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Opinion

Twelve Tips for Integrating Bioethics and Palliative Care in Medical Education

Doze dicas para integrar bioética e cuidados paliativos na educação médica

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ABSTRACT

It is important to integrate bioethics and palliative care (PC) in addition to providing the appropriate teaching of end-of-life care to future doctors. This article presents an evaluation of the updated literature and thus proposes to integrate the principles of bioethics with PC in medical schools. Accordingly, these 12 tips aim to highlight the necessary key points to help facilitate the teaching of PC and bioethics to medical students. These points are: addressing of bioethical theories according to the context experienced; supporting shared decisions; encouraging the development of a care plan based on beneficence, non-maleficence, and dignity; relieving uncomfortable physical symptoms and the avoidance of dysthanasia; promoting comfort through palliative sedation; understanding vulnerabilities and promoting the patient's autonomy; taking care of those who care; integrating spirituality and the respect of religious practices; taking care of family members and informal caregivers; understanding and respecting research participants; developing awareness of medically assisted death and ethical-legal limits; and including PC and bioethics themes in all student experiences related to terminality during medical school.

Keywords: Palliative Care; Bioethics; Medical Education.

RESUMO

É importante integrar a bioética e os cuidados paliativos (CP) para o ensino adequado dos cuidados de fim de vida aos futuros médicos. Este artigo apresenta uma avaliação da literatura atualizada e, assim, propõe integrar os princípios da bioética com os CP no ensino médico. Assim, as 12 dicas visam destacar pontos-chave e necessários para facilitar o ensino de CP e bioética para estudantes de medicina. Esses pontos são: a abordagem das teorias bioéticas de acordo com o contexto vivenciado; o apoio da decisão compartilhada; o incentivo ao desenvolvimento de um plano de cuidado baseado na beneficência, não maleficência e a dignidade; o alívio de sintomas físicos desconfortáveis e a prevenção da distanásia; promover conforto por meio da sedação paliativa; a compreensão das vulnerabilidades e promover a autonomia do paciente; cuidando de quem cuida; a integração da espiritualidade e o respeito pelas práticas religiosas; o cuidado de familiares e cuidadores informais; a compreensão e o respeito dos participantes da pesquisa; a consciência da morte medicamente assistida e os limites ético-legais; e a inclusão dos temas de CP e bioética em todas as experiências estudantis relacionadas à terminalidade durante o curso de medicina.

Palavras-chave: Cuidados Paliativos; Bioética; Educação Médica.

BACKGROUND

Medicine involves the task of taking care of people from the beginning to the end of their life. This includes the prevention and treatment of diseases, as well as monitoring those with incurable and terminal illnesses. Therefore, it is necessary to teach the principles of palliative care (PC) in medical education[1,2]. PC is an approach that improves the quality of life of patients – adults and children – and their families who are facing the problems associated with life-threatening illnesses.

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This is done through the prevention and relief of suffering by means of early identification and the impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual[3].

Bioethics, as an interdisciplinary science, arose in the 1970s from the studies of Potter in the area of global bioethics as well as Hellegers and Callahan in biomedical ethics[4]. In 1979, the abuse of research participants led to the publication of the "Belmont Report" and the first edition of the book, *Principles of Biomedical Ethic*[5], which is even today a pillar of principlism bioethics.

The issues of human life, healthcare, and research are essential for medical practice and are part of a doctor's daily life. The ethical theories that support bioethics have their origins in the humanities and if they are not addressed in undergraduate courses, they run the risk of making this type of knowledge underrepresented in medicine. It is interesting to bring together theories of everyday assistance, thus addressing bioethics at the beginning of the course, in internships as well as in continuing professional education[6,7].

PC is a generator of bioethical conflicts, as the actions of health professionals directly interfere in the quality and type of assistance that will or will not be offered to patients at the end of their life[8]. It is at this point that PC and bioethics are intertwined.

The purpose of this article is to describe 12 tips in which the precepts of bioethics can be integrated with medical education regarding PC.

