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# Palliative Care Network in Brazil

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## Abstract

Brazil is a country with great diversity and distinct realities, so there is a proportional challenge and complexity in offering a unified and integrated system which is accessible, of quality, and effective. Population aging and the increased incidence of chronic-degenerative noncommunicable diseases (NCDs) increase the need for palliative care (PC); however, public policies still need to be implemented so that this care encompasses adequate funding, professional training, and guaranteed medication. The first national policy for PC was recently proposed, providing guidelines for the organization of PC, emphasizing the importance of integration between the different levels of care and services in the Brazilian health system (SUS). Nevertheless, the challenges of this policy include the training of professionals, communication in the network, the absence of integrated health information systems, and effective mechanisms to finance this new modality of care.

**Keywords:** palliative care, health services, primary healthcare, health policy, community integration

## 1. Introduction

Populations have specific health preferences and needs, with characteristics manifested in demographic and epidemiological analyses. Health systems are organized according to each demand of this process [1].

Demographic data show that Brazilian population, mostly composed of young people, is changing. Life expectancy is simultaneously growing with the number of elderly people, while the number of births is decreasing [2].

Population aging results in a greater demand for health services and palliative care (PC). Chronic conditions, strongly related to this process, require special attention, and the reorganization of the system aimed at health promotion and healthy living habits is part of this new reality [3].

Currently, the Brazilian care model is fragmented, and there is an imbalance between preventive and curative actions, with predominance of medical care and focus on acute conditions [4].

The challenge and the complexity of providing a unified and integrated system which is accessible, of quality, and effective are proportional to the size of a country with great diversities and distinct realities [5].

All this complexity includes social plurality, more than one level of multidisciplinary and multiprofessional care, which receives resources from various sources and presents structural and technological inequality [4].

The organization of health has isolated levels that do not communicate with each other. Primary healthcare (PHC) is not related to secondary care, and none of them are related to tertiary care [1]. Thus, the lack of communication between healthcare levels prevents comprehensive care [6].

Comprehensiveness is part of the guidelines of the Unified Health System (SUS). It is a guiding concept of care that aims at treating each individual with respect, in his/her totality, valuing his/her needs and characteristics [7].

The healthcare networks (HCN) emerge within this context, mainly to interconnect the care levels and to integrate care itself [4].

The concept of HCN proposes a polyarchy, i.e., democratic, person-centered structure where health services communicate at all levels, and no level is more or less important than the other. It allows comprehensive care with promotional, preventive, curative, caregiving, rehabilitative, and palliative interventions. Thus, it offers a humanized and quality service to the population [8].

The Administrative Rule 4279, of December 30, 2010, regulates HCNs. It establishes guidelines for the organization of HCNs within the scope of the SUS. The networking system was necessary for a better health policy, a new structure based on the covenants for health, life, and in defense of the SUS, which assume responsibility for the regionalization and the health situation of Brazil and for strengthening the policy, principles, and guidelines of the SUS. PHC is the major coordinator of care, the gateway and communication center between users and health professionals. It distributes and redistributes assistance for all levels of healthcare horizontally, according to the needs. This explains the concept of networks [5].

The basic elements for the development of networks are well-defined population, based on registers performed on primary care level; operational structure, i.e., the relationship between the three different care levels of the network; care models, which are characterized in acute conditions that need technologies and also depend on the physiological response of each individual/community; and models of chronic conditions, in which promotion, prevention, rehabilitation, and palliative care actions take place [9].

Structurally, the health network presents the following aspects: management to articulate PHC activities with the other levels, support systems, pharmaceutical assistance, health information systems, logistic systems, user identification, clinical records, systems of regulated access to care, and transport systems, as well as a communication center that coordinates flow and counterflow in the care system [3].

The network system is quite innovative when compared to the fragmented one currently disseminated; however, obstacles are expected in new deployments, both due to the simple fact of the change and due to old unresolved problems in health. It is necessary to know the needs of the population to establish a fluid and organized flow of work. This adaptation allows healthcare levels not to be isolated and provides for the movement of people through the network. However, the reality is somewhat different, as the operation is complex, bureaucratic, and disjointed, often compromising the speed of service and its potential for problem-solving [4].

The care level that is closest to people's lives is the primary care, playing a vital role within the system. On the other hand, primary care has not been adequately qualified. Moreover, the difficulty to access the secondary level, specialized consultations, and diagnostic and therapeutic support services also demonstrates the fragility of the HCN [6].

Structural and bureaucratic issues are factors that hinder the comprehensiveness of care, as well as the passivity in the actions of the PHC [9].

Health professionals, as the key elements of the care system, experience all these complex obstacles in daily basis. They do not recognize the role they play within the network and are still attached to bureaucratic and inflexible routines [4].

