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ASKING TOO MUCH: AUTONOMY AND RESPONSIBILITY AT THE END OF LIFE¹

*Lois Shepherd*²

Are there no limits to patient autonomy? Sometimes it appears that way, especially when the issue is one of patient choices regarding life-sustaining treatment.

I want to examine four circumstances where there should be some limits to honoring a patient's wishes. The limits I want to discuss are not operational; they are moral. In other words, the problem is not that we cannot honor the patient's wishes because we are not sure what they are, such as might be the case in a dispute among family members, each of which recounts a different conversation with the patient. Other examples would be when the living will, as is almost always the case, is too vague to apply or subject to contrary interpretations or when a person who is attempting to speak for himself about his wishes is depressed, delusional, or has his capacity questioned on some other grounds. I want to remove, for the sake of argument, any of these operational obstacles to honoring the patient's wishes. In those cases, if we fail to honor the patient's wishes, it is because we conclude that they are not adequately understood or not legally tidy.

Instead, I am interested in thinking about situations in which *we should not honor the patient's wishes no matter how clear they are*. Here are four such cases worth considering. After discussing them, I will consider what they have in common.

SUICIDE

A recent incident in England has been touted as the first instance in which a person used a living will to commit suicide.³ Kerrie Woollorton poisoned herself, called an ambulance, and upon arrival at the hospital handed the

1. This article was discussed by the author at *The Journal of Contemporary Health Law and Policy's* November 11, 2009, Symposium, "The Current State of Bioethics in America," at The Catholic University of America, Columbus School of Law.

2. Professor of Law and Associate Professor of Biomedical Ethics, University of Virginia. I would like to thank Paul Shepherd, Aline Kalbian, and the editors of *The Journal of Contemporary Health Law and Policy* for their helpful comments on prior drafts of this essay.

3. *Coroner: Doctors Had to Let Woman Die*, AOL NEWS, Oct. 1, 2009, <http://news.aol.com/article/coroner-says-doctors-had-to-let-kerrie/697884> (last visited Oct. 9, 2009).

doctors a letter that refused treatment in the event of her suicide attempt. It was a perfectly unambiguous declaration of her wishes. The hospital complied, later explaining that its hands were tied; hospital personnel would have been violating her rights if they provided her with medical treatment, even though they believed it could have saved her life. According to news reports, “Doctors said they feared they would be charged with assault if they treated her because she had made her wishes clear. . . .”⁴ The coroner agreed that the hospital had acted appropriately.⁵

Living wills were never intended to be used as a legally binding measure by which individuals could refuse or reject rescue during a suicide attempt. Instead, they were developed as a means to allow patients to reject advanced medical technologies used to prolong the dying process.

It is true that in debates about the extent to which patient choice in such matters should be respected, opponents of liberal interpretations of individual choice have often compared a physician’s compliance with wishes to withhold or withdraw life-sustaining treatment to assisting in a patient’s suicide. But doctors, nurses, administrators, ethicists, judges, and lawyers involved in these matters now generally accept that respecting patients’ wishes to refuse treatment in the case of terminal illness or permanent vegetative state does not amount to assisting in their suicide. The terminally ill do not have the option to continue living; the permanently vegetative do not have the option of returning to sentient life. Even in other cases in which treatment is refused, our society has generally reached a consensus that it is ethical and legal to honor the refusal, and perhaps unethical and violative of an individual’s legal rights to fail to honor it. Examples of such cases may be when treatment is rejected because of religious beliefs or because the individual reasonably, on the basis of his or her own value system, believes that the burdens of the treatment outweigh its benefits.

In all of these cases our society does not typically think of the patients as committing suicide. Many professionals have even, at least partially, moved in the direction of recognizing that those who seek a physician’s prescription

4. *Id.*

5. *Id.* It is not clear to me why it mattered that her wishes were put in writing. If she arrived at the hospital with capacity and refused treatment, why would the same result not have been obtained? Moreover, a living will, at least in the United States, is not generally understood to apply, by itself, in an emergent situation. Prior to honoring a patient’s living will and signing an appropriate order—a Do Not Resuscitate (DNR) order, for example—health care providers must have the opportunity to determine whether the living will is valid, has not been revoked, and applies to the situation at hand. This takes some time and exercise of judgment, in contrast to following another doctor’s already executed order (again, like a DNR), that *can* be followed in emergent situations.

