

Ethical issues in end-of-life intensive and palliative care: withholding and withdrawing therapy

Introduction

Modern technologies used in medicine bring previously unusual forms of dying or surviving without further hope of improvement. This is a source of new dilemmas and many unanswered questions (ŠEVČÍK, Pavel a Martin MATĚJOVIČ, ed. *Intenzivní medicína*. 3., přeprac. a rozš. vyd. Praha: Galén, c2014. ISBN 9788074920660.). In this essay, I will address the issues of intensive care at the end of life, and in particular withdrawal and withholding (non-extension) of care, because I work as a physician at the ICU and quite often have to solve these issues in my clinical practice.

Each patient's situation needs to be looked at very individually. It is important to take into account the patient's history, the type of the main and underlying disease and the course and progress of diseases in time, and the future prognosis. It is necessary to consider whether it is at all possible for the patient to survive and for his subsequent quality of life to be acceptable. If the risks, side effects of treatment, discomfort and pain associated with current therapy cannot be expected to outweigh the benefits and lead to an improved prognosis, such therapy is considered futile. (ŠEVČÍK, Pavel a Martin MATĚJOVIČ, ed. *Intenzivní medicína*. 3., přeprac. a rozš. vyd. Praha: Galén, c2014. ISBN 9788074920660.) In this essay, I will specifically address the issue of withdrawal and withholding of care and the end-of-life decision-making process.

Main text of the essay:

Terminology

At the outset, it is necessary to define the basic concepts of palliative medicine and care. In the transition from curative to palliative care, treatment goals are redefined and treatments are implemented that contribute to achieving these goals. The aim of palliative care is to prolong life in an acceptable quality and must not itself actively contribute to euthanasia.

Non-extension care can be divided into primary and secondary care. In primary non-extension care, the patient is not admitted to intensive care unit at all. In secondary non-extension of care, although the patient is admitted to the ICU, there is no further escalation of care if he/she needs it. There is no increase in organ support (e.g. decision not to intubate, etc.); the concepts of 'do not escalate' (DNE), 'do not attempt resuscitation' (DNAR) or 'do not resuscitate' (DNR) fall into this category. (MACH, Jan. *Medicínské právo - co a jak: praktické*

radly pro lékaře a zdravotníky. Praha: Galén, [2015]. *Theatrum medico-iuridicum*. ISBN 9788074922183., RIETH, KATHERINE A. How do we withhold or withdraw life-sustaining therapy?. *Nursing Management (Springhouse)* [online]. 1999, **30**(10) [cit. 2022-12-08]. ISSN 0744-6314. Available: doi:10.1097/00006247-199910000-00008).

Withdrawing treatment means treatment measures already started are reduced (e.g. regular haemodialysis or circulatory support with catecholamines is stopped). (RIETH, KATHERINE A. How do we withhold or withdraw life-sustaining therapy?. *Nursing Management (Springhouse)* [online]. 1999, **30**(10) [cit. 2022-12-08]. ISSN 0744-6314. Available: doi:10.1097/00006247-199910000-00008).

Terminal weaning refers to discontinuation of ventilatory support with cessation of airway support (PAŘÍZKOVÁ, Renata. Paliativní léčba v intenzivní medicíně. *Intervenční a akutní kardiologie* [online]. 2011, 10/2011, (10), B15 - B17 [cit. 2022-12-03]. Dostupné z: <https://www.iakardiologie.cz/pdfs/kar/2011/89/05.pdf>).

Patient's previously expressed wish

"Previously expressed wishes" is a concept regulated by the laws of the Czech Republic (§ 36 Zákona č. 372/2011 Sb. *Zákon o zdravotních službách a podmínkách jejich poskytování*). It is therefore possible that in other legal systems this concept does not exist or is perceived differently. By expressing a prior wish, the patient may express consent or dissent for situations that may or may not arise and in which the patient will not be able to express this wish. A typical case might be a oncologically ill patient's opposition to possible resuscitation or a Jehovah's Witness's opposition to the administration of blood products. A previously expressed wish must be written, bear a certified signature and be made after being instructed by a general practitioner or specialist in the field. (§ 36 Zákona č. 372/2011 Sb. *Zákon o zdravotních službách a podmínkách jejich poskytování*).

