



## Palliative care in primary health care: Challenges for training in the Brazilian public system (Unified Health System - SUS)

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### Abstract

The improvement in biomedical and healthcare resources has led to an increased life expectancy in the Brazilian population. This aging, coupled with new lifestyle habits, has contributed to the occurrence of non-communicable chronic diseases - particularly cancers, often incurable - making palliative care (PC) emerge as the sole therapeutic recourse. PC involves an approach aimed at promoting the quality of life for patients and their families in the face of therapeutic non-resolvability and the inevitability of life continuation. Early case identification, comprehensive assessment, pain management, and addressing other psychosocial distress are fundamental elements of this practice. Furthermore, healthcare services need to organize themselves in response to this growing demand, with Primary Health Care being a fertile environment for providing this care. Besides allowing geographical, cultural, and emotional proximity of the patient to their loved ones, ensuring their final days with integrity and autonomy. Such care is still offered at other levels, based on the logic of Health Care Networks, comprehensiveness, humanization, referral and counter-referral. The challenge for the curricula of health education courses is to keep up with these changes, seeking to train professionals with a scientific and humanitarian basis consistent with this new clinical reality, whether in specific disciplines – teaching focuses on deepening the technical and human aspects; or through transversal teaching – discussing PC throughout the training, in any discipline. Thus, it is expected that professionals will provide care, offering comfort and tranquility to the patient and their families, collaborating in the humanization of the "ways of dying" in Brazil.

**Keywords:** Palliative Care; Primary Health Care; Professional Health Education; Humanization of Assistance

### 1. Introduction

The improvement in biomedical and healthcare resources has led to an increased life expectancy in the Brazilian population. This aging, coupled with new lifestyle habits, has contributed to the occurrence of non-communicable chronic diseases - particularly cancers, often incurable - making palliative care (PC) emerge as the sole therapeutic recourse.

PC involves an approach aimed at promoting the quality of life for patients and their families in the face of therapeutic non-resolvability and the inevitability of life continuation, acting through the prevention and treatment of pain and other psychosocial afflictions. The demand for PC is a current public health problem. Simultaneously, various support technologies have emerged, contributing to a higher quality of life and a life perspective for populations. Thus, the importance of PC is highlighted, as well as the need for the reorganization of the healthcare network and services to offer this therapeutic possibility [1].

It is worth noting that Palliative Care is not characterized by physical space but by the "(...) *care philosophy that materializes in the service provided wherever the patient may be*" [2:2004]. Thus, they can be developed in outpatient,

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hospital, and the patient's own home settings. In recent years, the focus has been on care within hospitals; however, studies indicate that an important location for this care to be carried out is in Primary Health Care (PHC), with the multi-professional teams of the Family Health Strategy (FHS) [1].

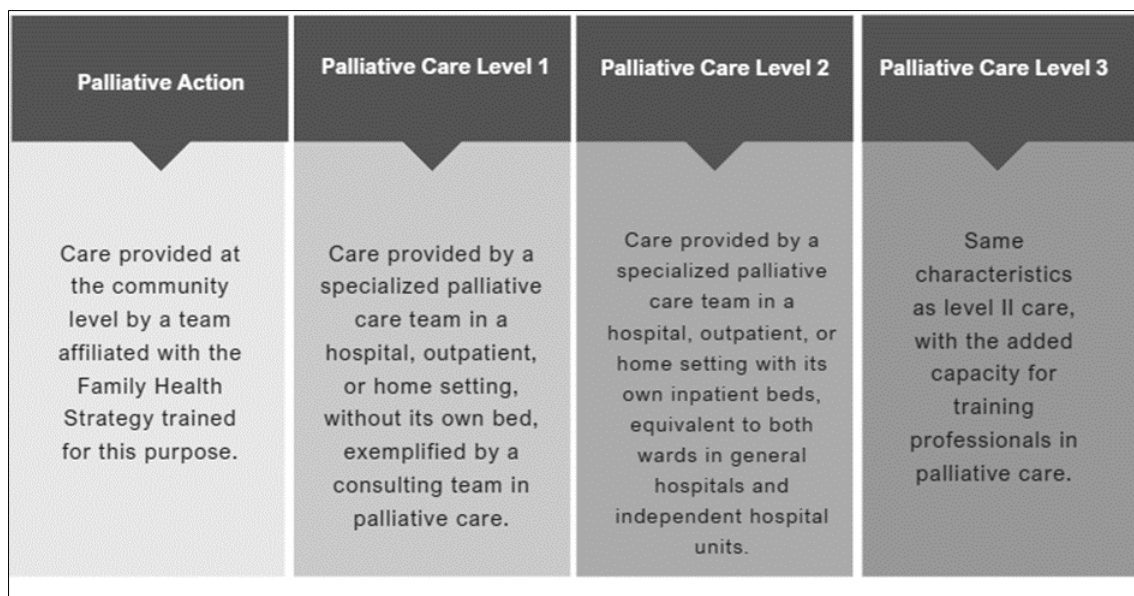
Therefore, this study aimed to discuss how palliative care develops in the context of PHC, highlighting the challenges for professional health education. This is a narrative review study, analyzing significant texts on the subject. For this purpose, articles, theses, dissertations, technical reports, books, and manuals available electronically were consulted. The texts were read in their entirety to extract ideas, discussing the findings of the authors.

