

Framework for decision-making and management of end-of-life decisions in Intensive Care Units: A modified protocol

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Abstract

End-of-life decisions are being made daily in Intensive Care Units worldwide. The spectrum of options varies from full-continued care, withholding treatment, withdrawing treatment, and active life-ending procedures depending on the institutional practices and legal framework. Considering the complexity of the situation and the legalities involved, it is important to have a structured approach toward these sensitive decisions. It does make sense to have a protocol that ensures proper documentation and helps ease the physicians involved in such decisions. Clear documentation in the format of a checklist would ensure consistency and help the entire medical team to be uniformly informed about the end-of-life plan.

Keywords: Checklist, end-of-life decisions, Intensive Care Unit

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Introduction

Over the past few decades, the process of dying has undergone a significant change. Previously, the physician would do whatever best they could, and when all the treatment options were exhausted, the patient was taken home to die within the realms of his home surrounded by the family members.^[1]

However, with the advent of modern life support systems, even a terminally ill-patient with severe multi-organ dysfunction can be kept alive. The result being that most patients die undergoing treatments meant to postpone death. Such treatments are most often futile.^[2]

This situation ushers a new set of medical and ethical issues. This means that a significant amount of healthcare is being delivered to dying patients, and we, physicians,

are now required to learn a new set of skills, to identify the patients who are going to die despite best and optimal medical care.^[3]

End-of-life decisions (EOLD) are made daily in Intensive Care Units (ICUs) worldwide. Wide variations, however, exist between countries, within countries, within cities, and even within the same ICU, based on the differences in religious beliefs and attitude of patients, families, physicians, and organizational policies. The spectrum of EOL care options also varies from full-continued care, withholding treatment, withdrawing treatment, and active life-ending procedures.^[4,5] Perceived futility by the physicians has been found to be the most common justification for the withdrawal of treatment in critically ill patients.^[6]

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The Indian scenario about EOLD has long been complicated by the fact that our legal system did not separate euthanasia from foregoing of life support treatments, something that is well settled in the developed world.^[7,8] The Law Commission of India in their 196th report (2006) brought in the first change when they clearly separated euthanasia from EOLD.^[9] A second report of the Law Commission in 2012 in the wake of the Aruna Shaunbag judgment endorsed the reforms suggested in the first report.^[10,11] It further elaborated that “passive euthanasia” should be allowed on humanitarian grounds and offers protection for doctors who genuinely act in the best interests of patients. A court procedure was, however, recommended for all EOLD on incapacitated patients.^[11] This would, however, make it impossible to implement such decisions in emergency and critical care situations, as the majority of these patients are incapable of making their own choices.^[12] The Supreme Court of India has re-ignited the issue by calling for a nationwide debate on the topic.^[10]

We as intensivists encounter two broad categories of patients, where we may be prompted to initiate these sensitive discussions. The first category is a terminally ill patient with high Acute Physiology and Chronic Health Evaluation score at admission and persistence of severe multi-organ dysfunction despite all optimal therapy. The outcome in this category is more or less predictable, and there are no significant dilemmas if EOL conversation is commenced.

The second category is a patient with chronic debilitating illness or a geriatric patient, who has been in and out of the hospital multiple times and is now on life support systems or requires to be put on life supports. The patient’s family does often initiate a discussion about the way forward. The biggest deterrent in taking an EOLD in this category is related to lack of any objective markers or scoring systems, which can predict the short-term and long-term outcomes. The patient’s family members often expect the physician involved to guide them and help them in this challenging situation. The physician is awkwardly caught between the ethical principles of beneficence and nonmaleficence on one end and the legal bindings on the other end. This second category becomes particularly challenging for the practicing physician.

Considering the complexity of the situation and the legalities involved, it would be pertinent to have a structured approach toward these sensitive decisions. It does make sense to have a protocol that ensures proper documentation and helps ease the physicians involved in such decisions. Clear documentation in the format

of a checklist would ensure consistency and help the entire medical team to be uniformly informed about the EOL plan.

Several versions of EOL clinical pathways exist around the world. Most of these pathways have been used in the patients with advanced malignancies. We in our ICU have applied – allow natural death in ICU, an open resource document developed by Alex Psirides and currently available at Wellington ICU web page for documentation and management of EOL.^[13] The document was first developed in 2009 and has been through several iterations and is now on version 6.1. The most recent modification has been with a focus on allowing natural death in ICU rather than being projected as withdrawal of therapy. We have found this to be a comprehensive document, which covers all important aspects of care pathways to be followed once an EOLD has been taken.

In our practice, we have however faced challenges, which have prompted us to add a few questionnaires, which ease the decision-making process. These questions have been adapted from the essential points discussed in the recently released joint statement of Indian Society of Critical Care Medicine (ISCCM) and Indian Association of Palliative Care (IAPC).^[8] We have tried to create a comprehensive document [Table 1] which attempts to provide a much-desired pathway detailing the relevant points required in the decision-making and then covering the quintessential medical concerns while allocating a patient to EOL pathway.