However, it does not have to be respected by the doctor provided it would actively lead to death. According to Dr. Těšinová, a wish also does not have to be respected if a long interval has elapsed since it was made and in the meantime the treatment options have improved. In this case, according to her, it can be assumed that if the patient knew this, he would not have expressed his wish. (TĚŠINOVÁ, Jolana. *Základní principy a terminologie v medicínském právu*, materials for Veřejné zdravotnictví a medicínské právo, obor Všeobecné lékařství, 1. lékařská fakulta Univerzita Karlova v Praze). A previously expressed wish is not the same as a negative reversal (refusal of a medical procedure).

If a previously expressed end-of-life wish regarding withholding or not withdrawing therapy is available and meets all the required essentials, it is a binding document and must be followed.

Many patients know the prognosis of their disease in advance and therefore have the opportunity to prepare for the end of life in this way. It is advisable to inform the healthcare facility where the majority of the patient's treatment takes place of the previously expressed wishes in order to minimise the risk of the healthcare not being carried out as required.

Basic ethical principles must always be respected. Patient autonomy and human dignity must be respected. All interventions should be made for the good and comfort of the patient according to the principle of 'primum non nocere' (Valentin A, Druml W, Steltzer H, Wiedermann CJ. Recommendations on therapy limitation and therapy discontinuation in intensive care units: Consensus Paper of the Austrian Associations of Intensive Care Medicine. *Intensive Care Med.* 2008 Apr;34(4):771-6. doi: 10.1007/s00134-007-0975-6. Epub 2008 Jan 8. PMID: 18180903.). If staff do not have sufficient information about the patient's health and prognosis in a timely manner, they are obliged to initiate full treatment to save the patient's life and restore health, including admission to the ICU a cardiopulmonary resuscitation. In the subsequent period after the patient's vital signs have been secured, information can be completed, anamnestic data and other information about the current condition and its cause can be obtained, as well as the medical history and any comorbidities that may lead to a reassessment of the extent of treatment provided.

Given the importance of decision-making in this matter, it is always necessary to have sufficient information and to assess trends in health status. According to Dr. Pařížková's article, the transition to palliative care certainly does not mean that e.g. a patient with, cancer, including metastatic spread, cannot be admitted and treated in intensive care if the cause is a reversible condition unrelated to the underlying disease or offers the hope that this cause will be eliminated and the patient will live with the current quality of life.

(PAŘÍŽKOVÁ, Renata. Paliativní léčba v intenzivní medicíně. *Intervenční a akutní kardiologie* [online]. 2011, 10/2011, (10), B15-B17 [cit. 2022-12-03]. Available: <https://www.iakardiologie.cz/pdfs/kar/2011/89/05.pdf>).

Ethical difference between withholding and withdrawing therapy

In spite of wide agreement by Western ethicists that there is no ethical difference between these two approaches - withdrawing – the removal of a therapy that has been started in an attempt to sustain health or life but is no longer effective – and withholding – the decision not to do further therapeutic interventions. According to some papers withdrawing life-sustaining therapy may in fact be preferable to withholding. According to Jean-Luis Vincent's paper, if withdrawal of therapy were not permitted, then ICUs would be full of hopelessly ill patients receiving therapies that no longer benefit them. (Vincent JL. *Withdrawing may be preferable*

to withholding. Crit Care. 2005 Jun;9(3):226-9. doi: 10.1186/cc3486. Epub 2005 Mar 4. PMID: 15987405; PMCID: PMC1175874.)

