



Special Feature

End-of-life care in the intensive care unit: Report from the Task Force of World Federation of Societies of Intensive and Critical Care Medicine



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ABSTRACT

End-of-life care in the intensive care unit (ICU) was identified as an objective in a series of Task Forces developed by the World Federation of Societies of Intensive and Critical Care Medicine Council in 2014.

The objective was to develop a generic statement about current knowledge and to identify challenges relevant to the global community that may inform regional and local initiatives.

An updated summary of published statements on end-of-life care in the ICU from national Societies is presented, highlighting commonalities and differences within and between international regions.

The complexity of end-of-life care in the ICU, particularly relating to withholding and withdrawing life-sustaining treatment while ensuring the alleviation of suffering, within different ethical and cultural environments is recognized.

Although no single statement can therefore be regarded as a criterion standard applicable to all countries and societies, the World Federation of Societies of Intensive and Critical Care Medicine endorses and encourages the role of Member Societies to lead the debate regarding end-of-life care in the ICU within each country and to take a leading role in developing national guidelines and recommendations within each country.

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The success of intensive care is not to be measured only by the statistics of survival, as though each death were a medical failure. It is to be measured by the quality of lives preserved or restored; and by

the quality of the dying of those in whose interest it is to die; and by the quality of human relationships involved in each death.

—GR Dunstan, University of London, 1984

1. Background

The broad goal of intensive care medicine is to ensure that our patients survive and return to a functional state that is acceptable to the

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individual patient. Despite best efforts, a proportion of patients will succumb to their illness, whereas others will survive with profound functional limitations. Individual patient outcomes are a consequence of the severity of the acute illness, the functional reserve of the patient, and the available resources

Rates and patterns of death and dying in the intensive care unit (ICU) vary across the world and are dependent on patient demographics, patterns of disease, and sociological influences that include available resources and cultural, religious, financial, and legal factors.

In high-income countries, particularly those with universal-access public health care systems or a predominance of privately funded systems, increased ICU resources and technological advances have resulted in an increase in the admission of patients with limited life expectancies. These include patients with advanced age, comorbidities, or terminal illnesses who previously would have succumbed to their illness or been denied admission to the ICU. As a consequence of the increased admission of these patients to the ICU, there has been an associated increase in end-of-life care in the ICU or acute care facility.

In low- and middle-income countries, limited resources create the need to prioritize or triage the admission of patients to the ICU who have a perceived higher probability of survival after admission to the ICU, thereby excluding patients with a greater risk of death or likelihood of poor functional survival. Other factors that may influence the decision to admit patients to the ICU in these settings include the potential duration of admission, where an extended admission effectively reduces the overall bed capacity of the admitting ICU; financial drivers such as the ability of the patient or family to pay for intensive care for an extended period; and, in some regions, sociopolitical drivers where preferential admission is given to “higher-ranking” citizens. Although end-of-life care in these ICUs follows the same ethical principles of high-income countries, the processes may be substantially influenced by local cultural and religious factors.

End-of-life care in the ICU poses a daily challenge for clinicians across the world for which a clear understanding of the global and local ethical, societal, legal, and cultural considerations is required.

Although a number of ethical standards and consensus statements for end-of-life care in the ICU have been developed and published by Intensive and Critical Care Societies predominantly from Western high-income countries, similar documents have not been formalized in many other countries, particularly low- and middle-income countries and those where non-Western cultures predominate.

To improve global end-of-life care in the ICU, there is an imperative for Intensive and Critical Care Societies across the world to develop consensus and evidence-based statements that define and guide processes and procedures for ethical and effective end-of-life care in the ICU relevant to each country and culture.

2. Objective

The World Federation of Societies of Intensive and Critical Care Medicine (WFSICCM) promotes the highest standards of intensive and critical care medicine for all mankind without discrimination [1].

