

## PALLIATIVE CARE IN PRIMARY HEALTH CARE: SCIENTIFIC PRODUCTION OF THESES AND DISSERTATIONS IN THE BRAZILIAN FRAMEWORK

Cuidados paliativos na atenção primária à saúde: produção científica de dissertações e teses no cenário brasileiro

Atención paliativa en la atención primaria de salud: producción científica de disertaciones y estas en el escenario brasileño

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### ABSTRACT

**Objective:** The study's main purpose has been to scrutinize the scientific production of Brazilian *stricto sensu* Postgraduate Programs addressing Palliative Care in Primary Health Care. **Methods:** It is a bibliometric literature review that was performed through searching Theses and Dissertations, formally presented from 2006 to 2017, available on Public Domain Portal, *Biblioteca Digital Brasileira de Teses e Dissertações (BDTD)*, Theses and Dissertations Database from USP, UFRJ and UFSC, as well as Theses and Dissertations from the CAPES Portal. **Results:** The sample consisted of 33 works of which 23 were Dissertations and 10 Theses. The found studies were mostly Dissertations, which were formally presented in 2015 and from the *Universidade de São Paulo (USP)*. Such researches were carried out in Family Health Strategy Programs and held health professionals as research subjects. **Conclusion:** Although incipient, the scientific production of Theses and Dissertations by Brazilian *stricto sensu* Postgraduate Programs can still contribute to the discussion amongst managers and health professionals vis-à-vis the development of Palliative Care in Brazilian Primary Health Care.

**Descriptors:** Palliative care, Primary health care, Bibliometrics, Quality of life, Chronic disease.

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## RESUMO

**Objetivo:** Analisar a produção científica de Programas de Pós-graduação *stricto sensu* brasileiros sobre Cuidados Paliativos na Atenção Primária à Saúde. **Método:** Revisão bibliométrica, realizada por meio da busca de Dissertações e Teses, defendidas entre 2006 e 2017, disponíveis nas bases de dados Portal Domínio Público, BDTD, Banco de Teses e Dissertações da USP, UFRJ, UFSC e Portal de Teses e Dissertações da CAPES. **Resultados:** A amostra foi constituída por 33 trabalhos, sendo 23 Dissertações e 10 Teses. Os estudos encontrados são, em sua maioria, dissertações defendidas em 2015, provenientes da USP, realizadas em Estratégias de Saúde da Família (ESF), tendo como sujeitos de pesquisa os profissionais de saúde. **Conclusão:** Ainda que incipiente, a produção científica de dissertações e teses produzidas pelos Programas de Pós-graduação *stricto sensu* pode colaborar para a discussão, entre gestores e profissionais de saúde, sobre o desenvolvimento dos Cuidados Paliativos na Atenção Primária de Saúde brasileira.

**Descritores:** Cuidados paliativos, Atenção primária à saúde, Bibliometria, Qualidade de vida, Doença crônica.

## RESUMEN

**Objetivo:** Analizar la producción de conocimiento de los programas de posgrado *stricto sensu* brasileños sobre Cuidados Paliativos en la Atención Primaria de Salud. **Método:** Revisión bibliométrica realizada por medio de búsqueda de disertaciones y tesis, defendidas entre 2006 y 2017, disponibles en las bases de datos Portal Dominio Público, BDTD, Banco de tesis y disertaciones de la USP, UFRJ, UFSC y Portal de Tesis y Disertaciones de la CAPES. **Resultados:** La muestra fue constituída por 33 trabajos siendo 23 disertaciones y 10 tesis. Los estudios encontrados son en su mayoría disertaciones, defendidas en 2015, provenientes de la USP, realizadas en Estrategias de Salud de la Familia (ESF), teniendo como sujetos de investigación los profesionales de salud. **Conclusion:** Aún que incipiente, la producción de científico de disertaciones y tesis por los programas de posgrado *stricto sensu* pueden colaborar para la discusión, entre gestores y profesionales de salud, sobre el desarrollo de los CP en la APS brasileña.