The twelve tips were carefully chosen based on the experience of the authors, who are professors and researchers and have been working with university education for years. A literature review on PC-related key themes was conducted and a set of practical actions to support medical education was proposed. The twelve tips are listed on Figure 1.

TIP 1 – ADDRESSING DIFFERENT BIOETHICAL THEORIES DEPENDING ON THE CONTEXT EXPERIENCED

It is interesting that students are introduced to the theories of bioethics in an organized manner so that they can understand them. For the different issues faced in healthcare, the varying theories may be more or less pertinent. The end of life involves issues related to macro-bioethics, meso-bioethics, and micro-bioethics[4].

Twelve Tips

1 ⇨ **Addressing different bioethical theories depending on the context experienced**
2 ⇨ **Supporting shared decisions**
3 ⇨ **Encouraging the development of a care plan based on beneficence, non-maleficence, and dignity**
4 ⇨ **Relieving uncomfortable physical symptoms and the avoidance of dysthanasia**
5 ⇨ **Promoting comfort through palliative sedation**
6 ⇨ **Understanding vulnerabilities and promoting the patient's autonomy**
7 ⇨ **Caring for those who care**
8 ⇨ **Integrating spirituality and the respect of religious practices**
9 ⇨ **Taking care of family members and informal caregivers**
10 ⇨ **Understanding and respecting the vulnerability of the research participants**
11 ⇨ **Developing awareness of medically assisted death and the ethical-legal limits**
12 ⇨ **Including PC themes and bioethics in all student experiences related to terminality**

Figure 1. Twelve Tips.

Macro-bioethics involves issues of a global nature, such as ecology and policies to protect human life. These global issues form a substrate in utilitarian theory, in which the greatest happiness or greatest benefit must be promoted for the greatest number of people[9]. However, the utilitarian theory faces criticism when it is interpreted outside the global context and approaches the practice of medical care[10]. Meso-bioethics, in turn, points to issues of a non-global collective, such as health system policies, whereas, micro-bioethics approaches issues of everyday healthcare, such as patient-doctor relationship, confidentiality, and decision-making[4].

In PC, bioethical issues are numerous. Students can be encouraged to think and discuss how the health system could be structured to promote adequate care for the end-of-life population, supported both by utilitarianism and principlism. In fact, each therapeutic measure in a terminal situation needs to be explained, understood, and consented to by the patient. The medical practice and care – even if it has no curative proposal – should aim at the well-being and/or the reduction of discomfort with respect to the autonomy of the sick individual, as described by the principlism theory[5] and the ethics of care[11,12].

TIP 2 – SUPPORTING SHARED DECISIONS

A shared decision-making approach is a model that engages both the doctor and the patient in health decisions when several paths are reasonable and possible[13]. However, the patient and the doctor have values that both of them wish to preserve[12] and it is also the duty of the professional to respect their ethical code and the laws. Although a shared decision is an ethical and clinically acceptable approach, it is not always taught at undergraduate level or regularly used in medical practice[14].

In general, shared decisions are composed of steps such as (1) the professional informs the patient that a decision is to be made and that the patient's opinion is important; (2) the professional explains the options and their pros and cons of each relevant option; (3) the professional and the patient discuss the patient's preferences and the professional supports the patient in their deliberation; and (4) the professional and the patient discuss the patient's wish to make the decision, and then they make or defer the decision, and discuss the follow-up[14].

The deliberative process is a model proposed by Gracia[15], in which the steps of assessing the facts, values, and duties for a reasonable, responsible, and prudent conclusion are described. The facts stage consists of a technical description of the situation, which is related to science and evidence that is constantly produced. The values involve both the individual and society, and are supported by the culture of a given historical range. The duties are to assess the circumstances and consequences of the decision. Extreme decisions are rarely appropriate and the best decision is likely to be at an intermediate point.

