Ethics, artificial nutrition, and hydration in terminal patients

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Abstract

Given the lack of scientific evidence, decisions regarding the administration of artificial nutrition and hydration in terminally ill patients constitute an important ethical dilemma due to the conflict between "treat" and "care" perspectives and the varying usage depending on the legal and cultural background across countries. This study aims to explain whether this practice configures a basic care intervention or a futile medical treatment. Therefore, we review the national guidelines and codes of ethics from several European countries. Countries such as Portugal, Italy, and Poland view it as a basic care intervention, whereas France, England, Norway, Ireland, Germany, Finland, Netherlands, Belgium, and Switzerland, as a medical treatment. Moreover, countries such as Romania, Croatia, and Hungary lack such legal framework. The different approaches regarding the care of terminally ill patients can reflect differences on cultural perspectives.

Keywords: Artificial feeding. Fluid therapy. End of life. Ethics, medical. Code of ethics. Medicine. Deontology.

Resumo

Dimensão ética da alimentação e hidratação artificiais no doente terminal

Dada a insuficiente evidência científica, decisões relativas à utilização de nutrição e hidratação artificiais em pacientes terminais configuram um importante dilema ético. Identifica-se um conflito entre as perspetivas de "tratar" e "cuidar", com variação quanto a sua utilização conforme o contexto legal e cultural de diferentes países. O intuito deste estudo é esclarecer se essa prática constitui uma medida de cuidado básico ou um tratamento fútil e desproporcionado. Procede-se a uma revisão das diretrizes e dos códigos deontológicos de diferentes países europeus. Em Portugal, na Itália e na Polônia, tal prática é vista como uma medida de cuidado básico; já em países como França, Inglaterra, Noruega, Irlanda, Alemanha, Finlândia, Holanda, Bélgica e Suíça, é considerada um tratamento fútil. Na Romênia, na Croácia e na Hungria, verifica-se um enquadramento ético e legal insuficiente. As diferenças de abordagem a doentes terminais podem ser reflexo das diferentes perspetivas culturais.

Palavras-chave: Alimentação artificial. Hidratação. Fim de vida. Ética médica. Código de ética. Medicina. Deontologia.

Resumen

Dimensión ética de la nutrición e hidratación artificial en los pacientes terminales

Dada la insuficiente evidencia científica, las decisiones sobre el uso de la nutrición e hidratación artificiales en los pacientes terminales constituyen un importante dilema ético. Se identifica un conflicto entre las perspectivas de "tratar" y "cuidar", con variaciones en su uso según el contexto legal y cultural de los diferentes países. El objetivo de este estudio es dilucidar si esta práctica constituye una medida de atención básica o un tratamiento fútil y desproporcionado. Se realiza una revisión de las directrices y códigos deontológicos de diferentes países europeos. En Portugal, Italia y Polonia, se considera esta práctica como una medida de atención básica; mientras que en países como Francia, Inglaterra, Noruega, Irlanda, Alemania, Finlandia, Holanda, Bélgica y Suiza, se considera un tratamiento fútil. En Rumanía, Croacia y Hungría, el marco ético y jurídico es insuficiente. Las diferencias en el tratamiento de los pacientes terminales pueden reflejar diferentes perspectivas culturales.

Palabras clave: Alimentación artificial. Fluidoterapia. Fin de la vida. Ética médica. Código de ética. Medicina. Deontología.

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End-of-life patients have a number of particular characteristics and needs, and decisions about the appropriate treatment for them can be quite difficult, as they involve ethical dilemmas and different opinions among health care professionals. In this context, one of the topics that has been particularly controversial in palliative care is the issue of artificial nutrition and hydration (ANH) ¹.

The progressively reduced oral intake of food and liquids exhibited by these patients as death approaches is one of the signs of the anorexia-cachexia syndrome, a very common condition in end-of-life patients affected by chronic diseases in an advanced state, such as neoplastic diseases and terminal dementia². This reduction can also constitute an important cause of stress for patients, relatives and health care professionals who care for the patient². In fact, when terminally ill patients lose the ability to maintain an adequate oral intake, the issue of hunger and eventual death soon becomes present³.

Both nutrition and hydration have an important meaning in human life, encompassing physical, psychological, social, cultural and spiritual dimensions⁴. For example, nutrition in children and patients constitutes an important human instinct, which is often difficult to suppress. "If we do not eat, we die" is assumed as an elementary truth, transversely known and felt. In turn, the opposite—that is, "people at the end of life often do not eat"—although also true, is not so well known and, above all, much more difficult to accept⁴.

When faced with anorexia exhibited by end-of-life patients, health care professionals often feel the need to pressure patients to ingest food or liquids. In case patients cannot be fed and hydrated in this manner, caregivers often demand that these patients be fed at all costs ⁴.

Thus, this leads to the issue of whether ANH should be adopted in end-of-life patients. This study aims to explain whether this practice configures a basic care intervention or a futile medical treatment. To this end, we review the national guidelines and codes of ethics from several European countries.

End-of-life patients

Reduced oral intake

The different causes of reduced oral intake in these patients include the anorexia-cachexia syndrome and loss of interest in food and beverages, for example due to changes in taste, problems in swallowing or digestion, or simply the lack of the feeling of hunger. In fact, loss of appetite and interest in food is part of the physiological process of dying ^{4,5}.

This anorexia is often associated with cachexia, with weight loss related to the reduction of muscle mass and adipose tissue ⁶. In terminal patients, cachexia is currently considered refractory to treatment ⁷ and is associated with an inflammatory response and a general catabolic state, resulting in persistent weight loss, with functional decline, occurring even with an approach aimed at reducing patients' oral intake ⁷. At an advanced stage, there is no evidence that the treatment of this syndrome, even if conducted effectively, has an impact on patient survival ⁷. That said, the objective of treatment in these cases should be mainly improving symptoms, rather than reversing nutritional deficits ⁶.

