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NUTRITION AND HYDRATION IN THE END-OF-LIFE CARE: ETHICAL ISSUES

A.R.
ARTIGO DE REVISÃO

NUTRIÇÃO E HIDRATAÇÃO EM FIM DE VIDA: QUESTÕES ÉTICAS

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ABSTRACT

The last decades brought huge advances in medical technology and pharmacology. One area that reflects this progress has been the administration of nutrition and hydration. These are controversial therapies at the end of life, especially when administered by artificial means. The objective of this review was to discuss and comprehend the current and global knowledge about ethical issues related to food, nutrition and hydration in the end-of-life care. The problematic situations analyzed include: advanced directives, the concept of basic human care or treatment, the meaning of food and fluids, the withholding and withdrawing of nutrition and hydration, risks and benefits of nutritional support and the concept of voluntary stopping eating and drinking.

KEYWORDS

Artificial hydration, Artificial nutrition, End of life, Ethics, Oral feeding, Palliative care

RESUMO

As últimas décadas originaram inúmeros avanços na tecnologia médica e farmacológica. Uma das áreas que reflete esse progresso tem sido a administração de alimentação, nutrição e hidratação. Representam áreas controversas do cuidar em fim de vida, especialmente se administradas pela via artificial. O objetivo desta revisão foi discutir e compreender o conhecimento atual e global relativamente às questões éticas relacionadas com a alimentação, nutrição e hidratação no fim de vida. As situações problemáticas analisadas incluíram: diretivas antecipadas de vontade, o conceito de cuidado humano básico ou tratamento, o significado da alimentação e hidratação, a suspensão e abstenção de nutrição e hidratação, riscos e benefícios do suporte nutricional e o conceito da cessação voluntária de nutrição e hidratação.

PALAVRAS-CHAVE

Hidratação artificial, Nutrição artificial, Fim de vida, Ética, Alimentação oral, Cuidados paliativos

INTRODUCTION

The foundation of the traditional medicine ethics was established by the Hippocratic Oath and the normative and ethical books containing the Hippocratic *Corpus*. In this oath the physician had the commitment to use medicine for patients' benefit (1). Furthermore, the Hippocratic tradition warned physicians not to cure people with advanced illness, not having determined it as a mere suggestion or guideline but something that should not be done (2).

In the Middle Age when Christianity established the moral foundations for Europe, the Hippocratic Oath has undergone several changes focused on Christian morality which modified the fundamental structure of that specific ethical code. Then the Medieval Church has raised human life to a sacred state, so that life should be preserved at all cost. Thus, the preservation of life has become the target of Medicine (1, 2). The emphasis given to compassion and brotherhood of man, central to Christianity, made beneficence and non-maleficence become the only reasons to be achieved in the practice of medicine (3).

In more recent times, according to some authors, medicine as a human activity is necessarily a form of charity. It is a response to the needs of an ill person that could die or suffer unnecessary from pain or disability without treatment (4). Although the medical field has evolved in order to promote good, this has been seen as a duty to cure the disease and preserve life (5). At this point, the art of care lost its purpose: caring (6). So if every illness occurs by natural means and if all diseases can be cured, then the preferred alternative is no longer letting nature take its course but fight the disease instead (2).

Medical advances, from the twentieth century were innumerable (7). The scientific, technological, social and economic development that occurred late last century solved many health problems. However, in the early twenty-first century we are faced with new challenges (8). Increased longevity has led people to discuss the consequences of prolonging lives and this created an increased number of

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patients beyond the therapeutic possibilities of cure and, consequently, more dependent for longer periods of time until death (9). Advances in medicine generated in human beings the idea of immortality, putting on the shoulders of health care professionals the responsibility and wisdom they do not have (9, 10).

At present it is necessary to recognize that the goals of a significant number of health care professionals are still linked to a preponderant biomedical model centered on the maintenance of life seen as absolute (10). In this specific case we are developing a review through the most controversial issues in the end-of-life care: food, nutrition and hydration. Here we review situations which health care professionals may be faced with: the meaning of food and fluids, advanced directives, Voluntary Stopping of Eating and Drinking (VSED), withholding and withdrawing of nutrition and hydration (11-16).