to hasten death, such as under Oregon's or Washington's statutes permitting this aid, are not really committing suicide. As terminally ill individuals, they do not have the option of living much longer; therefore, their motivation is not to substantially foreshorten their lives but to provide for a more peaceful and dignified death.⁶

But the English incident *was* a case of suicide as we typically understand it—as a tragic, often impulsive, and violent act by which a person shortens his or her own life due to problems with depression, psychological distress, or another mental health condition that can be treated or managed. The news reports of this particular case describe this kind of situation—the woman was twenty-six years old, swallowed anti-freeze, and had been depressed because of her inability to have a child.⁷

Kerrie Woollorton not only committed suicide and refused rescue, she affirmatively sought the assistance of health care providers to make the process more comfortable. Her “living will” stated that while she did not want life-sustaining treatment, she did “want to be comfortable as nobody wants to die alone and scared.”⁸

A person's protests cannot stop police or firefighters or other nearby individuals from trying to rescue her from a suicide attempt of this kind. Health care providers should not be expected to act any differently.

FUTILE TREATMENT

In 2008 the parents of Motl Brody, a twelve-year old Hasidic Jewish boy, sought a court ruling that a Washington, D.C. hospital continue to provide him with ventilator support and other medical treatment.⁹ The child had previously been declared dead under standards for determining brain death, but his parents protested, stating that this determination violated their

6. See generally Kathryn L. Tucker & Fred B. Steele, *Patient Choice at the End of Life*, 28 J. LEGAL MED. 305 (2007). The American Public Health Association and the American Academy of Hospice and Palliative Medicine have both adopted policies to avoid describing these practices as “assisted suicide.” *Id.* at 325.

7. *Coroner: Doctors Had to Let Woman Die*, *supra* note 3.

8. *Id.*

9. N.C. Aizenman & Michael Alison Chandler, *N.Y. Boy on Life Support in D.C. Dies*, WASH. POST, Nov. 17, 2008, at B01, available at <http://www.washingtonpost.com/wp-dyn/content/story/2008/11/17/ST2008111700764.html>.

family's religious beliefs.¹⁰ Prior to the court's ruling, the child's heart stopped beating, allowing medical professionals to declare him dead on the basis of lack of cardio-respiratory function. Cases such as this one—not common, but not extraordinary either—are commonly understood as involving a dispute about doctors' and hospitals' obligations to provide futile treatment.

After years of litigation in which patients were insisting on a right to refuse treatment against doctors' and hospitals' insistence on providing it, we have increasingly seen the opposite phenomenon: patients (or rather, their families or surrogates on the basis of patient wishes) insisting on treatment against the doctors' and hospitals' refusal to provide it.

The debate about what constitutes futile medical treatment—and who is allowed to determine if it is futile—is long-standing and far from over. For example, is it appropriate to consider quality of life assessments or a calculation of financial costs, so that a life-extending treatment may be considered futile because the life preserved is of such poor quality or the treatment is extremely costly? Do physicians and/or ethics committees get to define futility unilaterally, on an ad hoc basis, or should courts be involved?

The aim of this paper is not to enter this intricate yet worthwhile debate about appropriate understandings of futility, but instead to identify limits to patient autonomy about which we should be able to achieve a fairly wide consensus. For this reason, I want to be careful to define futility here in a very narrow sense, although one could argue for a broader definition. There are two situations about which there appears to be an ethical and legal consensus that life-sustaining treatment is futile, and that providers should not be required to provide it: when an individual is brain dead, and when a proposed treatment simply would not work.¹¹ Neither of these two instances involves moral judgments about acceptable success rates for a particular procedure in order for it to be worth undergoing, or about acceptable

10. Brain death, under the D.C. Code, could be determined upon the "irreversible cessation of all functions of the entire brain, including the brain stem. . . ." D.C. CODE § 7-601 (2008). All fifty states recognize that death may be determined using neurological criteria; alternatively, death may be determined on the basis of the irreversible cessation of cardio-pulmonary function. *See generally* Janet L. Dolgin & Lois Shepherd, *BIOETHICS AND THE LAW* 840-42 (Aspen Pubs. 2d ed. 2009). New Jersey and New York provide religious exceptions to the general rule permitting a determination of death on the basis of neurological criteria. *See* N.J. STAT. ANN. § 26:6A-5 (2007); N.Y. COMP. CODES & REGS. tit. 10 Health(c) § 400.16(e)(3) (2007).

