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THEMATIC SECTION: PALLIATIVE HEALTH CARE

Palliative care: pathway in primary health care in Brazil

Cuidados paliativos: percurso na atenção básica no Brasil

Cuidados paliativos: camino en la atención primaria en Brasil

Luis Fernando Rodrigues [1,2]
João Felipe Marques da Silva [3,4]
Marcos Cabrera [3]

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Abstract

In 2022, an important international report was published on the "value of death" not only in the field of health, but in relation to human societies in general. This report proposed to reimagine systems related to end of life in which death is understood not only as a physiological event but also as a relational and spiritual phenomenon with a value of its own and inseparable from life. It identifies the low priority given by most governments worldwide to the issue of alleviating suffering and supporting bereavement, evidenced by the low investment in palliative care. At the same time, we are witnessing in Brazil changes that threaten the feasibility of palliative care policies in primary health care. The denial of finitude within health systems is reflected in global indicators such as the quality of death index of The Economist *magazine, in which Brazil ranks 42nd, the global atlas of palliative care of the World Hospice and Palliative Care Alliance, where Brazil is in level 3b, and the global trends in opioid consumption of International Narcotics Control Board of the World Health Organization, in which opioid consumption in Brazil is in the hundreds of doses per million inhabitants per day. Despite notable advances in the legislative and executive fields with regard to palliative care, the Brazilian Unified National Health System (SUS) and primary health care have suffered important structural setbacks that will impact the design of public policy for palliative care. The goal of this article is to undertake an initial analysis of the impacts of current policies within this context and their repercussions in the construction of a solid policy for palliative care.*

Palliative Care; Psychological Distress; Death; Primary Care

[1] Unidade de Cuidados Paliativos, Hospital de Câncer de Barretos, Barretos, Brasil.
[2] Instituto Lótus de Cuidados Paliativos de Ribeirão Preto, Ribeirão Preto, Brasil.
[3] Universidade Estadual de Londrina, Londrina, Brasil.
[4] Faculdade de Tecnologia do Vale do Ivaí, Ivaiporã, Brasil.

Correspondence
L. F. Rodrigues
Av. 47 540, Barretos, SP 14780-755, Brasil.
lufe.luis@gmail.com

Legal framework and denial of death and suffering

In 2022, an important international report was published on the "value of death" not only in the field of health, but in relation to human societies in general [1]. This report proposed to reimagine systems related to end of life in which death is understood not only as a physiological event but also as a relational and spiritual phenomenon with a value of its own and inseparable from life. In their analysis of the COVID-19 pandemic, these authors criticized the low priority given by most governments worldwide to the issue of alleviating suffering and supporting bereavement, evidenced by the low investment in palliative care. At the same time, we are witnessing in Brazil changes that threaten the feasibility of palliative care policies in primary health care.

The fundamentals of primary health care have been established since the *Declaration of Alma-Ata* [2], with a focus on healing and rehabilitation and omission in relation to palliative care. In Brazil, the omission persists in the official documents that support the functioning of its society and the Brazilian Unified National Health System (SUS), namely the *Federal Constitution* of 1988 [3] and *Laws n. 8,080/90* [4] and *n. 8,142/1990* [5]. These gaps in Brazilian legislation can be understood as a behavior of denial of death and suffering, since they focus on actions related to health promotion, prevention, diagnosis, treatment and rehabilitation, not to mention care with finitude.

Palliative care and world indicators

The denial of finitude within the scope of health systems is reflected in some global indicators. The first of these is the quality of death ranking published by *The Economist* [6]. In the last edition of this index, published in 2015, 80 countries were surveyed in relation to 20 quantitative and qualitative indicators comprising five distinct categories, namely: (1) Palliative and healthcare environment, (2) Human resources, (3) Affordability of care, (4) Quality of care, and (5) Community engagement. In this survey, Brazil ranked 42nd, behind countries with more fragile economies such as Uganda, Ecuador and Malaysia.

In turn, in a recent survey on the quality of end-of-life care in the world [7], 181 key informants from 81 countries representing more than 80% of the world's population were interviewed. In this survey, Brazil ranked 79th as one of the worst places to die in the world.

