


Historical process and public policies related to palliative care in Brazil

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ABSTRACT

Palliative Care is a concept focused on improving the quality of life for patients and families in the face of life-threatening illnesses. Its principles include symptom relief, affirmation of life, consideration of death as a natural part, integration of psychological and spiritual aspects, active support to the patient until death, support to family members, and a multidisciplinary approach. In Brazil, the implementation of this concept must be aligned with national health policies, based on constitutional principles such as universality and equality. Resolution No. 41/2018, approved by the Tripartite Interagency Commission of the Ministry of Health, establishes guidelines for the organization of palliative care in the Unified Health System (SUS), considering the demographic transition and epidemiological changes. Although the SUS already superficially addresses palliative care, it still does not treat it as a public health policy with clear guidelines. The reorganization of the care model implies reviewing spaces, management, technologies, training of professionals and communication models, shifting the focus from recovery to the care and comfort of the patient. The need to integrate palliative care at all levels of health care in the SUS is highlighted, making its implementation a priority in the face of the growing technization of medicine, which often neglects the autonomy and dignity of the patient. The implementation of these guidelines will contribute to a more humanized and comprehensive approach to the SUS care network, recognizing palliative care as an essential component of health care.

Keywords: Palliative Care, Public Policies, Comprehensive Health Care.

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INTRODUCTION

PALLIATIVE CARE

Historical process of Palliative Care

The twentieth century witnessed remarkable progress in the field of medicine and in the understanding of care. However, despite significant developments and innovative discoveries in favor of health, the approach to patients in irreversible conditions, i.e., terminally ill, proved to be insufficient. Practitioners, focused on the continuous improvement of their healing capacities, have devoted considerable effort to the development of new methods for this purpose. (Stevens; Jackson; Milligan, 2009)

Based on the understanding of the interrelationship between body and mind, along with the appreciation of patients' autonomy and dignity, new perspectives in relation to care have emerged. Studies, such as the one conducted by the *Marie Curie Memorial Foundation* in 1952 in the City of London, have elucidated the anguish and deprivation faced by terminal cancer patients who received treatment at home. This research evidenced the need for institutions specialized in the care of these patients, equipped with material resources, adequate instruments and qualified professionals. (Saunders, 2001; Stevens; Jackson; Milligan, 2009)

Additional studies in the 1950s corroborated concerns about the suffering faced by terminally ill patients, attributed to the lack of professionals and institutions dedicated to their care. The urgent need was to understand effective strategies to ensure a dignified death for these patients. Hughes (1960) and Hinton (1963) addressed the inadequacy and neglect of the places that cared for terminal patients, as well as the mental and physical suffering of these individuals. These surveys have sparked significant debates, playing a crucial role in instigating and developing institutions specifically for this audience. (Saunders, 2001)

Hospices play a crucial role in the treatment of terminally ill patients, with records of their origin in medieval Europe to house pilgrims, the poor, orphans, women in labor, and the terminally ill, as propagated by Catholic and Protestant religious leaders (Carvalho; Parsons, 2012). Our Lady's Hospice in Dublin, developed in 1879, marked the beginning of this movement, which expanded to East London in 1900, with the opening of five additional institutions. In 1905, St Joseph's Hospice in London inspired the work of Dame Cicely Saunders, a central figure in the promotion of Palliative Care globally. (Saunders, 2001; Stevens; Jackson; Milligan, 2009)

Dame Cicely Saunders, renowned for her dedication to extending and popularizing Palliative Care, started the Modern Hospice Movement in 1957, founded on the principle of the "good death". Its purpose was to provide support and protection to the terminally ill patient. Saunders conducted a comprehensive survey of 1100 patients at St. Joseph's Hospice, representing an early milestone in the development of the Modern Hospice Movement. The focus of the research was to listen carefully to



the patients' complaints, resulting in the understanding of the patient's physical, psychological, and spiritual complexity. This approach highlighted the importance of considering all aspects that impact treatment development and individual well-being. (Floriani, 2021; Saunders, 2001) (Carvalho; Parsons, 2012; Saunders, 2001; Stevens; Jackson; Milligan, 2009)

