

End of life care: Issues and challenges

Advances in medical technology, diagnostics, transplantations, antibiotic therapy, and critical care have created bioethical dilemmas that confront physicians while dealing with terminally ill patients who are unlikely to survive. Clinicians tend to be less formally trained in providing good end-of-life care, and some may tend to avoid terminally ill patients. This tends to aggravate the isolation and loneliness experienced by the dying patients. Physicians have a vital and active role to play in providing care, support and solace in the final stages of the illness and, in guiding the patient and relatives through a complicated and frightening process. The physicians need to provide transition from focusing on cure and prolonging life to an approach of comforting the patient and ensuring quality of life. Physicians need to spend time listening carefully to patients' concerns and responding to them, in talking to patients, and in providing empathic responses on the backdrop of varied social settings and culturally influenced mindset.

The key issues in end-of-life care are: pain and symptom control, shared decision-making, psychological and spiritual support, and alternative sites of care.^[1,2] Meticulous attention should be provided to distressing pain and non-pain symptoms including physical discomfort, emotional suffering, and functional limitations affecting quality of life. Many of these symptoms can at least be alleviated, if not eradicated through liberal use of opioids, tricyclic and newer antidepressants, and non-steroidal anti-inflammatory drugs.^[3] Treatment of pain in terminally ill patients need not await ascertaining the precise cause of pain. Several studies show that many terminally ill patients are inadequately treated for relief of pain.^[4,5] This may be due to limited formal education on pain management, and a profound focus on diagnosis and treatment of underlying conditions rather than on patients' suffering. Psychiatric support can be provided in the form of neuroleptics for confusional states, and psycho-stimulants for depression. Non-pharmacologic approaches such as care of skin, mouth, orifices and stomas; adapting the surroundings at home to suit the disability; bowel and bladder management in bedridden patients; etc. can prove quite comforting. Unnecessary and discomforting treatments and diagnostic procedures that hold little promise of improving the quality of life are better avoided.^[6]

In "end-of-life situations" an informed patient and family can take appropriate decisions related to impending death. Patients and family members may not be able to make right choices and participate in decision-making unless they are well informed about the illness. It is the physician's duty to inform and empower them to make appropriate final decisions. In the Indian context, though the doctors are trained to be dispassionate and objective in deciding about diagnosis and treatment, they are required to be compassionate and play the

role of a counselor while dealing with terminally ill patients. The challenge for most physicians is to inform the patient and/or relatives regarding impending death without making them develop feelings of hopelessness or of being abandoned. The patient's view of good death can be very different from the physician's perspective. In the Indian society, 'good death' is synonymous with 'death with dignity' that is painless and peaceful, with no further bodily 'harm'. Medical goals are often overtaken by psychological and spiritual goals. Good end-of-life care requires eliciting a shared understanding of the patients' values and beliefs. Terminally ill patients may prefer to be at home during their last days, spending the rest of time with their beloved ones and extended family rather than staying in hospitals. Family members usually prefer that the death takes place at home, where they can perform social and pertinent rituals like reciting verses from religious texts, offering holy 'gangajal' to the patient in the final moments; these rituals are considered as ways to achieve 'moksha' - salvation after death.

A common observation since the middle of the 20th century has been that the advances in the medical science have put up new clinical and ethical dilemmas. These include decisions related to initiation of cardiopulmonary resuscitation in a patient with chronic incurable disease or withdrawal of ventilator support in situations wherein technologic interventions seem to prolong life (and misery) without any probability of recovery. It is generally agreed that all patients have a right to refuse medical interventions. Ethically, this right is based on the patient's autonomy and is implied by the doctrine of informed consent. All patients have a constitutional and an ethical right to refuse medical interventions. In the US, these human right issues are evolved, advanced and practiced through legislation and laws, and show that termination of medical treatments is now the norm. More than 85% of Americans die without cardiopulmonary resuscitation, and more than 90% of decedents in intensive care units (ICUs) do not receive cardiopulmonary resuscitation.^[7] Of decedents in ICUs, 90% die after the withholding or withdrawal of medical treatments, with an average of 2.6 interventions being withheld or withdrawn per decedent.^[7] There are many practical considerations in enacting this right. First, patients have a right to refuse any and all medical interventions, from blood transfusions and antibiotics to respirators, artificial hydration, and nutrition. Second, there is no ethical or legal difference between withholding an intervention and withdrawing it. Third, competent patients suffering from incurable diseases with no reasonable hope of recovery have the exclusive right to decide about terminating their own care. Fourth, the right to refuse medical treatment does not translate into a right to demand any treatment, especially ones that have no pathophysiologic rationale, that have already failed, or are known to be harmful. In India, there is as yet no clear-cut legislation on issues like

do-not-resuscitate (DNR), euthanasia, or living-will, where lacunae and unmet needs are perceived, but progress is pitifully slow over these highly debatable and contentious issues.

