Ethical and legal points of view in parenteral nutrition – Guidelines on Parenteral Nutrition, Chapter 12

Ethische und rechtliche Aspekte der parenteralen Ernährung – Leitlinie Parenterale Ernährung, Kapitel 12

Abstract

Adequate nutrition is a part of medical treatment and is influenced by ethical and legal considerations. Patients, who cannot be sufficiently fed via the gastrointestinal tract, have the fundamental right to receive PN (parenteral nutrition) even so patients who are unable to give their consent. General objectives in nutrition support are to supply adequate nutrition with regards to the prevention of malnutrition and its consequences (increased morbidity and mortality), and thereby promoting improved outcome and/or quality of life for the patient considering always the patient's needs and wishes. The requests of the patient to renounce PN should be respected where a signed living will is helpful. During the course of a terminal illness the nutrition has to be adapted individually according to the needs and wishes of a patient in the corresponding phase. Capability of consent should be checked in each individual case and for each measure on an individual basis. Consent should only be accepted if the patient is capable of recognizing the nature, meaning and importance of the intervention as well as the consequences of relinquishment of such an intervention, and is capable to make a self-determined decision. If the patient is not capable of consenting, the patient's living will is the most important document when determining their assumed will and legally binding. Otherwise a guardian appointed by the patient, or the representative appointed by the court (if the patient has made no provisions) can make the decision.

Zusammenfassung

Eine angemessene Ernährung ist Teil des medizinischen Behandlungsauftrags und wird in hohem Maße durch ethische und rechtliche Überlegungen beeinflusst. Patienten, die über den Gastrointestinaltrakt nicht ausreichend ernährt werden können, haben grundsätzlich Anspruch auf PE (parenterale Ernährung). Allgemeine Ziele der Ernährungstherapie sind die Gewährleistung einer im Hinblick auf Grundkrankheit und Ernährungszustand adäquaten Ernährung, das Vorbeugen einer Mangelernährung und deren Folgen – erhöhte Morbidität und Mortalität – und somit letztlich die Verbesserung der Prognose oder der subjektiven Lebensqualität des Patienten unter Berücksichtigung der Bedürfnisse und Wünsche des Patienten. Der Wille des Patienten zum Verzicht auf PE ist zu respektieren, wobei eine vorhandene unterschriebene Patientenverfügung hilfreich ist. Im Verlauf einer unheilbaren Erkrankung muss die Ernährung an die jeweilige Phase individuell unter Berücksichtigung der Bedürfnisse und Wünsche des Patienten angepasst werden. Die Einwilligungsfähigkeit ist in jedem Einzelfall und für jede Maßnahme erneut zu überprüfen und dann anzunehmen, wenn der Patient in der Lage ist, Wesen, Bedeutung und Trageweite des Eingriffs sowie des Verzichts auf einen solchen zu erkennen und eine selbst bestimmte Entscheidung zu treffen. Wenn der Patient nicht einwilligungsfähig ist, ist vor allem die Patientenverfügung das wichtigste Indiz bei der Ermittlung des mutmaßlichen Willens des Patienten und rechtlich verbindlich.

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Liegt diese nicht vor, entscheidet der von ihm benannte Vorsorgebevollmächtigte oder, falls der Patient insoweit keine Vorsorge getroffen hat, der vom Gericht bestellte Betreuer.

Preamble

Adequate nutrition is a part of medical treatment. Nutrition has a particular effect on the communicative and social needs of a person, and this is why questions regarding the commencement and cessation of PN are, to a great extent, influenced by ethical and legal considerations. In this section, criteria for decision making, legal requirements and potential procedural steps are presented to enable competent decision-making.

Fundamentals

Patients, who cannot be sufficiently fed via the gastrointestinal tract, have the fundamental right to receive PN. This also applies to the growing group of patients who are unable to give their consent. General objectives in nutrition support are to supply adequate nutrition with regards to the prevention of malnutrition and its consequences (increased morbidity and mortality), and thereby promoting improved outcome and/or quality of life for the patient. In the individual patient, the specific objectives of nutritional support are determined considering the patient's needs. Nutrition support should prevent weight loss, aims at improving the nutritional state and at providing a benefit on the overall clinical situation. In contrast, the aim of palliative nutrition carried out in patients with terminal diseases is support quality of life.

The decisions to start and to end PN should be made by the physician-in-charge, in consideration of the patient's wishes. Other caregivers involved in the treatment and relatives should also be involved in the decision-making process whenever possible and appropriate. In case of diverging views, an ethical consultation is strongly recommended.

The requests of the patient to renounce PN should be respected. In the case of non-existing informed consent and the necessity to determine the presumable wishes of a patient, it is helpful if the patient has previously recorded such wishes and mentioned the situations in which it should be followed, e.g. in a living will. The patient's medical consultation should include possible indications for enteral or parenteral nutrition as well as the consequences of relinquishing nutrition and fluid intake in the various phases of an illness, when drawing up a living will.

Indications for PN

The medical indication for artificial nutrition is classically present when the patient is not "allowed to or cannot" eat or be enterally fed. PN is indicated if the gastrointestinal tract is partially functioning or not functioning at all. Severe malnutrition may also be an indication for (at least partial) PN despite the possibility to provide enteral nutrition.

Medical, legal and ethical issues, as described below, are to be considered when deciding on the indication for artificial nutritional support. In the evaluation of medical criteria, it should be noted that a good nutritional state has a positive influence not only on outcome but also on subjective quality of life. Imminent malnutrition must be treated as an adverse risk factor for outcome.