Another study on the knowledge of professionals about this subject points out their lack of information regarding the healthcare levels available and their articulation [9].

Currently, the aforementioned population aging and the increased incidence in chronic-degenerative noncommunicable diseases have increased the need for palliative care. However, it is still necessary to implement public policies for the adequate financing of care, training of professionals, and provision of medications [10].

This chapter aims to present the political perspectives for the organization of a HCN for palliative care in Brazil.

## **2. Political perspectives of palliative care in the healthcare network**

The term “palliative” comes from the Latin term *pallium*, whose definition is “blanket,” “cover.” It was used to describe the robes offered to the pilgrims when they left the hospices. The purpose of this clothing was protecting them from the weather during the trips. At present, the word “palliative,” besides encompassing the notion of embracement and protection, contemplates the valuation of care to the human being based on a holistic approach [11].

Population aging causes the expansion of chronic-degenerative and incapacitating diseases, a fact that interferes in public health and in the capacity of provision of care by families and institutions [12].

Thus, PC in the twenty-first century basically consists in a skill that health professionals develop to care for the suffering of patients and their families facing life-threatening health situations [13].

Statistics released in 2012 by the Worldwide Palliative Care Alliance indicate that about 18 million people died on the planet suffering irrelevant pain due to inappropriate access to pain treatment. In Brazil, PC was introduced in the 1980s, and palliative medicine became a recognized medical area in 2011. Quality of life and symptom relief are crucial in this context [14].

However, in Brazil, the practice of PC has been evolving since the late 1990s. Official information from the National Academy of Palliative Care (NAPC) published in 2006 pointed out about 40 influential teams and 300 hospital beds assigned for such care [15].

Although primary care is the lowest cost strategy and has full impact on public health, the provision of PC in Brazil is still hospital-centered [13].

In view of this deficiency of care measures in primary care, it is necessary to raise the population’s awareness. However, this awareness will only happen through the expansion of knowledge about PC, clarifying the history, implementation, functionality, and applicability of PC.

The origin of the philosophy of PC is linked to the emergence of hospices (guest-houses). Hospices originated in the Middle Ages, and their outbreak influenced the pilgrimages of Christians to the holy places, due to the long distances traveled for months and even years [16].

The first hospice that demonstrated a holistic view of the human person was the St. Christopher’s Hospice, in London. It was created in the 1960s, in the twentieth century, by a nurse, physician, and social worker called Cicely Saunders. Saunders’s concern was to provide humanized care through pain relief and symptom control [16].



In 1990, the World Health Organization (WHO) established a definition for PC, which encompasses care measures and treatments aimed at pain relief in order to promote a better quality of life for terminally ill patients and their families. However, this definition initially applied only to cancer patients [15].

The Oncology Therapeutic Support Center was inaugurated in 1998. This was a hospital sector exclusively dedicated to PC. This is the first of a series of internal restructuring actions in the institute with the purpose of making the practice of cancerology more focused on the weighted provision of services to the population [17].

Thus, historically, the concept of PC was initially linked to cancer patients [18], but it was subsequently extended, although insufficiently, for patients in later stages of other chronic diseases that had similar needs [19, 20].

The history of PC is relatively contemporary in Brazil, the course of this discussion contributed to health professionals' understanding about the philosophy given to patients without prognosis of cure, thus promoting the process of care and valuation of the human being [21].

In order to implement palliative care for patients with pain, the Ministry of Health established the National Program for Pain Relief and Palliative Care within the SUS in 2002, through the Administrative Rule MS/GM no. 198 [10].

The Administrative Rule MS/GM no. 198 was revoked by the Administrative Rule MS/GM no. 3.150/2006, which established the Technical Council for Pain Control and Palliative Care, and this council began to be responsible for national guidelines on pain control and PC, for the organization of care networks in this context, and for training and qualifying professionals to address pain control. Policies directed to PC are of paramount importance for a quality care, ruled under the law [10].

The Brazilian Council of Medicine (CFM, in Portuguese), the body that regulates and supervises medical practice, has published different resolutions directly related to this topic and that will certainly promote important reflections and advances in this area. Four of these resolutions are worth mentioning, namely, resolution on the legitimacy of orthothanasia (CFM Resolution 1.805/06); resolution on the new Code of Medical Ethics, where PC is directly mentioned (CFM Resolution 1931/09); rule that defines palliative medicine as an area of action (CFM Resolution 1973/12); and CFM Resolution 1995/12, on advance directives [15].

The lack of a public policy on PC in Brazil is no longer a fateful reality because a resolution was approved (Resolution no. 41, October 31, 2018) with guidelines for the organization of PC in the light of continued care in the SUS, the Tripartite Interagency Committee, in the use of the attributions granted by item II of Art. 14-A of Law no. 8080, of September 19, 1990, and the provisions of item I of Art. 32 of Decree 7.508, of June 28, 2011, in accordance with item II of the sole paragraph of Art. 87 of the Brazilian Constitution [22, 23].

