

# Guidelines for end-of-life and palliative care in Indian intensive care units: ISCCM consensus Ethical Position Statement

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## Executive summary

### Purpose

To develop an ethical framework and practical procedure for limiting inappropriate therapeutic interventions to improve the quality of care of the dying in the intensive care unit through a professional consensus process.

### Evidence

Since the publication of the last guideline in 2005,<sup>[1]</sup> there has been an exponential increase in empirical information and discussion on the subject. The literature reviewed address key surveys, observational studies, randomized controlled and interventional studies as well as guidelines and recommendations for education and quality improvement from all over the world and India. Established and evolving bioethical and medico-legal opinions in the world and in India are also included in this review.

The search terms were: End-of-life care; DNR directives; withdrawal and withholding; intensive care; terminal care; medical futility; ethical issues; palliative care; end-of-life care in India; cultural variations.

### Materials and Methods

Proposals from the Chair were debated and recommendations were formulated through a consensus process. The members of the Committee took into

account the established ethical principles and procedural practices elsewhere in the world, incorporating the socio-cultural and legal perspectives unique to this country.

## Guidelines summary

- The physician has a moral and legal obligation to disclose to the capable patient/family, with honesty and clarity, the dismal prognostic status of the patient with justifications when further aggressive support appears non-beneficial. The physician is obliged to initiate open discussions around the imminence of death or intolerable disability, the benefits and burdens of treatment options and the appropriateness of allowing natural death.
- When the fully informed capable patient/family desires to consider the overall treatment goal of “comfort care only” option, the physician should explicitly communicate the standard modalities of limiting life-prolonging interventions.
- The physician must elicit and respect the choices of the patient expressed directly or through his family (surrogates) during family conferencing sessions

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### From:

Committee for the Development of Guidelines for limiting life-prolonging interventions and providing palliative care towards the end-of-life: Indian Society of Critical Care Medicine

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and work towards shared decision-making. He would thus ensure respect to the patient's autonomy in making an informed choice, while fulfilling his obligation of providing beneficent care.

- Pending consensus decisions or in the event of conflict with the family/patient, the physician must continue all existing life-supporting interventions. The physician however, is not morally or legally obliged to institute new therapies against his better clinical judgment in keeping with accepted standards of care.
- The case notes should clearly reflect, through faithful recording of the whole or gist of the proceedings of one or more of the family conferences, the decision-making process and the final decision based on medical appropriateness and patient's preferences, in order to ensure transparency and accuracy.
- The overall responsibility for an end-of-life decision rests with the intensivist/attending physician of the patient, who must also ensure that a general agreement of other members of the caregiver team exists for the decision.
- If the capable patient/family consistently desires that life support be withdrawn, or that he/she be discharged home to die in situations in which the physician considers aggressive treatment non-beneficial, the treating team is ethically bound to consider withdrawal of the life support modality in question although clear legal guidelines are lacking at present.
- A withdrawal or withholding decision should be implemented after completing a life support limitation form duly signed by the patient's family and the treating team. The physician is obliged to provide compassionate and effective palliative care to the patient and to attend to the emotional needs of the family.

### Background

"Dying can be a peaceful event or a great agony when it is inappropriately sustained by life support" Roger Bone<sup>[2]</sup>

In the context of critical care, the physician's approach to the patient has three dimensions: medical, ethical and legal. This is because care of the critically ill involves not only the application of complex and expensive life-supporting interventions, but also, when appropriate, their withholding or withdrawal.

Death is common place in the critical care unit. The dying patient frequently dies in critical care units: it is estimated that one in five Americans and 50% of hospitalized patients die using intensive care.<sup>[3]</sup> Elsewhere and in India, depending on the case mix 10–36% of patients admitted to ICU die.<sup>[4]</sup> Thus, for many when a therapeutic trial of intensive care has failed, life-supporting interventions only serve to render the dying process more prolonged and burdensome. End-of-life care (EOLC) is about the quality of dying. Without due care, instead of a "good death" (i.e., a peaceful end occurring in the presence of loved ones), the patient may needlessly experience an artificial and lonely end surrounded by the dehumanizing paraphernalia of critical care.<sup>[5]</sup> The manner in which death is managed may affect the survivors for the rest of their lives. Also, especially in the Indian context, prolonged and futile life support has undoubtedly imposed enormous economic and human cost on patients and their families that is avoidable. Scarce resources in terms of material and manpower can be optimally utilized for salvageable patients when released from futile applications.

When death seems inevitable or the possibility of restoring meaningful life appears remote, what is the responsibility of the physician? In today's world, the culture of technological imperative has given way to a pragmatic and humane approach as physicians realize that the mission of intensive care includes the avoidance of inappropriate use of aggressive interventions.<sup>[6]</sup> The first do-not-resuscitate (DNR) orders were written in 1976.<sup>[7]</sup> Death is increasingly anticipated and managed with an appropriate end-of-life decision (EOLD).<sup>[8]</sup> In the US, the proportion of patients dying with a decision to limit life support increased from 51% to 90% over the 5-year period from 1988<sup>[9]</sup> to 1992.<sup>[10]</sup> Presently, in the US and in Europe withholding or withdrawal precede death in up to 90% of dying patients in critical care units<sup>[11-13]</sup> and 10% of admissions.<sup>[13]</sup> Rates of foregoing of life-support therapy (FSLT) among dying patients in other parts of the world are as follows: Brazil (11–36%),<sup>[14]</sup> Lebanon (46%),<sup>[15]</sup> Hong Kong (59%),<sup>[16]</sup> China (54% withholding, 34% withdrawal),<sup>[17]</sup> South Africa (87%),<sup>[18]</sup> Israel (91%).<sup>[19]</sup>

In the US, high rates of burdensome transfers to hospitals towards the end-of-life among dependent elderly nursing home residents was identified as markers of poor quality EOLC.<sup>[20]</sup> In Pediatric ICUs, retrospective studies in the last decade suggest that 40–60% of all deaths follow an end-of life decision and EOLC practices have been standardized.<sup>[21,22]</sup> Such decisions are also common in neonatal care even to the point of intentional

shortening of the dying process.<sup>[23]</sup> Professional bodies have recommended early disclosure of prognosis, frank discussions and advanced planning in cancer patients when they are relatively healthy.<sup>[24]</sup> The competencies-based intensive care training for Europe (CoBATRiCE) defined through a multinational consensus includes several skills for end-of-life and comfort care as essential to intensive care training.<sup>[25]</sup>