The WFSICCM represents more than 80 Intensive and Critical Care Medicine Societies with a combined individual membership of 80 000 clinicians. As such, the WFSICCM is well positioned to provide clarity and direction about global principles of end-of-life care in the ICU, drawing from existing statements and consensus documents, from emerging research initiatives, and through dialogue and discussion at international meetings, such as the World Congress of the WFSICCM.

3. Methods

The strategic direction and task planning for the Task Force were developed by the WFSICCM Council at the regular meetings held via videoconferences and face-to-face meetings during 2014 and 2015. A member of the WFSICCM Council was nominated as the Chairperson

for the Task Force who would be responsible for overseeing the discussions and facilitating dialogue with representatives from Member Societies and identified key opinion leaders.

Through an electronic mailing list, Member Societies of the WFSICCM were invited to nominate 1 or more representatives to participate in each Task Force by forwarding and collating documents, statements, Web sites, and research outputs from each respective region.

Two satellite meetings were held during the International Symposium of Intensive and Emergency Medicine in Brussels on 18 March 2015 and at the World Congress of the WFSICCM in Seoul on 29 August 2015, where summaries of the responses from Member Societies were presented and discussed.

A final report was prepared by the Chair of the Task Force, circulated to Task Force members, and approved by the WFSICCM Council for publication

This report represents a summary document about end-of-life care in the ICU that includes procedures and processes relating to the withholding and withdrawal of life-sustaining treatments and principles directed at the alleviation of pain and suffering through effective palliative care. When distinctions between these processes were necessary, these were identified accordingly within the relevant context.

4. Selected statements on end-of-life care in the ICU from statutory bodies

A number of statements defining principles of end-of-life care in the ICU were identified during the iterative period.

In 2003, the Australian and New Zealand Intensive Care Society (ANZICS) published a 2-page document called the *ANZICS Statement on Withholding and Withdrawing Treatment*, designed to provide a principled-based best practice in the care of critically ill patients at the end of life [2]. This statement was based on previous statements primarily defining criteria for brain death for organ donation that had been developed over the previous 25 years. The 2003 Statement subsequently evolved over the following decade to become a consensus- and evidenced-based document about all aspects of end-of-life care in the ICU in Australia and New Zealand.

The 2014 ANZICS document highlights 10 principles of end-of-life care in the ICU that summarize the complexity and scope of the generic ethical processes:

1. The goals of intensive care are to return patients to a quality of survival that is acceptable to them and to reduce disability and, if these are not possible, to compassionately support the dying process. At all times, the aim is to minimize suffering.
2. Intensive care treatment is often life saving for patients with reversible critical illness. As predicting survival of an individual critically ill patient is imprecise, all patients should receive simultaneous attention to both therapeutic (and potentially burdensome) medical interventions, ensuring their comfort and controlling distressing symptoms. The balance of attention may shift between these objectives during the patient's critical illness, including the possibility that the only objective may be patient comfort and symptom control.
3. When a decision has been made that life-sustaining treatments are to be withheld or withdrawn, a palliative care plan should be implemented, in consultation with the patient and/or family and the ICU nurse, with a focus on dignity and comfort, considering physical, psychosocial, and spiritual needs. The use of medication for patient symptom control in this setting is ethically and legally appropriate, even though this may shorten life.
4. There is no ethical or legal obligation to provide treatments where considered medical opinion is that the burdens to the patient outweigh any potential benefits. Medical consensus should be achieved between the intensive care and other medical teams before changing the goals of treatment.

5. The adult patient who has the capacity to decide is entitled to refuse or withdraw consent for any treatment at any time, even if this may shorten his or her life.
6. Medical staff and their patients should aim to make a shared decision about treatment options. The process of shared decision-making involves a consensus among the patient (if the patient has the capacity to make decisions), a substitute decision maker or family (if the patient does not have the capacity to decide), the intensive care team, and other medical teams involved.
7. In cases when there is disagreement that cannot be resolved with discussion and time, consideration may be given to involving additional medical opinion(s), nonmedical professional opinions (elders, clerics, or spiritual advisers), clinical ethics consultation, or legal processes.
8. All decisions regarding the withdrawing or withholding of life-sustaining treatments should be documented in the clinical record. The documentation should include the basis for the decision, identify those with whom it has been agreed, and specify the treatments to be withheld or withdrawn.
9. The principles set out above apply equally whether withholding or withdrawing of life-sustaining treatments is being considered.
10. Every ICU and its hospital should develop and implement guidelines in accordance with these principles. This should include the evaluation of care at the end of life as a quality measure.