**Descriptores:** Cuidados paliativos, Atención primaria de salud, Bibliometría, Calidad de vida, Enfermedad crónica.

## INTRODUCTION

The demographic and epidemiological transition of developed and developing countries, such as Brazil, has caused social changes to meet the demands of population aging and the emergence of chronic Non-Communicable Diseases (NCDs), such as cancer, diabetes and cardiovascular diseases: many of which, in an advanced stage of evolution.<sup>1-5</sup> Among the 56.2 million deaths recorded worldwide, in 2015, more than 25.5 million (45%) resulted from serious health issues. Considering this amount, more than 80% of people who died with serious illnesses were from developing countries, with the majority having no access to Palliative Care (PC).<sup>6</sup> Access to PC is even less likely in certain communities, where the majority patients are living and where they want to stay. Therefore, millions of vulnerable people have their welfare rights denied.<sup>7</sup> Knowing these facts, it is clinically and morally

imperative that PC be integrated into Primary Health Care (PHC).<sup>7-9</sup>

According to the World Health Organization (WHO), PC are a care approach that aims to improve the quality of life of patients and their families facing a life-threatening disease, through the prevention and relief of suffering, through control of pain and other physical, psychosocial and spiritual problems.<sup>7</sup> Therefore, it is necessary that PC must be introduced in all levels of health care: from PHC to hospital care.

In Brazil, the largest country in Latin America and where PC are constantly growing, the public health system seeks to express, in its policies, the government's concern with this new scenario, to prepare all levels of health care, in to provide adequate assistance to people who need PC. With such intentions, in 2018, the Brazilian Ministry of Health published guidelines on the organization of PC within the scope of the *Sistema Único de Saúde (SUS)* [Brazilian Unified Health System], which highlights that this type of care should be offered anywhere in the health system, particularly in PHC.<sup>10</sup> Nevertheless, in the daily routine, there are several challenges to be faced for the consolidation of PC in PHC, such as the demand for professional training in the area, limited resources and the lack of adequate infrastructure.<sup>11-3</sup>

Therefore, it is necessary to address the scientific knowledge already available on this topic for the development of PC in PHC. Considering the important role of Brazilian *stricto sensu* Postgraduate Programs in the production and dissemination of knowledge, aiming to provide a solution to and/or minimize the needs of society, this work meant to scrutinize the scientific production of Brazilian *stricto sensu* Postgraduate Programs addressing PC in PHC.

## METHODS

It is a bibliometric literature review, which allows the monitoring of scientific productivity patterns over time, which helps to answer important questions about the progress of science.<sup>14</sup> Linked to other approaches, this design allows to view the content of research and learn about the dynamics and trends of science.<sup>15</sup> As the guiding axis of this Review, the following question was elaborated: What are the bibliometric indicators of the scientific production from Brazilian *stricto sensu* Postgraduate Programs addressing PC in PHC?

Targeting to search for Theses and Dissertations, the following databases were used: available on Public Domain Portal, *Biblioteca Digital Brasileira de Teses e Dissertações (BDTD)*, *Universidade de São Paulo (USP)*, *Universidade Federal do Rio de Janeiro (UFRJ)*, *Universidade Federal de Santa Catarina (UFSC)* and the Theses and Dissertations Portal from the *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES)* [Coordination for

the Improvement of Higher Education Personnel]. The descriptors used for the search were: Palliative Care, Basic Healthcare Services and Primary Health Care, (terms available in the Health Sciences Descriptors). For the combination of terms, the Boolean operator “AND” was used.

The bibliometric search took place from April to May 2019. The inclusion criteria were, as follows: Theses or Dissertations available in full, published over the period from 2006 to 2017, whose main theme was related to PC in PHC. There were excluded productions that either did not include the defined subject or did not complied with the specified timeframe.

After conducting the study search, the duplicates were removed. Then, a careful reading of the titles and abstracts was made, discarding scientific productions that were not directly related to the proposed object of study. The pre-selected works in the aforementioned stage were read in full, so that they were part of the final sample only to those who met the inclusion criteria for this review.

To facilitate organizing and analyzing the data, a table was elaborated using the Excel software, contemplating the bibliometric indicators investigated, as follows: work modality (Dissertation; Thesis), year of formal presentation, scenario and research participants, educational institution and location of the institution, in addition to keywords.

