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RESEARCH ARTICLE

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Consensus statements on end-of-life care in ICU – A Scandinavian multidisciplinary Delphi study

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Abstract

Background: End-of-life care in the Intensive Care Unit (ICU) is complex, requiring a balance of ethical, cultural and medical considerations while ensuring comfort and dignity for critically ill patients and their families.

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Aim: We aimed to develop a set of core domains for end-of-life care at Scandinavian ICUs along with corresponding consensus statements from patients, families and multidisciplinary experts.

Methods: In a three-round Delphi study, a multidisciplinary advisory board from Norway, Sweden, Finland, Iceland and Denmark, including ICU physicians, ICU nurses, palliative care specialists and a former ICU patient and family, developed potential end-of-life care domains of interest. Specialists with special competence/interest in end-of-life care and clinicians in all five countries were invited to rank these domains according to their importance and provide recommendations within each domain. The advisory board rephrased the recommendations into statements, which were sent out in the second round for participants to rate based on their level of agreement. Statements that did not achieve consensus in the second round were rephrased and redistributed in the third round.

Results: After the third Delphi round, 59 statements across 10 domains reached consensus. The domains were: 1. Communication at ICU admission, 2. Withholding and withdrawal of therapy and end-of-life care decisions in the ICU, 3. Meeting religious and spiritual needs and the needs of vulnerable patients in the ICU, 4. Extubation and termination of mechanical ventilation at the end of life in the ICU, 5. Management and monitoring of symptoms at the end of life in the ICU, 6. Continuous sedation at the end of life in the ICU, 7. Indicators for specialist palliative care consultations in the ICU, 8. Patient transfers from the ICU at the end of life, 9. Bereavement care and 10. Debriefing in the ICU following a patient's death.

Discussion: We developed core domains and consensus statements aiming at optimising end-of-life care that considers cultural and ethical nuances. The domains may help to shape end-of-life care guidelines in Scandinavian ICUs.

KEYWORDS
clinical practice guidelines, Delphi technique, end-of-life care, intensive care unit, palliative care

Editorial Comment
End-of-life care in critically ill patients can be influenced by regional cultural traditions and preferences, as well as by available resources. This Delphi review presents input from Scandinavian experts, including family members, on how this practice area can be perceived and approached.

1 | INTRODUCTION

End-of-life care in the Intensive Care Unit (ICU) encompasses a complex and multifaceted range of practices to mitigate suffering and provide dignity to critically ill patients nearing death.[1,2] End-of-life care practices span decision-making regarding withholding or withdrawing life support treatment, pain and symptom management, psychosocial support and facilitation of communication between healthcare providers, patients and families.[3,4] The complexity of ICU patients and the inherent uncertainty in critical care necessitate guidance to structure and strengthen end-of-life care in the ICU.

While end-of-life care practices vary across ICUs globally,[5,6] guidelines tailored to specific healthcare systems can enhance their applicability and effectiveness. Such guidelines must account for regional differences in healthcare resources,[7] legislative frameworks[8] and ethical and cultural standards[9] to ensure feasibility and cultural appropriateness.[10]

However, existing guidelines[11–17] may not fully account for the specific legal frameworks, ethical standards and healthcare resources in Scandinavian countries. This gap potentially leads to variability in end-of-life care practices across Scandinavian ICUs, which could impact the quality and consistency of care provided to critically ill patients and their families.[18–20]

To address this gap, we aimed to develop a set of domains and corresponding consensus statements from patients, families and multidisciplinary experts across Sweden, Norway, Finland, Iceland and Denmark.

2 | METHODS

We planned and reported this Delphi study[21] according to the Conducting and Reporting Delphi Studies (CREDES) Guidelines.[22]

2.1 | Setting

The Scandinavian healthcare systems are highly homogenous. Tax-funded and largely state-run healthcare services across Scandinavian countries operate under similar principles, ensuring universal access to healthcare for all citizens.[23]

2.2 | Delphi study participants

This Delphi study engaged three groups of participants: 1) A multidisciplinary advisory board responsible for designing the Delphi survey rounds, selecting appropriate Delphi survey respondents, analysing the survey results, phrasing consensus statements based on survey results and drafting and critically reviewing the manuscript, 2) Multidisciplinary local clinical respondents invited to participate in the first Delphi survey round and 3) Multidisciplinary end-of-life care experts invited to participate in all three Delphi survey rounds[24] (Figure 1).

