Ethical and Legal Aspects of Palliative Care in Heart Failure in Brazil

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Introduction

Terminal heart failure (HF) poses numerous difficulties to clinical practice, with ethical, moral, and legal dilemmas.[1] Given that it is an advanced stage of incurable and progressive diseases, the few therapeutic possibilities that are available and tolerated aim to delay evolution, attempt to maintain the balance of organic functions, control symptoms, and offer comfort to patients. Generally, the clinical context is complex, involving interaction with other morbidities, low functionality, frailty, and high symptomatology.[2-4]

There is undoubtedly a high risk of death, in addition to a risk of suffering from the conditions caused by the disease or resulting from treatments. Decision making in terminal HF is a challenge, in the continuous search for adequate therapies that offer strategies that benefit the patient, without adding more risks or damages than are already inherent to their clinical condition.[5,6]

Palliative care (PC) is an approach that aims to provide quality of life, comfort, and dignity to patients suffering from serious or life-threatening diseases.[2,4,5,7-10] For good medical practice at the end of life, the focus of care must be patient-centered, with the understanding that the patient is a person with their own life story and values, as well as an individual way of thinking, living, and existing.[1] Therapeutic decisions must be proportional to the estimated disease prognosis, and they must consider patients' values, expectations, and preferences, respecting the dignity of the human being.[5,7,8] It is essential to be familiar with the legal, ethical, and sociocultural issues that involve patients.[4,5]

Legal opinion

PC is a philosophy and a concrete means of providing health assistance. Founded on multiprofessional action, it is directed at patients and their families, with the aim of promoting health through prevention and intervention in relation to physical, psychological, social, and spiritual symptoms.[5] Although it is an ancient practice, given that any action that seeks relief from suffering can be included in this definition, it has been given a more concrete format since the second half of the twentieth century, recognized by the World Health Organization and diverse international bodies and associations.[1,5,6] In Brazil, it is represented by the National Academy of Palliative Care, founded in 2005.[5] The Brazilian Society of Cardiology also recommends PC actions in its guidelines.[2,3]

In Brazil, there is not any federal law that regulates PC, but some of its guiding principles can be found in documents, such as the Brazilian Federal Constitution of 1988. Article 1 guarantees the dignity of human beings as one of the fundamental pillars of the Democratic State of Law. Article 5 covers the right to life and liberty; privacy, honor, and image are inviolable, with the guarantee that no person will be subjected to torture or inhuman or degrading treatment.[11] Based on these laws, guidelines have been derived to prohibit the practice of dysthanasia, with futility and therapeutic obstinacy that prolong the process of dying with suffering, which is divergent from the proposal of promoting comfort and dignity.[5,9]

In São Paulo, Law number 10.241 (known as the "Mário Covas law"), in 1999, was an important legal advance for end-of-life care, guaranteeing patients' rights, such as physical integrity, individuality, respect for ethical and cultural values, in addition to allowing patients to refuse painful and excessive treatments that attempt to prolong life (dysthanasia); they also have the right to choose their place of death.[12] In 2018, the Brazilian Official Journal of the Union, number 225 provided for guidelines for the establishment of the national PC policy, within the scope of the Unified Health System. Also in São Paulo, in 2020, Law Number 17.292 instituted the state's PC policy.[13]

Even with medical literature, laws, and resolutions, the recognition of the terminal phase and decision making at the end of life is not a simple task, nor one with an immediate response.[4,7] It is necessary for deliberation to take place within a well-founded framework of clinical information, assertive prognostic elaboration, and consideration of therapeutic measures, adapting them to the consequences and expected outcomes.[2] Deliberation should consider not only technical, clinical, and scientific data, but also personal aspects of the patient and family as well as ethical-legal issues.[1]

Patients in the terminal phase of progressive and incurable disease are close to their end of life and, consequently, to death, which is a natural and expected event that ends this process. With the exception of heart transplantation and ventricular assist devices, when possible,[3] therapeutic strategies at this stage of the disease are not very effective in saving lives, and it is very likely that the institution or maintenance of certain interventions are considered futile (meaning that they do not achieve the proposed objective) and potentially harmful. Measures are disproportionate when their purpose is dissociated from real prognostic expectations,

Keywords

Ethics; Jurisprudence; Heart Failure; Palliative Care; Terminal Care

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Manuscript received March 25, 2022, revised manuscript April 14, 2022, accepted April 26, 2022

DOI: https://doi.org/10.36660/abchf.20220040

or when there is a high risk of causing harm faced with a low benefit. Dysthanasic practices are advised against, because they violate ethical principles of proportionality, non-maleficence, and prudence.[5]