## 2. Development

In several countries, such as Germany, the Netherlands, Canada, and England, PHC is considered the optimal territory for healthcare assistance and coordination of PC. This is because the geographic, cultural, and emotional proximity of these professionals is believed to contribute to the humanized provision of care, respecting the autonomy of patients and families. Additionally, in PHC, the patient's stay at home avoids their separation from the family in their final moments of life. Care in PHC also enables a comprehensive and humanized analysis of the individual, preventing the common fragmentation that occurs from the perspectives of multiple specialists usually involved in these cases [3].

PHC comprises a mode of care constituted by essential health care based on methods, practical technologies, and scientific evidence universally accessible to individuals, families, and communities through social control. This premise, originating from the Alma-Ata Declaration of 1978, proposed a new organization of health systems, focusing on the action of multidisciplinary teams at an individual and collective level, situated at the first level of attention in these systems [4-5].

Primary Health Care is also characterized by a space that values soft technologies, characterized by human relationships, and a comprehensive approach to the patient. The focus is on the encounter between individuals in the "professional-patient" relationship and in the care relationships between PHC professionals and the individual. This contact, through the use of soft technologies, allows the understanding of the complex dynamics that the patient undergoes, including psychological issues, the process of illness, the interaction with the disease, family elaborations, treatment management, and response to prognosis [6].



Source: Developed based on the National Academy of Palliative Care [7].

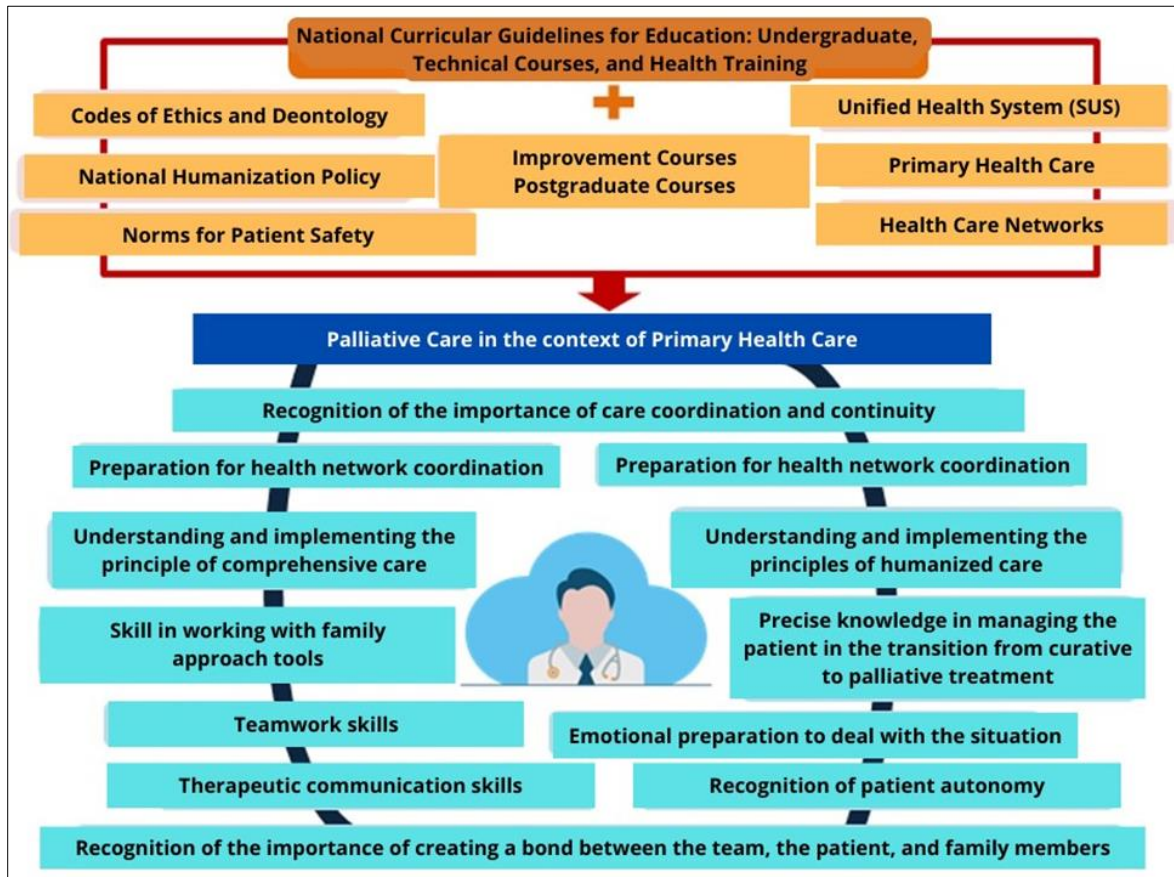
**Figure 1** Levels of attention in Palliative Care according to the National Academy of Palliative Care (ANCP)