PC decisions are delicate and can affect the patient's quality of life and survival time. Showing the student that the patient should be the center of care[16] and placing those involved into the stages of shared decisions will help in the understanding of comprehensive care. In paternalism, the professional takes on the decision because they believe that they possess the technical knowledge. Accordingly, the patient's autonomy is not respected, and the patient's solitary autonomy receives the information and is abandoned to make the decision without support. Autonomy is then recommended to be supportive and charitable[11,17].

TIP 3 – ENCOURAGING THE DEVELOPMENT OF A CARE PLAN BASED ON BENEFICENCE, NON-MALEFICENCE, AND DIGNITY

Care planning organizes the care provided to the patient[18] and should follow the tenets of the principlist theory of Beauchamp and Childress[5], according to which medical actions must be guided by beneficence and not maleficence. Beneficence focuses on promoting individuals´ well-being, the moral obligation to act for the benefit of others, with positive attitudes and not just abstaining from harmful acts. Non-maleficence consists of the medical obligation not to inflict harm or damage on the patient and comes from the Hippocratic concept, *primum non nocere* ("first, do no harm").

Dignity should guide care, as it supports the individual to be and feel like a person in so far as finding dignity at the end of one's life can be challenging. Dignity is defined as "the quality or state of being worthy, honored, or esteemed"[18]. Three broad areas have emerged as critical elements of dignity conservation in end-of-life care: 1) illness-related concerns, 2) a dignity-conserving repertoire, and 3) social aspects of dignity[19].

The principles are of singular importance in PC and can be taught when care planning is proposed. For example, when developing a care plan for a dementia patient, any therapeutic proposal should be based on well-being, reduction of suffering, and medical practice values. In the early stage of the disease, the use of memantine and cholinesterase inhibitors can improve cognition, but scientific evidence does not support the use of these medications in the advanced stage of the disease[20]. That is, a therapy is no longer beneficial with the progression of the disease and perhaps becomes inadequate if its administration is forced or carried out through a tube. It is necessary to teach students the task of explaining the care plan, the shared decision in due time, and to be supported by the principles of beneficence and non-maleficence.

Healthcare providers have a profound influence on how patients experience illness and on their sense of dignity; accordingly, dignity- conserving care has an important effect on the experience of patienthood. The "ABCDs" of dignity- conserving care – attitude, behavior, compassion, and dialogue – provide a framework to guide healthcare practitioners and students toward maintaining their patients' dignity[21]. In dignity therapy, the patient is placed in the central role and describes what dignity is in their perspective[22]. Of the patients undergoing this therapy, the majority were satisfied and experience an increase in their sense of dignity[23].

Dignity therapy can be performed at the bedside; moreover, it does not have the interpretative characteristic of other psychotherapies. In this way, students can conduct interviews or become involved in transcription and thus they will be able to understand what dignity is from the perspective of the end-of-life patient.

TIP 4 – RELIEVING UNCOMFORTABLE PHYSICAL SYMPTOMS AND THE AVOIDANCE OF DYSTHANASIA

Twenty first-century medicine is focused on scientific evidence and technologies that have been incorporated into care. This isolated fact is not a problem, as it has allowed for increased survival rates and cures for previously incurable diseases. However, PC is focused on patients who face the end of their life[2]. The focus is on relieving uncomfortable symptoms and quality of life.

The student should be guided to practices in PC, like treatment of pain and other uncomfortable symptoms – for example, respiratory, digestive and neuropsychiatric. The strategies are aimed at optimizing the patient's quality of life, and Wells et al.[24] demonstrated that students did not feel safe to offer care to patients who were dying.

If students are not properly oriented, they can maintain the same attitude that they showed when treating curable patients while caring for those with terminal conditions. Notably, such behavior is not adequate and dysthanasia is often the result. Dysthanasia has been defined as multiple medical actions that prolong death, often cause suffering to the patient, and are performed through obstinacy and therapeutic futility[25,26].

In pediatrics, dysthanasia is widely discussed. The complexity of a child's death means that they are rarely included in PC programs. Clark and Dudzinski[27] showed that children received cardio-pulmonary resuscitation even when the possibility of survival was remote and the quality of life was much worse.