The Surviving Sepsis Guidelines 2008 recommend that limitation of life support and realistic goals of management (1D recommendation) be discussed with the family in appropriate circumstances.<sup>[26]</sup>

Major conferences such as the European Society of Intensive Care Medicine, the International Symposium of Intensive Care and Emergency Medicine, the American Thoracic Society, and the Society of Critical Care Medicine routinely hold symposia devoted to end-of-life care.<sup>[27]</sup> A consensus statement on EOLC among several societies was prepared in 2003, which included the American Thoracic Society, European Respiratory Society, European Society of Intensive Care Medicine, Society of Critical Care Medicine and Société de Réanimation de Langue Française.<sup>[28]</sup> This consensus conference symbolizes a transnational mission to improving the care of dying patients in the ICU.

End-of-life issues and palliative care have come to be regarded as part of mainstream research deserving of grants, funds and collaborative research.<sup>[29,30]</sup> Attempts have been made to measure the quality of dying (quality of death and dying (QODD) score) and validated in the community setting.<sup>[31]</sup> This tool highlights the correlations between symptom control and the quality of death. If validated for critically ill patients, the QODD score could be a standard instrument to use for clinical, educational, research and quality control purposes in the ICU. Thus, end-of-life care is emerging as a comprehensive area of expertise in the ICU and demands the same high level of knowledge and competence as all other areas of ICU practice.<sup>[32]</sup>

### **Barriers to quality EOLC**

European physicians were reported to have had no difficulty in making end-of-life decisions in 81–93% of cases.<sup>[33]</sup> In contrast, these decisions have been perceived to be difficult in India due to a number of barriers: Unawareness of ethical issues, culture of heroic “fighting till the end,” lack of palliative care orientation and legal and administrative prejudices.<sup>[34,35]</sup> Recently, the Economist Intelligence Unit (EIU) ranked India’s end-of-life care last out of 40 countries.<sup>[36]</sup> India was reported to

have scored poorly in all of the indices: basic end-of-life care environment, availability, cost and quality of EOLC. The EIU gave India a score of 2/5 in public awareness of EOLC, which the report attributes in part to Indians’ reluctance to openly discuss death and dying. EIU also reported “lamentably poor” palliative care system in all parts of India except in Kerala, where there exists a community-driven hospice service. The palliative and hospice care movement that has grown exponentially in the US<sup>[20]</sup> is yet rudimentary in India.<sup>[37]</sup> The hospice movement in the US has gained wide approval from the public and professionals; 30% of dying patients receiving hospice care.<sup>[20]</sup> It endorses forgoing of all curative treatments when life expectancy is low. Such considerations are not confused with euthanasia.

The need for social and legal reform, however, is of vital importance to India for several reasons. There is an unbearable financial burden to the average patient as healthcare expenses are borne mostly by the individual.<sup>[38]</sup> Lack of appropriate policies for limiting life support make fair distribution of scarce facilities impossible in this populous country. Finally, a technologically lingering death takes away the serenity and dignity accorded to it by the prevailing cultural traditions and beliefs.<sup>[39,40]</sup>

EOLD in the Indian context with its unique social, cultural, economic and legal complexities have not been adequately studied. There is a paucity of empirical data on the frequency and the manner of foregoing life support in Indian ICUs. The Indian physician’s attitude, which would appear to favor limitation of therapies,<sup>[35]</sup> is severely hampered in practice by the lack of safeguards in the form of legal guidance. The Indian Society of Critical Care Medicine (ISCCM) in 2005<sup>[1]</sup> ushered in significant steps towards improving EOLD by providing a clearly stated professional position.

Reports of the rates of EOLD in India are scarce. The first report appeared as a single table in a review article.<sup>[41]</sup> It reported an unintentional foregoing of life support in 22% of deaths in a tertiary care hospital. Out of the 48 deaths preceded by some form of treatment limitation, 38 (79%) were discharged terminally as “left against medical advice (LAMA).” Planned discharges for terminally ill patients for ensuring “good death” have been reported from The Netherlands<sup>[42]</sup> and Tunisia.<sup>[43,44]</sup> However, LAMA in India often refers to a unilateral withdrawal decision by the family mainly because of unbearable financial and other burdens,<sup>[41]</sup> especially since the private sector dominates health-care delivery.<sup>[38]</sup> Physicians may tacitly endorse this practice as the only

way to prevent perceived social and legal complications of an FLST decision. The social and ethical implications of this practice have been discussed previously.<sup>[35,36,45-47]</sup>

Another report from India prospectively collected as a part of the international SAPS3 study data, recorded an average EOLD rate of 34% in four Mumbai hospitals.<sup>[48]</sup> EOLD preceded 41–50% of ICU deaths in two private hospitals and a cancer referral center that admits both paying and free patients. Most deaths in the cancer hospital and 44 and 27% in the private hospitals occurred outside ICUs. In the public hospital that caters to free patients, 23% deaths occurred in the ICU with an EOLD rate of only 19%. These data reveal physician reluctance for EOLD but not for the rationing of ICU beds. Later, two abstracts have reported EOLD rates of 19 and 91% in predominantly neurological patients<sup>[49]</sup> and elderly patients,<sup>[50]</sup> respectively.

In another recent single center study from a “closed” ICU,<sup>[47]</sup> EOLs preceded half of 88 patients who died, the majority being withholding or DNR decisions with withdrawals comprising only 7.5%. This study also documented implementation of EOLD through the pathway recommended by the 2005 ISCCM position statement.<sup>[1]</sup> Half the EOLs took place in the first week after admission to ICU. Advanced chronic disease, premonitory fully dependent state and unresponsiveness to treatment were most frequently cited reasons for these decisions. EOLD was not independently associated with age, APACHE 4 at 24 h of admission and comorbidities. EOLD significantly reduced the therapeutic and cost burdens towards the last 3 days of life. Notably, the use of carbapenems, which could amount to 50% of the expenditure on drugs,<sup>[38]</sup> was curtailed. The presence or absence of third party payment did not affect EOLs. A recent report from Tata Memorial Hospital, Mumbai showed an EOLD rate of 38% among cancer patients with a withdrawal rate as high as 29%.<sup>[51]</sup>

Cultural influences<sup>[52]</sup> and professional factors impact on EOLC practices.<sup>[53]</sup> In a review that included 102 publications,<sup>[53]</sup> white American and Northern European patients were found to receive less technologically intensive EOLC. Also, physicians with more experience and routinely working in ICU are less likely to recommend technologically intensive care.

