

## **Bioethics Reflection on Life Prolongation in End-of-Life Care**

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### **Abstract**

This paper intends to make a bioethics reflection on the prolongation of human life as a consequence of the use of techniques and methods used by current medicine. The term we use is dysthanasia, however, in the anglo-american world the term medical futility is more frequently used, and for this reason we consider it synonymous with the same practice of prolonging human life with the current technical and scientific paraphernalia. The aim of this paper is to find some bioethics guidelines for the best praxis of health professionals in the clinical of end-of-life care.

**Keywords:** Dysthanasia; Medical Futility; End-Of-Life Care; Bioethics; Principles

### **Introduction**

In today's society, in which technological and scientific advances occupy a prominent place, a certain idea of almost absolute power is generated, especially in the area of health. Indeed, in the last 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 in the past would have been fatal. We live longer, but in some circumstances, this prolongation of life is not accompanied with the desirable quality and dignity in the end. Effectively, when medicine made this prolongation of life feasible, it brought with it a set of legal and ethical discussions about the best ethical and professional conducts [1].

This reality of excessive use of technology has contributed to a dehumanization of health care provision, namely the use of disproportionate means of treatment and diagnosis in terminally ill patients [2]. 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 [3]. This empirical data makes us reflect on this problem, as someone said "medical technology, which is a blessing, can become a curse", reflecting the idea that, in certain circumstances, the use of certain technological procedures in the health field does not dignify the person, but rather reifies them. We believe that, more than the discussion on euthanasia, that has overflowed in recent years into the headlines, the practice of using all diagnostic/therapeutic means available to prolong lives by a thread, postponing death, the so-called dysthanasia or medical futility is an act still

very present in hospitals [2-7]. In addition, within the scope of health ethics, most of the controversies are located in the care of the person at the end of life, requiring reflection to establish benchmarks for decision-making in clinical settings [8,27].

### **Dysthanasia or medical futility**

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 in health care that aims at prolonging the process of death by means of treatments that have the sole purpose of prolonging the patient's biological life. This term, used with propriety by the world of ethics, is more foreign to health professionals, who more often adopt the colloquial 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 [9].

Our concern is very much centered on the possibility of finding professionals who do not have a 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, bringing more pain and suffering. As Pessini states so well: "This is the crux of the problem of *therapeutic obstinacy*, or futile and useless medicine, or simply *dysthanasia*, which can transform the end of our existence, making us mere prisoners of a technical apparatus that, rather than prolonging life at the

end of a human being's life, transforms these moments into a veritable torture of pain and suffering" [6] [translation ours]. This idea is also perceived by health professionals. According to Duarte *et al* [7], 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. There are patients who die "badly", die in the hospital environment with little dignity, receive aggressive treatments in the advanced stages of their disease, without or with little information on the treatment plan and, in some cases, die alone". [7]. [translation ours]

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

### Death, dying, and education

How do we die in our so-called digital society? Although we talk more about human death nowadays, it can be said with relative certainty that it is still a taboo subject [10,12,20].

"All taboos have fallen, like that of sex, but death is today, more than ever, forbidden to be shown, almost as something obscene or pornographic" [10] [translation ours]

This denial of death is inherent in the very actions of today's society because "technically it is admitted that we can die and take steps in life to preserve our own from misery. Truly, however, deep down inside ourselves, we do not feel mortal" [11]. [translation ours]

The very place of death has changed over time. The process of dying as a life event has moved over time from the family and home environment to health professionals and the hospital. There were generations in which the dying person would die at home, say goodbye to the family, resolve the last commitments in life, and everyone would naturally attend this event. Currently, and since the 1960s, the advances in resuscitation and medical intensivism have led to the hospitalization of death [12]. In Portugal, not escaping this trend, 60% of deaths occur in hospital units [13-14].

This social transformation of the place of death has 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 therapy), the development of adult intensive care units and, later, 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 implementation of the practice of dysthanasia or medical futility. But, despite this, and to achieve a practice consistent with the ethical principles of safeguarding human dignity, it is important to understand in detail the justification(s) that health professionals allege to continue to act and/or participate in these acts.