TIP 5 – PROMOTING COMFORT THROUGH PALLIATIVE SEDATION

When a patient has symptoms that are intolerable and refractory to treatment, palliative sedation is a therapeutic option. Physical symptoms such as pain, dyspnea, and delirium are the ones that most often present an indication of sedation – however, existential suffering may also find the indication[28–30].

The indication of palliative sedation alone is a conflicting task. The patient should be involved in the decisions, as sedation ends a person's biographical life and can interfere with their biological life[30]. Therefore, autonomy is directly affected. When prescribing it, the doctor must understand that the symptoms are refractory to the usual behaviors and are intolerable for the patient. Death, in general, occurs at a time not far from palliative sedation, so the prescription and administration of sedatives may encounter resistance from professionals. The interpretation that there is a relationship between sedation and medically assisted death can be uncomfortable, especially in countries where the practice is prohibited[31].

Students must be trained to relieve uncomfortable symptoms with pharmacological and non-pharmacological techniques. Furthermore, in the face of refractory diseases (RD), students must be able to prescribe palliative sedation with drugs and adequate doses. Palliative sedation techniques may be presented through guidelines[32–33], but students´ skills will be improved in practical experiences. Together with their supervisor, students can understand that palliative sedation is part of the medical arsenal and, by reducing suffering, there is the promotion of care, and no individual who is suffering should be deprived of dignified care at the end of their life.

TIP 6 – UNDERSTANDING VULNERABILITIES AND PROMOTING THE PATIENT'S AUTONOMY

Life is vulnerable as one is exposed to danger, illness and death. Getting sick makes a human being understand yet another form of vulnerability: the physiological. Torralba[12] wrote, "Living humanly means, therefore, living in vulnerability". It is important for students to understand that human life has a biological, emotional, social, and spiritual dimension. Illness, aging, suffering and exclusion affect the dimensions of individuals and the society that relates to them.

Students must understand and welcome this vulnerability, but they also should promote the autonomy of the terminally ill patient. Elderly people need progressive support in their daily activities; in addition, bedridden or unconscious individuals are completely dependent on care. However, it is important for students to understand that despite the need for care, the patient may have their autonomy preserved.

A living will, also known as an “advance directive,” allows a person to state their end-of-life medical treatment and care. According to Pirôpo et al.[34] the living will document is still a poorly understood concept that needs greater dissemination and knowledge among health professionals and the population, as it addresses the legitimacy of a patient’s rights at a crucial moment of their life. The majority of students have failed to understand the key elements of a living will and so medical school ethics curricula need to be improved to ensure competency with respect to understanding advance directives[35]. Students can receive training to help patients to write advance directives guided by ethics as well as lawful and personal values.

TIP 7 – CARING FOR THOSE WHO CARE

During medical training, both in undergraduate and medical residence, adaptive stress occurs and some students may have more difficulty with it than others. From the 43 countries studied, 27.2% of medical students had depressive symptoms and 11.1% had suicidal ideation during their training[36]. Doctors remain subject to stress in professional practice, comparable to that of air traffic controllers and firefighters and support through psychotherapy as well as therapeutic and reflection groups seems to be useful in medical training[37].

In the face of the act of caring, it is natural for the student to have emotional manifestations when performing assistance in PC as the student is rarely encouraged to think about their own emotions. It is important to promote spaces for conversations and group therapies along with learning from emotions. This will assist in the training of physicians with empathic attitudes who are capable of welcoming their own emotions along with those of their team and their patients[38,39]. The current scenario requires doctors with technical skills supported by scientific evidence, but also with human capabilities, such as empathy. If there is no space for the acquisition and improvement of affective skills, there is a risk of promoting trained doctors who are indifferent to suffering. Consequently, they become desensitized and are unable to empathize or are too emotionally fatigued to care.

