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e-SPEN guideline

ESPEN guideline on ethical aspects of artificial nutrition and hydration

Christiane Druml [a, *], Peter E. Ballmer [b], Wilfred Druml [c], Frank Oehmichen [d], Alan Shenkin [e], Pierre Singer [f], Peter Soeters [g], Arved Weimann [h], Stephan C. Bischoff [i]

[a] UNESCO Chair on Bioethics at the Medical University of Vienna, Collections and History of Medicine – Josephinum, Medical University of Vienna, Waehringerstrasse 25, A-1090 Vienna, Austria
[b] Department of Medicine, Kantonsspital Winterthur, Brauerstrasse 15, Postfach 834, 8401 Winterthur, Switzerland
[c] Division of Nephrology and Dialysis, Department of Internal Medicine III, Medical University of Vienna, Waehringer Guertel 18-20, 1090 Vienna, Austria
[d] Department of Early Rehabilitation, Klinik Bavaria Kreischa, An der Wolfsschlucht 1-2, 01731 Kreischa, Germany
[e] Department of Clinical Chemistry, University of Liverpool, Duncan Building, Daulby Street, Liverpool L69 3GA, UK
[f] Department of General Intensive Care and Institute for Nutrition Research, Rabin Medical Center, Beilinson Hospital, Petah Tikva, Jean Leven Building, 6th Floor, Tel Aviv, Israel
[g] Department of Surgery, Academic Hospital Maastricht, Peter Debeyelaan 25, P.O. Box 5800, 6202 AZ Maastricht, The Netherlands
[h] Department of General Surgery and Surgical Intensive Care, St Georg Hospital, Delitzscher Straße 141, 04129 Leipzig, Germany
[i] Department of Nutritional Medicine, University of Hohenheim, Fruwirthstr. 12, 70599 Stuttgart, Germany

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SUMMARY

Background: The worldwide debate over the use of artificial nutrition and hydration remains controversial although the scientific and medical facts are unequivocal. Artificial nutrition and hydration are a medical intervention, requiring an indication, a therapeutic goal and the will (consent) of the competent patient.

Methods: The guideline was developed by an international multidisciplinary working group based on the main aspects of the Guideline on "Ethical and Legal Aspects of Artificial Nutrition" published 2013 by the German Society for Nutritional Medicine (DGEM) after conducting a review of specific current literature. The text was extended and introduced a broader view in particular on the impact of culture and religion. The results were discussed at the ESPEN Congress in Lisbon 2015 and accepted in an online survey among ESPEN members.

Results: The ESPEN Guideline on Ethical Aspects of Artificial Nutrition and Hydration is focused on the adult patient and provides a critical summary for physicians and caregivers. Special consideration is given to end of life issues and palliative medicine; to dementia and to specific situations like nursing care or the intensive care unit. The respect for autonomy is an important focus of the guideline as well as the careful wording to be used in the communication with patients and families. The other principles of Bioethics like beneficence, non-maleficence and justice are presented in the context of artificial nutrition and hydration. In this respect the withholding and withdrawing of artificial nutrition and/or hydration is discussed. Due to increasingly multicultural societies and the need for awareness of different values and beliefs an elaborated chapter is dedicated to cultural and religious issues and nutrition. Last but not least topics like voluntary refusal of nutrition and fluids, and forced feeding of competent persons (persons on hunger strike) is included in the guideline.

1. Introduction

Every human being needs nutrition and hydration to live. As long as a person can eat and drink to cover the nutritional requirements and also wishes to do so, there is no need for intervention. Problems arise when a person cannot eat or drink anymore or does not get enough nutrients or liquids.

* Corresponding author. Tel.: +43 (1) 40160 26050.
E-mail addresses: christiane.druml@meduniwien.ac.at (C. Druml), peter.ballmer@ksw.ch (P.E. Ballmer), wilfred.druml@meduniwien.ac.at (W. Druml), frank.oehmichen@klinik-bavaria.de (F. Oehmichen), shenkin@liverpool.ac.uk (A. Shenkin), psinger@clalit.org.il (P. Singer), pb.soeters@ah-unimaas.nl (P. Soeters), Arved.Weimann@sanktgeorg.de (A. Weimann), bischoff.stephan@uni-hohenheim.de (S.C. Bischoff).

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Assisting the natural oral intake of food is an integral aspect of appropriate medical and nursing care. When independent ingestion of food and liquids is disturbed, nursing and medical procedures serve to cover the individual's vital need for nutrition as well as fulfill these natural requirements with the purpose of enabling the individual to participate optimally in his/her social environment. Nutritional therapy includes oral, enteral and parenteral ways of artificial feeding.

This guideline provides a critical summary for caregivers in regard to the ethics of artificial nutrition and hydration therapy. The guideline is focused on the adult; ethical aspects may differ in children and adolescents.

2. Methodology

This document was originally based on the main aspects of the guideline on "Ethical and Legal Aspects of Artificial Nutrition" published 2013 by the German Society for Nutritional Medicine (DGEM) [1]. However, the present guideline was extended and introduced a much broader view, namely the impact of culture and religion. The multi-disciplinary, international working group responsible for this document comprised representatives from Austria, Germany, Israel, the Netherlands, Switzerland and the UK.

The methodology followed in principle the new ESPEN guideline methodology published recently with some modifications [2]. In particular, we resigned to indicate levels of evidence, because for most issues clinical trials are lacking. However, appropriate literature was searched and included in the commentaries. Key words for the literature research were *artificial nutrition, enteral nutrition, parenteral nutrition, hydration, ethics, end of life, palliative medicine, dementia, culture, religion.* In view of the specific nature of the subject covered, it was not possible to evaluate the evidence in the literature using methods customary in the clinical field.

An initial draft of the chapter's focal points was presented in June 2015 and discussed in a meeting of the Working Group in Vienna to specify the layout in detail and discuss the main points of its content. The resultant draft text was circulated in the entire Working Group. Following incorporation of all comments and corrections, the Guideline was presented by the head of the Working Party during a Consensus Conference on the occasion of the ESPEN Congress in Lisbon, Portugal in September 2015. In addition to the Working Group, members of the ESPEN society were invited to comment and vote on the recommendations. In total, 74 experts participated in the conference. The range of voting participation was between 24 and 74 persons. If more than 90% of the participants agreed with the statement it was a *"Strong Consensus"* and if 75–90% of the participants agreed with the statements a *"Consensus"*. Less than 75% agreement did not occur. Feedback was taken into account. The text including the statements commentaries was finally approved by all members of the Working Group and by the members of ESPEN (members of the other ESPEN Guideline Working Groups and of the different ESPEN committees) via a Delphi process. Comments were taken into account. The terminology is oriented on the DGEM terminology [3] and the yet unpublished ESPEN terminology (Cederholm T et al. Manuscript in preparation).