The worldwide mapping of palliative care development was designed by the World Hospice and Palliative Care Alliance in partnership with several universities and palliative care societies [8]. In its latest review, Brazil was classified at level 3b on a six-point scale (1, 2, 3a, 3b, 4a and 4b) where lower levels indicate worse palliative care provisions. According to the methodology adopted in this work, countries at level 3b share the following characteristics: palliative care activism in several locations, multiple sources of funding, availability of morphine, palliative care services by a variety of providers, provision of training and education by palliative care organizations. However, Brazil persists with level 3a characteristics, which are limited availability of morphine, small number of palliative care services compared to population size, and lack of knowledge about palliative care of part of the population, professionals and politicians [9].

Another global indicator is the level of opioid consumption measured by the International Narcotic Control Board, the body of the World Health Organization (WHO) in charge of monitoring the consumption of narcotic drugs [10]. The unit used is the Defined Daily Dose for statistical purposes (S-DDD), expressed by million inhabitants per day. Latin American countries consume hundreds of S-DDDs while developed countries consume thousands of S-DDDs. Within Latin America, Brazil consumes less opioids than Argentina and Chile. In summary, in Brazil quality of death is poor, there is low access to potent opioids and palliative care supply is less than desirable.

Available data on the number of palliative care services in Brazil support this assessment. Despite the increase in the number of palliative care services in the country in the last decade, the ratio of services to population size is still quite low. In 2012, there were 92 services including the hospital, home and hospice areas [11]. There were 177 services in 2018, 191 in 2019 [12] and 198 in 2020 [13], a ratio of 0.94 services/million inhabitants, below Argentina and Chile (Table 1).

Table 1

Total number of palliative care services and their percentage in relation to population in some Latin American countries.

Country	Total of palliative care services	Rate per million inhabitants
Brasil	198	0.94
Argentina	482	10.79
Chile	244	13.41
Uruguay	85	24.50

Source: Pastrana et al. [13].

WHO estimates that about 40 million people die annually in need of palliative care. About 78% of them are in low- or middle-income countries and only 14% have adequate access to this kind of care [14]. In Brazil, it is estimated that over 885,000 people died in need of palliative care in 2019 [15], a huge number of patients experiencing unrelieved suffering at death. This is about hidden suffering.

An event that occurred in September 2021 during the Parliamentary Commission of Inquiry on the pandemic in the Brazilian Senate caught our attention and can serve as a qualitative indicator of misinformation about palliative care in the country. In a speech, an eminent senator referred to palliative care as a *"macabre specialty"* and *"promoter of euthanasia"*, showing a lack of understanding of the proposal of this type of care. This attitude did not surprise us, since in 2014 the literature already considered the poor knowledge of the Brazilian political class about palliative care to be one of the barriers to the development of this field in Brazil [9].

Contradictions

An important international report on palliative care and pain relief published in 2018 pointed to one of the fundamental contradictions of medical treatments in the modern world, where, on the one hand, some patients are overtreated, receiving unnecessary procedures, while others do have no access to opioids to relieve their pain. In the epigraph of this report is the harrowing story of a patient in India who was suffering from pain from lung cancer. At first, the patient experienced significant relief from this symptom with the use of morphine, but when his stock at the local health service ran out, he threatened to hang himself if the supply was not restored [16]. Unfortunately, a similar situation would not be surprising in Brazil.

Ongoing progress

In 2014, the World Health Assembly published *Resolution 67.19* [17], highlighting the preoccupation with non-communicable diseases and conditions, urging member countries to implement palliative care in their health systems, especially in primary health care and home care. The subject starts being addressed by public health policies in Brazil from the publication of ministerial decree 483, dated April 1, 2014, which redefines the care network for people with chronic diseases, including palliative care as a resource to be made available [18].

The subject gains visibility when the Brazilain National Council of State Health Departments (CONASS) takes the discussion to the Tripartite Intermanager Commission (CIT) and approves *Resolution n. 41/2018* [19], establishing the guidelines for a national palliative care policy, indicating the recognition of the importance of palliative care by the executive branch at the three levels of government.