11. Thaddeus M. Pope, *Medical Futility Statutes: No Safe Harbor to Unilaterally Refuse Life-Sustaining Treatment*, 75 TENN. L. REV. 1, 26-28 (2007).

outcomes in terms of life quality. Instead, they reflect the idea that health care providers should not be required to work violence on a body for no conceivable good end.

HAND FEEDING

A recent article in the *American Journal of Bioethics* by Thomas I. Cochrane argues that individuals should be able, through advance directives or through surrogates making decisions for them, to refuse hand-feeding in the event of later incapacity.¹² A living will that specifies wishes of this kind might resemble that of Dr. William A. Hensel, which was published over a decade ago in the *Journal of the American Medical Association*.¹³ Hensel wrote that if he ever suffered “irreversible central nervous system damage to the point that [he did] not recognize [his] family,” he would choose physician-assisted death, if it were legal. He continued, “If not, do not place food or water in my mouth. Instead, place it on my bed table. If I feed myself, I live another day; if I do not, I will die and that is fine.”¹⁴

Refusing future hand-feeding may seem like a natural extension of the idea that individuals who retain decision-making capacity can choose in the present to forego food or drink so that they may control the circumstances of their deaths. Philosopher Bernard Gert and medical doctors James Bernat and Peter Mogielnicki argued over fifteen years ago that competent chronically and terminally ill patients could take control of their dying process through patient refusal of hydration and nutrition without having to “requir[e] physicians to reject the taboos on PAS [physician-assisted suicide] and VAE [voluntary active euthanasia] that have existed for millennia.”¹⁵ More recently, Stanley Terman, together with the organization Caring Advocates, has worked to educate patients about this option.¹⁶

There has also been recent, broad acknowledgement that, for many people, the natural process of dying will suppress appetite and make the

12. See Thomas I. Cochrane, *Unnecessary Time Pressures in Refusal of Life-Sustaining Therapies: Fear of Missing the Opportunity to Die*, 9 *AJOB* 47 (2009).

13. See generally William A. Hensel, *My Living Will*, 275 *JAMA* 588 (1996).

14. *Id.*

15. James L. Bernat et al., *Patient Refusal of Hydration and Nutrition*, 153 *ARCHIVES OF INTERNAL MED.* 2723, 2723 (1993).

16. Stanley A. Terman, *THE BEST WAY TO SAY GOODBYE: A LEGAL PEACEFUL CHOICE AT THE END OF LIFE* 280-84 (Life Transitions Pubs. 2007).

intake of nutrition burdensome. In such cases, force feeding (whether through a feeding tube or by hand) seems inappropriate and not truly caring.¹⁷

But Cochrane's argument must be distinguished from these quite reasonable ways of respecting patients' wishes while still caring for them, and instead should be understood as the radical suggestion that it is. He is suggesting that patients who lack present decision-making capacity not be offered food, food that they might willingly and happily accept. Hensel's living will, moving and poetic as it is, might be read to mean as much. And if one might ask not to be offered food by mouth in some future physical or mental state, what is to prevent one from forbidding a tray of food being left at the bedside?

Cochrane's motivation for suggesting that individuals, or their surrogates, might refuse future hand-feeding is rather laudable. He is trying to find a way out of a practically common but theoretically underexplored dilemma: how a surrogate should make a decision for or against a therapy that is life-saving, but carries a high risk of leaving the patient in a condition the surrogate believes the patient would deem intolerable—with severe cognitive deficits, for example. If the therapy is extremely successful, the patient will enjoy substantial time in a condition not much altered from his original condition. If the outcome is less than ideal (e.g., the therapy is not successful), the patient may be saved, but severely altered and left in a condition in which the surrogate believes the patient would wish to refuse further life-sustaining treatment. The only problem is that sometimes there is no life-sustaining treatment as we commonly understand it—ventilator, feeding tube, dialysis—to refuse. Instead, the individual can breathe, eat, and so on without medical assistance. The “window” in which to refuse treatment has closed. Cochrane wants to keep that window open longer, to allow the surrogate to give the suggested medical procedure a try in the hope of a positive outcome. If the outcome is the one dreaded, then he wants to be able to undo the decision in effect, to get to the same outcome (death) that the surrogate would have chosen if he or she had, as if by crystal ball, known the way things would turn out.