2.3 | Advisory board construction

In collaboration with the Scandinavian Society of Anaesthesiology and Intensive Care Medicine (SSAI), an advisory board with 16 members was appointed. The members were selected based on their experience and expertise in end-of-life care, ensuring a balanced representation of different perspectives. The members comprised one representative from the SSAI Clinical Practice Committee (MHM), members of the 'End-of-life care in Scandinavian ICUs' (EIS-study) Group (ISD & PK: specialists in anaesthesiology, AHN: ICU nurse, MAN: palliative care specialist), four representatives appointed by the SSAI clinical practice committee, from Norway (ACR), Sweden (JM), Finland (JH) and Iceland (GT), all associated with SSAI and specialists in anaesthesiology, palliative care experts (MS, JL) with knowledge of ICU patients, ICU nurses with expertise in end-of-life care (ÅV, HIJ) and three patient/family representatives (patient-partners). Discussions (online and face-to-face) with the patient-partner representatives were conducted in Danish by (ISD, AHN) and conclusions were later presented and discussed with the rest of the advisory board.

All group discussions within the advisory board were conducted in English using the video conferencing platform Zoom (Version 5.0.2). Disagreements within the advisory board were resolved through facilitated discussions, clarifications or rephrasing of statements, and additional rounds of review.

2.4 | Recruitment and characteristics of respondents

The advisory board country representatives recruited 3–10 national respondents from each country with research or clinical experience in the ICU end-of-life care. These respondents are referred to in this paper as *national expert respondents*. Additionally, each member of the advisory board recruited respondents from their local clinical environment, referred to in this paper as *local clinical respondents*. The local clinical respondents participated only in the first Delphi round to generate a broader range of ideas and ensure that subsequent items would be of relevance to both experts and non-experts working in the ICU.[21]

The identity of the local clinical respondents was only known by the recruiting advisory board member, while the identity of the national expert respondents was known to the advisory board but remained anonymous to each other during the course of the study.

2.5 | Construction of domains

To inform the first Delphi round, all members of the advisory board were asked to submit possible domains of importance and relevance for a future guideline. The advisory board collaboratively reviewed the written domains for language clarity, correction of ambiguities and merged overlapping domains.

2.5.1 | Pilot-test of Delphi round one

To assess content and face validity, the questions for Delphi round one were piloted by 14 local Danish physicians and ICU nurses not eligible to be recruited as participants in the study. The participants in the pilot test were requested to identify any ambiguities or potential needs for improvement in the wording of the questions. Following this feedback, minor adjustments were applied to refine the wording of the questions and the description of the domains.

2.6 | Delphi round one

An electronic survey was distributed using REDCap[25,26] to *national expert respondents* and *local clinical respondents*. We collected demographic data from all respondents but did not ask respondents for religious background or ethnicity. The respondents were asked to rate the domains according to importance on a nine-point Likert scale (1–3: Not important, 4–6: Important, 7–9: Extremely important).[27] The respondents were also encouraged to provide their current practice and possible recommendations for each presented domain.

To ensure that the domains included in Delphi round one captured all relevant areas, not just those deemed important by the advisory board, respondents were provided the opportunity to suggest

	Advisory board	Local clinical respondents	National expert respondents
Physicians, ICU	7	33	20
Physicians, Palliative care	3	-	4
ICU Nurses	3	33	11
Patient-partners	3	-	-
Gender-ratio	8 / 8	41 / 24	25 / 8
Denmark	8	30	10
Iceland	1	28	4
Norway	3	9	7
Sweden	2	-	6
Finland	2	-	7
Tasks	• Suggest and phrase domains, preface • Recruitment of respondents, preface** • Distribution of electronic survey links, round 1-3** • Statistical and qualitative analysis, after round 1-2** • Merge domains, after round 1** • Phrasing of consensus-statements based on the qualitative analysis, from round 1. • Rephrasing of consensus statements after round 2 • Manuscript writing**	• Rate domains according to importance, round 1 • Suggest additional important domains, round 1 • Descrube current practice and recommendatons for each domain, round 1	• Rate domains according to importance, round 1 • Suggest additional important domains, round 1 • Describe current practice and recommendations for each domain, round 1 • State level of agreement, round 2 • Suggest changes to statements, round 2 • State level of agreement, round 3

*Not all sums add up because of missing data.
**Patient-partners in the advisory board did not contribute.

FIGURE 1 Characteristics and tasks for advisory board and respondents.

