

Concepts and debates in end-of-life care

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Abstract

Debates in India on end-of-life care assumed a new life after the petition in the Supreme Court in the case of Aruna Ramchandra Shanbaug, calling for withdrawal of life-sustaining therapy from a patient in a persistent vegetative state. The Court's landmark decision has led the way for discussing and developing guidelines on various situations in end-of-life care. This paper discusses some key concepts in end-of-life care – medical futility, palliative care, advance directives, surrogate decision making, physician assisted suicide and euthanasia – with reference to the guidelines of various medical associations and decisions in Indian courts.

At what point does life end in a meaningful way? That is as ethically and politically fraught a question as: at what point does life begin? What if the medical professional judges that treatment is futile or even detrimental to the patient's best interests? And what if the family disagrees with the doctor's judgment? If a patient's life has become intolerable, and he or she freely requests medical assistance to end it, should such intervention be allowed? Or is it tantamount to murder? How are such decisions arrived at, balancing the principles of autonomy, beneficence and non-maleficence?

Medical futility

The starting point of such discussions is the concept of medical futility, a notion that may seem abhorrent to many physicians. However, in the course of caring for a critically ill patient, it sometimes becomes apparent that further intervention is futile – it will only prolong the dying process.

Clinical paradigms of futile care may often involve life-sustaining interventions for patients in a persistent vegetative state or resuscitation efforts for the terminally ill (1,2). It is extremely difficult to define the concept of futility in a medical context, where a physician may determine that a therapy will be of no benefit to a patient and is thus not to be utilised (3). People may differ on their judgments of the utility, purpose and effectiveness of an intervention and how the three balance out in medical affairs (4). Claims of medical futility inherently involve a value judgment, and an objective, standard definition of futility would inevitably cause some patients to receive interventions, or to die, according to judgments with which they may disagree (5). Efforts continue to arrive at an optimum balance between the judgment of physicians and the wishes of the patient. Yet a working definition of the concept is necessary.

The American Medical Association Council on Ethical and Judicial Affairs has recommended a fair process approach,

where a case-by-case evaluation has been advised in all medical cases involving futility judgments. The emphasis of the approach is on fair process rather than on having a definition that is externally imposed on the involved parties. The approach to futility includes four distinguishable steps, the first aimed at deliberation and resolution, two steps aimed at securing alternatives in case of irrevocable differences and a final step aimed at closure when all alternatives have been exhausted (6).

An empirical study examining the effects of a procedural approach to futility retrospectively in a large, urban, academic centre reviewed 31 ethics consultations involving cases in which a physician wanted to write a do-not-resuscitate (DNR) order against the wish of the family. Ethics consultants helped to resolve disagreement in 17 of those cases, recommended no DNR order in seven cases, and recommended that a DNR order be written despite the family's wish in seven cases. Of the seven patients for whom a non-consensual DNR order was recommended, two died before the order was written, four died after the order was written, and one was discharged to a hospice (7).

The Futile Care Policy of the Santa Monica Medical Centre in the USA proposes a seven-step process to these decisions:

- Step 1:** Explanation of the nature of the ailment, the options and the prognosis, by the physician to the patient and family, allaying at the same time any concern of abandoning the patient.
- Step 2:** Provision of names of appropriate consultants for an independent opinion.
- Step 3:** Assistance of nurses, chaplain, social services and joint consultation with the physician.
- Step 4:** Calling in the hospital bioethics committee to offer advice and counsel the patient/family.
- Step 5:** Giving adequate time to the patient/family to consider the information given.
- Step 6:** Offering a substitute physician or hospital if the family remains unconvinced even after receiving all information in respect of the futility of further care.
- Step 7:** Invoking personal payment in case of insistence by the patient to continue treatment from which he/she can no longer benefit.

The hospital reports that the bioethics committee was involved in only about two per cent of cases and the majority of cases were resolved by joint consultative process between the patient and family with the health provider team (8).

