Original Article=

Dissertations and theses on palliative care in pediatric oncology: a bibliometric study

Dissertações e teses sobre cuidados paliativos em oncologia pediátrica: estudo bibliométrico Tesis de maestría y doctorado sobre cuidados paliativos en oncología pediátrica: estudio bibliométrico

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How to cite:
Dias KC, Batista PS, Fernandes MA, Zaccara
AA, Oliveira TC, Vasconcelos MF, et al.
Dissertations and theses on palliative care in
pediatric oncology: a bibliometric study. Acta
Paul Enferm. 2020; eAPE20190264.

DOI

http://dx.doi.org/10.37689/actaape/2020A002642





Keywords

Paliative care; Oncology; Pediatrics; Bibliometrics; Academmic dissertations

Descritores

Cuidados paliativos; Oncologia; Pediatria; Bibliometria; Dissertação acadêmica

Descriptores

Cuidados paliativos; Oncología; Pediatría; Bibliometría; Tesis académica

Submitted

September 10, 2019

Accepted

January 28, 2020

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Abstract

Objective: To analyze bibliometric indicators of studies originated from dissertations and theses on palliative care in pediatric oncology defended in Postgraduate Programs in the Brazilian scenario.

Methods: Bibliometric study conducted through the Bank of Theses and Dissertations of the Coordination for the Improvement of Higher Education Personnel (Portuguese acronym: CAPES) and the Brazilian Digital Library of Theses and Dissertations (Portuguese acronym: BDTD) between years 2008 and 2018 defended in Postgraduate Programs in Brazil.

Results: The investigated bibliometric indicators highlighted 60 studies (13 theses and 47 dissertations) conducted on palliative care in pediatric oncology. The Higher Education Institution with the highest scientific production was the Universidade de São Paulo. The southeast region stood out with the largest number of publications distributed in 18 programs. The Nursing field occupied a prominent position, followed by Psychology and Medicine. The qualitative methodological design was the most used in the studies. Most studies were conducted in specialized hospitals for cancer treatment.

Conclusion: A small number of studies originating from dissertations and theses on palliative care in pediatric oncology defended in Postgraduate Programs in the Brazilian scenario was identified in this investigation. Further studies are suggested to expand scientific production on the topic and disseminate scientific evidence within clinical practice of palliative care in pediatric oncology.

Resumo

Objetivo: Analisar indicadores bibliométricos de estudos oriundos de dissertações e teses sobre cuidados paliativos em oncologia pediátrica defendidas em Programas de Pós-Graduação no cenário brasileiro.

Métodos: Estudo bibliométrico realizado por meio do Banco de Teses e Dissertações da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) e da Biblioteca Digital Brasileira de Teses e Dissertações (BDTD), entre os anos de 2008 a 2018, defendidas em Programas de Pós-Graduação do Brasil.

Resultados: Os indicadores bibliométricos investigados destacam 60 estudos (13 teses e 47 dissertações) realizados sobre cuidados paliativos em oncologia pediátrica. A Instituição de Ensino Superior com a maior produção científica foi a Universidade de São Paulo, e a Região Sudeste foi a que mais se destacou com o maior quantitativo de publicações; estas foram distribuídas em 18 Programas. A área da Enfermagem ocupou posição de destaque seguida da Psicologia e da Medicina. O desenho metodológico mais utilizado nos estudos foi de natureza qualitativa. A maioria das pesquisas foi realizada em hospitais especializados para o tratamento de câncer.

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Conclusão: A pesquisa identificou um número reduzido de estudos oriundos de dissertações e teses sobre cuidados paliativos em oncologia pediátrica, defendidas em Programas de Pós-Graduação no cenário brasileiro. Sugerem-se novos estudos para ampliar a produção científica acerca do tema bem como para disseminar evidências científicas no contexto da prática clínica dos cuidados paliativos em oncologia pediátrica.