It is important to emphasize that PC involves an interpersonal relationship between caregivers and those being cared for, depending on a multidisciplinary but integrative approach to produce harmonious assistance for the individual and their family. Thus, faced with the growing demand for Palliative Care, it becomes challenging to have enough specialists for this assistance. This specialty is considered in care and not in the hyper-specialization of health, understanding caregiving professionals, generalists, and family members who provide primary assistance to these patients [1].

The National Academy of Palliative Care (ANCP) defines four levels of attention in palliative care, as shown in Figure 1.

In the first two levels of Palliative Care, PHC plays a central role, receiving guidance from specialized services when necessary and coordinating care. In the remaining levels, care is predominantly provided by specialized services, but the continuity of assistance by PHC can ensure that family and psychosocial care is maintained longitudinally and that the socio-cultural characteristics of families and patients are respected [3].

The attention to PC in PHC should not be understood as home care of the "home hospitalization" type. Programs of this kind are organized to assist patients suffering from advanced chronic diseases with high dependence, in traditional interventionist ways. In the case of PC in PHC, on the contrary, it involves introducing a specific type of care that can be organized and offered at all referral levels without discontinuity [8-9].



Source: Authors' elaboration.

**Figure 2** Skills and competencies required for health professionals in Palliative Care in Primary Health Care and Efforts in education to ensure professional training

PHC professionals have the unique privilege of accompanying their users throughout their lives and in various situations and moments of life. Just as birth is part of the daily routine for these professionals, with the pregnancy-puerperal cycle considered a priority for FHS, the process of death is also part of it. Professionals accompany the aging and weakening of their patients, the efforts of families to accommodate the additional care needs of their members, fears, insecurities, and therapeutic possibilities. Therefore, they cannot evade this moment because it is precisely in such situations that the full potential of PHC/FHS actions becomes evident. No other health service can stand side by side with these families with such propriety and face the path of palliation with constant presence, guidance, and support [3].

Thus, the use of family approach instruments, often seen in PHC, such as genograms and ecomaps, facilitates the professional's understanding of the characteristics of the attended family, identifies relationship characteristics, anticipates possible difficulties, and can contribute to communication and mediation between family members and the patient. Considering illness as a factor of relationship tension, it can assist in planning a dignified death.<sup>3</sup>

The Expanded Family Health and Basic Care Centers (NASF-AB) contribute to maintaining cases of palliative care in PHC, given that the support of psychologists, nutritionists, speech therapists, social workers, physiotherapists, occupational therapists, geriatricians, and other professionals increases the resolution of the PHC team and significantly adds to the range of possibilities for interventions and guidance that can be offered at this level of health care. This occurs without exposing the patient to techniques and approaches that increase their state of clinical frailty [3].

However, there are still several obstacles to incorporating PC into PHC, especially regarding the inability of professionals to deal with families and patients, and the lack of technological resources for monitoring cases. It is important to emphasize that PC in PHC is not limited to technical aspects but includes ethical challenges such as the decision on where the patient will die, how the health team workers experience the experience of witnessing death and mourning, as well as the identification and management of family and patient conditions for this type of care at home. These situations experienced by professionals pose ethical challenges, especially regarding communication between the team, family, and patient, and the lack of emotional and institutional support for caregivers who are exposed to wear and tear and injuries resulting from the care burden [1].