It is important that physicians recognize when a patient is nearing the end of life and understand that several symptoms or complications may not be reversible. Consistently, this needs to be conveyed to relatives and caregivers, in order to align their expectations regarding the reality of the patient's condition⁷.

Methods for administering ANH

Artificial nutrition (AN) can be administered via nasogastric tubes (NGT) or nasoduodenal tubes, percutaneous endoscopic gastrostomy (PEG), surgical placement of a feeding tube at the level of the duodenum or jejunum, and finally parenteral nutrition (PN)⁸. Artificial hydration (AH) methods include the use of hypodermoclysis or intravenous hydration⁸.

In terms of nutritional benefit obtained, no differences exist between administration performed enterally or parenterally 9. However, it is important consider that there is a

distinction between them regarding the risk of complications ¹⁰. One of the advantages of using the enteral route is the lower associated cost, in addition to fewer risks for patients, since the use of central lines leads to increased risk of sepsis and air embolism ⁸.

Thus, when there is still a functional intestine, the option for the enteric route should be the preferred. If there is no such alternative, it is essential to use the intravenous route for the administration of artificial nutrition, while hydration can be performed subcutaneously, in addition to the intravenous route?

Regarding AH, hypodermoclysis has been a widely used method in elderly patients over the last two decades⁸. It consists in subcutaneous fluid administration and is the preferred method over intravenous fluid administration, as it is considered safer, more effective and with lower associated costs⁸. These risks are usually associated with local reactions, namely edema or infection⁸.

Central or peripheral catheterization only for the purpose of providing intravenous hydration is rarely recommended in end-of-life patients ⁸. However, if this route is already available for other causes, the intravenous route for fluid administration is the preferred route ⁸.

Ethical Principles

Application to the issue of ANH

Regarding the use of ANH in terminally ill patients, several pertinent ethical issues arise. It is important to discuss and reflect on the subject, based on the four ethical principles: beneficence, non-maleficence, autonomy and justice ¹¹.

Respect for the principle of beneficence implies that the decision is made based on the best interests of the patient, considering their clinical context ¹¹. As such, the first point to be established should be whether the health care professional's decision will be beneficial to the patient in question.

The principle of non-maleficence, on the other hand, concerns avoiding interventions that may cause harm to patients ¹¹. That is, the harm caused by medical interventions can

only be acceptable if the benefits unequivocally outweigh the risks.

Starting by applying these two principles to the issue of ANH, it should be noted that while there is little evidence on the benefits of AN in terminally ill patients, it is important to consider that both enteric and parenteral nutrition are invasive procedures, which can lead to several complications and, consequently, negatively affect patient comfort and quality of life ¹².

There is no evidence demonstrating a significant relation between ANH administration in the last days of life and improved quality of life or increased survival in this group of patients ⁷. Some studies suggest that ANH use was not associated with improvement in nutritional status, reduction in inflammatory markers, prevention of aspiration pneumonia, reduction in the appearance of pressure ulcers or reduction in hospitalizations ¹³.

In the case of NGT, since it is an uncomfortable feeding method, it can aggravate or precipitate the appearance of some psychomotor agitation, sometimes requiring the application of physical or chemical containment measures to avoid the removal of the tube by the patient ¹⁴. The fact that the patient is immobile may increase the risk of pressure ulcers ¹⁴. There is also a chance of local complications and infection of the PEG insertion site ¹³, as well as obstacles associated with the presence of a central catheter, such as infection, bleeding or thrombosis ¹². These, in conjunction with the change in body image, constitute a set of factors that contribute to the discomfort associated with AN methods ⁷.

Differently from AN, which is generally not recommended in the last days of life, the decision to hydrate end-of-life patients has been the subject of further debate⁷.

In the particular case of AH, a 2014 Cochrane review, with the objective of determining the effects of AH on improving quality of life and increasing survival time in palliative care patients, concluded that good quality studies are insufficient to make definitive recommendations in this regard ¹⁵.

The association between the existence of symptoms and the presence of dehydration at the end of life involves some controversy. While some studies associate decreased fluid intake with an

important impact on symptoms ¹⁶, others consider that the relation between patient hydration status and the observation of symptoms is not significant ¹⁷. For example, the symptom of thirst is often one of the main concerns of the family when the patient's oral fluid intake decreases.

However, some studies indicate that the relation between the presence of thirst and hydration status in terminally ill patients is not significant ¹⁷. In fact, some consider that there is no direct association between thirst and hydration status, suggesting that both thirst and anorexia-cachexia syndrome are not reversible with ANH ⁶. In addition, thirst can often be relieved by topical, non-invasive measures such as fractional hydration, ice cubes and good oral care such as oral hydration ¹². Parenteral hydration is rarely recommended for the sole purpose of relieving xerostomia ^{18,19}.

On the other hand, a relation has been established between intravenous hydration and fluid overload, which, in turn, leads to increased pulmonary secretions, congestion, increased urinary output, nausea, vomiting, gastrointestinal secretions, ascites and edema, especially in patients with decreased or absent renal function ^{12,13}.

Conversely, dehydration can act as a natural anesthetic at the CNS level, through the production of ketones and other metabolites ⁸. Decreased diuresis as a result of the patient's lower hydration status may cause a lower need for bladder emptying or urinary catheter use ¹.

The treatment or prevention of hyperkinetic delirium—a frequent symptom that is often a cause of suffering for patients and family members and hinders patient handling by health care professionals—is an important benefit of the administration of artificial hydration. In this context, neurotoxicity by the accumulation of opioid metabolites can be associated with several neurological symptoms, namely decreased cognitive capacity, hallucinations, myoclonus or hyperalgesia.