The activities of the members of the Working Group were undertaken in an honorary capacity; the costs of the Working Group's one and only meeting were borne by ESPEN.

3. Requirement and definitions

Statement 1:

Prerequisites of artificial nutrition and hydration are

1. *an indication for a medical treatment and*
2. *the definition of a therapeutic goal to be achieved and*
3. *the will of the patient and his or her informed consent.*

In all cases however the treating physician has to take the final decision and responsibility. [Strong Consensus]

Commentary

When oral intake of food and liquids is not possible anymore or does not adequately provide nutrients, and medically assisted nutrition and hydration have to be considered, we are confronted with a medical intervention that requires specific rules indicated in the statement.

Artificial nutrition: includes oral nutritional supplements (ONS), enteral nutrition (EN) or parenteral nutrition (PN). Enteral delivery of nutrients includes nasogastric and nasogastrojejunal tubes or percutaneous endoscopic gastrostomy (PEG) or jejunostomy (PEG-J) or surgically induced feeding tubes. Parenteral delivery can involve peripheral intravenous access or central venous access [3].

Artificial hydration: provision of water or electrolyte solutions by any other route than the mouth. This can be achieved by tubes, intravenous and subcutaneous (= dermoclysis) administration [3].

4. Ethical framework

Statement 2:

The ethical principles "autonomy, beneficence, non-maleficence and justice" are internationally recognized. They are interrelated and have to be applied in the act of medical decision making. [Strong Consensus]

Commentary

These bioethical rules have been described by Beauchamp and Childress discussing moral issues since ancient times, for instance in the Hippocratic Oath. The four principles are independent of any specific ethical theory and can be applied universally. They are an "attempt to put the common morality and medical traditions into a coherent package" [4].

4.1. Respect for autonomy

Statement 3:

Autonomy does not mean that a patient has the right to obtain every treatment him or her wishes or requests, if this particular treatment would not be medically indicated. [Strong Consensus]

Commentary

The principle of autonomy recognizes the right and the capacity of a person to make a personal choice. The focus is on the individual and his or her ability to decision making in healthcare and research, on informed consent and refusal. Autonomy can only be exercised after having obtained full and appropriate information as well as having understood it (comprehension). The decision has to be taken without any undue coercion or pressure. Consent can be withdrawn at any time without giving a reason [5]. Self-determination includes the right to refuse support, even if such refusal may be difficult to understand by others.

Statement 4:

A competent patient has the right to refuse a treatment after adequate information even when this refusal would lead to his or her death. [Strong Consensus]

Commentary

For persons who cannot exercise their autonomy as they do not have the capacity to consent, there are usually legal representatives to play a decision making role. Persons who are incapable to consent are persons legally not entitled to give consent (minors), or

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persons who are incapacitated because of their mental disability or disease. Incapacity due to disease might be in an acute situation due to sepsis or stroke or on long-term. Both require a different approach [6].

Nevertheless even persons who are legally not capable to give consent have the right to express their wishes and their objection to a medical intervention should be taken into account.

In any case artificial nutrition and hydration are medical interventions and require a predefined achievable treatment goal and the informed consent of the competent patient [6].

4.2. Beneficence and non-maleficence

Statement 5:

If the risks and burdens of a given therapy for a specific patient outweigh the potential benefits, then the physician has the obligation of not providing (withholding) the therapy. [Strong Consensus]

Commentary

Health care personnel have the obligation to maximize potential benefits for their patients while at the same time minimizing potential harm for them ("Primum non nocere"). Still, there is a distinction between beneficence and non-maleficence as those two principles have clear and different obligations.

In maximizing potential benefits health care personnel have to follow professional obligations and standards: they have to provide appropriate treatment following a medical indication – including nutrition- and hydration-therapy. Each decision has to be taken on an individual level. This means that they have to take into account the "overall benefit", the possible results of the treatment in regard to the disease, the quality of life and the psychological and spiritual well-being [7]. Any disproportionate treatment has to be avoided. Prolonging of life may never be the sole goal and always has to be put in relation to the wellbeing of the patient. Prolonging of life may never turn into prolonging of the dying phase.

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 it is to be emphasized that if a therapy is being stopped, standard care or palliative care – comfort – still has to be provided to the patient [8].

Statement 6:

Even when artificial nutrition and hydration will be stopped, standard care to maintain a best possible quality of life to the patient has to be maintained. [Strong Consensus]

Commentary

Applied to artificial nutrition and hydration there are many indications for administering it which are beneficial and prolong life: In particular patients in short term critical care, or patients with gastrointestinal disease, patients with a chronic neurological disease or patients in a permanent vegetative state (see chapter 6.3). For many other conditions according to the current medical literature there is evidence that it is not beneficial as the risks, potential complications and burdens outweigh the benefits [9]. In these cases artificial nutrition and hydration should not be given. The decision to administer or withhold artificial nutrition and hydration should never limit offering the best palliative care to maximize comfort and quality of life to the patient. The present guideline selects specific situations in order to give guidance for the caregiver in difficult medical decisions.

Statement 7:

Artificial nutrition is used in accordance with a realistic goal of individual treatment, and the wishes of the patient himself/herself, and based on assessment of the situation by the doctor and other healthcare professionals. [Strong Consensus]

Commentary

The patients should always be viewed in the context of the achievable or indicated medical options as well as social and cultural values. An individual's nutrient requirements can be fully covered by tube feeding as well as parenteral nutrition. However, other needs like the enjoyment of food and social aspects of feeding including humane attention are not satisfied by these routes of food supply, and should not be neglected as such [9,10].