Likewise, the legislative branches of some states start to focus on the debate on the inclusion of palliative care in their health policies with initiatives in Goiás in 2017 [20], Rio Grande do Sul [21], Rio de Janeiro [22] and Paraná [23] in 2019, São Paulo in 2020 [24] and Minas Gerais in 2021 [25] (Table 2). Additionally, there are already examples of situations in which the legislature of some municipalities developed

Table 2

Leis estaduais que estabelecem a inserção dos cuidados paliativos nas políticas estaduais de saúde aprovadas até 2021 no Brasil.

Ano	State	Law
2017	Goiás	*Law n. 19,723*, July 10, 2017
2019	Rio Grande do Sul	*Law n. 15,274*, January 31, 2019
2019	Rio de Janeiro	*Law n. 8,425*, July 1st, 2019
2019	Paraná	*Law n. 20,091*, December 19, 2019
2020	São Paulo	*Law n. 17,292*, October 13, 2020
2021	Minas Gerais	*Law n. 23,938*, September 23, 2021

initiatives in this direction, such as the municipal bills still in discussion in Londrina (Paraná) and Ribeirão Preto (São Paulo) and in development in Curitiba (Paraná) at the time of writing.

Changes in primary health care

Unfortunately, changes in primary health care in recent years have directly threatened primary health care and palliative care in this context.

primary health care, the population's first point of contact with the health system, also makes it possible for people to move between different levels of care. In Brazil, primary health care was structured based on Comprehensive Health Actions, developed at the 8th National Health Conference and consolidated with the implementation of the Family Health Strategy (ESF) in the 1990s [26].

Subsequently, another advance in primary health care was the inclusion of the Family Health Support Centers (NASF), enabling the existence of multidisciplinary teams to support professionals on the front line of primary health care [27]. As of 2017, palliative care is explicitly stated in the new Brazilian National Primary Healthcare Policy [28], maintaining NASF with extended primary health care teams.

However, the reformulation of the Brazilian National Primary Healthcare Policy through subsequent ordinances has threatened the feasibility of implementing palliative care policies in primary health care. Projected funding for NASF teams has been abolished [29], followed by the lack of incentive for the incorporation of palliative care, given the absence of specific performance indicators [30]. In addition, the current per capita funding criterion contributes to reducing the amount of funds, which are now limited to the population registered with the system rather than the total local population estimated by the Brazilian Institute of Geography and Statistics, which is a more severe problem in an already underfunded system. Thus, universal access to primary health care has been threatened and, consequently, the dream of seeing palliative care being implemented in this context.

Therefore, at first (2008-2016), a pathway seemed possible to include the practice of palliative care in primary health care. With the ongoing changes in the technical and budgetary structures, the principles of universality, integrality and equity are threatened, making more remote the possibility of concrete improvement in mitigating end of life suffering for a large portion of the Brazilian population.

Despite all the efforts that have been made so far to develop palliative care in Brazil, much remains to be done. The emergence of important legal frameworks does not guarantee the existence or execution of a consolidated public policy in this area.

Implementation of palliative care as public policy

These arguments reinforce the role to be played by society in defending its rights and require a more detailed analysis of the current moment and the stages that need to be overcome so that palliative care may be effectively established as solid public policy in Brazil.

It is important to recognize that public policies also have their life cycle, didactically divided into five stages [31]: agenda setting; policy formulation; decision making; policy implementation; and policy evaluation. Each of these stages has its complexity, rhythm, timing and needs. The approval of laws happens in stage 2 and should go beyond providing guidelines on the issue, advancing in the technical and operational details of the topics involved in the implementation. In addition, the factors that interfere in this process must be understood, namely the political and economic context and the role of the various actors involved, especially the beneficiaries of the aforementioned policy, but also the political and social actors.

Conclusion

There is a systemic cultural of denial of death and the dying process, alongside a huge amount of avoidable global suffering related to end of life, which also affects Brazil. Palliative care, an approach acknowledged worldwide, is the first line of answer to these problems. In Brazil, palliative care is beginning to be recognized not only by healthcare professionals, but also by some state legislators and state executive branches. However, much still needs to be done to implement a consolidated palliative care policy in Brazil.

