OFFICIAL STUDY TITLE: PALLIATIVE CARE AND LEGAL ASPECTS OF TREATMENT LIMITATION DECISIONS IN ICU: A SURVEY OF CLINICIANS' PERCEPTIONS

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SURVEY ON PALLIATIVE CARE AND LAW PERCEPTION

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INTRODUCTION

In countries with patient/family autonomy-oriented end-of-life (EOL) legislation (1-8), published data indicate variation of healthcare professionals' awareness of the specific legal provisions and/or regulations enabling limitation of life-sustaining treatments (4, 5, 8). Furthermore, communication difficulties and/or uncertainties about the validity of previously recorded patient preferences (e.g. in the form of advance directives) may result in heterogenous application of pertinent EOL laws/regulations (9-12). This may include cases of poor compliance with, or even opposition to new laws (10, 12).

The absence of accurate and in-depth EOL legal knowledge of clinicians (4) may be associated with perceptions that applicable laws/regulations are either too restrictive (10) or excessively ″liberal″ for the patient (12). Furthermore, critical care physicians and/or nurses may lack specific knowledge about palliative care (13, 14). Accordingly, physicians/nurses may also not be aware of the palliative nature of their everyday practice or have a clear understanding of primary and specialist palliative care.

Given the above-mentioned knowledge gaps of healthcare professionals caring for critically ill patients, we propose to conduct a Europewide, descriptive survey for intensive care unit (ICU) clinicians, primarily aimed at addressing the following questions: 1) "How much of ICU everyday practice is palliative care and how is it practiced?"; and 2) ″How do clinicians perceive the medico-legal framework around therapy limitations, patient autonomy and prognostication discussions with patients and families?″ In addition, this survey will enable us to comparatively assess the perceived extent of ICU palliative care practice in the presence vs. absence of EOL legislation.

METHODS

Study participants and protocol approval

The target population of this descriptive, open survey will include ICU physicians and nurses working in at least 100 ICUs across at least 20 European countries. Each one of participating ICUs will be represented by one or more healthcare

professionals, and the target convenience-sample size will amount to at least 500 respondents (see also below-provided statistical analysis plan). This survey study is part of the European Union-funded Enhancing Palliative Care in ICU (EPIC) project (Proposal number: 101137221; HORIZON-HLTH-2023-DISEASE-03-01). The study protocol will be submitted for approval to the Scientific Council of Evaggelismos Hospital, Athens, Greece.

Informed consent and data protection

A similar methodology has been recently described (15). According to the Helsinki declaration, participation in research requires informed consent of the participant. According to Regulation 679/2016 {or General Data Protection regulation (GDPR) of the European Parliament and of the Council, "consent" of the data subject means any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her."

Participation in and completion of the current survey means that the participant accepts to share their knowledge on palliative care practice, EOL legislation and EOL practice in their country. The estimated time for survey completion is between 30 and 60 min.

The procedure for *"pseudonymisation"* is detailed below.
A set of 20 consecutive random numbers (range, 10-29) will be generated using "Research Randomizer (www.randomizer.org). Each one of the aforementioned numbers will be assigned to a European country (country code) drawn according to alphabetic order from the list of participating countries. Next to the 2 digits of the country code, a one-to-three-digit number will be placed to represent each participant's temporal order of participation relative to other participants from the same country. The country-specific, temporal order of participants will be determined according to the exact time of submission of the completed study questionnaire. This will form the personal, three-to-five digit code for each study participant.

The survey database will be hosted by the CHARITE Berlin Simulation and Training Centre. Data on questionnaire domains will be stored next to the participant's personal code in Microsoft Excel format. This electronic Masterfile will be stored onto the password-protected hard disk of a personal computer. In addition, next to the participant's personal code, we will enter the following personal data 1) age; 2) gender; 3) religion; 4 and 5) country and center/city of professional activity; 6) characteristics of the participant's ICU (e.g. general, medical, surgical, etc.); 7) the participant's professional focus (e.g. clinical, research, etc.); and 8 and 9) the participant's professional grade (e.g. consultant, professor, etc.) and ICU experience (in years of work). There will be no collection/recording of participants' names or electronic mail addresses. Therefore, the Masterfile will fulfill the criterion of *"pseudonymization*."

