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REVIEW

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Scientific Production of Dissertations and Theses on Palliative Care and Chronic Diseases: Bibliometric Study

Produção Científica de Dissertações e Teses Sobre Cuidados Paliativos e Doenças Crônicas: Estudo Bibliométrico

Producción Científica de Disertaciones y Tesis Sobre Cuidados Paliativos y Enfermedades Crónicas: Estudio Bibliométrico

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ABSTRACT

Objective: The study's purpose has been to verify bibliometric indexes for Master dissertations and PhD Theses on palliative care and chronical diseases published in Brazil. **Methods:** It is a bibliometric study through searching Masters dissertation and PhD theses finished between 2009 and 2018, on the database of the Biblioteca Digital Brasileira de Teses e Dissertações [Brazilian Digital Library of Theses and Dissertations], Portal of Theses and Dissertations of Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES), and the Public Domain Portal. **Results:** The corpus was composed by 36 studies (28 Masters dissertation and 8 PhD theses). We could find that in 2014 there was a higher number of research, and the Universidade Federal de Santa Cararina was the institution where most theses were written on the theme. Also, its hospital was the most recurrent case in study. **Conclusion:** Bibliometric indicators indicated that nurses developed a larger number of studies. Most studies are carried out using the qualitative approach and the scenario with the largest number of research was the hospital environment.

Descriptors: Palliative care, Chronical diseases, Nursing care, Terminality, Bibliometrics.

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RESUMO

Objetivo: Verificar indicadores bibliométricos de dissertações e de teses publicadas no Brasil sobre cuidados paliativos e doenças crônicas. Método: Estudo bibliométrico realizado através da busca de dissertações e teses, no período de 2009 a 2018, disponibilizadas nas bases de dados Biblioteca Digital Brasileira de Teses e Dissertações, Portal de Teses e Dissertações da Coordenação de Aperfeiçoamento de Pessoal de Nível Superior e Portal Domínio Público. Resultados: A amostra foi composta por 36 estudos, sendo 28 dissertações e oito teses. Averiguou-se um maior quantitativo de produções no ano de 2014, com a Universidade Federal de Santa Catarina como instituição de ensino que mais produziu acerca da temática, e o hospital o cenário mais investigado. Conclusão: Os indicadores bibliométricos indicaram que os enfermeiros desenvolveram maior quantitativo dos estudos. A maioria dos estudos se desenvolve por meio da abordagem qualitativa e o cenário com maior quantitativo de pesquisa foi o local hospitalar.

Descritores: Cuidados paliativos, Doenças crônicas, Assistência de enfermagem, Terminalidade, Bibliometria.

RESUMEN

Objetivo: El propósito del trabajo es verificar indicadores bibliométricos de disertaciones y tesis publicadas en Brasil sobre cuidados paliativos y enfermedades crónicas. Método: Este es un estudio bibliométrico realizado a través de la búsqueda de disertaciones y tesis, de 2009 a 2018, disponible en las bases de datos [Biblioteca Digital Brasileña de Tesis y Disertaciones], Portal de Tesis y Disertaciones de la Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) y Portal Domínio Público. Resultados: La muestra consistió en 36 estudios, 28 disertaciones y 8 tesis. Se verificó una mayor cantidad de producciones en 2014, con la Universidade Federal de Santa Cararina como la institución educativa que produjo más sobre el tema, y el hospital como el escenario más investigado. Conclusión: Los indicadores bibliométricos indicaron que las enfermeras desarrollaron una mayor cantidad de estudios. La mayoría de los estudios se desarrollan a través del enfoque cualitativo y el escenario con el mayor número de investigaciones fue el medio hospitalario.

Descriptores: Cuidados paliativos, Enfermedades crónicas, Cuidado de enfermería, Terminalidad, Bibliometría.

INTRODUCTION

Technological and scientific advances in health have spread considerably in recent years. Thus, people are living longer, with an increase in life expectancy; however, this growing scenario can prolong the natural process of death, and, as a result, increase the suffering of both the patient diagnosed with a life-threatening disease and all those involved in the situation.¹

Chronic diseases have particularities that are usually associated with different causes. They are characterized by gradual onset, with a normally uncertain prognosis, which develops over a long or often indefinite duration. They have a clinical course that changes over time, causing disabilities for patients. The practice of changes in lifestyle, the use of great technologies and the administration of continuous care are examples of actions implemented in the treatment of these diseases; which, however, do not offer a guarantee of cure, as indicated in the document Guidelines for the care of people with chronic diseases in the health care networks

and priority lines of care, of the Ministry of Health.²

Therefore, it is essential to practice alternatives that enable options in addition to painful treatment, providing an existence with less suffering. Thus, the search for the quality of life through less aggressive care must be implemented, with emphasis, therefore, on the Palliative Care (PC) approach.³

