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Alison McChrystal Barnes
Marquette University Law School

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Editorial Views: Choosing and Death

Can death be managed with dignity?

This editorial explores various world views on when, where, and how to—or, perhaps more importantly not to—end one's life when the benefits of continued medical care are diminished or futile. Developments in law in defining choices about dying show some courses of action.

By Alison McChrystal Barnes

“You Americans,” laughed my expatriate Cuban friend Marthe, “You think death is an option.”

Death is optional, Americans; a choice to be timed on life's Dayminder. A disaster perhaps, but *managed* so its impact leaves everything else—property, bereaved emotions, the principal's sense of prospective loss, and even the physical being of the dying and deceased—in the best possible condition. A dignified disaster.

Alison McChrystal Barnes is a professor of law at Marquette University, Milwaukee, Wisconsin.

In Cuba, soon after the renewal of limited U.S. contacts, groups of visiting American professionals toured hospitals and nursing homes, asking hard questions about the ethics of allocating scarce resources when the patient is old and ill. What treatments are used for the advanced-dementia patient with respiratory difficulty? Or for the aged cancer patient whose system might not well tolerate chemotherapy? The questions were virtually incomprehensible to the attending physicians, though their education as compared with U.S. training relies far less on new technology and far more on comfort care and hope and faith.

Those Cuba-based physicians might ask: Why treat for so little gain, and so speculatively. The view they might express is that the society, through the judgment of the professional, decides when care that *might* have therapeutic effect is nevertheless considered futile because the effect does not warrant the investment of professional time and skill, the allocation of a hospital bed, equipment, and drugs. This view is common worldwide, in large part because health care providers are more likely to be charged with such decision making than are professionals in the United States, where informed consent and, increasingly, informed demand for advertised drugs and hot media-image procedures shape the landscape of illness and its treatment.

While many would fight for ongoing care, others fear it—especially those who are seriously ill in the technologically wondrous U.S. health care system. They may reasonably fear being subject to tenacious “care pushers,” who view the patient's refusal of recommended treatment, albeit invasive, exhausting, and limited in effect, as a sign of unreason.

Thus, this is for many a crusade for rights on two fronts: the right to care on the one hand, and

the right to die on the other. In adopting health care policy, society should not consider one without the other.

The law has developed more in defining choices about dying, as outlined by our excellent authors, Jaeger and McKhann. In *Bouvia v. Superior Court*,¹ the California court considered the limits of a competent young woman's right to refuse nutrition while receiving other care in a hospital at public expense. The court found her choice to be a legitimate aspect of her autonomy. In *In re Quinlan*² and *Cruzan v. Director, Missouri Dep't of Health*,³ the Supreme Court clarified the right of the incompetent patient to have another refuse treatment based on the patient's preferences as expressed when competent. In *Brophy v. New England Sinai Hospital, Inc.*,⁴ and its progeny, the courts have confirmed that artificial nutrition and hydration are no different in kind from any other treatment that can be refused on behalf of an incompetent patient.

Forty-seven states and the District of Columbia have authorized the use of living wills, which provide the most authoritative evidence of the patient's wishes. The remaining three allow the designation of health care agents to make those decisions. Thirty-four explicitly permit patients to refuse artificial nutrition and hydration in their advance directives.

The focus has moved to the means to die. Few patients can bear the mayhem of using a gun. If family members help with the suicide by gun, they must live with their experience of the loved one's violent death and the high risk of criminal prosecution.⁵ The preferred means of death is drugs, but many have found that identifying, collecting, and utilizing the right amounts of the right drugs is a risky venture, too. A patient who regularly takes painkillers builds a tolerance to their potentially lethal effects. And, the patient's system may no longer metabolize drugs well enough to create the desired effect.⁶ Some drugs have rarely considered effects that counteract lethal metabolic action.

Yet, injected drugs generally are harder to obtain and raise questions about reasons for prescribing and purchasing where assisted suicide is illegal. In Oregon, the only state that authorizes prescriptions intended to cause death, lethal injections are prohibited.