Laudable motivation aside, how can doctors and nurses, or anyone, be asked to refrain from providing food and water to individuals who presently want it, who would experience the provision of food and water as pleasurable and as a form of care, and who would die without it? I do not think they can be asked to do this. Hensel himself recognizes how much he

17. Lois Shepherd, *IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO* 148-53 (Univ. of N.C. Press 2009).

may be asking of others, pleading for them to make “difficult choices” for which God may grant them courage.¹⁸

NON-BURDENSOME TREATMENT FOR PEOPLE WHO BECOME PROFOUNDLY DISABLED

The fourth situation in which I think limits on patient autonomy should be recognized is likely to be the most controversial, and I confess I find it problematic myself. It is illustrated by the 1992 Michigan case of Michael Martin.¹⁹ In 1987, Martin, a man in his early thirties, suffered devastating injuries in a vehicular accident. He stabilized into a state of severe physical and mental disability, where he depended on nursing care, a colostomy, and a feeding tube to survive. He was conscious, of that there was no doubt, although there was conflicting evidence on the degree to which he could interact with other people. In a hearing that would take place several years after the accident, a number of witnesses, including both lay and medical expert witnesses, would testify to his ability to nod his head yes or no appropriately in answer to simple questions and to follow simple commands with voluntary movements. The trial judge confirmed this assessment by personally visiting with Mr. Martin. The medical experts agreed that it was unlikely that Mr. Martin’s condition would improve.

Five years after the accident, his wife, who was also his legal guardian, sought court approval to remove his feeding tube and allow him to die. Mary Martin did not pursue the removal of her husband’s feeding tube on grounds that it was burdensome or that it would be in his best interests to remove it. According to a later court opinion, there was no evidence this was the case.²⁰ Instead, she sought the removal of the feeding tube on the basis of Michael Martin’s autonomy.

Mary Martin provided moving and persuasive testimony about conversations she and Michael Martin had had prior to his accident. These conversations centered around his not wanting to live in a state of dependency. While other witnesses testified that Michael, pre-accident, had said he would never want to live as a “vegetable,”²¹ Mary Martin testified

18. Hensel, *supra* note 13, at 588.

19. See generally *In re Martin*, 538 N.W.2d 399 (Mich. 1995). See also *Conservatorship of Wendland*, 28 P.3d 151 (Cal. 2001) (refusing to allow termination of artificial nutrition and hydration for severely disabled or minimally conscious patient).

20. *In re Martin*, 538 N.W.2d at 409.

21. *Id.* at 415 (Levin, J., dissenting).

that her husband's statements were broad enough to include other debilitating conditions. According to the Michigan Supreme Court, "She claimed that he was always bothered by, and intolerant of, people who were disabled or dependent on others and often stated that he would rather die than be dependent on people and machines."²² She supplied evidence of numerous similar conversations in which Michael indicated that if he "could not be the same person," then he would "not want to live that way."²³ Memorably, she testified that he had once told her, "Mary, promise me you wouldn't let me live like that if I can't be the person I am right now, because if you do, believe me I'll haunt you every day of your life."²⁴

Despite the quite persuasive evidence of Michael Martin's prior wishes, the Michigan Supreme Court concluded that the evidence did not meet the standard adopted in the case for such situations, which required clear and convincing evidence of pre-injury statements to refuse treatment under the specific circumstances that existed.²⁵

I am less convinced by this rationale than by the argument that there are limits to patient autonomy. The problem presented by this case would not be solved by the availability of additional, clearer, and better documented statements made by Michael Martin prior to his accident about the kind of life he would find intolerable. The fact was that his life was not intolerable. Rebecca Dresser argues that in cases such as this one, where pre-disability sentiments conflict with post-disability interests, the post-disability interests should govern.²⁶ Her willingness to impose limits on autonomy is justified by her concern for caring for the present, vulnerable individual. She has written, "If a patient can no longer appreciate the values that motivated the precommitment choice [i.e., the preferences set out in the advance directive], treatment decisions should take into account what now matters to the patient."²⁷

22. *Id.* at 402.

23. *Id.* at 412.

24. *In re Martin*, 538 N.W.2d at 412.

25. *Id.* at 413.

26. See Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823 (2003).

27. *Id.* at 1840 (alteration in original).

