DYING WITH DIGNITY – PALLIATIVE CARE

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When I started my training in palliative care many years ago, I had not seriously considered the possibility that one day I would have a patient ask me whether I would prescribe them a medication to end their life. As I’ve come to understand, many palliative care practitioners have been afraid that any association with this new ‘physician-assisted suicide law’ would further cement the misconception that palliative care is only about death—even as the field has fought so hard to change its image in the national conscience as a focus on life and living well at any stage of a serious illness. With our aging population and higher burden of chronic diseases, the need for palliative care has never been greater, and yet we have all had patients who decline our services because of the death stigma. As one palliative care physician would put it, “We are already thought of as the death squad. If we start prescribing a lethal pill, where will we be?”

So, what about me? Will I prescribe? I won’t know until I meet such a patient. But what I do know is that no matter what may be my personal beliefs, as a palliative care clinician, I will have to play a vital role in the care of that patient, facing her questions and concerns with compassion and expertise.

Death with Dignity is defined as the death which is allowed to occur in accordance with the wishes of the patient. An individual may choose to withdraw himself from chronic medical therapies, if there is less expectation of cure. Patients suffering from advanced malignancies, poor performance status, major depression, poor social support or a desire for palliative approach to end-of-life care, choose death rather than active treatment. The disabilities brought on by illness can force the dying into a position of complete dependence. Their quality of life can be so poor that they might actually prefer to leave this mortal world rather than linger on in a sub-human life, and the family might feel the same way. The helplessness of caregivers, who are generally family members, stems from extreme economic adversity as well as the insensitivity of the healthcare system. This is because the legal environment in India has encouraged a defensive healthcare practice, in addition to the culture of silence around death.

The vast majority of people will actually achieve a better quality of life through supportive care, and will not insist for a hastened death process, once their needs are met. I believe that if we provide accessible, high-quality palliative care focused on meeting medical, spiritual, and psychosocial needs, physician-assisted death will remain an option of last resort for our patients.

The editorial in the January 2016 issue of the [Indian Journal of Medical Ethics (Vol.16, No.1)](http://ijme.in/index.php/ijme/), titled “[Healing and Dying with Dignity: Where does India stand?](http://ijme.in/index.php/ijme/article/view/2327/4879)” by Sunita Bandewar and Sanjay Nagral gives a thorough understanding of the concept of dying with dignity, in a country like ours, (India), where living with dignity is the topmost priority of our Constitution.

Professor M.R. Rajagopal helps identify the systemic constraints which obstruct access to palliative care. He attributes this to a restrictive legal framework for the medical use of narcotic drugs and psychotropic substances, the paucity of healthcare professionals adequately trained in modern pain management science, and to the fact that "...palliative care is practically unknown in most parts of the country". Major changes in recent times should improve the situation: morphine is included in the list of essential medicines by the World Health Organization; the 'right to pain alleviation' is backed by various UN conventions to which India is a signatory; progressive amendments have been made to India's Narcotics, Drugs and Psychotropic Substances Act; and Palliative Care has been recognised as a medical speciality by the Medical Council of India (MCI). However, he argues, more is needed for these changes to have an impact. He points out that palliative care is low cost, and suggests that "... a society which does not provide palliative care to the needy, does not have a moral right to consider euthanasia". He underscores the role that healthcare professionals must play as advocates of palliative care, and spells out what they must demand from the MCI to ensure people's access to quality palliative care.

The word euthanasia, originated in Greece means a good death. Euthanasia encompasses various dimensions, from active (introducing something to cause death) to passive (withholding treatment or supportive measures); voluntary (consent) to involuntary (consent from guardian) and physician assisted (where physicians prescribe the medicine and patient or the third party administers the medication to cause death). Request for premature ending of life has contributed to the debate about the role of such practices in contemporary health care. This debate cuts across complex and dynamic aspects such as, legal, ethical, human rights, health, religious, economic, spiritual, social and cultural aspects of the civilised society.

The term “passive euthanasia" which was made legal in India in 2011 in response to the case of Aruna Shanbaug is still a grey area, with no clear distinction made by the Supreme Court between active and passive euthanasia. The Supreme Court has failed to adequately distinguish between active euthanasia which is viewed as killing and therefore immoral, and passive euthanasia, which is defined as withholding an intervention or withdrawing life support. The moral relevance of the patient's suffering has been neglected in the legal discourse on euthanasia in India. There is a need to look into the practical implications of legalising passive euthanasia. The main restrictions in current laws that permit passive euthanasia is only after approval of the High Court. This precautionary approach is based on the risk that the law can be misused, given the vast vulnerable population in India. We need a better legislation, with safeguards to prevent abuse. The law is essential to honour an individuals' right to self-determination and freedom from suffering, and the sanctity of life. The risks of misuse can be reduced if the law draws upon the experiences of other countries with similar legislation.