Statement 8:

Medical treatment is administered for the purpose of prolonging or preserving life (if necessary by accepting a transient deterioration in quality of life), or for the purpose of enhancing or preserving quality of life (if necessary by accepting a shortening the time left to live). [Consensus]

Commentary

Once the goal of treatment is defined, the physician and the nurse may suggest suitable methods to achieve this goal. Medical interventions intrinsically are associated with advantages and disadvantages or risks. From the medical point of view, one should employ the method that is effective and is likely to achieve the desired aim. The method should be associated with the lowest risk of potential harm. The risks and burden of artificial nutrition support regarding the creation of an access, the volume of fluid and the substrates to be administered should be included in these considerations. When bridging an acute and reversible disease or in patients with a permanent condition, these aspects may be rated very differently.

Statement 9:

In case the feasibility or efficacy of artificial nutrition is uncertain it is advisable to administer the therapy on a trial basis. In the event of complications or if the desired success is not achieved, the attempt should be discontinued. [Strong Consensus]

Statement 10:

The continued medical justification for artificial nutrition must be reviewed at regular intervals, determined in accordance with the patient's condition. [Strong Consensus]

Commentary

As the patient approaches the end of his life, the administration of food - specifically adapted to his needs in terms of calories and nutrients - becomes increasingly insignificant.

When the indication for artificial nutrition no longer exists (especially in case of no efficacy, therapy-resistant complications, or the immediate dying process), the doctor should be prepared to discontinue the nutritional therapy and communicate this decision clearly to the patient or his or her representative and family members, as well as the treatment team.

4.3. Justice

Statement 11:

Every individual is entitled to obtain the best care available. Resources have to be distributed fairly without any discrimination. On the other hand treatments which are futile and do only prolong the suffering or the dying phase, have to be avoided. In regard to limited resources there has to be proper use of ethically appropriate and transparent criteria. [Strong Consensus]

Commentary

The principle of justice refers to equal access to health care for all. Limited resources – including the time doctors and other health personnel and caregivers devote to their patients – have to be evenly distributed to achieve a true benefit for the patient. All the more, expensive nutritional therapies should always be, like any other therapy, provided solely when indicated. However

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undertreatment may never be the result of containing the growing costs of healthcare.

Basic principles: Based on the ethical principle of "non-maleficence" patient-centred awareness for metabolic and nutritional problems including the appropriate screening and assessment measures regarding the indication for artificial nutritional support is an essential medical requirement [11].

The risks of starving and inappropriate feeding in hospitalized patients are unequivocal [12].

There are clear data from the Nutrition Day about the risks for mortality from inadequate feeding in the hospital [13].

5. Fundamentals

5.1. Oral nutrition support and tube feeding

In the presence of a specific medical need or if the patient is unable to take in food orally, the natural diet can be fortified and supplemented with the aid of liquid diets (oral nutrition supplements, ONS). If this procedure proves insufficient, enteral nutrition (EN) can be applied to feed the patient via a tube and thus bypassing the action of swallowing. The most important point in oral nutritional support or tube feeding and an advantage over delivering fluids and nutrients by the parenteral route is to support intestinal functions to the greatest possible extent.

In defined combinations and preparation forms, industrially manufactured liquid supplements according to the EU Commission regulations [14] for oral administration and for gastric or enteral tube feeding serve clearly defined therapeutic aims and therefore constitute a type of artificial nutrition.

Tube feeding constitutes artificial nutrition in two respects: firstly, it uses industrially manufactured food for certain therapeutic medical purposes in a defined combination and preparation form, and secondly, it uses specific access routes to the gastrointestinal tract. Both the type and the access route selected for artificial enteral nutrition have their own specific benefits and risks.

5.2. Parenteral nutrition

When an individual's fluid and nutrient requirements cannot be covered sufficiently or not at all via the oral or enteral route, may nutrients and fluids be administered via the intravenous route. For these infusions an appropriate vascular access is required. Parenteral feeding and its access again are associated with specific benefits and risks.

5.3. Artificial hydration

Artificial hydration can be required also without artificial administration of nutrients. It can be performed via the enteral or parenteral (intravenous or subcutaneous) route. It has to be considered that also artificial hydration requires a specific goal (as artificial nutrition) and is associated with specific benefits and risks.

6. Special situations

Artificial nutrition can be performed nowadays in different settings (e.g. in hospitals, nursing care, at home). The ethical challenges, however, do not differ principally depending on this setting. In the following sections, particular settings and conditions are discussed in more detail with regard to ethical aspects.

6.1. Nutrition, hydration and old age

Statement 12:

Nutritional therapy for older patients is frequently intended not merely as a temporary measure, but to ensure a permanent supply of nutrition and hydration up to the end of life. Therapy can be effective until the dying phase in cases of chronic disease. The justification for such a treatment should be critically reviewed at regular intervals. [Strong Consensus]

Commentary

Older people are at special risk of developing dehydration. Impaired thirst sensation in the old is one of the leading causes. Age per se is also a risk factor of malnutrition and in addition old persons typically suffer from multiple diseases (comorbidities) resulting in malnutrition [15]. Age-related alterations call for complex ethical decisions because of the wide range of medical options [16,17].

In many instances old persons find it difficult to ingest food and the diversity of their diet is reduced. The interventions aimed at providing sufficient food of adequate quality and quantity is of crucial importance for preserving health and quality of life. The fact that, in the normal setting, human beings have cultivated the ingestion of food into a basic form of pleasure and an expression of the quality of life, gives rise to an ethical obligation in nutritional medicine: the ingestion of food should, as far as possible, convey a positive attitude towards life.

However, "nutrition until the end of life" does not basically differ from nutrition in the acute medical setting. The goal of therapy and the indication for starting and concluding the therapy should be established here in the same manner – while safeguarding the patient's self-determination.

Given the typical course of aging (which includes advancing multi-morbidity, the all-embracing psychosocial involvement of sick old people, processes that are often imperceptible, the advancing ineffectiveness of therapy), for a certain period of time it may not be possible to make a clear decision about potential treatment alternatives.

Statement 13:

As long as a well-founded decision cannot be made, the same principle applies as in all cases in which the preservation of life reaches its limits: in dubio pro vita (when in doubt, favor life). [Consensus]

Commentary

The application of this principle definitely encompasses the unconditional obligation to minimize or eliminate uncertainty as early as possible by initiating diagnostic measures and making all appropriate efforts to alleviate the situation.