Development and testing of the questionnaire

The final version of the questionnaire is presented in the Appendix of the current protocol. The questionnaire was developed based on published, relevant literature (16-23), investigator consensus and comments collected by preliminary testing; the latter comprised administration of the questionnaire to a total of 30 Danish, British and Greek ICU clinicians (10 from each country). Danish and British clinicians were asked to qualitatively assess the readability and understandability of the survey questions and provide comments for improvement as regards content and clarity. Greek clinicians were asked to first respond to the questionnaire, in order to obtain an estimate of the actual time required for survey completion, and subsequently also provide their comments on content and clarity.

In its finalized form, the survey consists of an introduction and 4 sections. The introduction includes core definitions concerning advance directives and shared decision making (16), palliative care (https://www.who.int/europe/news-room/fact-sheets/item/palliative-care), treatment limitation (17), active shortening of the dying process (or euthanasia) (17), and family (18). The first section aims at collecting data on participant characteristics, including age, gender, religion, location of professional activity (including hospital name), professional focus, grade and experience. The second section includes questions on patient-level, family-level and healthcare-level domains of palliative care (19-21), as well as participant-rating (5-point scale) of the importance of domain elements; these elements pertain to physical and psychosocial aspects of care, communication, family support and system-level support (19-21). The third section includes questions (and rating by 5-point scale wherever appropriate) about EOL legislation and practices such as and applicability of and clinician-compliance with advance directives, treatment limitation (i.e. withholding or withdrawing of life-sustaining treatments), euthanasia, terminal analgesia/sedation, EOL decision-making and family presence during cardiopulmonary resuscitation (17, 21). Lastly, the fourth section includes 12 questions with two-choice answers (i.e. yes/no) in the context of a recently introduced EOL practice score (17, 22) (with definitions of score subcomponents appended), and an additional 3 general questions about palliative care practice in the participant's ICU.

Website, survey promotion and access to the questionnaire

The electronic version of the questionnaire will be set up at a dedicated website using LimeSurvey. Invitation links for this mandatory survey (meaning: all website visitors are expected to fill the survey) will be sent Europe-wide by EPIC partner European Society of Anaesthesiology and Intensive Care (ESAIC) with the use of social media and email channels; ESAIC has approximately 18.000 followers. Additional invitation links will be emailed by the investigators to their networks of research associates; the latter will also be encouraged to share the invitation links with their own networks of colleagues/associates.

Additional protocol features

There are no planned incentives for participants. Data collection will be performed once from each participating center, within January 1st to July 30, 2024.

The questionnaire will be administered over a total of 22 electronic pages. The items (i.e. subsection questions) per page will range from 1 (open-ended questions) to 9 (multiple-choice questions). Options for responses such as "do not know" or "not applicable" are provided for all questions of sections 2 and 3 and question 25.1 of section 4. In addition, adaptive questioning (i.e. "do not know" or "not applicable" responses to the first question of a subsection triggering cancellation of all subsequent questions of that particular subsection) is used from question 15.1 through question 21.1 of section 3; this is aimed at reducing the number of questions in cases of 1) lack of participants' knowledge about whether certain EOL practices are legally allowed; or 2) participant awareness of absence of any preceding/current, local legalization of an EOL practice. In section 4, EOL practice score questions have by original protocol only 2 possible answers (17, 23), whereas questions 25.2, 25.3 and 25.4 are open ended.

The completeness of participants' responsiveness (i.e. ″all survey questions answered″) will be checked before questionnaire submission, and participants will be prompted through a "pop-up" dialog box to provide any missing responses, or indicate that they do not wish to respond to a specific question. Furthermore, just prior to questionnaire submission, another "pop-up" dialog box will display a pre-submission prompt to review (and revise if needed) the originally provided responses.

Internet protocol (IP) address data will be used to ensure the uniqueness of survey participants. More specifically, unlimited, repetitive access to the questionnaire will be allowed from an IP address of a client computer until survey submission. However, following submission of the filled questionnaire through an IP address, will result in discontinuation of survey accessibility through that particular IP address.

