Dying with Dignity—Free from Machines

Prahlad K Sethi¹, Nitin K Sethi²

In recent years, rapid advances in medicine and critical care have produced a plethora of procedures (endotracheal intubation, central venous lines placement, tracheostomy) and medical devices (mechanical ventilators, infusion pumps, dialysis machines) to support and sustain life. For physicians, caregivers and most importantly patients it is more important than ever before to make wise decisions about life-sustaining medical treatments. End-of-life (EOL) decision making process though is complex and involves difficult decisions for all concerned (patients, caregivers, physicians and nurses).

The Hippocratic Oath requires a newly minted physician to swear by the healing gods of Apollo, Asclepius, Hygieia and Panacea that he/she shall withhold certain ethical standards. The classical version of the oath hints at applying for the benefit of the sick, all measures that are required/available. Physicians hence by virtue of their training are programmed to support life by all measures at their disposal. The modern version of the oath advises physician to do the above while avoiding the twin traps of overtreatment and therapeutic nihilism. Unfortunately in medical schools across India, physicians in training are not taught how to avoid these two traps. When does a physician say no more? How does he communicate the futility of further medical treatment to the patient and the caregiver/family? There are no simple answers to the above questions. Disagreement about the goals of treatment between patient, family members and physician providers leads to misunderstanding and distrust.

For physicians it is important to treat the patient and family members humanely as EOL approaches. This begins with a clear explanation of the disease process and prognosis to the patient and his family. What is the life expectancy, what can the patient and family expect as the disease progresses? Will the various procedures and devices available to support and sustain life, have a meaningful outcome in the long term. For a physician it is important to prognosticate on not just life expectancy but also on the quality of life after these procedures/interventions. Will the patient be able to talk, eat, walk independently or will he be bed bound, dependent on a dialysis machine, with a tracheostomy and feeding tube? All these questions no matter how difficult, need to be addressed with the patient and his family. In the movie The Wrath of Khan (1982), Spock in his usual logical way says “the needs of the many outweigh the needs of the few” (“or the one”). Doctors have a moral obligation to not just the patient in front of them but also to the larger society. They have to wrestle with questions whether the medical resources currently devoted to their patient could be better utilized for care of other potentially salvageable patients. But a doctor should never forget that in the patient or family member’s eye “the needs of the one may outweigh the needs of the many”.

Case 1: A-85-year-old lady, diagnosed with a brain tumor (glioma) 3-4 months back and on antiepileptics, presented to the casualty with recurrent seizures. On presentation, she had a Glasgow Coma Scale (GCS) score of 3. She was loaded with IV antiepileptics. Though she warranted admission to the intensive care unit, she was admitted to the neurology floor respecting the wishes of her family who declined intubation and mechanical ventilation. Surprisingly her sensorium improved the next day and she started to communicate and accept orally. She though again declined. Respecting her and the family’s wishes, palliative care and comfort care measures were instituted. She went into a sudden cardiorespiratory arrest on day 3 and passed away peacefully with her family by her side.

Case 2: A-87-year-old lady, diagnosed with a brain tumor (glioma) 3-4 months back and on antiepileptics, presented to the casualty with recurrent seizures. On presentation, she had a Glasgow Coma Scale (GCS) score of 3. She was loaded with IV antiepileptics. Though she warranted admission to the intensive care unit, she was admitted to the neurology floor respecting the wishes of her family who declined intubation and mechanical ventilation. Surprisingly her sensorium improved the next day and she started to communicate and accept orally. She though again declined. Respecting her and the family’s wishes, palliative care and comfort care measures were instituted. She went into a sudden cardiorespiratory arrest on day 3 and passed away peacefully with her family by her side.

¹Department Neurology, Sir Ganga Ram Hospital, New Delhi; ²Department of Neurology, New York-Presbyterian Hospital, Weill Cornell Medical Center, New York, NY, U.S.A.
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known case of hypertension with coronary artery disease (CAD) status-post coronary artery bypass grafting (CABG) and angioplasty came to our casualty with sudden loss of consciousness. On examination, she was found to have left-sided hemiparesis with poor GCS score. CT head revealed sulcal effacement with early developing hypodensity in large area of right middle cerebral artery (MCA) territory. MRI brain confirmed large right hemispheric infarct and left posterior cerebral artery (PCA) territory infarct. After the poor prognosis was explained to the relatives, they decided to pursue palliative care. Do not intubate (DNI) and do not resuscitate (DNR) orders were signed. Patient went into cardiac arrest and passed away.

Case 3: A-86-year old bed bound male, known case of advanced Parkinson’s plus disease with dementia, presented with history of decreased oral intake, difficulty breathing, fever and altered sensorium for 2 days. He was encephalopathic with bilateral aspiration pneumonia and sepsis. After the poor prognosis was explained to family members, they elected against intubation and mechanical ventilation. He was managed on the neurology floor with oxygen, non-invasive mechanical ventilation (BiPAP), nebulization, chest physiotherapy with periodic suctioning along with IV antibiotics and other supportive care treatments. Due attention was given to hydration and nutrition status. Five days later, he developed sudden cardiorespiratory arrest and passed away.

