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Therapeutic obstinacy: when medical intervention hurts human dignity

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Abstract

The possibilities offered by technoscience turned therapeutic obstinacy into a frequent occurrence. Seeking to avoid this practice, health professionals experience ethical dilemmas of maintenance or suspension of treatments considered useless. This study describes the health professional's perception of dysthanasia and reflects on bioethical aspects involved in issues inherent to human beings. This is an integrative literature review carried out from articles published in the scientific databases SciELO and BVSsalud, from 2010 to 2020. Palliative care and bioethical principles are the main allies for the recovery of a patient's dignity, requiring specific legislation to support the professional and the patient. Dysthanasia consists of prolonging the life of patients considered incurable, which, in addition to not being in accordance with the principle of beneficence, results in maleficence due to exposure of the patient to a high incidence of pain and discomfort.

Keywords: Terminal care. Bioethics. Personal autonomy.

Resumo

Obstinação terapêutica: quando a intervenção médica fere a dignidade humana

Em razão das possibilidades oferecidas pela tecnociência, a obstinação terapêutica se tornou frequente. Buscando evitar tal prática, profissionais de saúde vivenciam dilemas éticos de manutenção ou suspensão de tratamentos considerados inúteis. O estudo descreve a percepção do profissional de saúde diante da distanásia e reflete sobre aspectos bioéticos envolvidos em questões inerentes ao ser humano. Trata-se de revisão integrativa da literatura realizada a partir de trabalhos publicados nas bases de dados científicos SciELO e BVSsalud, no período de 2010 a 2020. Cuidados paliativos e princípios bioéticos são os principais aliados para a recuperação da dignidade do paciente, sendo necessária legislação específica para respaldo do profissional e do paciente. A distanásia consiste em prolongar a vida de enfermos considerados incuráveis, o que, além de não estar de acordo com o princípio da beneficência, resulta em maleficência, devido à exposição à grande incidência de dor e desconforto.

Palavras-chave: Assistência terminal. Bioética. Autonomia pessoal.

Resumen

Obstinación terapéutica: cuando la intervención médica hiere la dignidad humana

En virtud de las posibilidades ofrecidas por la tecnociencia, la obstinación terapéutica se hizo frecuente. Para evitar dicha práctica, profesionales de la salud viven dilemas éticos con el mantenimiento o la suspensión de tratamientos considerados inútiles. El estudio describe la percepción del profesional de la salud ante la distanasia y reflexiona sobre aspectos bioéticos intervinientes en cuestiones inherentes al ser humano. Se trata de una revisión integradora de la literatura elaborada a partir de trabajos publicados en las bases de datos científicas SciELO y BVSsalud, durante el período entre 2010 y 2020. Los cuidados paliativos y los principios bioéticos son los principales aliados para la recuperación de la dignidad del paciente, aunque se necesita una legislación específica para respaldar al profesional y al paciente. La distanasia consiste en prolongar la vida de enfermos considerados incurables, lo que, además de no estar de acuerdo con el principio de la beneficencia, tiene como resultado la maleficencia, debido a que están expuestos a una gran incidencia de dolor y molestias.

Palabras clave: Cuidado terminal. Bioética. Autonomía personal.

The authors declare no conflict of interest.

Technical and scientific advances in medicine have allowed the extension of life, significantly reducing the number of deaths from natural causes. However, this may not be beneficial to the patient, since in some cases it represents dysthanasia^{1,2}, an extension of the dying process in which comfort measures are not offered and interventions end up being aggressive. As a result, many patients survive in a critical and chronic condition, with severe functional and cognitive impairments³.

The visible discomfort of many health professionals when dealing with the process of death and dying is due to the difficulty of openly approaching the subject during academic training, creating strangeness when the possibility of losing a patient arises⁴. Death remains a taboo for them, despite being a situation faced in daily practice.

Death is not a purely scientific process restricted to the field of medicine, as it also reaches the personal, cultural and religious dimensions. From the humanized perspective of palliative medicine, patients are recognized beyond their physical issues, receiving emotional, social and spiritual comfort^{1,5}. But accepting that science cannot win every battle is an issue that constantly anguishes health professionals, who can reveal a more intense lack of preparation if a patient, aware of their condition, expresses the desire to die and consent to the natural course of the disease – a clear manifestation of their autonomy, one of the pillars of contemporary bioethics¹.