It is estimated that PC is needed in about 40–60% of all deaths worldwide. However, in 2014, it was estimated that only 14% of the patients who needed these care received it, and 78% of these people lived in low- and middle-income countries [24].

According to the Worldwide Palliative Care Alliance, even if more than 100 million people would benefit annually from PC (including family members and caregivers), less than 8% of those who need this type of care would have their access guaranteed. In our reality, training in PC is rarely included in the educational curriculum of health professionals. In addition, the availability of pain drugs—the most basic topic when it comes to minimizing patient suffering—is woefully inadequate in most parts of the world, often because of concerns about its illicit use and drug trafficking [15].

In Brazil, it is estimated that between 521,000 and 536,000 people need PC, but this type of care tends to be indicated only in the end-of-life phase, restricting the performance of specialized teams in this area [25]. The WHO proposes the early initiation of PC and that this care walks together to curative treatment, seeking a better understanding of the actions, control of symptoms, and quality of life of the patients [26].

Providing PC since the beginning of the curative treatment makes it possible for the patients and their families to contact with the health team. As the chronic progressive disease evolves and the curative treatment loses effectiveness in controlling or modifying it, PC becomes more necessary and even exclusive because of the scenario of incurability. This management ensures the construction of a bond of trust between the patient-family-team triad, facilitating and contributing to the articulation and development of strategic plans of comprehensive and continuous assistance [27].

The *Economist* magazine evaluated the quality of death in 80 countries through the possibility of access to opioids, the existence of public policies focused on PC, and access to PC in health services. Brazil ranked 42nd, behind Chile, Costa Rica, Panama, Argentina, Uruguay, South Africa, Uganda, Mongolia, or Malaysia. Thus, in Brazil, many patients with severe diseases experience uncontrolled pain and do not receive palliative care [13].

PC is complex care dealing with physical, psychosocial, and spiritual problems at the end of life [28]. When faced with a life-threatening illness, most would rather die at home [29].

Available data indicate that most people around the world prefer to spend the last phase of their lives at home. To respect this preference and avoid or minimize overcrowding in hospitals, PC is necessary in PHC and home care. PHC physicians with basic PC training, availability of correct medications, and simple, safe, effective, and inexpensive equipment can effectively respond to the needs of these patients during home-based PC. The implementation of PC integrated into PHC can be of high quality and low cost for health systems and reduce dependence on outpatient and inpatient hospital services [24].

Given this context, the Brazilian SUS has perceived the need to improve health services to meet the PC and, therefore, has encouraged further studies that seek to broaden the qualification of healthcare professionals and to ensure continued care. Despite these efforts, the offer of PC is still hospital-centered, and yet only 10% of these institutions have a specific team for PC [13].

The inclusion of PC in PHC implies the execution of actions planned for this level of care and the coordination of care to users, respecting the WHO's precepts and guaranteeing comprehensiveness through the organization of HCNs. In this perspective, PHC is the best level of care for the provision and coordination of PC, since it has the potential to develop actions that favor quality of life and continuity of care, both inside and outside the home. Furthermore, care is provided close to the patient's families, avoiding unnecessary hospitalizations and decreasing the risk for infections [30].

Patients eligible for PC may need care with distinct complexities, which requires integration between the levels of care. Thus, early identification of patients eligible for PC has benefits, as aggressive diagnostic and therapeutic interventions are avoided, and unnecessary suffering and costs are reduced [31, 32].

Therefore, it is necessary to articulate the different components of the health system, creating a mechanism of reference and counter-reference for cases of clinical intercurrent [25].

According to the WHO [24], the implementation of a home-based PC service involves eight necessary steps:

1. Evaluation of patient needs and available resources
2. Establishment of formalization of the organization through reference terms and registration with authorities
3. Creation of a plan of action (which resources will be needed, how they can be obtained, target audience and services that will be covered)
4. Recruitment and development of an ongoing training program
5. Mobilization of resources
6. Integration within the health system, associating PC with the primary and tertiary care of the operator
7. Dissemination of the service
8. Encouragement of the participation of associations, groups, and students

In Brazil, PHC was implemented in 2006 through the Family Health Strategy, based on the ordinance of the Cabinet of the Minister/Ministry of Health No. 648, of March 28, 2006. Through this ordinance, home-based care becomes one of the tasks of PHC teams, especially FHS teams, which since their regulation have among their attributions the realization of care actions in the basic health unit, at the home of patients, and in the community [33].

However, on May 27, 2013, the Administrative Rule CM/MS no. 963 redefined home-based care within the scope of the SUS by reorganizing the work process of teams that provide home-based care in primary, outpatient, emergency, and hospital services, with a view to reducing the demand for hospital care and/or the length of hospitalization, promoting humanization of care, deinstitutionalization, and increase of autonomy of users [34].

