

## Care for dying patients

There is a conventional image about death and dying. Physicians are dedicated to saving lives; death is their enemy, a sign of defeat; and they do everything medical technology permits to keep patients alive, even against patients' wishes and best interests.

If this general image was ever true, it certainly is not in the 1990s. The recent paper by Prendergast and Luce<sup>1</sup> adds to a growing body of empirical data illustrating the realities of current care at the end of life. The good news is that the withdrawal or withholding of life-sustaining treatments is now standard practice. Even the SUPPORT study, which presented a generally negative assessment of care at the end of life, found that about 80% of patients died without a resuscitation attempt.<sup>2</sup> Other studies have suggested that life-sustaining care is withdrawn or withheld in 90–95% of patients.

In addition, there is accumulating data that in the vast majority of cases physicians initiate the discussion to withdraw or withhold life-sustaining treatment. Prendergast and Luce found that in the USA the idea of stopping treatment was initiated by the patient or surrogate in fewer than 12% of cases. Finally, studies have begun to identify four major reasons for stopping treatment (in descending order of importance): (1) poor prognosis, commonly expressed as futility; (2) poor cognitive capacity; (3) patients' desire not to have mechanical interventions; and (4) old age.<sup>3,4</sup>

Nevertheless, in the USA, the taboo against talking about death remains alive and well. Most decisions to withdraw or withhold life-sustaining treatment occur very late in the patient's course, in most studies just hours or days before death. Despite tremendous publicity, there remains very little advance care planning or prior discussions about limiting life-sustaining care or use of hospice care. Prendergast and Luce report that fewer than 5% of patients had an advance directive and even fewer had a prior "do not resuscitate" order. Cancer patients are the exception; they use advance directives at twice the national rate, enrol in hospice at three times the national rate, and die at home much more commonly than do patients with other diseases.

Because discussions are left till late in the patients' course of illness, most patients are mentally incompetent and incapable of participating in the decision to withdraw or withhold life-sustaining treatments. Generally, the health-care team and the family make the decisions. Prendergast and Luce found that only 3.4% of patients were competent to participate in these decisions.

How can we improve the care for patients at the end of life? An essential step has to be to get physicians, medical institutions, and patients to overcome the taboo against talking about death and dying. First, we need systematic training of physicians in communicating about death and dying. Ironically, as the Prendergast and Luce and other studies show, doctors seem willing to stop treatments; the challenge is to make them comfortable with talking about stopping treatments and advance care planning. This will require more than medical education's traditional "see one, do one, teach one" approach.<sup>5</sup> It will require a systematic education, from medical school through to continuing medical education, using practical techniques about how to introduce the topic, how to discuss

prognosis, how to explore options, and so on.<sup>6</sup>

Second, medical institutions need to focus on providing better care for dying patients. In most cases this would entail more time for communication with terminally ill patients and their families facilitated by ensuring reimbursement for cognitive encounters, better and more extensive home-care services, better palliative care (not just pain-control services), better coordination of inpatient, outpatient, and social services, as well as better and more extensive staff training on end-of-life care. In the current cost-conscious environment, many factors undermine such initiatives. However, incentives can be developed to encourage institutional change. For instance, accrediting agencies such as NCQA (National Committee for Quality Assurance) in the USA could begin assessing hospitals, managed-care organisations, and others on the basis of their care at the end of life. Relevant measures might include (1) the proportion of terminally ill patients with high levels of symptom distress (2) the proportion of patients who have discussed advance-care planning with their physicians, (3) the proportion of patients who die in hospital and at home, (4) the proportion of terminally ill patients who receive hospice or home care services, and (5) the proportion of health-care staff who have specific training in end-of-life care.

The most difficult group to change may be patients. They are bombarded by conflicting cultural messages, encouraging acceptance of death as natural while celebrating youth, denigrating old age, and longing for immortality. Years of public education programmes around advance care planning have had only limited success; decades more may be needed.

At the end of the 20th century the care of dying patients has the potential to be better than at any time in the past: there are more treatments to relieve pain and other symptoms, hospice and home-care systems are well developed, stopping life-sustaining treatments is accepted as ethical and legal, and commonly practised. But things are far from ideal: too many patients are unprepared for death, too many patients still have symptoms left untreated, too many patients are not involved in the decision to limit life-sustaining care, too many patients die in hospital, too many families are crushed by the burden of caring for a terminally ill relative. To overcome these problems we need to end the taboo against talking about death.

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