Due to the use of snowballing dissemination and sharing of invitation links, it will not be possible to calculate the survey response rate. However, survey completion rate will actually be calculated by dividing the total number of submitted questionnaires to the number of first-survey page visitors. Furthermore, questionnaire completeness rate will be calculated by dividing the number of questionnaires without any missing response to the total number of submitted questionnaires. Missing responses will correspond to questions to which participants will have indicated that they do not wish to answer (see also above).
Mutually contradictory responses from participants originating from the same study center, or the same city, or the same country constitute a possibility, especially for the third and fourth section of the survey (15, 17, 22-24). For example, two or more

participants from the same center/city/country may respond differently as regards the legal bindingness of advance directives. In such cases, mutually contradictory responses will be used to estimate the extent of country-specific variation in the perception of law and/or local palliative care practice.

Study outcomes

The primary outcomes will be the absolute numbers of positive (i.e. yes) responses to question groups 10 through 14 of survey section 2, 15 through 23 of section 3, and 24 and 25 of section 4.
Secondary outcomes will include 1) the absolute numbers of positive (i.e. yes) responses to question groups 10 through 14 of section 2 in the presence vs. absence of a positive response to question 24.12 of section 4.

Statistical analysis plan

Statistical analyses will include 1) descriptive statistics; 2) assessment of distribution normality (by Kolmogorov Smirnov test); 3) assessment of European country-/region-level heterogeneity in the responses; and 4) region-level comparisons of responses (17).

We expect to determine substantial heterogeneity in the responses, primarily between northern and southern Europe and central and southern Europe, and generally between countries with high vs low palliative care service integration.

High palliative care score will be defined as presence of at least 16 positive responses (out of 24 possible positive responses) to question groups 10 through 14 of survey section 2.

Generalized estimating equations (GEE) models with robust SEs and exchangeable working correlation structure accounting for the factor center (24) will be applied to examine associations between a high palliative care score, the 9 clinician demographic variables of survey section 1 [with ″country″ stratified according to ″northern, central or southern European region″ (17,23,24)], and the EOL practice score and/or its subcomponent EOL practice variables listed in question group 24 of survey section 4. The dependent variable in this analysis will be high palliative care score, yes or no. Reference category for region will be "southern Europe" (17). The maximum number of GEE explanatory variables will be 21. Consequently, our target sample size of 500 participants is expected to result in approximately 24 observations (i.e. response data-points) per variable; this exceeds the recommended threshold of 20 observations per variable (17,23,24,25) by 20% and establishes an adequate safety margin, aimed at addressing the possibility of missing responses.

Significance will be set at two-sided P <0.05. Analyses will be conducted using the latest versions of SSPS or R software.

Expected general benefits from the current study

Survey results will likely serve to refine the EPIC harmonized practice model of palliative care, further clarifying the concepts of primary versus specialist palliative care and ICU clinicians' role in the practice concept. Results from the survey on legal issues are expected to inform stakeholders involved in policy and legislation, and improve security for ICU clinicians in the respective countries and Europewide.

Expected benefits for the conduct of the EPIC trial

A factsheet on legal issues will be developed as tool for the EPIC intervention. Accordingly, work collecting information on the legal ambiguity around therapy limiting decisions in participating countries is already underway. This information will be incorporated into factsheets on legal aspects tailored to each country participating in EPIC, based on published evidence and expert opinion from the respective national centers. The factsheets are expected to achieve 1) improved awareness about national laws and regulations on therapy limitations; 2) legal constraints or deficits regarding EOL care and 3) applicability of the law to palliative care in ICU. These factsheets will be handed out during the EPIC crossover period to every ICU clinician in participating ICUs.

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APPENDIX. THE STUDY QUESTIONNAIRE

Palliative care and legal aspects of treatment limitation decisions in ICU
A survey of clinicians' perceptions

The primary objective of the current survey study is to obtain detailed information about European ICU clinicians' awareness of palliative care and relevant, local end-of-life (EoL) legislation.

Please note that by completing the following survey, you consent to participate in the study.

Definitions

Advance directive is an instrument that relays information concerning an individual's preferences and goals regarding medical procedures and treatments, especially those used for end-of-life care.

Advance care planning: A process that enables individuals to

- define goals and preferences for future medical treatment and care,
- thoroughly discuss these goals and preferences with family and health-care professionals
- record and review these preferences if appropriate.

The main objective of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious, chronic and/or acute/life-threatening illness.