Concerning the data analysis, descriptive statistics were used to summarize and present the results. The keywords were scrutinized using the Concept Mapping methodology, an evaluative tool that enables the organization of knowledge, promoting experiences that provoke reflection, search for understanding and information processing.<sup>16</sup> The keywords were gathered according to their conceptual thematic affinity, following a systematic organization in thematic classes.

## RESULTS AND DISCUSSION

The study sample consisted of 33 researches, 23 (69.6%) of which were Dissertations and 10 (30.3%) Theses, according to the following flowchart (Figure 1).

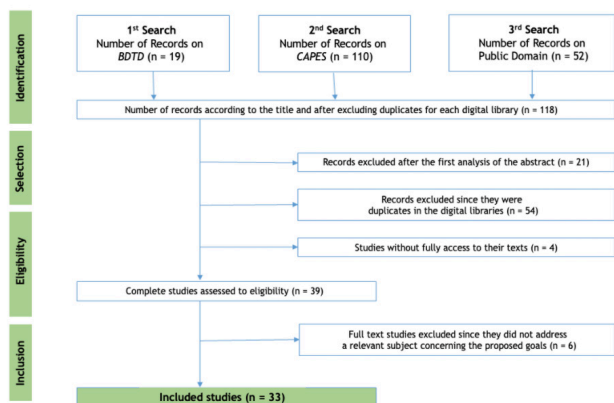


Figure 1 - Flowchart of the selection process for the publications included

in the study. João Pessoa city, Paraíba State, Brazil, 2019.

Regarding the year of formal presentation, in 2015, 10 (30.3%) studies were published; followed by 2017 with eight (24.2%) and 2011 with four (12.1%) of the publications. The remaining studies (33.4%) were distributed between subsequent years, except for 2008 and 2007, in which no publications were found on the subject in question. These results demonstrate that the studies addressing PC in PHC done by the Brazilian *stricto sensu* Postgraduate Programs have been intensified, notwithstanding both slowly and timidly. A probable explanation for this result is that the supply of PC in the country is centered on hospitals, as pointed out by the situational analysis and recommendations for structuring PC programs in Brazil, developed by the National Academy of Palliative Care (2018).

Table 1- Distribution of the scientific production according to each i

HIGHER EDUCATION INSTITUTION BY REGION	THESIS	DISSERTATION	N	%
<b>SOUTHEAST REGION</b>				
Universidade de São Paulo (USP)	01	07	08	24.2
Universidade Federal Triângulo Mineiro (UFTM)	01	02	03	9.0
Universidade Federal do Rio de Janeiro (UFRJ)	0	02	02	6.0
Universidade Federal Fluminense (UFF)	0	02	02	6.0
Universidade Federal de São João Del-Rei (UFSJ)	0	02	02	6.0
Fundação Oswaldo Cruz (FIOCRUZ)	0	01	01	3.0
Universidade Estadual Rio de Janeiro (UERJ)	0	01	01	3.0
Universidade Estadual de Campinas (UNICAMP)	0	01	01	3.0
Universidade Estadual Paulista (UNESP)	01	0	01	3.0
Pontifícia Universidade Católica de Minas Gerais (PUC Minas)	0	01	01	3.0
<b>NORTHEAST REGION</b>				
Universidade Federal da Paraíba (UFPB)	0	01	01	3.0
Universidade Estadual da Paraíba (UEPB)	0	01	01	3.0
Universidade Federal do Rio Grande do Norte (UFRN)	0	01	01	3.0
<b>NORTH REGION</b>				
Universidade Federal do Pará (UFPA)	01	0	01	3.0
Universidade Estadual do Pará (UEPA)	01	0	01	3.0
<b>SOUTH REGION</b>				
Universidade Fernando Pessoa (UFP)	01	0	01	3.0
Universidade Estadual de Londrina (UEL)	0	01	01	3.0
<b>CENTRAL-WEST REGION</b>				
Universidade de Brasília (UnB)	02	0	02	6.0
Universidade Federal de Goiás (UFG)	01	01	02	6.0
<b>TOTAL</b>	<b>09</b>	<b>24</b>	<b>33</b>	<b>100 %</b>

Source: Research data. 2019.

