

REVIEW

End-of-life practices: ensuring 'quality of dying' during withdrawal of life-sustaining measures

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Abstract

The majority of deaths on Dutch intensive care units (ICUs) occur after withdrawal of life-sustaining measures. While curative care centres on survival, end-of-life care focuses on 'quality of dying'. In end-of-life care, evaluation of all interventions is made in terms of whether they contribute to the patient's comfort. In general, adequate dosing of opioids and benzodiazepines can provide comfort. Contrary to popular belief, these medications do not hasten death. Pain, dyspnoea-associated distress, anxiety and excessive bronchopulmonary secretion should be routinely assessed, prevented and treated adequately. Withdrawal of life-sustaining measures can consist of withdrawal of mechanical ventilation and/or vasoactive medication; in case of the former, there is no ethical justification for a prolonged weaning process. Family-centred care and communication are essential in end-of-life care and continue even after the patient's death. End-of-life care should be a priority in each ICU to limit suffering and optimise quality of dying.

Introduction

'Death is not extinguishing the light; it is putting out the lamp because the dawn has come.'

Rabindranath Tagore

Most patients in the intensive care unit (ICU) are severely ill. The mortality of patients in the ICU is much higher than on the general wards. The average mortality in Dutch ICUs was 8.5% in 2014.^[1] In the Netherlands, 25.6% of all deaths occur in hospital (2012)^[2,3] and approximately 5% of the Dutch population died in the ICU (2014; estimated using CBS and NICE data).^[1,2] The majority of these deaths in the ICU occur after withdrawal of life-sustaining measures.^[4-7]

Renouncing life-sustaining treatments does not mean ending care; in fact, care needs to be intensified as death comes closer.

The coexistence of critical and palliative care is essential in contemporary ICU care.^[8] While curative care is centred on survival, end-of-life care focuses on what may be called 'quality of dying' by providing comfort and preventing 'avoidable distress and suffering for patients, families, and caregivers.'^[9] Although a 'good death' should ideally also include aspects such as dignity, worthiness and peacefulness,^[10] these may be incompatible with an ICU setting and are thus not the focus of this review.

Dignified and individualised end-of-life care is offered if the shift is made from attempting to cure to accepting death. Three distinct elements of end-of-life care are (1) withholding future life-sustaining interventions (e.g. cardiopulmonary resuscitation, dialysis, antibiotics, intravenous fluids); (2) withdrawing some or all life-sustaining measures (e.g. mechanical ventilation, vasoactive medications); and (3) ensuring pre-emptive, timely alleviation of dyspnoea-associated distress, anxiety, pain, and other distressing symptoms.^[11] In this review, we will focus on the last two: the period when life-sustaining measures are withdrawn and comfort measures are required to optimise the quality of dying.

End-of-life care is emerging as a comprehensive area of expertise in the ICU. It demands the same high level of knowledge and competence as all other areas of ICU practice. Interestingly, although a national guideline by the Netherlands Society for Intensive Care (NVIC) was published in 2009,^[11] there are still very few structured care plans and protocols for end-of-life care in critical care units. Ideally, all individuals who do not survive a critical illness should receive compassionate, comprehensive, patient- and family-centred attention directed at ensuring quality of dying. Here, we aim to present a structured approach for care at the end of life, including specific practical recommendations for this important and increasingly common situation in ICUs.

End-of-life practices in Dutch ICUs

In the Netherlands, limiting or withdrawing life-sustaining measures is ethically and legally justified under the principle of Dutch law. It has been documented in the Dutch Medical Treatment Act (Wet op de Geneeskundige Behandelingsovereenkomst (WGBO)), which bestows on physicians the authority to make decisions on withholding or withdrawing life-sustaining measures.^[11,12] The NVIC has published a national guideline on this topic,^[11] which stipulates key points in guiding the medical team in end-of-life care.