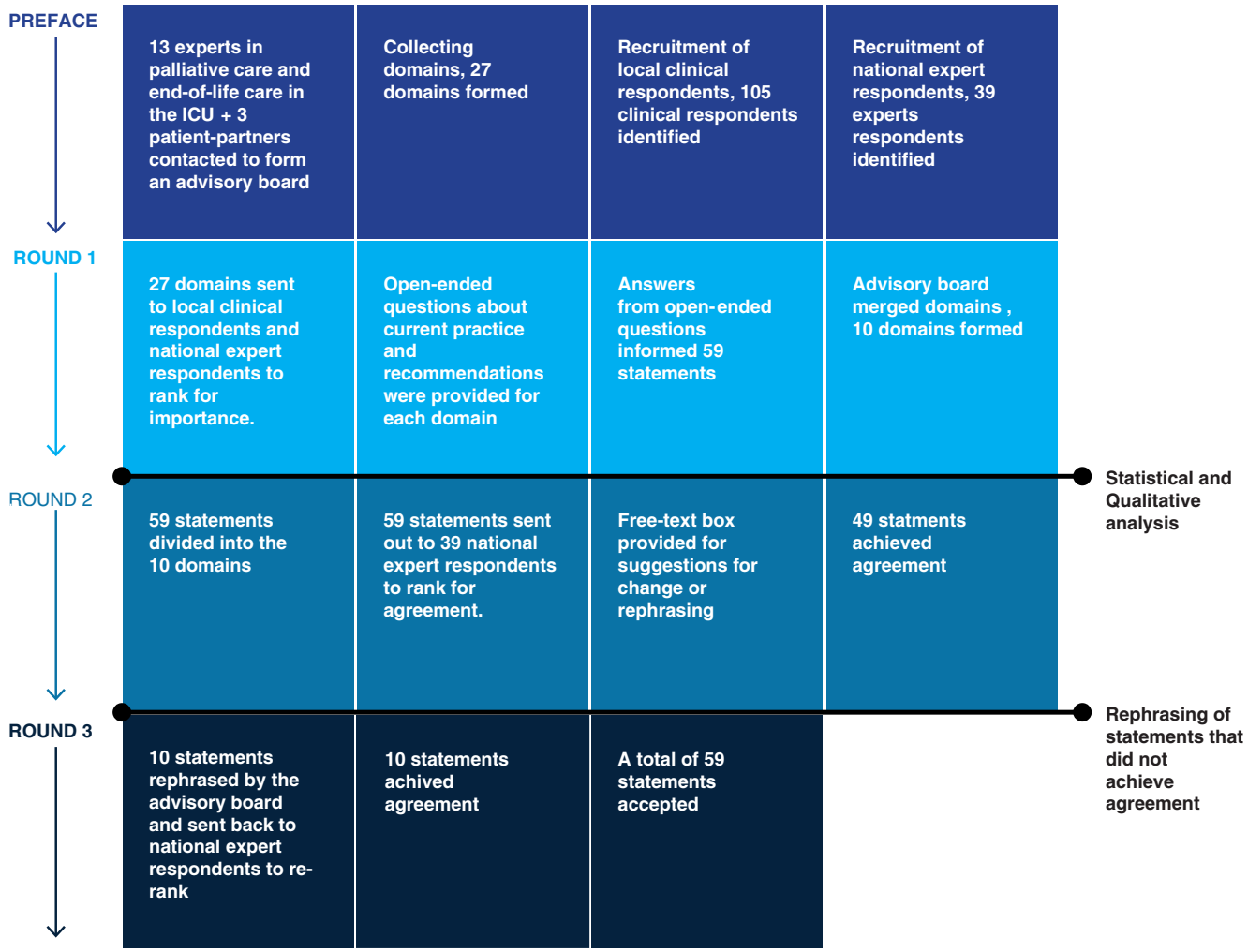

FIGURE 2 Flowchart of Delphi process.

additional domains or areas that were not covered in the initial set. Personal email reminders were sent once to those *national expert respondents* who had not responded within 14 days. Summary statistics for domain importance were reported as medians with interquartile range (IQR) (Figure 2).

2.6.1 | Analysis and management of data between Delphi round one and Delphi round two

An inductive content analysis focusing on the manifest content of data was employed following Elo and Kyngäs.[28] The analysis resulting in a list of statements was performed by the first author and subsequently discussed in the advisory board. Statements were discussed and revised by the advisory board for language clarity, correction of ambiguities and merging of overlapping statements. Statements developed in collaboration with the patient-partner panel were added at this point and marked as patient-partner statements. The domains from Delphi round one were merged into larger domains, and each statement generated in round one was subsequently organised into a relevant domain.

2.7 | Delphi round two

The aim of Delphi round two was to gather levels of the ICU end-of-life expert agreement. Statements generated from the analysis of Delphi round one were therefore exclusively sent to the *national expert respondents* in Delphi round two. The national expert respondents were asked to rank the statements according to their level of agreement on a 5-point Likert scale (1: Strongly disagree, 2: Disagree, 3: Neither agree nor disagree, 4: Agree, 5: Strongly agree). Consensus was a priori defined as more than 70% of respondents stating 'Agree' or 'Strongly agree'.[21,22,29] Non-consensus was defined as more than 70% of respondents saying 'Disagree' or 'Strongly disagree'. If respondents answered with 'Strongly disagree', 'Disagree', or 'Neither agree nor disagree', they were provided with an option for commenting or suggesting rephrasing to make the statements more agreeable to them (Figure 2).