Distributed by Brazilian regions (Table 1), it is noted that the highest production index occurred in the Southeast region, with 66% of publications. With regard to the institutions, the Universidade de São Paulo (USP) was the one that produced the most about PC in PHC (24.2%) (Table 1).

It is worth mentioning that the occurrence of the concentration of scientific production on PC in PHC, in universities in the Southeast, may be associated with the fact that more than 50% of PC services are concentrated in that region, and only 13 teams (less 10% of the total) in the North and Northeast.<sup>17</sup> In Brazil, there is an important spatial heterogeneity of scientific research activities, so that the distribution of publications and researchers is highly concentrated in the Southeast region, with emphasis on the

State Capitals.<sup>18</sup> This spatial concentration is related to the location of public university campuses, particularly State and Federal ones, which are responsible for most scientific activity, a common scenario in developing countries.<sup>18</sup>

**Table 2** - Distribution of scientific production according to research scenario, research participants and thematic focus for the studies' publication year (N = 33). João Pessoa city, Paraíba State, Brazil, 2019.

BIBLIOMETRIC INDICATORS	N	%
<b>RESEARCH SCENARIO</b>		
Family Health Unit	16	48.4
Home	09	27.2
Hospital	09	27.2
Health Institutions	08	24.2
<b>RESEARCH PARTICIPANTS</b>		
Health Professionals	19	57.4
Patients undergoing Palliative Care	12	36.3
Caregivers	02	6.0

Source: Research data, 2019.

Most of the studies were performed in Family Health Strategy Programs (48.4%), with health professionals (57.4%) and PC patients (36.3%) as research subjects (Table 2).

Commonly, there is a preference on the part of family members and patients for the provision of PC at home, whenever possible.<sup>19</sup> Thus, care at the end of life has become a necessary competence for PHC services, mainly due to the proximity that healthcare assistance provides. community health provides between patients/family members and teams.<sup>20</sup> Therefore, it is important to underline that health professionals must be prepared to meet the demand for PC in PHC.

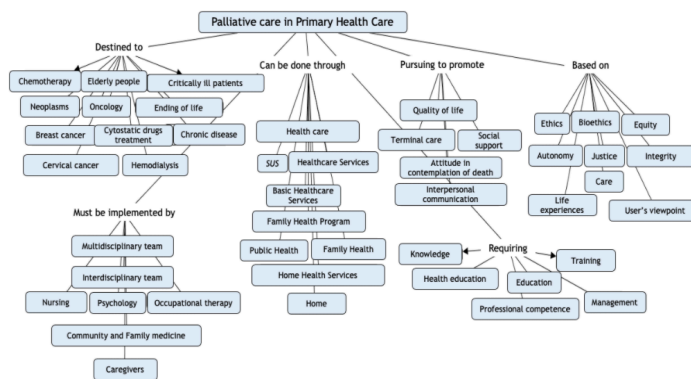
**Table 3** – Keywords of publications addressing palliative care in home

KEYWORD	FREQUENCY	KEYWORD	FREQUENCY
Palliative care	26	Autonomy	01
Primary Health Care	07	Self-efficacy	01
Nursing	05	Social support	01
	05	Attitude in contemplation of death	01
Quality of life			
Public health	05	Patient discharge	01
Bioethics	04	Health care	01
Home Care	03	Access to Healthcare Services	01
Basic Healthcare Services	03	Primary care	01
Family Health Program	03	Primary Health Care	01
Cancer	02	Breast cancer	01
Health education	02	Knowledge	01
Oncology nursing	02	Cervical Cancer	01
Completeness	02	Training	01
Oncology	02	Interpersonal communication	01
Home Care Services	02	Professional Competence	01
Care	01	Registered Nurses	01
Palliative Care in Oncology	01	Public Health Nursing	01
Care for Terminally ill Patients	01	Palliative Care Nursing in the End of Life	01
Terminal Care	01	Home Health Nursing	01
Palliative Care	01	Education	01
Palliative Care in the End of Life	01		01
Nursing care	01	Family Health Strategy	01
Caregivers	01	Interdisciplinary Team	01
Depression	01	Multiprofessional Health Team	01
Home	01	Karnofsky Performance Scale	01
Chronic disease	01	Fatigue	01
Intervention Study	01	Management	01
Hypodermoclysis	01	Life experiences	01
Hemodialysis	01	Mammography	01
Internship and Resident	01	Risk Measurement	01
Family and Community Medicine	01		01
Neoplasms	01	Death	01
User's viewpoint	01	Head and neck neoplasm	01
Tracking Programs	01	Elderly people	01
Chemotherapy	01	Psychology	01
	01	Family Health	01
	01	Brazilian Unified Health System (SUS)	01
Health services			
Information systems	01	Sleep	01
Occupational therapy	01	Pressure ulcer	01
Equity	01	Justice	01
Medication Administration Routes	01		

