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Source / Izvornik: **Journal of Critical Care, 2020, 58, 10 - 19**

Journal article, Accepted version

Rad u časopisu, Završna verzija rukopisa prihvaćena za objavljivanje (postprint)

<https://doi.org/10.1016/j.jcrc.2020.03.010>

Permanent link / Trajna poveznica: <https://um.nsk.hr/um:nbn:hr:105:441387>

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Download date / Datum preuzimanja: **2025-02-14**



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## Ethical Content of Expert Recommendations for End-of-Life Decision-Making in Intensive Care Units: a Systematic Review

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## **ABSTRACT**

**Purpose:** Intensive care unit health care professionals must be skilled in providing end-of-life care. Crucial in this kind of care is end-of-life decision-making, which is a complex process involving a variety of stakeholders and requiring adequate justification. The aim of this systematic review is to analyse papers tackling ethical issues in relation to end-of-life decision-making in intensive care units. It explores the ethical positions, arguments and principles.

**Methods:** A literature search was conducted in bibliographic databases and grey literature sources for the time period from 1990 to 2019. The constant comparative method was used for qualitative analysis of included papers in order to identify ethical content including ethical positions, ethical arguments, and ethical principles used in decision-making process.

**Results:** In the 15 included papers we have identified a total of 43 ethical positions. Ten positions were identified as substantive, 33 as procedural. Twelve different ethical principles emerged from the ethical arguments. The most frequently used principles are the principles of beneficence, autonomy and nonmaleficence.

**Conclusions:** We have demonstrated that recommendations and guidelines designed specifically by intensive or critical care experts for intensive care units promote similar ethical positions, with minimal dissenting positions.

**Key words:** intensive care units, end-of-life care, end-of-life decision-making, ethics

## **1.Introduction:**

Intensive care units (ICUs) are very specific as they provide patients with the most advanced treatments which can sustain life despite severe illness. However, ICUs are also a setting where patients approach the end of their lives, and death is common [1, 2]. ICU health care professionals must therefore be skilled in providing end-of-life care. Crucial in this kind of care is end-of-life decision-making, which is a complex process involving a variety of stakeholders and requiring adequate justification, while keeping the patient's best interests in mind [3]. A substantial variability in providing end-of-life care has been found between world regions, countries, even individual ICUs within a country [4]. Carefully designed protocols and guidelines can improve the quality of end-of-life care in the ICU [1, 4, 5].

Health care professionals working in ICU are often under pressure to make swift decisions and act accordingly in the context of multifaceted uncertainty. Any action or inaction can have important medical and ethical repercussions. General end-of-life guidelines can sometimes be inapplicable in said circumstances. Therefore, there is a need for recommendations and guidelines designed specifically by intensive or critical care experts for ICUs.

The aim of this systematic review is to analyse papers tackling ethical issues in relation to end-of-life decision-making in ICUs. It explores the ethical positions, the ethical arguments supporting these positions, and the ethical principles underlying these arguments.

## **2.Methods**

This systematic review was conducted and is reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines [6].

### 2.1. Search strategy

A literature search was conducted in February 2018 and in September 2019 in bibliographic databases and grey literature sources for the time period from 1990 to 2019. The year of 1990 was set as a limit because in that year the World Health Organization issued a report of an expert committee describing the concept of palliative care [7].

We included bibliographic databases (Ovid MEDLINE, PubMed, Ebsco CINAHL and EBSCO PsycINFO), and grey literature sources: repositories (ProQuest Dissertations & Theses Global (PQDT), DART

Europe E-theses Portal, EThOS, Networked Digital Library of Theses and Dissertations (NDLTD), OpenThesis, OpenAIRE, OpenGrey.eu), social network sites (CiteULike, Mendeley), and Google Scholar search engine. In the second search, we excluded CiteULike due to the shutdown of service from March 30th, 2019. Search strategies in bibliographic databases were conducted using MeSH terms and keywords related to "end of life", "palliative care" and "intensive care unit" terms.

Grey literature is usually understood as literature that is not formally published in sources such as books or journal articles [8]. Some examples are: theses and dissertations, conference papers/proceedings, presentations, newsletters, unpublished or ongoing studies, informal communication, and government documents.

In our grey literature search strategy, we needed to focus on the recurring terms noticed when conducting bibliographic database searches. Therefore, we focused on the commonly known terms such as "end of life", "palliative care", "intensive care unit". Since grey literature sources have limitations regarding the search, we needed to use the most common and core concepts of the search terms.

## 2.2. Inclusion / exclusion criteria

We retrieved 7445 documents after duplicates were removed. Three researchers conducted the screening process independently. The papers were firstly selected based on the title. They were only included if published in English between 1990 and 2019, and if they dealt with end-of-life decisions in adult ICU. This resulted in 6811 exclusions, leaving 634 papers (see figure 1).