Case 4: A-61-year old lady, having multiple co morbidities (old stroke with right sided hemiparesis, diabetes, hypertension, interstitial lung disease, old pulmonary tuberculosis, chronic liver disease with anemia) presented with complaints of diarrhea, fever and breathlessness for 2 days. She was found to have bilateral pneumonia with hypoxemia. After the poor outcome was discussed with relatives in terms of possibility of difficulty weaning off from ventilatory support, they elective to pursue comfort care measures. Patient was managed with IV antibiotics, antihypertensive, antidiabetic and other supportive treatments along with non-invasive (BiPAP) ventilation. She passed away 6 days after admission with her family by her bedside.

**Dying with Dignity**

On March 7th, 2011, the Law Commission of India, Ministry of Law and Justice in a landmark judgment recommended to the Government of India that terminally ill patients should be allowed to end their lives. By passing this judgment, India joined a small select group of nations that allow euthanasia in some form or other. This judgment has led to a vigorous debate in the media about euthanasia and the right to die. Just what is euthanasia and what is the difference between active and passive forms of euthanasia? The word euthanasia is derived from Greek: eu ‘well’ + thanatos ‘death’. The Oxford dictionary defines euthanasia as the practice of killing without pain a person who is suffering from a disease that cannot be cured\(^1\). The Stedman’s medical dictionary gives a more comprehensive definition and defines it as the act or practice of ending the life of an individual suffering from a terminal illness or an incurable condition, as by lethal injection or the suspension of extraordinary medical treatment\(^2\).

**Active euthanasia** (as for example mercy killing via a lethal injection or by giving an overdose of pain killers and sleeping pills) is currently illegal in almost all countries of the world. In most countries a physician who assists in active euthanasia can be prosecuted, lose his license to practice medicine and can even be jailed. The patient requesting active euthanasia can also be prosecuted. Put in another way the law as it stands now condemns a physician for actively killing someone (even though the patient requests it) but does not condemn a physician for failing to save a terminally ill patient’s life (aka active euthanasia is illegal but not passive euthanasia). Netherlands and Switzerland are two countries where active euthanasia is practiced openly though the medical, legal and social implications remain active topics for both professional and public debate. The courts in these two countries have allowed physicians to practice active euthanasia under certain strict conditions. In these countries too physician assisted euthanasia (the physician prescribes the lethal medication but it is the patient who self-administers the lethal medication) is more widely accepted (both by the public at large as well as ethically and morally by the physician community) than active euthanasia (physician administers the lethal injection himself). In Netherlands the following guidelines if followed strictly have traditionally protected physicians from prosecution: the patient’s wish to die must be expressed clearly and repeatedly, the patient’s decision must be well informed and voluntary, the patient must be suffering intolerably with no hope for relief however the patient does NOT have to be terminally ill (mental suffering is acceptable as a reason for performing assisted suicide and euthanasia in a patient who may be physically healthy), the physician must consult with at least one other physician, the physician must notify the local coroner that death resulting from unnatural causes has occurred\(^3\).

There is an ever increasing demand for the “right to die with dignity”. In an essay in the International Herald Tribune the right to die was defined as follows: “every person shall have the right to die with dignity; this right shall
include the right to choose the time of one’s death and to receive medical and pharmaceutical assistance to die painlessly. No physician, nurse or pharmacist shall be held criminally or civilly liable for assisting a person in the free exercise of this right.” A fundamental thought underlying the right to die is the belief that one’s body and one’s life are one’s own, to dispose of as one sees fit. So theoretically if one wants to commit suicide one should have the freedom/right to do so. Opponents of the right to die point out that legalizing the right to die may lead to irrational suicides. Different religions have different thoughts of view when it comes to the right to die. Hinduism in fact accepts the right to die for those suffering from terminal illnesses allowing death through the non-violent practices of fasting to death (Prayopavesa). Some Jains practice Santhara by which they seek voluntary death through fasting. Since the decision to practice Santhara is taken while one possesses a sound mind and is aware of the intent it cannot be equated to suicide which is usually carried out in haste when a person is in the midst of depression they point out.

A form of passive euthanasia and dying with dignity by withholding extraordinary life supporting measures (such as the decision to intubate and mechanically ventilate a terminally ill patient) is already routinely practiced in critical care units across India on a daily basis. In our experience once the hopelessness of the medical situation and the gravity of the illness is explained to the patient and the relatives, they comprehend and at times request discharge from the hospital so that the patient can take his last breath at home surrounded by family and friends. It is only when disagreements about the need, timing or mode of termination of care arise among family members or when a conflict of interest is perceived by the family members with respect to the treating physicians (‘they want him to die so that they can have the bed/ventilator’) that these cases reach the attention of the media and the public at large such as in the case of Aruna Shanbaug.

The right to die with dignity is a fundamental right of every person. The terms of this dignified death may vary from patient to patient. For some it may be dying at home surrounded by close family and friends, others in the hospital might wish to avoid the “trauma” of intubation and mechanical ventilation but continue with intravenous hydration and other comfort care measures, still others may wish for everything to be done. Doctors should explore patient and family’s wishes on these issues and respect them.

In the words of Frank Sinatra from his famous song “My way”...

“And now, the end is near
And so I face the final curtain
My friend, I’ll say it clear
I’ll state my case, of which I’m certain
I’ve lived a life that’s full
I’ve traveled each and every highway
But more, much more than this
I did it my way”

Men like “Tiger” Nawab Pataudi and Dara Singh not only lived their lives “their way” but also died on their own terms—with dignity.

“Dying can be a peaceful event or a great agony when it is inappropriately sustained by life support.” – Roger Bone

References