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Letter to the Editor

End of life care

With great interest did I read the letter published in the January edition of your journal on “**End of life care decisions in Indian Armed Forces Hospitals**”, contributed by Capt Sanjay Singhal and Brig Anup Banerji, SM. In the twentieth century, death was medicalised, sanitized and hidden in hospitals and modern medicine has failed to accept death as a natural process with both positive and negative dimensions.¹ However, the paradigm of End of Life (EOL) care has additional dimensions that need to be appreciated and internalized by the Armed Forces Medical Services.

Medical futility

For most terminally ill patients, two fundamental facts ensure that transition to death will remain difficult. First is the widespread and deeply held desire not to be dead and the second is medicine's inability to give patients a precise, reliable prognosis about when death will come. When death is the alternative, many patients who have only a small amount of hope will pay a high price to continue the struggle to live. In one study in the United States, patients suffering from carcinoma of the proximal stomach elected to undergo complete resection of the stomach, though being informed of a 5 year survival rate of 10%.² Likewise, in a survey of patients with high-cervical quadriplegia dependent on respirators for more than a year, 64% rated their quality of life as good or excellent on a 5 point scale.³ In caring for a severely ill patient, the transition from gravely ill and fighting death to terminally ill and seeking peace will remain a difficult decision to make. Physicians need to be careful about not imposing their own values on the patient and patient autonomy and shared decision making must always remain the cornerstone of any EOL care discussion. However, it may also be an ethical imperative to respect a patient's desire to fight to stay alive, even if treatment is burdensome, expensive or unlikely to succeed. Otherwise, medical practice may become the happy hunting ground for Jack “Dr Death” Kevorkian clones. Claims of medical futility will always involve a value judgement and an objective definition of futility will inevitably cause some patients to die according to judgements with which they may disagree.⁴

Withholding/withdrawal of medical treatment and advance directives

With advance in critical care, it has become accepted that prolongation of life does not mean a mere suspension of the act of dying, but contemplate a remission of symptoms enabling return towards a normal, functioning and integrated existence.⁵ However, withholding or withdrawal of a life-sustaining treatment will remain a clinical procedure that observes high degree of preparation and expectations of quality, practices of which will need carefully developed protocols to reduce inappropriate variations. Moreover, the patient should always be the centre of all such decisions concerning end of life care and his or his family's opinion will be the gold standard for ethical backing of all such decisions.

Number of reports has come out in scientific journals, indicating active utilization of end of life care decisions in Indian hospitals. In one study in the ICU of four major hospitals at Mumbai, limitation of care was identified in 49 out of 143 deaths, 25% of patients not being intubated terminally, 67% subjected to no further escalation of treatment and 8% having withdrawal of therapy.⁶

But what about legal guidelines to direct and control withdrawal of therapy as an end of life decision? Supreme Court of India has given a landmark decision on 07 Mar 2011, which has changed the landscape of end of life care in the country. This singular judgement was delivered to decide the fate of Aruna Ramchandra Shanbaug, the unfortunate nurse lying in a Persistent Vegetative State (PVS) at KEM Hospital, Mumbai since last 36 years. For the first time, the court has laid down a law, whereby a decision to discontinue life support for a patient in Coma or PVS can be taken by the parents or spouse by approaching the High Court under Article 226 of the Constitution of India.

However, the legal position in respect of patient consenting to forego life-sustaining therapy in terms of Advance Directives or DNR/DNE orders is still not clear. Suicide has been defined as a voluntary act of intentional self-destruction and remains to be a criminal offence in India. Various courts in India have upheld that Right to life under Article 21 does not include right to die and though Right to life may provide a right to live with dignity upto natural death, including a dignified procedure of death but does not comprehend extinction of life. Hence, physicians in India may offer palliative care as a viable end of life care option but withholding

life-sustaining therapy on orders of the patient may be considered as “Abetment to suicide” which is punishable under Section 306 of Constitution of India.

Physician assisted suicide and euthanasia

Physician assisted suicide (PAS) has now been accepted as one of many clinically and ethically distinguishable practices in end of life care, where medical help is provided to enable a patient to perform an act that is specifically intended to terminate his or her own life. Physician assisted suicide needs to be distinguished from Euthanasia, where the physician performs a deliberate act intended to take the patient's life.⁷

Many authorities support PAS as the duty of the physician to relieve patient suffering, originating from a vigorous understanding of the duty to respect patient autonomy. PAS has been legalized in various countries of the world, though serious debate is being pursued about whether medicine can arrogate to itself the task of relieving all human suffering, even near the end of life. However, Euthanasia has not been legalized anywhere except in Netherlands under very controlled condition.

Why have diverse end of life decisions taken on such vitality in recent years? Probably what seems more frightening today is the very real prospect of losing one's control over the dying process. In response, Advance Directives, PAS and euthanasia have emerged as viable alternatives to uphold the personal autonomy of the terminally ill patient to decide on the singular event of his human existence.

The emerging consensus for palliative care

Slowly but surely, a consensus is emerging towards a more rational end of life care intervention for the terminally ill by providing palliative care. Palliative care essentially affirms life and regard dying as a normal process, neither to be hastened not to be unnecessarily postponed. It offers a support system for patients with active progressive, far advanced disease and

helps the family to cope, maintaining focus on the quality of end of life.⁸ Patients receiving palliative care probably make the transition from gravely ill to dying with dignity and grace, thus giving up at least some of the struggle.

Encouragement, support, fidelity and realism will remain to be the cornerstone of good care. In the coming years, end of life care decisions will challenge the AFMS and it is high time that the Corps take a conscious step towards standardizing end of life protocols to be followed in service hospitals.

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