The next step involved reading the abstracts, resulting in 588 further exclusions, thus leaving 46 papers. The papers were only included if they provided positions or recommendations on end-of-life decision-making process in ICU and were developed by health care professional institutions or panels of intensive care experts on a national or transnational level. They were excluded if they dealt with only one method of treatment (i.e. only mechanical ventilation) or referred to a specific disease (i.e. dementia), if they included medical disciplines other than intensive care (i.e. cardiology) in the content, if issued by non-professional organisations or if they were national or transnational professional documents dealing with end-of-life issues on a general level, and not specifically focused on end-of-life decision-making in ICU.

One researcher read the full texts of 46 papers and went through the bibliographies for additional papers (snowballing technique). In case of uncertainty whether a specific paper satisfied the inclusion criteria another researcher was consulted, and a mutual decision was reached.

This resulted in 15 eligible papers, fourteen of which were detected by reading the full text, and one by scanning the reference list (see table 1). Only papers satisfying all of the inclusion and exclusion criteria were included in the review. Articles identified by snowballing technique were screened by the same criteria.

### 2.3. Qualitative analysis

The constant comparative method was used for qualitative analysis of the 15 included papers in order to identify ethical content including ethical positions, ethical arguments, and ethical principles used in the end-of-life decision-making processes [9, 10]. By this inductive method we were able to analyse the text by coding, categorizing, and comparing the data [11]. Passages of the text were labelled with an adequate code, which were subsequently compared, refined and categorized. In this process initial codes were changed as necessary, and ethical positions were created. Subsequently, we performed axial coding, i.e. connections between the categories of ethical positions were considered and they were grouped according to their content. It is important to stress that the boundaries between the ethical positions are not always strict as some of them overlap, and a clear distinction cannot be made in some cases. In cases of uncertainty another researcher was consulted, and a mutual decision was reached.

### **3.Results**

A total number of 15 papers which met the inclusion criteria - providing statements or recommendations on ICU end-of-life decision-making developed by critical or intensive care societies or experts, have been included for analysis (see table 1). Fourteen papers are country specific, while one is international. Seven are thematically mostly focused on withholding and withdrawing of treatment. Five papers tackle withholding/withdrawing of treatment as well as palliative care and terminal sedation. Two further papers are primarily dealing with palliative care and terminal sedation, and one final paper deals exclusively with intentional life-terminating actions.

**Table 1.** List of included papers

	Publication year and reference	Country	Issued by	Dealing with: Withholding / withdrawing treatment (WH/WD); Palliative care and terminal sedation (PC and TS); Intentional life-terminating actions (ILTA)
1	1990 (22)	USA	Task Force on Ethics of the Society of Critical Care Medicine	WH/WD
2	1990 (13)	USA	Society of critical care medicine / American college of chest physicians	WH/WD
3	2000 (24)	Canada	Critical care society	WH/WD
4	2001 (14)	USA	Ethics Committee of the Society of Critical Care Medicine	WH/WD; PC and TS
5	2002 (12)	Canada	Critical Care fellowship program directors, Intensive Care Division Chief, provincial Deputy Coroners/Medical Examiners, academic Adult intensivists	PC and TS
6	2003 (15)	Italy	Italian society of anaesthesia, analgesia, resuscitation	WH/WD
7	2006 (16)	Italy	Italian society of anaesthesia, analgesia, resuscitation	WH/WD; PC and TS
8	2008 (18)	Austria	Austrian Associations of Intensive Care Medicine	WH/WD
9	2008 (17)	USA	American College of Critical Care Medicine	WH/WD; PC and TS
10	2012 (19)	India	Indian Society of Critical Care Medicine	PC and TS
11	2014 (23)	International	Critical care societies worldwide	WH/WD; PC and TS
12	2014 (20)	India	Indian society of Critical Care Medicine & Indian Association of Palliative Care	WH/WD; PC and TS
13	2014 (26)	Belgium	Belgian Society of Intensive Care Medicine	ILTA
14	2016 (21)	Canada	Canadian Critical Care Society	WH/WD
15	2018 (25)	Canada	Canadian Critical Care Society	WH/WD

### 3.1. Content of the papers

The ethical content of the papers was analysed by firstly identifying ethical positions from the papers, secondly, by identifying ethical arguments supporting those positions, and finally, by identifying ethical principles used in the end-of-life decision-making processes.

In this review the term ‘ethical position’ is used for positions and recommendations which emerged from the qualitative analysis and pertain to the ethical aspect (e.g. patient’s rights, wishes and values should be respected), and not to the practical aspect of end-of-life decision-making (e.g. doses of medications used). Ethical arguments which emerged from the papers supporting an ethical position were noted. They contain an explanation and a reasoning why a certain ethical position should be followed (e.g. the principle of autonomy grants patients

with decision-making capacity the right to refuse any and all therapies, therefore patient's rights, wishes and values should be respected). Some ethical positions are not supported by clearly expressed ethical arguments. Those ethical positions are either mentioned in the papers as a supporting statement (a declaration), without a justification in form of an ethical argument (e.g. patient's desire, expressed in writing or verbally, must be held in highest consideration), or, for some ethical positions, there is a broader explanation or description pertaining to the ethical aspects of the positions (e.g. patient's wishes should be ascertained from capable patients, or surrogates when the patient is not capable of making decisions). Ethical principles, such as principle of autonomy, beneficence, etc., were in some cases mentioned in the papers in relation to some ethical positions and arguments, and were, therefore, analysed in this review.

