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Compassionate End Of Life Care: Needed Focus On Suffering

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The historian Philippe Aries [1] has described the transformation of dying through centuries, starting with “Tamed death,” in which death was familiar and people knew how to die; the dying and their families accepted death calmly; they knew when death was coming and what to do. Later came “One’s own death,” where death became more personalized. The dying had heaven to hope for or hell to fear; they had a stake in their death. The 18th century saw a shift in perspective towards “Thy death”, where death began to be dramatized, revered and feared - it began to be understood as discrete from the normal ebb and flow of life. And with 20th century, with the arrival of science and the modern hospital, came “Forbidden death” where death is “unwanted and fought against ... on the hospital bed, while one is unconscious, alone, and...[trying] to eschew death until the last minutes.”

If he were to write now, what would he have had to say about the further journey of death from the “hospital bed” to total isolation and suffering in the intensive care unit?

Though death is the inevitable consequence of life, this final transformation is a reality today. Only 10-15% of us will be blessed with a sudden death. For the others, unfortunately, the journey towards death is accompanied by physical, emotional, social, financial and spiritual issues that will make that journey often agonizing. The family’s suffering is under-recognized and can be so intense as to leave permanent scars in the body, mind and spirit running into the psyche of generations.

A medical system focused only on diseases, organs and chemistry, one that forbids death and stretches out the dying process, substantially adds to that suffering.

What would be important for me, say, in the last month of my life? If I had a Mercedes, it would be of no use to me; I would need an ambulance for transportation. If I had a huge beautiful mansion with a heated swimming pool, it would be of little consequence; I am unlikely to use more than a room or two to move about and then, maybe just one side of the bed. Most of my material possessions and achievements, I am sure, will not make me happy at that time.

What would be important is physical comfort, certainly. That is one of the things that palliative care focuses on. I would need to be free of pain and suffering as much as possible. That is denied to 98% of Indians today. Modern pain management and end-of-life care have got into MBBS curriculum only from 2019; controlled pain medicines are available only to less than 2% of the needy and though the new national health policy repeatedly talks about palliative care, it has no effective scheme for implementation. Ordinary modalities of treatment for common symptoms including

breathlessness or delirium would be inappropriate in the end-of-life situation and can indeed add to suffering.

Apart from physical comfort, the most important things to me at that time would be finishing unfinished business, companionship, the love that I get and the love that I am able to give. The presence of loved ones, a hand to hold, a few words like ‘I love you, dad’, the opportunity to say a farewell, to forgive and to be forgiven; these would be more precious than anything else.

Unfortunately, if I have some money in my pocket, those are precisely the things that would be denied to me.

Not only is the physical suffering not relieved; it is actually worsened by delirium and agitation which may occur in up to one-third of people incarcerated in an intensive care unit. And two-thirds of the elderly. This is particularly likely if there are inadequate or inappropriate pain management and sedation protocols, and if there is a tube in every orifice, artificial feeding even when one is feeling full, the inevitable retching that may follow and restraints on my arms and legs to prevent me from pulling the tubes out.

In the West, when found inappropriate and likely to cause more harm than good, artificial life support gets withdrawn in up to 90% of patients [1]. But in India such withdrawal happens only in 22% patients [2]. A large number of doctors believe that they have a responsibility to prolong life (for them, defined as a beating heart) at all costs, any suffering notwithstanding.

Such life support violates the very fundamental principle of medical ethics that a doctor’s duty is to ‘mitigate suffering. It is to cure sometimes, relieve often and comfort always. There exists no exception to this rule’ [2].

Then, how did this cruel transformation come about?

Two generations back, when I was a child in my village, death was accepted as part of life. I remember the death of an uncle. He got no pain relief when he was dying; true; but there were loving family members around him, holding his hand. In the background, a group of elders were sitting together in front of an oil lamp chanting hymns. The whole extended family had come offering support to the family. Eventually when he died, all relatives from far and near assembled there. And we children were by no means excluded. My friends and I watched how the body was prepared, was laid to rest facing south as the rituals demanded. A mango tree was cut down from the yard to make firewood for the cremation. All the family members, the men fighting back their tears and women wailing loudly, when too overcome assisted by a relative, circled the body in a clockwise fashion, kneeled at the head dropping a few grains of rice into the mouth (obviously a last holy meal) and touched the feet and prayed. When all had finished, the closest family members carried the body to the funeral ground, laid it to rest, and covered the body with coconut husks and firewood. Watching curiously, we children saw several more rituals followed by lighting of the pyre after which the closer relatives stayed on to offer comfort to the grieving family, some standing vigil near the funeral pyre for a while.

The more distant relatives who were not too overcome with grief, had taken over the kitchen. Members of the extended family took turns to look after the expenses for a day for the next 16 days, this relieving immediate family of worries of the expense and other mundane things. Everyone around was served a simple meal of rice gruel and lentils thrice a day. For those 16 days, the immediate family was never left alone; there was someone around to offer an informal kind of bereavement support, enabling the closest family to slowly come back to as near a normal a life as possible under the circumstances.

Half a century later, I saw how a colleague’s son-in law died. The man was in his late 40’s and had advanced cancer. He lived with his wife and high school-going son in an apartment in the middle of the city. Life for him was a series of travels between home and hospital often spending several days in an intensive care unit at a time. The residents of the neighboring apartments were polite and would ask after him, but there was no real support system. In a meeting of the residents’ association there was even a complaint about the frequent sirens of an ambulance and about too many visitors disturbing the peace.