Therapeutic obstinacy occurs when there are unnecessary extensions that will not benefit the terminally ill patient. The lack of familiarity with all aspects involving death in these situations may lead health professionals to experience feelings of impotence and frustration when facing a limited recovery of their patient. Moreover, health professionals often believe that death must be overcome, leading to the practice of dysthanasia⁴.

Dysthanasia is a useless treatment that only prolongs the pain, making any investment in a cure an attack to the dignity of the human person with the purpose of, at any cost, delaying death². In this situation, the focus is on the length of time of life and the use of all available therapeutic

resources to prolong it as much as possible – without considering that such interventions can violate the principle of dignity. Dysthanasia therefore contradicts what is expected of a good or dignified death, as its objective is not always associated with well-being, being conceptualized as a difficult death⁶.

The guarantee of human dignity is expressed in the 1988 Constitution of the Federative Republic of Brazil¹. Patients have the right to a dignified death, not being subjected to treatments that do not aim to offer a cure for a disease that threatens the continuity of life. With this, dysthanasia is replaced by orthothanasia: a good, correct and timely death, so that the process of death is not extended.

Given the above, this study describes the perception of health professionals about dysthanasia and reflects on bioethical aspects involved in issues inherent to human beings.

Theoretical Framework

Dysthanasia: the relentless and unnecessary search for a cure

Advances in medicine brought benefits to the health of the population and provided greater control of the death process, with the possibility of keeping the organism functioning electronically. As a result, the place of death changed, and what used to happen at home started to happen in the hospital environment¹.

From this change, humanization and palliative care gained visibility in procedures related to the death of patients. According to the International Association for Hospice and Palliative Care (IAHCP), *palliative care is active holistic care, offered to people of all ages who are in intense health-related suffering from serious illness, especially those who are at the end of life. The objective of palliative care is, therefore, to improve the quality of life of patients, their families and their caregivers*⁷. However, this treatment is usually offered late – in the very advanced course of the disease –, which prevents the maintenance of the quality of all the care provided⁵.

Palliative care recognizes the importance of life but considers death a natural process. For this,

it determines that care should not accelerate the arrival of death nor prolong life with disproportionate therapeutic measures. Palliative care integrates pain relief to biopsychosocial aspects as a care strategy, bringing together interdisciplinary skills so that the patient is provided with effective help to cope with the condition caused by the disease⁵.

In contrast to this humanized view of the patient's individual needs, dysthanasia consists of the exaggerated use of medical technologies. This practice, which etymologically means "dysfunctional death," occurs when the life of a critically ill patient is prolonged, that is, it is the obsessive application of therapeutic procedures in patients who will not be saved, so that the harm exceeds the benefit^{1,4}. Unlike dignity, this "aggressive therapy" is rejected by many experts in ethics and bioethics because of its impact on the quality of life of patients and their families¹.

Regarding legislation, the new Code of Medical Ethics reinforces that dysthanasia is an unethical practice and highlights palliative care. According to item XXII of Chapter I, referring to the fundamental principles, *in irreversible and terminal clinical situations, the physician will avoid performing unnecessary diagnostic and therapeutic procedures and will provide the patients under their care with all appropriate palliative care*⁸.

Curative training of health professionals

It is urgent to talk about death and dying

Dying under technologies that alleviate the suffering of terminal patients has become a process and no longer an episode⁵. Talking to the individual involved in this process is important, although an issue constantly neglected in our culture, mainly due to the discomfort people feel when approaching the subject. Health professionals must initiate this much-needed approach and, at the same time, mediate an efficient and open communication with the patient's family⁴.

Many health professionals are not prepared to introduce the topic, which makes this approach difficult. Furthermore, physicians are

trained from a curative perspective, in which death is associated with failure. In this regard, different studies mention that physicians must admit terminal illness, but for that to happen, teaching about death and dying during academic training is essential^{4,9}.

The curriculum of health professionals needs disciplines that include thanatology, but, as Souza and Lemônica¹⁰ show, university is unconcerned with the humanistic training of its students, prioritizing the technical aspect. Thus, there is no adequate preparation to deal with situations that are beyond what is technical, such as caring for terminal patients⁵. Therefore, training aimed at the treatment and diagnosis of diseases, as is the case in medicine, results in the difficulties faced by the physician when treating a terminal patient⁵.

Without discussions about the process of death and dying, the construction of knowledge generates the idea that resuming organic function means failure, giving rise to practices such as dysthanasia, which, with proper preparation, could be avoided⁴.