2.7.1 | Analysis and management of data before Delph round three

Statements that achieved agreement were retained, while those that resulted in non-consensus (>70% 'Disagree' or 'Strongly disagree') were omitted. Statements that did not accomplish either consensus or non-consensus were carried forward to Delphi round three. Statements that did not achieve consensus, along with the corresponding comments, were analysed by the first author, discussed in the advisory board and rephrased.

2.8 | Delphi round three

The rephrased statements, together with a summary and explanations of the results from Delphi round two, were sent to the *national expert respondents* in the third and final Delphi round. The *national expert respondents* were asked to rank the rephrased statements according to their level of agreement on the same 5-point Likert scale as used in Delphi round two. Unlike Delphi round two, the respondents were not provided the opportunity to suggest rephrasing of statements in case of disagreement (Figure 2).

3 | RESULTS

3.1 | Delphi round one

The advisory board constructed 27 domains to be presented for 39 invited *national expert respondents* and 105 invited *local clinical respondents* in Delphi round one. Thirty-five of the 39 (90%) invited *national expert respondents* participated in the first Delphi round. In addition, 67 of the invited 105 (64%) *local clinical respondents participated*, resulting in a total response rate of 71%. The *local clinical respondents* were younger, had less experience and were more evenly distributed regarding sex, type of hospital (university hospitals/regional hospitals), country and title than the *national expert respondents* (Table 1).

The respondents ranked all 27 domains as *important* or *extremely important*. The subsequent analysis of the free-text answers resulted in 59 unique statements, which the advisory board collaboratively organised into 10 central domains (Table 2).

TABLE 1 - Demographics for Delphi round 1 respondents.

	Local clinical respondents $n = 67$	National expert respondents $n = 35$
Age, years (no, %)*/**		
30–39	13 (19)	2 (6)
40–49	28 (42)	9 (26)
50–59	17 (25)	19 (54)
60–69	8 (12)	5 (14)
Gender*/**		
Female	41 (61)	25 (71)
Male	24 (36)	8 (22)
Country (no, %)*		
Denmark	30 (45)	10 (29)
Iceland	28 (42)	4 (11)
Norway	9 (13)	7 (20)
Sweden	–	6 (17)
Finland	–	7 (20)
Workplace (no, %)*		
University hospital	43 (64)	23 (66)
Regional hospital	23 (34)	9 (26)
Other	1 (1)	3 (9)
Title (no, %)*		
Nurse – ICU	33 (49)	11 (31)
Physician – ICU	33 (49)	20 (57)
Physician – Other	1 (1)	–
Physicians – Palliative care	–	4 (11)
Years of experience (no, %)*		
0–5	2 (3)	–
6–10	11 (16)	2 (6)
11–15	13 (19)	5 (14)
16–20	12 (18)	6 (14)
Above 20 years	29 (43)	22 (63)
Years of ICU experience (no, %)*		
0–5	5 (7)	–
6–10	16 (24)	3 (9)
11–15	14 (21)	8 (23)
16–20	13 (19)	10 (29)
Above 20 years	19 (28)	14 (40)

3.1.1 | Patient-partner panel statements

The patient-partner panel submitted four statements to Delphi round two; 1. A structured conversation with the patient and/or family members at ICU admission should hold an honest evaluation of prospects, consequences and expectations for further treatments, 2. Consider providing family members with written information about where to seek assistance early on, potentially even before the patient's passing. This guidance could cover areas such as financial and social support, as well as guidance on sick leave registration. 3. When transferring a patient from the ICU to other locations at the end-of-life, a written statement in the medical file should state patient/family member's wishes. 4. If an ICU patient has been transferred to another department at the end of life, an ICU staff member should make a visit to the patient the next day.

3.2 | Delphi round two

Thirty-one of the 39 (79%) *national expert respondents* participated in the second round. Of the 59 statements presented for the respondents in Delphi round two, 49 (83%) reached consensus and 17 (29%)

TABLE 2 Merged domains from Delphi round one.

1. Communication at ICU admission
2. Withholding and withdrawal of therapy and end-of-life care decisions in the ICU
3. Meeting religious and spiritual needs and needs of vulnerable patients in the ICU
4. Extubation and termination of mechanical ventilation at the end-of-life in the ICU
5. Management and monitoring of symptoms at the end-of-life in the ICU
6. Continuous sedation at the end-of-life in the ICU
7. Indicators for specialist palliative care consultations in the ICU
8. Patient transfers from the ICU at the end-of-life
9. Bereavement care following a patient's death
10. Debriefing in the ICU following a patient's death

statements reached over 90% agreement. No statements reached non-consensus. The advisory board analysed comments and reviewed suggestions for changes related to the 10 statements that did not reach consensus, resulting in 10 rephrased statements that were later sent out for the third and final Delphi round.

