A manifesto for palliative care in medical education: a study guided by the *Prague Charter*

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Abstract

The current medical training model, aimed at healing and the excessive use of technologies, predisposes medical students and physicians to dilemmas in judgment and decision-making regarding the limits of life, quality of life and death in patients with life-threatening and terminal diseases. The *Prague Charter* establishes palliative care as a right of patients and a legal obligation of governments. The present article aims to describe a didactic experience with undergraduate medical students, resulting in the production of a manifest for palliative care in the medical course of the Universidade Estadual da Bahia (State University of Bahia, Brazil). The results express the perceptions of the students about death and the paradigm shift that palliative care represents. The inclusion of palliative care teaching in undergraduate medical schools is an important step towards achieving best practices in health care.

Keywords: Palliative care. Education, medical. Death. Curriculum.

Resumo

Manifesto pelos cuidados paliativos na graduação em medicina: estudo dirigido da *Carta de Praga*

O modelo de formação médica atual, voltado para cura, e o uso abusivo de tecnologias predispõem aos estudantes de medicina e médicos dilemas em julgamento e tomada de decisões sobre limites da vida e qualidade de vida e de morte em pacientes com doenças potencialmente letais e terminais. A *Carta de Praga* é documento de afirmação dos cuidados paliativos como direito dos pacientes e obrigação legal dos governantes. O objetivo deste artigo é descrever experiência didática em estudo dirigido sobre a *Carta de Praga* com a produção, pelos alunos de graduação em medicina, do manifesto pelos cuidados paliativos da Universidade Estadual da Bahia. Os resultados expressam mudança na percepção da morte pelos alunos e novo paradigma que os cuidados paliativos propõem. A incorporação do ensino de cuidados paliativos na graduação em medicina é pressuposto essencial para boas práticas em cuidados de saúde.

Palavras-chave: Cuidados paliativos. Educação médica. Morte. Currículo.

Resumen

Manifiesto por los cuidados paliativos en educación en medicina: estudio dirigido de la *Carta de Praga*

El modelo de formación médica actual, dirigido a la curación y al uso abusivo de tecnologías, predispone a los estudiantes de Medicina y a los médicos a ciertos dilemas en el juicio y la toma de decisiones acerca de los límites de la vida, la calidad de la vida y la muerte en pacientes con enfermedades potencialmente letales y terminales. La *Carta de Praga* es un documento de afirmación de los cuidados paliativos como derecho de los pacientes y como obligación legal de los gobiernos. El objetivo de este artículo es describir una experiencia didáctica en un estudio dirigido de la *Carta de Praga*, con la producción, por parte de los alumnos de la carrera de Medicina, del manifiesto de cuidados paliativos de la Universidad Estadual de Bahía, Brasil. Los resultados expresan transformaciones en la percepción de la muerte por parte de los alumnos y un nuevo paradigma que proponen los cuidados paliativos. La incorporación de la enseñanza de los cuidados paliativos en la carrera de grado de Medicina es un presupuesto esencial para las buenas prácticas en cuidados de salud.

Palabras claves: Cuidados paliativos. Educación médica. Muerte. Curriculum.

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Declara não haver conflito de interesse.

http://dx.doi.org/10.1590/1983-80422017253209

The teaching of medicine in contemporary Western society is based on the technical-scientific model of the absolute value of healing, in which medical care, bedside medicine, touch, listening and the concerned look at the patient are displaced to a secondary level. In this context, death, an integral part of the life cycle, is now considered an undesirable event, extendable and that one intends to expel from everyday life [1].

These aspects of medical training place students and practitioners in dilemmas regarding judgment and decision-making about the limits of life and quality of life and death of patients with potentially fatal, incurable and progressive diseases. The consequences in medical practice are reflected in the abusive use of technology and unnecessary and futile interventions, called dysthanasia.

