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End-of-life decisions and palliative care in surgical intensive care units

Odlučivanje o kraju života i palijativna skrb u kirurškim odjelima intenzivnog liječenja

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Descriptors
TERMINAL CARE; PALLIATIVE CARE;
DECISION MAKING – ethics;
WITHHOLDING TREATMENT – ethics;
INTENSIVE CARE UNITS

SUMMARY. Medical advancements have significantly increased the possibilities of treating and survival of critically ill or injured patients. In intensive care units the ethical dilemma arises, questioning whether aggressive treatments merely postpone the inevitable end of life and become burdensome to patients. Palliative care and end-of-life treatment are an integral part of intensive care. Palliative care may improve the quality of life for patients facing serious illnesses, while end-of-life decisions relieve the patients from unnecessary aggressive treatments. The goal of palliative care is to provide relief from unpleasant symptoms, pain, and stress, enhancing the overall well-being of the individual and supporting both the patients and their family members throughout the illness trajectory. ICU clinicians require knowledge and competence on the main aspects of withholding/withdrawing interventions. They have to provide quality healthcare with respect to psychological, social, and spiritual distress. Knowledge of palliative care such as symptom relief, communication and end-of-life care should be taught on a regular basis. The main challenge in the end-of-life decision making is that dying patients in the ICU are often unable to participate. Decision making on withholding and withdrawing of life-sustaining therapies in ICU varies from country to country. This paper explores the ethical considerations surrounding end-of-life decisions and compares the annual practices in a tertiary surgical intensive care unit in Slovenia with those in other countries.

Deskriptori
SKRB NA KRAJU ŽIVOTA; PALIJATIVNA SKRB;
DONOŠENJE ODLUKA – etika;
USKRAĆIVANJE LIJEČENJA – etika;
JEDINICE INTENZIVNOG LIJEČENJA

SAŽETAK. Medicinski napredci značajno su povećali mogućnosti liječenja i preživljavanja kritično bolesnih ili ozlijeđenih pacijenata. Međutim, etičke dileme nastaju u jedinicama intenzivnog liječenja (JIL), postavljajući pitanje jesu li agresivni tretmani samo odgoda neizbježnog kraja života te postaju li opterećujući za pacijente. Palijativna skrb može poboljšati kvalitetu života pacijenata koji se suočavaju s ozbiljnim bolestima. Cilj je pružiti olakšanje od simptoma, boli i stresa, unaprjeđujući opće blagostanje pojedinca te podržavajući i pacijente i njihove obitelji kroz tijek bolesti. Kliničari u JIL-u moraju posjedovati znanje i kompetencije o glavnim aspektima neprovođenja ili prekida intervencija. Dužni su pružati kvalitetnu zdravstvenu skrb uz poštivanje psiholoških, socijalnih i duhovnih potreba pacijenata. Znanja iz područja palijativne skrbi, poput ublažavanja simptoma, komunikacije i skrbi na kraju života, trebala bi se redovito podučavati. Glavni izazov u donošenju odluka na kraju života jest taj što pacijenti u JIL-u često ne mogu sudjelovati u procesu odlučivanja. Donošenje odluka o neprovođenju i prekidu terapija za održavanje života u JIL-u varira od zemlje do zemlje. Ovaj rad istražuje etička razmatranja koja se odnose na odluke o kraju života, uspoređujući prakse u kirurškoj JIL tercijarne institucije u Sloveniji s onima u drugim zemljama.

The progress in medicine has substantially expanded the options for treating and extending the lives of critically ill or injured individuals. Despite the development of new technologies and the improvement of care, death rate in the ICUs remains high.[1] However, the question arises in intensive care units (ICUs) whether intensive treatments only delay the impending end of life, becoming a necessity to patients. That is why palliative care and end-of-life treatment are an integral part of intensive care. Palliative care may improve the quality of life for patients facing serious illnesses, while end-of-life decisions relieve the patients from unnecessary aggressive treatments. It is not self-evident that ICU healthcare workers are expert in providing optimal palliative care. The ethical dilemma in intensive medicine often revolves around the question of postponing the inevitable end of life or discontinuing treatment.[2]