Many professionals are insecure about not indicating, limiting, or suspending some procedures during terminal care due to concerns regarding being negligent or even blamed for the death. However, when considering that death is already an expected, natural, and proper event in the progression of the disease, if it becomes clear that the doctor could not or should not act to avoid the result, the death of a patient should not be understood as a result of on action or omission on the part of the doctor, but rather as inherent to the disease, with no professional penalty for the outcome.[5,10,14]

The Brazilian Federal Council of Medicine (CFM, acronym in Portuguese) published resolution 1805/2006, known as the "orthothanasia resolution", which states that physicians have permission to limit or suspend procedures and treatments that prolong the life of patients in the terminal phase of a serious and incurable disease, and they must continue to offer all necessary forms of PC.[5,15] Accordingly, the CFM is opposed to dysthanasia and objectively favors orthothanasia, recognizing the finitude of life and the need to allow death to occur in natural time, without prolonging it at the expense of additional suffering.

In the Brazilian Code of Medical Ethics, fundamental principle XXII, article 41, the CFM reinforces the need to respect the finitude of life in conditions of incurable, irreversible, or terminal diseases, and physicians must provide all necessary PC and limit diagnostic or therapeutic procedures that are unnecessary, useless, or obstinate.[5,16]

Article 41 also reiterates that doctors are prohibited from any form of abbreviation of life (euthanasia), which is considered homicide.[16] This practice differs from orthothanasia, because, in euthanasia, the medical action is directly responsible for death, and without this practice, death would not have occurred, and death is its final purpose. On the other hand, the objective of orthothanasia is care with comfort and respect for the natural time of the disease, death being a consequence of the disease and not of medical actions.[2,5,10]

Another relevant bioethical principle in patient-centered medicine is autonomy, which consists of giving voice and recognizing, in patients' expressed will, their values, desires, and preferences, so that medical conducts will be appropriate for them.[1,4,5,7-10]

The CFM validated advance healthcare directives with resolution 1995/2012,[5,17] wherein patients express the ways they would like, or not like to be treated and cared for at the end of life, making it possible to authorize a proxy to represent their will. The elaboration of directives is of great importance in order to better understand the adequacy of interventions and to assist in decision making during the terminal phase, and physicians should take them into account for greater alignment of conduct.[5,6,8] These manifestations must receive careful medical evaluation regarding their clinical relevance and ethical and legal adequacy.

Studies show that patients with advanced HF think about directives, but rarely express them to their physicians. Physicians, on the other hand, are generally unaware of their patients' directives, and they rarely advise patients to make them. Patients often complain about problems related to communication and express a desire for advanced life support measures based on unrealistic expectations of such treatments due to lack of information. Advanced HF patients are less likely to have PC discussions with their physicians than patients with cancer.[18]

With recognition of the terminal phase and prognostic evaluation, understanding the patient in question and mastering ethical and legal issues, there is a greater likelihood that complex decisions will be more assertive.[7] When actions in favor of survival become unlikely, given the prognosis imposed by therapeutic limitations or advanced disease stage, non-maleficence and respect for autonomy, which are also *prima facie* principles, take on greater relevance in the decision. With the individualization of care planning, at a time when comfort and dignity become the main focuses of care, therapies that had meaning and scientific evidence in earlier stages of the disease begin to lose value.[1,2,4,8,9]

Deciding not to refer patients with terminal HF to intensive care, not to indicate renal replacement therapy or vasopressors, not to proceed with cardiac resuscitation maneuvers or mechanical ventilation, to turn off the shock function on implantable defibrillators, to restrict antimicrobials or artificial diets, or to discontinue antiplatelet agents and statins are examples of legitimate and justifiable medical acts, applied to clinical practice in the condition of terminal and irreversible diseases, provided that the entire deliberation process has been respected.[2,4,5,8-10] It is essential for communication to be clear between all those involved, so that they are aware of the reasons and motivations that lead to the choice of a determined therapeutic plan, and this must be properly recorded in the medical records.[4,5,9,10]

Knowledge regarding the principles of PC is, therefore, fundamental and of great value in aiding the terminal phase of HF, and it should be incorporated into routine clinical practice in cardiology.

Author Contributions

Writing of the manuscript: Dei Santi DB.

Potential Conflict of Interest

No potential conflict of interest relevant to this article was reported.

Sources of Funding

There were no external funding sources for this study.

Study Association

This study is not associated with any thesis or dissertation work.

Ethics approval and consent to participate

This article does not contain any studies with human participants or animals performed by any of the authors.

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