There are several impediments to change in critical care practices in India: The approach to the patient is generally “paternalistic” as the concept of autonomy is weak in the prevailing cultural ethos. The physician’s orientation by his training is only to a curative rather

than palliative approach to disease no matter the phase of the illness. The physician is generally fearful of being accused of providing sub-optimal care or of possible criminal liability of limiting therapies. Adding to his dilemma there is a virtual absence of legal guidelines (although professional ethical position has been available since 2005) relating to deaths in intensive care units in India. It would appear, based on small surveys that legal anxieties have been the most important factor<sup>[35]</sup> to obstruct appropriate EOLs and “good patient death”.

### *The legal position in India*

Self-determination of patients relating to medical decisions is not well articulated in our Constitution.<sup>[41,54]</sup> Indeed the position of the law with respect to death in dignity is unclear, as Indian courts have only addressed appeals for Euthanasia.<sup>[34,55]</sup> In the US and in Europe the relevant laws have evolved over the last three decades to accommodate the changing paradigm,<sup>[56-58]</sup> while in India legal opinion is yet to fully explore the issue of terminal care.

### *The 196<sup>th</sup> Draft Bill of the Law Commission of India*

In a landmark development, the Indian Law Commission published a draft bill on “Medical treatment of terminally ill patients (for the protection of patients and medical practitioners)” in 2006.<sup>[59]</sup> It reviewed the case laws and legal guidelines from several countries and made some notable observations :

- Euthanasia and physician-assisted suicide remain criminal offences, but are clearly distinct from withholding and withdrawal of life support
- Adult patients’ right to self determination and right to refuse treatment is binding on doctors if based on informed choice
- The State’s interest in protecting life is not absolute
- The obligation of the physician is to act in the “best interests” of the patient
- Refusal to accept medical treatment does not amount to “attempt to commit suicide” and endorsement of FLST by the physician does not constitute “abetment of suicide”
- Withholding & withdrawal is viewed as an “omission to struggle” on the part of the physician that will not be unlawful unless there is a breach of duty towards the patient
- Applying invasive therapies contrary to patient’s will amounts to battery or in some cases to culpable homicide

### *Proposed reforms by The Law Commission of India*

- Clear definitions of competence, informed decision and best interests



- Recognizes patient's Right to refuse treatment
- If a competent patient makes an informed decision, it is binding on the doctor
- In case the decision is not an informed one, or in cases of minors or incompetent patients doctors can take decisions in the "best interests" (include medical, emotional, ethical, social and welfare considerations)
- Statutory body to constitute a panel of experts to authorize withdrawal and withholding of life support (FLST) decisions
- Three experts to be consulted for FLST decisions for incompetent persons
- The physician will consult the family but their views are not binding on him/her
- Advance directives, and legal powers of attorney shall be deemed invalid for decision-making as it may "create complications"
- Provides for Court declarations: Family/physician/hospital can move court on the question of lawfulness of withdrawal of life support. This is viewed as an "enabling", as opposed to mandatory, provision
- Recommends "expeditious" decisions by a division bench of the High Court. Declarations binding on civil and criminal courts in subsequent proceedings
- Recognizes patients' right to receive palliative care
- Directs Medical Council of India (MCI) to formulate guidelines on EOLC

### **The Aruna Shanbaug case**

In March 2011, *Aruna Shanbaug case*<sup>[55]</sup> received considerable public attention and could impact on physician practice in relation to EOLD.<sup>[60]</sup> The Supreme Court of India delivered the judgment on a plea for allowing "euthanasia" for a patient in vegetative state for 37 years. The appeal was in the form of a "Public Interest Litigation" filed by a social activist. The Court ruled that "involuntary passive euthanasia was allowed in principle" but must follow a strict procedure involving clearance by a High Court.

### **Implications of the Shanbaug judgment**

- In the *Shanbaug case*, the Court has only addressed implications of euthanasia (whether or not the patient has the right to live or die) and not the larger issue of terminal care of incurable patients (whether or not the patient has the right to self determination and to refuse treatment).
- Evidently there is confusion relating to terminology. "Involuntary Passive Euthanasia" used for FLST is a term long discarded and is no longer in contemporary medical usage.<sup>[61]</sup> In fact this term only refers to practices during the Holocaust in Nazi Germany.<sup>[62]</sup> In fact, in countries where Euthanasia is legal, it

is applicable only to competent, non critically ill patients. Also involuntary application of Euthanasia has no precedence in medical practice.

- End-of-life decisions are rooted in the principles of patient autonomy and humane care and not euthanasia. Implicit in the right of consent is the right to refuse all therapies including those that sustain life.

While the judgment itself was restricted to the specific area of whether euthanasia for an incompetent adult is constitutionally sustainable, several comments germane to patient's Rights were made by the Amicus Curiae (legal expert) appointed by the court:

a) "...in general in common law it is the Right of every individual to have the control of his own person free from all restraints or interferences of others. Every human being of adult years and sound mind has a right to determine what shall be done with his own body (p. 37, Art. 22)". This implies that a patient cannot be put on life support against his/surrogate's consent even if it is life saving.

b) "... It follows as a corollary that the patient possesses the right not to consent i.e. to refuse treatment (In the United States this right is reinforced by a Constitutional right of privacy). This is known as the principle of self-determination or informed consent (p. 38, Art. 23)". The usual end-of-life decisions in the ICU are based on refusal of consent and thus do not violate Suicide Laws.