Ethical Issues about Food, Nutrition and Hydration at the end of life

Advanced Directives

Firstly, before discussing ethical issues about nutrition and hydration we should be aware of the current legal setting in Portugal. In this country competent patients may express their wishes and decisions regarding what treatment related to nutrition and hydration they accept to take in the end of life. This can be done through advanced directives using a living will or/ and by a heath care proxy nomination (17, 18). By these two ways patients express their willingness consciously, within a free and informed decision-making process, regarding the nutritional care they wish to receive if it is not possible to express their wishes at a later stage of the disease (17, 18). So in these cases patients' autonomy prevails instead of what health care professionals may decide to be the best option. Advanced directives may not be followed, for example, if there is a new treatment in the course of the illness. However, if the patient is not competent to decide, health care professionals may have to make a decision based on what they assume the patient would want to do or based on information given by family members (18, 19).

Basic Human Care or Treatment

One of the ethical issues discussed in the end of life is if nutrition and hydration are considered basic human care or treatment (16, 18-21). Regarding this issue some authors refer that, in some cases, starting artificial nutrition and hydration (ANH) will only prolong suffering and consequently it is legitimate to withhold or withdraw these measures. Some authors argue that, from the moment nutrition is administered by the artificial route it should be considered as treatment and subjected to a rigorous assessment of risks and benefits and if it is considered futile it should be stopped (22, 23). Other authors report that if we compare ANH to breathing, as an indispensable element to life, we can consider it a basic care. However, even compared with other clinical situations, withdrawing ventilation or dialysis may somehow look different than suspending ANH (19).

According to some authors, withholding or withdrawing ANH may be justified in some circumstances, for any age group, like other life support technologies, and there is no morally relevant difference between the various life-support technologies and ANH (16,24). The Academy of Nutrition and Dietetics states that ANH are included in the definition of life-sustaining medical treatment (25) and they do not always contribute to the benefit of the patient (16,24). Other authors argue that ANH is unquestionably a basic care because it does not restore any basic life function so that it must be given to all human beings, simply because they are alive and if they are alive there is an obligation to provide them the means to be properly fed and hydrated (12, 17, 18, 26, 27). Another argument against is that withholding or withdrawing ANH may cause death with additional suffering and pain (20). The Academy of Nutrition and Dietetics refers that the concept of "when in doubt, feed" is applicable to most individuals. Feeding should start immediately when the patient is medically stable and continue until the treatment is futile (25).

The Meaning of Food and Fluids

Several authors point out that the concept of food, nutrition and hydration as a basic human care or treatment is based on the meaning that food and fluids have on human life (19, 21, 26-28). According to some authors, food and fluids play a central role in patients' life (29, 30) because they hold a physiological and psychological function (31) based on an emotional and symbolic significance (32) including cultural (33, 34), social (33, 35, 36, 37, 38, 39) religious (14, 37, 39, 40) and spiritual values and beliefs (12, 14, 27, 33, 35-38). Food and fluids, whether offered orally or by the artificial route, represent a form of affection and care (39, 40) and because of that, over time, the concept of nutrition and hydration started to be compared with food and drink as an extension of care, affection and support. From this perspective, withholding or withdrawing ANH means denying food and fluids to the patient (19, 35). ANH is not synonymous of feeding someone, nor eating or drinking. The person eats from a social point of view - orally or by mouth - and using normative social equipment - knife, cup or fork. ANH is not encompassed in the normative social component that oral feeding and drinking have. In fact, only just over a decade ago feeding tubes were called "forced-feeding" (19).

Withholding and Withdrawing Nutrition and Hydration

Withholding and withdrawing ANH at the end of life is a highly controversial topic. Many authors discuss whether this represents a form of neglect, euthanasia, assisted suicide, torture or worse: a way of making a person die slowly and painfully (20, 39). The symbolic character of affection associated with the act of eating and the idea of suffering associated with death by hunger and thirst is deeply rooted to the thinking of many societies worldwide (41). Relatives, in particular, very often refer that the loving one is not dying as a consequence of illness but as a consequence of starvation and thirst and this can cause conflict between families and health care teams (42-44).