The first section of the document is physician specific. The questionnaire is self-explanatory and is presented in the form of a checklist which can be filled up prior to scheduled family meeting. The principal step undoubtedly is the need to have a clear consensus among all the caregivers regarding the initiation of EOL discussion. The next important area of concern is subjective validation of medical futility as assessed by the medical team. If there is a difference in opinion among the treating team regarding the first two points, the initiation of such a discussion is usually kept on hold.

We have also given thought about incorporating Sequential Organ Failure Assessment score (SOFA score), as this could be one objective predictor of mortality at the time of such decisions despite its limitations.^[14] A high SOFA score will help ease the clinician in prognostication while counseling the attendants.

A recent article by Cardona-Morrell discusses a screening tool to identify elderly patients at the EOL

Table 1: Framework for decision-making and management of end-of-life

Framework for decision-making and management of end-of-life

Patient details: Name: UHID:	Diagnosis:
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Points discussed (N/A is not applicable)

1. Is there a consensus among the caregivers about the disease process:
 - Primary physician: Yes No N/A
 - Intensivist: Yes No N/A
 - Other caregiver team: Yes No N/A
2. Document the factors/clinical status favoring the decision about futility of care:
 - Physiological futility-Treatment that cannot achieve its physiological aim: Yes No N/A
 - Quantitative futility-Treatment that has < 1% chance of being successful: Yes No N/A
 - Qualitative futility-Treatment that cannot achieve an normal quality-of-life, treatment that merely preserves unconsciousness or fails to relieve total dependence on intensive care: Yes No N/A
 - Lethal condition futility-The patient has an underlying ailment that will not be affected by the intervention and will lead to death within weeks to months: Yes No N/A
 - Imminent demise futility-An intervention that will not change the fact that the patient will die in future: Yes No N/A
3. Sequential organ failure score (SOFA) _____
4. Documentation and testing for brain death (If applicable) Yes No N/A
5. Have all the relevant information been explained to the patient and their families (To be detailed below)
 - Diagnosis: Yes No N/A

- Prognosis: Yes No N/A
- Range of therapeutic options available: Yes No N/A
- Option of no therapy: Yes No N/A
- Risk: Yes No N/A
- Benefits: Yes No N/A
- Cost: Yes No N/A
- Consequences: Yes No N/A
- Designated decision makers in family identified: Yes No N/A
- Direct blood relations-spouse/children/parents attended the meeting: Yes No N/A

Details of the family meeting:

Date: Time:
 Family present: Staff present:
 Issues discussed:
 Final decision: Withdrawal/Withholding treatment/Do Not Resuscitate
 Patient involved in the discussion: Yes No

6. Is there a discrepancy among any of the family members about the understanding of the disease process and its progression? Yes No N/A
7. Have the family members been given the option of the second opinion? Yes No N/A
8. Has the family been explained about the legal position of our country about EOL decision? Yes No N/A
9. Have the family members been explained about the unpredictability of time of demise in the aftermath of an EOL decision? Yes No N/A
10. Have the family members been assured that due care will be taken to alleviate patient's pain and suffering? Yes No N/A
11. Other issues for consideration:
 - Admitting team informed: Yes No N/A
 - Palliative care team involvement: Yes No N/A
 - Spiritual/religious/cultural support required: Yes No N/A
 - Social work required: Yes No N/A
 - Organ donation discussed (if applicable) **: Yes No N/A

- Tissue donation considered (if age < 85 years) **: Yes No N/A
- Consideration of 'Going Home To Die': Yes No N/A
- Move to private room (if available): Yes No N/A

Treatment to stop (at TIME agreed with family)

Respiratory support: (Reduce support-please specify):

Extubation: Yes No N/A

Cease all oxygen therapy: Yes No N/A

Other treatment to cease:

Vasoactive medications: Yes No N/A

NG/PEG feed/TPN: Yes No N/A

Antibiotics: Yes No N/A

Intravenous fluids: Yes No N/A

Insulin: Yes No N/A

Renal replacement: Yes No N/A

Intra-aortic balloon pump: Yes No N/A

Pacemaker: Yes No N/A

(If internal +/-defibrillator, consider deactivation)

Removal of invasive lines:

NG tube: Yes No N/A

Arterial line: Yes No N/A

Pulmonary artery catheter: Yes No N/A

Peripheral cannula (e): Yes No N/A

Urinary catheter: Yes No N/A

ICP monitor/EVD: Yes No N/A

Other (please specify): Yes No N/A

12. Please review patient's medication charts and cease all non-palliative medications as required. Yes No
13. Ensure adequate intravenous access for administration of palliative medication. Yes No
14. Remove and cease ALL monitoring (pulse oximetry, ECG, blood pressure). Yes No
15. Cease ALL further investigations (blood tests, radiology). Yes No
16. Remove any restrictions on family visits (number of visitors, timings, duration). Yes No