This ordinance also presents the role of PHC in home-based PC, assigned as home-based care type 1 (HC1), with the goal of serving the population with the following characteristics: patients who have health problems controlled/compensated and with physical difficulty or impossibility of reaching a health unit and those requiring less complex care, with less frequency, and with less need for health resources [35].

This level of care (HC1) is integrated into two levels of home-based care (HC2 and HC3) carried out by home-based care multiprofessional teams (HCMT) intended for this purpose, upon the need of integration between levels. The role of the HCMT does not replace actions carried out at homes by PHC teams, especially the Family Health Strategy teams. On the contrary, by considering HC1 as the responsibility of these teams, the Ministry of Health recognizes that their work is a crucial axis, while the HCMT presents themselves as a complementary possibility, when the demands of the patients go beyond the solving capacity of PHC teams [33].

However, it is difficult to include PC in the context of PHC due to the lack of understanding of the professionals involved in this care and the difficulty of establishing an open and honest communication with the family. Moreover, providing training on PC seems not to be a priority for managers. In this line, there is a lack of subjects on the training of health professionals addressing this theme in the curricula, reinforcing that experience in PC comes with practice [30].

Therefore, the approach of PC in the HC area and also the recognition of HC as a space of great importance for the implementation of PC are pertinent.

The humanistic principles that guide PC are in line with those that guide HC, but the applicability of these principles in the context of HC in the public health system in Brazil is insufficient, valuing the curativist, technician, and biologic aspects of care [36].

In view of all the political context involving health in Brazil and based on the experiences of other countries in the elaboration and implementation of specific policies aimed at patients eligible for PC, through Resolution No. 41 of October 31, 2018, the Ministry of Health provided the guidelines for the organization of PC in the light of continuous integrated care within the SUS [24]:

Article 5 PC shall be offered at any point in the healthcare network, namely:

- I. Primary care: it is the network coordinator and care coordinator and will be responsible for following up users with life-threatening illnesses in its territory, with predominance of longitudinal care provided by primary care teams along with the expanded Family Health Center (NASF), with the support of the rest of the care network, whenever necessary.
- II. Home-based care: the home-based care teams, whose modality will be defined based on the intensity of care, observing the unique therapeutic plan, should contribute to preparing the patient's home to be the main *locus* of care in the end of life, whenever possible. It will be indicated for people who need PC in bedridden situation or restricted to home, whenever this is considered the most appropriate care offer.
- III. Ambulatory care: it should be structured to meet the PC demands from other levels of care of the network.
- IV. Emergency care: the services will provide care to relieve acute symptoms, focused on the comfort and dignity of the person, according to the best practices and available evidence.
- V. Hospital care: focused on the control of symptoms that cannot be controlled at another level of care.

In addition to the resolution presented by the Ministry of Health, there are other concerns, such as the elaboration of guidelines that guarantee the comprehensiveness and continuity of PC at all levels of care within the HCN with appropriate communication and commitment of the parties involved. It is necessary to establish means of accreditation for other services that need to integrate the network in a complementary manner because, according to studies, the growth of PC units or groups throughout Brazil is still very incipient. Providing technical and higher levels of training for teams is also an important item for consolidating the humanization of this care and raising awareness among professionals [37]. Studying the experiences of other countries is essential for the elaboration of proposals and optimization of resources.

Another important aspect to be mentioned is the need to broaden the articulation between the various health information systems with a view to subsidizing the evaluation of actions developed and decision-making. The broadening of communication between health systems favors the improvement of the quality of services and of management [38].

Prior to the implementation of the National Palliative Care Policy, isolated actions were carried out through initiatives of sectors within the health services concerned with the implementation of strategies for pain relief, which clearly shows



the scarcity of resources invested in PC. The implementation of PC is a challenge that requires commitment and investment from the government [39].

Therefore, the publication of this resolution is only the beginning of the path for regulation of PC in Brazil. New objectives need to be drawn so that the implementation of PC becomes effective and adequate to the Brazilian reality, providing comprehensiveness to the assistance and PC in its essence.

### **3. Conclusion**

Brazil has public policies focused on HCN in different types of assistance, with PHC as the driver of the network. However, the discussion about the organization of PC is still recent and demands major challenges. The first national policy for PC was recently proposed in the country, providing guidelines for the organization of PC and highlighting the importance of integration between the different levels of care and services in SUS. However, there are challenges for this policy, such as the training of professionals, communication within the network, and the lack of integrated health information systems and of effective mechanisms for financing this new modality of care in the country.

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### **Conflict of interests**


We declare that there is no conflict of interests in the accomplishment of this research.

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