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Palliative Care

The general palliative approach to patient care should commence early after the diagnosis of an incurable disease, intertwining with treatments aimed at slowing the progression of the underlying condition. Palliative care is intended for all patients facing a diagnosis of an incurable disease, irrespective of age, diagnosis, or prognosis.[3] As the underlying disease progresses, palliative care usually becomes predominant, focusing on the process of dying, death, and grieving. The goal is to ensure the best quality of life, dignity, respect, and adherence to the patient's wishes during the end-of-life period. Care for a dying patient is an integral part of comprehensive palliative care.[4] When facing a life-threatening illness, palliative care is equally important as standard ICU care. In addition to the intensive care therapy goals, palliative care focuses its efforts on maintaining or even improving the quality of life of patients and their relatives.[5]

Treatment plans are patient oriented and individualized, considering the patient's health status, suitable options, and their preferences. Timely recognition and appropriate interventions for emerging issues are crucial. Although the aims of palliative care and critical care may initially seem divergent, values and goals in critical care and palliative care are similar, as saving or prolonging life may conciliate with alleviating suffering and improving quality of life and death.[1] When faced with an oncological patient, palliative care does not replace the treatment but complements it. Together, they present an opportunity for a quality and prolonged life, even when a cure for the underlying malignant disease is no longer possible.

Effective communication skills and compassionate information delivery regarding the anticipated course of the disease and additional care options are essential components of palliative care. In the context of ICUs, implementing palliative care involves managing symptoms and signs of end-of-life illnesses, communicating with relatives, and setting care goals that ensure a dignified death. Palliative care in the ICU includes alleviating uncomfortable symptoms commonly encountered during ICU treatment: pain, thirst, anxiety, sleep disturbances, and a sense of dyspnea. The care at the end of life should never include only managing pain and other symptoms, but also has to show dignity and respect at time of death, which are typical issues regarding palliative care experience in the ICUs.[1]

Healthcare professionals, usually adopting a multidisciplinary approach, aim to manage the physical challenges arising from the advanced disease. ICU clinicians require knowledge and competence on the main aspects of withholding/withdrawing interventions and, in general, end-of-life supports, including adoptions of some treatment limiting and suffering, good communication with relatives, and how to afford some ethical issues.[1] They have to provide quality healthcare, addressing psychological, social, and spiritual distress. Employees in intensive care wards should at least go through basic qualification as part of regular training. Baseline knowledge of palliative care such as symptom relief, communication, and end-of-life care should be taught and developed as an in-house standard operating procedure.[5]

When the prolongation of treatment can no longer provide improvement for the patient's incurable disease or paradoxically proves to be a greater burden than a benefit, doctors decide on the cessation or withdrawal of treatment. The main challenge is that dying patients in the ICU often lack the capacity to participate in decision-making because of their underlying disease or because of sedatives and other psychoactive drugs; therefore, decisions are made by medical consultations.[6]

Decision making on withholding and withdrawing of life-sustaining therapies in ICU is not homogenous worldwide. This process depends on several factors such as legal, political, religious issues other than experience and patients' characteristics. Despite all knowledge, end-of-life decisions in ICU are difficult for patients, families, and doctors alike, yet they are increasingly common. However, the capacity of withdrawing or withholding aggressive and futile treatments should belong to the armamentarium of any ICU clinician.[7]

Hospitalization of a loved one in the ICU is a heavy burden for family members. A significant proportion of them experience anxiety (70%) and depression (35%). Some even develop acute stress disorder and post-traumatic stress disorder. Symptoms are more pronounced in the partners of the affected individuals and close family members.[8] Family satisfaction with treatment and care in the ICU is associated with effective communication with healthcare staff, a sense of involvement in decision-making, and specific measures contributing to the patient's comfort at the end of life.[9]

Decisions to abandon or withdraw treatment are common – in as many as 40 – 70% of deaths in ICUs. These kinds of decisions carry a lot of weight. Psychologically speaking, it is easier for clinicians to not start a treatment at all than to withdraw an existing therapy. In withdrawal, according to the literature, there is a greater feeling of actively ending life.[10]

A decision such as turning off the ventilator is ethically and morally more difficult for many to accept than the decision to abandon intubation. Regardless, the clinician is responsible for both decisions made and not made during treatment. The end result of giving up or withdrawing is ultimately the same, which is a shortened life. Therefore, most legal and philosophi-

cal analyses have concluded that there is no ethical, moral or legal difference between withholding or withdrawing treatment.[11]

Important Definitions in Palliative Care

End-of-Life State: A situation characterized by a severe deterioration in health due to the nature of the disease or other causes, where the patient's death can be expected in the near future.