In defining an indication for PN, there should be clarity as to the purpose and objective of PN, and the attitude of the patient towards it. The will of the patient, the prognosis and the subjective quality of life often changes repeatedly with treatment and duringthe course of a disease. Therefore, the indication of PN should be reviewed on a regular basis.

Contraindications

In addition to absolute medical contraindications, PN is also contraindicated when the patient can be sufficiently fed either orally or enterally via a nasogastric tube or PEG/PEJ, respectively. For legal and ethical reasons PN has to be omitted if the patient refuses to consent to PN or if the refusal is apparent from the presumed will, given the patient has known the ledge of possible consequences.

Medical responsibility in terminal care

The course of a terminal illness can be divided into the rehabilitation phase, preterminal phase and terminal phase [1]. The treatment objective during the rehabilitation phase, which can sometimes last for years, is to return or maintain the patient's independence and level of performance. Therapeutic objectives and the main focus of care need to be re-established in the preterminal phase, which can last weeks and months, and in the terminal phase during which the death of the patient is imminent [1], [2], [3], [4]. The main objectives in these last phases are to alleviate symptoms and suffering, maintaining quality of life, enabling self-determination and supporting a "good death" [1], [3], [4], [5], [6], [7], [8], [9]. Classical objectives of nutrition, such as maintaining nutritional status, retaining functions, and a positive influence on the course of illness or life span, are of little relevance in terminal care.

The task of suppressing uncomfortable feelings of hunger and thirst are of prime importance. The needs and wishes of the patient may change during the last phase of life, where individual person differ in the behaviour and needs

until their death. Artificial nutrition is only indicated after carefully considering the potential risks and benefits based on the new objectives [1], [2], [3], [8], [9]. According to studies, patients often have a dry mouth, premature feeling of satiation, sickness and dysgeusia, but rarely feel hungry and thirsty. Hunger and thirst can, however, often be addressed with only small amounts of oral fluid and food intake. Indiscriminate and high fluid intake can be problematic if it results in oedema (particularly pulmonary oedema), shortness of breath, nausea, vomiting, and increased urine production. A detailed observation of the patients is necessary, as symptoms of xerostomia and thirst do not correlate with the body's hydration state. Parenteral fluid intake does not always result in improvements of thirst symptoms. The feelings of xerostomia and thirst are also caused by medications, oxygen therapy, breathing through the mouth as well as fear and depression. Measures such as lip care (cleaning and retaining moisture in lips) and mouth care with mouth washes, frequent offers of fluids, and the application of ice chips or ice cubes should be the main interventions at the outset of treating xerostomia and thirst [1], [2], [7], [9], [10], [11]. Hydration may be necessary if a patient still complains of thirst despite good care. Further reasons may be sudden, unexplained confusion, unexplained agitation as well as the increased toxic actions of drugs. Low amounts of fluid, i.e. 1000 ml/24 h, should be administered via peripheral access in order to prevent dehydration [3], [7], [8], [9].

Legal aspects

Patients capable of giving consent

The insertion of a central venous catheter and administration of PN are legally assessed as physical bodily harm, which are, therefore, only permissible with the patient's consent [12], [13], [14], [15], [16]. As long as the patient is capable of consenting, she/he will be the sole receiver of a comprehensive document of clarification, which must contain potential complications and risks as well as the consequences of not having treatment. Consent and clarification of the patient must be documented.

Capability of consent does not mean legal capability in terms of civil law. Children and teenagers over the age of 14 are usually capable of giving consent. Patients, for whom a legal guardian has been appointed due to health matters also remain potentially capable of consent in all areas. Capability of consent should be checked in each individual case and for each measure on an individual basis. Consent should only be accepted if the patient is capable of recognizing the nature, meaning and importance of the intervention as well as the consequences of relinquishment of such an intervention, and is capable to make a self-determined decision. If the capability of consent has been established by the physician, the opinion of the guardian, relatives or persons responsible for the care and custody of the patient is legally irrelevant [5], [12].

Capability of consent can be lifted for complex questions, but may remain for simple questions. It, therefore, should be checked whether the decision for or against nutrition can be fully understood, intellectually and emotionally, by the patient [5], [12].

Patients who are not capable of consenting

If the patient is not capable of consenting, a guardian appointed by the patient, or the representative appointed by the court (if the patient has made no provisions) can make the decision. The commencement of legal proceedings to appoint a guardian is only legally waived in urgent cases. The local court is responsible.

The patient's living will is the most important document when determining their assumed will. If the patient has made statements in a living will regarding PN and situations in which it is to be rejected, then this living will is legally binding for the doctors, guardians and representatives according to current jurisdiction [13], [14] and the guidelines of the Federal Chamber of Physicians [6], [17]. A legal investigation of nutrition withdrawal is only necessary (according to the current jurisdiction of the Federal Court of Justice [13], [14]) when there is an indication for nutrition from a medical point of view, but the guardian chooses to go against medical advice and refuse nutrition, and the issue cannot be resolved.

Although the decision to introduce PN can necessitate the commencement of guardianship proceedings, it does not require judicial authorisation. An analogous use of § 1904 of the German Civil Code does not come into consideration despite the existing risks of inserting a central venous catheter, because although the risk of death cannot be completely excluded due to the risk of infection, the insertion of a central venous catheter is not evaluated as "typically life threatening" in terms of § 1904 of the German Civil Code.

Individual questions on liability and organisation

Prescription and administration of PN is the task of the doctor. The doctor remains responsible even if individual steps are delegated to nursing staff. The personal responsibility of the pharmacist for the preparation and mixing of the composition remains unaffected. The compositions used and the quantity prescribed, as well as the serial number of the bag, should be documented.

Notes

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