

Research in Palliative Care in Brazil

doi: <https://doi.org/10.32635/2176-9745.RBC.2021v67n3.1934>

Pesquisa em Cuidado Paliativo no Brasil

Investigación en Atención Paliativa en Brasil

Livia Costa de Oliveira¹

INTRODUCTION

Palliative care is multi-disciplinary approach that improves the quality of life of patients with life-threatening diseases and their families through prevention and relief of suffering by means of early identification, correct assessment and treatment of the pain and other symptoms, whether physical, psychosocial or spiritual¹.

The demand for this type of care is growing because of the world population ageing, increase of cancer incidence and other chronic non-communicable diseases in addition to the recent outbreak of the coronavirus disease 2019 (COVID-19) which makes urgent the necessity of specialized care for relief of human suffering and attention to complicated grief².

According to the Global Atlas of Palliative Care², even before the COVID-19 pandemic was determined on March 11, 2020, 56.8 million people needed this type of care, great part because of the oncologic disease. And despite more patients are now receiving palliative care in the world, this is only 12% of this need being met².

In order to actually develop palliative care ensuring the population suitable access, political and educational barriers, availability of medication and implementation of this type of care need to be resolved². The training of health professionals in different levels of attention, guidelines to the general population and studies in the area are included in the scope of education³.

Therefore, the scientific development about palliative care is linked to its progress in a country or region⁴. The objective of this article is to address the current scenario of the existence and distribution of research groups and the scientific publications on palliative care in Brazil.

DEVELOPMENT

There is a cultural stigmatization which levels palliative to end-of-life care associated to huge gaps in teaching and research that need to be resolved to balance this equation.

Palliation should start at different levels of complexity at the onset of any manifestation of a condition/life-threatening disease together with therapeutics able to change its course, assuming relevance as much as curative therapeutics have proven ineffectual¹.

For instance, oncologic palliative care can be divided in three different phases: initial, when the patient has an incurable disease, but with better prognosis, functionality, and nutritional condition; advanced, with poor prognosis, functional and nutritional status further to an increasing burden of anguishing symptoms and end-of-life phase, that is, the imminence or active process of death whose goal of the care is to provide comfort during this process on a priority base⁵⁻⁷.

Consequently, it is necessary that the scientific development is able to respond to conflicting aspects of each one of these moments not only related to the end-of-life care, a period where the design of the studies can involve complex ethical issues. It is paramount to conduct trials within strict methodological parameters able to produce high level evidences, ensuring the required rationale to elaborate protocols that grant the improvement of the clinical practice in palliative care through all its phases and the formulation of health-related policies about this subject.

Research on palliative care today is predominantly targeted to cancer. According to data of the National Council of Scientific and Technological Development (CNPq) Research Groups⁸, the first Palliative Care Research Group in Brazil was created in 1994. Ever since, different groups have been created and currently there are 60 accredited in the whole country unevenly distributed across the Geographical Regions: Southeast (n=23; 38.3%); Northeast (n=18; 30.0%); South (n=13; 21.7%); Midwest (n=4; 6.7%) and North (n=2; 3.3%)⁸.

Of the Research Groups in Palliative Care of the Southeast Region, ten (43.5%) are from Rio de Janeiro, seven (30.4%) from Minas Gerais and six (26.1%) from São Paulo. In Rio de Janeiro, these groups can be found

¹National Cancer Institute José Alencar Gomes da Silva (INCA), Palliative Care Unit. Rio de Janeiro (RJ), Brazil. Orcid iD: <https://orcid.org/0000-0002-5052-1846>
Corresponding author: Livia Costa de Oliveira. Rua Visconde de Santa Isabel, 274 – Vila Isabel. Rio de Janeiro (RJ), Brazil. CEP 20560-120. E-mail: lilycostaoliveira@gmail.com



in “*Universidade Federal Fluminense* (UFF) (n=5; 50.0%); “*Universidade Federal do Rio de Janeiro*” (UFRJ) (n=2; 20.0%); “*Fundação Oswaldo Cruz*” (Fiocruz) (n=2; 20.0%) and National Cancer Institute José Alencar Gomes da Silva (INCA) (n=1; 10.0%)⁸.

Simultaneously, an increasing body of knowledge was accumulated in the last decades, nevertheless, far from the desired. According to Lima et al.⁹, the number of articles in palliative care developed by South American investigators has considerably grown in a 20-year period (between 1998 and 2017) in the databases PubMed, Embase, LILACS and Web of Science. And among the countries evaluated (a total of 656 articles analyzed), Brazil (n=389; 59.3%) was the country with the highest number of articles, followed by Argentine (n=118; 18.0%), Chile (n=85; 13.0%) and Colombia (n=64; 9.7%).