We have identified a total of 43 ethical positions. Ethical arguments were identified for 37 of those positions. In those 37 positions with identified ethical arguments, for only 3 we did not find any additional information or supporting statement. There are 6 positions for which we did not find ethical arguments in any of the papers, however we found either a supporting statement or additional information.

A distinction was made between substantive and procedural positions, and we have decided to analyse them separately. The substantive positions express certain values and offer unambiguous direction (e.g. 'euthanasia is not permissible'), while the procedural positions pertain to hands-on decisions made in everyday practice and decision-making process (e.g. 'patients' capacity should be assessed'). Ten positions were identified as substantive, and the rest of the 33 positions as procedural, as listed in tables 2 and 3, respectively.

### 3.2. Substantive positions

The substantive positions, drawn from our qualitative analysis, and ethical principles are listed in table 2, including the references to the papers where supporting statements and additional information, and ethical arguments connected to each position are provided.

The substantive positions were grouped under the 6 categories of medical end-of-life practices as categorised by the Dutch research team: euthanasia, physician-assisted suicide, ending of life without explicit patient request, intensified alleviation of symptoms (taking into account possible hastening of death), forgoing of life-prolonging treatment, and continuous deep sedation [27].

Two substantive positions emerged as the most prominent: patients' pain and suffering should be alleviated, even if it may hasten death, and withholding and withdrawing of treatment are morally equal, and permissible. Both were mentioned in all of the included papers. Other substantive positions mentioned in ten or



more papers state that palliative care should be provided to all ICU patients until the end of their lives, and medically futile treatments - that offer no benefit to the patient - should not be offered, maintained or started.

Even though euthanasia and physician-assisted suicide are permitted by law in some countries, only one paper clearly states that medical assistance in dying is decriminalized in specific circumstances [25], while two papers state that physician-assisted suicide is not legal [19, 20]. Several papers conclude that euthanasia is illegal in certain countries at the time they were published [17, 19, 20, 24]. Some of the papers also state that forgoing life-sustaining treatments, palliative care and terminal sedation are not the same as euthanasia [12, 14-17, 25]. Only one of the included papers exclusively supports and discusses the issue of intentional shortening of the dying process by administering sedatives in a larger dose than needed for patient comfort [26]. This paper does not clearly state whether it pertains to patients who have not given their explicit consent, but one can understand from the text that it is describing cases where patients do not have capacity, nor have they made such requests while capable. Continuous deep sedation, also referred to as terminal or palliative sedation, is mentioned in three papers and merely differentiated from euthanasia [12, 14, 16].

The substantive positions stating that forgoing life-sustaining treatments, palliative care and terminal sedation are not the same as euthanasia is placed under two different Dutch categories (euthanasia and continuous deep sedation), as it pertains to both.

### 3.3. Procedural positions

Since the medical end-of-life practices as categorised by the Dutch research team have only 6 categories, certain positions that were identified in our qualitative analysis could not be classified in those categories. Table 3 shows the list of the procedural positions, which we decided to collect under themes according to their content. Again, we identified supporting statements and additional information connected to each position, ethical arguments, and ethical principles that can be drawn from these ethical arguments.

The procedural positions relate to the decision-making process. Some are focused on certain stakeholders such as patients, family, surrogates and members of the medical team. Others provide guidance on what to keep in mind during the decision-making process and how to deal with certain issues that may arise. We have distinguished 8 content themes of procedural positions: patient related, family / surrogate related, obligations to patients and families, medical team related, treatment justification, transparency, general principles of the ICU, miscellaneous.

Two procedural positions emerged as the most prominent: effective communication with the patient, family, surrogates and between ICU team is of paramount importance, and good medical records should be kept. Both were mentioned in all of the included papers. Other positions mentioned in ten or more papers state that patients' rights, wishes and values should be respected, shared decision-making model is the preferred way of making end-of-life decisions, psychosocial needs of the patients and families should be met, and disagreements between any of the involved parties should be resolved.

There are no dissenting opinions in the aforementioned positions, except on the resort to institutional ethics committees. Many of the papers support the notion of resorting to institutional ethics committees in order to resolve a disagreement [13, 15-17, 19, 20, 22, 23, 25]. However, one paper expresses the opinion that such action is inadvisable [18]. It is argued that committees comprising of individuals who are not in immediate contact with the involved patient and critical care medicine do not possess the required insight and experience to make any substantial contribution to the process.