Autonomy at the end of life and respect for human dignity

Based on four fundamental principles – autonomy, beneficence, non-maleficence and justice – bioethics rescues the patient's civil rights. For much of the 20th century, the principle of beneficence supported the physician-patient relationship, so that physicians had their therapeutic choices justified – even if this implied the extension of life – by the "protection" they owed to the patient. Thus, restoration of health at all costs, considering its own criteria and without the patient's consent, was legitimized by medical paternalism².

Such view enables reflections on the autonomous behavior of human beings, manifested by decision making in the face of a therapeutic approach based on the respect for freedom of choice, which is established by the principle of autonomy. This can only be exercised when the health team shares with the patient information about their health^{2,11}. Rejecting or consenting to the hospital practices they will experience during their disease process is, in practice, the patient's

right to determine what will be done to their body – thus defending their dignity^{2,12}.

This principle also encompasses quality of life, being an essential factor to choose which medical interventions will be performed, and well-being is given by the ability to interact with other people, with oneself, and with life¹². Broadening the debate about autonomy and the right to die means to raise a question inherent to the human being: “afflicted by an incurable disease, what kind of quality of life will I have at the end of life?” Ethical, legal and moral factors that involve the process of illness – and death – of a patient should thus be debated, so that their will is respected at the end of their life¹³.

Method

This is an integrative literature review carried out in the BVS and SciELO databases using the descriptors “dysthanasia,” “bioethics” and “autonomy,” united by the connective “and.” Data collection took place in April 2020 and

followed the independent double-blind method. The research question was: “What is the relationship between dysthanasia and the curative training of Brazilian health professionals?”

The following inclusion criteria were adopted: scientific articles available online in full; which contained the descriptors in the title or abstract; written in Portuguese, Spanish or English; and published between 2010 and 2020. This time frame was chosen due to the increase in publications on the importance of palliative care and bioethics for terminally ill patients. Studies that did not meet the central theme, editorials, dissertations, theses and studies found in more than one database, were excluded.

Results and discussion

Nine scientific articles were found and, after analysis, adequacy to the review theme and exclusion of duplicates, six were selected: one in Spanish and five in Portuguese (Table 1).

Table 1. Articles selected from the BVS and SciELO databases on dysthanasia and bioethics, published between 2010 and 2020

Year	Author	Title	Conclusion
2011	Stolz C, Gehlen G, Bonamigo EL, Bortoluzzi MC ¹⁴	“Manifestação das vontades antecipadas do paciente como fator inibidor da distanásia”	Ethical and legal regulation of advance wills is a favorable measure to respect the patient’s autonomy and a relevant inhibiting factor against dysthanasia.
2013	Oliveira MZPB, Barbas S ¹⁵	“Autonomia do idoso e distanásia”	Studies and Brazilian legislation must evolve to favor adequate medical conduct at the right time of treatment, avoiding the maintenance of false hopes for dying patients and their families, as well as excessive expenses when life can no longer be saved and excessive suffering in cases where death is already announced, in addition to legal proceedings against physicians who favor human dignity and make rational use of technology.
2014	Kovács MJ ¹⁶	“A caminho da morte com dignidade no século XXI”	It is necessary to open space for reflection and practices on dying with dignity in Brazil, especially regarding the development and improvement of palliative care programs, so that the quality of life and death is consistent in our environment.

continues...

Table 1. Continuation

Year	Author	Title	Conclusion
2014	Santos DA, Almeida ERP, Silva FF, Andrade LHC, Azevêdo LA, Neves NMBC ¹⁷	"Reflexões bioéticas sobre a eutanásia a partir de caso paradigmático"	Medical activity must be supported by the Hippocratic legacy, which teaches to <i>improve, when possible, relieve when necessary, and always console</i> ¹⁸ . So, the understanding that death is an intrinsic condition of the nature of living beings, to which everyone is destined, must come from health professionals – and extend to society as a whole. Its inevitability implies considering that the phenomenon permeates and transcends cultural traits, ethical principles and scientific assumptions related to defined historical contexts and periods. Currently, the phenomenon is a controversial issue as societies deny it peremptorily, which is reflected in the formation of academic areas of health and in the practice of services that deal directly with death. It is urgent to reflect on this theme to transform the perception and practices related to death and dying, without confusing legitimate processes, such as orthothanasia, and illegitimate ones, such as euthanasia, as intended in this discussion.
2015	Lima MLF, Almeida ST, Siqueira-Batista RS ¹⁹	"A bioética e os cuidados de fim da vida"	The discussion of current aspects and a minimum framework of bioethical tools to address the issues mentioned is essential for any health professional who works with patients in the process of dying, to allow a dignified passing, which presupposes the acceptance of desires of the person, without impositions based on technique and/or paternalism.
2017	Ríos RM ²⁰	"Acceso universal de los cuidados paliativos: derecho universal a no sufrir: análisis desde la visión bioética y de derechos humanos"	This literature review presents evidence that palliative care must be universally provided and the lack of provision for it violates a fundamental human right.

