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# Bioethics and Palliative Care in Primary Health Care

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## Abstract

In order to respect the patient's right to die at home, with quality and respect, discussions about bioethical problems involving palliative care in the context of primary health care are relevant. Among bioethical problems, communication problems regarding the diagnosis and treatment, the maintenance or discontinuation of futile treatments, the adoption of aggressive and lifelong measures by the emergency mobile service, and the problems involving equal access to care stand out. It is important to emphasize that health systems must incorporate palliative measures in primary care and enable professionals to provide this type of care.

**Keywords:** palliative care, bioethics, primary health care, health personnel, health systems

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## 1. Introduction

The preferred place to die among people throughout the world is their home; however, many still die in hospitals, with at least one admission in the last year of life [1–3].

Thus, it is essential that palliative care (PC) be seen as a responsibility of all health professionals, not only of those in the secondary and tertiary level of care but also in primary health care (PHC) [1].

However, several bioethical problems still persist when it comes to respecting this right of patients. These problems must be debated in order to seek the benefit of patients and their families, respecting their right to die with dignity.

## 2. Bioethical problems in the context of PHC

### 2.1. Bioethics and PC: Concepts and definitions

The emergence of bioethics took place in the 1970s, from the concern with the extent that advances in science, especially in the field of biotechnology, have acquired [4].

The word “bioethics” emerges as a neologism originating from the Greek words *bios* (life) and *ethos* (ethics), being conceptualized as the “systematic study of human conduct in the area of life sciences and health care while this conduct is evaluated in light of values and moral principles” ([5], p. 116).

Among the various models of analysis and reflection in bioethics (libertarianism, virtues, casuistry, narrative, care, and principlist ethics) [6], we have chosen a more detailed approach in this chapter, also known as principlist ethics, proposed by Tom Beauchamp and James Childress in the book *Principles of Biomedical Ethics*.

This model has been widely used to solve problems related to biomedical ethics in Brazil. It focuses on four principles: beneficence, non-maleficence, autonomy, and justice. None of them has a hierarchical position in relation to each other, and the situation in question is what will determine the principle that will have priority [7].

The principle of beneficence requires that actions aim at the creation of a good or result in benefit to the human person. It means the duty to maximize benefits and minimize damages [7]. The principle of non-maleficence underscores the moral obligation not to inflict intentional harm and to avoid all foreseeable harm [8]. The principle of autonomy means recognizing the patients’ ability to deliberate about their personal goals and act in the direction of their deliberations [9]. The basic conditions for this autonomy are acting intentionally, without restrictions or external or internal influences that may determine the control of the action and fully understand its meaning [10]. The principle of justice emphasizes that provisions must be made to each one according to his needs and demands must be expected from each one according to his abilities, and it is argued that equal cases require equal treatment. There can be no justification for discrimination based on economic, social, racial, or religious criteria [11].

The bioethical principles cited express the search for the protection of the human person as a guideline for the current and future practice of medicine [12].

In this context, it becomes relevant to discuss the bioethical problems related to PC because they raise dilemmas involving rights and quality of life of patients under PC and their families.

The World Health Organization (WHO) defines PC as “assistance promoted by a multidisciplinary team that aims to improve the quality of life of patients and their families in the face of a life-threatening disease, through prevention and relief of suffering, early identification, impeccable assessment and treatment of pain and other physical, social, psychological and spiritual symptoms” ([13], p. 83). PC measures seek to guarantee the patient’s quality of life to the detriment of prolonged life [2, 14].

The demand for PC is a current public health problem worldwide, given the progressive aging of the population, with consequent substantial increase in the number of elderly people who experience a greater incidence of chronic degenerative noncommunicable diseases. The importance of PC is evident in this context, as well as the reorganization of health systems in order to ensure the provision of health care [15, 16].

In Brazil, activities related to PC need to be regularized in the form of a law. There is still a great deal of ignorance and prejudice, especially among physicians, health professionals, hospital managers, and the judiciary branch [17].