In contrast to this hegemonic position in medicine, in the late 1960s, Elisabeth Kübler-Ross developed a study on the psychology of death in terminal patients [2] and Dame Cicely Saunders established a model of humanized and integral care for terminal patients [3]. Derek Doyle, founder and first president of the International Association for Hospice & Palliative Care (IAHPC), in his considerations about the death that occurs in front of health professionals, states *that what we should be ashamed of is not death, but the failure to alleviate suffering when, as we all know, there are ways of doing so* [4].

In 1990, the World Health Organization (WHO) defined palliative care as *the active total care of patients whose disease is not responsive to curative treatment* [in which the] *control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount* [and that] *the goal of palliative care is achievement of the best quality of life for patients and their families* [5], seeking, mainly, to assist oncological patients. In 2002, the WHO revised the concept to *an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual* [6].

The concept of palliative care seeks to rescue the foundation of care not only technical, restricted to the treatment of the pathology, but extending to the other dimensions of the individual who has the disease. Palliative care seeks to encompass social, psychological and spiritual aspects that permeate the patient's history in order to plan and implement actions aimed at alleviating their suffering, involving medical and non-medical professionals in teamwork. This conception of palliative care belongs to the current contrary to the hegemonic model of medical, traditional, Cartesian and technical training [7] that marks the teaching of contemporary Western medicine.

The history of the teaching of palliative care in Brazil has, as one of its exponents, Professor Marco Túlio, a professor in the medical school of the Federal University of São Paulo (Universidade Federal de São Paulo - USP) in the 1990s [8]. Over the last 25 years, the theme has gradually been inserted in the large areas, even if offered in a fragmented way or offered in elective courses, which are not part of the compulsory curriculum [9]. Without proper formal standardization of contents, the study of the subject is transmitted in an insufficient way, preventing the student acquisition of the minimal knowledge necessary to develop competences and abilities.

The new national curricular guidelines of 2014 for undergraduate medical courses signal to the possibility of progress towards a better ethical and human training for students. These guidelines consider the need to incorporate content in order to acquire *humanistic, critical and reflexive skills,* (...) *based on ethical principles and follow-up of the death process* as an integral part of medical training [10]. This requirement can contribute very much to the debate and the effective incorporation of palliative care teaching in medical training in Brazil, in an integrated and integral way.

The *Prague Charter* [11] is a document affirming palliative care as patients' rights and legal obligation of the governors. This document was drafted by the main organizations promoting palliative care in the world: the European Association for Palliative Care (EAPC), the International Association for Hospice & Palliative Care (IAHPC), (WPCA) and the Human Rights Watch (HRW). The *Prague Charter* calls on governments, especially from underdeveloped and developing countries, to take responsibility for patients' access to palliative care. It also instigates the academic institutions of these countries to stimulate the training of health professionals to be capable to act, among other aspects, on the effective care of patients [11].

Methods

Having the aim to describe a didactic experience based on the reflection about the contents of the *Prague Charter*, the present article is based on an activity developed in the elective course on Thanatology and Palliative Medicine of the undergraduate medical course of the University of the State of Bahia (Universidade do Estado da Bahia – UNEB) medical school. It illustrates how the approach and appropriation of knowledge by undergraduate medical students, besides the analysis of issues related to care in life and death, can contribute to the technical and human training of these future professionals.

It is, therefore, a descriptive study of directed activity on the *Prague Charter* with the ultimate objective of elaborating a manifesto for palliative care. The participating class, composed of 23 students, was divided into five study groups, and each group had the task to elaborate a text declaring their manifesto for palliative care. In the process of discussing the texts, each group was asked to highlight a relevant aspect of the content discussed, composing the final part of the manifesto for the palliative care of the class of 2012.1 of the UNEB medical school (Annex 1). The content of the texts produced by the students is transcribed and analyzed by the author from the syllabus and the objectives proposed for the activity in this course.