From an ethical point of view it is sometimes discussed if withholding and withdrawing ANH is associated with the concept of killing or letting die by starvation and thirst. However it is clear that hunger is defined as a condition that occurs when a person wants to eat but have no food. The feeling of hunger is present in this case. For a terminally ill person hunger is not present (45) and if undernutrition occurs it is not synonymous of starvation nor dehydration is identical to thirst (24). In addition, several studies report that patients in the end of life who are not fed or hydrated feel comfortable and some authors report euphoric feelings that may be explained by the release of endorphins (45).

According to the European Society for Clinical Nutrition and Metabolism (ESPEN) withdrawing or withholding a treatment that provides no benefit or has become disproportionate is, from an ethical and a legal point of view, the same. However these guidelines emphasize that if a therapy is being stopped, standard or palliative care and comfort still have to be provided to the patient (46).

Dementia is one of the most discussed diseases regarding these issues due to patients' lack of decision-making capacity. Related to this, ESPEN emphasizes that the decision to discontinue artificial feeding in dementia might be misunderstood as an order "do not feed" as nutrition is associated with life and its absence with starvation. For patients with eating difficulties, the feeding care plan should be called oral "comfort feeding" (46).

However, patients with dementia who require tube feeding only for a period of time in regard to disease directed treatment with a perspective of returning to oral intake, have an acceptable risk/ benefit ratio (46).
In the dying patient there are no clear criteria to ascertain the beginning of the dying phase, therefore nutritional intervention in this phase of life should be followed individually (46). The Academy of Nutrition and Dietetics recommends against the use of ANH in the terminal phase of dementia (25).
Other disease where ethical issues arise is the persistent vegetative state and ESPEN guidelines indicate that once the diagnosis of persistent vegetative state is established an advanced directive or the presumed will of the patient have to be considered and stopping ANH may be an option (46).
Generally, whatever the disease, the Academy of Nutrition and Dietetics states that feeding may not be desirable if death is expected within hours or a few days (25).

Risks and Benefits of Nutritional Support

ANH is subject to considerable risks that may contribute negatively to patients' comfort, quality of life, well-being and survival. For example, regarding enteral nutrition, nasogastric tubes may not only cause aspiration pneumonia particularly in debilitated patients but also diarrhea, vomiting and esophageal perforation, Percutaneous endoscopic gastrostomy may cause nausea, vomiting, among others (16, 17, 47).
If Parenteral Nutrition becomes an option, the use of central venous catheters may cause pneumothorax, bleeding and infection. The use of peripheral venous catheters may also result in pain and infection (16, 17, 26). In patients with decreased or absent renal function, fluid administration may cause peripheral or pulmonary edema (16, 17, 47).
According to ESPEN, Parenteral Nutrition has become an integral part of palliative care in cancer mainly, allowing increased survival in terminal patients without gastrointestinal access who would have died from starvation and not primarily from their malignant disease (46).
According to the same association, if the risks and burdens of ANH for a specific patient outweigh the potential benefits, then there is an obligation of withholding it. These guidelines also emphasize that in case the feasibility or efficacy of ANH is uncertain it is advisable to administer this therapy on a trial basis. In case of complications or if the desired success is not achieved the attempt should be discontinued. The justification for ANH must be reviewed at regular intervals, determined in accordance with the patient's condition (46).