Caring for patients with chronic diseases, according to the philosophy of palliative care, is an efficient way to offer better conditions for the continuity of life, preventing, treating, performing actions for them or even guiding their family. After reviewing in 2002, the World Health Organization (WHO) called palliative care as an approach whose main objective is to provide the quality of life to patients and family members who face diseases that directly affect their daily lives, aiming to offer relief from pain and suffering, as well as their prevention and also the identification of physical, psychosocial, and spiritual problems.⁴

Therefore, for better assistance and promotion of palliative care for both the patient and the family, it is necessary for a multidisciplinary team, composed of physicians, nurses, psychologists, social workers, nutritionists, and spiritual counselors, for example. This team aims to meet the biopsychosocial and spiritual needs of the patient and their family.⁵

Considering the importance of the theme in the area and the incipient number of studies on palliative care and chronic diseases in national and international literature, the interest in developing a study guided by the following question stands out: what are the bibliometric indicators of Master dissertations and PhD theses published in Brazil about palliative care and chronic diseases? To this end, the study aims to verify the bibliometric indicators of dissertations and theses published in Brazil on palliative care and chronic diseases.

METHODS

This is a bibliometric study, which aims to analyze the quantitative aspects of scientific productivity over time and contributes to answering relevant questions about the progress of science.⁶

The bibliometric analysis method is used to allow the visualization of the metric studies of the recorded information, as well as the scientific dissemination and the chronological development of these productions. It is worth mentioning that it is a highly relevant tool for research on the scientific production of a country, institution, journal.⁷

The survey of publications was carried out in May 2019. The following digital libraries were consulted to select the dissertations and theses analyzed: *Biblioteca Digital Brasileira de Teses e Dissertações* (BDTD) [Brazilian Digital Library of Theses and Dissertations], Portal of Theses and Dissertations of the Coordenação de Aperfeiçoamento de

Pessoal de Nível Superior (CAPES) and Public Domain Portal. The choice of the referred libraries is justified by their relevance in the academic scenario and by the easy access to the studies defended in several graduate programs in the country.

The descriptors "palliative care" and "chronic diseases", terms included in the Health Sciences Descriptors (DeCS) and the Medical Subject Headings (MeSH), were used to contemplate the search. The Boolean operator AND was used to combine the terms.

The following inclusion criteria were adopted in the selection of the corpus: dissertations and theses available in full, developed from 2009 to 2018, whose main theme was related to palliative care and chronic diseases.

After the search, the duplicate texts were removed. Then, a careful reading of the titles and abstracts was performed, disregarding scientific productions that were not directly related to the proposed object of study. The pre-selected works in that first moment were read in their entirety, being part of the final sample only those that met the inclusion criteria of this review.

To make the analysis of the selected scientific production feasible, a table was built with Excel software, contemplating the bibliometric indicators investigated: educational institution, year of defense, professional training, research modality, research-level (dissertation/thesis), focus theme, group participating in the study, main study outcome and descriptors used. Then, a descriptive statistical analysis was carried out, with the distribution of frequency in absolute numbers (n) and relative frequency (%) arranged in figures and tables, in addition to the use of a conceptual map to facilitate understanding of the content of the theme in a systematic way, developed from the descriptors.

RESULTS AND DISCUSSION

The search resulted in 102 studies, of which 66 were excluded because they did not meet the criteria. The study sample was, therefore, composed of 36 dissertations and theses that address the theme "palliative care and chronic diseases", disseminated in digital libraries from 2009 to 2018, as shown in the flowchart below (**Figure 1**).

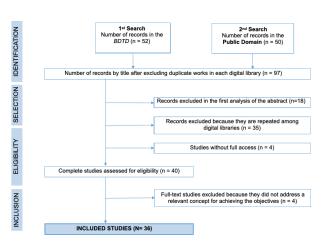


Figure 1 - Results of the analysis according to the prism model. *João Pessoa* City, *Paraíba* State, Brazil, 2019

From a total of 36 works, it appears that 28 (77.0%) consisted of master dissertations and eight (23.0%) in PhD theses. The following image shows the period of publication of the texts.