Emotional, social, and economic distresses among terminally ill patients and relatives can be more complex than physical suffering. Patients often suffer from isolation, fear and anxiety, feeling like a burden on loved ones, diminished self-esteem, economic strains, and spiritual predicaments. Key interventions include combating psychological isolation. Successful psychological interventions have been shown to promote quality of life without influencing survival.^[8] Spirituality, defined contextually, can provide comfort and support during the terminal days. A physician's role is to understand how spirituality influences the patient's coping and to help the dying person to explore these issues and find supportive resources. A rational healthcare system should also address the suffering of the family and close friends of the dying patient. Bereavement care is a neglected field of medicine. The physician has an important role in assisting in bereavement through sensitive attention to the family before and at the time of death; attending funeral rituals; writing condolence letters and answering later questions about death, and illness. Services of counselors should be enlisted to help families cope with the stressful situation. In addition, hospitals could provide a separate quiet place for family members to pray and seek solace. In our hospital, there is a prayer place of the widely revered deity 'Ganesha' where family members seek solace, and a counselor helps to address the anxiety and sorrow of distressed relatives. All these interventions help to improve the end-of-life care.^[9]

An important component of hospice approach to death is that patients and families are happier to be treated at home rather than in hospitals. Globally, access to palliative care is limited, and is highly under-developed in India. Palliative care describes comprehensive (physical, psychological, and spiritual), interdisciplinary services that focus on alleviating suffering and promoting quality of life for patients (and their families) facing a life-threatening or terminal illness. These approaches provide comfort to dying patients without necessarily modifying the underlying medical condition. Palliative care means a healthcare modality that provides for relief of suffering and improvement in the quality of life in various illnesses.^[10] In the US, palliative care is slated to become a new specialty under the American Board of Internal medicine. The palliative care residency programs include inpatient consultation, dedicated inpatient units, ambulatory care, and home care with or without hospice. Palliative care has a role in the earliest phases of life-threatening diseases, but assumes a more crucial role in the final three to six months of common terminal diseases e.g. advanced cancer, heart failure, respiratory failure, end-stage liver and renal failure, AIDS and debilitating fatal neurological diseases. In Indian settings, four conditions usually qualify for specialized palliative care: stroke patients with extensive supra-tentorial neuronal damage who have not shown any improvement to initial therapeutic measures and eventually turn fatal; chronic refractory heart failure requiring repeated prolonged hospitalizations without much improvement in quality of life; longstanding chronic obstructive airways disease with carbon dioxide retention and

respiratory failure requiring repeated artificial ventilation; and disseminated malignancies with widespread metastases with metabolic and endocrine complications.

Hospice programs offer a widely recognized form of palliative care in the US. Hospice refers to a specific government-regulated form of end-of-life care under different government and private healthcare schemes. Hospice care is typically given at home or a nursing home by an interdisciplinary team that includes a physician, nurse, social worker, chaplain, volunteers, bereavement coordinator, and home health aides, who collaborate with the primary care physician, patient and family. Bereavement services are offered to the family for a year after the death. Hospice regulations in the US require that a patient agree to forgo measures with curative intent and to focus on comfort. Also, to be eligible for a Medicare-certified hospice program, the primary physician must certify that the patient is likely to die within six months if the illness runs its usual course. In the UK, the NHS End of Life Care Program is part of an overall strategy to give people greater choice in their place of care and death, and to provide training for health and social care staff to help care for people at the end of their lives.^[11] It aims to reduce the number of emergency admissions to acute care for those who wish to die at home, and reduce the number of patients transferred from care homes to acute care in the last week of their life. In our opinion for any hospice program in India, a strict time prediction of six months should be replaced by a flexible time span ranging from one month in cases like disseminated cancers to a longer period for incapacitating and life-limiting neurological disease. A median expected survival time of 100 days should be acceptable in the Indo-Asian context. In one study, many people dying in institutions had unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect.^[12] Family members of terminally ill patients who received care at home with hospice services reported a favorable dying experience.^[12] A relatively newer concept in hospice care is palliative care in inpatient units, which are furnished like home. They are quieter, and decorated with personally important objects from each patient. Patients wear their own clothes, pets are allowed, families, including children have unlimited visiting liberty. They can bring food and are permitted to stay overnight. Palliative care can be improved in long-term care facilities, including innovations in advance care planning, staff training, and systematic changes in clinical care practices.^[13]

In India, inpatient care is provided in the wards or ICUs of government or private hospitals. In the past most deaths used to occur in wards. With the mushrooming of ICUs, the situation has changed in the last two decades. Now, ICUs tend to account for 10-20% of all deaths. The shortage of inpatient beds renders admission to only serious patients in wards, and only critical patients in the ICUs.^[14,15] The end-of-life care to terminally ill patients usually suffers in the pursuit of availability of beds in hospitals. Day care centers as an option for terminally ill patients has not grown, and palliative care is almost nonexistent. The elderly population forms a significant proportion of candidates for palliative care due to multiplicity of coexisting chronic diseases, but the old age homes in most Indian cities also shun

the elderly who are sick and require prolonged nursing care.^[16] It is the need of the hour in India to develop healthcare infrastructure and policies for acceptable end-of-life care in the form of palliative care, hospice care, and day care centers, which will offload the hospitals and spare the beds for acute care. This has various components viz. social, economic, legal, ethical, medical and mental health. The challenges in the field of end-of-life care in India are the need of government initiatives akin to Medicare-funded hospice care in the US and the NHS end-of-life care program in the UK; starting residency programs in palliative care in the medical colleges; investment in palliative care sector with public-private partnership; educating the practicing physicians on various issues of palliative care including communication skills; and forming associations of palliative care physicians to establish the standards of end-of-life care in India.

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