Shared decision-making: shared decision-making is a collaborative process that allows patients, or their surrogates, and a possibly/preferably multidisciplinary team of healthcare professionals to reach consensus on which treatment strategies and interventions - including life-support limitation and palliative care- accord with the patient's values, goals, and preferences. [Adopted from Resuscitation. 2021;161:408-432].

Palliative care: is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (adopted from the WHO 2014 definition).

Treatment limitation/euthanasia**:** Treatment limitation in the form of withholding or withdrawing life-prolonging treatments should NOT be confused with euthanasia, which means active, intentional, and painless termination of a person's life by another person

acting at the request of the dying person.

Family: is defined by the patient or, in the case of minors or those without decision-making capacity, by their surrogates. In this context, the family may be related or unrelated to the patient. They are individuals who provide support and with whom the patient has a significant relationship.

Clinician Demographics

1. Age
(number)

2. Gender
Male, Female, Other

3. Religion
Buddhist, Catholic, Christian, Greek Orthodox, Hindu, Jewish, Muslim, Protestant, Other, None

4. Country of your professional activity
Austria, Belgium, Bosnia and Herzegovina, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Finland, France, Georgia, Germany, Greece, Hungary, Iceland, Ireland, Israel, Italy, Kosovo, Montenegro, Netherlands, Norway, Poland, Portugal, Romania, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, United Kingdom, Other (please specify)

5. Name of hospital/healthcare facility and city of your professional activity
(free text)

6. Characteristics of your intensive care unit (ICU)
6.1 General/mixed, Medical, Surgical, Other
6.2 University-affiliated, Not University-affiliated
6.3 Number of ICU beds (number)

7. Your professional focus (please choose all that apply)
Clinical, Education, Research, Management, Other (please specify)

8. Your grade (please choose all that apply)
Nurse, Trainee / non-specialist, Consultant / specialist,
University-related (Lecturer/Professor), Other (please specify)

9. Your professional intensive care experience
Less than 5 years, 5 to less than 10 years, 10 to 20 years, More than 20 years

Perceptions about provision of care for end of life / treatment limitation decisions

Please use the following 5-point scale to rate the level of importance (regarding routine/usual/standard practice) of the following domains of end-of-life patient care. Please note that the term ″importance″ corresponds to what the clinician considers as important for the care of ICU patients who are nearing end-of-life and have a documented poor prognosis.

1=unimportant
2=low importance
3=average importance
4=high importance
5=maximum importance

At the end of each domain, it is possible to clarify your responses and/or add other comments

10. Physical aspects of care

10.1. The patient's pain is assessed at least once daily, depending on their individual needs
10.1.1. Is this part of your routine practice? Yes, No, Don't know
10.1.2. Importance rating. 1,2,3,4,5

10.2. Pain relief is part of the daily ward round goals
10.2.1. Is this part of your routine practice? Yes, No, Don't know
10.2.2. Importance rating. 1,2,3,4,5

10.3. The patient's breathing/dyspnea is assessed at least once daily, depending on their individual needs
10.3.1. Is this part of your routine practice? Yes, No, Don't know
10.3.2. Importance rating. 1,2,3,4,5

10.4. Relief of dyspnea is part of the daily ward round goals
10.4.1. Is this part of your routine practice? Yes, No, Don't know
10.4.2. Importance rating. 1,2,3,4,5

10.5. The patient's other symptoms are assessed at least once daily, depending on

their individual needs.
10.5.1. Is this part of your routine practice? Yes, No, Don't know
10.5.2. Importance rating. 1,2,3,4,5

10.6. Optimizing symptom control is part of the daily ward round goals
10.6.1. Is this part of your routine practice? Yes, No, Don't know
10.6.2. Importance rating. 1,2,3,4,5

10.7. Comments (free text)

11. Psychosocial aspects of care

11.1. Various aspects of the patient's life are considered in their daily care [For example: psychological (such as anxiety), Social, Spiritual, Existential, Financial]
11.1.1. Is this part of your routine practice? Yes, No, Don't know
11.1.2. Importance rating. 1,2,3,4,5

11.2. The patient is encouraged to participate in daily activities when able
11.2.1. Is this part of your routine practice? Yes, No, Don't know
11.2.2. Importance rating. 1,2,3,4,5