Contributors

L. F. Rodrigues contributed to the design, writing and organization of the text. J. F. M. Silva and M. Cabrera contributed to the writing and organization of the text.

Additional informations

ORCID: Luis Fernando Rodrigues (0000-0001-6177-3769); João Felipe Marques da Silva (0000-0001-7198-8528); Marcos Cabrera (0000-0001-9786-9674).

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Resumo

Em 2022, foi publicado um importante relatório internacional acerca do "valor da morte" não apenas no campo da saúde, mas nas sociedades humanas de forma geral. Este relatório se propôs a reimaginar sistemas relacionados ao fim da vida nos quais a morte seja compreendida não apenas como um fenômeno fisiológico, mas também relacional e espiritual, com valor próprio e inseparável da vida. Identifica-se a baixa prioridade dada pela maior parte dos governos ao redor do mundo para a questão do alívio do sofrimento e dos cuidados com o luto, representada pelo baixo investimento em cuidados paliativos. Ao mesmo tempo, assistimos no Brasil a modificações ameaçadoras à exequibilidade de políticas de cuidados paliativos na atenção básica. A negação da finitude no âmbito dos sistemas de saúde se reflete em alguns indicadores mundiais, como o ranking de qualidade de morte da revista The Economist*, em que o Brasil se encontra na 42ª posição, o mapeamento mundial de cuidados paliativos da Aliança Mundial de Cuidados Paliativos em Hospitais, no qual o Brasil se encontra no nível 3b, e o consumo mundial de opioides pelo Órgão Internacional de Controle de Entorpecentes, da Organização Mundial da Saúde, no qual o consumo dessas substâncias em nosso país está na casa das centenas de doses por milhão de habitantes por dia. Apesar de avanços notáveis nos campos legislativo e executivo no que se refere à temática dos cuidados paliativos, o Sistema Único de Saúde (SUS) e a atenção básica vêm sofrendo reveses importantes a nível estrutural que irão causar impacto na estruturação de uma política pública de cuidados paliativos. Este artigo procura fazer uma análise inicial dos impactos das políticas atuais dentro desse cenário e suas repercussões na construção de uma política de cuidados paliativos sólida.*

Cuidados Paliativos; Sofrimento Emocional; Morte; Atenção Básica

Resumen

En 2022 se publicó un importante informe internacional sobre el "valor de la muerte" no solo en el campo de la salud, sino en las sociedades humanas en general. Este informe se propuso reimaginar sistemas relacionados con el fin de la vida en los que la muerte se comprenda no solo como un fenómeno fisiológico, sino también relacional y espiritual, con un valor propio e inseparable de la vida. Se identifica la baja prioridad dada por la mayor parte de los gobiernos en todo el mundo para la cuestión del alivio del sufrimiento y de los cuidados con el duelo, representados por la baja inversión en cuidados paliativos. Al mismo tiempo, asistimos en Brasil a modificaciones amenazadoras a la viabilidad de políticas de cuidados paliativos en la atención básica. La negación de la finitud en el ámbito de los sistemas de salud se refleja en algunos indicadores mundiales como el ranking de calidad de la muerte de la revista The Economist *en que Brasil está en la posición 42; el mapeo mundial de cuidados paliativos de la Alianza Mundial de Cuidados Paliativos y Hospicio donde Brasil se encuentra en el nivel 3b y el consumo mundial de opioides por la Junta Internacional de Fiscalización de Estupefacientes de la Organización Mundial de la Salud en el que nuestro consumo de opioides está en los cientos de dosis por millón de habitantes por día. A pesar de los notables avances en los ámbitos legislativo y ejecutivo en lo que se refiere a la temática de los cuidados paliativos, por otro lado, el Sistema Único de Salud brasileño (SUS) y la atención básica vienen sufriendo importantes retrocesos a nivel estructural que repercutirán en la estructuración de una política pública de cuidados paliativos. Este artículo pretende hacer un primer análisis de los impactos de las políticas actuales, dentro de este escenario, y sus repercusiones en la construcción de una política sólida de cuidados paliativos.*

Cuidados Paliativos; Distrés Psicológico; Muerte; Atención Básica

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