**Table 2.** List of substantive positions and ethical principles with references to papers where related supporting statements / additional information and ethical arguments are provided

<b>CATEGORIES OF END-OF-LIFE PRACTICES</b>	<b>SUBSTANTIVE POSITIONS</b>	<b>PAPERS WITH A SUPPORTING STATEMENT / ADDITIONAL INFORMATION (references)</b>	<b>PAPERS WITH ETHICAL ARGUMENTS (references)</b>	<b>ETHICAL PRINCIPLES AND PAPERS WHERE THEY ARE PROVIDED (with references)</b>
Euthanasia	Euthanasia is not permissible	17, 19, 20, 24		
	Forgoing life-sustaining treatments, palliative care and terminal sedation are not the same as euthanasia		12, 14-17, 23, 25	-Doctrine of double effect - 14, 17
Physician - assisted suicide	Physician assisted suicide is not permissible	19, 20, 25		
Ending of life without explicit patient request	Shortening of the dying process by administering sedatives can be desirable in some cases <sup>a</sup>		26	
Intensified alleviation of symptoms (possibly hastening death)	Patients' pain and suffering should be alleviated, even if it may hasten death	12, 13, 15, 18, 21-24, 26	12, 14-17, 19, 20, 22, 23, 25	-Respect for patient's dignity – 22, 25 -Doctrine of double effect – 12, 16, 17, 19, 20, 25 -Professional duty – 14, 15, 16, 19 -Nonmaleficence - 19, 20, 25 -Beneficence - 25
	Palliative care should be provided to all ICU patients, until the end of their lives	12, 15, 17, 18, 21, 25, 26	14, 16, 19, 20, 23, 25	-Professional duty – 16 -Beneficence - 19 -Nonmaleficence – 20 -Autonomy -23 -Respect for patient's dignity - 23
Forgoing of life-prolonging treatment	Medically futile treatments - that offer no benefit to the patient - should not be offered, started or maintained	15, 22, 26	13, 15-20, 24-26	-Nonmaleficence - 15, 18 -Proportionality of care – 26 -Social justice - 15, 20 -Respect for patient's dignity – 15 -Beneficence – 20
	The dying process should not be prolonged	15, 24	16, 18, 19, 23, 26	-Beneficence - 18, 19, 23 -Professional duty - 16, 18 -Nonmaleficence – 18 -Proportionality of care - 26
	Withholding and withdrawing of treatment are morally equal, and permissible	12-26	13-17, 22-24, 26	-Professional duty – 13 -Beneficence - 15, 17, 22, 26 -Nonmaleficence - 15, 26 -Autonomy – 17, 22, 23, 26
	There are no intrinsic moral differences between categories of treatment in a decision to WH/WD treatment	22		
Continuous deep sedation	Forgoing life-sustaining treatments, palliative care and terminal sedation are not the same as euthanasia		12, 14-17, 23, 25	-Doctrine of double effect - 14, 17

WH/WD withholding / withdrawing

<sup>a</sup> Not clear if the paper pertains to incapacitated patients

**Table 3.** List of procedural positions and ethical principles with references to papers where related supporting statements / additional information and ethical arguments are provided

<b>THEMES ACCORDING TO CONTENT</b>	<b>PROCEDURAL POSITIONS</b>	<b>PAPERS WITH A SUPPORTING STATEMENT / ADDITIONAL INFORMATION (references)</b>	<b>PAPERS WITH ETHICAL ARGUMENTS (references)</b>	<b>ETHICAL PRINCIPLES AND PAPERS WHERE THEY ARE PROVIDED (with references)</b>
Patient related	Patients' rights, wishes and values should be respected	12, 14-16, 18, 19, 23, 24	12, 13, 15, 17, 19, 20, 22, 24, 25	-Autonomy – 13, 15, 17, 19, 20, 24, 25 -Privacy – 13 -Nonmaleficence - 19
	Patients' capacity should be assessed	13, 22, 23	19	-Autonomy - 19
	Patients should be encouraged to make advance care plans, which should be respected	12, 13, 15, 19, 22, 23, 25	16, 18, 23, 24, 25	-Autonomy – 16, 23, 24, 25
	Substitute judgement or patient's best interest model should be used when making a decision for patients who lack capacity	13, 15, 17, 23-25	13, 15, 17, 19, 23, 24	-Autonomy - 19
	Quality of (remaining) life should be judged from the patient's perspective	15, 19, 25	19	
	Patient care and treatment should be individualized	12, 21	13, 14, 17, 25	-Beneficence – 13, 17, 25 -Respect for patient's dignity – 14 -Social justice - 25
Family / surrogate related	Wishes of the family and surrogate decision-makers should be considered	13-15, 18, 22, 26	17, 22	-Compassion - 17 -Beneficence - 22
	Surrogate decision makers should be identified, and a clear hierarchy established	13, 19, 22, 25	20	-Professional duty - 20
Obligations to patients and families	Decision makers (patients and surrogate decision makers) should be adequately informed before making a decision	13, 17, 21, 24, 25	19, 20, 22, 24	-Beneficence – 19 -Autonomy – 19, 20, 24
	An informed consent should be obtained from the patient or surrogate	16, 19, 23	15, 19, 20, 22, 25	-Beneficence – 19 -Autonomy – 15, 19
	Shared decision-making model is the preferred way of making end-of-life decisions	14-16, 22, 24	13, 16, 17, 19, 20, 23	-Respect for patient's dignity - 16 -Autonomy – 20 -Beneficence – 20
	Psychosocial needs of the patients and family should be met	13, 14, 18, 20-23	12, 17, 19, 20	-Beneficence – 19 -Nonmaleficence – 20
Medical team related	Values of ICU team must not interfere with the provision of unbiased and non-judgmental care	19, 25	13, 24	
	Patient can be transferred to another physician	22, 24	13, 19, 22	
	Final decision about the treatment is the physician's responsibility	15, 18, 19, 26	16	-Beneficence - 16
	Physician and the medical team should act as patients' advocates	14	13,15, 19	-Beneficence - 13, 15, 19 -Professional duty - 15
	Needs of the ICU team should be recognized and respected	12, 14, 21	17	
	Attending physician should assume responsibility for coordinating patient care	13, 20, 22, 23	13, 20	
	A multidisciplinary team should make decisions about end-of-life care	21, 23, 25	17	
Education of staff should be encouraged	12, 14, 17	23		
Treatment justification	Patient's wishes may be overridden in certain situations	23	15, 17, 20, 22-25	-Beneficence – 20, 22 -Social justice - 20 -Nonmaleficence - 23