c) "...courts in the West are in favor of passive euthanasia provided the decision to discontinue life support was taken by responsible medical practitioners. If the doctor acts on such consent there is no question of the patient committing suicide or of the doctor having aided or abetted him in doing so. It is simply that the patient, as he is entitled to do, declines to consent to treatment which might or would have the effect of prolonging his life and the doctor has in accordance with his duties complied with the patient's wishes (p. 38, Art. 24)". By current medical definitions, refusal of consent does not constitute euthanasia (*vide infra* for definitions).

d) "...the decision to withdraw the life support is taken in the best interests of the patient by a body of medical persons. It is not the function of the Court to evaluate the situation and form an opinion on its own. In England, for historical reasons, the *parens patriae* jurisdiction over adult mentally incompetent persons was abolished by statute and such a declaration would be necessary only in case of dispute. Court has no power now to give its consent. In this situation, the Court only gives a declaration that the proposed omission by doctors is not unlawful (p. 40, Art. 31)." This forms the crux of the contemporary legal opinion on the subject. The judgment is thus silent on the wider issue of EOLC.

The judgment reviews the legal guidelines from elsewhere in the world. It quotes from the Dutch Law

(p. 44, Art 53): “.....with the exception of several situations that are not subject to the restrictions of the law at all, because they are considered normal medical practice. These are : 1) stopping or not starting a medically useless (futile) treatment; 2) stopping or not starting a treatment at the patient's request; 3) speeding up death as a side-effect of treatment necessary for alleviating serious suffering.” The ISCCM guidelines are about this aspect of patient care and do not touch upon issues pertaining to euthanasia.

### **Brain death**

In article 10, page 82, the *Aruna Shanbaug* judgment recognizes brain death as equivalent to death, removing the legal ambiguity that brain death was hitherto recognized only in the context of Human Organ Transplantation Act 1994.

### **Ethical foundations for EOLDs**

Bioethical principles fundamental to critical care practice have been well debated and firmly established.<sup>[32,63]</sup> Among the four cardinal ethical principles upon which the practice of critical care is grounded in the West, particularly in the US, respect for patient's autonomy has come to take precedence over the other three, namely, beneficence, non-maleficance and distributive justice.<sup>[6,12,56,57,64,65]</sup>

### **Autonomy**

Means the Right to self determination, where the informed patient has a Right to choose the manner of his treatment. To be able to exercise his autonomy directly the patient should be competent to make decisions and choices. According to US law, in the event that the patient has lost his decision-making capacity, his autonomy is maintained by his wishes expressed in advance in the form of a Will, or by his wishes as expressed by surrogates acting on his behalf (“substituted” judgment i.e., “what would the patient want given the present circumstances”).<sup>[6]</sup> Substituted judgment does not imply personal preferences of the surrogates/proxy. Advance care planning, healthcare proxy, Advance Directives/Living Will in the US are tools to protect patient autonomy. In the *Quinlan* case the US Supreme Court clearly affirmed that the surrogates have the right to refuse any unwanted treatment even if life sustaining.<sup>[56]</sup> Therefore withdrawal of therapy is legally not killing but “allowing the patient to die” of the underlying illness. If the patient's values and preferences are not known then the “best interest” standards are to be applied.

### **Beneficence**

Beneficence implies acting in what is (or judged to be) in

patient's interest. In critical care, increasingly the physician is expected to care for patients with a high risk of death. As the physician is expected to act in the best interests of the patient and his family, his responsibility should extend beyond medical treatment to ensuring compassionate care during the dying process. In this context, the physician's expanded goals include facilitating (neither hastening nor delaying) the dying process, avoiding or reducing the sufferings of the patient and his family, providing emotional support and protecting the family from financial ruin. This is not to be confused with Euthanasia, which is a direct intervention by the physician to hasten the dying process by administering a lethal injection. When the physician, acting unilaterally, makes decisions for the patient, he is said to be “paternalistic”.<sup>[56,57]</sup> Respect for patient's autonomy requires that Beneficence also consist of educating the patient to enable him to make an informed choice.

### **Non-maleficance**

Means to do no harm, to impose no unnecessary or unacceptable burden upon the patient. This is subject to varied interpretation, as the same act may be construed as harmful or beneficial depending on the circumstances.<sup>[64]</sup> In practical terms, it requires the physician not to act contrary to the patient's values and perspectives. The doctrine of double effect makes a distinction between intention and merely foreseen consequence. Although Euthanasia is illegal in most countries, aggressive symptom control is allowed even if it might appear to hasten (shorten) death.<sup>[28,32]</sup>

### **Distributive justice**

Means that patients in similar circumstances should receive similar care. Physicians need to have a socially responsible behavior, which makes it their duty to make optimal use of the material, financial and human resources under their control. The physician may thus provide treatment and resources to one with a potentially curable condition over another for whom treatment will be futile.<sup>[28,64]</sup>

### **When to initiate end-of-life (EOL) discussions**

A workable instrument of mortality prediction is necessary to identify situations where EOL discussions can begin. Whether a patient is going through the dying process or not is not always clear. Often the clinician's judgment is colored by his own biases and attitudes towards death.<sup>[66-68]</sup>

As with any diagnostic process, identifying these situations needs expertise and experience. Each of the following criteria is not to be used in isolation, but in

the context of the entire clinical history and status of the patient. When faced with prognostic uncertainty, the physician should not take precipitous decisions but wait for the disease process to unfold. The following list is not to be regarded as definition of medical futility, but should help the physician to recognize when to start discussions on EOL issues.

### **Bedside checklist for initiating EOL discussions**

1. Advanced age coupled with poor functional state due to one or more chronic debilitating organ dysfunction. e.g., end-stage pulmonary, cardiac, renal or hepatic disease for which the patient has received/declined standard medical/surgical options.
2. Catastrophic illnesses with organ dysfunctions unresponsive to a reasonable period of aggressive treatment.
3. Coma (in the absence of brain death) due to acute catastrophic causes with nonreversible consequences such as traumatic brain injury, intracranial bleeding or extensive infarction.
4. Chronic severe neurological conditions with advanced cognitive and/or functional impairment with little or no prospects for improvement, e.g., advanced dementia, quadriplegia or chronic vegetative state.
5. Progressive metastatic cancer where treatment has failed or patient has refused treatment.
6. Post-cardiorespiratory arrest poor neurological recovery after at least 3 days (7 days in case of therapeutic hypothermia).
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.

