

END - OF - LIFE CARE

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Science and technology have offered medical therapies the potential to treat serious illnesses where once the medical professionals could only provide comfort. Physicians feel the need to aggressively fight against illness and death. Many physicians and health care workers have come to believe that they have failed if they do not save the patient from death. We frequently attempt to prolong life at all cost. Unfortunately we often only succeed in prolonging the dying process.

A great limitation of our teaching programmes and medical training is that physicians are not sufficiently educated in End-of-Life care. When surveyed by the American Medical Association in 1997-98 only 4 of 126 American Medical schools required a separate course in the care of the dying. (Indian data is not available). We are not only ill equipped but are afraid to care for the dying.

The end of person's life is a very important time for him and his family. The American Medical Association's Institute of Ethics has devised a programme to equip physicians and nurses with knowledge, skills and attitude to relieve suffering and improve the quality of life of person with life-threatening illness (EPEC and ELNEC curriculum)

Several studies indicate that most patients and families who are living with a life threatening illness can expect to experience multiple physical symptoms and psychological, social, spiritual and practical issues, many of which may be concurrent. These problems add to patients and family sense of suffering and reduce their quality of life. In one study of patients with cancer, inpatients had an average of 13.5 symptoms and outpatients averaged 9.7 symptoms. Many of these symptoms were previously not seen as patients died quickly. In all studies of symptom prevalence, pain, nausea, vomiting, constipation and breathlessness are very significant. There also are significant financial issues associated with care giving. In one study 31 percent of families lost most of their savings caring for their loved ones.

Recently the Indian Society of Critical Care Medicine drew up evidence-based guidelines for limiting life prolonging interventions and providing palliative care towards the end-of-life in Indian intensive care units. This is a landmark and should provide the basic protocol for the ICUs all over India to provide compassionate care towards the end-of-life. The purpose of these guidelines is to minimize inappropriate treatment and optimize comfort and care for terminally ill patients in the ICU by standardizing the process of foregoing life support (see appendix: Guidelines)

Traditionally questions of end-of-life care were resolved through decision making by physicians in conjunction with patients and their families. In the United States, physicians are increasingly asking patients to complete advance

directives and documenting these directives in case files. This helps ensure that well meaning health care workers do not subject patients to inappropriate interventions to prolong life against the will of the patient.

The four cardinal ethical principles upon which the practice of palliative care is based are:

1. **Autonomy:** an informed patient has the right to choose the manner of his treatment if he is competent to make decisions. In the event that he is incompetent his advance directives or wishes of surrogate acting on his behalf must be respected.
2. **Beneficence:** acting in patient's best interest, including decreasing suffering, treatment of pain, protecting the family from financial ruin. (This is not to be confused with Euthanasia, which is illegal in India)
3. **Non- malfeasance** - to do no harm, to impose no unnecessary or unacceptable burden upon the patient.
4. **Distributive justice** means that patients in similar circumstances should receive similar care.

Decisions regarding End-of-Life can be taken only after the patient and his family are adequately counselled regarding his true prognosis and possible options. A workable instrument of mortality prediction is necessary to identify situations where End-of-life discussions should be initiated. It is not always clear when a patient is going through the dying process

Checklist for initiating EOL discussions:

1. Advanced age coupled with a poor premorbid state due to chronic debilitating diseases. e.g., advanced chronic obstructive pulmonary disease (COPD) requiring home oxygen and/or bilevel pressure support or with severe impairment of quality of life; advanced interstitial lung disease on oxygen therapy with failed medical treatment, chronic renal failure requiring long term dialysis, chronic liver disease, advanced congestive heart failure.
2. Catastrophic illnesses with organ dysfunctions unresponsive to a reasonable period of aggressive treatment.
3. Prolonged coma (in the absence of brain death) due to acute non reversible causes or chronic vegetative state.
4. Incurable chronic severe neurological states rendering meaningful life unlikely e.g. Progressive dementia, quadriplegia with ventilator dependency.
5. Progressive metastatic cancer where treatment has failed or patient refuses treatment.
6. Post cardio-respiratory arrest non-restoration of comprehension after a few days.
7. Comparable clinical situations coupled with a physician prediction of low probability of survival.

8. Patient/family preference to limit life support or refusal to accept life support.

Each of these criteria is not to be used in isolation but in the context of the entire clinical history and status of the patient.

Appendix (Source: ISCCM Website)

Definitions:

Definition of Palliative Care:

Palliative care is a positive, humanistic and technically powerful part of the general practice of medicine. The skills that physicians use to relieve suffering and improve quality of life have been termed palliative medicine.

Withdrawal of life support:

The cessation and removal of an ongoing medical therapy with the explicit intent not to substitute an equivalent alternative treatment. It is fully anticipated that the patient will die following the change in therapy primarily because of the underlying disease conditions.

Withholding of life support:

The considered decision not to institute new treatment or escalate existing life support modalities (intubation, inotropes, vasopressors, mechanical ventilation, dialysis, antibiotics, intravenous fluids, enteral or parenteral nutrition) with the understanding that the patient will probably die from the underlying condition.