11.3. The patient's treatment preferences are considered in their daily care
11.3.1. Is this part of your routine practice? Yes, No, Don't know
11.3.2. Importance rating. 1,2,3,4,5

11.4. Comments (free text)

12. Communication and EoL care planning with the patient / family in ICU

12.1. Comprehensive and understandable information about the patient's diagnosis is provided.
12.1.1. Is this part of your routine practice? Yes, No, Don't know
12.1.2. Importance rating. 1,2,3,4,5

12.2. Comprehensive and understandable information about the patient's projected disease course is provided
12.2.1. Is this part of your routine practice? Yes, No, Don't know
12.2.2. Importance rating. 1,2,3,4,5

12.3. Comprehensive and understandable information about available treatment

options is provided
12.3.1. Is this part of your routine practice? Yes, No, Don't know
12.3.2. Importance rating. 1,2,3,4,5

12.4. Comprehensive and understandable information around of end-of-life care is provided
12.4.1. Is this part of your routine practice? Yes, No, Don't know
12.4.2. Importance rating. 1,2,3,4,5

12.5. The patient is involved in end-of-life decision-making (e.g. withholding/withdrawing life-sustaining treatments) when able.
12.5.1. Is this part of your routine practice? Yes, No, Don't know
12.5.2. Importance rating. 1,2,3,4,5

12.6. The family is involved in end-of-life decision-making (e.g. withholding/withdrawing life-sustaining treatments)
12.6.1. Is this part of your routine practice? Yes, No, Don't know
12.6.2. Importance rating. 1,2,3,4,5

12.7. Comments (free text)

13. The role of and support for the family

13.1. The family's role in care is recognized and supported
13.1.1. Is this part of your routine practice? Yes, No, Don't know
13.1.2. Importance rating. 1,2,3,4,5

13.2. The family's expert knowledge of the patient and advocating for patient needs are valued
13.2.1. Is this part of your routine practice? Yes, No, Don't know
13.2.2. Importance rating. 1,2,3,4,5

13.3. The family is being supported to prepare for the patient's death; an opportunity to say goodbye is ensured if feasible.
13.3.1. Is this part of your routine practice? Yes, No, Don't know
13.3.2. Importance rating. 1,2,3,4,5

13.4. Care is extended to the family after the patient's death: family members are followed up after the patient's ICU death
13.4.1. Is this part of your routine practice? Yes, No, Don't know
13.4.2. Importance rating. 1,2,3,4,5

13.5. Comments (free text)

14. System-level multidisciplinary support

14.1. Is there effective cooperation among members of the treating team? Yes, No, Don't know
14.1.1. Importance rating. 1,2,3,4,5

14.2. Do you think that end-of-life decisions should include an interdisciplinary team of healthcare professionals? Yes, No, Don't know
14.2.1. Importance rating. 1,2,3,4,5

14.3. Do you think that end-of-life decisions should include the patient (if feasible)? Yes, No, Don't know
14.3.1. Importance rating. 1,2,3,4,5

14.4. Do you think that end-of-life decisions should include the family? Yes, No, Don't know
14.4.1. Importance rating. 1,2,3,4,5

14.5. Do you think that end-of-life decisions should include others? Yes, No, Don't know
14.5.1. If yes, please specify who?
14.5.2. Importance rating. 1,2,3,4,5

14.6. Comments (free text)

Perceptions about legal framework for end of life/ treatment limitation decisions

Please use the following 5-point scale to rate the importance of the following elements of treatment limitation decisions; please note that ″your country″ = ″the country in which you work″

1=unimportant
2=low importance
3=average importance
4=high importance
5=maximum importance

At the end of each domain, it is possible to clarify your responses and/or add other comments

15. Regarding Do-not-attempt cardiopulmonary resuscitation (DNACPR) orders

15.1. Are they legally allowed in your country? Yes, No, Don't know *(if no/Don't know – move on to question 16.1.)*

15.2. Do you feel comfortable with existing legislation? Yes, No, Don't know, Not applicable (NA)
15.2.1. Importance rating. 1,2,3,4,5

15.3. Do you feel empowered to apply the existing legislation? Yes, No, Don't know, NA
15.3.1. Importance rating. 1,2,3,4,5