Voluntary Stopping of Eating and Drinking

VSED is remarkably understudied (48, 49) and the discussion about this kind of decision is recent in literature. Nonetheless it is known that the use of this practice has been described at least since ancient Greece, for achieving a good death (12).
In literature, VSED has also been referred as: voluntary refusal of food and fluids, voluntary terminal dehydration, voluntary death by dehydration, terminal dehydration, stopping eating and drinking, patient refusal of hydration and nutrition, and indirect self-destructive behavior (50). It is defined as the attitude of competent patients – so without cognitive impairments - with advanced chronic diseases that willing to die decide to stop feeding and hydration or to stop eating and drinking orally because unacceptable suffering persists (51-53). This definition does not include the cessation of nutrition or hydration for other reasons, such as loss of appetite or inability to eat or drink due to disease's progression (51). Some patients are motivated by physical factors such as debility, weakness, and pain. However in most cases, reasons to the request for a hastening death are: weariness with the dying process, desire to control the circumstances of death, feeling that quality of life is poor, desire to die at home and feeling that life lacks meaning (50). Other reasons pointed out by some authors are: deterioration of health status, the burden of living outweighing any associated benefit, and no perspective or reason to be alive. Palliation may be ineffective and may not relieve discomfort which reinforces patients' wish to hasten death. Being tired of living or "having it done" is also expressed by many patients, according to some authors (51-53). Many patients usually experience a combination of these and other factors (50). In this context, all patients have the right to refuse nutrition and hydration, because it is a decision legally and medically acceptable for a competent patient (52, 54). It can also be considered a form of suicide and therefore be considered illegitimate (51). Other authors believe that collaborating with patients who wish to hasten death is morally impermissible (51, 54, 55). However, if a patient makes this decision, health care teams have no right to coerce the patient to act otherwise or impose feeding and/ or artificial hydration (51).
Death by VSED usually takes 10 to 15 days (56) and may begin with increased suffering by the presence of hunger and thirst, however in the terminally ill that usually does not happen. Anorexia, a symptom usually prevalent at this stage, may even facilitate compliance with the decision. Xerostomia accompanying dehydration can be solved by moistening the mouth. In fact, VSED does not seem to involve significant discomfort. Fasting leads to the release of endorphins, contributing to patient's comfort. However, it requires a persistent decision and therefore it should not be an impulsive act, as it often happens with suicides. The period of time until death is an opportunity for the patient to eventually change the previous decision and start eating and drinking again (51).
Many patients develop weight loss, lethargy, weakness and increasing immobility. Reduced food intake causes less gastric contractions and leads to reduced hypothalamic stimulation and anorexia. With glucose and protein lacking from diet the body will turn to the metabolism of fat stores. As a result, ketone levels raise and suppress hunger and thirst. The use of fat as the main energy source may lead to muscle breakdown, greater endogenous water production and a reduced need for fluid intake. Decreased urea production means that less water needs to be excreted by kidneys (57). Some authors state that VSED is considered an alternative to physician assisted suicide and voluntary active euthanasia (51, 54). According to ESPEN, the renouncement of food and fluids may be regarded as an expression of self-determined dying by way of an autonomous decision towards one's own life, but should not be confused with severe depression or disease related lack of appetite (46).

Artificial Hydration

Regarding to hydration some authors consider it separately from nutrition because they are different therapies (46). The controversy associated with artificial hydration not only involves medical paradoxical positions from a technical point of view, but also an intense debate about the ethical issues associated. ESPEN indicates that it can be performed by the enteral route or by hipodermoclyses. It has to be considered that artificial hydration requires a specific goal (as artificial nutrition) and it is associated with specific benefits and risks (46).
Controversy is mainly generated about the advantages and disadvantages of it (14, 42, 43). Among the criteria for starting artificial hydration potential benefits must be taken into account, such as preventing or alleviating symptoms which are frequent and cause great distress in the late stages of life (12). If the option is not hydrating, this may be beneficial for some patients because it may increase the sensation of analgesia with less episodes of incontinence (58-62). Among the arguments against artificial hydration they include

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various risks, such as prolonging life in agony, increasing pain and other symptoms (60, 61, 63).

Artificial hydration has sometimes the same symbolic, cultural or religious meaning as food. This meaning should be respected in the decision-making process at the end of life. In this context, values and moral principles, such as respect for life, death and human dignity must also be taken into account (63, 64). If the patient is thirsty this symptom can be alleviated with simple and noninvasive measures such as mouth care, wetting the mouth and lips using ice chips, crushed ice, unsweetened tea or water or artificial saliva (17, 61). Several discussions about dehydration often catalogue a long list of troubling symptoms that can contribute to the loss of quality of life and comfort (Table 1).

The issue of rehydration is also a concern. It is used to the symptomatic relieve of delirium and to improve glomerular filtration which mitigates the adverse effects associated with the accumulation of opioid metabolites (61).

