field of research. At the national level, Brazil has been showing increasing investments in the area, with the increase in the number of postgraduate programs.<sup>18</sup>

**Table 3:** Distribution of studies on palliative care and children with cancer in relation to the country where the research was conducted and its respective language, from 2006 to 2016 (N = 58)

Country	Number	%
África	1	2,0%
Brazil	29	50,0%
Canadá	3	5,0%
Chile	2	4,0%
Colômbia	1	2,0%
Cuba	1	2,0%
EUA	14	24,0%
Holanda	2	4,0%
Malaysia	2	4,0%
Nigeria	1	2,0%
Poland	1	2,0%
Sweden	1	2,0%

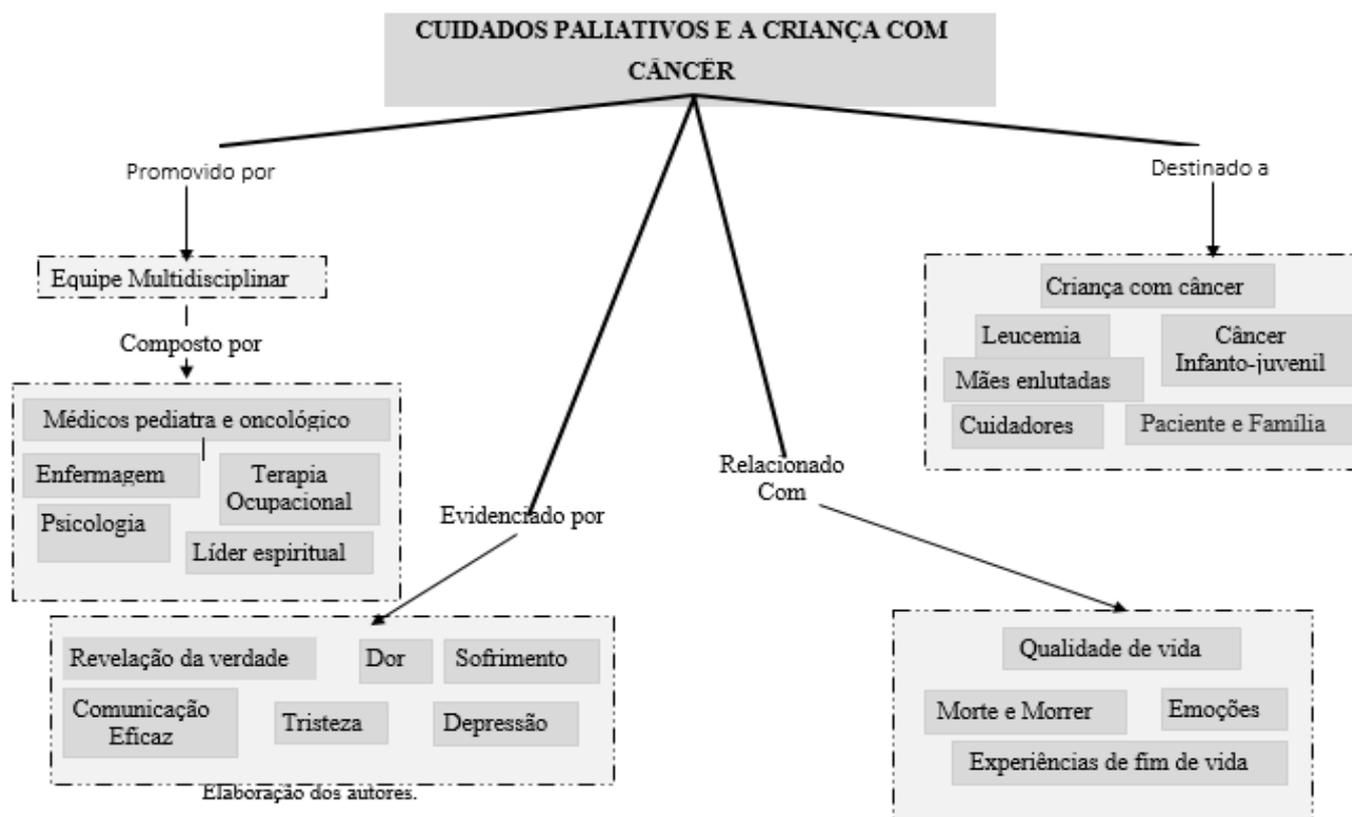
Authors' elaboration.

The 58 published articles that made up the sample were concentrated in 12 countries. The largest number of publications came from Brazil (50.0%). Then the United States (24.0%), Canada (5.0%), Malaysia (4.0%), the Netherlands (4.0%), Chile (4.0%), Cuba (2.0%), Sweden (2.0%), Africa (2.0%), Poland (2.0%), Colombia (2.0%) and Nigeria (2.0%).

In Brazil, most of the studies were carried out in the state of Rio de Janeiro. This is justified by the fact that the region is a great center of reference for research on the subject. Then come the states of São Paulo and Minas Gerais, and with a smaller number of publications, Paraíba, Ceará and Alagoas.

A study published in 2016 characterized Brazilian research groups in Palliative Care registered in the Directory of Research Groups of the National Council for Scientific and Technological Development (CNPq) between 1994 and 2014. The results indicated that 44% of the research groups are in the Southeast region, and 37% in the Northeast region. It is in these regions where there is a greater concentration of study groups related to Palliative Care. The study also concluded that research is essential for the development of practices, new care technologies and the investigation of new topics that are relevant in palliative medicine, as scientific production contributes to spreading knowledge and understanding the different nuances of palliative care.<sup>19</sup>

As for the most used language, 35 (60.0%) of the articles were written in English; 21 (32.0%), in Portuguese; and four (8.0%) in Spanish. With regard to language, the results show, in this study, the pre-eminence of the English language on the theme 'palliative care and the child with cancer', showing that even countries whose official language is not English, such as Brazil, for example, they also publish their work in this language, which has been increasingly consolidated.