Withholding or withdrawing medical treatment

Following the judgment that treatment is futile, the question arises as to withdrawal or withholding of medical treatment. While this is a matter of much discussion, it is acknowledged that such a practice is common worldwide (9). A majority of deaths in the ICU in many parts of the world now occur following a decision to limit life-sustaining therapy (10,11). In an analysis of 14,488 patients from 282 ICUs in several different geographical areas, deaths occurring after a decision to restrict life-sustaining treatments vary from 26% of all deaths in the ICU in Central and South America to 48% in Central and Western Europe (12). Other studies have shown that life support was withdrawn or withheld in 59% of patients who did not survive in Hong Kong (13), 53% in France (14), 45% in Lebanon (15) and 41% in Sweden (16).

The decision to limit life-sustaining therapy can take one of two forms: withholding or withdrawal. Withdrawal of therapy is defined as the removal of a therapy that was started in an attempt to sustain life but has become futile and is now just prolonging the dying process. Withholding refers to the concept of no therapeutic escalation by DNAR (do not attempt to resuscitate) or DNE (do not escalate) orders.

With advances in critical care, it has become accepted that prolongation of life does not mean a mere suspension of the act of dying, but contemplates remission of symptoms enabling a return to a normal, functioning, and integrated existence (17). Ethically, there is no distinction between withholding and withdrawing a mode of therapy, once one accepts the fact that there is no duty or obligation to consider the use of interventions considered to be disproportionate (18). Any medical intervention must operate within the confines of a reasonable possibility to cure, ameliorate, improve or restore a quality of life that will be satisfactory to the patient.

However, withholding or withdrawing life-sustaining treatment is a clinical procedure that deserves a high degree of preparation and expectations of quality and, like many aspects of critical care, a carefully developed protocol for such practices will be necessary to reduce inappropriate variation. Moreover, the patient should always be the centre of all decisions concerning end-of-life care, and his or her family's opinion will be the gold standard for ethical backing of all such decisions.

The British Medical Council (19) recommends documentation of the decision to withdraw or withhold medical therapy. This includes:

- the relevant clinical findings,
- details of discussions with the patient,
- details of discussions with the healthcare team,
- details of discussions with others (relatives),

- details of treatment given, stopped or withheld, and
- review date, if appropriate.

Advance directives

Advance directives, which empower patients to decide on future treatments when they may lack the mental capacity for decision making, have received legal and ethical sanction for end-of-life care decisions in various countries. The three general categories of advance directives may be written statements or documents, oral statements made to providers or family, or naming a proxy or surrogate to make healthcare decisions. Healthcare ethics and law in several countries have recognised these forms of advanced directives as an extension of a competent person's autonomy, to be used in situations when a person lacks competence or decision-making capacity.

Written directives have found favour all over the world and three different types of advanced directives are presently in practice:

- living will – an expression of a person's desire regarding their own future treatment when death is imminent.
- durable power of attorney – naming a specific person as a surrogate decision maker.
- terminal care document – a document which names a decision maker and expresses choices about specific treatments, often including choices of mechanical ventilation, nutrition and hydration.

Patients may supplement these typical forms with more extensive expressions of values or desired treatment in specific clinical situations, making such advance directives disease-specific (18, 19). Clinicians, being aware of illness trajectories, are expected to initiate discussions when reviewing the current status of the patient in end-stage disease (20). However, mental competence and informed consent of the patient for advance directives will remain essential requirements for such end-of-life care decisions. Moreover, surrogate decision making has come under a cloud, following studies finding proxy decisions to be relatively inaccurate in relation to the previously expressed wishes of the patient (21, 22).

Physician-assisted suicide and euthanasia

Physician-assisted suicide (PAS) has now been accepted as one of many clinically and ethically distinguishable practices in end-of-life care, where medical help is provided to enable a patient to perform an act that is specifically intended to terminate his or her own life. This must be distinguished from euthanasia, where the physician performs a deliberate act intended to take the patient's life, through for example, a lethal injection (23). In differentiating euthanasia from PAS, the key difference is the role of the patient in exercising autonomy and self-direction. In the former, the patient is a passive recipient of dangerous medical paternalism while in the latter, the patient actively participates in a conscious and explicit decision-making process and requests assistance, often self-administering the agent for committing suicide. Euthanasia has been further

categorised as active, when the physician is deliberately terminating the life of the patient, or passive, which translates into withdrawal or withholding of life-sustaining treatment.

