

Ethical and Legal Issues in End-of-life Care: The Case of Life Prolongation

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ABSTRACT

This article aims to make an ethical and legal reflection on end-of-life care, specifically on life- prolongation resulting from technical and diagnostic investment in current health care. This practice called dysthanasia, which in practice is also known as therapeutic obstinacy or futility in care - which is still present in health care - is well described and censored in the deontological codes of doctors and nurses and legal texts (specifically in Portugal). However, despite these documents and the national and international guidelines that contribute to preventing this phenomenon, we conclude that in parallel we need to promote death education - especially end-of-life bioethical issues -, for health professionals in particular, and society in general. The awareness of this issue, through education, will contribute to the empowerment of citizens, more humanization of health care, and, above all, a way to prevent the acts of prolonging the dying process.

Keywords: Dysthanasia; therapeutic obstinacy; futility; end-of-life care; medical ethics code; nurse ethics code; death education.

1. INTRODUCTION

The progress of technology and pharmacological advances in the health field force society in general and the health sciences in particular to face very complex ethical problems [1-4]. One of the greatest ethical problems facing doctors and nurses, in particular, today has to do with the limits of the therapeutic effort in end-of-life care. How can professionals deal with this reality of death and dying? When the person is at the end of life, how should health professionals make their decisions? Should they implement all measures at all costs, prolonging the life that will inexorably end? Should they limit treatments? What about the person's autonomy? When to withhold or withdraw treatment in end-of-life care? When making ethical end-of-life decisions, should healthcare professionals observe the quality of life rather than the prolongation of biological life? What legal and ethical

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documents do health professionals have for guidance? These and other questions are present in day-to-day healthcare. We need to reflect on this reality so that end-of-life care can be humanized.

2. TECHNOLOGICAL ADVANCES VS LIFE PROLONGATION

Nowadays, technological and scientific advances occupy a prominent place in society, and a certain idea of almost absolute power is generated, especially in the area of health. Indeed, in recent decades, scientific and technological development in health has been overwhelming and has brought countless benefits to humanity. Today, with all the therapeutic paraphernalia, we have managed to prolong human life in situations that would have been fatal in the past. We are living longer, but in some circumstances, this prolongation of life is not accompanied by the desirable quality and dignity. This prolongation of life corresponds to prolonging the process of death, or postponing it, without looking at the quality of life even in the final stretch. Indeed, when health care made this prolongation of life feasible, it brought discussions about the best ethical and professional conduct [4-8].

This reality of excessive use of technology has contributed to the dehumanization of health care provision, namely the use of disproportionate means of treatment and diagnosis in terminally ill patients [9]. In a retrospective study (2010-2015) involving 92,155 cancer patients in hospital units in Portugal published in 2020 in the journal *European Society for Medical Oncology Open*, the authors reported a 71% prevalence of aggressive end-of-life care [10]. This empirical data makes us reflect more deeply on this issue. As someone said, "medical technology, which is a blessing, may become a curse", translating the idea that, in certain circumstances, the use of certain technological procedures in the health field does not dignify the person, but, on the contrary, reifies them. In this line of thought, we believe it is pertinent to reflect on a subject that, in our opinion, is somewhat hidden, but which is relevant in bioethics: dysthanasia. We believe that more than the discussion on euthanasia that has overflowed in recent years into the newspaper headlines, the practice of using all diagnostic/therapeutic means available to prolong lives by a thread, postponing death, is an act still very present in hospitals [9-14]. Despite this evidence, this debate "...has in large part been neglected, not only in treatment decisions at the bedside but in public discussions—comfort care—the physician's obligation to alleviate suffering, enhance well being and support the dignity of the patient in the last few days of life"[15].

3. DYSTHANASIA: THERAPEUTIC OBSTINACY OR FUTILITY CARE

Etymologically, the word dysthanasia comes from the Greek *dýs*, "evil" + *thanasía*, "death", which can be translated as slow death, with great suffering. In pragmatic terms, we may consider dysthanasia as the practice within the scope of healthcare that aims at "... prolonging the process of death using treatments that only have the purpose of prolonging the patient's biological life." [16]. This term, used with propriety by the world of ethics, is more foreign to health

professionals, who more often adopt another colloquial synonymous nomenclature of different countries. In other words, it is more usual in the European world to speak of therapeutic obstinacy and in the Anglo-American world of medical futility [17]. However, these terms are difficult to define, note that in a systematic review of the literature conducted in 2016, some authors concluded that the term "... medical futility is complex, ambiguous, subjective, situation-specific, value-laden, and goal-dependent concept which is almost always surrounded by some degrees of uncertainty" [18]. Our concern is very much centered on the possibility of finding professionals who do not have well-founded ethical training and who replace acts of care with invasive and disproportionate acts, in a vain attempt to do everything to save the person, causing more pain and suffering. As Pessini so well states:

"This is the core of the problem of «therapeutic obstinacy» or futile and useless medicine, or simply «dysthanasia», which can transform the end of our existence, making us simple prisoners of a technical apparatus that, rather than prolonging life at the end of a human being's life, transform these moments into veritable torture of pain and suffering" [13] [translation ours].

This idea is also perceived by health professionals. According to Duarte et al, referring to oncologists from the clinical and university hospital of Santiago de Compostela:

"From the experience of several decades of some members of the Oncology Service of our institution, the perception of the existence of therapeutic aggressiveness in cancer patients at the end of life in our environment has been generated. Some patients die «badly», die in the hospital environment with a little dignity, receive aggressive treatments in the advanced stages of their disease, with little or no information on the treatment plan, and, in some cases, die alone" [14] [translation ours].

What is the root and cause(s) of certain attitudes to prolonging human lives that are inexorably at an end? Why do health professionals, in certain circumstances, not suspend or even initiate certain procedures for the person at the end of life as a sign of respect for dignity and not as a synonym of failure? Why do some families demand from health professionals all (un)possible efforts to increase the precarious survival of their loved ones?

4. THE DISPLACEMENT OF DEATH AND DYING

Even though nowadays, we talk more about human death, we can say with relative certainty that it is still a taboo subject [19,20].

"All taboos have fallen, such as that of sex, but death is today, more than ever, prohibited from being shown, almost like something obscene or pornographic" [19] [translation ours].

This denial of death is inherent in the very performance of current society because "...technically it is admitted that we can die and take steps in life to preserve our own from misery. In truth, however, deep within ourselves, we do not feel mortal" [21] [translation ours].

Society itself views death as a failure of healthcare. As is rightly noted in an editorial in *The Lancet Respiratory Medicine*: "Public perception of death and dying also needs to be addressed so that unrealistic expectations from medical treatments can be managed and death is not seen as a failure" [22].

The very place of death has changed over time. The process of dying as a life event moved over time from the family and home sphere to health professionals and the hospital. There were generations in which the dying person died at home, said goodbye to the family, resolved the last commitments in life and everyone watched this event with naturalness. Currently, and since the 1960s, the advances in resuscitation and medical intensive have led to the hospitalization of death [24]. In Portugal, no escaping this trend, 60% of deaths occur in hospital units [25, 26]. This transformation led to the transfer of death and dying from the family sphere to health institutions [8].

This social transformation of the place of death led to a progressive forgetting of it in the community context and even, to its denial. If we add to this fact the technological advances especially directed to life support (ventilators and therapeutics), the development of intensive care units for adults and, later, the neonatal intensive care units, among other technological achievements, we have the necessary ingredients to lead the imaginary of health professionals to the possible triumph over death and the practice of dysthanasia. This is a problem that affects all health professionals but more so nurses who are permanent with patients and families [23].

However, despite this, and to achieve a practice consistent with the ethical principles of safeguarding human dignity, we should understand in detail the justification(s) that health professionals claim to continue to act and/or participate in these acts.

Jox et al [12] in a qualitative study, in which they interviewed 18 physicians and 11 nurses from intensive care and palliative care units of a hospital in Germany about the futility of care, highlighted the following causal factors:

- Personal justifications:
- Ignorance of palliative options;
- Hope for a miracle;
- Fear and worries about death, litigation, the reaction of the patient and family if nothing was done;
- Other emotions: hope, grief, guilt, compassion, and pride struck;
- Institutional barriers:
- Delays in establishing a diagnosis;
- Delay in establishing consensus;

- Delay in identifying the needs/wants of the patient or family;
- Considering professional ethics mandatory in this practice;
- Automated care practice model of the hospital;
- Request of the patient and/or family in the maintenance of therapies.