Resumen

Objetivo: Analizar indicadores bibliométricos de estudios oriundos de tesis de maestría y doctorado sobre cuidados paliativos en oncología pediátrica defendidas en Programas de Posgrado en el escenario brasileño.

Métodos: Estudio bibliométrico realizado por medio del Banco de Teses e Dissertações de la Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) y de la Biblioteca Digital Brasileira de Teses e Dissertações (BDTD), entre los años 2008 y 2018, defendidas en Programas de Posgrado de Brasil.

Resultados: Los indicadores bibliométricos investigados destacan 60 estudios (13 tesis de doctorado y 47 tesis de maestría) realizados sobre cuidados paliativos en oncología pediátrica. La institución de educación universitaria con mayor producción científica fue la Universidad de São Paulo, y la región sudeste fue la que más se destacó con el mayor cuantitativo de publicaciones; estas se distribuyeron en 18 Programas. El área de Enfermería ocupó una posición destacada, seguida de Psicología y Medicina. El diseño metodológico más utilizado en los estudios fue de naturaleza cualitativa. La mayoría de las investigaciones fue realizada en hospitales especializados en tratamiento de cáncer.

Conclusión: La investigación identificó un número reducido de estudios oriundos de tesis de maestría y doctorado sobre cuidados paliativos en oncología pediátrica, defendidas en Programas de Posgrado en el escenario brasileño. Se sugieren nuevos estudios para ampliar la producción científica sobre el tema, así como también para difundir evidencias científicas en el contexto de la práctica clínica de los cuidados paliativos en oncología pediátrica.

Introduction

Cancer is the leading cause of death from diseases in the juvenile population aged between 1 and 19 years, both in Brazil and in developed countries. When diagnosed early, the cure estimate is up to 80% of cases. In developed countries, mortality rates are lower given the better conditions of medical access, diagnosis and treatment services. In Brazil, these improvements have not been noticed in the same proportion yet and cancer cure rates in children and adolescents vary significantly, ranging from 50% in the north region, 60% in the northeast, 65% in the midwest, 70% in the southeast and 75% in the south. When there are no more possibilities of cure, palliative care appears as an alternative to specialized therapeutic care. (1)

In Brazil, pediatric palliative care has developed exponentially the last decade through the implementation of public policies within the scope of the National Health System (Brazilian SUS) after the creation of a National Policy for the Prevention and Control of Cancer in 2013 with Ordinance number 874 of May 16, 2013 and the publication of guidelines for the organization of palliative care linked to continuous care integrated into SUS with Resolution number 41 of October 31, 2018. (2) According to the report published by the National Academy of Palliative Care (Portuguese acronym: ANCP), arising from

the situational analysis and recommendations for structuring palliative care programs in Brazil, attention is drawn to the precariousness and unequal availability of this care in the national scenario. Out of the 177 palliative care centers registered in the country, only 21% are dedicated to pediatric care, and more than 50% of the total amount of centers is available in the southeast region of the country and focused on hospital care. (2)

Palliative care in the pediatric field is increasingly recognized as part of the care of children with diseases that threaten the continuity of life. Conceptually, the aim of such care is to improve the quality of life of patients and their families throughout the course of disease and alleviate the discomfort and stress of children experiencing life-threatening conditions and their families. It includes specific care practices for reducing unpleasant symptoms provided by a multiprofessional team focused on biopsychosocial and spiritual dimensions. (3)

Improving pediatric palliative care is an urgent national need, given the relevance and positive impact of palliative care measures on the quality of life of sick children and their families. Hence the need for greater dissemination of the knowledge produced in Brazilian postgraduate programs about palliative care in pediatric oncology through studies providing greater visibility to scientific production from dissertations and theses on the subject, for example, from bibliometric research.

Bibliometric studies enable the direction of new investigations on the topic and contribute to obtain indicators of scientific production by identifying temporality, origin of works, themes and methodologies employed. (5) Considering the importance of investigating bibliometric indicators that evaluate the scientific activity on the theme, it is valid to conduct a study guided by the following question: What is the characterization of dissertations and theses on palliative care in pediatric oncology defended in Postgraduate Programs in Brazil? Therefore, the aim of the study was to analyze bibliometric indicators of studies from dissertations and theses on palliative care in pediatric oncology defended in Postgraduate Programs in the Brazilian scenario.