The statements submitted by the patient-partner panel reached generally high agreement. Three out of four statements reached ≥90% agreement and only one patient-partner statement did not reach consensus (69% agreement) in round two. The statement was rephrased according to the comments submitted by the *national expert respondents* and carried to round three.

3.3 | Delphi round three

Thirty-one of the 39 (79%) national expert respondents participated in the third round. All 10 revised statements reached consensus, and hereof seven statements (70%) reached over 90% agreement.

The patient-partner statement; *If an ICU patient has been transferred to another department at the end-of-life, an ICU-staff member should make a visit to the patient the next day* was rephrased to; *If an ICU patient has been transferred to another department at the end-of-life, consider follow-up by a specialized palliative team, ICU liaison nurse or ICU team member depending on the patient's palliative needs*. The statement subsequently reached 100% agreement in round three.

All four patient-partner statements consequently reached consensus; three (75%) reached over 90% agreement.

After completion of all three Delphi rounds, a total of 59 unique statements achieved consensus. Twenty-four statements (41%) reached over 90% agreement. The final statements are shown in Table 3; for a full overview of initial and revised statements, see supplementary material Table S1.

4 | DISCUSSION

This Delphi study is the first attempt to construct a set of best-practice statements from patients, families, palliative care, and ICU experts to guide clinical practice for end-of-life care tailored to Scandinavian ICUs. The 59 statements represent guidance within 10 domains relevant to ICU patients, their families and the ICU staff.

The final statements in this study cover consensus about end-of-life care for ICU patients with diverse trajectories, ranging from patients who die during active therapy, immediately when treatment is withdrawn or patients who are gradually weaned from the ventilator and die within days or weeks.[5,6,30,31] Patient diversity in the ICU influences clinical practice for end-of-life care, and not all statements are applicable to all patients. Practice encompasses the clinical state of the patient, ethical decision-making about withholding or withdrawing life-sustaining treatments and navigating legal frameworks and various cultural and personal values that affect patients' and families' preferences and expectations.[5,32–34]

4.1 | Domains

The 10 domains identified in this study highlight key areas of focus for developing structured end-of-life care in Scandinavian ICUs.

The multicultural study by Sprung et al.,[12] the North American study by Clarke et al.,[4] the Japanese study by Tanaka et al.[35] and the latest *European Society of Intensive Care Medicine (ESICM) guidelines on end of life and palliative care in the ICU* by Kesecioglu et al.,[15] each present a domain-centred approach to form consensus statements on the ICU end-of-life care, similar to our study.

The domains in the ESICM guideline: Communication, Decision-Making, Interprofessional collaboration, Palliative care and Family-centered care share several thematic similarities with our findings and therefore strengthen the validity of both studies.

The ESICM guideline presents consensus on communication and shared decision-making by highlighting the importance of including patients and families at the time of admission to clarify goals of care and personal wishes.[15]

Although our study shares similarities in the domains with the above-mentioned studies,[4,12,15,35] the detailed consensus statements and the focus of the questions differ substantially. Through our Delphi process, we present consensus statements encompassing a detailed guidance on steps from ICU admission to bereavement support and debriefing of ICU staff.

Our study supplements the ESICM guideline[15] and the research by Clarke,[4] Tanaka[35] and Sprung,[12] by uniquely addressing the specific domains: Extubation and termination of mechanical ventilation, Management and monitoring of symptoms, continuous sedation, patient transfers from the ICU at the end of life and debriefing in the ICU following a patient's death.

This distinction in methodology highlights the variation in how expert opinions and evidence can be synthesized to address similar research questions. Combining these approaches could potentially make the consensus even more robust, as it integrates both practical insights from a broad range of multidisciplinary staff and the collective expertise of recognized authorities.

TABLE 3 Consensus for Scandinavian end-of-life care regimes in Intensive Care Units. Respondents' agreement with statements.