The barriers to causing a quiet death have generated frightening, heart-wrenching stories of the

bedside watch, when the maximum effects of the drug begin to pass, the patient still lives, and the anguished watchers must decide whether to proceed to cause a death or definitively turn back by seeking emergency help. The likelihood of this terrible pass has become sufficiently common that a plastic bag is widely recommended among supplies for every such watch. In these circumstances, the plastic bag and the means to secure it over the patient's head represent a desperate act. Yet worse, patients, however close to death, may fight the bag, the plastic on the face, the physical obstruction to inhaling. The helper asks: Did he or she decide not to do it?

The market works, and the humor is dark. A Canadian company has devised a plastic tent for the upper body that slowly decreases the amount of available oxygen without collapsing and physically interfering with inhaling. You can read while you wait!

Advocates for assisted dying have turned their hopes to physicians' control over potentially death-causing drugs. In Oregon, physicians are authorized to write prescriptions at the written request of a terminal patient to provide drugs that will end life.⁷

Yet, the ethical implications and practical results of such a path should cause everyone to pause. The physician whose goal has been the life and best obtainable health of a patient becomes the source of the lethal means. Further, the medical curriculum must change to encompass knowledge to make the physician reliably effective in treatment of the complaint of ongoing life.⁸ Even research agendas must expand. There are, after all, no clinical trials on the effectiveness and side effects of drugs used to cause human death. All assisted suicide prescriptions are therefore an "off-label" use of the drug, untested by the means we test other drugs.

In the courts, the eloquent endorsement of assisted suicide by the Ninth Circuit *en banc* in *Compassion in Dying v. Washington*⁹ and rulings in sister circuits were superseded by a unanimous rejection by the Supreme Court in *Vacco v. Quill*¹⁰ and *Washington v. Glucksberg*,¹¹ which distinguished between refusing life-prolonging treatment and choosing assisted death, even for those who are deemed to be terminally ill.

Who can choose care and who can choose when to die? Patients who believe that others—from

other backgrounds or more advantages—are more likely to be accorded choices in care are likely to oppose assisted dying. People with disabilities and their advocates see it as another opportunity to undervalue their quality of life. Poor members of minority groups fear that life-sustaining treatment will be allocated by the same mechanism as most U.S. health services, according to the ability to pay.¹² The experience of the Dutch, who authorize assisted death upon repeated requests from the patient by declining to prosecute participating physicians, suggests that the slope really is slippery; incompetent patients have received their doctors' "help" to die.

Many careful philosophers are divided on the wisdom of assisted dying.¹³ The Catholic Church, which actively opposed the Oregon initiative, also speaks with sensitivity and intellectual energy to the issues of terminal patients, their pain, and their hopelessness.¹⁴

Prospective rules, however, are hard to come by. Typical of movements on behalf of individual rights, the momentum comes not from advocates for the aged but from those dying untimely, of AIDs or other scourges primarily affecting younger people.¹⁵ The extension of their vigorous advocacy model of "independent choice = extreme result" to the circumstances of many older, chronically disabled and frail might be a very poor fit.¹⁶

A good result of the political movement for assisted dying is improvement in care of those who are ill and in pain.¹⁷ Medical societies, however well-meaning, have been instrumental in impeding the development of effective treatment because of the risk of patient impairment and death. The apparent intransigence of the medical culture in some states may logically be linked to an American preoccupation with stoic toughness, fear of liability, and the dearth of hard medical information about the appropriate use of barbiturates and other strong drugs as treatment for pain.¹⁸ Many physicians have recognized the failure of prevailing care and sought to improve upon it. Yet, much still needs to be done in terms of knowledge and practice.

The question of payment for care of terminally ill patients continues its politically motivated roller-coaster ride.¹⁹ Generous Medicare hospice benefits are under investigation for services to patients who do not qualify for hospice.²⁰ Facilities seeking extended benefits for assisted-living and nursing

home patients in some short-term crisis are curtailed from freely invoking hospice care, and letting the chips fall for the patient who has only two hospice intervals in a lifetime (plus an extension of the second until death). A consortium of influential foundations endorses the adoption of a Medicare billing code for hospital-based palliative care, expanding the program's focus on acute care and treatment.