### **Rationale**

Absolute certainty in the anticipation of death is impossible. However, mortality prediction is central to communication and decisions in the critical-care setting. A variety of scoring systems have been developed based on physiological variables, however, none is reliable enough to be adequate for individual patients.<sup>[69,70]</sup> Physician subjective estimates of intensive care survival <10% are associated with a high probability of subsequent life support limitation and intensive care mortality,<sup>[69,71]</sup> but it is difficult to standardize.<sup>[72]</sup> Absolute objectivity in mortality prediction has so far been elusive. The American Thoracic Society definition of futility is therefore suggestive rather than definitive: "a life-sustaining intervention is futile if reasoning and experience indicate that the intervention would be highly unlikely to result in a meaningful survival for that patient".<sup>[73]</sup>

End-of-life decisions are not based on mortality prediction alone. Crucial to these decisions are quality of life estimates integrated with patient/family preferences and therefore a strictly evidence-based decision cannot be expected. Since it is rooted in "patient- and family-centeredness" it needs to be individualized.

Despite these difficulties empirical data has accumulated that can guide the physician's predictive judgment. Indirect evidence for the validity of the "checklist" is found in the form of epidemiological data on ICU mortality and ICU use by decedents,<sup>[3]</sup> prospective and retrospective observational studies on FLST<sup>[12,13,69,70]</sup> and from predictive tools that have been used in prospective studies on DNR and FLST in both Emergency Room and ICU setting.<sup>[74,75]</sup> These data help to identify the patient characteristics that physicians generally use for limiting aggressive therapy.

In the US, Angus *et al.*<sup>[3]</sup> reported epidemiological data, which revealed that among infants most deaths occurred in hospitals, especially ICUs while above the age of 75 years both ICU and hospital admissions at the time of death decreased, and beyond 85 years, it was the least at 14%. ICU use was found to be limited for metastatic cancer as compared to acute myocardial infarction. These data clearly suggest that advanced age and certain disease conditions lead the physicians to limit ICU admission and aggressive treatments

According to a multicenter, prospective, observational study in Europe, decisions for limitation were related to age and diagnosis among others.<sup>[13]</sup> Age, poor prognosis and poor quality of life were among the reasons cited in studies from France<sup>[12]</sup> and Canada.<sup>[70]</sup> In the latter series, the mean age of patients undergoing withdrawal of support was 65 +/- 14.6, most of whom had severe or extreme dysfunction of at least one organ system. They also found that the timing of FLST decisions from ICU admission depends on the type and severity of the disease. In a recent US survey, 19% of the elderly in nursing home setting have a risk ratio of 2.10 for transition to an ICU in the last month of life that has been identified as a marker of poor quality of EOLC.<sup>[20]</sup>

It should be noted that "cut off" values for age or duration of observation before considering EOLC are hard to determine as they vary with the overall health status of the patient and the nature of his disease.

Evidence from DNR directives or ICU admission policies also helps to define how physicians may anticipate death with a view to initiating EOL discussions. Sinuff *et al.*<sup>[74]</sup>



found that physician prediction of low probability of survival, physician perception of patient preference to limit life support, medical rather than surgical diagnosis and age are the strongest independent determinants of DNR directives. An earlier study by the same group<sup>[76]</sup> did not find age or severity of illness as independent predictors for FLST decisions for the latter as compared to setting DNR directives are more complex requiring physician-family consensus. Similarly, Le Conte *et al.*<sup>[75]</sup> reported the determinants of DNR directives to be advanced age (mean age 75 +/-13 years), chronic cardiopulmonary disease, metastatic cancer or patients with acute non-treatable illness.

In another Canadian study,<sup>[77]</sup> it was found that having DNR and FLST checklists improved the conduct of EOLC in the ICU as perceived by nurses. In acute processes, response to therapy may often be surprisingly good and observations over time or serial scoring coupled with physician prediction may improve prognostication.<sup>[72]</sup> In the ETHICUS<sup>[13]</sup> study, the greatest frequency of limitations occurred for acute neurological diseases. For quadriplegics, the option of home ventilation should be offered along with information and counseling, but the choice of the patient or family should guide the decision.

In the US as many as 60% of deaths from strokes, heart failure and traumatic brain injury has some form of treatment withdrawal.<sup>[78]</sup> Among patients of traumatic brain injury, early palliative care discussion resulted in decreased rate of unnecessary elective surgeries and increased rate of withdrawal of mechanical ventilation without tracheotomies. Where there is no reluctance for withdrawal of mechanical ventilation, a time-limited trial of intensive care would be possible in cases with uncertain prognosis.<sup>[32]</sup>

The bedside neurological examination remains one of the most reliable and widely validated predictors of functional outcome after cardiac arrest.<sup>[79]</sup> The absence of neurological function immediately after return of systemic circulation (ROSC), however, is not a reliable predictor of poor neurological outcome. The reliability and validity of neurological examination as a predictor of poor outcome depends on the presence of neurological deficits at specific time points after ROSC. Absence of pupillary light response, corneal reflex, or motor response to painful stimuli at day 3 provides the most reliable predictor of poor outcome (vegetative state or death).<sup>[80]</sup> The somatosensory-evoked potentials (SSEP) are probably the best and most reliable prognostic neurophysiologic test because it is influenced less by common drugs and metabolic derangements.<sup>[81]</sup>

Neuroimaging or EEG alone may be unreliable for the prognostication of futility.<sup>[80]</sup>

Prognostication strategies established in patients who were not treated with hypothermia might not accurately predict the outcome of those treated with hypothermia. Hypothermia may mask neurological examination or delay the clearance of medication, such as sedative or neuromuscular blocking drugs that may mask neurological function.<sup>[80]</sup>

#### *For pediatric patients*

Worldwide pediatricians are becoming more proactive in managing death and dying.<sup>[21,22,82]</sup> In a survey of 33 French ICUs, 40% of dying children had an end-of-life decision predominantly among neurological emergencies.<sup>[83]</sup> The EACRCPCH guidelines<sup>[84]</sup> cite the following situations as justification for limitation and withdrawal of interventions: 1. The permanent vegetative state 2. The “no chance” situation where there is expectation of imminent death despite aggressive treatment 3. The “no purpose” situation where there is decrease in quality of life despite potentially extended survival. 4. The “unbearable” situation where in the face of progressive illness further treatment is more than that can be borne.