Death is a recurring subject for health professionals, but many of them still consider it a taboo⁴. Among the various reasons for this is the fact that the subject is little discussed during professional training, causing embarrassment in the face of the possibility of a patient's death. Another factor of great relevance is the feeling of impotence in the face of limited cure, which in many cases favors the onset of dysthanasia⁴.

Approaches that aim to maintain life at any cost are unnecessary, exaggerated, and insufficient, and, in addition to ignoring the suffering of patients and their families, they produce false hope. Therapeutic obstinacy causes the illusion of longevity in patients with no chance of cure or minimal maintenance of quality of life, being

a futile and distressing treatment for them²¹. Palliative care is an alternative to this situation, because it breaks this taboo to expand and develop the dignity of the person in a terminal situation, so that, without them, patients are often subject to violation of fundamental human rights²⁰.

Although knowing the truth about the disease and prognosis is a patient's right, health professionals often neglect crucial details for understanding, drastically reducing the patient's choices at the end of life⁴. Space for this reflection must be created and death with dignity put into practice, especially in palliative care programs, so consistent quality of life and death exist¹⁶.

Regarding bioethical aspects, current ethical and legal regulations on advance directives is

the main instrument favorable to the respect and autonomy of the patient, often being one of the most important factors in preventing dysthanasia¹⁴. For this reason, the discussion about the current situation and the construction of a bioethical foundation are extremely necessary for the issues presented in this study. This is mainly aimed at the role and support of the health professional in offering a dignified death, which presupposes acceptance of the person's wishes, without technician/technological imposition, respecting the patient's autonomy¹⁹.

Technological advances and their application to patients raise moral questions about the limits of the exercise of health professions in search of a cure and the need to discuss death²². Another factor of great relevance is the Brazilian legislation, which lacks specific laws on the subject, leaving health professionals or patients unsupported, especially those who opt for the living will or the advance directives of will¹⁵.

In 2012, the Federal Council of Medicine²³ approved CFM Resolution 1,995, which provides for advance directives of will, specifying that the patient has autonomy, together with the physician, to decide whether or not to carry out useless procedures during end-of-life care. The patient is guaranteed the right not to prolong their suffering, based on the bioethical principle of autonomy¹⁷.

But even with CFM Resolution 1,995/2012, many questions are raised about the dynamics in cases of terminal illness: to what extent can the will of the patient, family, and physician, within their plurality and interests, interfere in the therapeutic conduct? Is the health professional prepared to practice orthothanasia, enabling a better quality of death for the patient¹⁷?

Bioethical issues related to care should be discussed to stimulate reflections on the meaning of technological advances and their practices, to continuously support health professionals in decision making²⁴. Maintenance of false hopes in patients and families, overspending when life can no longer be saved, and suffering when announcing death and facing lawsuits are some of the consequences of dysthanasia. Many of these situations are caused by the lack of specific legislation to support patients and professionals^{15,17}.

Final considerations

Dysthanasia is the extension of the life of patients considered incurable and occurs in a context of constant physical, emotional, psychological, and spiritual suffering. In this situation, the professional causes maleficence, shifting away from beneficence.

The actions of health professionals are extremely important and intended to ensure autonomy and human dignity, taking into account that each patient must be treated individually, according to their physical, psychological and spiritual wishes and needs. Thus, even if the patient's provisions are contrary to the medical decision, dialogue between the parties is necessary, with exposure of the benefits and harms of the treatments.

The activity of health professionals must be supported by their codes and principles, aiming to cure when possible, relieve when necessary and comfort always. Therefore, such a professional must understand that death is an intrinsic condition of the nature of living beings, to which everyone is destined, and often a treatment that extends life can be interpreted and perceived as torture.

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