Table 1

Consequences of dehydration (12, 47, 61, 65)

BODY SYSTEM AFFECTED	CONSEQUENCES
Cardiovascular	Hypotension, tachycardia, syncope, dizziness, fatigue, possible decrease of pericardial fluid
Gastrointestinal tract	Constipation, decreased secretions, cramps, pain and vomiting
Metabolic	Hypernatremia, hyponatremia, hypercalcemia
Mouth	Dry mouth, thirst, difficult in talking
Neuromuscular	Cramps, myoclonus, ataxia, neuromuscular irritability
Neuropsychiatry	Mood and personality changes, apathy, lethargy, confusion, coma, obtundation, decreased cerebral oedema, seizures
Pulmonary	Dry airway, decreased pulmonary congestion, wheezing, cough and pleural effusion
Skin	Poor turgor, predisposition to develop pressure ulcers
Urinary Tract	Decreased glomerular filtration, decreased of clearance of normal metabolic products and creatinine, azotemia, accumulation of metabolites, decreased urinary tract infections

CRITICAL ANALYSES AND CONCLUSIONS

It is now 2,500 years since Hippocrates stated his four pillars of medical ethics. Autonomy, beneficence, non-maleficence and justice have formed the foundations of decision-making process to medical ethics, but as the years went by, those principles were ignored, changed, distorted and for several times misinterpreted. The ethics of caring for those with feeding and drinking issues towards the end of life have been challenged by the introduction of artificial interventions.

From this literature review we can affirm that advanced directives should be encouraged before capacity to decide is lost. In order to achieve this, patients and also family members must be always informed about the possibility of elaborating advanced directives through a living will and/or by nominating a healthcare proxy. Despite the existence of this possibility it seems that currently in Portugal the population is not aware of this information.

After completing this review, we observed that the same ethical issues discussed decades ago are the same today. In a lot of issues we concluded that there was not a huge development in the area of nutrition and hydration in the end-of-life care although VSED seems to be more often referred in the literature. Despite this, there is still lack of original research in this field. Decision-making regarding ethical issues in palliative and end-of-life care may interfere with feelings, emotions and attitudes. As some authors affirm (16, 17, 29, 63) in several occasions, health care professionals are faced with their own professional dilemmas and with the fear of being accused of killing or letting someone die. Legally, withdrawing and withholding nutrition and hydration is indistinguishable however many patients, family members, and health care professionals find removal to be more emotionally charged because it is compared to abandon or neglect. Some authors (16, 17) emphasize that Nutritionists working in palliative care must develop their interventions from the point of view of risks and benefits, and the benefits of nutritional support should always outweigh the risks. The same authors (16, 17) state there is a strong need to integrate Nutritionists in palliative care teams in order to clarify myths, doubts and fears surrounding feeding, nutrition and hydration. They also reinforce that there is lot of work to be done in this field and it is imperative that Nutritionists develop in-depth knowledge about clinical nutrition, medicine, cultural and religious values, health care and law issues, communication and empathetic strategies in order to use their knowledge with patients and family members.

In Portugal, the Nutritionists' Code of Ethics has general guidance that can be related to all areas of nutritional sciences. It encompasses the values and ethical principles that should guide the performance of Nutritionists. It also reflects a foundation of ethics and deontology for them, valuing the general principles of autonomy, non-maleficence, beneficence and justice. It specifies that Nutritionists must not act in areas which they do not have proper knowledge and education and it makes reference to patients' dignity and the Nutritionists' duty to make nutritional interventions after an informed choice, respecting always patients autonomy. It is known that the contents of this document are also intended to draw the attention of Nutritionists to the need for an ongoing discussion about ethical issues, which is not exhausted in the Code.

Although palliative and end-of-life care is a very delicate area, Nutritionists' professional code of ethics should clarify every possible intervention about specific clinical cases in this caring area and clarify the Nutritionist´ role in ethical deliberation.

As a professional class, there is also a strong need for Nutritionists to define their core, clinical and ethical skills and competences in the area of palliative and end-of-life care.

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