The Thanatology and Palliative Medicine course is offered to the students of the eighth semester of medical school. Being inserted in the axis of Ethics and Humanism of the pedagogical project, it has the course Bioethics in Medicine as prerequisite, which is offered in the first semester. With a workload of 30 hours, distributed in two hours a week for 15 weeks, the course is offered in conjunction with another one of the same axis, Ethical Dilemmas, in which ethical aspects of medical practice are discussed using real clinical cases that raise issues of medical deontology.

The Thanatology and Palliative Medicine course initially addresses and discusses non-forensic thanatology, studying death and its conception in different historical moments. It considers human development, health and disease processes, the situation and the sensations of the health professionals before patients, family and work colleagues, as well as the ethical dilemmas involved with the termination of life, imbricated in the study of palliative care. One of the proposals for the teaching of palliative care is based on active methods that aim to stimulate the search for knowledge and the development of activities of reflection and analysis of the subject by the students [12]. This was the basis for the creation of this instrument entitled "Manifesto for Care Palliative".

Results

The results of this work are based on the five texts elaborated by medical students, starting with the analysis of the *Prague Charter* and the contents worked during the semester in the Thanatology and Palliative Medicine course. The texts bring the perception of students about death as a natural event in the life cycle and in the processes of health and illness, also in the context of palliative care, as expressed in the following fragments:

"*Because we are all going to die! In death we make a choice. The process of dying does not have to be the way we are used to seeing. Life is a cycle and death is part of it.* (...) *We can see it with dignity, as part of this process. And having dignity in dying requires care and attention.*" (text 1);

"*The importance of providing palliative care to the patient lies in the need to ratify death as a natural process.*" (text 4).

The texts demonstrate the appropriation of the concept of palliative care ratified by the WHO and its applicability by the students. They also highlight the prevention and relief of physical, psychic, spiritual and social symptoms and the care initiated by a multidisciplinary team with patient and family as early as possible, not only in the terminal or advanced phase of the disease, thus providing a better quality of life and assistance adequate in death:

"*Care* (...) *involves pain relief, psychological assistance, access to medicines, such as opioids, as well as interventions that allow for a better quality of life*" (text 2);

"*The World Health Organization (WHO) defines palliative care as the care that provides quality of life for patients and their families,* (...) *by addressing life-threatening disease processes, preventing and alleviating suffering through early identification and thorough assessment of pain and other physical, psychological, spiritual, and social problems.*" (text 3);

"*In order to take care of this new demand of patients, it is fundamental to look at the individual as a single being, in order to meet particular demands, be they physical, psychological or spiritual.*" (text 4);

"Palliative care is not limited to the end of life." (text 3);

"Multidisciplinary attention, including care during the mourning process, is necessary for the family." (text 5).

The results demonstrate the paradigm shift that the teaching of palliative care can represent in the medical training for the care of the life and the quality of death of the patients, when establishing orthothanasia as opposed to dysthanasia and euthanasia, as the texts express:

"The associations of palliative care actions bring a dignified sense to death. They invite the authorities and rulers to see the death process as a right of relatives and people who are about to die. (...) There is no intention to abbreviate death, but to provide quality to death." (text 1);

"Not to anticipate or delay death" (text 5);

"The importance of providing palliative care (...) *avoiding unnecessary prolongation of life, by overuse of ineffective therapeutic methods that would only afflict life even more. "* (text 5);

"Health care in Brazil, in general, is aimed at avoiding death (with a focus on curing diseases). When it is no longer possible to cure the patient, he/she is considered "out of therapeutic possibility", having their treatment neglected by the professionals." (text 3);

"The care (...) provides an improvement in the quality of life and resolution of (...) expensive and aggressive treatments." (text 5).

The resulting texts then compose the manifesto for palliative care, in which the students call on:

"Authorities and government to see the process of dignified death as a right of the family and the people who are on the verge of death." (text 2);

"Government entities to guarantee the right of access to palliative care for patients and their families, promoting public health policies and providing essential medicines, as well as the training of professionals involved in care." (text 4);

"Academic institutions, university hospitals, universities and all those sectors to support and promote the training of human resources for palliative care." (text 3);

"The adoption of palliative care in a systematic way in Brazil, as this is essential to guarantee integral care for patients." (text 1);

"The need for a holistic approach that associates scientific knowledge, competence, and attitudes to alleviate patient suffering." (text 5).