Methods

This is a bibliometric study, which is a design that provides more visibility to metric studies of the information recorded. The three operational steps described below were considered for the development of this study. In the first step, a survey of dissertations and theses about palliative care in pediatric oncology was carried out. In the sample selection, publications about the theme were collected from the Bank of Theses and Dissertations of the Coordination for the Improvement of Higher Education Personnel (Portuguese acronym: CAPES) and the Brazilian Digital Library of Theses and Dissertations (Portuguese acronym: BDTD).

To select the sample, the terms "palliative care" and "child" and "cancer" were used. Then, the following inclusion criteria were specified: publications in the forms of dissertations and theses published in Portuguese in the period between January 2008 and December 2018. Since this is a bibliometric study, it is important that the time frame includes a high number of publications of dissertations and theses in order to expand the sample and obtain a significant number of studies.

In the second step, data collection was performed. To this end, an instrument developed by the authors was used to count the scientific activity production and generate bibliometric indicators.

The instrument included the following variables: title, type of publication, researcher's training, name of the institution, year of defense, region, methodological design, keywords and articles originated from the dissertations and theses. The data collection period was from March to July 2019. Data were obtained by reading the abstracts and, when these did not present the necessary information, full texts were used. For the selection of studies, the checklist recommendations of the Statement for Reporting Systematic Review and Meta-Analyzes of Studies – PRISMA⁽⁵⁾ were followed, as shown in figure 1.

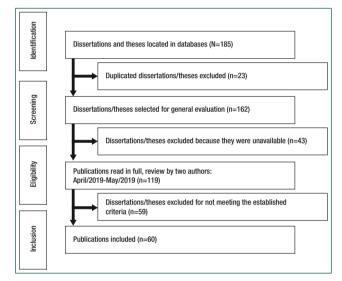


Figure 1. Flowchart of the study selection process adapted from PRISMA

Data obtained from dissertations and theses selected for the study were extracted based on the proposed instrument for data collection. Information was presented by means of graphical representations and analyzed quantitatively by means of absolute frequency and percentage with use of the Microsoft Office Excel* 2010.

A concept map was used for the organization of keywords. This tool includes the graphic reproduction of related and linked concepts through propositions and keywords. In Nursing research, concept maps are used to stimulate reflection through critical thinking, evaluate nursing actions, and contribute to problem solving and synthesis of concepts in terms of care. (6)

In this study, the concept map demonstrated the thematic concept association between the keywords

mentioned in the selected dissertations and theses and the study context. The keywords were grouped from the main ones, Palliative Care and Pediatric Oncology, since these were the subject of the study, and organized in thematic classes, although not hierarchically.

Results

In the time frame between 2008 and 2018, sixty (60) scientific productions of dissertations and theses on palliative care aimed at children with cancer were identified, of which 47 (78%) master's theses

and 13 (22%) doctoral theses. The greatest number of findings was between years 2011 and 2014, with a relatively stable behavior, and 2014 was the year with the highest number of dissertations (9%) and theses (23%). Regarding the geographic region of the institution to which researchers were linked, the southeast presented 36 (60%) productions of theses and dissertations distributed in 18 Postgraduate Programs. Following this pattern, the northeast stood out with 14 works (23%) distributed in nine Postgraduate Programs, as shown in table 1 in absolute numbers and percentages.