Hydration may prevent the accumulation of opioid drug metabolites and metabolites of other drugs, thus resulting in improvement or prevention of delirium⁶. In fact, it is considered

that the administration of artificial hydration, using hypodermoclysis, may have a role in relieving symptoms, whether precipitated or aggravated by dehydration ^{1,12}.

Allowing the dying process to occur in the absence of ANH administration in terminally ill patients is justifiable from an ethical perspective ¹. The argument that the sensation of substantial pain and suffering would result from the non-initiation or interruption of ANH is not supported by studies with end-of-life patients ¹.

The provision of food and fluids by oral route should be encouraged in cases it is still possible, since, in addition to affording comfort and pleasure to patients, it also gives them a sense of autonomy and dignity ^{14,19}.

The principle of autonomy corresponds to the recognition of the patients' right to make decisions regarding the health care provided to them ^{10,11}. In several countries, respect for this principle is ensured by the informed consent process, in which patients must receive all information, deciding whether to accept the treatment in question ⁴. Therefore, respect for patient autonomy implies that they understand the nature of their health problem, the objectives, benefits and risks of the interventions, as well as the alternatives to the proposed treatment, including the option of not receiving any intervention ^{10,11}.

The establishment of advance directives is a means of optimizing respect for the principle of autonomy, emphasizing the importance of preparing the living will or assigning durable power of attorney for health care, so the principle of autonomy can continue to be respected if the patient is no longer able to make these decisions ¹².

Respect for autonomy does not imply that patients will have access to any medical intervention they request, regardless of whether it is considered appropriate or not based on the clinical context ¹⁰.

The principle of justice presupposes that the same treatment is offered to patients with equal medical needs. This principle is associated with the concept of proportionality of decisions taken for each clinical situation, with an equitable distribution of health care resources ^{10,11}.

Deontological understandings about ANH

Both in terms of ethical discussion and in terms of decision-making, it is essential to clarify whether ANH is a basic care measure or a medical treatment.

Some authors argue that ANH is a medical treatment, since, unlike oral nutrition and hydration, ANH requires interventions or procedures performed by health care professionals ¹². When considered as a treatment, its non-initiation or interruption is legitimate, according to the analysis of the risks and benefits of its use ¹².

Other authors consider that nutrition and hydration—even if administered artificially—constitute a basic care measure that should be provided to any human being. According to them, as long as the individual is alive, they must necessarily receive the means to remain adequately nourished and hydrated ²⁰. There is also the argument that, in addition to physiological reasons, nutrition and hydration can relieve feelings of hunger and thirst, which are primordial emotions of human consciousness ²⁰.

For example, the Academy of Nutrition and Dietetics considers ANH as any other medical treatment ²¹. The Code of Ethics of the Portuguese Medical Association considers that nutrition and hydration, even if administered artificially, constitute a basic support intervention, and not an extraordinary means of maintaining life ²².

The 2016 guidelines of the European Society for Clinical Nutrition and Metabolism (ESPEN) indicate the prerequisites that must be complied with before the administration of ANH. They are: the existence of an indication for its implementation, the definition of a treatment objective and the patient's will, as well as the existence of their informed consent ²³.

Thus, by considering ANH as a medical treatment, its implementation requires the existence of an indication and a treatment objective ^{10,23}. The indication is based on scientific evidence, considering the expected benefits and potential risks. It also requires informed consent from the patient or their representative, if the patient is unable to decide ^{10,23}.

Considering ANH as a treatment, physicians are not required to provide it to the patient if, based

on their clinical judgment, there is insufficient evidence to support its implementation or if the risks or adverse effects associated with it outweigh the benefits ¹⁹.

In countries such as Portugal, patients who are able to decide can express their will as to the type of treatment desired, related to nutrition and hydration, for the end of their life. Such choice may be made by preparing advance directives or by assigning power of attorney for health care ¹². Thereby, patients can—even in a more advanced phase, in which it is no longer possible to express their will—have their decision complied with. Thus, patient autonomy should be prioritized over the health care professionals' choice as to the best option ¹². Therefore, it is important that health care professionals encourage the preparation of advance directives before decision-making ability is lost.

On the other hand, family members may consider that the individual should always receive food and liquids, even if administered artificially, as a basic support measure ^{10,24}. This view is largely associated with the significance that foods and liquids have in human life, since—whether provided orally or artificially—they represent a form of affection and care ¹². The symbolism of affection associated with the act of eating and the idea of suffering related to hunger and thirst are deeply rooted in various societies ^{12,24}.

Family members often report that it is the lack of food and fluids that is killing the patient, and not the progression of their underlying disease ¹². These beliefs that are not adapted to reality may be at the origin of conflicts between family members and health care professionals ^{12,24}. Accordingly, it should be clarified to family members that the use of ANH is not necessary for patients to be comfortable ²⁴. Effectively, when adequate palliative care is provided, symptoms such as hunger and thirst can be effectively managed without the need for ANH administration ²⁴.

However, in fact, in some countries or cultures, ANH is considered a basic care measure, not a treatment ¹⁹. In these circumstances, ANH can be interrupted only if the patient is terminally ill and has expressed their will to discontinue nutrition and hydration ¹⁹.

Point 5 of article 67 of the Code of Ethics of Portuguese Physicians states that hydration and nutrition are not considered extraordinary means of maintaining life, even if administered artificially ²², being considered, therefore, that ANH is a basic need of the patient, and not a treatment.

Contrary to what is found in the Portuguese Code, in the Spanish Code no reference is made to how interventions such as the ANH are understood from a deontological point of view ²⁵. However, there is a general consensus that both the interruption and non-initiation of life support measures (respiratory, hemodynamic, nutritional, among others), when there is no curative objective, constitute good medical practice ²⁶. Similarly, the use of drugs to relieve suffering, even if it results in a shortened survival, is also considered good medical practice ²⁶.