Saunders' understanding of pain and its impact on patients' lives highlighted her as a crucial figure in the development of palliative care, possibly even as the main protagonist. However, the discussion about the origin of Palliative Care is widespread. In the United States of America, for example, in the period from 1967 to 1969, Elizabeth Kubler-Ross played a significant role in documenting essential accounts in her book "On Death and Dying" that altered perspectives on death. She was responsible for establishing the hospice movement in the region in the 1970s. (Stevens; Jackson; Milligan, 2009)

PALLIATIVE CARE IN BRAZIL

The increasing life expectancy in the population has generated a more optimistic attitude towards the cure of various diseases, moving away from discussions about death, unless linked to tragedies or unforeseen accidents. However, this perception may be undergoing changes, especially in the wake of the Covid-19 pandemic. Even before the pandemic, the Global Atlas of Palliative Care indicated that approximately 56.8 million people were in need of care related to life-threatening illnesses. (Soares *et al.*, 2021) (Connor; Gwyther, 2018)

According to the World Health Organization, Palliative Care (PC) is an approach that seeks to improve the quality of life of patients and their families in the face of life-threatening diseases. This approach includes the prevention and relief of suffering, early identification and impeccable treatment of pain and other physical, psychosocial and spiritual aspects. The fundamental principles of PC encompass symptom relief, affirmation of life, consideration of death as a natural process, integration of psychological and spiritual aspects, active patient support, assistance to family members, and a multidisciplinary approach (WHO, 2014) (Carvalho; Parsons, 2012).

The term "palliative", derived from "pallium" (cloak in Latin), relates to the protection of the patient, respect for their dignity and autonomy, and solicitous accompaniment during the dying process. Palliative Care involves comprehensiveness in the treatment of patients and their families, considering several dimensions and specificities. In the Brazilian context, Palliative Care must be aligned with the constitutional principles of national health policies, such as universality, equality/equity, comprehensiveness, decentralization, prevention, and community participation. (Grant; Back; Dettmar, 2021) (Mendes; Valencia; Santos, 2018)

In Brazil, the discussion on Palliative Care began in isolation in the 70s, but only in the 90s was it implemented in a more organized way, with Professor Marco Túlio de Assis Figueiredo



leading the creation of the first courses focused on Palliative Care at the Federal University of São Paulo. However, this practice is not yet fully consolidated, facing organizational and implementation challenges at the three levels of health complexity. To overcome these obstacles, policies have been implemented to structure and organize palliative care strategies in Brazil (Boaventura *et al.*, 2019; Mendes, Vasconcelos and Santos, 2018).

PUBLIC HEALTH POLICIES

Public Policies are decisions that address issues of public order and seek to meet collective interests. They represent structured strategies through a complex decision-making process, impacting reality. These policies materialize government action and can have distributive, redistributive, or regulatory functions, triggering ongoing debates on the modernization of the State. (Giovanni; Nogueira, 2015)

The study of Public Policies is influenced by values and ideals that guide the relationship between State and Society. This study comprises four main stages: formulation, implementation, monitoring and evaluation. The implementation of policies is an essential prerequisite for the administrative activity of the State, representing not only a recommendation, but also a legal requirement. Responsibility for this implementation rests with formal authority and has been increasingly shared through various mechanisms involving the participation of civil society. (Giovanni; Nogueira, 2015) (Alves; De Mendonça Cruz, 2022)

HISTORY OF PUBLIC HEALTH POLICIES IN BRAZIL

The right to health is considered a fundamental principle of the human being, and this right is described in the Federal Constitution of Brazil, in addition, it is a human right that is contained in article 25 of the Universal Declaration of Human Rights. Public policies deal with the set of programs and activities developed by the government, whose actions are carried out with public assets. The first health policies in Brazil were elaborated in the 16th century with the arrival of the royal family of Portugal and their implementation faced obstacles due to the lack of medical professionals for (Brazil, 1988; Sathler; Ferreira, 2022) structured care. (Honorato *et al.*, 2019)

The first public health policies in Brazil were developed in the 16th century with the arrival of the royal family from Portugal to the country. The implementation of these policies faced obstacles and due to the lack of medical professionals for structured care, there was a proliferation of the so-called "Apothecaries" in the country, the name given to the professionals who handled medicines and other products for therapeutic purposes sold in apothecaries in the colonial period of Brazil. (Honorato *et al.*, 2019)