"Do Not Resuscitate" (DNR/DNAR): A form of treatment withdrawal, a decision not to attempt resuscitation.

Withholding Treatment: The decision not to initiate additional or intensify current treatment, which can be judged as merely prolonging the dying process, being unjustified and not in the patient's best interest.

Withdrawing Treatment: The cessation of ongoing treatment judged as merely prolonging the dying process, being unjustified and not in the patient's best interest.[2]

Table 1. Deceased in days from decision making
Tablica 1. Preminuli u danima od donošenja odluke

	SICU 1st decision making / JIL 1. odluka	SICU 2nd decision making / JIL 2. odluka	Department since 1st decision making / Odjel od 1. odluke
Number of patients / Broj pacijenata	79	11	21
Deceased / Umrli	56	7	15
Days since decision making / Dani od odluke	1,98	0,86	29,73
MIN	0,00	0,00	0
MAX	12,00	3,00	104
Standard deviation / Standardna devijacija	2,96	1,21	37,34

End-of-life decisions in the University Medical Centre Ljubljana surgical ICU

In 2022, the medical board deliberated on the continuation of treatment and palliative care for 79 patients in the Medical Centre Ljubljana surgical intensive care unit (SICU). In 11 cases, a second decision-making process took place. Of the patients with signed palliative care documents, 56 died in the SICU, on average 1.98 days after the first decision and 0.86 days after the second decision (Table 1).

Twenty-one patients were transferred to other departments, with 15 of them eventually passing away on those units. Three of the patients were transferred to other departments only after the second decision making. The average time until death on other units was 23.93 days (min. 0, max. 104 days).

Out of a total of 90 limitations, the most frequent limitation was to withhold resuscitation (88), followed by withholding of mechanical heart support (74), withholding of surgical interventions (68), withholding of hemodialysis and hemofiltration (66), withholding of diagnostic procedures (53) and withholding of vasopressors (53), withholding of transfusion (49), withholding of chemotherapy (46), withholding of mechanical ventilation (25), withholding of antibiotic treatment (23), withholding of nutrition (13), withholding of intubation (5) and withholding of hydration (1) (Figure 1).

The medical board withdrew inotropic or vasopressor support from therapy most often (33), followed by 20 withdrawals of hemodialysis and hemofiltration, 13 withdrawals of antibiotics, nine withdrawals of blood products, three withdrawals of nutrition and one withdrawal of chemotherapy and mechanical ventilation. The medical board did not withdraw hydration and mechanical support of the heart in any of the cases (Figure 2). The type and frequency of withholding and withdrawal differed between the first and second decision making (Figure 3, Figure 4).

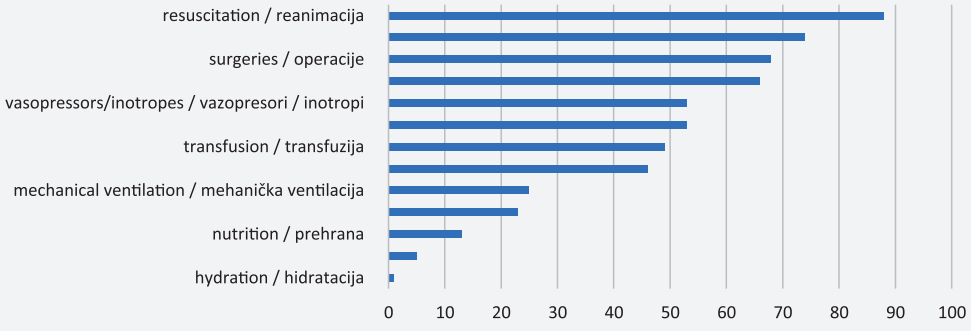

Figure 1. Withholding treatment (total)
Slika 1. Suzdržavanje od tretmana (ukupno)