Conclusion

The issues of dying and choice are increasingly complicated. When? Where? What help? Who pays? The legal and social model of the good death is in a period of dynamic evolution. *Elder's Advisor* welcomes the thoughtful comments of readers on the experiences of their clients and their own experiences and approaches to the issues of dying and choice.

We hope to prepare a reader forum on your comments. Please send e-mail to elderlaw@marquette.edu or write to *Elder's Advisor*, P.O. Box 1881, Milwaukee, WI 53201.

Endnotes

1. *Bouvia v. Superior Court*, 179 Cal. App. 3d 1127 (1986).
2. *In re Quinlan*, 355 A.2d 647 (N.J. 1976).
3. *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261 (1990).
4. *Brophy v. New England Sinai Hospital, Inc.*, 497 N.E.2d 626 (Mass. 1986).
5. *See State v. Gilbert*, 487 So. 2d 1185 (Fla. Dist. Ct. App. 1986).
6. *See, e.g.*, Barbara Insley Crouch, *Toxicological Issues with Drugs Used to End Life*; and Stephen Jamison, *When Drugs Fail: Assisted Deaths and Not-So-Lethal Drugs*, both from the Haworth Document Delivery Service, The Haworth Press, Inc., (N.Y. 1996) (originally printed by the Pharmaceutical Products Press).
7. In 1997, over 60 percent of Oregon voters rebuffed an effort to repeal the nation's first assisted suicide law, passed in 1994 with a vote of 50 percent.

8. See J. Cameron Muir, Lisa M. Krammer, & Charles F. von Gunten, *Training Physicians in Palliative Care*, GENERATIONS, Spring 1999, at 91.
9. 79 F.3d 790 (1996) (holding that assisted suicide, like abortion, is an intimate personal choice protected by the Constitution).
10. 521 U.S. 793 (1997).
11. 521 U.S. 702 (1997).
12. The fear of being cut off from care is not unique to the United States, however. When the Northern Territory of Australia authorized voluntary euthanasia in 1995, aborigines and their advocates protested and sought repeal. See S. Karene Witcher, *Northern Territory, A Place Apart, Learns Price of Euthanasia*, WALL STREET J., Jan. 22, 1997, at A1.
13. See, e.g., Ezekial Emanuel, *Whose Right to Die?*, ATLANTIC MONTHLY, March 1997, at 73 (asserting that advocacy for physician-assisted suicide is based on a number of prevailing myths about medical care, including but not limited to terminal patients' desire for death and the importance of pain in a patient's decision to die).
14. See M. Garey Eakes & Alex L. Moschella, *Two Cases that Never Should Have Happened: The Misuse of Religious Doctrine in Cases Concerning the Withdrawal of Artificial Life Prolonging Medical Treatment*, NAELA Q., Summer 1999, at 4, 6.
15. See Sheryl Gal Stolberg, *Considering the Unthinkable: Protocol for Assisted Suicide*, N.Y. TIMES, June 11, 1997, at A1.
16. See Timothy J. Keay, *Palliative Care in the Nursing Home*, GENERATIONS, Spring 1999, at 96.
17. See Anne M. Wilkinson & Joanne Lynn, *Death Isn't What It Used to Be: A Proposal for MediCaring: An Innovative Model of Care for the Last Phase of Life*, NAELA Q., Summer 1999, at 12.
18. See, e.g., Hoover v. HCFA, 676 So. 2d 1380 (Fla. Dist. Ct. App. 1996) (reversing physician's license restriction and probation for prescription of painkillers for seven patients with intractable pain). See also Alexandra Dylan Lowe, *Facing the Final Exit*, A.B.A. J., Sept. 1997, at 48.
19. See Bruce C. Vladeck, *The Problem Isn't Payment: Medicare and the Reform of End-of-Life Care*, GENERATIONS, Spring 1999, at 52.
20. A patient must have a prognosis determined by the treating physician with the expectation of death within six months.