Thirty-five Postgraduate Programs were identified, and out of that total, the Programs of the

Table 1. Distribution of studies on palliative care in pediatric oncology by region, higher education institution, postgraduate programs, dissertations and theses (n=60)

Region	Institution	Postgraduate Programs	Dissertations	Theses	Dissertations/ Theses
			n	n	n(%)
Northeast	Universidade Católica de Recife	Language Sciences	1	-	1(2)
	Universidade de Fortaleza	Psychology	2	-	2(3)
		Collective Health			
	Universidade Federal do Maranhão	Maternal and Child Health	1	-	1(2)
	Universidade Federal da Paraíba	Nursing	4	2	6(10)
	Universidade Estadual da Paraíba	Health Psychology	1	-	1(2)
	Universidade Federal do Rio Grande do Norte	Nursing	2	-	2(2)
		Psychology			
	Universidade Federal de Pernambuco	Child and Adolescent Health	-	1	1(2)
North	Universidade Federal do Pará	Psychology	1	-	1(2)
Southeast	Universidade de São Paulo - Ribeirão Preto	Psychology	11	3	14(23)
		Public Health Nursing			
		Psychiatric Nursing			
	Universidade Metodista de São Paulo	Psychology	1	-	1(2)
	Universidade de São Paulo – São Paulo	Nursing	5	4	9(15)
		Clinical Psychology			
		Neurology			
	Universidade Estadual do Rio de Janeiro	Nursing	2	-	2(3)
		Collective Health			
	Universidade Federal do Rio de Janeiro	Nursing	1	-	1(2)
	Escola Nacional de Saúde Pública Sergio Arouca, Rio de Janeiro	Public Health	2	-	2(3)
		Bioethics, Applied Ethics and Collective Health			
	Pontifícia Universidade Católica, Rio de Janeiro	Psychology	-	1	1(2)
	Pontifícia Universidade Católica de São Paulo	Clinical Psychology	2	-	2(3)
	Universidade Federal de Minas Gerais	Health Sciences	1	-	1(2)
	Fundação Oswaldo Cruz	Health Sciences	-	1	1(2)
	Universidade Estadual de Campinas	Medical Sciences	1	-	1(2)
	Faculdade de Medicina de Botucatu, Universidade Estadual Paulista	Nursing	1	-	1(2)
South	Universidade Federal de Santa Maria	Nursing	1	-	1(2)
	Universidade Federal do Espírito Santo	Collective Health	2		2(3)
	Universidade Federal do Rio Grande do Sul	Social Psychology	1	1	2(3)
		Child and Adolescent Health			
Midwest	Universidade de Brasília	Human Development and Health Processes	3	-	3(5)
		Bioethics			
	Universidade Federal de Goiás	Music	1	-	1(2)
Total	25	35	47	13	60(100)

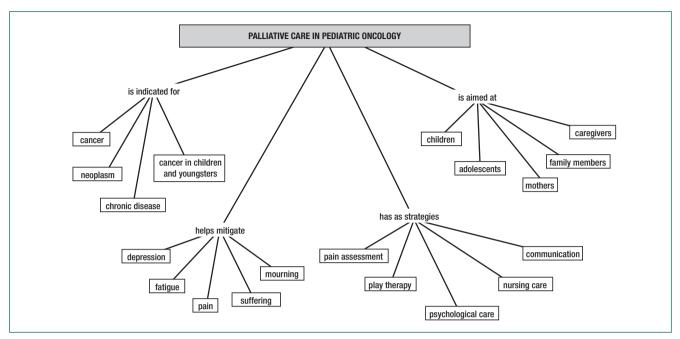


Figure 2. Concept map developed from the keywords of dissertations and theses selected for the study

Universidade de São Paulo (USP), Ribeirão Preto campus, produced the greatest number of dissertations and theses, accounting for 23% distributed among the Postgraduate Program in Psychology, the Postgraduate Program in Psychiatric Nursing and greater emphasis to the Postgraduate Program in Nursing in Public Health, with nine works (15%) out of this percentage. The Postgraduate Program in Nursing at the Universidade Federal da Paraíba presented six (10%) works in the period, four of which were master's theses and two doctoral theses (Table 1).