In Dutch ICUs withholding or withdrawing life-sustaining measures is common. Four studies^[4-7] have reported the frequency of withdrawal of life-sustaining measures in Dutch ICUs. Spronk et al.^[6] reported in their study in two Dutch ICUs that 293 out of 2578 (11%) of the patients died in the ICU. Of this group, 56% died after withdrawal of life-sustaining measures, thus comprising 6% of the total population. In the study by Verkade et al.^[4] 218 out of 1353 (16%) of the patients died in the ICU, of whom 84% after withdrawal of life-sustaining measures, comprising 15% of the total patient population. In two studies by Epker et al. respectively 68%^[5] and 79%^[7] of the patients died after withdrawal of life-sustaining measures. Although end-of-life practices differ between patient populations^[11] and regional cultures,^[13] the percentages of withdrawal reported in the Netherlands are comparable with those found in ICUs of 17 European countries, where an average of 72.6% of ICU non-survivors died after withdrawal of life-sustaining measures.^[14] There is no medico-legal distinction between withholding and withdrawing life-sustaining measures in the Dutch Medical Treatment Act.^[12] Withdrawal of treatment is ending dispro-

portionate care and providing comfort care.^[15] Disproportionate care can be defined as treatment that is inappropriate because patients were too sick (often referred to as futile care) or too well to benefit from ICU treatment or because the amount of treatment received is mismatched to the prognosis or treatment goals.^[15] The shortening of life that may occur during this process is thus merely a consequence of withdrawing life-sustaining measures, never its intention.

It is important to understand that allowing the patient to die by withdrawing life-sustaining measures is different from euthanasia, also practised in the Netherlands (albeit rare in the ICU setting^[16]). Euthanasia is solely applicable to the deliberate and active termination of a patient's life at his or her explicit and repeated request after fulfilling strict criteria.^[17]

Practical aspects of withdrawing life-sustaining measures in the ICU

General guidelines: preparation

When life-sustaining measures are withdrawn, the process of withdrawal — immediate or gradual — must be carefully considered and executed as humanely as possible. Clinicians should have an explicit plan for the steps involved in withdrawal of life-sustaining measures (*figure 1*). End-of-life decisions are preferably shared decisions between family and the medical team.^[18] Conversations about end-of-life care issues may be emotionally challenging for staff and families. These end-of-life issues are also associated with significant psychological distress in both family members^[19] and healthcare providers.^[20] Timely preparation of the patient's relatives for the withdrawal process is a key component. In particular, families should be well pre-