In a broad contextualization, in 1892, the first bacteriological laboratories were created to improve sanitary conditions in urban cities, which at the time were very precarious. Then, in the first decades of the 20th century, the charity funds appeared, which were a kind of collective savings for workers who served as insurance for their families, but it was only for those who contributed this aid. (Boschetti; Behring, 2006)

In 1953 the Ministry of Health (MS) was created and in 1956 the National Department of Rural Endemic Diseases (DNERU) was created, with the aim of promoting health education for the rural population. In order to provide a greater stimulus for the population to be inserted in the labor market, in 1966, the National Institute of Social Security (INPS) was created, but there was a neglect of those who did not have some type of contribution. (Leite, 1981) (Mota, 2007)

Brazilian society was marked by numerous conflicts, and in the 1980s the health movement was initiated, represented by a collective of health professionals with the support of political parties opposed to the State that proposed the universalization of access in a conception of health as a social right and duty of the State. It was only in 1988 that this right was recognized as a responsibility of the State, through the Federal Constitution, which takes upon itself the duty of universalizing health, representing a milestone for the development of public health policies in the country. (Sarreta, 2009) (Honorato *et al.*, 2019)

Health was integrated into social protection policies, becoming part of Social Security to guarantee rights related to social security, health and social assistance. This establishes that health is a right of all and a responsibility of the State. The Unified Health System (SUS) was created, introducing a new approach to the prevention, protection and recovery of health. Its guidelines include control, decentralization, hierarchization, regionalization, and territorialization. In the principles and guidelines of the SUS, everyone's right to health is highlighted, and it is the responsibility of the State to guarantee this right to Brazilians. The principle of social justice ensures equal opportunities for the use of available resources while meeting the needs of the population (Lucchese, 2004). (Marques, 2008; Souza; Costa, 2012).

The SUS faces challenges in becoming a constitutional system due to the influence of neoliberal policy. Neoliberal hegemony is blamed for the scrapping of health, reflected in negligence in care, lack of funding, inefficient supervision and lack of structure. The current challenge is to preserve universality and promote comprehensive health care. (Honorato *et al.*, 2019)

In the context of Palliative Care, the Brazilian Association of Palliative Care was founded in 1997, and exclusive buildings were established to offer such care in institutions such as the National Cancer Institute. Specific programs have been implemented in hospitals such as the São Paulo State Public Servant's Hospital since 2000, incorporating volunteers from different religions. The Special Care Hostel was inaugurated in 2004 at the Hospital do Servidor Público Municipal de São Paulo.



(Cruz; Andrade; Andrade, 2021; Da Silva; Silveira, 2015; Ferrai *et al.*, 2008; Maciel, 2006; Paim, 2020)

HUMANIZATION OF PUBLIC HEALTH CARE AND HUMAN RIGHTS

The right to health is guaranteed by law, as described in Ordinance No. 1,820, of August 13, 2009, which provides for the rights and duties of health users. This conception of health, understood as a human right, was deliberated at the 8th National Health Conference, in 1986, and obtained legitimacy in the Federal Constitution of 1988, in article 196 (Santos; Kuhn, 2021)

The Charter of Rights and Duties of the Health User (2018) brings as its first guideline that every person has the guarantee of health promotion, prevention, protection, treatment and recovery. In the second guideline, it refers to comprehensive health care, in an ethical and humanized way. In the third, it points out the right to inclusive, humanized and welcoming care, performed by qualified professionals, in a clean, comfortable and accessible environment. The fourth guideline states that every person should have their values, culture and rights respected in relation to health services. (Brasil, 2018)

The concept of humanization was established at first, based on two health programs in the Brazilian public sector, the Program for the Humanization of Hospital Care (PNHAH), created through Ordinance No. 881, of June 19, 2001, and the Program for Humanization in Prenatal Care and Birth (PHPN), created through Ordinance No. 569/GM, on June 1, 2000. However, both were limited to the hospital area. It was only in 2003 that the Ministry of Health created the National Humanization Policy (PNH) based on the revision of the PNHAH, expanding the proposal of humanization beyond hospitals to include the entire SUS network and established a policy focused on work processes and health management. Almeida *et al.* 2019)

Ferreira and Artman (2018) assert that the Humanization Policy reaffirms the need to invest in the quality of care, considering respect for the user and dignity of the health worker, as indicated in the triple inclusion: users, workers, and managers. Such thinking reinforces that the NHP implies a change in the work processes, meeting the needs and better satisfaction of the subjects involved in the production of health, whether they are managers, workers or users Almeida *et al.*, 2019).