Jox *et al.* in a qualitative study, in which they interviewed doctors and 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 about palliative options;
- Hope for a miracle;
- Fear and worries about death, litigation, patient and family reaction if nothing was done;
- Other emotions: hope, grief, guilt, compassion, and pride struck;
- Institutional barriers:
- Delays in establishing diagnosis;
- Delay in establishing consensus;
- Delay in identifying the needs/wants of the patient or family;
- Considering professional ethics mandatory of this practice;
- Model of the hospital's automated care practice;
- Request of the patient and/or family in the maintenance of therapies [5].

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 training deficits in the values and principles that support good clinical practice. Despite this finding, we are of the opinion that there is an upstream measure that can help prevent this practice of unduly prolonging human life. As already mentioned, the concealment of death and dying in contemporary society contributes greatly 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, that is, integrate this experience in the curricula of compulsory education [15-18], in the curricula of higher education, especially in health courses [19-20] and, in the training of the population in general. Death education that is, creating conditions so that the issue of death and dying to be discussed socially in all its facets, with a strong focus on bioethical issues [20]. For health professionals, this continuous training will certainly help to alleviate fear, anxiety, depression and communication difficulties in the clinical relationship of certain borderline situations [21-22].

### Guiding documents for best practice in end-of-life care

In this regard, we find that there are different approaches to establishing guidance standards to help healthcare professionals with decision making in the event of conflict.

In the United States of America, a report entitled *Medical futility in end-of-life care* by the American Medical Association (AMA) appeared in 1999 with the illustration of a procedural methodology with three phases and several steps until the decision of which treatments to suspend or not to initiate in the person at the end of life [23].

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 guidance to professionals on ethical decision-making in a more analytical and descriptive way [24]. In Portugal, the establishment of ethical criteria for good clinic 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 submitted to public consultation, in January 2008, at the National Consensus Conference on Withholding and Abstaining Treatment in Terminally Ill Patients, a set of ethics guidelines as a tool to assist in these complex decision-making processes [8].

Later, in 2014, the Council of Europe (CoE), through its Bioethics Committee, released a guide entitled *Guide on the decision-making process regarding medical treatment in end-of-life situations*, which sets out, in summary and informative form, the principles to be applying when taking decisions concerning treatment at the end of a person's life [25].

All these documents refer to the need to respect the dignity of the person at the end of life, and seek on this basis, in a procedural or more analytical way, to find a consensus of principles that determine the best praxis.

### Bioethics Principles

For a better deepening and theoretical foundation, we briefly analyze dysthanasia/medical futility under the four principles of Beauchamp and Childress' Principlism Model: autonomy, non-maleficence, beneficence and justice. This model is one of the most disseminated in the Bioethics world and has a wide expression in clinical practice [26- 28].

#### Autonomy

Beauchamp and Childress point to personal autonomy as the regulation of one's own, free, without external interference and personal limitations [27]. It is important to recognize the capacity and legitimacy of the individual to take responsibility for personal choices. To observe good professional practice, the requirement of adequate information and freedom in the decision (without constraints or coercion) must be present. However, in the case of dysthanasia/medical futility, when practiced, we are facing a clear disrespect for the person's autonomy and the adoption of a paternalistic posture. Autonomy does not imply the right to receive all treatment, especially when this is considered disproportionate. Respect for the principle means that health care decisions, especially with regard to withholding and abstaining from treatment in end-of-life patients, require a compromise between the will of the person, with their values and beliefs, and the assessment of the health care professional observing professional duties [25]. In observation of this principle, there is an ethical and legal instrument in many countries, including Portugal, the Advance Directives or in a more reductive way, the Living Will, which allows the person to write a document in advance, which is binding for health professionals, stating what care they want or do not want to receive when they are in an end-of-life situation and are unable to express their will. This exercise of prospective autonomy leads, on the one hand, to the person's accountability and awareness of end-of-life care and, on the other hand, prevents dysthanasia/medical futility [2,29].