Consensus statements	Agreement (%)
1. Communication at ICU admission	
A. A conversation with the patient and/or family members at ICU admission should • Create a psychological safe space for the patient and family members to express the patient's wishes and expectations during the ICU stay • Take place in a private and undisturbed environment • Create space and time for questions • Be repeated in order to allow reflections and acceptance	100
B. To obtain the needed information at ICU admission, the conversation should clarify • Patient's wishes, living will or advance directives • The patient's medical status and cognitive performance prior to ICU admission • The patient's/family's understanding of the situation	97
C. Information of the patient and family members at ICU admission should touch upon the following themes: • Current critical illness and its progress/regress • An honest evaluation of prospects, consequences and expectations to further treatments[a] • The plan for the ICU therapy options and potential therapy restrictions • The plan if the patient deteriorates • Information and advice about psychological and physical stress to the family during an ICU stay	90
2. Withholding and withdrawal of therapy and end-of-life decisions in the ICU	
A. While the ultimate responsibility for withholding, withdrawal or end-of-life decisions rests with the physician, it is crucial to consider perspectives from other staff members. Therefore, decisions regarding end-of-life care should be preceded by a multidisciplinary conference involving the ICU physician, ICU nurse, other ICU-staff members, possible palliative care consultant or other physician involved in the patient care, allowing all to contribute to the decision-making process.	87
B. Multidisciplinary conferences about withholding, withdrawal and end-of-life decisions in the ICU must be a safe space for ICU-staff and staff members from other departments to contribute and express perspectives about the patient's care	97
C. Before any decisions about withholding or withdrawal of therapy are documented in the medical file, it is imperative to inform the patient and/or their family members about the decisions	83
D. Do not resuscitate /Do not intubate (DNR/DNI) orders should be evaluated and documented at ICU admission, evaluated daily, but a new documentation is needed only after a change in orders	100
E. When approaching patients or families with decisions about withholding or withdrawal of life-sustaining therapy consider the following: • Summarize the admission • Explain as detailed as wanted by the families, the current situation • Explain the medical and ethical reasons for therapy withdrawal • Wherever possible/relevant, treatment decisions should be made together with the patient (shared decision-making) • Create space and time for questions • Plan multiple conversations • Give the patient and/or their families time to accept the situation (given the trajectories in the ICU, time could be hours)	97
F. Conversations with the patient and/or family members about withholding/withdrawal of therapy and end-of-life decisions in the ICU should be led by an experienced ICU-physician, with participation of the ICU nurse. Palliative care consultant or other physician involved in the patient care can participate if needed	83
G. When documenting decisions about withholding or withdrawal of life-sustaining therapy and end-of-life decisions, a statement in an easy-to-access location should address the following: • Present staff, patient and family members • Current critical illness and its progress/regress • Decisions about other treatment limitations, e.g., antibiotics, nutrition etc. • End-of-life care decisions • Rationale for the decisions • Medical grounds for the decisions • Who made the decisions • Plan for management of symptoms • Patient's wishes • The patient's/family's understanding of the situation	90
H. When documenting the medical grounds for withholding or withdrawal of life sustaining therapy, consider the following items: • Comorbidities • Frailty • Current critical illness and its progress/regress • Prognosis	90

TABLE 3 (Continued)

Consensus statements	Agreement (%)
• Treatment options	
3. Meeting religious and spiritual needs, and needs of vulnerable patients in the ICU	
A. Spiritual, religious and cultural preferences should be clarified and possibly accommodated early to meet patient and family needs	90
B. ICU departments must respect and work to support all religious, spiritual or cultural needs	80
C. ICU departments should welcome all religious, spiritual and cultural leaders to support patient and their family	90
D. In order to meet patient's religious and spiritual needs educational material about important aspects and requests of the most well-known religions should be available to ICU staff	94
E. ICU staff should be mindful of the requirements of socially vulnerable patients, who may lack support from family or family members	93
4. Extubation and termination of mechanical ventilation at the end-of-life in the ICU	
A. Decisions about weaning from ventilatory support should depend on the patient's status, patient's wishes, patient's awareness and expected time to death	80
B. Consider gradually weaning the patient from mechanical ventilation, if the patient is awake and/or the expected time to death is days/weeks	77
C. Consider abrupt discontinuation of mechanical ventilation with or without extubation, if the patient has spontaneous ventilation	80
D. Consider terminal weaning including reduction of inspired fraction of oxygen, peep, support and/or respiratory rate to allow an increase in PCO2 before discontinuation of mechanical ventilation with or without extubation, in case of severe lung failure	77
E. When terminating non-invasive ventilation consider weaning or discontinuation under titration of palliative drugs.	93
F. Consider non-invasive ventilation to manage respiratory distress if pharmacological treatment of symptoms is not enough, if it provides comfort for the patient, or if prolongation of the patient's life is desired for reaching a short-term goal (e.g., meeting a family member)	87
G. Support and comfort the awake patient during weaning	90
H. Inform and prepare family members about the weaning and/or extubation procedure and expected outcome and consequences (e.g., death rattle, secretion, respiratory distress)	100
I. Consider extubation at the end-of-life if the patient can maintain an open airway and has slow or normal, spontaneous ventilation	90
J. Consider using oropharyngeal or nasopharyngeal airways or positioning the patient on the side to maintain an open airway after extubation	80
K. Consider using glycopyrrolate or atropine to reduce secretions prior to extubation	80
L. Consider extubation to enable communication if the patient is awake	87
M. Consider extubation to avoid prolongation of the dying process	83
N. Consider to leave a tracheostomy in place when terminating respiratory life support if it provides comfort to the patient	87
O. Move the patient to a private room before extubation or other withdrawal of life-sustaining therapy	77
5. Management and monitoring of symptoms at the end-of-life in the ICU	
A. Consider discontinuing fluid, nutrition and antibiotics at the end-of-life in ICU, if time to death is expected to be hours/a few days	93
B. Only medications contributing to patient comfort or with palliative purpose should be continued if time to death is expected to be hours/a few days	100
C. When decision has been made to withdraw life-sustaining therapy consider • Terminating vital sign monitoring or • Pausing monitors and silence alarms in the room or • Minimizing the use of monitoring devices and monitors in the room.	100
D. Use validated scoring instruments to access pain, anxiety, delirium, dyspnoea and respiratory distress at the end-of-life in the ICU	83
E. Use sweating, frowning, tachycardia and respiratory rate as clinical markers for pain, anxiety and respiratory distress	90
F. Consider using antiemetica regularly to treat nausea and vomiting	87
G. Consider using paracetamol administered regularly to treat fever to achieve patient comfort	87
H.Avoid using icy baths and active cooling to treat fever at the end-of-life	87
I. Manage the patient's symptoms of respiratory distress and/or suffocation using opiates and sedatives in refractory doses or as continued infusion	100
J. At the end-of-life in the ICU continue on-going pain management and supplement with opioids in refractory doses or as infusion as needed	97