Many authorities support physician-assisted suicide as the duty of the physician to relieve patient suffering, originating from a clear understanding of the duty to respect patient autonomy (24). The suffering of patients at the end of life may be great, ranging from somatic symptoms to psychological morbidities. It encompasses interpersonal suffering like dependency on others to existential suffering based on a sense of hopelessness, indignity or the belief that one's life is coming to an end in a biological sense. In terminal illness, physician-assisted suicide is viewed as an act of compassion that respects patient choice and fulfils the obligation of non-abandonment towards the ethical duty of physicians to his patients (25, 26). Proponents for PAS argue that the decision to end one's life is intensely personal and private, harms no one, and promotes demedicalisation of death by putting the ultimate break on unrestrained use of medical technology at the end of life (27, 28).

In a series of 56 such cases, the decision to seek PAS was more often associated with concerns about loss of autonomy and control than with fear of pain or suffering (29). In the Netherlands, loss of control and 'tiredness of life' were more frequently reported than pain as the reasons for requesting euthanasia (30). A very small number of patients actually make a request for PAS or euthanasia. In Oregon, only one per cent of dying patients make a specific request for PAS and out of them, only 0.1% will actually die by PAS (31). However, this percentage has been found to be significantly higher in the Netherlands, with 17% of terminally ill patients choosing to die by means of euthanasia and three per cent by means of PAS (32).

Both PAS and euthanasia have opponents in the medical fraternity. Serious questions have been raised about whether medicine can arrogate to itself the task of relieving all human suffering, even near the end of life. It is argued that the physician, who remains with the dying patient, suffers with the patient in compassion, and enlists the support of family and friends in alleviating interpersonal or existential suffering of the patient, has acted with compassion without abandoning the patient, though not participating in assisted suicide on the patient's request (33). Physicians have demurred at the idea that they may become party to a decision of intentionally bringing death to a patient (34) and may consider such decisions as compromising the patient-physician relationship (35). Finally, the power to prescribe assisted suicide carries with it a profound risk for misuse and abuse (36).

Societies are divided on the issue of legalising PAS and euthanasia, though suicide and attempted suicide have been widely decriminalised. Though PAS enjoys significant public and physician support (37, 38), assisting the suicide of a patient remains a statutory offence in most parts of the world, whereas euthanasia is legal in only two countries, namely the Netherlands and Belgium.

The first legal sanction for PAS came in the state of Oregon,

USA, by virtue of its Death with Dignity Act, 1997, which has now been followed by the states of Washington, Montana and Hawaii. The Death with Dignity Act has allowed terminally ill patients to request a lethal dose of drugs, under the condition that two doctors confirm they have less than six months to live; a mentally competent adult patient makes one written and two oral requests at an interval of at least 15 days, and the doctors are confident that the patient is not suffering from psychiatric morbidity (39).

Euthanasia was legalised in the Netherlands by the Termination of Life on Request and Assisted Suicide Act, 2002. The Act states that euthanasia and PAS are not punishable if the attending physician acts in accordance with the criteria for due care; these criteria focus on the request being from a mentally competent patient with unbearable and hopeless suffering (40). Subsequently, Belgium followed in the footsteps of the Netherlands by legalising the practice of euthanasia in September 2002. However, the point to be noted is that PAS and euthanasia have been legalised in both these countries to be practised in very specific cases and under very specific circumstances. Moreover, each case of euthanasia needs to be reported to a regulatory commission for retrospective analysis of compliance with legal provisions.

The emerging consensus for palliative care

The decision to forego life-sustaining treatment is ethically and clinically distinct from requests for physician assistance with suicide or euthanasia (41). Although the Hippocratic Oath proscribes euthanasia and assisted suicide (42), abating treatment has been considered appropriate when patients are "overmastered by disease" (43).

Palliative care essentially affirms life and regards dying as a normal process, neither to be hastened nor to be unnecessarily postponed. It offers a support system for patients with active, progressive, far advanced disease, and helps the family to cope during the patient's illness, maintaining focus on the quality of end of life (44).

Recent research has identified patient perspectives in respect of quality end-of-life care, which point towards the domains of pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control and strengthening family relationships (45). Another study has identified pain management, preparation for death and the importance of being treated as a whole person as factors considered important at the end of life by patients and their families (46).