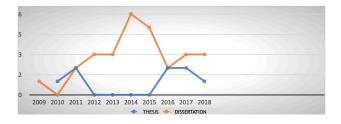


Figure 2- Quantitative distribution of the production of dissertations and theses for the year of publication of the studies (N = 36). *João Pessoa City, Paraíba* State, Brazil, 2019

Regarding the temporal dynamics, a larger number of studies is observed in Figure 2 in 2014, with six studies (16.6%), followed by the years 2015 and 2017, with five (13.8%) each; from 2011, 2016 and 2018, with four studies (11.1%) each; from 2012 and 2013, with three (8.3%) each, and from 2009 and 2010, in which only one study was found published in the digital libraries selected for the research (figure 2).



Figure 3– Distribution of scientific production by regions (N = 36). *João Pessoa* City, *Paraíba* State, Brazil, 2019

Distributed by Brazilian regions, it is noted that the

highest production index occurred in the Southeast Region, with 41% of publications, as shown in figure 3.

Table I – Distribution of scientific production by institution and by type, by professional training, by research scenarios and thematic approaches (N and %), in the period from 2009 to 2018. *João Pessoa* City, *Paraíba* State, Brazil, 2019

HIGHER EDUCATION INSTITUTION	THESE	DISSERTATION	N	%
SOUTHEAST REGION	0.1		02	0.3
Universidade Federal de São Paulo (UFSP)	01	02	03	8.3
Universidade de São Paulo (USP)	01	02	03	8.3
Universidade Estadual Paulista (Unesp)	01	01	02	5.5
Faculdade de Medicina da Universidade de São Paulo (FMUSP)	0	01	01	2.7
Universidade Estadual do Rio de Janeiro (UERJ)	0	01	٠.	
Universidade Católica de Santos (UNISANTOS)	0	01	01	2.7
Universidade Federal de Juiz de Fora (UFJF)	0	01	01	2.7
Pontifícia Universidade Católica de São Paulo (PUC- SP)	0	01	01	2.7
Universidade Federal do Espírito Santo (UFES)	0	01	01	2.7
Universidade Federal do Triângulo Mineiro (UFTM)	0	01	01	2.7
NORTHEAST REGION				
Universidade Federal da Paraíba (UFPB)	0	03	03	8.3
Universidade Estadual da Paraíba (UEPB)	01	01	02	5.5
Universidade Federal do Rio Grande do Norte (UFRN)	0	02	02	5.5
Universidade de Fortaleza (UNIFOR)	0	01	01	2.7
Universidade Federal de Maranhão (UFMA)	0	01	01	2.7
Universidade Federal de Pernambuco (UFPE)	01	0	01	2.7
Universidade Federal do Ceará (UFC)	0	01	01	2.7
Universidade Católica do Salvador (UCSAL)	0	01	01	2.7
SOUTH REGION				
Universidade Federal de Santa Catarina (UFSC)	01	03	04	12.5
Universidade Federal do Rio Grande do Sul (UFRGS)	01	02	03	8.3
Universidade Estadual de Londrina (UEL)	01	0	01	2.7
CENTRAL-WEST REGION				
Universidade de Brasília (UnB)	0	01	01	2.7
TOTAL	8	28	36	100%
PROFESSIONAL QUALIFICATIO	N		N	%
Nursing			17	47.3
Psychology			7	19.6
Medicine			5	14.0
Secial service			2	5.5
Physiotherapy			2	5.5
Dentistry			1	2.7
Law			1	2.7
Occupational therapy			1	2.7
TOTAL			36	100
RESEARCH SCENARIOS			N	% %
Hospital			29	79.2
Family health strategy			4	12.5
University			3	8.3
TOTAL			36	100
			N	% %
THEMATIC ADDROACHES			15	38.9
THEMATIC APPROACHES Ouality of life				50.7
Quality of life				19.6
Quality of life Nursing care			7	19.6
Quality of life Nursing care Terminality			7	12.5
Quality of life Nursing care Terminality Pain			7 4 4	12.5 12.5
Quality of life Nursing care Terminality Pain Communication			7 4 4 3	12.5 12.5 8.3
Quality of life Nursing care Terminality Pain Communication Spirituality			7 4 4 3 2	12.5 12.5 8.3 5.5
Quality of life Nursing care Terminality Pain Communication			7 4 4 3	12.5 12.5 8.3

Table 1 shows that the *Universidade Federal de Santa Catarina* (UFSC) was the higher education institution that produced the most about palliative care and chronic diseases, with four (12.5%) works. Concerning the professional training of the authors of the studies, the Nursing area stood out as the profession with the largest number of publications, with 17 studies (47.2%), with predominant studies developed in the hospital setting (79.2%) addressing subjects about quality of life (38.9%).