In 2008, the American College of Critical Care Medicine published a comprehensive statement for recommendations of end-of-life care in the ICU [3]. Some principles of end-of-life care are based on important US court cases between 1914 and 1990:

1. That competent patients have the right to determine how their bodies can be used and that informed consent was required before therapeutic interventions could be performed.
2. That competent patients have the right to refuse interventions that, if they became incompetent, could be exercised by surrogate decision makers under principle of substituted judgment.
3. That surrogates could refuse any and all interventions on behalf of patients based on a benefit-burden analysis.
4. That lacking surrogate knowledge of patient wishes, decisions could be made using best interests standards if the burdens of interventions outweigh the benefits and if the pain of living is such that administering the intervention is considered to be humane.
5. That although the right of competent patients to refuse interventions is accepted, individual States are allowed to set the level of evidence to determine the prior wishes of incompetent patients with which surrogate decision are made.

Subsequent recommendations were not primarily based on an evidence grading system because most recommendations were based on ethical and legal principles that are not derived from empirically based evidence. These recommendations broadly included:

1. That care plans be family centered.
2. That ICU clinicians be competent in all aspects of this care, including practical and ethical aspects of withholding and withdrawal of life-sustaining treatments and the use of multiple modalities to ease the suffering of the dying process.
3. Recognizing the important distinction between consequences that are intended and those that are merely foreseen—often referred to as the *doctrine of double effect*.
4. Communication and compassionate approaches to discussing options for organ donation.
5. Understanding the extension of end-of-life care beyond death.
6. Development of educational curricula, research priorities, and quality-improvement efforts.

In 2014, an Ethics Round Table Conference assembled 21 intensive care physicians at the World Congress of the WFSICCM in Durban, South Africa, to discuss 4 issues relating to end-of-life care in the ICU:

1. Although the majority agreed that there is no difference between withholding and withdrawing life-sustaining treatments, a position that accords with most ethicists and professional organizations, a minority of physicians did not accept their equivalency. This is likely to reflect differences in cultural and religious perspectives [4].
2. There was consensus that advanced age could not be a sole criterion on which health care decisions, specifically at the end of life, could be made. In that perspective, it was considered imperative that data demonstrating outcome differences between elderly and nonelderly patients are presented in relation to forgoing life-sustaining treatments [5].
3. The group identified that there was wide variation in patterns and methods of withdrawal of mechanical ventilation within the context of end-of-life care in the ICU. There was agreement that a degree of individualization within the clinical context was necessary [6].
4. There was majority agreement that systematic documentation of interdisciplinary opinions and practices was necessary to establish agreement relating to principles and procedure of end-of-life care in the ICU. Of these, 8 recommendations were made [7]:

- a. Knowledge of local, cultural, and religious practice and expectations within the legal context.
- b. An early (within 48 hours) discussion of goal-of-care discussions to discuss withholding or withdrawing of life-sustaining treatments where appropriate.
- c. That although physicians are most likely to initiate end-of-life care discussions in the ICU, patients, relatives, and nurses have the right to trigger these discussions.
- d. Treating ICU and specialty-related physicians should reach consensus regarding withholding or withdrawing life-sustaining treatments before formal discussions with the patient/surrogate.
- e. That although consensus to trigger discussions about withholding or withdrawing life-sustaining treatments is commonly made on the bedside round, appropriate and necessary forums should be scheduled as required, particularly in difficult cases.
- f. That the decision to trigger discussions about withholding or withdrawing life-sustaining treatments is based on the principle that the patient's best interests are no longer served by continuing life-sustaining treatments.
- g. That although there are no universal triggers for initiating discussions about withholding or withdrawing life-sustaining treatments, a number of time-based criteria based on the probability of survival within the context of specific diagnoses and organ failures may be considered.
- h. That neither age alone nor illness severity should be considered as a sole criterion to initiate discussions about withholding or withdrawing life-sustaining treatments.