In France, for example, the suspension of artificial nutrition and hydration has not constituted a violation of the law since April 2005 ^{27,28}. In fact, the aforementioned law specifies that any treatment can be limited or interrupted in end-of-life patients, and artificial nutrition and hydration are considered a treatment as per this law ^{27,28}.

In the UK, a law was established in 1992 that defines ANH as a form of treatment rather than a means of basic support. In the 2018 guidelines of the British Medical Association (BMA), applicable to England and Wales, the term clinically assisted nutrition and hydration (CANH) is used instead of artificial nutrition and hydration (ANH), emphasizing the idea that nutrition and hydration provided by this route constitute a form of medical treatment ²⁹. Also according to these guidelines, the use of ANH in patients with advanced dementia is not recommended ²⁹.

Similarly, the General Medical Council, in the guidelines for the treatment and care of end-of-life patients considers ANH a medical intervention, also stating that it should be seen in the same way as other medical interventions: nutrition and hydration provided by tube are seen legally as a medical treatment, and should be treated in the same way as other medical interventions ³⁰.

The Care of dying adults in the last days of life guidelines of the National Institute for

Health and Care Excellence (NICE) recommend continuous monitoring of patients submitted to artificial hydration, in addition to a review of the risks and benefits associated with the procedure. The decision to continue or discontinue the administration of artificial hydration should be made considering the risk-benefit balance and the will of the patient ³¹.

Until 2018, in England and Wales and Northern Ireland, judicial authorization was required so physicians could interrupt artificial nutrition and hydration in patients in a permanent vegetative state or in a state of minimal consciousness, even in cases where both the family and health care professionals agreed that this decision would serve the best interests of the patient ³². However, since July 2018, following a decision of the Supreme Court, in cases where there is a consensus between physicians and the family regarding the interruption of ANH, it can be interrupted without requiring judicial approval in England and Wales ³⁰.

In Norway, ANH is also considered as a form of treatment: if it is decided that life-sustaining treatments are not in the patient's best interests, suspension of nutrition and hydration should be considered ³³.

In the Irish Code of Ethics, Guide to Professional Conduct and Ethics for Registered Medical Practitioners, it is also considered that ANH is a form of treatment, and its administration is not required if it does not benefit the patient: there is no obligation to start or continue treatments, including resuscitation, or provide nutrition and hydration through medical interventions, if it is decided that the treatment is unlikely to have an effect; or may cause the patient more harm than benefit; or will probably cause pain, discomfort or stress to the patient that outweigh the benefits it may provide ³⁴.

Similarly, in the Irish Hospice Foundation's guidelines on the management of nutrition and hydration in palliative care for people with dementia, it is recommended that it should not be used in people with advanced dementia ³⁵.

Although the German Medical Code of Ethics has no concrete reference to ANH ³⁶, the German Medical Association considers AH as a form of treatment, which can therefore be

limited, with remaining obligation to address symptoms such as thirst through palliative care methods ³⁷. However, in practice, what happens sometimes is that German physicians have some reservation regarding the limitation, not only of ANH in particular, but of life support treatments in general—an aspect that, in part, is related to the particular history of the country, more specifically the atrocities that took place in the Nazism period ³⁷. In addition, in the German oncology guidelines related to the palliative care of patients with incurable neoplasms, the administration of ANH in terminal patients is discouraged ³⁸.

The Romanian medical code of ethics does not specify standards for the treatment of end-of-life patients ³⁹. In Austria, from an ethical and legal point of view, ANH is considered equivalent to other life support measures. In the recommendations regarding therapeutic limitation and discontinuation in intensive care units (ICU), prepared by a consensus of the Austrian Associations of Intensive Care Medicine, it is considered that ANH constitutes a medical treatment, and can be interrupted in cases where the patient is in a process of irreversible death ⁴⁰.

In an opinion prepared by the National Advisory Board on Social Welfare and Health Care Ethics (ETENE), published by the Finnish Ministry of Health in 2012, it is stated that providing ANH to the patient in a state of imminent death is not compatible with allowing them to have a natural death: allowing a natural death implies abdicating measures whose application at the time of imminent death of the patient would be directed to pathological changes in the patient's body and which in practice would have no impact. These include the supply of liquids and nutrients or blood products to the end-of-life patient 41.

In the Slovenian Medical Code of Ethics there is also no concrete reference to the particular case of ANH, only that, when performing diagnostic and therapeutic procedures on terminally ill patients, physicians must consider the patient's quality of life and will. The physician should not initiate or suspend measures when they are considered futile or when the risks of treatment outweigh the benefits. Failure to initiate or discontinue palliative care is ethically unacceptable 42.

In the Slovenian ethical recommendations for the decision of treatments and palliative care

in terminally ill patients in ICUs, it is understood that a treatment, once considered futile after weighing the risks and benefits, can be limited or interrupted, and adequate palliative care must be maintained ⁴³.

In Croatia, a country with which Slovenia shares a similar sociocultural context, the physicians' perception is that the country's legal framework is manifestly vague and restrictive 44. They consider that the legal framework establishes patient survival as the final objective of each medical intervention, and there is no legal support for the interruption of treatments for end-of-life patients 44. In addition, that country still lacks clear regulations for advance directives 44. In fact, in Croatia, none ofthe forms of advance directive is regulated by law, with the exception of transplantation of human organs for medical purposes—in which case advance directive is allowed 44.

In the Croatian Medical Code of Ethics, prepared by the Croatian Medical Chamber and the Croatian Medical Association, there is a brief reference to the case of end-of-life patients: the continuation of intensive treatment in a patient in an irreversible terminal state is not clinically justifiable, since it deprives the dying patient of their right to a dignified death 45. However, there is no definition as to treatments that are considered means of basic care and those that are not.