	Certain medical therapies or procedures with no reasonable medical benefit can be provided to the patient		14, 15, 18, 22, 24, 25	-Beneficence – 24, 25 -Compassion – 24, 25
	Treatment goals should be regularly evaluated	17	13, 18, 22, 24, 25	-Social justice - 25
	Limited resources should be fairly allocated	13, 15	18-20, 24-26	-Social justice – 24, 25 -Proportionality of care - 26 -Beneficence – 20, 26 -Fairness - 18 -Professional duty - 19
	ICU care should be initiated or continued in cases of disagreement, reasonable doubt or uncertainty about patient's condition or wishes	13, 15, 16, 19, 20, 24, 25	18	
Transparency	Consensus between the members of the medical team regarding goals and strategies of treatment should be established	15, 18, 19, 20, 23-26	14, 16	
	Good medical records should be kept	13, 15, 16, 21-26	12, 14, 17-20	-Transparency - 19
	Effective communication with the patient, family, surrogates and between ICU team is of paramount importance	18, 21-23, 25, 26	12-17, 19, 20, 24, 25	-Beneficence – 15, 16
	Disagreements between parties on any level should be resolved	13, 15-20, 22-25	18	
General principles of ICU	Admission to ICU can be denied	20	15, 16, 18, 24	-Social justice – 18, 24 -Fairness - 15 -Autonomy – 16 -Beneficence - 16 -Nonmaleficence – 16, 20
	Every ICU should establish certain formal rules and protocols	18, 25		
Miscellaneous	After death care should be provided to all dying patients	20		
	Organ donation is an integral part of end-of-life decisions	14, 17		

### 3.4 Ethical principles

Twelve different ethical principles emerged from the ethical arguments for a total of 26 substantive and procedural positions (see table 4). Some positions are based on only one principle, while others on as much as 5. Overall, the most frequently used principles are the principles of beneficence, autonomy and nonmaleficence.

In the substantive positions 8 principles arise. The principle of nonmaleficence and beneficence are most frequent, followed by the principles of professional duty. The doctrine of double effect is mentioned only in the substantive group. In the procedural positions 11 principles emerge. The principles of beneficence, nonmaleficence and autonomy are most frequently used. Principles of privacy, compassion, fairness and transparency are mentioned only in the procedural group.

The principle of self-determination was mentioned in two papers separately from the principle of autonomy. However, both principles are supported by same ethical arguments and, as they encompass same ideas, the principle of self-determination was here grouped under the principle of autonomy.

The principle of fairness which usually conveys the same meaning as the principle of social justice was mentioned in two papers and is mentioned here as a separate principle as it pertains to slightly different ethical arguments than the principle of social justice regarding the same categories of positions.

