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Editorial

End of life care: should we struggle on, or let go?

'Life is pleasant. Death is peaceful. It's the transition that's troublesome'

Isaac Asimov (1920–1992)

Medical science is advancing so rapidly that, presently, most terminally ill patients receive technology driven end of life (EOL) care.¹ This is widely perceived as excessive and inappropriate use of technology.² Numerous studies have found the medical care of the dying to be unnecessarily prolonged, painful, expensive and emotionally burdensome to both patients and their families.^{3,4} Often the patients themselves are not in a state to consent for withdrawal of life support, the families are reluctant to take the decision and doctors continue futile treatment out of fear of litigation. Continuation of life support under these circumstances imposes a large financial burden on the families and denies more deserving patients the scarce critical care resources. In this situation, particularly when patient's relations have exhausted their funds, many corporate hospitals encourage them to opt for discharge against medical advice and arrange transfer to the nearest Govt Hospitals.⁵ With this questionable practice, they manage to shift the responsibility, avoid sticky situations of uncleared bills and tout lower mortality figures than the public institutions. An estimated 80% of the population pays for their medical treatment and this seems to be a major factor in 'pauperising' many families.

Pre-terminal admission to the ICU of patients in extremis without any reversible element in their illness is commonplace, and difficult to restrict. Against this backdrop, acceptance of mandate from terminally ill patients to limit their EOL care will abbreviate the suffering, improve ICU resource availability and curtail futile expenditure.

Any critically ill patient admitted to the ICU must be given aggressive resuscitative treatment and life support till it becomes evident that the illness is terminal and the efforts are futile. Presumption of prolongation of life unless there are directives to the contrary is the guiding principle for initial treatment and is consonance with ethics and legality. Once the illness is deemed terminal and irremediable, EOL care options range from withholding further escalation in life support, withdrawing life sustaining interventions, to withholding resuscitation. These measures, together termed as 'passive euthanasia' by the Supreme Court, are legally permissible provided certain conditions are met. Active euthanasia is illegal in India and most countries of the world. Active

euthanasia may be may be *physician assisted* which legalised in Oregon, Washington and Montana states of USA and in Switzerland. It could be *physician administered* which is legalised only in Netherlands and Belgium. Numerous criteria have to be fulfilled for both forms of active euthanasia to guard against misuse.^{6,7} The term passive euthanasia is not universally used, most countries refer specifically to the measures it encompasses. Active euthanasia is referred to as euthanasia.

Patients who are likely to die within few days to few months, generally less than 12 months, despite treatment are the subset for EOL decisions and care.⁸ A century earlier such patients would have passed away peacefully, surrounded by their family. In the present era, death occurs after an interminable period amidst bleeping monitors and machines, isolated from near and dear ones. There is an urgent need then to shift focus from increasing the duration of survival to improving the quality of remaining life and allowing the patient to die with dignity. A special subset of patients for end of life decisions is permanent vegetative states (PVS) who can live for decades on tube feeding and expert nursing care. They may also be considered for withdrawal of life support on request by relations or caregivers as in Aruna Shanbaug's case.

Before implementing any EOL decisions, there should be no ambiguity in the diagnosis, the condition should be irreversible and progressive. There should be no medical breakthrough around the corner which could reverse or largely alleviate the condition. Lastly, the planned course of action should be in the best interest of the patient.

Once decision is made to switch over to end of life care, the patient should be treated with profound compassion with particular attention being paid to pain relief and palliation. Patient's relatives should be allowed to spend sufficient time with him and provided emotional support where needed. Paramedical staff should give this patient as much attention as any other to avoid giving impression that substandard care is being rendered. Excellent communication with patient if conscious and frequent interaction with his relations and friends is a vital component in care of the terminally ill and is extremely conducive towards making difficult decisions. A second opinion from an expert colleague is always advisable before declaring the case as irremediable and terminal. If the patient or relatives want external expert of their choice to opine, this should be permitted if possible. Proper records of interaction between the panel of doctors and the patient or his relations should be maintained in a register, particularly if consent for withdrawal of support is not forthcoming.

Sometimes, relations would want to try out alternatives such as homoeopathic medicines. These are usually harmless and permitting their use after due cautions on side effects gives them the satisfaction of 'having tried out everything'. Use of religious music through iPod or cell phones could be permitted and is appreciated by the relations. In the Armed Forces, PBOR patients or their relatives are hesitant to interact with senior doctors. An easily approachable junior doctor appointed as a patient counsellor could facilitate their airing of doubts and grievance. However, when withdrawal or withholding of life support is being contemplated, direct interaction between the treating panel of doctors and patient or relation is mandatory. If the patient has given prior consent for organ or tissue donation after death or relations consent on his behalf, the transplant coordinator should be brought into the picture.

Amongst the four cardinal principles of medical ethics, autonomy and beneficence have the greatest bearing on end of life care. Autonomy gives the patient right of choice in his treatment. As elucidated by the apex court, a patient's refusal to take life saving medication despite awareness that he would die without it cannot be construed as suicide. By extension, withholding/withdrawing life support on request of the fully informed patient, will not be construed as abetment of suicide. Hence, provisions of IPC under which these acts are punishable offences do not apply. Informed decision to refuse treatment implies that the patient is informed of (i) the nature of his illness, (ii) any alternative forms of treatment that may be available, (iii) the consequences of these forms of treatment, (iv) the consequences of refusing the treatment.^{6,9}

In case the patient is incompetent, or has not given consent, withholding/withdrawing life support should be guided by the principle of beneficence (it should be in the best interest of the patient) and pass the Bolam test (conforming to accepted standard of care). The treating medical practitioner should obtain opinion of three experts in fields pertaining to patient's illness and in critical care. The experts should be empanelled by a statutory body. Hence it is important for the Hospital Director to get relevant specialist under him empanelled as in the case for declaring brain death. The decision should be recorded and communicated to the relations by the panel. If they wish to contest the decision in nearest high court, the withdrawal of support should be postponed till high court decision is conveyed or 15 days elapse whichever is earlier.⁹ All forms of advance directives are legally invalid in India due to apprehensions of misuse. For PVS patients, the guidelines laid by the Supreme Court in the Aruna Shanbaug case needs to be followed till a law on the subject is enacted.

It is always prudent to follow guidelines laid down by professional bodies especially when there is likelihood of litigation. Guidelines published by Indian Society of Critical Care Medicine (ISCCM) in Jul 2012 could be followed till MCI publishes one.¹⁰

As brought out by Datta et al in this issue, there are many lacunae in our health care for the terminally ill which require discussion, consensus and legislation.¹¹ Although ISCCM has made a beginning by prodding the Govt to action vide the 196th law commission report on medical treatment of the terminally ill dated 2006, there are still a number of unresolved issues viz:

1. Advance directives such as living will and medical power of attorney for withdrawal/withholding life support treatment could be permitted in special circumstances with built in safeguards, e.g. in octogenarians.
2. Law on withdrawal of life support in PVS patients needs to be enacted.
3. Administrative action is required with regard to:
 - a. Increasing the penetration of free tertiary care services across the country.
 - b. Providing incentives for Health Insurance.
 - c. Establishment of more Hospices for the terminally ill.
 - d. Establishment of Palliative care centres.
 - e. Incentives for Support groups.

The Govt at all levels is more likely to pay heed to public demand rather than requests from the medical fraternity. The movie 'Guzzarish' and the recent Aruna Shanbaug case have created some awareness. Regular public debates on these issues along with extensive media coverage are perhaps the most expeditious way forward.

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