Regarding data inherent to the professional training of the authors of studies, Nursing was the profession with the largest number of defenses, 29 studies (48%), followed by Psychology with 19 studies (32%), Medicine with seven studies (12%) and the remaining six distributed among Physiotherapy, Philosophy, Dentistry, Bioethics and Music Therapy, with one study for each profession (2%). In relation to the method adopted in the 60 productions chosen for the study, there were 49 qualitative studies (82%), seven quantitative studies (12%) and four quantitative and qualitative studies (6%). The keywords of theses and dissertations that comprised the sample of the present study were grouped and analyzed, and the

most evident ones were used to build a concept map presented in figure 2.

Discussion

The data revealed an increase in the number of dissertations and theses since 2011, and this result shows advances in palliative care as an important reality in the area of Health as a whole. This finding may be related to the publication of Resolution CFM 1973/2011 of the Federal Council of Medicine that created palliative medicine among other areas of activity. In addition, palliative care was associated with specialties in medical practice, such as pediatrics.⁽⁷⁾

The regional concentration of productions was greater in the southeast region, and smaller in the north region. Regarding the program, the Postgraduate Program in Public Health Nursing at the Universidade de São Paulo, Ribeirão Preto campus stood out. In 2017, the last year analyzed by Capes, there were 681 Postgraduate Programs in the area of Health Sciences in Brazil. Of these, most were concentrated in the southeast. (8)

Research indicate a great inequality between regions, and the reason is the distribution of re-

sources. The southeast received more than 50% of resources from the National Council for Scientific and Technological Development and only a little more than 2% went to the north of the country, data updated by the Geocapes (Brazilian statistical agency) portal on August 20, 2018. This scenario is unlikely to reduce the differences, and this situation will continue to be perpetuated, thereby resulting in a greater concentration of Postgraduate Programs and also reaching a higher percentage of masters and doctors in the south and southeast regions. (9)

Among health professionals working in palliative care services, the nursing team stood out. A study shows significant data in relation to the Brazilian scientific contribution for nursing practice in palliative care for children and adolescents with cancer, with Brazil as the country with the largest number of publications. (10)

The methodological design of most studies was qualitative, which is a methodology aimed at investigating phenomena and exploring the magnitude of events, with focus on singularities and meanings.⁽¹⁰⁾

Regarding the articles originating from dissertations and theses, an important biometric indicator was observed in relation to the dissertation titled "Palliative care: dialogical relationship between nurses and children with cancer", which disseminated the findings in three articles published in scientific journals of nursing, health and other related areas, namely: The importance of communication in pediatric oncology palliative care: focus on Humanistic Nursing Theory, Revista Latinoamericana de Enfermagem, year of publication 2013; Palliative care to child with cancer, Revista Enfermagem UERJ, year 2013; Nurses' experience in caring for a terminally ill child: study in the light of the humanistic theory of nursing, Revista Ciência, Cuidado e Saúde, 2014.

According to scholars on evidence-based practice, the dissertation titled "Benefits of play therapy as palliative care in children hospitalized with cancer" was the study with the highest level of scientific evidence, because this was a quantitative, experimental, analytical study and a non-randomized clinical trial. (11) It is classified at level 3: evidence

obtained from well-designed clinical trials without randomization. The classification of the level of evidence was based on the Evidence-Based Practice in Nursing and Healthcare. (12)

Regarding the scenario where studies were conducted, the hospital setting was the most prevalent, accounting for 98% of studies, 1% were published in a Philanthropic Institution of support to children with cancer and 1% with professionals from the municipality of Criciúma (state of Santa Catarina) who work with terminally ill children and adolescents. With regard to Brazilian states, all have at least one hospital specialized in oncology, where patients can perform from exams to more complex surgeries, accounting for the total of 317 units and centers of care qualified for cancer treatment. (13)

Still according to the survey, the prevalent care model is the outpatient type (53%), which serves patients with cancer and other life-threatening pathologies. In the studies, the prevailing population assisted was of adults (88%) and the elderly (84%), with public funding. (13)