15.4. Do you feel empowered to document DNACPR? Yes, No, Don't know, NA
15.4.1. Importance rating. 1,2,3,4,5

15.5. Is the treating team involved in the decision for DNACPR Yes, No, Don't know, NA
15.5.1. Importance rating. 1,2,3,4,5

15.6. Is the patient involved in the decision for DNACPR (if feasible)? Yes, No, Don't know, NA
15.6.1. Importance rating. 1,2,3,4,5

15.7. Is the family involved in the decision for DNACPR? Yes, No, Don't know, NA

15.7.1. Importance rating. 1,2,3,4,5

15.8. Are other persons (e.g. religious leader) involved in the decision for DNACPR? Yes, No, Don't know, Not applicable (NA)
15.8.1. If yes, please specify (free text)
15.8.2. Importance rating. 1,2,3,4,5

15.9. Comments (free text)

16. **Regarding advance directives**

16.1. Do they exist in your country? Yes, No, Don't know, Not applicable (NA) *(if no/Don't know/NA – move on to question 17.1.)*

16.2. Are they legally binding in your country? Yes, No, Don't know, NA

16.3. Do you feel comfortable with existing legislation? Yes, No, Don't know, NA
16.3.1. Importance rating. 1,2,3,4,5

16.4. Do you feel empowered to apply them? Yes, No, Don't know, NA
16.4.1. Importance rating. 1,2,3,4,5

16.5. Do you feel empowered to document them? Yes, No, Don't know, NA
16.5.1. Importance rating. 1,2,3,4,5

16.6. Are they regularly reviewed (e.g. every 5 years)? Yes, No, Don't know, NA
16.6.1. Importance rating. 1,2,3,4,5

16.7. Comments (free text)

17. Terminal analgesia / sedation

(the use of analgesics and sedatives in dying patients until the point of death)

17.1. Is it legally allowed in your country? Yes, No, Don't know, Not applicable (NA) *(if no/Don't know/NA – move on to question 18.1.)*

17.2. Do you feel comfortable with existing legislation? Yes, No, Don't know, Not applicable (NA)
17.2.1. Importance rating. 1,2,3,4,5

17.3. Do you feel empowered to apply it? Yes, No, Don't know, NA
17.3.1. Importance rating. 1,2,3,4,5

17.4. Do you feel empowered to document it? Yes, No, Don't know, NA

17.4.1. Importance rating. 1,2,3,4,5

17.5. Is the treating team involved in the decision for terminal sedation? Yes, No, Don't know, NA
17.5.1. Importance rating. 1,2,3,4,5

17.6. Is the patient involved in the decision for terminal sedation? (if feasible)? Yes, No, Don't know, NA
17.6.1. Importance rating. 1,2,3,4,5

17.7. Is the family involved in the decision for terminal sedation? Yes, No, Don't know, NA
17.7.1. Importance rating. 1,2,3,4,5

17.8. Comments (free text)

18. Withholding of treatment (i.e. avoiding escalation of an already administered treatment or avoiding to add a new treatment)

18.1. Is it legally allowed in your country? Yes, No, Don't know, Not applicable (NA)
(if no/Don't know/NA – move on to question 19.1.)

18.2. Do you feel comfortable with existing legislation? Yes, No, Don't know, Not applicable (NA)
18.2.1. Importance rating. 1,2,3,4,5

18.3. Do you feel empowered to apply it? Yes, No, Don't know, NA
18.3.1. Importance rating. 1,2,3,4,5

18.4. Do you feel empowered to document it? Yes, No, Don't know, NA
18.4.1. Importance rating. 1,2,3,4,5

18.5. Does it include feeding? Yes, No, Don't know, NA
18.5.1. Importance rating. 1,2,3,4,5

18.6. Does it include hydration? Yes, No, Don't know, NA
18.6.1. Importance rating. 1,2,3,4,5

18.7. Comments (free text)

19. Withdrawing of treatment (i.e. stopping/removing an already prescribed/ongoing treatment)

19.1. Is it legally allowed in your country? Yes, No, Don't know, Not applicable (NA)

(if no/Don't know/NA – move on to question 20.1.)