In Hungary, as in other countries, the patient can choose to accept or refuse the proposed treatment, except for life-sustaining interventions, since in this case the treatment can only be refused if the patient has an incurable disease, with a short life expectancy despite adequate medical treatment ⁴⁶. In addition, the expression of their will must be carried out formally, by means of a living will ⁴⁶.

As in other countries, Hungary also has an insufficient ethical and legal framework regarding decisions to approach end-of-life patients. In fact, in that country, the legal framework limits the option of suspending life-sustaining treatment even if there is an explicit request from the patient, while topics such as the futility of medical treatments are not addressed by law⁴⁶.

Thus, physicians are forced to make these decisions without any ethical or legal support,

and, for this same reason, there is major individual variability in terms of decisions in this regard ⁴⁶. Another factor that also seems to significantly influence this decision process is the availability or lack of means ⁴⁶.

In a study that analyzed the differences in terms of the prevalence of potentially inappropriate treatments in the last week of life in six European countries (England, the Netherlands, Finland, Belgium, Italy and Poland), it was concluded that, in relation to the use of ANH, the country with the highest frequency of use was Poland, while the Netherlands was the country with the lowest frequency of use ⁴⁷. It was also concluded that, in cases of advanced dementia, the frequency of use of ANH was low in England, Finland, the Netherlands and Belgium, but was considerably higher in Italy and Poland, particularly the administration of AH ⁴⁷.

In addition to the aforementioned policy on the use of ANH in terminally ill patients in England and Finland, the similar low prevalence of use of these means in Belgium and the Netherlands can be explained by the culture of these countries in terms of palliative care, namely by the existence of greater openness in relation to different options and decisions regarding the care provided to terminally ill patients ⁴⁷.

In fact, in the Netherlands, the administration of ANH in end-of-life patients is often seen as a disproportionate measure, and treatments considered futile in patients with advanced dementia are avoided ⁴⁸. Thus, the decision to discontinue ANH in these patients is relatively frequent in this country, and ANH is mainly administered for a short period ⁸. This practice is consistent with the policy advocated by the Dutch Association of Nursing-Home Physicians (NVVA), which recommends some reservation in the decision to initiate ANH in patients with advanced dementia ⁴⁸.

In Belgium, the National Council of the Order of Physicians, in 2003, issued an opinion on topics such as euthanasia and palliative care, as well as other medical decisions on end-of-life patients, stating that interrupting or not providing treatment is ethically acceptable in case it is scientifically established that it is no longer expected to lead to a significant improvement in the patient's condition, and that treatments aimed at prolonging life do not increase the patient's comfort, causing only

discomfort and suffering ⁴⁹, which may contribute to the low prevalence of ANH use in that country.

Also, according to the Law of 22 August 2002 on patients' rights, it is stated that if the patient's representative does not agree with the decision that a certain treatment should be interrupted or not started and requests the responsible physician to prolong the patient's life by artificial means, the best interests of the patient prevail over the opinion of the representative. This principle is applicable not only for interventions, but also for suspension or non-initiation of a treatment ⁴⁹.

On the other hand, the high prevalence of ANH use in Poland and Italy can be explained, among other reasons, by the legal context and, possibly, by a lower adoption of early health care planning. Therefore, issues such as treatment decisions in end-of-life patients are not discussed, which leads, on the one hand, to the rise of ethical and legal issues and, on the other hand, to greater pressure from family members for treatments such as ANH ⁴⁷.

In the case of Poland, the high prevalence of ANH use can be explained by the fact that the procedure is considered a basic care measure in the country, and not a medical treatment, and therefore cannot be discontinued ⁵⁰. Similarly, the high prevalence of ANH use in Italy can be explained by the country's legal framework. In fact, in 2009, the Italian Council of Ministers approved a bill that determined that artificial nutrition and hydration should always be administered, regardless of the circumstances, since they were considered basic support measures, fundamental to human life ⁴⁷.

In 2017, a law (known as Legge sul testamento biologico) was passed that stipulated the right to refuse or suspend ongoing treatments, diagnostic tests or any type of means of maintaining life, including artificial nutrition and hydration. Another factor that may also contribute to the high prevalence of ANH use, particularly in Italy, is the strong Catholic religious tradition in that country, which argues that life is sacred and should be preserved at all costs ⁵¹.

In a similar study, in which ANH suspension practices were compared in six European countries (Belgium, Denmark, Italy, the Netherlands, Sweden and Switzerland), similar results were obtained.

In it, Italy was the country where this practice was less frequent and the Netherlands, where it was more frequent, followed by Switzerland, Belgium and Sweden ⁵². In all countries, non-initiation was more recurrent than suspension of ANH, which can be partly justified by the fact that the latter can be perceived by family members as cause of death ⁵².

In fact, in Switzerland, there has been a progressive increase in the percentage of patients who die after suspension of treatments aimed at prolonging life by artificial means ⁵³. This practice is in line with the Swiss Academy of Medical Sciences (SAMs) national guidelines for the care of end-of-life patients. They state that the suspension or non-initiation of life support measures may be indicated or justified when a patient is in the process of dying, including ANH in this definition, as well as artificial respiration and cardiopulmonary resuscitation ⁵⁴.

Final considerations

Successive medical and technological advances over the years have led to increased average life expectancy, with a consequent aging of the population.

Both health care professionals and institutions care for increasingly older patients; hence, there is an increased number of people with advanced or terminal diseases. Thus, ANH-related decisions will become more and more common. Therefore, it is essential that health care professionals and institutions are aware of the benefits and risks of this practice and how to approach it.

Despite some evidence that dehydration and lack of food do not contribute to the suffering of end-of-life patients, and may even contribute to greater comfort for these patients, the use of ANH in this context remains an important ethical issue.

The variability in terms of care practices for end-of-life people, as well as the differences in deontological understandings regarding these actions between different countries, give rise to numerous challenges in this regard.

