

SELECTED SUMMARY

Options at the end of life

BASHIR MAMDANI

811, N. Oak Park Avenue, Oak Park, Illinois 60302, USA. e-mail: bmamdani@comcast.net

Quill TE. Dying and decision making—evolution of end-of-life options. *N Engl J Med* 2004;**350**:2029–32.

The author describes the choices that he and his family made to make his father’s death peaceful. His father’s condition had begun to deteriorate rapidly from an ill-defined dementing illness. The father had made his wishes clear: he did not want to prolong dying. The family struggled to find a way to honour the father’s wishes.

In the past 13 years, palliative care has come to focus on relief of uncomfortable symptoms and improving the quality of life for severely ill patients and their families. Unlike hospice care, palliative care is offered alongside the active treatment of a patient’s underlying disease, regardless of the prognosis.

Hospices only accept patients with less than six months to live, who are willing to forgo all treatments. Unfortunately, patients like to receive some potentially effective treatments even when the chances of success are low. Therefore, few dying patients receive hospice care. Recently, hospices broadened their criteria to include patients with end-stage illnesses lasting longer than six months. The author’s father was accepted into one such local community hospice.

Discussions about last-resort practices have also evolved. Although the US Supreme Court had ruled in 1997 that there was no constitutionally protected right to physician-assisted suicide (PAS), the court indicated that it would not interfere with state-based efforts at legalisation. The justices were concerned about the current inadequacies of access to

and delivery of palliative care, and about the absence of empirical data of the risks and benefits of legalisation.

In Oregon, where PAS was legalised by referendum in 1998, it has accounted for less than 0.1% of deaths per year. Most of these patients had been enrolled in hospice programmes. They were primarily motivated to choose PAS by loss of autonomy, loss of control of their bodily functions, decreased ability to enjoy life and tiredness of waiting to die. Unrelieved pain and clinical depression were never a factor. This is an important point as groups that oppose PAS have insisted that if these two factors are adequately addressed, there would be no need for PAS.

What might be the other last-resort options available to patients like the author’s father? Table 1 from the *New England Journal of Medicine*, shows the five main options in rough order of consensus about acceptability.

The author’s father had been a staunch advocate of choice at the end of life. Because he had now lost the capacity to make decisions for himself, the family had to decide on his behalf. In collaboration with the hospice team, his primary physician and other consultants, the family elected to try low-dose phenobarbital to reduce his relentless agitation and insomnia. With this mild sedation, he appeared more peaceful. He awakened periodically to exchange a few words, but he almost completely stopped eating and drinking. He died peacefully five days later.

Commentary

By the late 1970s, Americans became concerned with the high cost of dying (80% of the total individual life-long

Table 1. Last-resort options for responding to intolerable suffering

Option	Legal status	Ethical consensus	Decision-maker
Proportionately intensive symptom management	Legal	Consensus	Patient or surrogate
Stopping or not starting potentially life-sustaining therapy	Legal	Consensus	Patient or surrogate
Sedation to unconsciousness to relieve intractable symptoms	Legal	Uncertain	Patient or surrogate
Voluntarily stopping eating and drinking	Legal	Uncertain	Patient only
Physician-assisted suicide	Illegal (except in Oregon)	Uncertain	Patient only

health care expenditure occurs in the last year of life). The futility of the expenditure and the undignified impersonal lonely death in an ICU led to the passage of the ‘death with dignity’ laws that required hospitals to ascertain the patient’s wishes (advance directives and DNR [do not resuscitate] orders) at the time of admission (1). The logical conclusion of this trend was the approval, by referendum, twice, of the Oregon Physician Assisted Suicide law in 1997 (2).

When a conservative government committed to ‘right to life’ came to power in 2000, the Federal government challenged the constitutionality of the law. In April, an appeals court dismissed the government’s suit saying that the voters had approved the bill by referendum, and the Federal government had no legal basis to challenge the will of the people of Oregon.

How is this article relevant to India?

The life expectancy for people of India has been increasing steadily. This is particularly true for most of the middle class where life expectancy is rapidly approaching that of their counterparts in the West. Inevitably, we see many more elderly patients with debilitating chronic illnesses such as terminal chronic heart failure (CHF), chronic obstructive pulmonary disorder (COPD), malignancies and dementias. Many such patients need 24-hour care for several months. Most are cared for by their families and/or hired caregivers when families can afford them. Our social ethos and family structure still enable most people to die peacefully at home.

Patients and families are clear that it is not death that they are afraid of—it is the process of dying that terrifies them. Of the options mentioned in the table, the first two could be done at home when there is a clear understanding between the doctor and patient/family. Patients may refuse nourishment towards the end and this too can be managed at home as has been done in the USA (3, 4).

Many families are emotionally unable to handle the prolonged suffering of their loved ones and want to take the patient to a local hospital to ease the suffering. What happens next depends on the level of communication between the doctor and patient/family. The family may run into a situation where the doctors, under the impression that they are legally required to do so, may use high-tech medicine to keep the patient alive, even if the patient and family don’t really want it. Doctors have been accused of using aggressive measures simply to make more money! Often, doctors get confusing and contradictory requests from a large extended family. Few patients designate a single person as their surrogate to make health care decisions in case they get incapacitated.

In such a situation, the doctors and hospital administrators do not want to withhold treatment in case this leads to filing of a law suit later by an aggrieved relative whose wishes were ignored.

Terminal patients need a hospice that provides comfort care, rather than a hospital which provides aggressive medical care. Many readers of this Journal may agree that we do need such nursing care facilities as the nuclear families, which are increasing in number, are unable to handle the 24-hour care for weeks. Hospice personnel make home visits to assist the family or administer the needed treatment within the hospice facility itself.

There is reluctance on the part of both the medical community as well as the patient/family to talk about distressing details. Doctors need to start talking to patients and their family about the futility of treatments that only prolong death. Until this major block is overcome, we will not be able to proceed to the next step—putting the wishes of the patient in writing such that they are legally binding on the medical profession.

Advance directives, such as no extraordinary life-sustaining measures, need the backing of laws to be enforceable in medical institutions. We also need to educate people about the advisability of awarding power of attorney for health care to a trusted family member. This person can liaise between the medical staff and patient/family to make appropriate decisions and submit a copy of the advance directives, if needed. These decisions have to be made widely known among the family members, so unseemly and emotionally unsettling squabbles are avoided towards the end.

In the US, where most care is paid for by third-party payers such as insurance companies or the government itself, the payers have a strong incentive for avoiding futile expenditure. Thus, laws were enacted to facilitate DNR orders and advance directives. What will be the stimulus for such changes in India?

References

1. Cassel CK. ICD-9 code for palliative or terminal care. *N Engl J Med* 1996;**335**:1232–4.
2. Sullivan AD, Hedberg K, Hopkins D. Legalized physician-assisted suicide in Oregon, 1998–2000. *N Engl J Med* 2001;**344**:605–7.
3. Quill TE, Lo B, Brock DW. Palliative options of last resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA* 1997;**278**:2099–104.
4. Ganzini L, Goy ER, Miller LL, Harvath TA, Jackson A, Delrot MA. Nurses’ experiences with hospice patients who refuse food and fluids to hasten death. *N Engl J Med* 2003;**349**:359–65.