This process would be against the four ethical principles. It is against the respect of autonomy of the patient, because who wishes to remain life-supported 'artificially' with no hope for recovery and quality of life? It is against beneficence, because it is the therapy that carries no advantage. It is also against the principle of nonmaleficence, because continuing therapies can cause distress and discomfort despite of analgesia and sedation. Finally, last ethic principle as we consider distributive justice, so in this case the ICU bed would be not available for another patient who may benefit from ICU care due to continuing ineffective therapy. (Vincent JL. *Withdrawing may be preferable to withholding*. Crit Care. 2005 Jun;9(3):226-9. doi: 10.1186/cc3486. Epub 2005 Mar 4. PMID: 15987405; PMCID: PMC1175874.)

According to Jean-Luis Vincent's paper allowing withdrawal of therapy gives the patient every chance of benefiting from that therapy. As an example, he cites an elderly, frail patient and the question of whether or not he would benefit from antibiotic therapy and connection to artificial lung ventilation during a respiratory infection. In this case, it is possible that the patient would benefit from therapy. In the case of non-administration of therapy, the patient would certainly die. It is therefore possible to perform what is known as an ICU test - admit the patient to the ICU and start full therapy; if full therapy is unsuccessful, an assessment can be made a few days later as to whether to start withdrawal of therapy. (Vincent JL. *Withdrawing may be preferable to withholding*. Crit Care. 2005 Jun;9(3):226-9. doi: 10.1186/cc3486. Epub 2005 Mar 4. PMID: 15987405; PMCID: PMC1175874.)

Jean-Luis Vincent's highlights in the paper that it is really necessary to communicate thoroughly with the patients and their relatives, they must be aware that this is just a 'test' and the chances of survival are not high, and that therapy will be withdrawn if it is not seen to be effective. (Vincent JL. *Withdrawing may be preferable to withholding*. Crit Care. 2005 Jun;9(3):226-9. doi: 10.1186/cc3486. Epub 2005 Mar 4. PMID: 15987405; PMCID: PMC1175874.)

In the study *Withdrawing or withholding treatments in health care rationing: an interview study on ethical views and implications* its authors Liam Strand and Lars Sandman discussed the ethical perspective on the difference between withholding and withdrawing therapy. They lead on 14 semi-structured interviews with physicians and patient organization representatives. One of the conclusions was that participants commonly express internally inconsistent views regarding if withdrawing or withholding medical treatments should be deemed as ethically equivalent. In terms of prognostic differences, and the patient-physician relation and communication, there is some discrepancy which carry a moral significance and makes withdrawing psychologically more difficult for physicians (and also for the patients). (Strand, L., Sandman, L., Tinghög, G. *et al*. *Withdrawing or withholding treatments in health*

care rationing: an interview study on ethical views and implications. *BMC Med Ethics* 23, 63 (2022). <https://doi.org/10.1186/s12910-022-00805-9>.)

The position of relatives in end-of-life decisions

People close to the patient have no legal right to be involved in end-of-life care decisions. (Valentin A, Druml W, Steltzer H, Wiedermann CJ. Recommendations on therapy limitation and therapy discontinuation in intensive care units: Consensus Paper of the Austrian Associations of Intensive Care Medicine. *Intensive Care Med.* 2008 Apr;34(4):771-6. doi: 10.1007/s00134-007-0975-6. Epub 2008 Jan 8. PMID: 18180903). However, it is advisable to take the situation and the views of relatives into account and to have good communication with them. (If the patient has agreed to provide information to relatives. If the patient has refused to provide information to relatives, this wish should be respected and the information cannot be given). (C.M. Danbury, C.S. Waldmann, *Ethics and law in the intensive care unit, Best Practice & Research Clinical Anaesthesiology, Volume 20, Issue 4, 2006, Pages 589-603, ISSN 1521-6896, <https://doi.org/10.1016/j.bpa.2006.10.002>*).