In fact, it is observed that the treatment of these patients depends to a large extent on the health care systems and the cultural context of the place where they live.

Taking into consideration the deontological understandings analyzed, it is found that, in northern Europe, ANH is mostly considered as a futile and disproportionate treatment, being, therefore, recommended against. In southern Europe, ANH is often considered as a basic care measure, which must be maintained.

Still, the importance of respecting patient autonomy constitutes a point of consensus across almost all countries discussed.

Finally, it is important to note that currently, in some countries, end-of-life patient care practices, such as ANH, are still not adequately regulated from a political and legal perspective. In this sense, it should be noted that adequate planning in this context can be important not only to reduce costs associated with the treatment of these patients, but also to improve the quality of the care provided to patients.

To this end, the establishment of standards and guidelines, as well as a clarification of the legal framework, can constitute important tools. This lack of legal framework and support for the medical decision, in addition to possibly promoting tension in the relationship between patient family members and health care professionals, leads to the adoption of the practice of "defensive medicine" in the approach to these end-of-life patients.

References

- **1.** Geppert CMA, Andrews MR, Druyan ME. Ethical issues in artificial nutrition and hydration: a review. J Parenter Enteral Nutr [Internet]. 2010 [acesso 19 out 2023];34(1):79-88. DOI: 10.1177/0148607109347209
- 2. Del Río MI, Shand B, Bonati P, Palma A, Maldonado A, Tobada P *et al*. Hydration and nutrition at the end of life: a systematic review of emotional impact, perceptions, and decision-making among patients, family, and health care staff. Psychooncology [Internet]. 2012 [acesso 19 out 2023];21(9):913-21. DOI: 10.1002/pon.2099

- 3. Whitworth MK, Whitfield A, Holm S, Shaffer J, Makin W, Jayson GC. Doctor, does this mean I'm going to starve to death? J Clin Oncol [Internet]. 2004 [acesso 19 out 2023];22(1):199-201. DOI: 10.1200/JCO.2004.02.056
- **4.** Van de Vathorst S. Artificial nutrition at the end of life: ethical issues. Best Pract Res Clin Gastroenterol [Internet]. 2014 [acesso 19 out 2023];28(2):247-53. DOI: 10.1016/j.bpg.2014.02.005
- Hallenbeck J. Tube feed or not tube feed? J Palliat Med [Internet]. 2002 [acesso 19 out 2023];5(6):909-10.
 DOI: 10.1089/10966210260499104
- 6. Dev R, Dalal S, Bruera E. Is there a role for parenteral nutrition or hydration at the end of life? Curr Opin Support Palliat Care [Internet]. 2012 [acesso 19 out 2023];6(3):365-70. DOI: 10.1097/SPC.0b013e328356ab4a
- 7. Hui D, Dev R, Bruera E. The last days of life: symptom burden and impact on nutrition and hydration in cancer patients. Curr Opin Support Palliat Care [Internet]. 2015 [acesso 19 out 2023];9(4):346-54. DOI: 10.1097/SPC.000000000000171
- **8.** Heuberger RA. Artificial nutrition and hydration at the end of life. J Nutr Elder [Internet]. 2010 [acesso 19 out 2023];29(4):347-85. DOI: 10.1080/01639366.2010.521020
- Bozzetti F, Amadori D, Bruera E, Cozzaglio L, Corli O, Filiberti A et al. Guidelines on artificial nutrition versus hydration in terminal cancer patients. European Association for Palliative Care. Nutrition [Internet]. 1996 [acesso 19 out 2023];12(3):163-7. DOI: 10.1016/s0899-9007(96)91120-x
- 10. Schwartz DB, Barrocas A, Annetta MG, Stratton K, McGinnis C, Hardy G et al. Ethical aspects of artificially administered nutrition and hydration: an ASPEN position paper. Nutr Clin Pract [Internet]. 2021 [acesso 19 out 2023];36(2):254-67. DOI: 10.1002/ncp.10633
- 11. Varkey B. Principles of clinical ethics and their application to practice. Med Princ Pract [Internet]. 2021 [acesso 19 out 2023];30(1):17-28. DOI: 10.1159/000509119
- 12. Pinho-Reis C, Sarmento A, Capelas ML. Nutrition and hydration in the end-of-life care: ethical issues. Acta Port Nutr [Internet]. 2018 [acesso 19 out 2023];15:36-40. DOI: 10.21011/apn.2018.1507
- 13. De D, Thomas C. Enhancing the decision-making process when considering artificial nutrition in advanced dementia care. Int J Palliat Nurs [Internet]. 2019 [acesso 19 out 2023];25(5):216-23. DOI: 10.12968/ijpn.2019.25.5.216
- 14. Pessoa A, Marinho R, Amaral TF, Santos M, Mendes L, Marinho A et al. Alimentação na demência avançada: documento de consenso da Sociedade Portuguesa de Medicina Interna e da Associação Portuguesa de Nutrição Entérica e Parentérica. Med Interna [Internet]. 2020 [acesso 19 out 2023];27(1):80-8. DOI: 10.24950/ Guidelines/Consensus/1/2020
- **15.** Good P, Richard R, Syrmis W, Jenkins-Marsh S, Stephens J. Medically assisted hydration for adult palliative care patients. Cochrane Database Syst Rev [Internet]. 2014 [acesso 19 out 2023];(4):CD006273. DOI: 10.1002/14651858.CD006273.pub3
- **16.** Bozzetti F, Amadori D, Bruera E, Cozzaglio L, Corli O, Filiberti A *et al.* Guidelines on artificial nutrition versus hydration in terminal cancer patients. Nutrition [Internet]. 1996 [acesso 19 out 2023];12(3):163-7. DOI: 10.1016/s0899-9007(96)91120-x
- 17. Fainsinger RL, MacEachern T, Miller MJ, Bruera E, Spachynski K, Kuehn N *et al*. The use of hypodermoclysis for rehydration in terminally ill cancer patients. J Pain Symptom Manage [Internet]. 1994 [acesso 19 out 2023];9(5):298-302. DOI: 10.1016/0885-3924(94)90187-2
- **18.** Cerchietti L, Navigante A, Sauri A, Palazzo F. Hypodermoclysis for control of dehydration in terminal-stage cancer. Int J Palliat Nurs [Internet]. 2000 [acesso 19 out 2023];6(8):370-4. DOI: 10.12968/ijpn.2000.6.8.9060
- 19. Cardenas D. Ethical issues and dilemmas in artificial nutrition and hydration. Clin Nutr ESPEN [Internet]. 2021 [acesso 19 out 2023];41:23-9. DOI: 10.1016/j.clnesp.2020.12.010
- 20. Rady MY, Verheijde JL. Nonconsensual withdrawal of nutrition and hydration in prolonged disorders of consciousness: Authoritarianism and trustworthiness in medicine. Philos Ethics Humanit Med [Internet]. 2014 [acesso 19 out 2023];7:9-16. DOI: 10.1186/1747-5341-9-16
- 21. Maillet JO, Schwartz DB, Posthauer ME. Position of the academy of nutrition and dietetics: ethical and legal issues in feeding and hydration. J Acad Nutr Diet [Internet]. 2013 [acesso 19 out 2023];113(6):828-33. DOI: 10.1016/j.jand.2013.03.020