PC measures are still confused with euthanasia, and there is a huge concern related to the use of opioids, such as morphine, for pain relief. There are still few PC services available and even fewer offering care based on scientific and quality criteria. The vast majority of services still require the implementation of standardized models of care that guarantee efficacy and quality [17].

Before the growing demand for PC, it is difficult to count on a sufficient number of specialists to provide this care. This perspective of health care should not only be relevant among specialists, but the concern with PC measures should also involve general healthcare professionals, caregivers, and family members who provide primary care to such patients [18]. Thus, discussions about the structuring of PC measures in PHC become necessary, given the patients' preference for receiving this kind of care at home.

## **2.2. PHC context**

Since the middle of the last century, movements have gradually redefined health systems around the world in order to promote better health for the population. Two initiatives were internationally impactful and affected health policies in Brazil: the health promotion movement and the PHC movement [19].

Health promotion was first defined in the early twentieth century, encompassing health education actions and structural actions of the state to improve the living conditions of the population [20].

The WHO promoted the First International Conference on Health Promotion in 1986, issuing in that moment the Ottawa Charter for Health Promotion [19, 21]. This document reinforces the expanded concept of health and its determinants, including biological, social, economic, cultural, educational, political, and environmental conditions [19].

In 1975, the expression "primary health care" was first incorporated into the WHO documents and an international conference on the topic culminated in the Declaration of Alma-Ata (1978), where health was recognized as a fundamental right, emphasizing the universal access to services and the intersectoral actions [19, 22]. PHC has been defined as "essential health care based on scientifically sound and socially acceptable methods and technology, which make universal health care accessible to all individuals and families at a cost that the community and the country can afford to maintain at every stage of their development" ([19], p. 7).

However, the epidemiological, demographic, and social transformations fueled by globalization, urbanization, and aging populations pose challenges of a magnitude that was not foreseen three decades ago [23].

PC practices are inserted in this context, although poorly structured and incorporated by the trend toward health systems focused on a limited supply of specialized curative care, consisting of services fragmented by approaches to disease control and with immediate objectives, and an expansion of the deregulated marketing of health [23].

### 2.3. Bioethical issues in PHC

#### 2.3.1. *How to prioritize patient preferences?*

Meeting patient preferences continues to be the major concern in PC quality. For these preferences to be met, medical support and the involvement of the patients and their family in decision-making are essential [2].

In a study carried out with families of deceased patients who received PC, it was observed that their level of satisfaction with the care offered was almost twice higher among those whose relatives died at their preferred place [3].

It is known that home PC measures are related to higher chances of meeting these preferences [2], thus highlighting the importance of PHC in this process. In a study [1], PHC health professionals reported the desire to prioritize the patients' preferences; however, they did not know when and how to have end-of-life conversations with them. Such difficulty arises from the resistance of patients and of the society itself in talking about "death" and PC.

Another study [24] showed that knowledge of religious beliefs and values around death can be useful for preparing professionals to care for patients under PC. This study also stressed that while planning such care, the wishes of the patients should be communicated or documented so that they may be maintained in case of incapacity, as in the decision-making with respect to maintenance of treatments. Studies have shown that more religious patients prefer to maintain life-prolonging treatments [25, 26].

Decisions involving treatments and the end-of-life process also run through legal issues. Regulations differ from one country to another, and such differences may affect the patient's choices. In general, the principle of autonomy dictates that physicians have the duty to provide detailed information on the available therapeutic options and that patients have the right to refuse measures that go against their personal values [27].

However, in situations where such autonomy cannot be exercised, advanced directives can be adopted to ensure that patients' wishes are met when they are conscious. However, the adoption of this type of document by patients is still not common, and an educational and informational process is necessary with the society to raise awareness about its importance [28].