### **Guidelines for limiting life-support interventions**

#### *Guideline 1*

The physician has a moral and legal obligation to disclose to the capable patient/family, with honesty and clarity, the dismal prognostic status of the patient with justifications when further aggressive support appears non-beneficial. The physician is obliged to initiate open discussions around the imminence of death or intolerable disability, the benefits and burdens of treatment options and the appropriateness of allowing natural death.

#### *Rationale*

Respect for patient's autonomy and the imperative to act in his best interest are the basis for providing timely, transparent, accurate information along with its balanced and individualized interpretation, as worldwide we move away from the “paternalistic” model of care.<sup>[13,28,32,56,65,73]</sup> The patient/surrogates are thus able to make a genuinely informed choice.

It is important for the physician to identify a suitable family member as a surrogate decision-maker for the patient, as studies have shown that less than 5% of patients are able to communicate with the physician regarding issues relating to life support.<sup>[9,10,28]</sup>



The “family” means spouse, children, parents, siblings and the next of kin who is available or even a trusted friend, though a hierarchy of surrogates does not exist in Indian Law for making medical decisions.

Advance directive stating the patient’s preference is not a practice in India but public awareness in this regard should be encouraged. Prior informal expression of preferences by the patient should receive due consideration. Curative and palliative measures are coexistent but varying in degree at different phases of critical illness.<sup>[32,58]</sup> Therefore, the physician must initiate discussions early with a clear expression of the patient’s condition. Waiting, watching, and postponing discussions on prognosis may be more stressful to the family as well as the ICU staff.<sup>[24,85]</sup>

### Practice points

- It is important that the physician gives as accurate a prognosis as is possible, clarifying that uncertainty is inherent in the treatment of critical illness, in a language and in terms that the family can understand.
- It is the responsibility of the physician to inform the capable patient or his family the diagnosis, prognosis, the range of therapeutic interventions available as well as the option of no therapy, including their risks, benefits, costs and consequences.<sup>[32,73]</sup>

### Guideline 2

When the fully informed capable patient/family desires to consider the overall treatment goal of “comfort care only” option, the physician should explicitly communicate the standard modalities of limiting life-prolonging interventions.

If the patient or family do not desire the continuation of life-supporting interventions, the available options for limiting the supports should be identified as follows:

1. Do-not-resuscitate status (DNR)
2. Withdrawal of life support
3. Withholding of life support

Definitions: modified from (11)

### Full resuscitation (CPR)

Aggressive ICU management up to and including resuscitative attempts, in the event that cardiorespiratory arrest occurs.

### Withdrawal of life support

The cessation and removal of an ongoing medical therapy with the explicit intent to 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).

### Active shortening of the dying process (SDP)

Deliberate administration of large doses of drugs (barbiturates, morphine) until death ensues.

### Physician-assisted suicide (PAS)

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.

Requests for Euthanasia have been turned down (*K Venkatesh vs State of Andhra Pradesh, Aruna Shanbaug vs The Union of India*). In fact, suicide and abetment to suicide are declared punishable by the Indian Penal Code,<sup>[41]</sup> though this is not the case in most countries.

As per the Indian Penal Code and the Supreme Court ruling the committee of the Indian Society of Critical Care Medicine forbids the use of Euthanasia and Physician-Assisted Suicide.

Euthanasia is allowed in the Netherlands and Belgium under certain strict regulations and is applicable only to conscious and competent patients who directly appeal for it. PAS is legal only in the State of Oregon in the US.

In India, in *Gian Kaur vs State of Punjab*,<sup>[86]</sup> the Supreme Court has ruled that the Right to life enshrined in the article 21 of the constitution cannot be interpreted to include a Right to die. However, the point of reference here was abetment to suicide as the validity of suicide laws was being challenged. Gian Kaur was accused of abetting the suicide of her daughter-in-law not in the

context of terminal illness but in a case of immolation. The plea of the accused was that abetment is not unlawful if suicide itself was not. The Supreme Court disallowed such an interpretation and the judges clarified that only taking of one's life in health is unlawful, not the pursuing of a natural end towards death in dignity. The right to privacy sanctions choosing a dignified process of death which is indeed the basis of legislations for limiting life support throughout the developed world.

### **Brain death**

An 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.

In India, brain death was initially defined only for the purpose of beating heart organ retrieval in the Transplantation of Human Organ Act 1994. Outside of this context, in the *Aruna Shanbaug* case the judges have ruled that brain death is equivalent to death (p. 52, Art 103). In the opinion of the Committee, there should no longer be any ambiguity in this regard in physicians' communication to the patient's family.

### **Guideline 3**

The physician must elicit and respect the choices of the patient expressed directly or through his family (surrogates) during family conferencing sessions and work towards shared decision-making. He would thus ensure respect to the patient's autonomy in making an informed choice, while fulfilling his obligation of providing beneficent care.

### **Rationale**

Communication with the family is the key to making appropriate decisions and ensuring quality EOLC in the ICU.<sup>[28,32,58,87-93]</sup> If the best interests of the patient and family are to be served, they should be involved in an informed decision-making process at the outset. Surrogates need to be well informed and free from incapacitating anxiety and depression to be able to function effectively as substitute decision-makers for the patients.

Early and effective communication facilitates a more smooth transition from curative to palliative care, reduces the frequency of futile care and decreases the frequency of conflicts and potential for litigation between families and healthcare workers.<sup>[32,87,93-95]</sup>

The correlates of effective communication and family satisfaction include the provision of adequate time, frequent and consistent information provided by a single contact physician, preferably an intensivist, adequacy of physician and nurse staffing and help from the family physician.<sup>[87-89]</sup> Ensuring enough time for the family to ask questions and express themselves further enhances family satisfaction.<sup>[96]</sup>

Empirical evidence from other cultures may not be applicable in India, where data on the impact of socio-cultural influences upon family needs are sparse. In a multicenter survey in North India,<sup>[97]</sup> 536 family members of 238 patients were included. The instrument of the survey was an Indian customized version of the modified Molter's questionnaire.<sup>[89]</sup> Out of the five domains in the instrument (Information, Comfort, Support, Assurance and Proximity), the priority for the Indian family in this study would appear to be Information needs (e.g., details of patient's condition and discussion on prognosis) as opposed to Assurance needs (e.g., that patient is well cared for, having hope) for the American family.