In another literature review study, the following reasons for practicing futility of care are given:

- Patients'/family members' requests and persistence;
- Healthcare professionals' personal, beliefs, and attitudes;
- Organizational factors and fear of getting involved in medical litigation;
- Social, cultural, and religious factors [18].

From the data presented in this study, we found that health professionals deal poorly emotionally with the issue of death, present difficulties in the area of communication with the patient and/or family, and in some cases there are formative deficits within the values and principles that underpin professional ethics.

What documents guide him towards ethical best practice professional time in end-of-life care?

We will go through the deontological documents of doctors and nurses in Portugal (the reality that I know in more detail) and move on to other national and international documents that can guide ethical decision-making at the end of life.

5. ETHICAL AND LEGAL GUIDELINES

In the health context, more specifically in the practice of end-of-life care, two actors are more systematically confronted with these ethical problems of decision-making not to initiate or suspend disproportionate treatments: physicians and nurses. The codes of ethics of these two professional groups set out a set of duties to act well and are based on principles and values that point to respect for the person's dignity and the consequent humanization of care. In this scope, dysthanasia is well identified as a practice censured by professional deontology. About the medical code of ethics, we found that the Medical Ethics Code (2016)[27] prohibits the practice of dysthanasia:

Chapter II

End of Life

Article 65

- 1- The physician shall respect the patient's dignity at the end of life.
- 2- Physicians are prohibited from aiding suicide, euthanasia, and dysthanasia.

Article 66

Palliative care

1. In situations of advanced and progressive illnesses where treatments do not allow for reversal of the natural course of the illness, the physician shall direct his or her action toward the well-being of the well-being avoiding therapeutic futility, namely the use of diagnostic and therapeutic means that may, in themselves, induce further suffering without any benefit being derived therefrom.

As regards the Nurses' Code of Ethics (2015) [28], the wording is not as explicit as in the previous code, but when reading the articles, we can identify the prohibition of dysthanasia, starting with article 99 -"General principles: 1- Nursing interventions shall be performed with the concern to protect the freedom and dignity of the human person and the nurse". But it is in a later article that this position is more evident, especially in paragraph d):

Article 103

Of the rights to life and quality of life

The nurse, in respecting the right to life of the person during the entire life cycle, assumes the duty to:

- a) To attribute equal value to the life of any person, and therefore protects and defend human life in all circumstances;
- b) To respect the bio-psychosocial, cultural and spiritual integrity of the person;
- c) To participate in professional efforts to value life and the quality of life;
- d) To refuse to participate in any form of torture, cruel, inhuman, and degrading treatment. (our underlining).

In Portugal, in addition to this deontological orientation that professional groups observe, a legal orientation must be added, Law no. 31/2018 of 18 July [29], which lists a set of rights of the person at the end of life, namely the right not to suffer in a sustained, disruptive and disproportionate way:

Article 4

Therapeutic and Diagnostic Obstinacy

Persons in advanced disease and at the end of life have the right to be treated by the care goals defined in their treatment plan, previously discussed and agreed upon, and not to be subject to dysthanasia, through therapeutic and diagnostic obstinacy, namely

through the application of measures that prolong or aggravate in a disproportionate way their suffering, by the deontological codes of the Portuguese Medical Association and the Portuguese Nurses Association and by clinical guidelines approved for such purpose.

These items of ethical-deontological and legal documents that consider dysthanasia as malpractice are fundamental for the guidance of health professionals. However, when professionals are confronted with practical reality, with ethical conflicts, they must guide their actions by consensual values and principles, requiring guidelines. These guidelines "... will provide direction and potentially reduce unnecessary conflicts, which can arise among healthcare providers, patients, families, and community" [6].

In this context, there are different approaches to establishing guidelines to help health professionals make decisions in the event of a conflict.

In the United States of America, a report entitled *Medical futility in end-of-life care: report of the Council on Ethical and Judicial Affairs*, published by the American Medical Association (AMA) in 1999, illustrated a procedural methodology with three phases and several steps until a decision is made on the treatments to be suspended or not to be initiated for the end-of-life patient [30].

In the United Kingdom, later in 2007, a manual entitled *Withholding and withdrawing life-prolonging medical treatment*, by the British Medical Association (BMA), was also released, which also provides professionals with more analytical and descriptive guidance on ethical decision-making [31].