#### Non-maleficence

The principle of non-maleficence obliges health professionals to refrain from intentionally performing actions that may cause harm [27]. This principle does not oblige to prolong biological life, or to initiate or maintain a treatment, without taking into account the pain, suffering and

discomfort it causes to the person. In this line, we note that attitudes towards prolonging human life, especially at the end of life, are clearly in collision with the maxim of professional ethics *primo non nocere*. In other words, the appropriate ethical guideline will be to refrain from treatments that are futile or disproportionate to the risks and constraints that may result [25].

#### Beneficence

Proper ethical conduct tells us that we should refrain from causing harm to others, but also contribute to their well-being. This is the core of the principle of beneficence, which is broader than the previous principle, since, in the case of health professionals, they must take positive action to achieve the well-being of others, and not only refrain from causing harm [27]. The prolongation of life at the cost of invasive and painful therapies is an action that is not led by the positive promotion of good.

#### Justice

Briefly, when we speak of the principle of justice, and more specifically of distributive justice, we refer to equal, equitable, and appropriate distribution in society, determined by norms that build social cooperation [27]. In this line of thought, we think it is clear that the practice of dysthanasia/ medical futility leads to the waste of human and material resources that could be useful and highly beneficial in people with the possibility of recovery. It has, in many circumstances, a high economic cost, wasting resources that could serve to increase the quality of community life and not to prolong biological life per se, combining pain and suffering.

#### Conclusion

Advances in healthcare, especially in medical technology, have contributed to the prolongation of human life even in the context of terminality. Health professionals have to deal daily with death in a society that still considers it taboo. In this environment of finitude denial, what limits should be set for the use of therapies in a person at the end of life? Studies show aggressive end-of-life care. Although dysthanasia or medical futility is considered bad practice, and its ethical and legal prohibition is well defined, health professionals present several reasons for continuing certain treatments in terminally ill people. The presentation of guidelines and reflection on the principles that underlie the action, together with education, may be a way to prevent these practices and humanize end-of-life-care.

#### References

1. Kasman DL. When is medical treatment futile? A guide for students, residents, and physicians. *Journal of general internal medicine*, 2004; 19(10): 1053-1056. <https://doi.org/10.1111/j.1525-1497.2004.40134.x>
2. Nunes R, Melo H. *Testamento Vital*. Coimbra: Almedina, 2011.
3. Martins-Branco D, Lopes S, Canario R, et al. Factors associated with the aggressiveness of care at the end of life for patients with cancer dying in hospital: a nationwide retrospective cohort study in mainland Portugal. *ESMO Open*; 2020; 5:e000953. doi:10.1136/esmoopen-2020-000953
4. Pessini P. *Distanásia: Até quando investir sem agredir?* São Paulo: Editor of Centro Univ. S. Camilo/Loyola Edições, 2001.