However, it is not possible to affirm that the quality of these publications matches this trend of growth. In addition, few of these studies adopted qualitative designs⁹, which would hinder to address different palliative care related demands not only of physical burdens but psychosocial suffering too¹ from patients and their loved ones.

Future studies attempting to enhance the evaluation with quality of a broad spectrum of concerns of patients and family/caretakers (separately or as a “whole entity”) of physical, psychosocial, or spiritual nature should be developed. It is paramount to evaluate the correct utilization of health resources that actually are able to meet the most relevant demands of this population, corroborating the promotion of equity, one of the doctrinarian principles of the National Health System (SUS) and chosen theme of the year by The Worldwide Hospice Palliative Care Alliance for the campaign of World Palliative Care Day on October 9, 2021: Equity in access to Palliative Care¹⁰.

CONCLUSION

Today, research in palliative care in Brazil found in the scientific literature is extremely reduced. One of the current challenges is to build solid information able to expand the development of this type of care and open possibilities for the correct management with equity of the relevant characteristics and demands of this population in all its facets, reflecting in the quality of the life and death as well.

ACKNOWLEDGMENTS

To the Direction of Palliative Care of INCA for the support and confidence to all the research fronts that have been conducted. To the Nutrition in Palliative Care Research Group (NutriPali), of which I belong

since its creation in 2016. It was attempted to promote the scientific development in Nutrition and Oncologic Palliative Care through this group.

CONTRIBUTIONS

The author participated of all the phases of the manuscript and approved the final version to be published.

DECLARATION OF CONFLICT OF INTERESTS

There is no conflict of interests to declare.

FUNDING SOURCES

None.

REFERENCES

1. World Health Organization. National cancer control programmes: policies and managerial guidelines [Internet]. 2nd ed. Geneva: WHO; 2002 [cited 2021 Apr 1]. Available from: <http://www.who.int/cancer/publications/nccp2002/en/index.html>.
2. Connor SR, editor. Global atlas of palliative care [Internet]. 2nd ed. London, UK: Worldwide Palliative Care Alliance; 2020. [cited 2021 Apr 9]. Available from: <http://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>
3. Stjernsward J, Foley KM, Ferris FD. The public health strategy for palliative care. *J Pain Symptom Manage*. 2007;33(5):486-93. doi: <https://doi.org/10.1016/j.jpainsymman.2007.02.016>
4. Cheong WL, Mohan D, Warren N, et al. Palliative care research in the Asia Pacific region: a systematic review and bibliometric analysis of peer-reviewed publications. *J Palliat Med*. 2019;22(5):545-52. doi: <https://doi.org/10.1089/jpm.2018.0447>
5. Rosaneli CF, organizadora. Contexto, conflitos e escolhas em alimentação e bioética. Curitiba: PUCPRESS; 2016.
6. Magalhães ES, Oliveira AEM, Cunha NB. Atuação do nutricionista para melhora da qualidade de vida de pacientes oncológicos em cuidados paliativos. *Arch Health Sci*. 2018;25(3):4-9. doi: <https://doi.org/10.17696/2318-3691.25.3.2018.1032>
7. Amano K, Morita T, Koshimoto S, et al. Eating-related distress in advanced cancer patients with cachexia and family members: a survey in palliative and supportive care settings. *Support Care Cancer*. 2019;27(8):2869-76. doi: <https://doi.org/10.1007/s00520-018-4590-6>
8. Diretório dos Grupos de Pesquisa no Brasil Lattes [Internet]. Brasília, DF: Conselho Nacional de Desenvolvimento Científico e Tecnológico. [data desconhecida] – [acesso 2021 abr 15]. Disponível

em: http://dgp.cnpq.br/dgp/faces/consulta/consulta_parametrizada.jsf

9. Lima C, Paiva BSR, Santos Neto MF, et al. The impact of international research collaborations on the citation metrics and the scientific potential of South American palliative care research: bibliometric analysis. *Ann Glob Health*. 2021;87(1):32. doi: <https://doi.org/10.5334/aogh.3158>
10. Worldwide Hospice Palliative Care Alliance [Internet]. London, UK: WHPCA; c2015. World Hospice and Palliative Care Day; [cited 2021 Apr 2]. Available from: <http://www.thewhpca.org/world-hospice-and-palliative-care-day>

Recebido em 23/4/2021
Aprovado em 26/4/2021