Statement 14:

The renouncement of food and drink 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. [Strong Consensus]

Commentary

Frequently advanced age is associated with frailty and isolation as well as the absence of future perspectives, because of which older people forfeit their will to live and cease to ingest food as well as fluids in order to die.

It may be difficult to differentiate between a person's conscious relinquishment of the will to live and a psychiatric or organic disease calling for treatment; this needs a thorough medical evaluation. Provided no psychiatric disease is present or the psychiatric disease cannot be significantly improved by a therapy attempt, the tentative initiation or continuation of nutritional therapy must be adequately justified by the fact that it offers the patient realistic chances of improving his or her quality of life. This has to be

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communicated extensively with the patient in order to obtain consent to the treatment. Voluntary cessation of intake will be discussed in chapter 8.3 *Voluntary refusal of nutrition and fluids*.

6.2. Nutrition, hydration and dementia

Statement 15:

The decision to discontinue artificial feeding 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 requiring support an individual care plan has to be established. Such a feeding care plan should be called "comfort feeding" to avoid the negative connotation of the wording. Especially in regard to medical decisions at the end of life, appropriate terminology has to be carefully chosen. [Strong Consensus]

Commentary

Advanced stages of dementia are often associated with reduced nutrient intake which results in weight loss. In these situations caretakers and families are confronted with the decision regarding tube feeding to provide adequate nourishment for these patients. However it applies also in this situation that medically assisted nutrition and hydration are medical interventions and not only basic provision of food and fluids. Furthermore existing evidence shows that long term perspectives of those patients are not improved nor the risk of aspiration reduced when given nutrition via tubes. Another considerable risk for patients with dementia is that they are likely to be restrained while being fed via a tube as well as additional problems associated with the repeated removal of the feeding tube and/or the vascular access.

Still patients with dementia are increasingly given artificial nutrition via PEG-tube as their family members or surrogate decision makers feel that they cannot leave them "starve to death" [18]. Here, feeding is of "symbolic significance". Another reason is the lack of adequate information of physicians and nursing teams about the medical evidence as well as the bioethical and legal backgrounds [19,20]. Hence families and legal representatives do not get appropriate information about the risks and benefits of such a therapy and feel guilty to leave the patient without food and liquids.

"Comfort feeding" is a term avoiding negative connotations and defining an individualized feeding care plan [21]. Words shape our thinking, and our thoughts lead our acts. Words like "stopping artificial nutrition" are perceived negative and raise fear although they express evidence based fact [22]. In addition, approach may be different according to countries and cultures. For example, Mediterranean countries are more permissive regarding enteral feeding in dementia reporting increased length of life without effect on quality of life [22–24].

Statement 16:

For patients with advanced dementia priority should always be given to careful eating assistance (feeding by hand). [Consensus]

Commentary

Patients with dementia who require tube feeding only for a period of time in regard to disease directed treatment with a perspective of oral intake of food again, have an acceptable risk/benefit ratio. As long as patients with dementia have decisional capacity, they have to be included in the communication [25–27].

6.3. Nutrition, hydration and persistent vegetative state

Statement 17:

Artificial nutrition and hydration should be given in any case of uncertain prognosis. [Consensus]

Commentary

Persistent vegetative state is defined as an unconscious state after severe brain injury that lasts longer than a few weeks [28]. Terms and legal implications vary in the different countries. There is broad ongoing discussion about accuracy of diagnosis, the potential of recoveries and the extent of care such patients should receive, which exceeds by far the scope of this document.

After one year of posttraumatic persistent vegetative state, recovery is extremely unlikely. For non-traumatic persistent vegetative state chances of recovery after three months are exceedingly rare [28].

Statement 18:

Once the diagnosis of persistent vegetative state is established an advance directive or the presumed will of the patient have to be considered. If there is evidence which is applicable for the given case it has to be followed. [Strong Consensus]

Commentary

Several cases of patients with persistent vegetative state have received worldwide attention by the media. In all these cases the question of dispute was a potential withdrawing or continuation of artificial nutrition and hydration. For those patients feeding by hand is not an option, so the withdrawing of artificial nutrition and hydration would lead to their death. The presence of a potentially achievable and beneficial treatment goal is a prerequisite for patients in a persistent vegetative state in addition to their presumed or expressed will.

6.4. Nutrition, hydration and palliative care

Statement 19:

Artificial nutrition has become a part of palliative care, e.g. in neurological and in cancer patients, with the potential to increase survival and quality of life in selected patients. Long term home enteral and parenteral nutrition programs should be considered (for details see disease-related guidelines). [Strong Consensus]

Commentary

The WHO defines palliative care as an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems. Palliative care is a life-affirming approach that views dying as a normal process that, while it should not be accelerated, ought not to be impeded or prolonged either. The aim is to foster and sustain an optimal quality of life until death.

Parenteral nutrition has become an integral part of palliative care in cancer mainly, allowing increased survival in terminal cases without gastrointestinal access and who would have died from starvation and not primarily from their malignant disease. Long-term home parenteral nutrition programs are including these patients with reasonable results [29,30]. However, good evidence should support the use of artificial nutrition for each disease that may trigger the need for palliative care.

6.5. Nutrition, hydration and the dying patient (terminal illness)

Statement 20:

There are no clear criteria to ascertain the beginning of the dying phase. Therefore, a nutritional intervention in this phase of life should be followed in an individualized manner. [Consensus]

Commentary

While death is clearly defined and irrevocable, the end of a person's life is a process. This process is expandable per se and defining its beginning is subject to individual views and interpretation. In general the health state of old persons or people with debilitating diseases are slowly deteriorating. At a certain point

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deterioration accelerates, patients become bedridden and become dependent for most if not all functions to sustain life. Generally these patients suffer and derive no pleasure or feelings of wellbeing in this situation. This period may be prolonged by nutritional support, if people are predominantly starving and when a gain or preservation of quality of life is possible. If this is not possible, the intention of this treatment in dying persons is to satisfy hunger and thirst [31]. An individual's expressed wishes and needs may change in the final phase of his or her life. In fact, each person demonstrates a different type of behavior until the time of death. The indication for artificial nutrition should therefore be established at this time after careful and individualized consideration of the potential risks and benefits with the purpose of providing end-of-life care [32,33]. Administration of fluid and energy is not always needed at all times in this phase of life. Patients do frequently experience dryness of the mouth, an early sensation of saturation, nausea and an impaired sense of taste, but rarely hunger and thirst. Thirst generally results from unpleasant dryness of the oral cavity and crust formation and can be frequently relieved by oral care and small quantities of fluids, less than necessary to relieve dehydration. Parenteral administration of fluid does not necessarily alleviate the individual's thirst [8,34,35]. Besides, dryness of the mouth and thirst may also be the effect or side effect of medication, oxygen therapy, breathing through the mouth, or anxiety and depression. Therefore, dryness of the mouth and thirst should first be counteracted by nursing measures such as lip care (cleaning and moistening the lips) and mouth care with mouthwash, as well as repeated provision of small amounts of fluids. In the rare case that a patient is thirsty despite optimal care or when dehydration is associated with delirium, the effectiveness of artificial hydration could be reviewed but is doubtful in the dying phase [36,37]. At this time palliative sedation is another option and is increasingly applied [38].