Psychological, family and spiritual aspects emerge as fundamental elements in the provision of humanized care in Palliative Care. In this context, it is imperative that the patient does not experience the feeling of abandonment and reaches a level of acceptance in relation to the life lived, facing death as a natural process. Family connection also plays a crucial role in this process, as the designated family member maintains a pre-existing emotional bond with the patient. In addition, numerous studies corroborate that the patient's spirituality not only provides greater control over stress and greater resistance to pain, but also contributes to the achievement of inner peace. These



pillars provide welcoming to the patient and an efficiently humanized care (Freitas, 2020) (Abdullah; Hussein; Barla, 2019). (Freitas, 2020) .

CHALLENGES AND POTENTIALITIES OF HEALTH MONITORING IN THE 2030 AGENDA IN BRAZIL

The 2030 Agenda has emerged as one of the great global proposals for commitment and accountability with current and future society and represents the maturation of several actions that have been developed over the last decades by institutions around the world, especially by the United Nations (UN). Ratified in September 2015, the 2030 Agenda established a set of 17 Sustainable Development Goals (SDGs) and 169 targets (Cabral; Gehre, 2020; Martins *et al.* , 2022).

This Agenda also reinforces the commitment to the development of all nations and peoples, as well as in all segments of society, differing from other international agreements due to the thematic breadth of the commitments and the recognition of the integrality of their objectives, with the interdependence of the economic, social and environmental dimensions for sustainable development (Elder; Bengtson; Akenji, 2016; Martins *et al.* , 2022).

The official SDG indicators are considered an important instrument to ensure the implementation of the targets, however, several challenges need to be overcome for this instrument to reach its full potential. Already in its conception, a series of political disputes in the construction and definition of the indicators were observed. In addition, the scarcity of official data is pointed out by the technical and financial insufficiency of the monitoring capacity (Martins *et al.* , 2022).

Health is mainly represented by SDG 3, which proposes to "ensure healthy lives and promote well-being at all ages", based on 13 targets and 28 unique indicators. In addition to SDG 3, the 2030 Agenda aims to address health from the concept of Social Determinants of Health (SDH), covering a much larger set of objectives, targets and indicators of the Agenda (Cabral; Gehre, 2020).

The 2030 Agenda, updated in 2016, emphasizes the importance of upskilling in the context of integration initiatives, aimed at promoting physical and mental health, as well as general well-being. Its purpose is to increase quality life expectancy for the entire population, with emphasis on the aspiration to achieve universal health coverage and ensure access to high-quality health care. The central principle of the 2030 Agenda is that no individual should be excluded from these benefits. In line with the ideals of this agenda, it is imperative to accelerate the progress already made in reducing neonatal, infant and maternal mortality. The goal is to eliminate all preventable deaths by the year 2030, providing a significant improvement in the quality of life for all those who seek to achieve it. (Martins *et al.* , 2022)

In this way, the importance of the quality of care aimed at humanization is connoted, based on the 2030 Agenda, reflecting concepts experienced by humanity and the need for work aimed at health



promotion, prevention and education, so that the patient in palliative care can review moments of recovery and control of undesirable symptoms. seeking quality in the act of humanized care, with human rights, and sensitizing its patients to a sustainable lifestyle, peace and non-violence, and global citizenship (Cabral; Gehre, 2020).

IMPLEMENTATION OF PALLIATIVE CARE IN PUBLIC HEALTH POLICIES IN BRAZIL

Palliative Care incorporates the concept of adopting conventional life-sustaining measures (proportional means of health care) and, at the same time, makes it possible to prioritize what is ethically and medically justifiable, to the detriment of what is merely medically possible. This approach does not imply abandoning the patient, but rather aims to provide comfort from the moment of diagnosis of a life-threatening condition to the terminal outcome, with the patient and the quality of their end of life being the sole and exclusive priority (Schaefer, 2020).

Due to the demographic transition caused by the aging of the population and the epidemiological change in the causes of mortality in recent times, the Tripartite Interagency Commission of the Ministry of Health approved Resolution MS No. 41/2018, providing for the guidelines for the organization of palliative care within the SUS at all levels of health care (art. 5). It is worth noting that the SUS already has guidelines that superficially address Palliative Care, but not yet as a public health policy, with important guidelines and values (Sidom; Zabol, 2015; Schaefer, 2020).

