

## EDITORIALS

# Impact of life-prolonging technologies on end-of-life care in India

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The debate on end-of-life care is just beginning in India but has been going on in developed countries for some decades. Since our conditions are markedly different from those obtaining in Europe or America, it is good that we are charting our own path.

This issue features three essays that will help further discussion. The most touching of these is the first person account by Dr. Rastogi. In his opening paragraph he highlights a fact that all of us must ponder. Advances in medical technology have now made it possible to keep the heart beating far longer that it would have in decades gone by. The crucial questions Dr Rastogi asks, and indeed all doctors looking after seriously ill patients must ask are: At what cost are we keeping the patient's heart beating? Is the ultimate outcome likely to bring happiness or sorrow to the family?

I see, all too often, patients in our intensive care wards who are sarcastically but realistically referred to as cabbages. There they lie, in deep coma, oblivious to the world and likely to remain so. Relatives come, offer affection, encouragement and hope but the recipient of this outpouring of concern and love will never know of their attendance or their sentiments. The irreparably damaged brain has rendered the patient insensitive in all senses of the term.

Even when doctors are certain – from their tests and assessments – that the patient will never regain meaningful consciousness, they persevere in their ministrations. Deep coma and attendant paralysis renders the patient vulnerable to a variety of complications – infections, pressure sores on parts of the body bearing weight, clotting of blood in the veins of the lower limbs and danger of these clots suddenly breaking loose and invading the veins of the lungs. Often these patients cannot breathe and are therefore made to do so by a machine. All this care comes at a horrendous cost.

No relative would begrudge cost if the outcome is likely to bring happiness. Even the poorest of the poor at hospitals such as the KEM Hospital in Parel, Mumbai, will manage to gather the required funds, often by selling the small plot of land owned by the family or the mangalsutra adorning the mother's neck.

Decisions on whether or not to continue such expensive care should, rightly, be made by the relations. Unfortunately, faced with the prospective loss of a loved one, emotion overpowers reason. "Please do whatever you can to save his life, doctor" is the statement most doctors hear from the responsible relation.

It is only when days and weeks later, after paying huge sums that the family often can ill afford, when the family sees the patient in almost exactly the same condition that questions on efficacy of treatment emerge. When searching questions elicit information from the doctor to the effect that no one can predict whether or not the patient will improve beyond this stage, panic sets in. At this stage, the law will not allow termination of life and so the tragic drama must be played out till, eventually, infection or some other complication calls the finale.

Dr Jindal discusses some of the questions that we must consider in all strata of our society, now. Does an individual possess the right to refuse treatment? Who else can decide on treatment option? Who is to bear the costs of life prolonging treatment? To what extent is the medical team responsible for the terminal care?

India needs legally valid guidelines on these and other crucial issues. We need to know the conditions under which a person in full possession of his senses can dictate that doctors should not embark on dramatic, expensive measures to save his life when the prospect of meaningful existence is virtually non-existent. Such a person is in dread of being a 'living corpse' with tubes sticking out of every imaginable and unimaginable orifice in his body. He also wishes to spare his relations crippling costs and prolonged agony.

We also need legally valid guidelines on whether, under specified circumstances – such as the presence of wide-spread malignant cancer or a mercilessly progressive disease that paralyses the patient and will eventually render him unable to breathe or swallow so that he may choke to death – the doctor can be empowered to follow the patient's order to stop any further treatment. This is not termination of life. It is a decision to prevent tragic and soul-deadening prolongation of a life that has lost all meaning and, in any event, is soon to end.

Western countries have legally valid empowerment of the patient such that he can issue an 'Advance Directive,' 'Living Will,' 'Do not resuscitate' (DNR) order and 'Durable Power of Attorney for Health Care.' We desperately need such empowerment of our citizens.

Guidelines already laid down need to be widely disseminated and acted upon. The definition of brain death is now part of an Act passed by Parliament and yet we see so much misconception on it. Endless tragedy has followed the decision by hospital administrators to refuse clinicians in their institutions to take off all life-support systems once the diagnosis of brain death has been made.

Finally, we need to consider the dilemma posed by the death, some months ago, of 25 year old K Venkatesh from muscular dystrophy in Hyderabad. Aware that he would soon die no matter what his doctors did for him, he pleaded that they be allowed to harvest his organs for transplantation so that other lives would be saved. This heroic gesture was fully supported by his mother, K. Sujatha. Since there was a grave risk that Venkatesh, in his enfeebled state, would suffer widespread infection that would make transplantation of organs impossible, Venkatesh and Sujatha pleaded that his organs be harvested by terminating his life.

Venkatesh did not seek an escape from an ordeal or from suffering. He wished to perform a final act of service to his fellow beings before his inevitable and imminent death. As Sujatha put it, 'euthanasia' and 'mercy-killing' were mere terms that meant nothing for them. Alas! Venkatesh's wishes could not be respected. His organs could not be used to save other lives.

The crucial factor to be underlined is that all that needs to be done – some of which has been briefly referred to above – must be achieved by society at large and not by the medical profession. Rightly, doctors have been criticised for their paternalistic attitude towards patients and relatives. It is therefore fitting that the movement to bring the necessary changes in our law and practices into being must be made by society.

Who forms society? The masses, desperately concerned about their next meal, are unlikely to spearhead changes. The responsibility must, perforce, fall upon our intelligentsia – professors, scientists, lawyers, philosophers, social workers, media experts, civil servants and others – to arrive at a consensus on each of the various issues after honest, practical and soul-searching discussion and debate. The consensus decisions can then be discussed among widening circles before being incorporated in law.

We are already far behind the rest of the world in empowering our citizens to make their own decisions on the ending of their lives. It is high time we catch up.