6.6. Nutrition, hydration and nursing care

Statement 21:

Artificial nutrition should never be used for the purpose of reducing the workload and effort of nursing. [Strong Consensus]

Commentary

Especially tube feeding should be evaluated very carefully. Even in cases of an indwelling PEG, all options of natural food intake should have been exhausted (the pleasure of eating, the attention of nursing personnel, practicing the intake of food) [18,39–41]. In persons with dementia or those with severe cerebral damage, a feeding tube may still be used as a legitimate nursing aid in specific situations [20,42–44]. Even if provision of food through a tube involves less time and effort and may unburden the situation because the nursing staff need not be concerned about the patient's intake of fluid and calories it should be ensured that: all other options of adequate and natural food intake have been exhausted,

- a clear goal of treatment and a medical indication exist
- the feeding tube is used supportively
- the measure will offer foreseeable benefits for the patient because the time thus saved is used for the patient himself/herself and the patient can thus be cared for in his/her own home environment.

6.7. Nutrition, hydration and the intensive care unit (ICU)

Statement 22:

Artificial nutrition and hydration are standard therapies in critically ill patients. In this setting, as well as in other settings, it applies that when there is no treatment goal anymore – therapies are not indicated anymore (futile), they have to be withheld or withdrawn. [Consensus]

Commentary

Withholding or withdrawing a treatment that provides no benefit or has become disproportionate is from an ethical and a legal point of view the same. However it is to be emphasized that if a therapy is being stopped, standard care or palliative care comfort still has to be provided to the patient. This implies that even when artificial nutrition and hydration is stopped, standard care to maintain a good quality of life to the patient has to be maintained [45].

Even though often practiced in daily work, hydration and artificial nutrition should not be necessarily continued in ICU patients in the dying phase. Nevertheless there is still ongoing controversy and discordant belief in practice when to terminate artificial nutrition and hydration. This is due to the fact that there is more additional emotional value attached to provision of nutrition and hydration than for instance continuing antibiotics or other treatment, even though artificial nutrition and hydration can have adverse effects such as catheter complications and infections. In addition, hydration may even prolong and aggravate the dying phase [46,47].

7. Will, information and consent of the patient

7.1. The patient's right

Statement 23:

The will of the adult patient who is capable to provide consent and make judgments has to be respected in any case. [Strong Consensus]

Commentary

The basic requirements of informing the patient and obtaining his or her consent should be adhered to very carefully in nutritional therapy [7]. Artificial nutrition is a medical intervention and requires the informed consent of the patient [48] or the consent of his or her authorized representative (parents, care-giver, custodian or attorney). In a case of automatic entitlement of representation the representative should be selected according to the provisions of the respective laws in various countries. It should be ensured that, in the absence of a medical indication for nutritional therapy, the patient or his or her representative is informed by the physician, who is responsible for establishing and justifying the absence of an indication.

Statement 24:

As is true for any other medical intervention, the patient and his or her authorized representative should be informed about the nature, significance and scope of the measure, including potential complications and risks. [Strong Consensus]

Commentary

The information must include alternative treatment options (i.e. alternative routes of nutrition), as well as withholding artificial nutrition and its biological consequences. This information should be given in a decision making process. In case of surrogates an unbiased counsel of the physician may be helpful [49].

The ethical principles of informing a patient are violated when the decision-maker is biased by opinions and beliefs for instance in a situation where the patient is unconscious and the decision-maker is urged to act otherwise by family or surrogates, saying that the patient “may die of hunger or thirst”. Here, as in other situations, wording has to be chosen in a careful and prudent way [22].

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The patient's informed consent and the details of the explanation given to the patient should be documented in writing.

The patient or the authorized representative may dispense with further explanation. Such a waiver of clarification also must be carefully documented in writing.

7.2. The patient's capacity to consent

Statement 25:

Even if the patient is not legally competent in accordance with civil law, he/she might be still capable of expressing his/her wishes and participating in the decision-making process. [Strong Consensus]

Commentary

The patient is able to give his consent and make a judgment when he can see the benefits, risks and scope of the intervention or when no treatment is instituted, and the patient is able to make an autonomous decision. The decision to apply artificial nutrition is simple from the intellectual point of view, yet a complex emotional issue. The patient's ability to consent should, in principle, be reviewed anew by the treating physician with regard to every therapeutic decision, and documented in writing along with the details of the explanation provided to the patient. The focus should be on the psychological or legal point of view to make a decision. In doubtful cases a psychiatric or neurological consult may help to decide whether the patient is able to make a sound judgment.

7.3. The patient's incapacity to consent

Statement 26:

In case a patient is unable to give consent and make judgments, the representative (authorized according to different rules depending on the countries law and practice) takes the decision. The representative has to implement the presumed will of the patient. If the representatives' decision is delayed, the physician should start artificial nutrition according to evidence based medical indication. [Strong Consensus]

Commentary

In the case of a patient who is unable to provide consent, one should first determine whether the patient's consent to artificial nutrition was provided in advance, for instance verbally or in a written advance health care directive, or was explicitly not provided or refused [50,51].

An advance health care directive is a direct expression of the patient's will. It is a binding document for physicians and nursing staff, provided it includes statements concerning clearly defined situations. The expression of a will or advance health care directive may be revoked by the patient at any time even informally. This may occur explicitly, for instance verbally, or even by specific forms of behavior. Repetitive reflex-driven gestures should not be interpreted as refusal to be treated.