To be clear, the type of situation that I am concerned with is when a patient's prior wishes indicate a refusal of life-sustaining treatment in a condition in which the patient is conscious, non-terminal, has some meaningful interaction with others, and the benefits of treatment and continued life outweigh their burdens. The concept of "meaningful interaction" is left open; it is not important for the argument that its exact meaning be specified.

Much of the law—both cases and statutes—that requires us to honor a patient's prior preferences to refuse life-sustaining treatment has been developed in order to respond to situations in which the individual in question is terminally ill or in a permanent vegetative state (or is permanently unconsciousness).²⁸ Living will statutes, for example, often permit a person to specify his or her wishes regarding life-sustaining treatment in these two situations.²⁹ Similarly, many state statutes grant immunity from liability for a surrogate's decision to remove life-sustaining treatment in these two situations, as long as the guidelines in the statute are followed.³⁰

We have little law, however, to guide us in the situation when someone is dependent upon life-sustaining treatment, but is living in a stable, profoundly disabled state that they had earlier indicated they would wish to avoid by refusing treatment.

Once Michael Martin stabilized into a condition of profound disability, with potentially many years of life ahead, he came to resemble a person who had lived with severe cognitive limitations from birth or a young age. We do not generally allow family members or others to refuse non-burdensome life-sustaining treatments (such as antibiotics for pneumonia or another infection) in these situations. To do so would be an unacceptable discrimination against persons on the basis of their disabilities.

This is a substantial reason why removing Michael Martin's feeding tube on the basis of his autonomy does not seem right. On the surface, honoring

28. Shepherd, *supra* note 17, at 135; *see, e.g.*, In the Matter of Quinlan, 355 A.2d 647 (N.J. 1976) (permanent vegetative state); In the Matter of Conroy, 486 A.2d 1209 (N.J. 1989) (terminal condition); Cruzan v. Director, Missouri Dep't. of Health, 497 U.S. 261 (1990) (permanent vegetative state).

29. *See, e.g.*, OHIO REV. CODE § 2133.02 (2009).

30. David Orentlicher, Mary Ann Bobinski & Mark Hall, *Bioethics and Public Health Law* 283 (Aspen Pubs. 2d ed. 2008); Dan Larriviere & Richard Bonnie, *Terminating Artificial Nutrition and Hydration in Persistent Vegetative State Patients: Current and Proposed State Laws*, 66 NEUROLOGY 1624 (2006); *see, e.g.*, N.C. GEN. STAT. § 90-322 (2007); FLA. STAT. §§ 765.109, 765.305 (2004) (also including "end-stage condition").

his previous wishes looks much like the good we do when we honor a terminally ill person's wishes. But we should take a careful look at those statements that Mary reported Martin as having made prior to the accident. Can Michael Martin's intolerance of people with disabilities and who are dependent bind us to treat him in the same way? If removing the feeding tube from Michael Martin in the *absence* of his pre-injury statements does not feel right, how does the *presence* of those statements—which place his (and society's) discriminatory attitudes in bold relief—make it better?

REASONABLE LIMITS

What *right* does Michael Martin have to haunt Mary Martin for being unable to remove his feeding tube? Or William Hensel to ask his children to find the courage not to feed him by hand? None. Nor did Kerri Woollorton or the family of Motl Brody have a right to the responses they sought from doctors and hospitals. In each of the four situations presented, what is being asked of health care providers or surrogates or family—not to attempt rescue of another person from a blatant suicide attempt, to provide futile treatment that does nothing more than violence on a body, to refuse food and water to a person who may want it, and to ignore the needs of a vulnerable individual because of intolerant views of disability and dependency—is inherently unreasonable. These demands are unreasonable because they ask people to deny their basic impulses to treat others humanely for reasons that do not justify such a request.

Not only do individuals have no right to make such demands, they have a responsibility not to make them. When we discuss the law and ethics of end-of-life decision-making, we tend to talk about a patient's autonomy and others' responsibilities to respect that autonomy. Sometimes—though not often enough—we talk about other responsibilities that are owed to patients, like the duty to care for them, to respect their privacy, or to treat them with dignity. We do not, however, think enough about the responsibilities that patients owe to others when, capable and in relative health, they sit down to write a living will or talk with loved ones about wishes regarding life support. That future patient is each of us. In this role we tend to worry most about protecting our rights. But we have to be careful that in setting out our own wishes, we do not ask others to deny their own humane responsibilities. That is asking too much.