Do not intubate/resuscitate (DNI/DNR):

Aggressive ICU management up to, but not including endotracheal intubation (DNI) or attempts at CPR (DNR). As per the Indian Penal Code, the committee of the Indian Society of Critical Care Medicine forbids the use of Euthanasia and Physician Assisted Suicide.

Physician assisted suicide:

A medical doctor provides patients with means to kill themselves

Euthanasia:

The intentional killing of a patient by the direct intervention of a doctor, ostensibly for the good of the patient or others.

Brain death:

Irreversible cessation of all functions of the brain including the brainstem. In the US, brain death is death. This category does not include patients who maintain brainstem function, such as patients with persistent vegetative state.

Guidelines for limiting life-prolonging interventions and providing palliative care towards the end of life in Indian Intensive care units (Source ISCCM Website)

1. The physician has a moral obligation to inform the capable patient/family, with honesty and clarity, the poor prognostic status of the patient when further aggressive support appears non-beneficial. The physician is expected to initiate discussions on the treatment options available including the option of no specific treatment.
2. When the fully informed capable patient/family desires to consider comfort care, the physician should explicitly communicate the available modalities of limiting life-prolonging interventions.
3. The physician must discuss the implications of forgoing aggressive interventions through formal counseling sessions with the capable patient/family, and work towards a shared decision-making process. Thus, he accepts patient's autonomy in making an informed choice of therapy, while he fulfils his obligation of providing beneficent care.
4. Pending consensus decisions or in the event of conflicts between the physician's approach and the family's wishes, all existing supportive interventions should continue. The physician however, is not morally obliged to institute new therapies against his better clinical judgment.
5. The proceedings of the counseling sessions, the decision-making process, and the final decision should be clearly documented in the case records, to ensure transparency and to avoid future misunderstandings.
6. The overall responsibility for the decision rests with the attending physician /intensivist of the patient, who must ensure that all members of the caregiver team including the medical and nursing staff represent the same approach to the care of the patient.
7. If the capable patient/family consistently desires that life support be withdrawn, in situations in which the physician considers aggressive treatment non-beneficial, the treating team is ethically bound to consider withdrawal within the limits of existing laws.
8. In the event of withdrawal or withholding of support, it is the physician's obligation to provide compassionate and effective palliative care to the patient as well as attend to the emotional needs of the family.

Informed consent

Informed consent is a fundamental ethical principle that underlies contemporary medical care. Patients and their attendants must have a clear and complete understanding of all therapies that are being planned.

Informed consent must include:

1. The problem the treatment would address.
2. What the treatment / procedure involves.
3. What is likely to happen if the patient decides not to have the treatment.
4. Benefits of the treatment.
5. The side effects / problems created by the treatment.

Ventilator withdrawal (to be done only in accordance with the law)

There are no tested protocols on this topic but two approaches have been described based on the literature and expert opinion. While discussing whether to institute or withdraw artificial ventilation the outcome of the intervention should be clearly defined. The goals of care should be clarified and elaborated in the light of the patient's medical condition.

1. Immediate Extubation
2. Terminal Weaning

Immediate Extubation: The tracheal tube is removed after suctioning. Humidified oxygen can be given after that. While immediate extubation is ethically sound some may be concerned that it is a form of direct killing of the patient.

Terminal Weaning: The ventilator rate, positive end expiratory pressure (PEEP) and FiO₂ are gradually decreased while the tracheal tube is kept in place. CO₂ narcosis may stimulate endorphin release and further sedate the patient. At this point of time Midazolam or opioids may be administered to prevent breathlessness and anxiety. It is important to ensure that after disconnecting the ventilator, the patient does not suffer from breathlessness and anxiety opioids (like morphine 2mg IV) help to relieve the sense of breathlessness. Midazolam & Lorazepam are effective anxiolytics. An intravenous bolus of Midazolam 1-2 mg may be enough. When the patient is sedated the tube may be removed after thorough suctioning. If the patient develops distress after withdrawal higher doses of morphine and/or Midazolam may need to be used.

Pain

Many fear that pain will suddenly increase as the patient dies but there is no evidence that this occurs. Pain is difficult to assess in the semiconscious/obtunded patient but may be associated with grimacing and continuous facial tension. Transitory tachycardia may also signal pain. Fleeting forehead tension, restlessness and agitation associated with dreams & hallucinations may accompany terminal delirium and should not be confused with pain. As dying patients experience diminished hepatic function and renal perfusion routine dosing or infusion of morphine should be discontinued to prevent an increased risk of delirium due to the accumulation of active metabolites. Fentanyl that has inactive metabolites may be preferred to treat breakthrough pain (expression of continuous pain).

Terminal delirium

Delirium frequently presents as confusion, restlessness and/or agitation with or without day-night reversal. Agitated terminal delirium can be very distressing and family members remember that their loved one died a horrible death, in terrible pain. Midazolam may be given as boluses of 0.5mg every 15 minutes, titrating to effect. In some patients Benzodiazepines may have an excitatory effect and may

not settle the patient. In these patients Haloperidol 0.5 to 2mg may be used to start and titrate intravenously or subcutaneously till the desired effect is obtained. Seizures may be managed with higher doses of Benzodiazepines. Antiepileptics like phenytoin or fos phenytoin may become necessary.

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