(Continues)

TABLE 3 (Continued)

Consensus statements	Agreement (%)
K. Bolus administered midazolam is first choice for anxiety management at the end-of-life in the ICU	77
L. Bolus administered morphine or midazolam is first choice for dyspnoea management at the end-of-life in the ICU	73
6. Continuous sedation at the end-of-life in the ICU	
A. If the patient is already on continuous sedation and analgesia consider continuing the infusions at the end-of-life despite terminating active treatment and even extubation to achieve control of symptoms of anxiety, pain and respiratory distress	97
B. Consider using continuous sedation and analgesia at the end-of-life for patients whose suffering cannot be sufficiently relieved with other methods including analgesics and anxiolytics	100
C. Consider continuous sedation at the end-of-life in the ICU if other treatment does not sufficiently relieve the suffering of a patient.	97
7. Indicators for specialist palliative care consultations in the ICU	
A. Consider involving a specialist palliative care team or consultant for end-of-life patients in the ICU, in the following situations: • Advanced and/or complicated symptom management • If the patient previously has been affiliated with a palliative care team • Advanced psychosocial needs of the patient or the family • Awake or alert patients • If the patient is transferred to another ward. • If patient is transferred home or to other out-of-hospital location • Younger patients (and children)	93
8. Patient transfers from the ICU at the end-of-life	
A. Avoid transfers to other locations if there is a risk of the patient dying during transport	93
B. When transferring a patient from the ICU to other locations at the end-of-life a written statement in the medical file should state the following: • Patient's wishes • The patient's/family's understanding of the situation • Decision about DNR/DNI orders • Decisions about other treatments not offered, e.g., antibiotics, nutrition • Medical reasons for decision • A joint palliative care plan	93
C. When transferring a patient from the ICU to other locations at the end-of-life, the written statements in the medical files should be accompanied by face-to-face communication between the ICU staff and the personnel in the receiving location	90
D. If an ICU patient has been transferred to another department at end-of-life, consider follow-up by specialized palliative team, ICU liaison nurse or ICU team member depending on the patient's palliative needs[a]	100
E. ICUs should support and identify the options and resources available for patients who wish to withdraw life-sustaining therapy and transition to end-of-life care at home, nursing home, general hospice ward, hospice or specialized palliative care ward	87
9. Bereavement care following a patient's death	
A. A multidisciplinary follow-up meeting with the family should be offered at the ICU 1–2 months after the patient's death	76
B. The family should be provided with a contact telephone number for the ICU to address any questions during the initial days following the death	86
C. If the family members need advanced professional help after the patient's passing, they should be referred to their general practitioner for bereavement support	86
D. Local documents about religious, cultural, or social services assistance should be provided to the family after death	86
E. Consider providing family members with written information about where to seek assistance early on, potentially even before the patient's passing. This guidance could cover areas such as financial and social support, as well as guidance on sick leave registration[a]	97
10. Debriefing in the ICU following a patient's death	
A. Consider using structured debriefing sessions following a patient's death in the ICU, if any staff member requests it or if the case has been particularly difficult or challenging	97
B. When using debriefing in the ICU following a patient's death, address the following aspects: • Staff members' experiences • Clinical considerations • Ethical considerations • If known, family members' experiences • Learning points	93

[a]Statement from patient/partner advisory board representative.