Source: Research data, 2019.

In addition to 'Palliative Care' and 'Primary Health Care', the most used keywords were 'Nursing', 'Quality of life', and 'Public Health', as shown in Table 3.

The following Concept Map was presented by analyzing the keywords (Figure 2), which was elaborated either from the terms sense's similarities or the morphological relationship between the words.



**Figure 2** – Concept Map elaborated based on the descriptors from the Theses and Dissertations selected for this study. João Pessoa city, Paraíba State, Brazil, 2019.

Through the Concept Map, it was possible to identify that PC in PHC are intended for people with serious illnesses and must be implemented by a multidisciplinary team. This data corroborates with the one indicated by the WHO concerning the concept of PC.<sup>7</sup> Anyone affected by a serious, progressing disease that threatens life can benefit from PC. Furthermore, considering the complexity of care, since it must meet the needs of the human person and be multidimensional, this care must also be provided by a multidisciplinary team.

Providing care means to promote quality of life, being guided by issues related to bioethics. It is possible to see that the promotion of PC in PHC allows patients the possibility to continue in their family and social milieu, with specialized multidisciplinary and/or interdisciplinary care and willing to offer support and guidance to family members and/or caregivers, avoiding recurrent and often unnecessary hospitalizations. The user under PC remains in a family environment, with reduced risks and comprehensive care, which contributes to the improvement and maintenance of his quality of life, in addition to providing the release of hospital beds for curative treatment and professional opportunity in a new proposal to PC.<sup>21</sup>

As the Concept Map points out, PC in PHC require knowledge and actions based on ethical and bioethical principles. In autonomy and justice! Concerning the principle of autonomy, this is configured as the most relevant to bioethics, assuming that the existence of the autonomous person is necessary, by taking into consideration the exercise of moralities. The latter can

choose and act according to its wishes, and respect for this autonomy is indispensable, as long as it does not result in harm to others. The person must have reasonable maturity and awareness of his choices.<sup>22</sup>

Regarding the principle of justice, this reflection is necessary and pertinent, amid the need to offer PC to patients with imminent death, since, concerning health care, justice is based on the premise that people are guaranteed equal rights. Accordingly, it becomes inevitable the recognition of the differences of each patient and the adequacy of care to their needs, which will equitably offer more attention to those who need it most.<sup>23</sup>

Nonetheless, health professionals must be trained to offer this type of care. In order to do so, it is of utmost importance that the multidisciplinary/interdisciplinary team develops certain skills and competencies, necessary to help patients and families adapt to the limitations imposed by the disease.<sup>24</sup>

## CONCLUSIONS

According to the results, the scientific production of Brazilian *stricto sensu* Postgraduate Programs addressing Palliative Care in Primary Health Care. The found studies were mostly Dissertations, which were formally presented in 2015 and from the USP. Such researches were carried out in Family Health Strategy Programs and held health professionals as research subjects. Through the Concept Map, it was possible to identify that PC in PHC are intended for people with serious illnesses, and such services must be provided by a multidisciplinary team.

Providing care means to promote quality of life, being guided by issues related to bioethics. Nevertheless, health professionals must be trained, hence, they can offer this type of care effectively.

Despite the restricted number of databases consulted, this work pursues to contribute to a prominent, and always necessary, discussion amongst managers and health professionals, vis-à-vis the development of PC in Brazilian PHC.

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