

On Killing Patients with Kindness: An Appeal for Caution

Alan J. Weisbard and Mark Siegler

Since the cases of Karen Quinlan in 1976 and Nancy Cruzan in 1990, there has been an increasing trend to let formerly competent but now incompetent patients die, especially if they are in long-term comas or have a chronic, debilitating condition.

In classic ethical theories, acts tend to be judged either by their motives or by their consequences. In this selection, Alan Weisbard and Mark Siegler ask us to be clear about the motives for "allowing" incompetent patients to die. Usually, justification for such a decision proceeds from the substituted judgment standard. This standard makes an assumption about what the patient would have decided, when competent, about what should be done to him if he later became incompetent. A different standard, best interests, stresses what is in the best interests now of the incompetent patient.

Do these standards reflect the reality of decision-making in such cases? Some legal commentators believe they do not, claiming they merely mask the family's desire for the financial and emotional ordeal to end. Some physicians agree, admitting that they feel relief when they no longer need to attend to such uncommunicative patients whose conditions can very rarely be improved.

Weisbard and Siegler warn that families and physicians may have mixed motives for wanting a quick death for such patients. They recommend that society and physicians give these patients the benefit of every doubt.

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The powerful rhetoric of "death with dignity" has gained much intellectual currency and increasing practical import in recent years.¹ Beginning as a plea for more humane and individualized treatment in the face of the sometimes cold and impersonal technological imperatives of modern medicine, this rhetoric brought needed attention to the plight of dying patients not wishing to "endure the unendurable."² It has prompted legal and clinical changes empowering such patients (and sometimes their representatives) to assert some control over the manner, if not the fact, of their dying. The "death with dignity" movement has now advanced to a new frontier: the termination or withdrawal of fluids and nutritional support.

The increasing acceptability in respected forums of proposals to permit avoidable deaths by dehydration or malnutrition—proposals which, a few years ago, would almost certainly have been repudiated by the medical community as medically objectionable, legally untenable, and morally unthinkable—is evidenced by a slew of recent contributions to the medical and bioethics literature,³ and by a sprinkling of court decisions.⁴ This new stream of emerging opinion, supporting the explicit ethical and legal legitimation of this practice, is typically couched in comforting language of caution and compassion, by persons of undoubted sincerity and good faith. But the underlying analysis is, we fear, unlikely to long remain within these cautious bounds.

Careful scrutiny suggests what is ultimately at stake in this controversy: that for an increasing number of incompetent patients, the benefits of continued life are perceived as insufficient to justify the burden and cost of care; that death is seen as the desired outcome; and—critically—that the role of the health care professional is to participate in bringing this outcome about. Fearful that this development bodes ill for patients, health care professionals, the patient-physician relationship, and other vital societal values, we feel compelled to speak out against the all-too-rapid acceptance of withdrawal of fluids or nutritional support as accepted or standard medical practice. While recognizing that particular health care professionals, for reasons of compassion and conscience and with full knowledge of the personal legal risks involved, may on occasion elect to discontinue fluids and nutritional support, we nonetheless believe that such actions should generally be proscribed, pending much fuller debate and discussion than has yet taken place.

QUALIFICATIONS

We do not intend to address here the deep philosophic issues posed by the moral status of the permanently unconscious. There is much philosophic dispute concerning whether the permanently unconscious are living persons who possess rights and interests, whether the obligation of care fully extends to such patients, and whether such patients should and eventually will be encompassed within a broadened understanding of brain death. The present authors take somewhat different views on these questions and present no joint

position here on the withdrawal of fluids and nutritional support from patients reliably diagnosed as permanently unconscious.

Nor is our principal concern with decisions by competent, adult, terminally ill patients who contemporaneously or through advance directives (living wills, durable powers of attorney, or carefully considered, reliably witnessed, oral statements) direct that their process of dying not be prolonged through such techniques as those required to maintain life-sustaining nourishment and hydration. We encourage fuller discussion of these issues among patients, families, and medical professionals at a time the patient is able to participate in an informed and thoughtful fashion. We caution only that patients should be made aware that some "artificial" techniques may be useful in making them more comfortable and in easing the dying process, and should not be rejected unthinkingly by those seeking a more "natural" death. Further, as the much publicized case of Elizabeth Bouvia⁵ reminds us, neither physicians nor health care institutions may be compelled to assist in, or to preside over, the suicides of patients, especially those who are not terminally ill.