The theme developed in the studies was demarcated during the reading of the abstracts associated with the descriptors, having been represented by a conceptual map constructed linearly, as shown in **figure 4**.

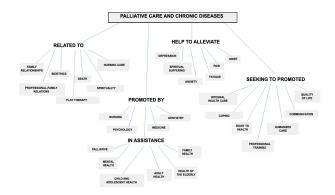


Figure 4 - Conceptual map elaborated from the keywords of the dissertations and theses selected for the study. João Pessoa, PB, Brazil, 2019.

After analyzing the dissertations and theses from Brazilian postgraduate courses, it was found that most of the work was developed in the southeast region, since most postgraduate courses are located in that region, offering subsidies for the development of studies focused on chronic diseases and palliative care.⁸

Also noteworthy is the significant contribution of the *Universidade Federal de Santa Catarina* (UFSC) to the development of publications on the subject. It is important to mention that, in the Brazilian scenario, organized palliative care services started in the States of *Santa Catarina* and *São Paulo*.⁹

Among the health professionals who work in palliative care services, nurses stood out. This greater participation may have been encouraged by the Code of Ethics for Nursing Professional, which contains specific mentions about palliative care in Chapter II - DUTIES, in Art. 48 in its sole paragraph, namely: "In cases of serious incurable diseases and terminals with an imminent risk of death, in line with the multi-professional team, offer all palliative care available to ensure physical, psychological, social, and spiritual comfort, respecting the will of the person or their legal representative". 10

Therefore, nursing assumes the fundamental responsibility about the maintenance of palliative care, recognizing that the strategies of this practice must be individual, centered on the patient, establishing communication with the family and aiming at comprehensive care. 11

Therefore, interventions by nursing professionals in palliative care should be initiated at the very beginning of the diagnosis, together with curative care, and continue throughout the treatment, seeking to manage the control of pain and all the global symptoms presented. Thus, with early recognition and implementation of treatment, patients under palliative care will achieve an excellent quality of life.¹²

Concerning the methodological approach, the use of qualitative research stands out, which requires that the researcher has the capacity for abstraction, analytical competence, respect for the uniqueness of the other's experience, ample theoretical reflection, among others, being, therefore, a complex approach.¹³

As for the theme analyzed over the period, there is a diversity of subjects, as shown in **Figure 3** in a conceptual map. Conceptual mapping is an instrument that allows representing and organizing knowledge that is related between concepts, being understood as units of meanings. ¹⁴ The map proposed in this study has four groups. The first relates palliative care and chronic diseases to play therapy, bioethics, death, spirituality, nursing care, family relationships, and professional-family relationships.

Play therapy, a study entitled: Benefits of play therapy as palliative care in children hospitalized with cancer, showed, through statistical analysis of the psychic defenses variables, a substantial quantitative significance. These results are positively reaffirmed in the qualitative analysis of play therapy as palliative care, which promotes certain developmental conditions, meeting some needs specific to childhood, such as those that favor the maintenance of a positive relationship between children and their caregivers. Through the care inserted by play therapy, the feeling of protection and the behavioral and social limits can be developed and established, as well as the reinforcement of psychic defenses and the work with psychosomatic disorders.¹⁵

In relation to bioethics, a subject that encourages reflection, especially when referring to death, it seeks to provide an end without pain and suffering. In this context, it is necessary to highlight, as emphasized in the corpus, respect for the principles of bioethics in the practice of palliative care, as well as respect for human dignity and professional secrecy and privacy. Thus, such professionals must adopt ethical conduct, aiming at protecting the patient and providing their well-being based on guiding ideas such as beneficence and autonomy.¹⁶

Another correlation pointed out on the map relates palliative care and chronic diseases to spirituality. This aspect is highlighted as an important resource in palliative care for providing strength, comfort, and faith, in addition to enabling improvement in the clinical condition of patients and acceptance and coping with the disease.¹⁷

The religious/spiritual approach as part of the care offered can positively alter the quality of life of patients, reducing depressive symptoms, for example. Incorporating tools that evaluate this aspect, as well as enabling the insertion in the treatment of professionals able to collaborate with the spiritual issue can be decisive points for those under palliative care.¹⁸

As the research points out,¹⁷ the main demands in this aspect of patients in palliative care refer to family support, forgiveness, love, belief, faith, and hope. According to this study, to meet these needs, the communication strategy stands out, which is configured as a necessary element to promote the health of patients, allowing the professional to obtain essential information for palliative treatment, contributing to minimize disturbing feelings and emotions, related to the finitude process.