Consider starting symptom-specific treatment in awake patients:

- Pain (Morphine 1–2.5 mg q1 h, Fentanyl 10–25 mcg q1 h)
- Anxiety or distress or delirium (Midazolam 1–3 mg q1 h, Haloperidol)
- Nausea or vomiting (Ondansetron 4–8 mg q6 h, Haloperidol 0.5 mg PRN)
- Secretions (Buscopan 20 mg q2 h, ma × 120 mg/d, Glycopyrrolate)
- Skin care: Positioning, comfort beds, and pressure point care
- Mouth care: Hydrate with unflavoured sponge tipped swab q2–4 h
- Eye care: Methylcellulose eye drops

Baseline opiates should be continued in all patients with previous exposure. If the patient is awake, then all pre-existing infusions should continue. Be wary of withdrawal symptoms if infusions are ceased in any patient.

All infusions should be single agent only, symptom specific, titrated to desired effect and discussed with medical staff prior to escalation

Consent by the family members:

Name	Relation with patient	Signatures
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Form completed by: Date: Time:

Name	Designations	Signatures
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**If yes: Follow institute specific protocols/care pathway for donation after brain death (DBD) or donation after cardiac death (DCD) whichever is applicable

Credit Note:

Adapted, with permission from the AND-ICU form V 6.1, Wellington ICU New Zealand

and quantify the risk of death in hospital or soon after discharge to minimize prognostic uncertainty and avoid potentially harmful and futile treatments. They have attempted to create an unambiguous checklist, which may assist clinicians in reducing uncertainty patients who are likely to die within the next 3 months and help initiate transparent conversations with families and patients about EOL care.^[15]

The third step would be testing and documentation of brain death wherever applicable.^[16]

The second section of the document is pertinent to patient's families. This has again been formulated based on EOL care pathways recommended by ISCCM and IAPC.^[8] We have also tried to inculcate valuable points discussed by Australian and New Zealand Intensive Care Society in their extensive statement on care and decision-making at the EOL for critically ill patients.^[17] This portion of the document highlights the importance of having all discussions of EOL in the context of mutual respect for all participants. The first step details the important points discussed with the family members which includes clinical status, range of treatment options offered, short-term and long-term prognosis. A text box has been provided in the table to physically document the details of family members and treating team present at the time of the meeting. It is also important at this stage to identify the designated decision makers of the family who will be taking these crucial decisions on behalf of the entire family. The treating team needs to ensure that one of the designated decision makers is a direct blood relation. The relevant details of the clinical discussion and the points discussed are also documented in the space provided. Disagreements can arise regarding treatment limitation decisions, or about other aspects of EOL care. Any discrepancy among any of the family members about the understanding of the disease process and its progression is documented. The form also documents that the family members have been given the option of the second opinion. Once the family members appear to be receptive about the decision about EOL discussion they are explained about the legal position of our country about EOLD. Even when an emotionally difficult decision is taken, the unpredictability about the time to demise complicates the situation as these patients continue to sustain on life support systems despite the decision to withdraw all aggressive management or nonescalation of current therapy. The document does address this particular issue, and the same is duly explained and documented.

The dying ICU patient's EOL plan should be individually tailored, holistic and properly documented.^[17] The third

part of the protocol is a modified version of an excellent document being used in Wellington ICU that details the management of EOLD. The major portion of the document has been retained in its original format with certain modifications made to suit the Indian scenario. The first part of this section addresses the social aspects of EOL situations highlighting the need for involvement of palliative care team and spiritual support wherever applicable. The document does mention whether organ donation has been discussed in appropriate patients. This is primarily a reminder rather than a mandatory requirement. The care pathway presented subsequently would not be used if a patient is to become a donor through either the donation after brain death or donation after cardiac death pathway. In these situations, the pathway needs to be modified with an aim for organ preservation and preparing the patient for donor care pathway as per the institutional protocols. The remaining section lucidly addresses the key concepts with regards to continuation/discontinuation of respiratory therapy, invasive lines, medications, and monitoring. It details the symptom-specific medications to be used in awake patients assigned to EOL pathway. The document wraps up with endorsement by the family members and the treating team involved.

Conclusion

The document attempts to provide a much-desired pathway detailing the relevant points required in the decision-making and then covering the quintessential medical concerns while allocating a patient to EOL care pathway. The authors intend to keep a registry of the form for future audit and modifications. We believe that this document can provide the background for further refinement of the algorithms and help ease the documentation and implementation of EOL care.

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Conflicts of interest

There are no conflicts of interest.

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