### **Practice points**

We can however integrate the generalizable points into ICU practice in India:

- The discussions should be between the family and an intensivist. The presence of a nurse and a junior doctor will ensure consistency in subsequent discussions. It is desirable for the primary consultant and/or the family physician to be present. The communication should be patient-centered aimed to understand the patient as a person. This has been found to establish a healing relationship with the family.<sup>[98]</sup>
- There should be multiple conferencing of adequate duration. Family must be given adequate time and opportunity to ask questions and to express their views and emotions so that they do not feel "rushed" into a decision. This should also be done in a manner that ensures privacy, in a waiting room or similar area.<sup>[90]</sup>
- The possibility of death should be discussed along with the medical and palliative treatment options. The intensivist should enquire into any previously stated terminal care wishes or preferences directly or indirectly expressed by the patient. The discussions should include the relevant economic, ethical and legal issues.<sup>[99]</sup>
- The family members may express feelings of guilt or remorse that should be resolved with patience. It might be useful to remind the family that death is inevitable and medical science cannot offer cure

in all situations; that during the dying process the patient needs a humanistic approach rather than a purely technical one. The family should receive assurances that due care will be taken to alleviate patient's pain and distress.<sup>[100]</sup> In case the family has difficulties in accepting the possibility of death, counseling by a professional psychologist may be considered.

#### **Guideline 4**

Pending consensus decisions or in the event of conflict with the family/patient, the physician must continue all existing life-supporting interventions. The physician however, is not morally or legally obliged to institute new therapies against his better clinical judgment in keeping with accepted standards of care.

#### **Rationale**

The physician should not unduly influence the family in decision-making.<sup>[9,28,73]</sup> Though the emphasis on patient autonomy versus medical paternalism varies in different countries and societies,<sup>[6,12,28,57]</sup> the worldwide trend is towards a shared decision model.<sup>[6,28,65]</sup> This would minimize the influence of physician preferences, social and religious biases on the issue of forgoing life support.

Several professional recommendations support the view that the physician may not be pressurized to apply treatments he does not find appropriate.<sup>[28,101]</sup>

#### **Practice points**

- The physician should guard against imposing his own values on end-of-life decisions or be in any way manipulative or coercive.
- Decision may be taken in a stepwise manner towards deescalating the treatment through discussions until the clinical picture becomes clearer to the family.
- Conflicts may be resolved through improved communications, deferring decisions, seeking second opinions, or a psychologist's consultation.
- For conflict resolution one may seek the help of other senior physicians of the hospital or the hospital's ethics committee, if in existence.
- The physician may not subject a patient to a particular therapy, even if the family may demand it, if it is against his professional judgment.

#### **Guideline 5**

The case notes should clearly reflect, through faithful recording of the whole or gist of the proceedings of one or more of the family conferences, the decision-

making process and the final decision based on medical appropriateness and patient's preferences, in order to ensure transparency and accuracy.

#### **Rationale**

Documentation implies transparency, clarity, and evidence of an evolving decision-making process that indicates appropriate care on the part of the physician. This would be helpful to the physician to demonstrate his bona fide intentions in the event of litigation. It would provide security for the patient in case of mala fide intentions on the part of caregivers or his own family.

It would also ensure that the patient is informed of all the therapeutic choices available and that overall management plans are spelt out for him. Clear documentation is strongly recommended by European professional societies<sup>[28]</sup> and the American Thoracic Society.<sup>[73]</sup>

#### **Practice Point**

Details of the communications between the medical team and the family should be documented accurately and completely.

The Committee does not regard the signature of a family representative to be a mandatory requirement. The specific modalities withheld or withdrawn should be documented.

#### **Guideline 6**

The overall responsibility for an end-of-life decision rests with the intensivist/attending physician of the patient, who must also ensure that a general agreement of other members of the caregiver team exists for the decision.

#### **Rationale**

The physician in charge of the patient is ultimately responsible for the decision although the process requires full participation by the family/patient. The burden of the decision should not be put upon the family as several studies have found surrogates wanting in decision-making capabilities for the patient.<sup>[102-104]</sup> The leadership role assumed by an intensivist with his experience and expertise generates trust and confidence in the family.<sup>[28]</sup> Physicians/intensivists should minimize inconsistencies between members of the treating team.<sup>[87]</sup>

#### **Practice point**

Medical decisions and prescriptions should be made by the primary physician/intensivist. This should take into

consideration and integrate the opinions of the various subspecialists involved in the patient's care. The primary physician/intensivist should ensure communication and uniformity between the various members of the healthcare team.

### **Guideline 7**

If the capable patient/family consistently desires that life support be withdrawn, or that he/she be discharged home to die in situations in which the physician considers aggressive treatment non-beneficial, the treating team is ethically bound to consider withdrawal of the life support modality in question although clear legal guidelines are lacking at present.

#### **Rationale**

Physician's obligation to respect patient's autonomy and to act in the patient's best interests does not permit him to continue a futile treatment even though the legal position is unclear. In the absence of case law, the physician may be apprehensive of the potential for litigation in the future. Obtaining signed consent for withdrawal of support may be viewed as protective to the physician but as coercive to the family. The process of withdrawal must find a suitable balance between the two concerns. This is because throughout the developed world the patient has the legal Right to refuse all treatment<sup>[105-108]</sup> and because there is wide consensus regarding the equivalence of withholding and withdrawal of life support.<sup>[32]</sup>

#### **Practice points**

- Since Indian Law has no clear stand on end-of-life issues except that suicide and abetment to suicide are punishable offences,<sup>[41,54,86]</sup> withdrawal even with the expressed consent of the patient or next of kin can be misinterpreted post hoc. If the physician is uncertain about withdrawal he may offer the family gradual de-escalation or non-escalation of curative interventions.
- The physician must ensure clear documentation of the detailed discussions with members of the family who should be specified. The concerned physician, family member or both may then sign the records.
- Terminal care may be offered in the ICU, or in another area of the hospital in keeping with the wishes of the family. If the patient is discharged from the hospital pre-terminally as a shared decision, an appropriate discharge process ("discharged on request" or "Terminal discharge") in keeping with the hospital policy should be followed.