7.4. Advance directives

Statement 27:

Patients are authorized/encouraged to establish an advance directive or a living will according to the specific laws in their countries. Certain requirements have to be fulfilled to ensure validity. Valid advance directives must be respected according to the country's laws and by the treating physicians. [Consensus]

Commentary

In the situation that a patient has lost the capacity to consent previously expressed wishes have to be taken into account. Wishes expressed in advance can take various forms. For example if the patient has confided his views to a family member, or close friend or other persons of trust, this can be documented in order to establish proof of his (presumed) will. A representative can also be appointed to bear witness to and pass on the patient's wishes when the patient is incapacitated and cannot express his wishes. A patient can refuse a treatment in an advance directive. He cannot ask for a specific treatment if there is no medical indication for this treatment [52,53].

Laws regarding advance directives (legal documents that allow a person to write down his or her wishes in case he or she is not capable anymore to take part in a decision making process) are increasingly introduced within States. This proves that autonomy is replacing the old paternalistic attitude within medicine. Among the most important issues regarding the content of such a document are the use of dialysis and respirators, resuscitation in case of cardiorespiratory failure, organ and tissue donation, tube feeding and admittance to an intensive care facility. Hospitals and other health care institutions should be encouraged to inquire upon admission whether the patient has special wishes in order to avoid later confusion. Nationally promoted and established advance care planning programs are urgently needed [54,55].

7.5. Presumed consent

Statement 28:

In the absence of an effective statement of the patient's will in a specific situation, one should proceed in accordance with the patient's presumed will. The patient's authorized representative is obliged to determine the patient's presumed will. [Consensus]

Commentary

Cues expressed by the patient must be adequately documented in writing. Communication with family members, doctors, nurses and other people close to the patient must be included, when they disclose important aspects that will help to clarify the patient's presumed will.

Decisions about artificial nutrition made on the basis of presumed consent should be preferably made in consensus by all involved persons in order to ensure widespread acceptance of the proposed measure. The starting point is the patient's self-determination and autonomy. In case of disagreement between the involved persons the treating physician should decide or a clinical ethics committee may be consulted, if established in the institution [56].

The treating physician and the authorized representative must check whether the decision regarding the patient's presumed consent is overlaid by emotional concern or personal interests. It should be ascertained that authorized representatives in close personal relationship with the patient express their consent or refusal in alignment with the patient's interests and not on the basis of irrelevant considerations. As is true for the patient, the authorized representatives should also be able to comprehend the benefits and risks of medical interventions in order to express their authentic and accountable will. If the patient's presumed will is interpreted in different ways, the treating physician should decide. In some countries the involved persons may request a judicial decision.

7.6. Quality of life

Statement 29:

Quality of life must always be taken into account in any type of medical treatment including artificial nutrition. [Strong Consensus]

Commentary

While for oncological patients well established tools to assess quality of life are available [57], widely accepted instruments for

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patients with cognitive impairment, suitable for use in clinical routine, do not exist in a satisfying way to the present day. Nevertheless, even the patient whose competence is largely impaired gives clues as to his perception of quality of life by appropriate expressions or statements. Also the patient who is unable to give consent or make a judgment should be informed about the proposed measures; the communication should be aligned to his or her comprehension abilities. The patient's statements or reactions should be taken into account as appropriate.

Statement 30:

Whether a patient removes a feeding tube because the foreign object bothers him or because he wishes to express his refusal of "life-preserving" nutrition must be interpreted according to the patient's previous statements, values, and life decisions. [Consensus]

Commentary

In any case one should avoid deviating from a decision previously made by the patient in autonomous condition, merely because one is operating on the speculative notion that in case the patient is not able to take a decision, in the present situation he or she would probably make a different decision. However, if a patient, unable to give consent or make a judgment, does clearly, persistently and explicitly express refusal of nutritional therapy; this treatment should not be used. However, it is mandatory to establish the reason for this persistent refusal. For example, is it grounded on symptoms which can be overcome with another form of administration of nutrition?

8. Difficult decisions and ethical dilemmas

8.1. Disagreement and tensions among decision makers

Statement 31:

To achieve a mutually acceptable solution or a compromise, one should utilize all options. These include obtaining a second opinion, a case discussion in ethics, clinical ethics counseling, or obtaining the recommendations of a clinical ethics committee. [Strong Consensus]

Commentary

This applies for patients who cannot consent, when a statement is difficult to interpret or when a patient is demanding a futile therapy. Complex decisions or disagreement result from differing interpretations of an appropriate or realistic therapeutic goal and, consequently, the potential indication for various medical interventions [58]. Even the presumed will and well-being of a patient may be interpreted differently by the persons involved in the decision [59,60].

In the event of differing opinions when determining the patient's will, judicial authorities may be approached as the last option. It should only be used in exceptional cases because, depending on the individual case and regardless of the final decision, it may damage the patient's relationship with his representatives on the one hand, as well as the patient's relationship with nursing and medical staff. A judicial decision can be dispensed with when there is no unequivocal medical indication for nutritional therapy (such as inefficacy, therapy-resistant complications, or a patient in the immediate dying phase).

Statement 32:

In the absence of an indication and lack of achieving a treatment goal or in the absence of consent, nutritional therapy should be discontinued. This may lead to individual emotional and/or ethical conflicts among family members or team members (doctors, nursing staff and members of other therapeutic professions). [Consensus]

Commentary

This statement relies on solid scientific evidence showing that in specified situations nutritional support has no beneficial influence on body composition, function and well-being. However, differing religious or cultural beliefs and views may lead to differing interpretations of indications, treatment goals and effects by patients, bystanders and caregivers. This should be taken into account in the communication between them and may even, at least temporarily, skew decisions to make.

Caregivers who do not agree with the discontinuation of artificial nutrition for reasons of conscience or religion cannot be forced to do this. In such cases they must shift the responsibility to another person to ensure that the patients will is observed.

Independent of these individual reasons of conscience, suitable organizational precautions must be taken at in-hospital and outpatient treatment and care institutions to ensure that appropriate end-of-life care is provided. Special consideration must also be given when a patient is moved from one hospital or institution to another institution within regard to information on artificial nutrition and hydration.