Discussion

According to the WHO, in 2015, 40 million people worldwide needed palliative care and, of that total, 78% were in underdeveloped or developing countries, with only 14% receiving them effectively [13], which reveals the lack of access to physicians and/or palliative care services. For the WHO, the shortage of training and awareness of health professionals on the importance of palliative care is one of the biggest barriers to improving the access of patients to care [12]. Since 2006, the World Medical Association has advocated the inclusion of palliative care training in medical schools both in developed and developing countries [14].

In 2007, the EAPC published a curriculum model in palliative care for medical schools in Europe [15], which could also be used in developing countries. The purpose of the document is to provide students with a program that enables them to develop attitudes and acquire the knowledge and skills necessary for patient and family care.

This model establishes recommendations for teaching strategies, as well as on-the-job learning with direct contact with patients and families, as well as problem-based learning techniques. These techniques always integrate ethical aspects to the teaching of palliative care in an integrated, horizontal and vertical way in the curriculum during the entire medical school course [15].

International literature, since the late 1990s, has shown that introducing palliative care teaching in medical graduate training trains professionals who are better prepared to deal with patients at the end of their lives, to handle physical symptoms, and to address psychosocial and spiritual aspects effectively. Some studies have also shown that specific training in palliative care establishes better communication of bad news to patients with life-threatening diseases [16,17] and prepares students to deal with the possibility of death of patients [18].

The teaching of palliative care in medical education in Brazil remains timid and restricted in medical school curricula. Even when offered, they are squeezed between contents of large areas, with insufficient working hours, considering what is minimally necessary to the appropriation of this content. The subject is given in a non-horizontal way, making it difficult to integrate the other topics of study.

When evaluating the teaching of end-of-life care, rather than palliative care, in 179 medical courses in Brazil, one study showed that only 35% addressed the subject in medical school curricula, in courses that were non-specific or non-focused on the subject. In addition, 33.9% attributed low priority to the teaching of end-of-life care; 73% of the courses considered the time available insufficient for teaching; and 65.6% of the courses pointed to the lack of specialized teaching staff as one of the great barriers to the teaching of end-of-life care [9]. Another Brazilian study showed that the compulsory nature of subjects with a focus on life termination in medical school, enables more students to learn about palliative care [19].

The 2014 national curriculum guidelines for undergraduate medical courses determine the mandatory approach and approach to palliative care in medical curricula. These guidelines can bring about changes in medical education and training. However, since its regulation, no action has yet been taken by medical and educational entities and associations, such as the Federal Council of Medicine (Conselho Federal de Medicina - CFM) and the Ministry of Education, to discuss the implementation of guidelines in courses on ethics and humanities, including palliative care, in medical courses.

In Brazil, since the end of the 1990s, there is a growing number of new graduate courses in palliative care, especially in large centers, like in developed countries, in order to meet the need for capacity building of medical and non-medical health professionals [20]. Palliative care was recognized by the CFM as an area of action, entitled palliative medicine, in 2011, through Resolution CFM 1,973/2011, revoked by Resolution CFM 2,149/2016 [21].

Some examples of professionals who can work in the area are specialists in medical clinic, pediatrics, geriatrics, neurology, anesthesiology, family and community medicine, cancerology, head and neck surgery and intensive medicine. Thus, the area of action in palliative care is regulated, making it fundamental to discuss and incorporate the contents of palliative medicine in medical school, in the four major areas of training and in elective disciplines in the axis of ethics and humanism. In this way, it will be possible to train physicians capable in the technical, human and ethical aspects, which are fundamental requirements for the good practice of these professionals.