**Figure 2:** Conceptual map prepared from the descriptors mentioned in the studies included in the research

With regard to descriptors, it was observed that the most frequently employed in the articles selected for the study were: palliative care and children. These terms are included in Health Science Descriptors (DeCS) and Medical Subject Headings (MeSH).

To organize the descriptors, a conceptual map was prepared, shown in Figure 2, in order to present all the keywords collected in the articles that made up the sample of this research to facilitate the understanding of the content, structure and interrelationships knowledge in the phenomenon identified.<sup>20</sup> Thus, some important aspects were addressed, such as: the promotion of palliative care for children with cancer; factors evidenced and related to palliative care and to whom this care approach is intended.

The first axis of words on the map exposes the relevance of the multidisciplinary team in palliative care, whose role is increasingly indispensable in this process, as each one contributes and is important. This multidisciplinary team has the main objective of providing well-being for those whose disease does not respond to curative treatment. They must bring together the skills of an interdisciplinary team to help the patient and their families adapt to the changes in life imposed by the disease, pain, suffering and the biopsychosocial and spiritual implications and promote the necessary reflection so that they can face this threatening condition life.<sup>21</sup>

Research carried out with the objective of knowing the perceptions, knowledge and practices of the multidisciplinary team in the care of children undergoing palliative care in a pediatric oncology unit identified that the

team seeks to include the family in the construction of the unique therapeutic project to guide this moment of cancer treatment, valuing it as a protagonist in the care that is given to the child. In a collective conception, communication, relationships and respect are valued, characterizing the essence of care that sustains trust, perspective and hope in the most difficult moments. On these occasions, in order to provide this child with affection and comfort, the team must provide reservations to strict rules.<sup>22</sup>

From this perspective, palliative care requires teamwork that enables the subject to experience a global being, which needs to be seen from a biological, psychological, social and spiritual perspective. The palliative team must see the patient beyond the disease, making room for subjectivity.<sup>23</sup>

The second axis of words makes it clear that it is extremely important to reveal the truth through effective communication. This is justified because hiding the truth harms the right to autonomy, which groups the idea of respect and dignity to the person, who, as a bearer of innate psychic abilities, has the right to decide on the treatments and interventions to be submitted or not consent.<sup>24</sup>

Research indicates that, in order to include patients in decision-making regarding their treatment, it is imperative that they are informed of the severity and evolution of the disease that affects them and that the truth between the patient, the family and the health team is essential so that he can exercise his autonomy and maintain a relationship permeated with trust. For this, professionals must develop communication skills, as a way to ensure dignity in the finiteness of life.<sup>25</sup>

As for the third and fourth axis of descriptors, they concern the quality of life and end-of-life experiences of the child with cancer and the family caregiver. Childhood cancer causes severe changes in family dynamics and profoundly compromises family experiences in different proportions, as it causes a rupture in future plans and dreams.<sup>26</sup> In this context, the mother is the main caregiver, who follows the entire course of the disease the child until the final stage of his life and experiences feelings of anguish, anxiety, fear and fear in the face of the possibility of his premature death. Such feelings generate a lot of suffering for her. Despite this, she demonstrates that she is meeting her child's needs during this process and tenderly exercising her role as a good mother, providing the affection, comfort and security he needs, showing her loving and protective face.<sup>27</sup>

It should be noted that the fear, suffering and uncertainty that a potentially fatal disease imposes are presented as the premature rupture of the child's life and the dreams that the parents had planned, in addition to the fact of losing such a fragile and loved person. At this juncture, the child, the adolescent and their family lack a health care approach that focuses on the quality of their life.

A study carried out with nurses observed that, from the perspective of quality of life, these professionals emphasize playing as something that should be valued in the act of caring. Playing is distracting and is a way to take the child away from the peculiar moment they are experiencing.<sup>28</sup>

Therefore, the map highlights palliative care and the promotion of palliative care for children with cancer, a care approach aimed at children and their families. This is a process in which, in most cases, the mother is the main caregiver, which is why the multidisciplinary team has an indispensable role and must provide the patient with an improvement in the quality of his/her life.

#### 4. Conclusion

As already mentioned, the objective of this research was to analyze bibliometric indicators of publications about palliative care that are provided to children with cancer, from 2006 to 2016, disseminated in online journals available in the Latin American Literature and of the Caribbean in Health Sciences (LILACS), the Medical Literature Analysis and Retrieval System Online (MEDLINE) and the Nursing database (BDENF).

There was a greater quantity of studies related to the theme in Brazil and disseminated in the journal of the Anna Nery Nursing School and the Gaucha Nursing School. Regarding language, most articles were published in Portuguese, followed by English, and a small number of publications in Spanish. The survey found that most researchers who address the topic 'Palliative care and children with cancer' have PHD and PhD degrees.

With regard to international studies, it was concluded that there are gaps in relation to important information for research, such as the education and titles of the authors. This shows that journals must recognize the importance of these data, as they promote the characterization of scientific

production. In this aspect, bibliometrics is extremely important in the field of research, which shows the gaps and allows knowledge of different areas.

The results also showed that the number of publications in the national and international scope is still very small. For this reason, new studies that expand the discussions about children with cancer in the context of Palliative Care are essential, in order to motivate the inclusion of the theme in the curricula of health professionals, so that they improve the care provided to the child and the family.

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