However, it is not acceptable for relatives to decide on the course of end-of-life care. The decision is always up to the attending physician. With thorough and empathetic communication with relatives and consistent documentation of the process, the risk of conflict should be minimised. According to the Austrian recommendations for intensive care, if the conflict is imminent, then treatment could be temporarily continued to allow time for better understanding and acceptance by relatives (Valentin A, Druml W, Steltzer H, Wiedermann CJ. Recommendations on therapy limitation and therapy discontinuation in intensive care units: Consensus Paper of the Austrian Associations of Intensive Care Medicine. *Intensive Care Med.* 2008 Apr;34(4):771-6. doi: 10.1007/s00134-007-0975-6. Epub 2008 Jan 8. PMID: 18180903).

Conclusion

The termination of curative and the initiation of palliative care is a complex issue and each patient must be assessed individually. Withholding of care may be psychologically easier for the caregivers and the patient's loved ones, but some studies suggest that the patient may benefit from ICU tests and eventual withdrawal of care.

General recommendations for clinical practice in the Czech Republic follow the guidelines of the Czech Medical Chamber. The initiation of palliative care can be initiated by anyone in the team treating the patient, the patient's family or the patient's circle of relatives. Whenever possible, the patient's wishes must be respected and the opinion of the family and relatives

should be included in the decision to initiate palliative care, but delegating responsibility to the family/relatives for the decision to switch to palliative care is not acceptable. All members of the healthcare team should be involved in the decision-making process, but the final decision to initiate palliative care is the responsibility of the head of the unit or his/her designated physician. Everything should be properly documented and the goals, benefits and risks of the procedures should be regularly reassessed. The priority of palliative care is the comfort of the patient - the removal of pain, discomfort and distress. A very important issue is that the presence of family or loved ones should always be allowed unless the patient has refused it. (RECOMMENDATION No. 1/2010 of the Board of Directors of the Czech Medical Chamber)

References:

ŠEVČÍK, Pavel a Martin MATĚJOVIČ, ed. *Intenzivní medicína*. 3., přeprac. a rozš. vyd. Praha: Galén, 2014. ISBN 9788074920660.

Vincent JL. *Withdrawing may be preferable to withholding*. Crit Care. 2005 Jun;9(3):226-9. doi: 10.1186/cc3486. Epub 2005 Mar 4. PMID: 15987405; PMCID: PMC1175874.

Valentin A, Druml W, Steltzer H, Wiedermann CJ. *Recommendations on therapy limitation and therapy discontinuation in intensive care units: Consensus Paper of the Austrian Associations of Intensive Care Medicine*. Intensive Care Med. 2008 Apr;34(4):771-6. doi: 10.1007/s00134-007-0975-6. Epub 2008 Jan 8. PMID: 18180903.

Strand, L., Sandman, L., Tinghög, G. *et al.* Withdrawing or withholding treatments in health care rationing: an interview study on ethical views and implications. *BMC Med Ethics* **23**, 63 (2022). <https://doi.org/10.1186/s12910-022-00805-9>

RIETH, KATHERINE A. How do we withhold or withdraw life-sustaining therapy?. *Nursing Management (Springhouse)* [online]. 1999, **30**(10) [cit. 2022-12-08]. ISSN 0744-6314. Available: doi:10.1097/00006247-199910000-00008

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TĚŠINOVÁ, Jolana. *Základní principy a terminologie v medicínském právu*, materials for Veřejné zdravotnictví a medicínské právo, obor Všeobecné lékařství, 1. lékařská fakulta Univerzita Karlova v Praze

MACH, Jan. *Medicínské právo - co a jak: praktické rady pro lékaře a zdravotníky*. Praha: Galén, [2015]. Theatrum medico-iuridicum. ISBN 9788074922183.

§ 36 Zákona č. 372/2011 Sb. *Zákon o zdravotních službách a podmínkách jejich poskytování*

DOPORUČENÍ PŘEDSTAVENSTVA ČLK č. 1/2010 k postupu při rozhodování o změně léčby intenzivní na léčbu paliativní u pacientů v terminálním stavu, kteří nejsou schopni vyjádřit svou vůli

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