Final considerations

Including the Thanatology and Palliative Medicine course in the curriculum of the UNEB medical school allows for an in-depth look into topics related to the humanization of patient care in suffering from life-threatening diseases, and in particular in situations of termination and near death. In the manifesto for palliative care, developed by the students, it is possible to identify the conception of death as a natural event in the medical care context. In addition, it expresses key aspects of the *Prague Charter*, such as the right of patients to humanized care and the duty of government and society to guarantee access to health services and professionals trained in such care. It is clear, therefore, that the students realized the importance of the reflections brought by the theme.

Adding palliative care to medical school training is an important prerequisite for effective practice. It may allow, among other things, the development of assertive and humanized attitudes and decisions by students and medical professionals. Therefore, in the educational sphere, there is an immediate need for a wide discussion among the players involved, aiming to establish recommendations of curricular models for the disciplines of the axis of ethics and humanism, among them the discipline of palliative care. In the same way, it is necessary to incorporate these contents in the curriculum, in order to meet the requirements for the training of technically qualified physicians who know how to do, but also know how to be human and ethical in their professional performance.

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Recebido: 30.1.2017
Revisado: 30.5.2017
Aprovado: 21.6.2017

Annex

Manifesto for palliative care

Text 1

Communication

Because we are all going to die!

In death we make a choice. The process of dying does not have to be the way we are used to seeing. Life is a cycle and death is part of it. We can look at death differently. We can see it with dignity, as part of this process. And having dignity in dying requires care and attention.

The associations of palliative care actions bring a dignified sense to death. They invite the authorities and rulers to see the death process as a right of relatives and people who are about to die.

There is no intention to abbreviate death, but to provide quality to death.

How is it possible and in what situations can we offer palliative care? Trained health professionals, sensitized for having gone through to undergraduate and postgraduate courses, form multidisciplinary teams capable of offering palliative care.

Patients with chronic, infectious, oncological and cardiovascular diseases, among other progressive and incurable conditions, along with their relatives, deserve to have palliative care during the treatment and after the death of the patients.

Palliative care involves pain relief, psychological counseling and access to medications such as opioids, as well as interventions that enable better quality of life.

For this reason, it is important that the authorities adopt palliative care in a systematic way in Brazil, as this is essential to guarantee comprehensive care for patients. To have health not only as absence of disease, but as physical, psychic and emotional well-being in the presence of disease, with multidisciplinary and familiar support in the end, is to die with dignity.

Text 2

Manifesto for palliative care

The World Health Organization (WHO) defines palliative care as the care that involves pain relief, psychological assistance, access to medicines, such as opioids, as well as interventions that allow for a better quality of life for patients and their families. Palliative care is a human right recognized by the United Nations Convention, and has been respected by most countries.

Currently, chronic degenerative diseases (CDD) are the leading cause of death in the world. These diseases usually occur with symptoms that are amenable to treatment through palliative care, such as pain, asthenia, depression, among others. There is already evidence of the effectiveness of palliative care. It is therefore necessary to implement health policies that stimulate their application.

Considering this scenario, we invite rulers to develop global health policies and ensure the full applicability of the right to palliative care to all patients and families who need it. It is important to emphasize the need for authorities and governments to see the process of death with dignity as the right of the family and the people who are about to die.

We also invite academic institutions, university hospitals, universities and all sectors that can support and promote resources for palliative care.

Text 3

To the general community

Considering that the World Health Organization (WHO) defines palliative care as the care that provides quality of life for patients and their families, it is important to emphasize that such care is a human right recognized by the United Nations Conventions. However, like all human rights, in the current context of globalization, it has not been respected by most countries. Palliative care is introduced by addressing life-threatening disease processes, preventing and alleviating suffering through early identification and thorough assessment of pain and other physical, psychological, spiritual, and social problems.

The importance of providing palliative care to the patient lies in the need to ratify death as a natural process by avoiding unnecessary prolongation of life with the overuse of ineffective therapeutic methods that would only inflict more suffering.