19.2. Do you feel comfortable with existing legislation? Yes, No, Don't know, Not applicable (NA)
19.2.1. Importance rating. 1,2,3,4,5

19.3. Do you feel empowered to apply it? Yes, No, Don't know, NA
19.3.1. Importance rating. 1,2,3,4,5

19.4. Do you feel empowered to document it? Yes, No, Don't know, NA
19.4.1. Importance rating. 1,2,3,4,5

19.5. Does it include feeding? Yes, No, Don't know, NA
19.5.1. Importance rating. 1,2,3,4,5

19.6. Does it include hydration? Yes, No, Don't know, NA
19.6.1. Importance rating. 1,2,3,4,5

19.7. Comments (free text)

20. Euthanasia in adults

20.1. Is it legally allowed in your country? Yes, No, Don't know, Not applicable (NA)
(if no/Don't know/NA – move on to question 22.1.)

20.2. Do you feel comfortable with existing legislation? Yes, No, Don't know, Not applicable (NA)
20.2.1. Importance rating. 1,2,3,4,5

20.3. Do you feel empowered to apply it? Yes, No, Don't know, NA
20.3.1. Importance rating. 1,2,3,4,5

20.4. Do you feel empowered to document it? Yes, No, Don't know, NA
20.4.1. Importance rating. 1,2,3,4,5

20.5. Is the treating team involved in the euthanasia decisions?
Yes, No, Don't know, NA
20.5.1. Importance rating. 1,2,3,4,5

20.6. Comments (free text)

21. Euthanasia in children

21.1. Is it legally allowed in your country? Yes, No, Don't know, Not applicable (NA)

(if no/Don't know/NA – move on to question 22.1.)

21.2. Do you feel comfortable with existing legislation? Yes, No, Don't know, Not applicable (NA)
21.2.1. Importance rating. 1,2,3,4,5

21.3. Do you feel empowered to apply it? Yes, No, Don't know, NA
21.3.1. Importance rating. 1,2,3,4,5

21.4. Do you feel empowered to document it? Yes, No, Don't know, NA
21.4.1. Importance rating. 1,2,3,4,5

21.5. Is the treating team involved in the euthanasia decisions?
Yes, No, Don't know, NA
21.5.1. Importance rating. 1,2,3,4,5

21.6. Comments (free text)

22. Regarding EoL decisions

22.1. Do families participate in EoL decisions (adults)? Yes, No, Don't know
22.1. Importance rating. 1,2,3,4,5

22.2. Do families participate in EoL decisions (children)? Yes, No, Don't know
22.2.1. Importance rating. 1,2,3,4,5

22.3. For adults: Are EoL decisions reached through shared decision making? Yes, No, Don't know
22.3.1. Importance rating. 1,2,3,4,5

22.4. For children: Are EoL decisions reached through shared decision making?
Yes, No, Don't know
22.4.1. Importance rating. 1,2,3,4,5