Torralba[12] described a vast amount of emotions that are presented before the end of a life which influence the attitudes of health professionals. Understanding the nature of emotions – both one’s own and that of the interlocutors – helps students to put themselves in the place of a human being who provides care and who, at the same time, needs to be taken care of. On the other hand, if a doctor were completely free from the possibility of pain and suffering, he or she would not be able to provide care, because they would be unable to understand a patient’s suffering and pain. Subsequently, through contact with patients, becoming vulnerable allows us to unmask this false illusion that we are not affected by suffering. Moreover, not learning to deal with negative emotions has caused medical students to move away from areas such as PC[40]. Teaching students how to recognize their own emotions and learn to deal with their own suffering is part of medical education, and we must provide these spaces during their medical education.

TIP 8 – INTEGRATING SPIRITUALITY AND RESPECT OF RELIGIOUS PRACTICES

Spirituality has been defined by Puchalski et al.[41] as the “dynamic dimension of human life that relates to the way persons – individual and community – experience, express and/or seek meaning, purpose, and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant, and/or the sacred”. Nevertheless, religion often refers to an organized system of faith, beliefs, practices, rituals, and language that characterizes a community, usually based on the belief in a divine being[42].

In PC, where care is defined as the promotion of biopsychosocial and spiritual well-being (WHO 2018), an approach to spirituality is of special interest. Among patients, 45% of them want their spiritual needs to be addressed within their care. However, spirituality is an often neglected aspect within medical education[43].

It is important to stimulate the education of future doctors on themes involving spirituality, religion, and spiritual anamnesis through the application of the appropriate tools. Students will be able to understand the role of spirituality in human health and learn about the most popular religions in society. It is not a matter of encouraging proselytism, but introducing basic concepts of spirituality as a form of comprehensive care and expression of the patient’s values. Most students enjoyed the one-hour practice in which they learned the concept of spirituality/religion and were introduced to the “FICA Spiritual History Tool” instrument[44].

TIP 9 – TAKING CARE OF FAMILY MEMBERS AND INFORMAL CAREGIVERS

Since family members provide a considerable amount of the care for people with terminal illnesses their own health may suffer as a consequence. The complexity of palliative care means that the emotional distress and burden that primary family caregivers suffer can be particularly high[45]. A caregiver's burden is a multidimensional, biopsychosocial reaction resulting from an imbalance of their demands. This is relative to the caregiver's personal time, social roles, physical and emotional states, financial resources, and formal care resources in addition to the other multiple roles they fulfill in their normal life[46].

The student can be taught to support and pay attention to the caregiver. The caregiver should be allowed to participate during consultations in order to expand the relationship with questions about the situation regarding care and to encourage the inclusion of more people in care to reduce the burden. Moreover, the caregiver should be asked about physical and emotional well-being. The caregiver burden can be observed through speech or attitudes that denote excessive anxiety and suffering, and also measured using scales, such as one from the Zarit Burden Interview[47].

In family conferences, students can be motivated to participate and interact with the caregiver, directly asking about fatigue and stress, thus allowing for strategies. Perpiñá-Galvañ et al.[45] described anxiety, fatigue, and overload as frequent problems that were associated with a worsening of health.

TIP 10 – UNDERSTANDING AND RESPECTING THE VULNERABILITY OF THE RESEARCH PARTICIPANTS

Scientific research is important for the acquisition of knowledge concerning scientific evidence and for achieving the best outcomes in medicine. It is important that studies respect the rules that guide research ethics and include country-specific resolutions. However, every research participant is in some way vulnerable, as they may suffer physical and emotional damage related to the experiment[5]. In the specific context of PC, patients who are fragile and/or elderly, have multiple physical symptoms, and have emotional, social, and spiritual needs. In this scenario, the vulnerability of the end of life is added to that of research[48].

Notably, there is a need for consistent PC research. To increase the palliative scientific evidence, there is a need to expand research in clinical trials. A historical review of studies conducted with a focus on the global development of PC observed that there is a high focus on evaluation and views of stakeholders; predominantly observational research approach and few interventional studies were identified[49].