Euthanasia opposers argue that, if we embrace ‘the right to death with dignity’, people with incurable and debilitating illnesses will be disposed from our civilised society. The practice of palliative care counters this view, as palliative care would provide relief from distressing symptoms and pain, and support to the patient as well as the care giver. Palliative care is an active, compassionate and creative care for the dying.

These opposers also quote from Constitution of India. ‘Right to life’ is a natural right embodied in Article 21 but suicide is an unnatural termination or extinction of life and, therefore, incompatible and inconsistent with the concept of ‘right to life’. It is the duty of the State to protect life and the physician's duty to provide care and not to harm patients. If euthanasia is legalised, then there is a grave apprehension that the State may refuse to invest in health (working towards Right to life). Legalised euthanasia has led to a severe decline in the quality of care for terminally-ill patients in Holland. Hence, in a welfare state there should not be any role of euthanasia in any form.

Euthanasia opposers also claim that attempts to suicide or completed suicide are commonly seen in patients suffering from depression, schizophrenia and substance users. It is also documented in patients suffering from obsessive compulsive disorder. Hence, it is essential to assess the mental status of the individual seeking for euthanasia. In classical teaching, attempt to suicide is a psychiatric emergency and it is considered as a desperate call for help or assistance. Several guidelines have been formulated for management of suicidal patients in psychiatry.

The opposers claim about ‘Malafide intention*’*. In the era of declining morality and justice, there is a possibility of misusing euthanasia by family members or relatives for inheriting the property of the patient. The Supreme Court has also raised this issue in the recent judgement. ‘Mercy killing’ should not lead to ‘killing mercy’ in the hands of the noble medical professionals. There is an urgent need to protect patients and also medical practitioners caring the terminally ill patients from unnecessary lawsuit.

Another problem they foresee is Emphasis on care*.* In olden days, majority of the patients died before they reached the hospital but now it is converse. Now modern medical sciences have advanced to such a great extent, life can be prolonged. This phenomenon has raised a complex situation. Earlier disease outcome was discussed in terms of ‘CURE’ but now, the diseases such as cancer, AIDS, diabetes, hypertension and mental illness are debated in terms best ‘CARE’, since cure is distant. The principle is to add life to years rather than years to life with a good quality palliative care. The intention is to provide care when cure is not possible by low cost methods. The expectation of society is, ‘cure’ from the health professionals, but the role of medical professionals is to provide ‘care’. Hence, euthanasia for no cure illness does not have a logical argument. Whenever, there is no cure, the society and medical professionals become frustrated and the fellow citizen take extreme measures such as suicide, euthanasia or substance use. In such situations, palliative and rehabilitative care comes to the rescue of the patient and the family. At times, doctors do suggest to the family members to have the patient discharged from the hospital wait for death to come, if the family or patient so desires. Various reasons are quoted for such decisions, such as poverty, non-availability of bed, futile intervention, resources can be utilised for other patients where cure is possible and unfortunately majority of our patient's family do accordingly. Many of the terminally ill patients prefer to die at home, with or without any proper terminal health care. The societal perception needs to be altered and also the medical professionals need to focus on care rather in addition to just cure. The motive for many euthanasia requests is unawareness of alternatives. Patients hear from their doctors that ‘nothing can be done anymore’. However, when patients hear that a lot can be done through palliative care, that the symptoms can be controlled, now and in the future, many do not want euthanasia anymore.

Commercialisation of health care is a potential hazard if euthanasia is legalized. Passive euthanasia occurs in majority of the hospitals across the county, where poor patients and their family members refuse or withdraw treatment because of the huge cost involved in keeping them alive. If euthanasia is legalised, then commercial health sector will serve death sentence to many disabled and elderly citizens of India for meagre amount of money. This has been highlighted in the Supreme Court Judgement.

Research has revealed that many terminally ill patients requesting euthanasia, have major depression, and that the desire for death in terminal patients is correlated with the depression. In Indian setting also, strong desire for death was reported by 3 of the 191 advanced cancer patients, and these had severe depression. They need palliative and rehabilitative care. They want to be looked after by enthusiastic, compassionate and humanistic team of health professionals and the complete expenses need to be borne by the State so that ‘Right to life’ becomes a reality and succeeds before ‘Right to death with dignity’. Palliative care actually provides death with dignity and a death considered good by the patient and the care givers.