In 2015, a conjoint statement from the American Thoracic Society, the American Association of Critical Care Nurses, the American College of Chest Physicians, the European Society of Intensive Care Medicine, and the Society of Critical Care Medicine defined 4 key recommendations for requests for potentially inappropriate treatment in ICUs [8]:

1. Institutions should implement strategies to prevent intractable treatment conflicts, including proactive communication and early involvement of expert consultants.
2. The term *potentially inappropriate* should be used rather than *futile* to describe treatments that have at least some chance of accomplishing the effect sought by patients but that clinicians believe that ethical considerations justify not providing them. Conflicts regarding

potentially inappropriate treatments should be managed by a fair process of conflict resolution where possible.

3. Use of the term *futile* should be restricted to the rare situations in which surrogate decision makers request interventions that simply cannot accomplish their intended physiological goal.
4. The medical profession should lead public engagement efforts and advocates for policies and legislation about when life-prolonging technologies should not be used.

Cross-specialty statements on end-of-life care have been published, including a 2014 statement by the Indian Society of Critical Care Medicine and the Indian Association of Palliative Care [9], where principles for an integrated care plan for dying patients unique to the Indian context is defined, including:

1. The attainment of a “good” death that is a fundamental human right, with the emphasis on quality of life and quality of death.
2. A continuum of palliative care that supports the patient and family during the end-of-life phase, during the process of dying, and after the death phase and bereavement period.
3. Definitions of infrastructural requirements for good end-of-life care.

Specialty-specific statements, specifically in high-risk patient populations such as neurocritical care, have been published, including a statement by the Improving Palliative Care in the ICU Advisory Board in 2015 [10]. This statement highlights the challenges that neurocritically ill patients and their families face following the often sudden onset of devastating cognitive and functional changes, in the context of uncertain prognostication and in the specific context of brain death and organ donation.

Substantive textbooks from international authors, such as Rucker's *End of Life Care in the ICU: From Advanced Disease to Bereavement* [11], Michalsen and Hartog's *End of Life Care in der Intensivmedizin* [12], and others from Oxford University Press, provide comprehensive expert-based overviews of the complexity of end-of-life care in the ICU [13].

National governmental statements have recently been published, including consensus statements by the Australian Commission for Safety and Quality in Healthcare [14], the Parliamentary and Health Service Ombudsman in the United Kingdom [15], and the Swiss Academy of Medical Sciences [16].

In 2014, the World Health Organization, through the World Palliative Care Alliance, published a *Global Atlas for Palliative Care at the End of Life* [17]. This comprehensive document defines the prevalence, incidence, demographics, and resource considerations regarding palliative care across the globe, placing the emerging of end-of-life care in the ICU into perspective.

5. International variations

Marked differences in global practices of end-of-life care have been published in international surveys, including:

1. A survey of 504 European intensive care physicians from 16 western European countries in 1999 reported substantial differences between stated beliefs and actual end-of-life care practices, particularly relating to the admission of patients with little prospect of survival and methods of withholding and withdrawal of life-sustaining treatments [18].
2. The ETHICUS study [19] that reported medical practices regarding end-of-life care in Europe in 2003, concluding that difficulties among European intensivists regarding end-of-life care were uncommon but that interregional differences were evident.
3. The WELPICUS study [20] that reported consensus for only 81% of 81 definitions and statements from 32 countries in 2014.
4. The Asian survey of 16 countries and regions in 2015 [21] where wide practice variations were evident but where active withdrawal of life-sustaining treatments was rare.