**Table 4.** List of ethical principles and related ethical positions

PRINCIPLE	RELATED ETHICAL POSITIONS (with references)
Autonomy	<ul style="list-style-type: none"> <li>- Patients' rights, wishes and values should be respected (13, 17, 19, 20, 24, 25)</li> <li>- Patients' capacity should be assessed (19)</li> <li>- Patients should be encouraged to make advance care plans, which should be respected (16, 23, 24, 25)</li> <li>- Substitute judgement or patient's best interest model should be used when making a decision for patients who lack capacity (19)</li> <li>- Decision makers (patients and surrogate decision makers) should be adequately informed before making a decision (19, 20, 24)</li> <li>- An informed consent should be obtained from the patient or surrogate (19)</li> <li>- Shared decision-making model is the preferred way of making end-of-life decisions (20)</li> <li>- Palliative care should be provided to all ICU patients, until the end of their lives (23)</li> <li>- Withholding and withdrawing of treatment are morally equal, and permissible (17, 22, 23, 26)</li> </ul>
Privacy	<ul style="list-style-type: none"> <li>- Patients' rights, wishes and values should be respected (13)</li> </ul>
Nonmaleficence	<ul style="list-style-type: none"> <li>- Patients' rights, wishes and values should be respected (19)</li> <li>- Psychosocial needs of the patients and family should be met (20)</li> <li>- Patient's wishes may be overridden in certain situations (23)</li> <li>- Admission to ICU can be denied (based on conscious patient's denial of treatment or living will) (16, 20)</li> <li>- Patients' pain and suffering should be alleviated, even if it may hasten death (19, 20, 25)</li> <li>- Palliative care should be provided to all ICU patients, until the end of their lives (20)</li> <li>- Medically futile treatments - that offer no benefit to the patient - should not be offered, started or maintained (15, 18)</li> <li>- The dying process should not be prolonged (18)</li> <li>- Withholding and withdrawing of treatment are morally equal, and permissible (15, 26)</li> </ul>
Respect for patient's dignity	<ul style="list-style-type: none"> <li>- Patient care and treatment should be individualized (14)</li> <li>- Shared decision-making model is the preferred way of making end-of-life decisions (16)</li> </ul>

	<ul style="list-style-type: none"> <li>- Patients' pain and suffering should be alleviated, even if it may hasten death (22, 25)</li> <li>- Palliative care should be provided to all ICU patients, until the end of their lives (23)</li> <li>- Medically futile treatments - that offer no benefit to the patient - should not be offered, started or maintained (15)</li> </ul>
Compassion	<ul style="list-style-type: none"> <li>- Wishes of the family and surrogate decision-makers should be considered (17)</li> <li>- Certain medical therapies or procedures with no reasonable medical benefit can be provided to the patient (24, 25)</li> </ul>
Beneficence	<ul style="list-style-type: none"> <li>- Patient care and treatment should be individualized (13, 17, 25)</li> <li>- Wishes of the family and surrogate decision-makers should be considered (22)</li> <li>- Decision makers (patients and surrogate decision makers) should be adequately informed before making a decision (19)</li> <li>- An informed consent should be obtained from the patient or surrogate (19)</li> <li>- Shared decision-making model is the preferred way of making end-of-life decisions (20)</li> <li>- Psychosocial needs of the patients and family should be met (19)</li> <li>- Final decision about the treatment is the physician's responsibility (16)</li> <li>- Physician and the medical team should act as patients' advocates (13, 15, 19)</li> <li>- Patient's wishes may be overridden in certain situations (20, 22)</li> <li>- Certain medical therapies or procedures with no reasonable medical benefit can be provided to the patient (24, 25)</li> <li>- Limited resources should be fairly allocated (20, 26)</li> <li>- Effective communication with the patient, family, surrogates and between ICU team is of paramount importance (15, 16)</li> <li>- Admission to ICU can be denied (16)</li> <li>- Patients' pain and suffering should be alleviated, even if it may hasten death (25)</li> <li>- Palliative care should be provided to all ICU patients, until the end of their lives (19)</li> <li>- Medically futile treatments - that offer no benefit to the patient - should not be offered, started or maintained (20)</li> <li>- The dying process should not be prolonged (18, 19, 23)</li> <li>- Withholding and withdrawing of treatment are morally equal, and permissible (15, 17, 22, 26)</li> </ul>
Professional duty	<ul style="list-style-type: none"> <li>- Surrogate decision makers should be identified, and a clear hierarchy established (20)</li> <li>- Physician and the medical team should act as patients' advocates (15)</li> <li>- Limited resources should be fairly allocated (19)</li> <li>- Patients' pain and suffering should be alleviated, even if it may hasten death (14, 15, 16, 19)</li> <li>- Palliative care should be provided to all ICU patients, until the end of their lives (16)</li> <li>- The dying process should not be prolonged (16, 18)</li> <li>- Withholding and withdrawing of treatment are morally equal, and permissible (13)</li> </ul>
Social justice	<ul style="list-style-type: none"> <li>- Patient's wishes may be overridden in certain situations (20)</li> <li>- Patient care and treatment should be individualized (25)</li> <li>- Treatment goals should be regularly evaluated (25)</li> <li>- Limited resources should be fairly allocated (24, 25)</li> <li>- Admission to ICU can be denied (18, 24)</li> <li>- Medically futile treatments - that offer no benefit to the patient - should not be offered, started or maintained (15, 20)</li> </ul>
Proportionality of care	<ul style="list-style-type: none"> <li>- Limited resources should be fairly allocated (26)</li> <li>- Medically futile treatments - that offer no benefit to the patient - should not be offered, started or maintained (26)</li> <li>- The dying process should not be prolonged (26)</li> </ul>
Transparency	<ul style="list-style-type: none"> <li>- Good medical records should be kept (19)</li> </ul>
Fairness	<ul style="list-style-type: none"> <li>- Limited resources should be fairly allocated (18)</li> <li>- Admission to ICU can be denied (15)</li> </ul>
Double effect	<ul style="list-style-type: none"> <li>- Forgoing life-sustaining treatments, providing palliative care and terminal sedation are not the same as euthanasia (14, 17)</li> <li>- Patients' pain and suffering should be alleviated, even if it may hasten death (12, 16, 17, 19, 20, 25)</li> </ul>