Historically, health systems have organized themselves to meet the curative dimension of medicine, or only during the illness process as a unique curative vision and goals. However, with demographic and epidemiological changes, the palliative dimension comes in by allocating care throughout the course of the disease, whether in its chronic or acute process, with a focus on symptom control and prioritizing the autonomy of patients and their families (article 2, sole paragraph, MS Resolution No. 41/2018), which also includes their social protection (Schaefer, 2020).

The attitudes and competencies needed to promote high-quality PC [palliative care] overlap with those needed for excellent PHC [primary health care]: communication skills; understanding of the reality and peculiarities of the patient's way of life; commitment to comprehensive and integrated patient and family care; attention to psychosocial and spiritual issues; emphasis on the patient's quality of life and independence; respect for the patient's values, goals and priorities in the management of their health condition; provision of care in the community, due to cultural diversity; Collaboration with other professionals, including experts (Castilho; Silva; Pinto, 2021)

Even before MS Resolution No. 41/2018, the humanization of health was already a transversal policy of all integrating instances of the SUS, which value aspects of the subjective, collective, and social dimension of care and management of the public system (Schaefer, 2020).



Of the fundamentals for the insertion of palliative care in the SUS, the following stand out:

- (i) CFM Resolution No. 1,805/2006, which provides for orthothanasia;
- (ii) SAS/MS Ordinance No. 1,083/2012, which provides for the clinical protocol and therapeutic guidelines for chronic pain;
- (iii) CFM Resolution No. 1995/2012, which provides for the use of advance directives of (health) will;
- (iv) The recommendation of the 67th Assembly of the World Health Organization (2014) for the development, strengthening and implementation of evidence-based palliative care policies.
- (v) CFM Resolution No. 2,156/2016, which establishes the criteria for admission and discharge from the intensive care unit;
- (vi) Ordinance GM/MS No. 2/2017, annex IX, which establishes the National Policy for the Prevention and Control of Cancer in the Health Care Network for People with Chronic Diseases within the scope of the SUS; Annex X, which establishes the National Policy for Comprehensive Child Health Care within the scope of the SUS; Annex XI, which establishes the National Health Policy for the Elderly; Annex XII, which approves the National Primary Care Policy of the SUS; Annex XXIV, which establishes the guidelines for the organization of the hospital component in the Health Care Network; Annex XXV, which approves the National Policy on Integrative and Complementary Practices of the SUS; and Annex XXVIII, which provides for the financing and execution of the Basic Component of Pharmaceutical Services within the scope of the SUS;
- (vii) The Consolidation Ordinance GM/MS No. 3/2017, which establishes the organization of long-term care to support the Urgency and Emergency Care Network and other Thematic Health Care Networks of the SUS;
- (viii) The Consolidation Ordinance GM/MS No. 5/2017, GM/MS, which deals with home care and hospitalization;
- (ix) The Consolidation Ordinance GM/MS No. 6/2017, which deals with the financing of the basic and specialized component of pharmaceutical services;

It is necessary to make it mandatory for palliative care to be understood as a guarantee of rights already provided for in the Policy for the Humanization of Care and Management, in the National Humanization Policy (PNH) of the SUS and in the National Program for Pain Assistance and Palliative Care, treated not only as national programs, but also as part of the Brazilian health policy. (Brasil, 2009), (Ministry of Health (MoH), 2013) (Brasil, 2002),

Therefore, the care model implies the need to review the spaces, the organization of management and technologies, the multiprofessional relationships, the training and qualification of



the professionals who will work in palliative care, the communication models and the organization of health actions itself, shifting the axis of health recovery to the care and comfort of the patient. guidelines clearly established by MS Resolution No. 41/2018 (Schaefer, 2020).

Through this, it is possible to recognize palliative care as an important field of health care throughout the SUS care network, determining its planning and integration into public systems with specific sectoral policies. The effectiveness of this care at all levels of health care in the Brazilian Unified Health System and the guidelines established in MS Resolution No. 41/2018 should be a priority at a time when the technization of medicine resumes the concern with diseases rather than with the patient himself, his autonomy and his dignity (Castilho; Silva; Pinto, 2021; French *et al.*, 2022; Schaefer, 2020).



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