To highlight current differences in practices, an international panel of experts presented international perspectives of “withdrawing” life support in the ICU in 2015 [22]. Disparate practices across selected countries were presented and included:

1. Argentina, where decisions to withdraw life support are made on the best clinical evidence but in the absence of specific guidelines.
2. Austria and Germany, where decisions to withhold and withdraw life-sustaining treatments are regarded as ethically equivalent.
3. Belgium, where the Belgian Society of Intensive Care Medicine published a consensus document in 2014 stating that the dying process may be sometimes shortened with the use of medication [23].
4. Belgium and the Netherlands, where euthanasia is legal but not generally applicable to ICU patients.
5. China, where there are neither local nor national legislation governing withdrawal of life-sustaining treatment and no consensus regarding futile treatment and marked cultural and religious diversity and financial considerations in some of the population.
6. Israel, where the Israeli Terminally Ill Law (2005) prohibits stopping continuous life-prolonging treatments but allows stopping intermittent life-prolonging treatments.
7. Italy, where decisions to limit intensive care are based directly on the conscious patient or indirectly on the family reaching the closest will in accordance with the patient stated and interests.
8. Japan, where resource limitations are mitigated through very high medical insurance levels and where withdrawal of life support is considered to be illegal.
9. Singapore, where the law is aligned with a family-centric approach to facilitate likelihood of meaningful survival and the patient's known wishes.
10. South Africa, where limited ICU facilities affect decision making and where there is no formal legal basis for end-of-life care decisions.
11. South Korea, where every intervention, particularly regarding end-of-life care, is decided after extensive family discussions, which occasionally include financial considerations.
12. Turkey, where there are large variations among physicians in terms of understanding and attitudes to end-of-life care, probably reflecting religious and cultural diversity, differences in resources, and an absence of medical guidelines or legal regulations.

6. Research initiatives

In 2010, a single-center, prospective cohort study assessed the efficacy of asking oncologists a “surprise” question in patients with advanced cancer. The question “Would you be surprised if this patient died in the next year?” provided a high index of prediction in patients where the question was answered in the negative [24]. Similar exercises have been conducted with general practitioners and medical specialities [25]. There is a logical imperative to conduct a similar study of this simple yet effective exercise in patients in the ICU.

In 2015, a multicentered, Canadian mixed-methods study defined a holistic, integrated palliative and spiritual care plan into critical care practice by defining a set of wishes to fulfillment for dying patients and their families [26]. This study represents emerging qualitative and quantitative studies in end-of-life care in the ICU that will ultimately inform clinical practice.

7. Educational and training initiatives

There is increasing recognition that specific education; training; and, in some instances, certification are required by intensive and critical care physicians and clinicians.

While education initiatives specifically focused on the identification, certification, and management of potential organ donors, either through the determination of brain death or donation after cardiac death has a prominent place in training and education of end-of-life care in the

ICU, general and specific principles relating to nonorgan donors are equally required.

The Australian and New Zealand College of Intensive Care Medicine, the sole stand-alone learned College of Intensive Care Medicine in the world, has a highly developed training program that has evolved over the last 30 years and currently includes specific mandatory training modules on communication with patients and relatives in relation to end-of-life care in the ICU and for organ donation [27].

8. Summary and conclusion

Although the WFSICCM endorses that ethical principles must form the basis of end-of-life care in the ICU, it recognizes that marked global variations and differences exist that reflect the diversity of human cultures and societies.

No singular statement can therefore be regarded as a criterion standard applicable to all countries and societies.

However, the WFSICCM endorses and encourages the role of Member Societies to lead the debate regarding end-of-life care in the ICU within each country and to take a leading role in developing national guidelines and recommendations within each country.

A further role of the WFSICCM Task Force for end-of-life care in the ICU is to identify commonalities and differences in practices, to collate a repository of Member Society consensus statements, and to facilitate debate and future research for end-of-life care in the ICU.

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