22.5. Comments (free text)

23. Family presence during Cardiopulmonary resuscitation (CPR)

23.1. For adults: is family presence allowed during CPR? Yes, No, Don't know
23.1.1. Importance rating. 1,2,3,4,5

23.2. For children: is family presence allowed during CPR? Yes, No, Don't know
23.2.1. Importance rating. 1,2,3,4,5

23.3. Comments (free text)

24. In your daily practice in ICU, do you have:

24.1. Intensive care unit (ICU) routine family meetings? Yes, No

24.2. ICU daily deliberation for appropriate level of ICU care? Yes, No

24.3. ICU end-of-life discussions during weekly meetings? Yes, No

24.4. ICU written triggers for limitations? Yes, No

24.5. ICU written end-of-life guidelines? Yes, No

24.6. ICU end-of-life protocols? Yes, No

24.7. ICU palliative care specialty consultations? Yes, No

24.8. ICU ethics consultations? Yes, No

24.9. ICU staff taking communication courses? Yes, No

24.10. ICU staff taking Bioethics Courses? Yes, No

24.11. Country end-of-life guidelines? Yes, No

24.12. Country end-of-life legislation? Yes, No

24.13. Any additional comments (free text)

EOL Practice Variable	Definition
Routine family meetings	Regular (i.e. on admission and at least twice a week) scheduled conferences of at least one member of an ICU patient's family and at least one member of the treating team aimed at a) determining/clarifying the patient's health status, and comorbidities, b) patient values, preferences, and goals concerning treatment options; and c) conveying honest, accurate, and evidence-based information about patient clinical status and current/updated prognosis.
Daily deliberation for appropriate level of care	Routine daily discussions among members of the ICU treating team aimed at confirming that medical/surgical interventions administered to a patient are not disproportionate and/or do not contradict his/her preferences.
EOL discussions during family meetings	Conferences (on admission, and followed up at least as appropriate/feasible) of at least one member of an ICU patient's family and at least one member of the treating team aimed at determining and/or revising/adjusting EOL treatment goals according to the evolution of the patient's clinical course and (particularly changes) of prognosis, and ″previously clarified″ EOL values/preferences. This variable focuses on a specific type of family meetings' content aimed at achieving consistency between patient wishes and provided EOL care.
Written ICU triggers for limitations	A set of written, pre-specified medical and/or bioethical criteria for limiting LSTs in the ICU. Examples of such criteria may include: family request, presence of a pertinent living will that has to be respected, irreversible condition, un-survivable injury, severe brain injury with poor prognosis (e.g. minimally conscious state), high Sequential Organ Dysfunction Assessment Score plus]poor response to acute illness treatment, multiple organ failure (≥3 organs), non-beneficial therapy, and terminal illness.
Written ICU EOL guidelines	Written ICU recommendations (e.g. shared decision making, or obligation to inform the family about poor patient response to treatment, and/or lack of expected benefit from available and/or ongoing LSTs), with a written expectation to be followed for EOL decision-making and application of EOL decisions.
Written ICU EOL (symptom management) protocols	A written set of ICU recommendations and standards aimed at preventing any kind of patient distress (e.g. pain, dyspnea, delirium) during the application of LST limitation decisions on withholding and/or withdrawing of LSTs); written ICU EOL protocols may be based on recent, pertinent recommendations on how to perform withdrawing of LSTs.
Palliative care consultations	Consultations and/or liaison with specialists from the hospital's (specifically designated) palliative care service, focused on the treatment of symptoms (e.g. dyspnea, pain, or delirium), rather than the treatment of any underlying disease processes. Psychosocial and spiritual needs may also be attended to in patients who do not require sedation and are able to communicate. Such consultations may take place whenever LST limitation is considered, in the context of communication of available treatment options to the patient/family. An exception to the former requirement pertains to the presence of an intensivist with palliative care expertise in the ICU treating team.
Ethics consultations	Consultations and/or liaison with a specialist from the hospital's (specifically designated) clinical ethics committee, focused on addressing of any ensuing ethical dilemmas and/or challenges, including disagreements (that cannot otherwise be resolved) between surrogate decision-makers, between the patient/family and the ICU treating team, health care professionals or others.

EOL Practice Variable	Definition
Communication courses	Lessons focused at developing or improving the capability of 1) expressing oneself clearly, honestly, and accurately (about available treatment options), and also in a way that is readily understood by the patient/family; and 2) providing psychological support, and showing empathy to the patient/family.
Bioethics courses	Lessons focused on improving the knowledge, understanding of the widely accepted four Principles of Bioethics, and/or the capability of effectively addressing ethical dilemmas and challenges of routine clinical practice.
Country EOL guidelines	Written recommendations by national medical societies, or statutory governing bodies, for EOL decision making and EOL practices (e.g. symptom control and/or procedure for withdrawal of mechanical ventilation) in the ICU.
Country EOL legislation	A set of laws aimed at addressing commonly ensuing ethical issues as part of routine clinical practice (e.g. Should advance directives always be followed? Are withholding or withdrawing of LSTs, or active shortening of the dying process legally allowed?, etc.).
EOL practice score	The sum of binary (i.e. 0 or 1) grading of the 12 EOL practice variables according to their absence (=0) or presence (=1); score range: 0-12.

25.1. Do you believe that there is adequate focus on palliative care needs in your ICU?

Yes, to a very high degree
Yes, to a high degree
Yes, to some degree
Yes, but to a low degree
No, not at all
Do not know

25.2. In your opinion, what facilitates provision of palliative care in your ICU?
(free text comments)

25.3. In your opinion, what are the barriers to the provision of palliative care in your ICU?
(free text comments)

25.4. Other comments regarding palliative care in ICU? (free text comments)

Thank you very much for your help