According to the Worldwide Palliative Care Alliance, while more than 100 million people annually could benefit from hospice and palliative care, less than eight per cent of those in need actually access it. In a first ever global study, the current environment for end-of-life care services was evaluated across 40 countries to measure "Quality of Death Index" by the Economist Intelligence Unit, a business analysis group. The study found that few nations, including rich ones with cutting

edge healthcare systems, incorporate palliative care strategies into their overall healthcare policy with Denmark and Finland ranked 22nd and 28th respectively. Unfortunately, India ranked last out of the 40 countries studied (47).

In caring for a severely, progressively ill patient, what will remain difficult is moving through the transition from severely ill and fighting death to terminally ill and seeking peace, shifting the goals of treatment from cure or longer survival to preservation of comfort and dignity. Some patients seem to accept the coming of death quite easily and for them, a transition to palliative care becomes straightforward. But for many, hope persists and surrender becomes excruciating (48). Dying patients and the families who receive palliative care in a hospice are more satisfied with their care than those who do not (49). A contributing factor may be that patients receiving palliative care have made this transition, thus giving up at least some of the struggle.

The Indian scenario

End-of-life care decisions are not unfamiliar in the Indian context, with the Upanishads accepting that death is the only certain issue in life. The Indian Society of Critical Care Medicine Ethical Position Statement has laid down exhaustive guidelines for limiting life-prolonging interventions for terminally ill patients in Indian intensive care units and providing palliative care towards the end of life by standardising the process of foregoing life support, thus attempting to assist Indian clinicians in decision making when confronted with difficult end-of-life situations (50). The guidelines deliberate on various end-of-life situations and provide both rationale and advisories for healthcare workers to address such situations in the intensive care setting. However, it is not known whether these guidelines are being used widely in critical care units around the country.

A number of reports from India have been published in scientific journals, indicating that end-of-life care decisions are being practised in Indian hospitals. In one study done in the ICUs of four major hospitals at Mumbai, limitation of care was identified in 49 out of 143 deaths. In these 49 cases, 25% of patients were not intubated terminally, 67% were subjected to no further escalation of treatment and therapy was withdrawn for 8% of patients (51). Another study reveals that almost half the patients dying in the ICU of the study hospital (49% of deaths) were preceded by end-of-life decisions to limit therapy by a withholding or do-not-resuscitate order (52).

Further, until recently, the legality of withdrawal or withholding of care has been disputed in the courts. Both abetment of suicide (Sec 306 IPC) as well as attempt to commit suicide (Sec 309 IPC) are criminal offences in India, which is in contrast to many western nations. The Indian courts have been repeatedly agitated in the past by a large number of cases, where the relatives of patients in coma or persistent vegetative states prayed for end-of-life decisions including withdrawal of life-sustaining treatment. In *P Rathinam vs Union of India* 1986, the Supreme Court upheld the plea of withdrawal of life

support by stating that the right to life under Article 21 of the Constitution of India can be said to bring in its trail the right not to live a forced life (53). However, this decision was quickly overturned by a different bench of the same court in *Gian Kaur vs State of Punjab*, where it was upheld that the right to life does not include right to die. The court opined that the right to life provides the right to live with dignity until natural death, including a dignified procedure of death, but does not comprehend extinction of life (54). Hence, both euthanasia and physician-assisted suicide remain criminal offences under the Indian Constitution.

On March 7, 2011, the Supreme Court of India's decision on the case of Aruna Shanbaug, a nurse of KEM Hospital in Mumbai, may have set in motion a change in the landscape of end-of-life care in the country. Aruna, who was brutally assaulted and strangled by an orderly on November 27, 1973, suffered from brain damage as a result of the assault, and is lying in the same hospital in a persistent vegetative state (PVS) for the last 38 years. The court ruled, for the first time in India, that the decision to discontinue life support for a patient in a coma or PVS can be taken by the parents, spouse, and other close relatives in the best interest of the patient – though no such withdrawal was permitted in the case of Aruna. The decision can also be taken by the doctors attending the patient or a body of persons acting as a "next friend". However, to prevent any misuse of the decision, the Court directed that any such application for withdrawal of life support will require sanction of a High Court bench of at least two judges under Article 226 of the Constitution of India, and the Court will be assisted by a committee of three reputed doctors to be nominated by the Court in taking such decisions (55). Time will tell whether a similar law gets codified by the Parliament at a later date, so as to provide appropriate legislation in keeping with the changing needs of the terminally ill and critical care medicine.

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