- 22. Lisboa. Procuradoria-Geral Distrital de Lisboa. Regulamento nº 707/2016, de 21 de julho. Regulamento de Deontologia Médica [Internet]. Lisboa: Procuradoria-Geral Distrital de Lisboa; 2016 [acesso 19 out 2023]. Disponível: https://bitly.ws/3esoj
- 23. Druml C, Ballmer PE, Druml W, Oehmichen F, Shenkin A, Singer P *et al.* ESPEN guideline on ethical aspects of artificial nutrition and hydration. Clin Nutr [Internet]. 2016 [acesso 19 out 2023];35(3):545-56. DOI: 10.1016/j.clnu.2016.02.006
- **24.** Casarett D, Kapo J, Caplan A. Appropriate use of artificial nutrition and hydration-fundamental principles and recommendations. N Engl J Med [Internet]. 2005 [acesso 19 out 2023];353(24):2607-12. DOI: 10.1056/NEJMsb052907
- **25.** España. Organización Médica Colegial de España, Consejo General de Colegios Oficiales de Médicos. Código de deontología médica: guía de ética médica [Internet]. Madrid: CGCOM; 2011 [acesso 19 out 2023]. Disponível: https://bitly.ws/3espp
- **26.** Cabré L, Casado M, Mancebo J. End-of-life care in Spain: legal framework. Intensive Care Med [Internet]. 2008 [acesso 19 out 2023];34(12):2300-3. DOI: 10.1007/s00134-008-1257-7
- **27.** Baumann A, Audibert G, Claudot F, Puybasset L. Ethics review: end of life legislation the French model. Crit Care [Internet]. 2009 [acesso 19 out 2023];13(1):204. DOI: 10.1186/cc7148
- **28.** Lemaire F. The project of a law concerning patients' rights at the end of life. Presse Med [Internet]. 2005 [acesso 19 out 2023];34(7):525-8. DOI: 10.1016/s0755-4982(05)83965-x
- 29. England. Royal College of Physicians. British Medical Association. Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent: guidance for decision-making in England and Wales [Internet]. London: BMA; 2018 [acesso 19 out 2023]. Disponível: https://bitly.ws/3esq4
- **30.** England. General Medical Council. Treatment and care towards the end of life: good practice in decision making [Internet]. Manchester: GMC; 2022 [acesso 19 out 2023]. p. 56. Disponível: https://bitly.ws/3esqU
- 31. Hodgkinson S, Ruegger J, Field-Smith A, Latchem S, Ahmedzai SH. Care of dying adults in the last days of life. Clin Med [Internet]. 2016 [acesso 19 out 2023];16(3):254-8. DOI: 10.7861/clinmedicine.16-3-254.
- **32.** Kitzinger C, Kitzinger J. Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state: family experiences. J Med Ethics [Internet]. 2016 [acesso 19 out 2023];42(1):11-7. DOI: 10.1136/medethics-2015-102777
- 33. Norway. Norwegian Directorate of Health. Decision-making processes in the limitation of life-prolonging treatment [Internet]. Oslo: Norwegian Directorate of Health; 2013 [acesso 1 mar 2023]. p. 28. Disponível: https://bitly.ws/3esrZ
- 34. Ireland. Medical Council. Guide to professional conduct and ethics for registered medical practitioners (Amended) [Internet]. Dublin: Medical Council; 2019 [acesso 19 out 2023]. p. 33-4. Disponível: https://bitly.ws/3estg
- **35.** Hartigan I, Robinson S, O'Sullivan M, McLoughlin K, Gallagher P, Timmons S. Palliative Care for the Person with Dementia: Guidance Document 4: Management of Hydration and Nutrition [Internet]. Dublin: Irish Hospice Foundation; 2016 [acesso 19 out 2023]. Disponível: https://bitly.ws/3estQ
- **36.** Germany. German Medical Association. Professional Code for Physicians in Germany [Internet]. Berlin: German Medical Association; 2021 [acesso 19 out 2023]. Disponível: https://bitly.ws/3esuW
- 37. Jox RJ, Krebs M, Fegg M, Reiter-Theil S, Frey L, Eisenmenger W *et al.* Limiting life-sustaining treatment in German intensive care units: a multiprofessional survey. J Crit Care [Internet]. 2010 [acesso 19 out 2023];25(3):413-9. DOI: 10.1016/j.jcrc.2009.06.012
- 38. Alemanha. German Cancer Society, German Cancer Aid, AWMF. German Guideline Programme in Oncology: Palliative care for patients with incurable cancer, Extended version- Consultation version 0.1 [Internet]. Berlin: German Cancer Society, German Cancer Aid, AWMF; 2014 [acesso 19 out 2023]. AWMF-registration number 128/0010L. Disponível: http://leitlinienprogramm-onkologie.de/Leitlinien.7.0.html
- **39.** Romania. Romanian College of Physicians. Code of Medical Ethics of the Romanian College of Physicians from November 4, 2016 [Internet]. Bucharest: Romanian College of Physicians; 2016 [acesso 19 out 2023]. Disponível: https://bitly.ws/3esyH