### **Guideline 8**

A withdrawal or withholding decision should be implemented after completing a life support limitation

form duly signed by the patient's family and the treating team. The physician is obliged to provide compassionate and effective palliative care to the patient and to attend to the emotional needs of the family.

#### **Rationale**

A hospital policy on EOLC and a defined standard operating procedure along with an Ethics committee to oversee such decisions can be very useful to facilitate such decisions.<sup>[109]</sup>

The US Supreme Court implicitly endorses the practice of using analgesics and sedatives to ensure that no patient dies in pain or distress.<sup>[32]</sup> However, in high doses side effects may take place that may hasten the dying process. Physician-assisted suicide needs to be distinguished from these as hastening of death is unintended, the primary goal of therapy being only alleviation of pain dyspnea, or distress. Quill and associates termed it "the double effect" to distinguish the intended and unforeseen effects.<sup>[63]</sup> With the transition of the primary goal of treatment from "cure" to "care", symptomatic management of pain and distress should be intensive, though calibrated despite the unintended risks of sedation and respiratory depression.<sup>[110]</sup>

Since the Court cannot recognize intentions, we should take care to document the use of opiates and the indication for their use.<sup>[56]</sup> This reduces the likelihood of misinterpretation or abuse.<sup>[32,56]</sup>

#### **Practice points**

A life-support limitation form should be duly filled and signed by two or more members of the family and treating team. The form should carry the following details: diagnosi(e)s, reason(s) for end-of-life decision, whether or not the patient has decision-making capacity, the modality of life support limitation, specifics what should be withheld/withdrawn and what should be continued. Signatures of the representatives of an ethics committee, if in existence are desirable for authentication. Education of all members of the caregiver team and resolving doubts and fears is crucial to successful implementation of end-of-life decisions. It is also imperative that the members of the caregiver team be trained on all aspects of palliative care to ensure quality EOLC.<sup>[111]</sup> Research has shown that quality of EOLC is poor at present and several interventions show promise.<sup>[112]</sup>

When patient undergoes withdrawal/withholding of life-sustaining modalities, the physician is ethically



obliged to continue to provide care that would alleviate the patient's and family's distress.

- All ethical issues relating to withdrawal should be discussed thoroughly with the family.
- If the patient is conscious and *compos mentis*, he should be clearly and with sensitivity explained what is expected to happen when a support is withdrawn. He should be reassured that possible pain or distress will be prevented by medication and prompt action should be taken for symptom relief.
- The optimal dose of opiates is determined by increasing the dose until the patient's comfort is ensured. There is no maximum dose recommended.<sup>[58]</sup>
- The physician should continue to be available to the family for guidance and counseling.
- For patients discharged home for terminal care suitable arrangements for transport and home care should be made. If endotracheally intubated, the patient should be extubated only upon being reached home (after anticipatory sedation to prevent pain/distress as for withdrawal in-hospital). A tracheotomy may remain and oxygen supplementation is optional.
- The patient's family should be allowed free access to the patient during the last days of his life.<sup>[30,31,88,89]</sup> In this situation, it would be permissible to allow children to visit the patient. The family should be encouraged to participate in the general care and nursing of the patient.<sup>[32]</sup> Music, books, TV etc. that can help alter the environment should be made available. The patient should be allowed every opportunity to experience spiritual meaning and fulfillment. Performance of non-obtrusive bedside religious services or rites should be encouraged.

### **Medical futility and unilateral decisions by physicians**

There are situations when the patient's family may insist on continuing life-support or adding new interventions despite hopeless prognosis.<sup>[113]</sup> The physician may have to act against his better judgment and thus face loss of self-esteem and professional integrity. Even in cases of documented brain death, there have been occasions when supports have had to be continued due to surrogates' unreasonable stand that everything possible should be done. We are obliged to define these situations and seek legal instruments to implement unilateral withdrawal of support.

### **What constitutes medical futility?**

Here we are referring to clinical situations where in the absence of brain death the physician believes that

continuing life support is futile. Clear and unequivocal situations of medical futility are rare.

Futility may be "quantitative" (how low are the odds of success) or "qualitative" (what are the desired ends).<sup>[114]</sup> There is no consensus among physicians about the exact definition of futility. More often than not, the issue is conflict resolution.<sup>[73,94,95]</sup> There may be misunderstandings regarding prognosis, the family may be pursuing unrealistic and unwanted plans, or the physician may be seeking to impose his ideas on the family. In extraordinary instances, the physician may face the prospect of overriding family demands to take a unilateral decision based on ethical principles. Examples of situations where the physician may consider unilateral action: patient has a prognosis of imminent death; patients with metastatic cancers in whom treatment has failed or has been declined; the very elderly with dementia; chronic vegetative state with organ dysfunction.

The proposed course of action may be:

- A second opinion from another physician not hitherto involved in the care of the patient.
- Multiple counseling sessions with the family explicitly informing the family the hopeless prognosis of the patient and the futility of continuing life support.
- If the family is intransigent, then suggesting transfer to another treating team willing to continue supports.
- To set up a committee of doctors to counsel the family. The committee may also take the help of a social worker, psychologist or priest to help resolve barriers to understanding. Seeking a judicial review of medical cases for EOLDs has no precedence in India but has been recommended by the Indian Law Commission and the *Shanbaug* judgment. Therefore, from the legal perspective unilateral action is not available to the Indian physician at present.

### **Conclusions**

Setting goals appropriate to clinical situations of poor prognosis are an integral part of critical care. Quality critical care requires that the practice be well grounded in ethical principles and that the ICU staff is trained in the skills of end-of-life care. A consensus regarding the practices relating to end-of life care in Indian ICUs should eventually lead to the evolution of appropriate legislation in keeping with the changing needs of critical care practice.

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