The wife was supported by her father but neither the medical system nor any part of the community extended any support to her. They had one consultation with a palliative care team; but could not accept their help as they feared the man would be discouraged with the mistaken belief that palliative care is only for end of life. The schoolboy who was about to attend an examination was sent away to live with a cousin as his studies should not be disturbed. The wife and her father chose to take on all the emotional and social suffering by themselves; but they could hardly think from the point of view of the boy who must have been living with intense emotional distress with no one to share it with.

When they reached the hospital, the wife (fortunately prepared by the one interaction with a palliative care professional), explained to the doctors how distressing he found an intensive care unit to be, how he got an uncontrollable panic attack during his last stay in an ICU and how the family has decided that the rest of his treatment should happen in a hospital room where she or her father could be with him. Nevertheless, in the middle of the night when his condition deteriorated further, they were told, “We have no choice, his oxygen saturation has fallen dangerously low; we have to move him to an ICU”. The man died isolated in an intensive care unit which had earlier given him uncontrollable panic. He died with his arms and legs restrained because he had tried to pull the tubes out. Neither the wife nor the father in law could be with him in his last moments because they were allowed into the intensive care unit only for five minutes each in the morning and in the evening.

The man died suffering. The dying man never got the opportunity to say a final farewell to the boy and the son never got an opportunity to come to terms with his loss. What all hidden scars in his mind would the son be living with?

And who knows what all memories the wife may be living with? Will she ever in her life be able to remember with a smile the good times that they had had together? Wouldn’t the intensity of his suffering always haunt her?

Most of suffering of a surviving family is never known to others. But one who could express it, Sindhu, wrote about it in a newspaper. She explained how her father died in suffering in an intensive care unit.

“My 84-year-old father, my best friend, was enduring raw, intrusive medical procedures against his own wish. All skin and bones, he looked defenseless and at the mercy of doctors, his arms tied up, vulnerable, and agonized.

My father, the only person who could love me even when I wasn’t lovable; the one who taught me the rules of living simply, the one who told me my first stories during our evening walks, with whom I felt protected walking in the world.

The sight of him stripped of any sense of comfort or dignity on that hospital bed was unbearable. His frail body slipped out of his hospital dress, bared at the shoulder. He winced as a needle stuck in his neck wedged into the flesh when he rolled his head on the pillow in distress.....

.....*The same evening, I walked into the ward after my mother had come out. Even as I was approaching his bed, I heard him plead, his voice slurred. ‘‘Please don’t torture me.’’ His swollen palms were red, bearing evidence of the many failed attempts made to get a vein. His arms were tied to the side of the cot so he wouldn’t pull out the tubes when he was more conscious. Through his half-open eyes I could see his pupils dashed around blindly. My heart bled each time he moaned. I wanted to die in his place’’.*

So, we have a health care system that is all brain and sees only diseases and ignores the human being.

It’s error of omission is the failure to provide access to palliative care and pain relief.

It’s first error of commission is the inappropriate, inhumane end of life care in intensive care units. Humane, rational End-of-Life-Care policies supported by legislation is essential to prevent such suffering.

And the second error of commission is the financial destruction of families in India. A study published in 2018 shows that 55 million Indians are pushed below the poverty line by catastrophic health expenditure. That is more than 4.2% of the population in one year. According to World Bank data, India is among the worst 12 countries as far as such destruction is concerned.

Needed: Focus on suffering

It is the order of the day for medical education to be focused exclusively on curing diseases and not on suffering. This could be resultant on the influence of increase in technology and industry-involvement in health care. Quality of health care in India is ranked 154 among 195 countries in the world [2] while quality of care at end of life is ranked as one of the worst 15 countries in the world [2], which prompted a British oncologist, Dr Sankha Mitra to opine that in India “the poor die in misery of neglect, the middle class die in misery of ignorance and the rich die in misery on ventilators. No one gets a dignified and pain-free death”.

India has no law covering end-of-life care or on withholding/withdrawing artificial life support. In the absence of law, a verdict by the Supreme Court of India on 09 March 2018 would be valid. According to this, a person’s wishes on end of life care, prepared in the form of advance directives (living will) will be valid and binding on the medical system. If treatment (including artificial ventilation) is considered futile, it can be withdrawn. Unfortunately, the verdict has also put in a complicated procedure for its implementation, which makes it all time-consuming and impractical.

But no law would work unless the medical system focused on suffering as an entity and accepted death as the inevitable consequence of life and not an enemy to be fought even when it knows that in that particular context, the fight is futile. If hospitals accepted rational end of life care as its responsibility, what would it be doing?

The Indian Society of Critical Care Medicine (ISCCM) has provided guidelines on the subject -

Guideline 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.

Guideline 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 (Do not resuscitate; withholding life support; withdrawing life support).

Guideline 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 fulfills his obligation of providing beneficent care.

Guideline 4: Pending consensus decisions or in the event of conflicts between the physician's approach and the patient's/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.

Guideline 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.

Guideline 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.

Guideline 7: If the family/capable patient 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.

Guideline 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.

India does not have a law governing end of life care. In that context, a verdict of the Supreme Court of India of 09 March 2018 [3] becomes relevant. It reiterates the value of life, not only in its length but also in quality, accepting death as the inevitable consequence of life and ensuring some preservation of dignity to its very end. It makes advance directives (living will) legally binding on the doctor/hospital and permits withdrawal of artificial life support when its continuation is deemed inappropriate.

However, it has put in several procedures for implementation of such withdrawal. They were meant to prevent abuse of the system, but in effect has prevented practical use of the procedure, so much so, not even one case of withdrawal of life support through that procedure is known to have happened in India in the last one year and several months.

But the procedure laid down by the Supreme Court need to be relevant only when there is any conflict of opinion or uncertainty. If the treating doctors and family members are all on the same page about the matter, the ISCCM guidelines can be applied and much needless suffering can be prevented.

References

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