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
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 Domínio 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 puede colaborar para la discusión, entre gestores y profesionales de salud, sobre el desarrollo de los CP en la APS brasileña.
Descritores: 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. 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). 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. Knowing these facts, it is clinically and morally imperative that PC be integrated into Primary Health Care (PHC).

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. 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. 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.

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. Linked to other approaches, this design allows to view the content of research and learn about the dynamics and trends of science. 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. 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).

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. 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. 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.18

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.

<table>
<thead>
<tr>
<th>BIBLIOGRAPHIC INDICATORS</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>RESEARCH SCENARIO</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Health Unit</td>
<td>16</td>
<td>48.4</td>
</tr>
<tr>
<td>Home</td>
<td>09</td>
<td>27.2</td>
</tr>
<tr>
<td>Hospital</td>
<td>09</td>
<td>27.2</td>
</tr>
<tr>
<td>Health Institutions</td>
<td>08</td>
<td>24.2</td>
</tr>
<tr>
<td>RESEARCH PARTICIPANTS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health Professionals</td>
<td>19</td>
<td>57.4</td>
</tr>
<tr>
<td>Patients undergoing Palliative Care</td>
<td>12</td>
<td>36.3</td>
</tr>
<tr>
<td>Caregivers</td>
<td>02</td>
<td>6.0</td>
</tr>
<tr>
<td>Source: Research data, 2019.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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. 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. 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 care.

<table>
<thead>
<tr>
<th>KEYWORD</th>
<th>FREQUENCY</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care</td>
<td>26</td>
</tr>
<tr>
<td>Nursing</td>
<td>27</td>
</tr>
<tr>
<td>Quality of life</td>
<td>15</td>
</tr>
<tr>
<td>Family Health Program</td>
<td>12</td>
</tr>
<tr>
<td>Health education</td>
<td>12</td>
</tr>
<tr>
<td>Caregivers</td>
<td>12</td>
</tr>
<tr>
<td>Care, Palliative Care</td>
<td>10</td>
</tr>
<tr>
<td>Education</td>
<td>10</td>
</tr>
<tr>
<td>Personal care</td>
<td>9</td>
</tr>
<tr>
<td>Pain</td>
<td>9</td>
</tr>
<tr>
<td>Depression</td>
<td>9</td>
</tr>
<tr>
<td>Retired</td>
<td>9</td>
</tr>
<tr>
<td>Community and Family Medicine</td>
<td>9</td>
</tr>
</tbody>
</table>

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.

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. 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 milieus, 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.

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. 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.

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.

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.

REFERENCES


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