Students often participate as assistants in research groups. PC patients and their families may be in extreme vulnerability and could accept invitations to participate in research that aims to cure terminal illnesses or increase survival. Researchers cannot guarantee success, so doctors must take care to explain the consent form, research proposals, and how the patient will be included in the study, consequently minimizing their suffering and offering adequate assistance to them.

TIP 11 – DEVELOPING AWARENESS OF MEDICALLY ASSISTED DEATH AND THE ETHICAL-LEGAL LIMITS

The desire to speed up or have control over the dying process is not part of the PC, but the doctor must be able to talk about the proposals. Some believe that medically assisted death is always morally wrong, while others argue that, under some circumstances, suicide may be a decision that patients with decision-making capacity should be allowed to make[50–52].

Some patients request a medically assisted death either through assisted suicide or euthanasia. Not all countries allow these practices, which means that patients include other techniques to accelerate death. On a scale from minor to major ethical conflict, there is the use of potent medications (such as opioids and sedatives) or the stopping or not starting of life-sustaining therapy. Other types of palliative sedation in order to obtain unconsciousness and accelerate death in the spectrum of assisted death can include the voluntary stopping of eating and drinking, physician-assisted suicide, as well as voluntary or active euthanasia[50].

Unlike the other forms of assisted death, voluntarily stopping eating and drinking does not need a doctor to be a direct part of the process[51]. However, the doctor may be called on to reduce uncomfortable symptoms. The student should be encouraged to understand the values involved, the moral code, and the laws of the country[52]. The clinician should explore the patient's fears and distress, and honestly explain what can and cannot be promised.

Other interesting issues can be addressed in medically assisted death. Like any medical procedure, it is also subject to complications such as nausea, difficulty with venous puncture, and even just not working, as about 1.1% of patients woke up from the attempt. In countries that allow it to be practiced, such as the Netherlands and Belgium, the death request, in general, was related to depression and a loss of sense of autonomy/dignity, and not with pain or physical suffering[53].

It is important to teach a student to understand the issues that lead a patient to ask for medically assisted death, as well as the implicit risks – and to include it, or not – according to the ethical-legal limits.

TIP 12 – INCLUDING PC THEMES AND BIOETHICS IN ALL STUDENT EXPERIENCES RELATED TO TERMINALITY

PCs and bioethics must occupy their space in medical practice, otherwise they will be part of an environment that is dissociated from the reality of future doctors. If the objective is to train competent doctors, students should understand that death is a part of life and it is the physician's task to offer technical, ethical, and humanized assistance in all periods of life.

In medical instruction, contact with death begins during the first anatomy and dissection classes. Students oscillate between treating the corpse as a person and as an object of study or as a "specimen"[54]. Actions such as encouraging students to write letters to family members, reading letters from donor families, having a meeting with family members, and showing videos of the donor when they were still alive have stimulated professionalism, humanization, and the promotion of empathy among students[55–57].

Including PC themes and bioethics in the various clinical and surgical disciplines is a manner of bringing the student's attention toward this topic. The subject of death must be avoided, and it should only occupy the hidden curriculum and not be integrated into medicine in general[58]. The patient should be the center of care, not the disease. Teaching should be about how to communicate bad news with empathy, deciding on therapies and care associated with well-being, and not offering unnecessary therapies. It should be taught that medicine needs to be supported by technique, ethics, and the humanities all at the same time and without dissociation.

FINAL CONSIDERATIONS

The 12 tips described above were focused on the integration of PC and bioethics in medical education. In this way, end-of-life care becomes ethical and comprehensive, and thus proportional to the patient's needs. The conflicts frequently encountered in the terminality of life can be addressed with good medical practice, supported by scientific evidence, bioethics, and the humanization of care. In the absence of education in these areas, there is a risk of training doctors who do not know how to take care of patients facing the end of their life or how to face bioethical conflicts themselves.

Medical students need to be gradually inserted into the PC environment during their medical education in order for them to acquire the necessary competencies as well as to develop professionalism.

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