#### **4. Discussion**

The overall aim of this review was to analyse papers tackling ethical issues in relation to end-of-life decision-making in ICUs, by exploring the ethical positions, arguments and principles. Our analysis shows there are several ethical positions which are mentioned in a large percentage of the included papers, meaning that a certain level of agreement, at least in the theoretical scope, exists. This discussion is focused on the most frequently identified ethical positions in our review.

Communication between all involved parties and on all levels is mentioned in all included papers. It is of paramount importance and has direct influence on all aspects of care as it enhances trust, provides support to patients and families, decreases conflict and aids in making timely and appropriate decisions [24, 25].

However, insufficient and inadequate communication between the medical team and the family is common and can have serious consequences [28]. Hinkle et al. explored factors associated with family satisfaction with end-of-life care in critically ill adult population and found that higher satisfaction is related to good communication [29]. A literature review conducted by Morgan concerning end-of-life care in adult critical care units in UK confirms that, as it was found that poor communication with families is the most commonly documented source of dissatisfaction, while skilful communication is considered as a means to resolve conflict [30].

Good communication is a vital component of quality critical care and key in upholding other recommendations, such as: respect for patient's wishes and values, informing the decision makers, obtaining informed consent, establishing consensus between members of the medical team, resolution of disagreements. In other words, good communication is a critical precondition underlying other recommendations and ethical principles, such as autonomy and nonmaleficence. Therefore, in everyday practice, it needs to be implemented to the fullest possible extent.

Our analysis yields only one ethical principle directly pertaining to communication – beneficence. It is mentioned in two included papers stating that it helps in making appropriate decisions in the patient's best interest, which is not surprising concerning all of the effects good communication has on end-of-life decision-making.

Keeping good medical records is another ethical position mentioned in all included papers. It indicates appropriate care, provides a means of assessing physician's intentions, and helps all team members discern the



reasons behind the decisions. Reasons for the decision to withhold or withdraw life-sustaining treatment should be entered in the patient's medical record [1].

A retrospective study conducted by Kirchhoff et al. concluded that comprehensive documentation of end-of-life care in ICU is lacking [31]. Such findings are unfortunate, as careful documentation provides a way of ensuring transparency, which is the only ethical principle ascribed to this position and identified in our review. Even though our review did not identify ethical principles of professional duty and doctrine of double effect underpinning the position of good medical records, they are connected. Physicians' professional duties entail the provision of good standard of practice and care. By noting in the medical records each aspect of care provided, physicians confirm and leave physical trace of their conduct and fulfilment of obligations towards patients. Improperly kept medical records are not equivalent to inadequate standard of practice and care. However, in striving for betterment and provision of wholesome end-of-life care, good medical records should be kept, and both principles of professional duty and transparency upheld. The principle/doctrine of double effect allows for patient's suffering to be alleviated even if it may hasten death, under the justification that death was not intended, but merely a foreseeable side-effect. In end-of-life situations it is the intent that makes a difference whether a patient's death following an administration of sedatives and narcotics is an unethical, or even felonious act or not. Adequately kept medical records enable the assessment of physician's intentions, provide clear explanation and rationale for decisions made, and ensure physician's innocence if ever being scrutinised.

Our review found that alleviation of patient's pain and suffering, even if it may hasten death, is a widely accepted ethical position, also mentioned in all included papers. It is closely related to the position that palliative care should be provided to all ICU patients, until the end of their lives, though the two differ. Provision of palliative care encompasses relief of suffering, but also psychological and spiritual support of patient and their closest ones, and provision of comfort. Both positions are supported by ethical principles of respect for patient's dignity, professional duty and non-maleficence.

Lemiengre et al. found that the prevalence of ethics policies on pain and symptom control is low in written institutional policies on end-of-life decisions [32], while Mast et al. found a lack of palliative care content and pain management in the context of end-of-life care in nationally developed guidelines for chronic, non-curable, life-limiting diseases [33]. Our findings suggest that both positions are extensively recognized as being significant in end-of-life decision-making process, therefore they should be mentioned more often and thoroughly elaborated in other guidelines related to end-of-life issues. Perhaps the reason for the discrepancies lies in the fact that our

research focused on units of intensive and critical care, where decisions must be made much more swiftly, and the medical team is possibly more experienced in administering opioid and sedative medication. Especially as it is accepted that palliative care must be instigated from the moment the patient enters the ICU [28].

The position that withholding and withdrawing of treatment are morally equivalent, and permissible was confirmed by all of the included papers in our review. It is supported by several ethical principles: professional duty, beneficence, nonmaleficence and autonomy. However, there are some minority opinions and cultural differences which do not equate the two. [34, 35, 36].