In Portugal, the establishment of ethical criteria for good clinical practice emerged with the debate promoted by the Department of Bioethics and Medical Ethics of the Faculty of Medicine of the University of Porto (FMUP), which was submitted to public consultation, in January 2008, at the *National Consensus Conference on Suspension and Withholding of Treatment in Terminally Ill Patients*, a set of ethical guidance guidelines, as a tool to assist in these complex decision-making processes [32].

Later, in 2014, the Council of Europe (CoE), through its Bioethics Committee, launched a guide entitled *Guide on the decision-making process regarding medical treatment in end-of-life situations*, which presents, in a summarised and informative way, the principles that may be applied to decision-making regarding treatments for people at the end of life [33].

In summary, all these documents aim to prevent or at least decrease dysthanasia. Can we add anything else that may lead to a greater humanization of end-of-life care?

6. EDUCATION AND EMPOWERMENT

We believe that, besides the ethical, deontological, and legal guidelines, there is an upstream measure that may help prevent this practice of unduly prolonging human life. As already mentioned, the concealment of death and dying in contemporary society largely contributes to the difficulties that professionals face in caring for the person at the end of life. Society needs to (re)place the issues of the end of human life in the daily discussion, i.e., integrate this experience into the curricula of compulsory education [34-37], in higher education curricula, especially in health area courses [20,38,39] and, in the training of the general population. Death education, that is, creating conditions so that the topic of death and dying can be socially discussed in all its facets, with a strong focus on bioethical issues [20]. Just as we have in the area of public health policy guidelines for the promotion of sexual health, healthy eating, or promotion of physical activity, so it is also essential to assume death education as an area of public health that will lead to mental health gains in the population [20,40,41]. For health professionals, this continuous training will certainly contribute to a reduction in fear, anxiety, depression, and communication difficulties in the clinical relationship of certain borderline situations [42,43]. Certainly, decision-making at the end of life will be more on the values and preferences of the person and less on the idea of the invincibility of medicine, the fear of legal proceedings, or the multiple difficulties that lead to not starting or not suspending therapeutic actions that are harmful to the person and only prolong biological life. One of the most important aspects of this debate concerns communication, i.e. beyond respect for the autonomy of the dying person, there must be permanent and effective communication between health professionals, the patient and, if possible, the family [44].

In addition, this educational path may lead to the empowerment of the person through the implementation of advance directives [20,45]. In other words, the social awareness of death and dying may be the motto for the person to start talking about the end of life and reflecting on his/her values and preferences at this stage. Reflecting on this issue and carrying out an advance directive or, in a more restricted sense, drafting a living will - using the language of Portuguese legal documents (Law no. 25/2012 of 16 July) [46] - will certainly contribute to a decrease in the prevalence and incidence of dysthanasia, improving the quality of care and reducing the suffering of patients, families, and professionals [47].

7. CONCLUSION

According to the philosopher Edgar Morin, regarding the reluctant themes of the 20th century:

"... the return of death is a major civilizational event and the problem of living with death will be increasingly deeply inscribed in our living (...) Once again, the path of death should take us deeper into life, as the path of life should take us deeper into death [48] [our translation]

Effectively, despite the scientific progress in the area of medicine that has contributed to the survival of patients with previously lethal pathologies [49], death and dying are significantly present in hospitals. Health professionals have to deal with this reality daily, in a society that still sees death as taboo. In this environment of denial of finitude, what limits should be set in the diagnostic and/or therapeutic interventions in caring for the person at the end of life?

We agree with Michael Ashby, professor, and director of, palliative care, Royal Hobart Hospital, Southern Tasmania who states: "Caring for dying patients is not about prolonging life at all costs"[4]. However, studies have shown that there is therapeutic and diagnostic aggressiveness in end-of-life care and professionals refer to a panoply of arguments to engage in this practice.

Despite the ethical and legal guidelines, regarding the censorship of dysthanasia, we observed its practice in health care, especially in end-of-life situations. This fact leads us to the proposal of including the issue of death and dying - with emphasis on end-of-life bioethical problems/dilemmas - in the educational scope of health professionals in particular and society in general. We have argued, as Kellegar [50] states: "... the need to make death education a public health priority, taking its place alongside all other public health campaigns that contribute to national health and well-being"

In short, raising the awareness of health professionals and the community about death and dying will be an invaluable contribution to citizen empowerment, a greater humanization in the provision of health care, and, above all, to prevent undignifying the process.

COMPETING INTERESTS

Author has declared that no competing interests exist.

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