The need for training, continuous education, and support for PHC professionals regarding PC involves reinforcing skills and competencies, as shown in Figure 2.

Therefore, it is necessary to develop skills and competencies (blue squares), emphasizing empathetic and therapeutic communication; preparation for the articulation of the health network; the principles of humanization and completeness of patient care in PC; emotional preparation to deal with the situation; patient management in the transition from curative to palliative treatment. In this way, the education of these professionals reverberates in the relationship and treatment of patients and families, favoring the bond and obtaining more adequate responses to the ethical and psychosocial challenges experienced by teams in the care of people whose continuity of life is threatened [1].

Although home care can be one way to intervene in the needs of the population in Palliative Care, it is essential to ensure that this care prioritizes user protection; caregiver care; and adequate support for the professional team. Thus, the articulation between levels of care - that is, between Health Care Networks (HCN) - and intersectoral network articulation is fundamental to ensure this prepared care and attention [10].

It can be stated that, considering the path taken by patients at the end of life and their families, quality performance in Primary Health Care is more important than ever. Facilitated and guaranteed access near home; management of constant symptoms; and sensitivity and respect for the realities experienced in communities may not change the clinical outcome (death), but certainly, palliative care makes all the difference for patients and their families in this stage of the end of life [3, 11].

Therefore, it is important to bring to the discussion the authors Mello, Fontanella, and Demarzo [2009], who highlight that work in PHC or Basic Care, although it has an image of apparent simplicity, is, in reality, complex, characterizing itself as a fundamental and essential territory for health: "(...) *at the same time that some understand 'basic' coming from the base, fundamental, and not from basic, simple; others interpret 'primary' as first, principal, and not as elementary or rudimentary*" [12:205].

Adding and concluding, authors discuss:

In this breadth of Primary Care, the Family Health team faces the needs of people in the process of death, which are not specific to the moment of life - proximity to death; but also, or mainly, related to the context of life. As the intervention in the health-disease process goes beyond the competence of the health professional, as it depends on access to determinants and conditioning factors of health, the needs of people in the process of death can be better met if intersectoral efforts are made. Considering the principles of the SUS, Primary Care, and the National Humanization Policy, the systematization of guidelines and actions for implementing Palliative Care in Primary Care is considered essential due to the existing demand for Family Health; the epidemiological dimension of the population in the country; the possibility of providing better care conditions to the patient and their family in the home environment; and, mainly, because care in the process of death is characterized by care in and for life [12:440].

## 2.1. Final Considerations

Health education in undergraduate, specialization, and postgraduate courses must keep pace with these changes, seeking to train professionals with biotechnological and humanitarian foundations consistent with a new clinical reality

and a growing discussion about care and humanization. Thus, for the strengthening of the subject, PC should be included in health education curricula, either in specific disciplines, where teaching focuses on deepening technical and human aspects, or through cross-cutting teaching, where PC can be discussed throughout the training, in any discipline. This inclusion can be considered fundamental for the consolidation of PC in Brazil. National Curriculum Guidelines for Education should be reconsidered to include these contents not only in health undergraduate programs but also in the training of technicians and other professionals who make up health teams. Besides this, concepts and principles of the Unified Health System (SUS), Primary Health Care, Health Care Networks, Codes of Ethics and Deontology, Patient Safety Legislation, and the National Humanization Policy (PNH) must be always integrated.

One of the basic principles of SUS is the comprehensiveness of care, which means considering the entirety of the individual, services, and care – which should necessarily include end-of-life care. Similarly, and in line with SUS, Primary Health Care is guided by the principles of "care coordination, bond and continuity, comprehensiveness, accountability, humanization, equity, and social participation." Moreover, as a legal framework, the National Humanization Policy advocates for identifying social health needs. Therefore, the application of these principles and definitions requires the incorporation of Palliative Care into the context of Primary Health Care.

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### 3. Conclusion

It is believed that a fundamental point for the consolidation of palliative care in Brazil is education. This enables not only the training of specialized PC professionals but also other professionals, teams, and agents who, in the face of a patient with an advanced and terminal illness, are prepared to provide care that offers comfort and tranquility to the patient and their family, contributing to the humanization of "ways of dying" in Brazil and in countries with public health systems.

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