With relation to consolidated services in palliative care, a study showed that 50% of the 177 Brazilian palliative care services operated in the state of São Paulo. Only 13 services operated in the north and northeast regions of the country. (14)

The concept mapping method is a tool for organization and representation of knowledge between concepts that facilitates strategic reflection. The concepts are also called semantic units or units of meaning. In the concept map (Figure 2), the most frequent keywords were organized into four axes related to the theme 'palliative care and pediatric oncology'. (15)

The first and second semantic axes of this study relate to the indication and to whom palliative care is aimed. Such care is indicated for all patients (elderly, adults, children and adolescents) with a life-threatening disease. It can be started with curative therapy and the earlier the beginning of palliation, the better for quality of life promotion of those involved in this process. (16)

This study demonstrated that palliative care in pediatric oncology is indicated to treat cancer in children and youngsters and chronic diseases, also covering mothers, caregivers and their families. The intensity of care varies throughout the disease evolution, since the focus and objectives progressively shift from an emphasis on disease-modifying treatments to approaches with exclusively palliative intentions that will impact mainly on quality of life. (17)

The third axis concerns the control of symptoms, such as pain, fatigue, psychological distress and mourning. In palliative care, the therapeutic approach aims at relieving symptoms that compromise quality of life by integrating interdisciplinary and interprofessional actions with dedication quantified according to the concrete care needs.

The challenge of the palliative team is to care for human beings in their entirety particularly in actions related to their pain and biopsychosocial and spiritual suffering with scientific and technical capacity, in addition to sensitivity to the suffering of others, which can facilitate comprehensive and humanized care. (18) Interdisciplinary care is a central element of cancer treatment and provides a solid basis for incorporating additional elements of palliative care into pediatric oncology. (19) The fourth and final axis of the concept map relates to communication as a strategy in palliative care in pediatric oncology, and is also related to play therapy, psychotherapy and nursing care.

Note that the communication between the palliative care team, patients and their family members affect the experience of the disease and the care plan, as well as the satisfaction of people involved in this care. The language should be clear and simple, if necessary, using playful materials to facilitate understanding and support the patient, with use of communication skills that minimize the emotional impact caused by difficult news. (20)

Child care is a complex service that requires technical-scientific knowledge and emotional capacity from professionals in order to help families cope with the end of life, including the mourning period. (21) Therefore, the mourning process needs to be discussed for offering a better support to those involved (child and family), since they are frail because of a difficult situation. Everyone needs embracement, respect and care of their specificities. (22)

Regarding nursing care in palliative care, a study emphasizes that nurses are the professionals directly linked to patients, from the diagnosis of a life-threatening disease until its finitude. (23) For this reason, it is their role to listen and understand the needs of patients much more, and support them in times of distress, when facing a life-threatening disease. (24) A study indicates that professionals in the palliative care team seek to share various knowledge with the aim to establish the structures of this singular care, in which the exchange of knowledge and experiences helps them to plan their actions. (24) Another highlighted aspect is the development of individualized therapeutic planning with the proposal to insert the family and value the child with cancer as essential members of care. (25)

The promotion of palliative care is key for children with a life-threatening disease such as cancer. Therefore, health professionals, particularly nurses, should provide comprehensive care aimed at improving the child's quality of life, and support their family members to cope with difficult situations throughout treatment until the mourning period.

Conclusion

The study identified a small number of studies originating from dissertations and theses on palliative care in pediatric oncology defended in Postgraduate Programs in the Brazilian scenario. However, the bibliometric indicator relevant to the keywords shows that the referred theme is under development, because the number of thematic axes presented in the concept map highlights the variety of its scope. Further studies are suggested to expand scientific production on the topic and disseminate scientific evidence in the context of clinical practice of palliative care in pediatric oncology.

Collaborations

Dias KCCO, Batista PSS, Fernandes MA, Zaccara AAL, Oliveira TC, Vasconcelos MF, Oliveira AMM and Andrade FF declare that they contributed to

the study design, analysis and interpretation of data, writing of the article and approval of the final version to be published.

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