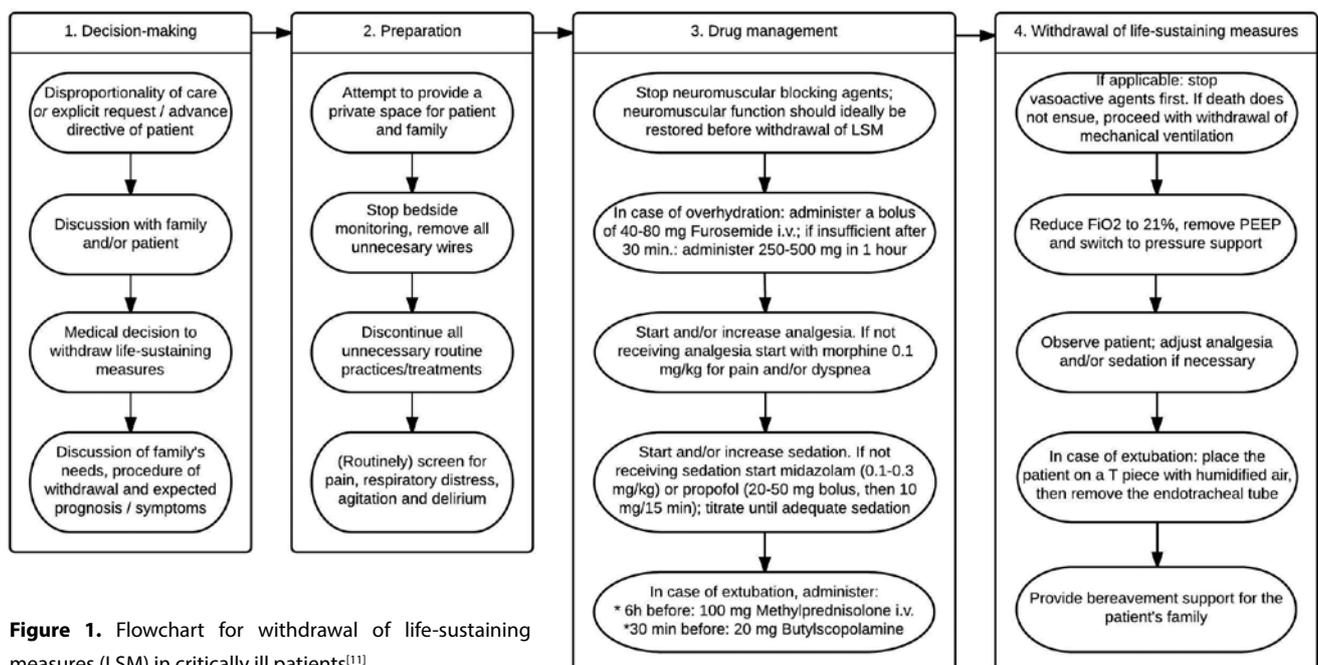


Figure 1. Flowchart for withdrawal of life-sustaining measures (LSM) in critically ill patients^[11]

pared for the normal respiratory patterns that often precede death. The decision to withdraw life-sustaining measures should be clearly documented and follow the local protocol.

Common life-sustaining measures that are withdrawn are mechanical ventilation, vasoactive medications and dialysis.^[5,11] Other supportive therapies such as intravenous fluids, parenteral nutrition and antibiotics can be stopped completely.^[21]

Preferably, a dedicated team should provide continuity of care for these patients and their relatives. The role of the nursing team in particular is the key factor during end-of-life care.^[22] If possible, a private ICU room for the patient is recommended to provide comfort and privacy for both the patient and his family. To minimise disturbances as much as possible, all monitoring equipment at the bedside should be on standby, unnecessary wires and leads should be removed and routine practices should be discontinued.^[21]

Drug management

During cessation of life-sustaining measures, the patient may rapidly become distressed. For this reason, it is crucial that the treating medical team is educated about palliative drug management in end-of-life care and has the appropriate medications readily available at the bedside.

Palliative sedation and opioids

An essential component of the process of withdrawing life-sustaining measures is ensuring adequate sedation and analgesia in a terminally ill patient in the last hours or days of a dying patient's life. It can be difficult for clinicians to treat pain and suffering adequately when patients cannot self-report their symptoms because of difficulty in identifying behavioural indicators of these symptoms.^[23] For this reason, signs and symptoms of respiratory distress, grimacing, pain and agitation should be assessed closely to ensure adequate comfort.

In general, patient comfort is attained by adequate administration of opioids and palliative sedation. If dyspnoea-associated distress is present, opioids should be titrated to a higher dose. Morphine is the preferred analgesic respiratory distress agent for terminal ICU care^[24] because of its efficiency,^[25] price^[25] and potentially beneficial euphoric effects.^[26] Fentanyl is used to manage pain,^[27] but should not be the agent of choice to prevent or treat terminal distress as it may induce chest rigidity and subsequent breathlessness by increasing muscle tone.^[28]

Most ICU patients are sedated, in which case therapeutic sedation becomes palliative sedation; i.e. sedation with the intention to decrease consciousness during the dying process.^[29] In end-of-life care, sedatives are used to relieve terminal stress and provide anxiolysis and symptom relief.^[30,31] Midazolam and propofol should be the agents of choice for sedation during end-of-life care. Both have a rapid effect and can be titrated easily.^[24,32] In case of delirium, increasing sedation is often preferred to more conventional therapy with haloperidol.^[11,33] In patients

who are sedated for a prolonged period, tolerance can develop and pose problems in end-of-life care.^[32] If this occurs, the dose can be increased or substituted with an alternative agent;^[32] this is assessed on a case-to-case basis.

A frequently phrased concern in the discussion on end-of-life drug management is the fear of hastening death by administration of high doses of analgesia or sedation. However, several studies have shown that this is not the case.^[34-37] It is important to educate and inform both clinicians and patients' families about this, as not doing so could result in undertreatment of pain and cause additional distress for the family. Given the large variability in individual responses, previous drug exposure and tolerance, no single standard pharmacological approach or dose is recommended; doses should be titrated individually and based on signs of discomfort or distress.