Nor, finally, do we mean to be understood as necessarily advocating the use of that modality of providing hydration or nutritional support considered most likely to extend survival time maximally without regard to other relevant factors, including the intrusiveness of the technology to the patient in comparison with the plausible alternatives, or the nature and likelihood of serious side effects. Our position is intended as neither vitalist nor absolutist, except with regard to our insistence on providing sufficient assistance to preclude painful hunger or thirst and to avoid directly causing death (as perceived by health care professionals and the wider society) by failing to provide food and water minimally necessary to preclude death by starvation or dehydration.

CRITIQUE

Our focus, then, is primarily on the withdrawal of fluids and nutrition from patients possessing the capacity for consciousness who have not competently rejected such support. While concerns may seem premature in light of the qualifications and thoughtful discussions of both substantive and procedural safeguards expressed in several recent contributions to the literature,⁶ we remain troubled that the underlying analysis, once accepted by clinicians and courts, will not long be confined within the limits initially set forth.

What, then, is the underlying analysis, and why do we find it so potentially troubling? The argument rests on the dual propositions that, first, the provision of fluids and nutritional support by "artificial" means constitutes "medical interventions guided by considerations similar to those governing other treatment methods,"⁷ and that, second, judgments regarding the withdrawal of such interventions should be based on calculations of the "burdens and benefits" associated with the treatment (sometimes also referred to as

"proportionality"). These propositions are rooted in the work of the President's Commission for the Study of Ethical Problems in Medicine,⁸ were adopted by the California appellate court in the *Barber and Nejd*⁹ case, and play a central role in the analyses set forth by several recent commentators.¹⁰

We do not dispute that the "benefits and burdens" formulation is useful in a number of contexts and marks a clear analytic improvement over unconsidered references to "extraordinary measures" or "artificial means," terms which have introduced much unnecessary confusion and provide little real assistance in decisionmaking. What we find troublesome is the assertion that physicians, families, courts, or other third parties can properly conclude that the "burdens" of [providing] fluids and nutrition—a generally unconvincing catalogue of potential "complications" or "side effects"—outweigh the benefit, sustaining life. (We recognize that, in rare cases, the provision of fluids and, particularly, nutritional support may be medically futile or counterproductive in sustaining life, and we do not here recommend that such futile or counterproductive steps be mandated.)

Advocates of withdrawing fluids and nutritional support that are effective in, and necessary for, sustaining life justify their position by arguing that a speedy and painless death is in the patient's "best interests" (a claim with little foundation in existing law, which has traditionally viewed the preservation of life, at least for noncomatose patients, as a core component of "best interests"). While the argument is compassionately made, and may be persuasive in certain cases, it fails to acknowledge explicitly that its objective may be attained more swiftly, more directly, more honestly, through the administration of lethal injections. Homicide is, in this setting, the ultimate analgesic. But to the extent active euthanasia is rejected—we think wisely—by existing law and medical ethics, we believe a similar conclusion is generally mandated for withdrawal of fluids and nutrition, and for much the same reasons.

If active euthanasia has found little support thus far in either medical or legal circles, the reasons are not confined to an exclusive concern with prolonging the life of the patient. The courts have made clear that respirators and dialysis machines are not legally mandated in all cases of respiratory or renal failure, even where their withdrawal is thought likely to result in death. In this sense, the withdrawal of fluids and nutrition is subject to a similar analysis. But in another and—we believe—more powerful sense, the result is quite different, at least in terms of our society's moral perceptions and self-image.

Withdrawal of respirators and dialysis machines can be seen, and *is* seen and emotionally understood, as the removal of artificial impediments to "letting nature take its course." Death can be understood in such cases as the natural result of the disease process. In cases where death may indeed be the desired (and ultimately unavoidable) outcome, it can be allowed to come without imposing a heavy burden of guilt and moral responsibility on physicians or family members for acting to bring it about, and without challenging important social barriers against killing.¹¹ And sometimes, as in the case of Karen Quinlan, nature can surprise us: the patient can survive despite some experts' predictions to the contrary.

The case of withdrawing fluids and nutritional supports is different in critical respects. Although the techniques for providing such supports may be medical, and thus logically associated with other medical interventions, the underlying obligations of providing food and drink to those who hunger or thirst transcend the medical context, summoning up deep human responses of caring, of nurturing, of human connectedness, and of human community. Social scientists and humanists have only begun to explore the deeper social meanings and ramifications of depriving patients of "food and water," of permitting deaths from starvation or dehydration. While sophisticated observers may argue that the image of "starvation" or "thirst" may be misleading in the cases of some patients, particularly the unconscious, or that limited nutritional intake may slow the progress of a cancer, it is far from clear that such explanations will be compelling to the public, or even, perhaps, to many members of the health professions, particularly if the practice of withholding fluids and nutritional supports takes root and is applied to an ever broader class of patients.