It is fundamental to offer physical, psychological, social and psychological comfort to the person in terminal condition, in order to make the process of dying less painful and more humane.

Health care in Brazil, in general, is aimed at avoiding death (with a focus on curing diseases). When it is no longer possible to cure the patient, he/she is considered "out of therapeutic possibility", having their treatment neglected by the professionals.

Palliative care is not limited to the end of life. Access to palliative care is part of the right to health, and its implementation must be interdisciplinary. The adoption of palliative care in a systematic way in Brazil is essential to guarantee comprehensive care for patients. One of the effective ways is to involve academic institutions, university hospitals, universities and all those sectors that support and promote the training of human resources for palliative care.

Text 4

Communication to society

Since the end of the 20th century, Brazil has undergone a period of epidemiological transition and a consequent increase in chronic no communicable diseases (CNCDs), which are the main causes of death today.

Thus, attention and care for chronic and terminally ill patients through palliative care becomes essential. Palliative care is defined as care that improves the quality of life of patients and their families by addressing the problems associated with life-threatening illnesses by preventing and alleviating suffering through early identification and thorough evaluation of pain and other physical, psychological, social and spiritual problems. Moreover, the importance of providing palliative care to the patient lies in the need to ratify death as a natural process. There is no intention to abbreviate death, but to provide quality to death.

In order to take care of this new demand of patients, it is fundamental to look at the individual as a single being, in order to meet particular demands, be they physical, psychological or spiritual. Multidisciplinary attention to the patient and his family network, including the during the process of mourning is necessary

In addition to individual care, palliative care can avoid aggressive and costly treatments that would not improve the patient's quality of life at a relatively low cost. Therefore, it is the duty of government entities to guarantee the right of access to palliative care for patients and their families, promoting public health policies and providing essential medicines as well as the training of professionals involved in care.

Text 5

To the Brazilian population

I write this to clarify the importance of the practice of palliative care in university hospitals and the learning of this practice in academic institutions and universities.

According to the World Health Organization, palliative care aims to improve the quality of life of patients with chronic, progressive, terminal and incurable disease through interdisciplinary measures aimed at both the patient and the family and community. There is an approach to problems associated with life-threatening illnesses, preventing and alleviating suffering through early identification and thorough assessment of pain and other physical, psychological, spiritual and social problems.

The relevance of palliative care practice is to affirm life and consider death as a natural process; not to anticipate or delay death. To this end, it is necessary to take measures to meet the individual needs of patients, regardless of where they are cared for, whether at home or at a health facility. The care is not limited to the end of life, since an early intervention to monitor the disease provides an improvement in the quality of life and resolution of the need for expensive and aggressive treatments.

In Brazil, as in developing countries, accessibility to palliative care is limited or non-existent. Such a situation can lead to unnecessary suffering in millions of patients per year.

In the current scenario, there is an increase in the prevalence of chronic, degenerative diseases and an increase in the survival of these patients, evidencing the need for support for the psychosocial and spiritual problems that arise with the progression of the disease. There is a need for a holistic approach that associates scientific knowledge, skills, and attitudes to alleviate patient suffering.

The importance of providing palliative care is in avoiding unnecessary prolongation of life, by overuse of ineffective therapeutic methods that would only afflict life even more. And multidisciplinary attention, including care during the mourning process, is necessary for the family.

The students of the 2012.1 class of the medical course of the State University of Bahia call on:

1. Authorities and government to see the process of dignified death as a right of the family and the people who are on the verge of death.
2. Government entities to guarantee the right of access to palliative care for patients and their families, promoting public health policies and providing essential medicines, as well as the training of professionals involved in care.
3. Academic institutions, university hospitals, universities and all those sectors to support and promote the training of human resources for palliative care.
4. The adoption of palliative care in a systematic way in Brazil, as this is essential to guarantee integral care for patients.
5. The need for a holistic approach that associates scientific knowledge, competence, and attitudes to alleviate patient suffering.