A study mentions three distinct situations involving bioethical problems in existential decision-making: the first situation concerns the ethical responsibility of informing patients about the available treatment options and future implications of the diagnosis; the second

situation concerns the retention or implementation of long-term supportive therapies without therapeutic utility; and the third situation relates to the continuation or discontinuation of measures that sustain life in different cases. In some countries, there is a fourth option, which is of hastening death through the application of active drugs [27].

Regarding the continuation of life support or maintenance therapies, this problem arose with the discovery of mechanical ventilation. On the one hand, the physician has the authority to limit treatment in cases of requests for prolonged futile therapy; however, the right of the patients or their families to actively participate in decision-making should be respected [27].

It is worth mentioning that in the context of PHC, the action of mobile urgency and emergency services, which often end up starting to provide aggressive and life-prolonging therapies still in the home setting, which may be in direct conflict with the objectives of care to a patient under PC [29].

Considering the patients' preferences for rejecting aggressive and life-prolonging measures, besides the preference to die at home, a study pointed out that patients want to avoid visits from mobile care because they are tiring, distressing, and disturbing and because many times this service ends up leading them to a hospitalization [30].

Some factors are reported as having the potential to prevent urgent mobile care and/or hospitalization, namely, the respect for patients' preferences, functional status, and family support that the patient is subjected to. As factors related to the health system, we can mention the existence of primary interdisciplinary domiciliary care teams [30].

Thus, it is necessary that countries invest in models to integrate the different services and levels of care in order to guarantee access to quality PC to patients and their families [31].

### *2.3.2. How to guarantee access to palliative care in PHC?*

Lack of access to home palliative care is still a problem in several countries. It may result in non-compliance with the patients' preferences on care and place of death [2]. It is also known that, despite advances, access to PC measures is still greater among cancer patients than among patients affected by other chronic conditions [32].

Regarding the inequality of access related to the different chronic conditions eligible for PC, a study pointed out that for this discussion one must invoke the bioethical principle of justice, which requires that similar cases must be treated in a similar way. That is, patients with conditions eligible for PC need treatment similar to that offered to cancer patients, regardless of diagnosis [32].

Among other reasons for the lack of access to PC in PHC, the limited resources, the lack of support equipment, and the lack of home care services prepared to assist patients eligible for PC are worth mentioning [2].

This issue should also be discussed under the scope of the principle of justice in the allocation of health resources and services, so as to ensure to all not only equipment and drugs aimed at the control of physical symptoms but also non-pharmacological interventions focused on the

psychosocial-spiritual aspects of these patients, seeking to reduce the suffering and existential anguish attached to the dying process [14, 33].

The lack of trained professionals in PHC for providing PC can also be an obstacle to access. A study [1] reported that PHC professionals identified themselves as “generalists” in PC and most of them demonstrated a lack of confidence and skills needed to identify and care for patients at the end of life, making mention of lack of experience in this type of care.

Thus, the importance of training PHC professionals to nonspecialized PC measures is paramount. They must seek to develop skills in the management of incurable symptoms, communication with patients and their families, and identification and treatment of basic psychological and spiritual problems [1, 33]. A systematic review [34] showed that participating in PC training programs reduces the stress of nurses and improves their communication, attitudes, knowledge, and confidence in caring for PC patients.

Another issue that may influence the access to PC in PHC is the lack of integration within the healthcare network. It is known that the integration of services facilitates the continuity of care, improves the quality of life, and reduces the occurrence of unnecessary hospitalizations for patients. A study [35] highlighted the importance of integrated systems and multidisciplinary meetings.

### 3. Conclusions

The discussions presented here demonstrate the need for a better structuring of health systems around the world for the incorporation of PC into PHC, considering the importance of this level of attention for the improvement of the quality of life and respect for the patients’ right to decide on the place of death. Moreover, such incorporation will result in benefits in terms of cost-effectiveness, reducing unnecessary expenses with hospitalizations and unnecessary therapies. It should be emphasized that for this purpose, PHC professionals must be trained to acquire the necessary skills to provide this type of care.

### Conflict of interest

The authors declare that there is no conflict of interest in the work presented.

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