Further, unlike withdrawal of respirators or dialysis machines, withdrawal of fluids and nutrition cannot so readily be seen as "letting nature take its course." Dehydration or lack of nutrition become[s] the direct cause of death for which moral responsibility cannot be avoided. The psychological and social ramifications of bringing death about in this fashion will, in our view, be difficult or impossible to distinguish from those accompanying lethal injections or other modes of active euthanasia. There will be no surprises: withdrawal of all food and water from helpless patients must necessarily result in their deaths.

Given the demographic trends in our society—the dramatically increasing pool of those characterized as the "superannuated, chronically ill, physically marginal elderly," those Daniel Callahan has labeled "the biologically tenacious"—denial of fluids and nutrition may well become "the nontreatment of choice."¹² The process is tellingly illustrated by two recent court cases. Clarence Herbert, the patient whose death gave rise to the homicide prosecution in *Barber*, was initially understood, at least by his wife, to be brain dead. In fact, Herbert was comatose but not brain dead, although the quickness of diagnosis and the subsequent nontreatment decisions led to some troubling questions of the adequacy of both diagnosis and prognosis. The sequence of decisions is instructive. First the respirator was removed. When Herbert failed to succumb as predicted, intravenous feeding was discontinued. Only then—a week later—did Herbert "comply" with the course desired, and expire.¹³

Similarly, in the *Conroy* case, the patient's nephew had previously refused to authorize surgery for his aunt's gangrene.¹⁴ When that condition proved not to be terminal, the nephew apparently expressed his disinclination to authorize other life-extending measures.¹⁵ Only when this decision failed to bring about the desired result—death—did the nephew and physicians contemplate the next step: termination of fluids and nutrition supplied by nasogastric tube.

Both these cases illustrate a troubling dynamic, one much like a self-fulfilling prophecy. Once a determination has been reached—perhaps for understandable and humanitarian reasons—that death is the desired outcome, decisionmakers become increasingly less troubled by the choice of means to be

employed to achieve that outcome. The line between "allowing to die" and "actively killing" can be elusive, and we are skeptical that any logical or psychological distinction between "allowing to die" by starvation and actively killing, as by lethal injection, will prove viable. If we as a society are to retain the prohibition against actively killing, the admittedly wavering line demarcating permissible "allowing to die" must exclude death by avoidable starvation. We frankly acknowledge that our concern here extends beyond a solicitude for the outcome for the patient to include our fears for the impact of decisions and actions on family members, health care professionals, and societal values, which will survive the death of the patient. If these separate and additional concerns are to be discounted, we are hard-pressed to understand the remaining justifications for prohibition of active euthanasia in the perceived "best interests" of the incompetent patient.

We have witnessed too much history to disregard how easily society devalues the lives of the "unproductive"—the retarded, the disabled, the senile, the institutionalized, the elderly—of those who in another time and place were referred to as "useless eaters."¹⁶ The confluence of the emerging stream of medical and ethical opinion favoring legitimation of withholding fluids and nutrition with the torrent of public and governmental concern over the costs of medical care (and the looming imposition of cost-containment strategies which may well impose significant financial penalties on the prolonged care of the impaired elderly) powerfully reinforces our discomfort. In the current environment, it may well prove convenient—and all too easy—to move from recognition of an individual's "right to die" (to us, an unfortunate rephrasing of the legally more limited right to refuse medical treatment) to a climate enforcing a socially obligatory "duty to die," preferably quickly and cheaply.¹⁷ The recent suggestions that all new applicants for Medicare be provided copies of "living wills" or similar documents illustrate how this process may unfold.¹⁸ Our concern here is not with the encouragement of patient self-determination regarding medical care, including decisions about dying, which we vigorously support, but rather with the incorporation of such strategies *as a method of cost control*.