The Euthanasia supporters, who strongly believe in ‘Right To Die’, counter-argue in the following ways:

Caregivers burden*:* ‘Right-to-die’ supporters argue that people who have an incurable, degenerative, disabling or debilitating condition should be allowed to die in dignity. This argument is further defended for those, who have chronic debilitating illness even though it is not terminal such as severe mental illness. Majority of such petitions are filed by the sufferers or family members or their caretakers. The caregiver's burden is huge and cuts across various domains such as financial, emotional, time, physical, mental and social. Hence, it is uncommon to hear requests from the family members of the person with psychiatric illness to give some poison either to patient or else to them. Coupled with the States inefficiency, apathy and no investment on health is mockery of the ‘Right to life’.

Refusing care*:* Right to refuse medical treatment is well recognised in law, including medical treatment that sustains or prolongs life. For example, a patient suffering from blood cancer can refuse treatment or deny feeds through nasogastric tube. Recognition of right to refuse treatment gives a way for passive euthanasia.

Right to die: Many patients in a persistent vegetative state or else in chronic illness do not want to be a burden on their family members. Euthanasia can be considered as a way to upheld the ‘Right to life’ by honouring ‘Right to die’ with dignity.

Encouraging the organ transplantation*:* Euthanasia in terminally ill patients provides an opportunity to advocate for organ donation. This in turn will help many patients with organ failure waiting for transplantation. Not only euthanasia gives ‘Right to die’ for the terminally ill, but also ‘Right to life’ for the organ needy patients.

Constitution of India reads ‘right to life’ is in positive direction of protecting life. Hence, there is an urgent need to fulfill this obligation of ‘Right to life’ by providing ‘food, safe drinking water and health care’. On the contrary, the state does not own the responsibility of promoting, protecting and fulfilling the socio-economic rights such as right to food, right to water, right to education and right to health care, which are basic essential ingredients of right to life. Till date, most of the States has not done anything to support the terminally ill people by providing for hospice care.

If the State takes the responsibility of providing reasonable degree of health care, then majority of the euthanasia supporters will definitely reconsider their argument. We do endorse the Supreme Court Judgement that our contemporary society and public health system is not matured enough to handle this sensitive issue, hence it needs to be withheld. However, this issue needs to be re-examined again after few years depending upon the evolution of the society with regard to providing health care to the disabled and public health sector with regard to providing health care to poor people.

It may appear premature to focus on a discourse on end-of-life care in a country where the right to life and decent healthcare is still severely compromised. However, with the rapid and widespread advance of market medicine and the availability of technology, the growing needs of palliation as well as withdrawal of care come up daily in the real world of clinical medicine. Moreover, the evolution of deceased donation has unfortunately been inextricably linked to the development of an end-of-life care philosophy in intensive care. The linking of organ donation with brain stem death in the Transplantation of Human Organs Act of 1994 has led to a bizarre situation: when families of brain dead patients give consent for organ donation, the organs are removed after which life support systems are withdrawn, but if the family does not consent to donation and asks for the ventilator to be disconnected, the request is turned down.

There is also a need to develop conceptual clarity regarding euthanasia, assisted dying and other related terms which are often used interchangeably and without precision. We have a long way to go before we can have in place a legal framework for end-of-life care and euthanasia or assisted dying that is informed by the Constitution of India and international conventions.

“Palliative sedation” is a legitimate end of life option—but not the only option. Unlike aid in dying, it requires that patients suffer intractable pain, and it lacks the safeguards required in aid in dying

Palliative sedation was originally called “terminal sedation,” as the intent is to bring about the patient’s death. Palliative sedation is the continuous administration of medication, to the point of coma, to relieve severe, intractable pain that cannot be controlled while the patient is conscious.

Palliative sedation is an option used when nothing else works to control a patients’ suffering, usually from pain. As such, its use requires that the patient suffers before it is utilized. Once the patient becomes unconscious, all life support is sometimes withdrawn or withheld.

Palliative sedation takes days to weeks to produce death. As such, it may seem to be a less humane way than aid in dying to help a dying patient manage their dying process, but in reality, it is NOT so. Palliative sedation is not a “natural” death, as some would suggest. It involves the administration of powerful sedatives, and often the withholding or withdrawal of food and hydration.

Palliative sedation is done to commence the dying process when all hope is lost – just like aid in dying—but without any of the safeguards. Palliative sedation has none of the protections that aid in dying does. There is no written patient consent, no required statutory determination that a patient has capacity, no physician obligation to assess depression, no mandatory reporting of related actions in the patient’s medical record, and no reporting to the Department of Health when it occurs. It can also be requested by a health care agent or surrogate for those who lack capacity.

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