The domains and consensus statements found in this study are based on opinions from Scandinavian experts in the ICU end-of-life care and show high levels of agreement on the consensus statements. This high level of agreement can be attributed to the fact that the Scandinavian experts share a very homogeneous cultural background, use a similar approach to decision-making and have comparable legislative frameworks. In addition, the SSAI provides exchange programs for trainee doctors and organizes advanced Inter-Nordic ICU educational programs for specialists in anaesthesiology,[36] reinforcing the collaboration and possible uniformity of Scandinavian ICUs.

Scandinavian countries are well known for their secularity.[18,19] Religious beliefs, traditions and decisions regarding withholding or withdrawing life support may not hold the same significance as they do in cultures where religion has a greater influence on traditions and laws. This may be part of the reason why our study showed higher levels of consensus regarding end-of-life care decision-making compared to the globally performed study by Sprung et al.[12] While that study has been foundational in its field, the rapid advancements in the establishment of end-of-life care into the ICUs since its publication may limit its applicability to current practices.

4.2 | Multidisciplinary decision-making

Consensus statements found in this study regarding multidisciplinary decision-making needed to be revised to reach agreement. The necessary revision emphasized the physicians' legal responsibility for medical decisions while also promoting a beneficial multidisciplinary approach to end-of-life decisions in the ICU.

Nurses, being directly involved in patient care, often have a closer and more continuous relationship with patients and their families. This proximity may lead nurses to recognize signs of physical and emotional suffering more readily, impacting their views on futility[37] while ICU physicians may prioritize interventions that maximize survival, even if quality of life is compromised. These varying viewpoints and potential disagreements on the level of therapy can create challenges for multidisciplinary decision-making.[38]

4.3 | Strengths and limitations

This study has several strengths. First, we included patient-partner representatives in our advisory board and allowed the first Delphi round to be open to local clinical respondents without specific expertise in end-of-life care. This approach made the findings relevant not only to end-of-life care experts but also to those directly involved in the ICU care and may also increase the likelihood of dissemination and clinical use of the guideline/statements. A second strength is the input from a diverse multidisciplinary group of experts while allowing for anonymity, which encouraged honest and unbiased responses. The study also enabled systematic refinement of expert opinions through iterative feedback and analysis, developing robust consensus and reliable conclusions. Additionally, this study provides a structured approach to synthesizing and organizing expert knowledge. The flexibility of the process in accommodating a wide range of expert perspectives and the potential for consensus building contribute to the credibility and applicability of the study's findings.

The study is not without limitations. First, it was difficult to fully integrate all the information from the open-text section of the survey. This is a common issue with online platforms due to a potential lack of clarity. While the online Delphi method was more practical and could reach an international audience, the written answers may have been less rich compared to a focus group format. Additionally, certain survey questions were open to interpretation, possibly due to the international nature of the project and the significant proportion of non-native English-speaking participants.

This study did not register the respondents' religious or cultural background. Furthermore, it was not possible to include all relevant ethnicities in the advisory board which could result in cultural bias. Thus, while general principles of end-of-life decisions prevail, clinicians must recognize that there may be special considerations related to patients´ and families' cultural background.

Lastly, consensus bias could be present, as efforts to reach a consensus may pressure participants into conforming to the majority view, even if they have legitimate alternative perspectives. This may have led to higher agreement rates in Delphi round three, with more statements ultimately achieving consensus.

4.4 | Clinical implementation and perspectives

Our findings are essential for guiding Scandinavian healthcare professionals and institutions in providing compassionate and effective care to critically ill patients and their families. Future research must focus on the development and implementation process of a guideline for Scandinavian ICU end-of-life care.

5 | CONCLUSION

This Delphi study produced 59 consensus statements across 10 domains, providing the first comprehensive framework for end-of-life care in Scandinavian ICUs. These statements, developed with input from multidisciplinary experts and patient-partners, reflect the unique cultural, ethical and healthcare contexts of Scandinavian countries. By addressing the specific needs and challenges of end-of-life care in Scandinavian ICUs, these consensus statements lay the groundwork for developing standardised, culturally appropriate clinical practice guidelines. Implementation of these guidelines has the potential to significantly improve the quality and consistency of end-of-life care for critically ill patients and their families across Scandinavian ICUs.

AUTHOR CONTRIBUTIONS

All members of the advisory board except the three patient-partner representatives acted as co-authors on this paper. ISD and AHN designed the overall study. The advisory board collaboratively

designed all three Delphi rounds, phrased and reviewed the written domains for round one, reviewed, rephrased and merged the domains for round two, reviewed the consensus statements in round two and rephrased the consensus statements in round three. ISD and AHN performed the statistical and qualitative analyses. ISD wrote and prepared the original draft. The advisory board reviewed and edited the manuscript.

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The remaining 19 expert respondents wanted to remain anonymous.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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