8.2. Withholding and withdrawing nutrition and hydration support therapy

Statement 33:

A medical treatment, which does not provide any benefit or has become disproportionate can be withdrawn or withheld. Limitation of treatment may imply progressively withdrawing it or reducing the dose administered to limit side effects. [Strong Consensus]

Commentary

As stated above, artificial nutrition and hydration are medical interventions which require an indication for achieving a treatment goal and the informed consent of the competent patient. Artificial nutrition and hydration are useful, if they are given in order to improve the life expectancy and quality of life of the patient. Artificial hydration can be given to prevent or reverse distressing symptoms of dehydration. The decision to withhold artificial nutrition can be taken while hydration is continued. There is consensus that artificial nutrition and hydration should not solely be used to reduce the workload of the nursing staff.

In some countries or cultures artificial nutrition and hydration are not considered as medical treatment which can be limited, withheld or withdrawn if certain conditions apply. Instead they are considered to fulfill the basic needs of the patients. In these circumstances artificial nutrition and hydration can only be withdrawn if the patient is at the end of life and has expressed a wish to end nutrition and hydration (see chapter 7.4). However some argue that even "oral feedings are not always ethically obligatory, and that in appropriate circumstances patients and surrogates may authorize the withdrawal of all forms of nutrition and hydration, whether administered orally or by tube" [61].

In end of life situations, the purpose of treatment and care is, above all, to improve the patient's quality of life. Decisions to withhold or withdraw a treatment that provides no benefit or has become disproportionate are from an ethical and a legal point of view identical. However it should be emphasized that if a therapy is being stopped, comfort care still has to be provided. This implies that even when artificial nutrition and hydration are discontinued, standard care has to be maintained (see chapter 4.2). In recent years palliative sedation is increasingly applied in end of life situations, consisting of sedation and in case of pain or dyspnea combined with morphine [38].

Beauchamp and Childress conclude in their chapter on "Non-maleficence" [4] in regard to artificial nutrition and hydration that

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it is sometimes legitimate to withhold or withdraw it for incompetent patients under the following conditions:

1. the procedures are highly unlikely to improve nutritional and fluid levels
2. the procedures will improve nutritional and fluid levels but the patient will not benefit
3. the procedure will improve nutritional and fluid levels and the patient will benefit, but the burdens of artificial nutrition and hydration will outweigh the benefits (e.g. artificial nutrition and hydration can be provided only with essential physical restraints etc.).

The competent patient may refuse artificial nutrition and hydration without consideration of those conditions.

8.3. Voluntary refusal of nutrition and fluids

Statement 34:

Voluntary cessation of nutrition and hydration is a legally and medically acceptable decision of a competent patient, when chosen in disease conditions with frustrating prognosis and at the end life. [Strong Consensus]

Commentary

It has been shown that competent patients sometimes voluntarily refuse nutrition and fluids to hasten death that is yet not imminent while they are receiving palliative care either at home or in hospice. The statement does not refer to patients with eating disorders.

Reasons can be a last resort in response to unbearable suffering as well as an autonomous decision of a person of very old age to hasten death. The control over timing and manner of death is the major concern for these individuals, especially if other options are either not legally permitted in their countries (physician assisted suicide) or not allowed due to their religious or cultural beliefs. This applies to artificial nutrition and hydration as well as to orally ingested food. In the Netherlands a survey has estimated that about 2, 1% of deaths per year are self-directed due to cessation of food and liquids. This form of death has been considered to be a good or dignified form of dying by a majority of nurses in Oregon (USA) and relatives of the deceased person in the Netherlands [62,63].

However, adequate comfort has to be furnished to these patients. Terminally ill patients who are given a choice often limit food and fluid intake volitionally when the primary goal is to provide comfort and to avoid suffering [64].

In order to guarantee that their autonomous decision to forgo nutrition and hydration will be respected also under the condition of an arising cognitive impairment or the situation that they are not competent anymore, patients should be encouraged to establish an advanced directive according to the pertaining legal requirements and to adequately inform their family.

8.4. Culture and religion

Statement 35:

There should be awareness and obligatory education for medical personnel to enable them to treat patients appropriately to their spiritual needs. Respect for religious, ethnic and cultural background of patients and their families has to be granted. [Strong Consensus]

Commentary

We live in increasingly multicultural societies and are confronted with the various beliefs and attitudes regarding the body and human life originating in different cultures and religions [65]. Therefore, respect for religious, ethnic and cultural background of patients and their families has to be granted [66]. Many physicians and other medical personnel do have only limited knowledge and are not familiar with specific values and preferences in serious disease and at the end of life within other cultures. Additionally, the background of the treating physician and the team has to be taken into consideration as their own beliefs and cultural values may be in conflict with clinical recommendations. For them – including the nutritionists -, a basic knowledge of different systems is mandatory. As attitudes towards death and dying differ in our societies, it is advisable to speak with the patient or the patient's family in order to get appropriate information. Even if – for Western individuals – the ethical principle of respect for autonomy has a prima facie priority and has replaced the paternalism of the past, some cultures see autonomy not directed by the individual but by the group – the family or the community. This has to be respected by the treating team as long as collective autonomy does not harm the patient's voluntary will. If information about the specific preferences cannot be obtained, a conservative approach is recommended [67,68].

8.4.1. Religious specifics

8.4.1.1. Christianity: catholic church. In regard to treatments, there is a distinction between “ordinary” in the sense of proportionate and thus obligatory and “extraordinary” in the sense of disproportionate and thus optional means. Transferred to medicine, extraordinary care means “optional” care – procedures which involve grave burden for oneself or another. Under the term “optional” fall interventions, that are excessively expensive or are associated with too much suffering or otherwise unattainable. The Catechism of the Catholic Church in its actual version states that “Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of “overzealous” treatment. Here one does not will to cause death; one's inability to impede it is merely accepted. The decision should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests always must be respected.” [69].

The often misinterpreted statement by Pope John Paul II from 2004 was directed at the situation of persons in persistent vegetative state and artificial nutrition and hydration. In such a state the intrinsic value and personal dignity of a human being does not change and artificial nutrition and hydration must be considered “in principle, ordinary and proportionate and as such morally obligatory insofar as and until it is seen to have attained its proper finality, which in the present case [of Theresa Schiavo] consists in providing nourishment to the patient and alleviation of his suffering”. This means that for permanently unresponsive patients who are not otherwise dying, tube feeding should be presumed to be ordinary and proportionate [70]. The term which is of importance in this statement is the “proper finality” of the patient which a physician would most probably define as the cure of the pathological condition from which the patient suffers and the return to health and normal physiological functioning. This interpretation clarifies the long standing presumption held by Catholic moralists that all patients as part of routine care are to be given food and liquids, even if necessary by artificial means of administering the same to those patients who cannot swallow. Additionally, the statement of Pope John Paul II has clarified that in particular cases this presumption wanes when it is clear that this treatment modality would be futile or very burdensome [71].