Communication, as evidenced by the research Palliative care for cancer patients: a bibliometric study, especially in relation to death, considered one of the main challenges experienced by patients and their families, is essential. In this sense, communication, made up of verbal and nonverbal elements, provides confidence, being inherent to a good and effective human relationship, in addition to being fundamental to any type of health care.¹⁹

Additionally, the study²⁰ emphasizes the importance of family and professional relationships for palliative care practices, being of great relevance for developing bonds and security. The second group refers to some members of the multi-professional team, which aim to promote comprehensive care for the patient and their family, whether those adults, the elderly, children, adolescents, users of health services in palliative care or health mental. This team should unite the skills of each professional to help those involved during the painful process, meeting the biopsychosocial and spiritual needs, as highlighted in the research Palliative care: an approach based on the health professional categories.²¹

Among the attitudes and skills necessary to offer quality palliative care, the study entitled: What are the ethical problems in palliative care in primary health care, point out as essential: theoretical and practical knowledge about diseases and symptoms; communication skills; the development of empathy; understanding the reality and peculiarities of the patient's way of life; the commitment to comprehensive and integrated care for the patient and their family; attention to psychosocial and spiritual issues; the emphasis on the patient's quality of life and independence; respect for the patient's values, objectives and priorities in the management of their health condition, and the collaboration of other professionals, including specialists.²²

The third group refers to the relief of symptoms that affect the quality of life of the patient and their family. In palliative care, the therapeutic approach aims to improve the quality of life, by relieving pain and other physical, psychological, spiritual, and social symptoms.

In this sense, the study stands out: Physical exercise in patients with different levels of Doença Pulmonar Obstrutiva Crônica (DPOC) [Chronic Obstructive Pulmonary Disease], which developed an interdisciplinary protocol for the control of pain, dyspnea, and hypersecretion in patients under palliative care, in phase three of terminality, in an Intensive Care Unit (ICU). This protocol contemplates the

main interventions to be performed by professionals in the treatment of patients in palliative care, which are presented according to the professional category, however, they must be performed in an interdisciplinary way. The construction of this protocol made it possible to look together at a problem experienced every day, recovering its strengths and outlining conducts that can improve patient care in palliative care.²³

Still on pain relief, the study Living with pain: The Perspective of Children and Adolescents in Palliative Care reveals that patients under palliative care who use drugs and non-pharmacological alternatives, such as massage, hydrotherapy, acupuncture, and cryotherapy experience an improvement in their daily life. ²⁴

From this perspective, it is found that symptom control, continuous commitment to the patient and family and physical, psychological, and spiritual support are essential care at the end of life.

The fourth group, in turn, refers to the aspects that palliative care seeks to promote to the patient, family, and professional. Treating patients using palliative care entails humanized care, therefore, understanding the incurable nature of certain diseases and life expectancy is the first step towards respecting the right to health and autonomy in these cases.²⁵

It is also important to mention that some of the studies consulted point to a lack of knowledge about palliative care, especially in the management of symptoms and more complex clinical complications, as a limiting factor for the good performance of professionals, who report that they are not updated due to lack of time to devote to studies, as evidenced by the dissertation: What are the ethical problems in palliative care in primary health care?²²

This lack of knowledge by health professionals about palliative care contributes to the emergence of ethical problems related to what is characteristic of this type of care, such as monitoring the death and grief process, communicating bad news, handling symptoms, and complex clinical situations.²²

For this reason, to make palliative care a reality, it is essential that teaching on this theme is included in the process of training health professionals, in addition to the increase in scientific research in Brazil on the subject. On the other hand, mobilizing the State to implement public policies that consolidate access when needed by anyone to this assistance will provide full care, given that everyone deserves it, according to Miriam de Oliveira Melo, in the Multi-professional Team and Palliative Care: Interfaces for health promotion in Primary Care, live with dignity, especially in the last days of life.²⁶

CONCLUSIONS

The bibliometric indicators that made up this investigation indicated that the largest number of studies on the theme was

developed by nurses in graduate nursing programs that make up the Southeast Region. It is identified that the majority of scientific production is developed through the qualitative approach and presents the hospital as a research setting.

The results of this study also showed that the number of publications on the subject in the national scene is still reduced. For this reason, it is hoped that this work can contribute to the spread of new research on chronic disease in the context of palliative care, with the aim of motivating the training of health professionals to offer better assistance to patients and to their families.

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