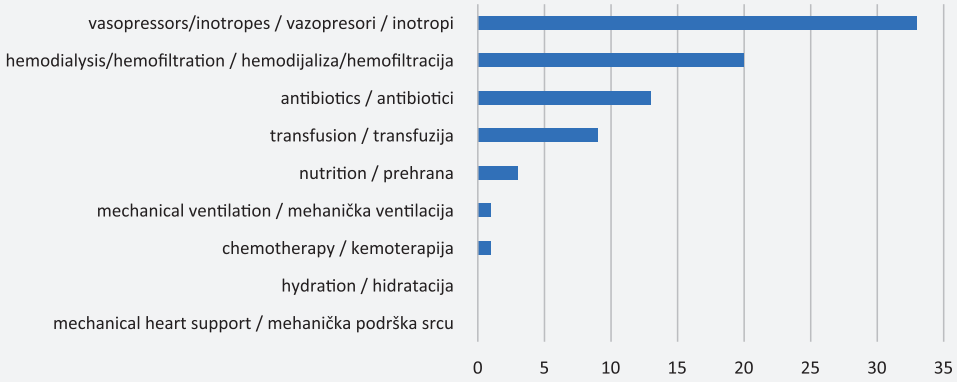

Figure 2. Withdrawing treatment (total)
Slika 2. Povlačenje tretmana (ukupno)

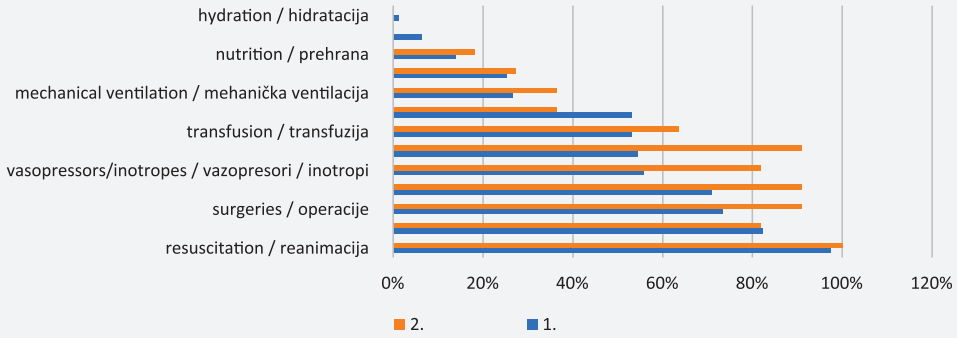

Figure 3. Withholding treatment (by group)
Slika 3. Suzdržavanje od tretmana (po grupama)

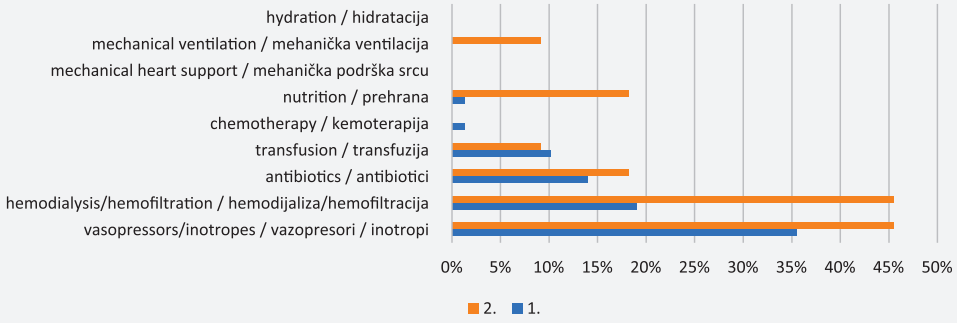

Figure 4. Withdrawing treatment (by group)
Slika 4. Povlačenje tretmana (po grupama)

In 2022, 463 patients were admitted to the SICU, 87 (18.8%) patients died, 57 (65.5%) of them with a signed palliative care document.

Comparison with Other European Countries

In most European countries patients in ICUs have treatment limitations at the end of life. Patients with treatment limitations are often older, more fragile, have more severe illnesses, and are less frequently elective admitted to ICUs. Treatment limitations occur more frequently in Northern European countries than in Eastern and Southern European countries.[12]

In a multicentric study conducted in France 52% of deceased patients had signed palliative care documents,[13] while in Italy 62% of patients had signed such limitations.[14] In Spain, only 6.6% of deceased patients had palliative care documents.[15] Norway reported a 53% prevalence of palliative care documents in a tertiary clinical centre.[16] There was a difference in data

Table 2. End-of-life treatment limitation prevalence worldwide according to the ETHICUS-2 study
Tablica 2. Učestalost odluka o kraju života diljem svijeta prema istraživanju ETHICUS-2

Region / Regija	Witholding treatment / Suzdržavanje od tretmana	Withdrawing Treatment / Povlačenje tretmana
Africa/Afrika	20%	13%
Latin America / Latinska Amerika	61%	6%
North America / Sjeverna Amerika	54%	36%
Asia / Azija	42%	39%
Australia / Australija	45%	46%
Central Europe / Središnja Europa	47%	37%
North Europe / Sjeverna Europa	38%	53%
South Europe / Južna Europa	42%	25%
Worldwide / Svijet	44%	36%

collecting, types of ICUs included and exclusion of brain-damaged patients between the studies.