5. Jox RJ, Schaidler A, Marckmann G, Borasio GD. Medical futility at the end of life: the perspectives of intensive care and palliative care clinicians. *Journal of Medical Ethics*, 2012; 38(9): 540–545. <https://doi.org/10.1136/medethics-2011-100479>
6. Pessini P. Vida e morte na UTI: a ética no fio da navalha. *Revista Bioética*, 2016; 24(1): pp. 54-63. [https://revistabioetica.cfm.org.br/index.php/revista\\_bioetica/article/view/1190/1409](https://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/1190/1409)
7. Duarte FJB, Calvo MSR, Pan JRA. La agresividad terapéutica y la oncología líquida. *Cuadernos de Bioética*, 2017; XXVIII (1): 71-81. <http://aebioetica.org/revistas/2017/28/92/71.pdf>
8. Nunes R. *Proposta sobre suspensão e abstenção de tratamento em doentes terminais*. *Revista Bioética*, 2009; 17(1): 29-39. [https://revistabioetica.cfm.org.br/index.php/revista\\_bioetica/article/view/77](https://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/77)
9. Pessini P. Distanasia: Até quando investir sem agredir? *Revista Bioética*, 2009; 4(1). [https://revistabioetica.cfm.org.br/index.php/revista\\_bioetica/article/view/394](https://revistabioetica.cfm.org.br/index.php/revista_bioetica/article/view/394)
10. Barros de Oliveira JH. *Viver a Morte*. Coimbra: Livraria Almedina, 1998.
11. Ariès P. *Sobre a História da Morte no Ocidente desde a Idade Média*. Lisboa: Teorema, 1989.
12. Macedo JC. An approach to death education. *MOJ Gerontology & Geriatrics*, 2019; 4(6): 276-278. DOI: [10.15406/mojgg.2019.04.00220](https://doi.org/10.15406/mojgg.2019.04.00220)
13. Machado MC, Couceiro L, Alves I, Almendra R, Cortes M. *A morte e o morrer em Portugal*. Coimbra: Almedina, 2011.
14. Gomes B, Sarmiento VP, Ferreira PL, Higginson IJ. Estudo epidemiológico dos locais de morte em Portugal em 2010 e comparação com as preferências da população Portuguesa [Epidemiological study of place of death in Portugal in 2010 and comparison with the preferences of the Portuguese population]. *Acta medica portuguesa*, 2013; 26(4): 327–334. <https://www.actamedicaportuguesa.com/revista/index.php/amp/article/view/429/3706>
15. Dickinson GE. “A Quarter Century of End-of-Life Issues in U.S. Medical Schools. *Death Studies*, 2002; 26: 635-646. DOI: 10.1080/07481180290088347.
16. Clark V. “Educação.” In HOWARTH, Glennys; LEAMAN, Oliver (org.). *Enciclopédia da morte e da arte de morrer*. Rio de Mouro: Circulo de Leitores, 2004: 192-195.
17. Macedo E, Macedo JC, Gomes MF, Peres PE. Educar para a morte e a promoção da saúde mental. *Revista Portuguesa de Enfermagem de Saúde Mental*, 2010; 3:48-53.
18. Herrero PR, Gascón AH, Yubero VM. The inclusion of death in the curriculum of the Spanish Regions, *Compare: A Journal of Comparative and International Education*, 2020; 1-19. DOI: 10.1080/03057925.2020.1732192
19. Oliveira-Cardoso ÉA, Santos MA. Grupo de Educação para a Morte: uma Estratégia Complementar à Formação Acadêmica do Profissional de Saúde. *Psicologia: Ciência e Profissão*, 2017; 37(2): 500-514.
20. Macedo JC. *Death Education*. Berlin: LAMBERT Academic Publishing, 2020.
21. Lester D, et al. Effectiveness of death education program by methods of didactic, experiential and 8A model on the reduction of death distress among nurses. *International Journal of Medical Research & Health Sciences*, 2016; 5(7): 60-71.
22. Dadfar M, Lester D. The effectiveness of 8A model death education on the reduction of death depression: A preliminary study. *Nursing Open*: 2019; 00: 1–5.
23. American Medical Association. *Medical futility in end-of-life care: report of the Council on Ethical and Judicial Affairs*. *JAMA*, 1999; 281(10): 937-941. doi: 10.1001/jama.281.10.937
24. British Medical Association. *Withholding and withdrawing life-prolonging medical treatment*. 3rd ed. London: BMA, 2007. DOI: 10.1002/9780470757994.
25. Council of Europe. *Guide on the decision-making process medical treatment in end-of-life situations*. Strasbourg: COE, 2014.
26. Ferrer JJ, Alvarez JC. *Para fundamentar la bioética* Madrid: UP- Comillas/Desclée De Brouwer, 2003.
27. Beauchamp TL, Childress JF. *Principles of biomedical ethics*. 8 ed. New York: Oxford University Press, 1999.
28. Grant SB, Modi PK, Singer EA. Futility and the care of surgical patients: ethical dilemmas. *World journal of surgery*, 2014; 38(7): 1631–1637. <https://doi.org/10.1007/s00268-014-2592-1>
29. Macedo JC. Contribution to improve advance directives in Portugal. *MOJ Gerontol Ger*. 2020;5(1):27–30. DOI: [10.15406/mojgg.2020.05.00225](https://doi.org/10.15406/mojgg.2020.05.00225)