Finally, we would urge that efforts in this field be rechanneled from demonstrating that some patients' quality of life is too poor, too "meaningless," to justify the burdens of continued life, toward the challenge of finding better ways to improve the comfort and quality of life of such patients. In particular, we hope the current debate will stimulate further discussion of the merits of different modalities of providing fluids and nutrition. For example, with the development of endoscopic placement techniques for gastrostomy tubes, this superficially more invasive "surgical" procedure may prove safer and more comfortable for many patients than the nonsurgical insertion of nasogastric tubes, which are sometimes a source of continuing discomfort for patients and are more likely to elicit the use of restraints to prevent the deliberate or accidental removal of the tubes. More attention must be paid to the clinical, institutional, economic, and legal implications of these and other alternatives.

CONCLUSION

When coupled with powerful economic forces and with the disturbing tendency, both among professionals and in the broader society, to disvalue the lives of the "unproductive," the compassionate call for withdrawing or withholding fluids and nutrition in a few, selected cases bears the seeds of great potential abuse. Little is to be lost, and much potentially gained, by slowing down the process of legitimation, taking stock of where we have come and where we are going, improving our methods of comforting and caring for the dying without necessarily hurrying to dispatch them on their way, and deferring any premature legal, ethical, or professional approval and legitimation of this new course. The movement for "death with dignity" arose in response to deficiencies on the caring side of medicine; it would be sadly ironic if this latest manifestation served to undercut the image of physician as caring and nurturing servant and to undermine deep human values of caring and nurturance throughout society.

NOTES

1. Portions of this paper appeared, in a somewhat different form, in Mark Siegler and Alan J. Weisbard, "Against the Emerging Stream: Should Fluids and Nutritional Support Be Discontinued?" *Arch. Intern. Med.* 145:129-132 (January 1985).
2. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922, 97 S. Ct. 319, 50 L. Ed. 2d 289 (1976).
3. See, e.g., David W. Meyers, "Legal Aspects of Withdrawing Nourishment from an Incurably Ill Patient," *Arch. Intern. Med.* 145:125-128 (January 1985); Rebecca S. Dresser and Eugene V. Boisaubin, Jr., "Ethics, Law and Nutritional Support," *Arch. Intern. Med.* 145:122-124 (January 1985); Joanne Lynn and James F. Childress, "Must Patients Always Be Given Food and Water?" *Hastings Cent. Rep.* 13:17-21 (October 1983); S. H. Wanzer et al., "The Physician's Responsibility Toward Hopelessly Ill Patients," *N. Engl. J. Med.* 310:955-959 (1984).
4. *Barber v. Superior Court of the State of California*, 195 Cal. Rptr. 484 (Cal. App. 2 Dist. 1983); *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985). *In the Matter of Mary Hier*, 18 Mass. App. 200, 464 N.E.2d 959, app. den., 392 Mass. 1102 (1984).
5. *Bouvia v. County of Riverside*, Superior Ct. of St. of Calif., Riverside County, No. 159780 (1984).
6. See note 3.
7. Lynn and Childress, *supra* note 3, at 18.
8. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment*. Washington, D.C.: U.S. Government Printing Office (1983).

9. See note 4, *supra*.
10. See note 3, *supra*.
11. See generally, Alan J. Weisbard, "On the Bioethics of Jewish Law: The Case of Karen Quinlan," *Israel L. Rev.* 14:337-368 (1979); Robert A. Burt, "Authorizing Death for Anomalous Newborns," in Aubrey Milunsky and George J. Annas (eds.), *Genetics and the Law*, New York: Plenum Press (1975); Robert A. Burt, "The Ideal of Community in the Work of the President's Commission," *Cardozo L. Rev.* 6:267-286 (1985).
12. Daniel Callahan, "On Feeding the Dying," *Hastings Cent. Rep.* 13:22 (October 1983).
13. See Barber, *supra* note 4, and Bonnie Steinbock, "The Removal of Mr. Herbert's Feeding Tube," *Hastings Cent. Rep.* 13:13-16 (October 1983).
14. Conroy, *supra* note 4.
15. Personal communications to author.
16. The reference is to the Nazi euthanasia program. While the authors have been unable to locate an explicit reference to "useless eaters," Nazi usage of the phrase "useless mouths" is documented by Nora Levin, *The Holocaust: The Destruction of European Jewry: 1933-1945*. New York: Schocken (1968), 302.
17. Recent remarks on "the duty to die" attributed to Colorado Governor Richard Lamm are illustrative, *New York Times*, March 29, 1984 at A16, col. 5.
18. Proceedings of the House of Delegates, American Medical Association 133rd Annual Meeting, June 1984 at 177 (commenting on recommendations of Advisory Council on Social Security).

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