An international multicentric study focusing on patients over 80 years old reported a 27.2% prevalence of palliative care documents in deceased patients.[12] The ETHICUS-2 study from 2021 compared end-of-life decisions all over the world (Table 2).[17]

At the University Medical Centre SICU in Slovenia, 65.5% of deceased patients had treatment limitations, and 38% had treatment withdrawal at the time of death. Data included the patients after traumatic brain injury.

Discussion

The results of this study showed that from a total of 436 patients 87 (18.8%) died, 56 (70.9%) of them having a signed palliative care document. The medical board reviewed the continuation of treatment and palliative care in 79 patients hospitalized at the SICU at the Medical Centre Ljubljana. Eleven patients required a second end-of-life decision making because of a change in their health status. It is important to note that almost 30% of patients with treatment limitation lived to be transferred to a department or even discharged from a tertiary hospital. Treatment limitations are therefore a tool to assist the doctor in conceptualization and planning of medical care. The number of deceased is relatively high in comparison to other countries. That is probably due to the seriousness of critical condition most of our hospitalized patients are in. Furthermore, time to death after decision making is short, marking the inevitably fatal situation.

The decision to withhold resuscitation most often does not come as a surprise. It is also commonly withheld decision in other countries.[17] For instance, in a German university medical centre ICU, every patient with an end-of-life decision has a do-not-resuscitate order.[18] Cardio-pulmonary resuscitation itself is a demanding, thorough procedure and therefore not suitable for most patients with treatment limitations. Resuscitating a patient with minimal cardio-pulmonary reserve can be more of a burden than treatment for many palliative patients. The next most commonly withheld therapies are invasive procedures such as mechanical heart support, surgical interventions, hemodialysis and hemofiltration. According to our study, there were less withdrawals than withholdings. This finding is in accordance with the Ethicus-2 study.[17]

End-of-life strategies in patients with mechanical heart support are especially intriguing. ECPR (ECMO cardiopulmonary resuscitation) patients have a guarded prognosis at the time of cannulation; however, when there is a severe acute brain injury, multi-organ failure, or a poor likelihood of recovery without an exit strategy, such as transplant or ventricular assist device, ECMO decannulation can be considered as part of the process for withdrawal of life-sustaining therapy. Early life support therapy withdrawal in ECPR was correlated with worse prognostic indicators for critical illness, including early low pH and elevated serum lactate levels.[19] Withdrawing an LVAD is also a demanding decision. Clinicians have varying perspectives on withdrawing LVAD support, particularly in patients with destination therapy LVADs. Those most directly involved in the process, such as LVAD nurses and surgeons, often view LVAD deactivation as an act similar to "active killing," given the device's lifesaving nature. This perception contrasts with other clinicians who are less involved in the deactivation process, and they are more likely to see LVAD withdrawal as analogous to discontinuing other forms of life support.[20]

Conclusion

At the end of life each patient is in a unique and irreplaceable situation. Treating physicians are often in a dilemma about what is beneficial for the patient's health and which therapy unnecessarily delays the natural course of the disease towards death. Encouraging more people to express their wishes in advance regarding the types of treatment they would prefer and which measures they would abandon in the case of a critical illness is essential. When patients end up in the ICU they often lose the capacity for independent decision-making. Treatment withdrawal and limitation are considered ethically, morally, and legally equivalent, al-

though clinical physicians more readily opt for the latter. Mortality in the Slovenian central SICU is comparable to other European countries. Similar to developed countries, decisions about treatment limitations are made before the patient's death, allowing for a dignified death without unnecessary artificial life extension.

INFORMATION ON CONFLICT OF INTEREST

The authors declare that there are no conflicts of interest relevant to this work

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AUTHOR'S CONTRIBUTION

Conception or design of the manuscript: PG, AKL, PG, MŠ

Data acquisition, analysis or interpretation: PG, AKL, PG, MŠ

Drafting of manuscript: PG, AKL

Critically revising for important intellectual content: PG, AKL, PG, MŠ

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