8.4.1.2. Christianity: protestant church. In contradistinction with the Catholic Church in which there is one doctrine, there are widely differing stances towards end-of-life questions between the many subgroups within the Protestant church. Some of them are so

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different from mainstream Protestantism that they can hardly be called Protestant. Care givers should take these differences into account specifically in end of life situations. In most other Protestant churches and in some other Western populations, a majority feel that intolerable suffering, strongly impacting quality of life may justify measures to accelerate death.

In practice the influence of Luther and Protestantism has during the last half millennium led to a rather liberal approach to ending life and withholding or withdrawing treatment including nutritional support and hydration. This development goes hand in hand with secular changes in which most churches have far less directive authority and power in European countries than a century ago.

At present, very few care givers would understand the reasoning among conservative Catholics and other churches that nutrition and hydration are part of basic care and therefore cannot be withheld in the dying phase. The changes in views on how to deal with the end of life has led to the situation that in most North-West-European countries the treating physician does not need to adapt treatment to specific religious beliefs in the great majority of cases including Catholic believers, although the Catholic doctrine is formally different and for instance strictly enforced in other parts of this world (e.g. the Philippines) [72]. This applies to early life questions (abortion, birth control etc.) as well as to end of life questions.

An important reason promoting these attitudes at the end of life in our world is that in the majority of cases elderly people are involved in the last two years of their lives and already having gone through many treatments, invalidation and suffering. It may also apply to younger people with for instance end stage cancer, heart, lung failure etc. In these situations bystanders, next of kin etc. feel it as an act of mercy when treatment is discontinued (also nutrition and hydration) when the patient suffers with no outlook on improvement and wishes to die.

However, ethnicity may influence the concept of autonomy. In some cultures the family or/and other bystanders take the decisions. When the treating physician deems recovery from illness impossible or when the burden of treatment is not tolerated by the patient, decisions to withhold or withdraw treatment are made by physicians after informing and preferably acquiring understanding of the patient. Treatment can only be applied when the patient is consenting.

When the patient is unable to reliably express willingness to be treated and when there is no advance directive or legal representative, physicians must decide after careful consultation of the partner, family and others, and record decisions and the underlying considerations carefully in the medical files. Representatives of the Protestant church, when present, are generally supportive, but do not play a primary or initiating role in the decision.

Comparable considerations apply to the dying phase. Withholding or withdrawing treatment is based on the conviction that treatment is not effective and may even be harmful. Several measures are possible not to prolong dying and suffering needlessly. Palliative sedation consists of administration of low dosages of an appropriate sedative and if necessary opiates in low dosages when the patient is dyspneic or is suffering from pain. Nutritional therapy has no benefit and is not successful in dying patients who generally are unable to eat normally. A nasal gastric or gastroduodenal tube would be necessary, causing discomfort and risking to cause aspiration and coughing. Most dying patients are not hungry or thirsty and the normal hypotension, hypoxia and hypercapnia, which commonly underlie a natural course of dying, may be prolonged when patients receive rehydration fluids. Withdrawing or withholding treatment is considered to be measures of an identical nature because they are based on the judgment that treatment is not beneficial. However comfort therapy is required to treat other complaints a patient might have due to a dry crusty mouth, decubital ulcers, incontinence and others. Despite general agreement in the majority of cases, physicians should remain sensitive to the beliefs of their patients and recognize that in some Protestant or other religious groups with more conventional beliefs differences exist how to make decisions and how to treat. Appreciation of these differences enhances patient care and minimizes conflict [73].

8.4.1.3. Jewish halacha. The Halacha or Jewish legal system differentiates between active and passive actions and therefore between withholding and withdrawing life-sustaining therapies [74]. For conservative and orthodox Jews the preservation of life is also a value with high priority and continuous treatments which have been started may not be stopped. Therefore artificial nutrition and hydration cannot be refused. Halacha allows the withholding of life-prolonging treatment if it pertains to the dying process but forbids the withdrawing of life-sustaining therapy if it is a continuous form of treatment. Fluids and food are considered as basic needs and not treatment. Withholding food and fluids from a vegetative or dying patient is unrelated to the dying process and therefore is prohibited and regarded as a form of euthanasia. If the patient is competent and not convinced by the medical team to change his mind, he/she may not be forced to receive the food or fluids. However, when approaching final days of life and when food and fluids may cause suffering or complications, it is permissible to withhold them if it is known that this was the patient's wish [75].

8.4.1.4. Islam. Although the literature about futility and potential harm of artificial nutrition and hydration at the end of life is universally known, from the perspective of Islam nutritional support is considered basic care and not medical treatment. If the withholding or withdrawing of artificial nutrition and hydration results in starvation, this is seen as of greater harm than potential complications of that treatment. Starvation has to be avoided. However, the principle of avoiding or minimizing harm has to be followed and also applied to the delivery of artificial nutrition and hydration. "The decision of withholding or withdrawing artificial nutrition and hydration from the terminally ill Muslim patient is made with informed consent, considering the clinical context of minimizing harm to the patient, with input from the patient, family members, health care providers, and religious scholars" [76].

8.5. Forced feeding (this chapter does not discuss patients suffering from anorexia nervosa)

Statement 36:

Providing nutrition against the will of the patient who is able to give his/her consent or make judgments (enforced feeding) is generally prohibited. [Strong Consensus]

Commentary

Although the legal situation might differ in some countries, the World Medical Association has established clear guidelines for physicians involved in managing people on hunger strike. According to the *The World Medical Association Declaration of Tokyo*. The forced feeding of hunger strikers who are mentally competent is not allowed. *"Hunger strikers should not be forcibly given treatment they refuse. Forced feeding contrary to an informed and voluntary refusal is unjustifiable. Artificial feeding with the hunger striker's explicit or implied consent is ethically acceptable"* [77–80].

Conflict of interest

None.

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