Neuromuscular blocking agents

Neuromuscular blocking agents should be discontinued and/or not introduced. They may mask signs of discomfort and therefore create a risk that patients will die with inadequately recognised and treated symptoms.^[38] Additionally, neuromuscular blocking agents may potentially hasten (or even cause) death after withdrawal of life-sustaining measures by causing (residual) weakness of the breathing muscles.^[38]

Additional drug management

If mechanical ventilation is withdrawn, it is important to anticipate and take precautions to prevent excessive bronchopulmonary secretion, which can cause a death rattle in some patients. Although death rattle was not found to be associated with patient respiratory distress,^[39] it is essential to take precautions to prevent it, as death rattle may be traumatising for both the patient's family^[40] and the medical team.^[41] Prevention and treatment of excessive secretion are accomplished by administering an anticholinergic drug such as butylscopolamine or glycopyrrrolate.^[42] Next to this, iatrogenic overhydration should be treated with furosemide.^[3,43] Oral suctioning and a lateral positioning of the patient may aid in reducing symptoms of excessive secretion or death rattle.^[44]

Withdrawal of life-sustaining measures

An important decision to make in the process of stopping life-prolonging therapies is choosing the order of withdrawal. The most important life-sustaining measures in the ICU are mechanical ventilation and administration of vasoactive agents.^[5,45] In the study by Epker et al.^[5] 55% of the patients died after withdrawal of mechanical ventilation alone, 35% died after withdrawal of both mechanical ventilation and vasoactive agents and 10% died after withdrawal of vasoactive agents only. The order of withdrawal is influenced by the specific situation of the patient and is individually decided. In patients who are dependent on both vasoactive agents and mechanical

ventilation, the vasoactive agents should be discontinued first;^[11] in this case, the patient will die while being mechanically ventilated. In patients who are dependent solely on mechanical ventilation for survival, considerable variation in practice attends to the process of stopping ventilator support.^[5,46-49] Gradual reduction of oxygen or ventilator support with careful titration of medication can prevent dyspnoea, yet a prolonged weaning process is not warranted, as it will contribute to the patients' suffering by prolonging the dying process.^[50] The Dutch NVIC guideline recommends reducing oxygen therapy to a maximum FiO₂ of 21%, removing positive end-expiratory pressure and switching to pressure support ventilation.^[11] In patients who are fully dependent on mechanical ventilation (e.g. patients with brain stem lesions, lacking impulses for spontaneous ventilation) this may lead to death within minutes, yet in other patients, the process may take hours or even days. Withdrawal of mechanical ventilation is part of the transition to appropriate comfort-oriented care. Whether patients should be extubated when ventilator support is withdrawn continues to be controversial. Advocates for extubating propose to free both patient and his family from artificial technology and provide a more natural death. Additionally, it has been shown that palliative extubation is associated with improved family satisfaction.^[51] However, in the European Ethicus study,^[14] only 9% of patients were extubated. Interestingly, physician characteristics rather than patient characteristics influence this decision in an international study.^[49]

Bereavement support

End-of-life care does not end the moment the patient has died; as part of a family-centred and compassionate approach to end-of-life care, it is essential to provide bereavement support for the family.^[8] Before, during and after the dying process, the medical team should attempt to explore the patient's family's wishes and belief system to be able to support the family as best they can.^[18,52] There is increasing evidence that clear communication between the medical team and the family both pre- and post-mortem reduce psychological morbidity.^[19,24] Furthermore, it is important to realise that the medical team may also have bereavement needs.^[24]

Conclusions

End-of-life care is a fundamental component of ICU care, which requires an equally high level of expertise and planning as life-sustaining care. Recommendations regarding end-of-life in the ICU often cannot use an evidence grading system because most of the recommendations are based on ethical, social and legal principles that are not derived from empirically based evidence but mostly from clinical evidence. Nevertheless, recommendations to use and design a detailed end-of-life protocol will facilitate structured and careful examination of the different decisions and problems encountered in the course of withdrawal

of life-sustaining measures. Importantly, the vast majority of patients are not able to take part in end-of-life decision-making due to their illness and/or sedation; communication between the medical team and the family is thus essential. It is important that the family understands that withdrawal of life-sustaining measures is not equivalent to withdrawing care. Doctors and nurses should receive training in withdrawing life-sustaining measures and be educated in the facts and fictions surrounding this process. By providing holistic and adequate end-of-life care, maximal efforts are made to optimise the 'quality of dying'; thus providing some light in a time of darkness.

Disclosure

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