- **40.** Valentin A, Druml W, Steltzer H, Wiedermann CJ. Recommendations on therapy limitation and therapy discontinuation in intensive care units: consensus paper of the Austrian Associations of Intensive Care Medicine. Intensive Care Med [Internet]. 2008. [acesso 19 out 2023];34:771-6. DOI: 10.1007/s00134-007-0975-6
- **41.** Finland. National Advisory Board on Social Welfare and Health Care Ethics. Human dignity, hospice care and euthanasia [Internet]. Helsinki: ETENE; 2012 [acesso 19 out 2023]. p. 3. Disponível: https://bitly.ws/3eszL
- **42.** Slovenia. Medical Association of Slovenia. Medical Chamber of Slovenia. Code of Medical Ethics [Internet]. Ljubljana: Medical Chamber of Slovenia; 2016 [acesso 19 out 2023]. p. 4. Disponível: https://bitly.ws/3esAU
- 43. Grosek S, Orazem M, Groselj U. Notes on the development of the Slovenian ethical recommendations for decision-making on treatment and palliative care of patients at the end of life in intensive care medicine. Pediatr Crit Care Med [Internet]. 2018 [acesso 19 out 2023];19(8S Suppl 2):48-52. DOI: 10.1097/PCC. 00000000001606
- **44.** Ćurković M, Brajković L, Jozepović A, Tonković D, Župan Ž, Karanović N *et al*. End-of-Life decisions in intensive care units in Croatia-pre covid-19 perspectives and experiences from nurses and physicians. J Bioeth Inq [Internet] 2021 [acesso 19 out 2023];18(4):629-43. DOI: 10.1007/s11673-021-10128-w
- **45.** Croatia. Croatian Medical Chamber Assembly. Code of medical ethics and deontology [Internet]. Zagreb: Croatian Medical Chamber Assembly; 2016 [acesso 19 out 2023]. p. 4. Disponível: https://bitly.ws/3esF4
- **46.** Zubek L, Szabó L, Diószeghy C, Gál J, Élö G. End-of-life decisions in Hungarian intensive care units. Anaesth Intensive Care [Internet]. 2011 [acesso 19 out 2023];39(1):116-21. DOI: 10.1177/0310057X1103900119
- **47.** Honinx E, Van den Block L, Piers R, Van Kuijk SMJ, Onwuteaka-Philipsen BD, Payne SA *et al.* Potentially inappropriate treatments at the end of life in nursing home residents: findings from the PACE cross-sectional study in six European countries. J Pain Symptom Manage [Internet]. 2021 [acesso 19 out 2023];61(4):732-42. DOI: 10.1016/j.jpainsymman.2020.09.001
- **48.** Van Wigcheren PT, Onwuteaka-Philipsen BD, Roeline H, Pasman W, Ooms ME, Ribbe MW *et al.* Starting artificial nutrition and hydration in patients with dementia in the Netherlands: frequencies, patient characteristics and decision-making process. Aging Clin Exp Res [Internet]. 2007 [acesso 19 out 2023];19(1):26-33. DOI: 10.1007/BF03325207
- **49.** Belgium. Belgian Advisory Committee on Bioethics. Opinion n° 41 of 16 April 2007 on informed consent and "D.N.R." Codes [Internet]. Brussels: Belgian Advisory Committee on Bioethics; 2007 [acesso 19 out 2023]. p. 15. Disponível: https://bitly.ws/3esFV
- **50.** Pawlikowski J, Muszala A, Gajewski P, Krajnik M. Discontinuation of hydration and nutrition in vegetative or minimally conscious state: position statement of the Polish Association for Spiritual Care in Medicine. Pol Arch Intern Med [Internet]. 2021 [acesso 19 out 2023];131(1):111-3. DOI: 10.20452/pamw.15746
- 51. Giammatteo J, Treglia M, Pallocci M, Petroni G, Cammarano A, Quintavalle G et al. LAW n° 219/17: reflecting on shared care plan. Clin Ter [Internet]. 2020 [acesso 19 out 2023];171(5):e401-6. DOI: 10.7417/CT.2020.2248
- **52.** Buiting HM, Van Delden JJM, Rietjens JAC, Onwuteaka-Philipsen BD, Bilsen J, Fischer S *et al.* Forgoing artificial nutrition or hydration in patients nearing death in six European countries. J Pain Symptom Manage [Internet]. 2007 [acesso 19 out 2023];34(3):305-14. DOI: 10.1016/j.jpainsymman.2006.12.006
- **53.** Bosshard G, Zellweger U, Bopp M, Schmid M, Hurst SA, Puhan MA *et al.* Medical end-of-life practices in Switzerland: a comparison of 2001 and 2013. JAMA Intern Med [Internet] 2016 [acesso 19 out 2023];176(4):555-6. DOI: 10.1001/jamainternmed.2015.7676
- **54.** Switzerland. Swiss Academy of Medical Sciences. End-of-life care [Internet]. Basel: SAMS; 2013 [acesso 19 out 2023]. Disponível: https://bitly.ws/3esHh

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