Furthermore, studies researching practical aspects of end-of-life care in ICUs have showed that withholding treatment is more common than withdrawing [37, 38]. This suggests that, even though there seem to be no apparent ethical dilemmas, there are other factors influencing the decision-making process. It is suggested that the reason for differences (be it international, or within the same country, even the same ICU) is rooted in socio-cultural diversity, legal context, patient characteristics, and physicians' beliefs, practices and prior experiences [39, 35]. The ETHICUS study has shown regional differences in Europe, and that religious affiliation affects physician's decisions on the matter [38]. Withholding of treatment is perceived as less difficult and more of a passive action, even though the end result is the same. A general increase in both withholding and withdrawing of life-sustaining treatments has been noted in European ICUs [39, 40]. Perhaps, with time there will be a decrease in difference in frequency of withholding in comparison to withdrawing life-sustaining treatments as both actions become more common, the respect for patient autonomy takes even more sway and more patients make advanced care plans.

The intentional shortening of the dying process is supported in only one of the included papers [26]. Nonetheless, studies confirm that it happens on rare occasions in several countries [38, 41]. Most countries do not allow the shortening of the dying process under current law regulations, meaning potentially illegal actions are taking place. Furthermore, the question of informing the patient and family members arises. Most shortening of the dying process therapies are preceded by withholding or withdrawing of treatment [38]. As those actions are common and legal in most countries, one assumes that the patient and family members were included in the discussion and informed about the decision. On the other hand, it can be presumed that in some cases of shortening of the dying process, due to the delicacy, sensitivity, and legal relativity of the situation, patients and family members have not been informed. This indicates another gap between theory and practice, and an important one.

When it comes to disagreements on any level about treatment of patients, most of the included papers recommend several ways of resolution, starting from communication and its improvement, and leading up to judiciary institutions. Ten of the papers propose that disputes be resolved by an institutional mechanism - the ethics committee. However, the recommendations of Austrian associations of intensive care medicine do not support such a view [18]. When describing the process of decision-making and the relevant parties, not the process of disagreement resolution *per se*, they express the opinion that decisions on therapy limitation and discontinuation should be reached on the basis of medical facts, and that the individuals who are not in direct contact with the patient, or are not concerned with critical care medicine, do not possess the requisite insight and experience to make substantial contribution in the decision-making process.

A study conducted by Schneiderman et al. has shown that ethics consultations in ICU lead to significant reduction in nonbeneficial treatments, and it was agreed by both medical professionals, patients and surrogate decision makers that ethics consultations are helpful in addressing treatment conflicts [42]. It has been shown that both ethics and palliative care consultations lead to a reduced length of stay in the ICU, and even a reduced number of ICU admissions for patients at high risk of death if the palliative care consultations occurred upon hospitalization [43, 44]. Palliative care experts try to improve the quality of dying and death (including ethical and legal aspects of decision making, the goal-setting with families experiencing high levels of distress or conflicts among members), all the while reducing the burden for caregivers, and possessing the required experience, knowledge and understanding [45]. In the cases where critical care societies or institutions do not recommend consultations by ethics committees or persons who are usually not involved with the patients or are not involved in critical care, a potential solution could be reached by providing palliative care consultation services.

The first step towards a better implementation of mentioned recommendations, which would lead towards a better end-of-life care in general, is education. Four of the included papers mention the significance of further education of ICU team members, as it would enable them to become expert in decision making and the practical aspects of end-of-life care which are in accord with the cultural, legal, and religious norms of practice environment. Enhanced professional education and training are the way for the necessary changes to ensure that all critically ill patients and their families obtain an excellent level of palliative care able to successfully meet their needs [45].

This systematic review has several limitations. Only papers in English were included, which may have led to the omission of other pertinent papers. The papers predominantly originate from western European and

North American countries which share similar socio-economic conditions, leading to potentially distorted results of similarity in promoted ethical positions.

## 5. Conclusion

We have demonstrated that recommendations and guidelines designed specifically by intensive or critical care experts for ICUs end-of-life care promote similar ethical positions, with minimal dissenting positions. However, some of the included papers do not provide ethical arguments nor principles for proposed positions, which could be considered as essential in order to be able to comprehensively judge their content and ensure ethical coherence/traceability. This is of critical importance due to the high variability of decision-making process and its final outcomes, and inadequate implementation of these seemingly widely shared propositions, as shown in previously mentioned studies [28, 31, 33, 38]. Further research is warranted in order to detect differences, if there are any, between ethical content of end-of-life decision-making in ICUs and on other medical wards and in other institutions.

**Acknowledgements:** Not applicable

**Funding:** This article is a part of 'Values and decisions at the end of life' (VAL-DE-END) project funded by Croatian Science Foundation (grant number: IP-2016-06-2721). (The sponsor had no role in study design; in the collection, analysis and interpretation of data; in the writing; and in the decision to submit the article for publication)

**Declarations of interests:** None

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