



FUTILE CARE

Physicians Should Not Be Allowed To Refuse to Treat

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Americans are in the midst of a great reversal in medical ethics. We have come a long way from the era of Karen Ann Quinlan, when patients and their families were desperately trying to get treatment stopped. At that time clinicians believed they had a moral duty to treat to the last gasp. The outcome of that debate was a patients' rights movement, which gave patients the right to refuse medical treatment, even if refusal would lead to death. It also gave families the right and the responsibility to function as surrogates for patients, trying to do what patients would have wanted, when patients' wishes are known, and trying to determine patients' best interests in cases where they are not.

Now, 18 years later, the debate has shifted. Some patients are asking for treatment that some care givers believe to be useless. Some patients

insist on receiving what physicians believe to be "futile care"; others are arguing that physicians should have the right to refuse to provide care they deem futile.¹

MEDICALLY INAPPROPRIATE: A MISNOMER

On December 14, 1989, 86-year-old Helga Wanglie slipped on a rug and broke her hip.² She was treated at Hennepin County Medical Center in Minneapolis. She developed a series of respiratory tract infections and was placed on a respirator from which physicians were unable to wean her. She was transferred to a nursing home, where she suffered cardiac arrest and was left in a persistent vegetative state (PVS), on a ventilator and nasogastric tube. The healthcare team's unanimous conclusion was that the treatment was futile and "medically inappropriate."

But what can *medically inappropriate* mean

Summary Eighteen years after the era of Karen Ann Quinlan, the debate over futile care has shifted. Now some patients are asking for treatment that care givers believe to be useless. In virtually all cases of so-called futile care, the real disagreement is not over whether a treatment will produce an effect; it is over whether some agreed-on potential effect is of any value.

An obvious reason to resist providing care believed to be futile is that it appears to consume scarce resources and therefore burden others. However, for care that affects the dying trajectory but appears to most of us to offer no benefit, the proper course is for society—not clinicians—to cut patients off.

Under certain circumstances patients should have the right to receive life-prolonging care from their clinicians, provided it is equitably funded, even if the clinicians believe the care is futile and

even if it violates their consciences to provide it. Society is not in a position to override a competent patient who prefers to live even if life prolongation is burdensome. For incompetent patients, if a clinician believes a treatment is actually hurting a patient significantly, he or she may appeal to a court to have it stopped.

A society that forces people to die against their will produces more offense than one that forces healthcare providers to provide services that violate their consciences. And medical professionals have a social contract with society to control the use of medical, life-prolonging technologies. Thus clinicians should be obliged to render the desired care if at least the following conditions are met: an ongoing patient-physician relationship, no colleague capable and willing to take the case, a clinician competent to provide the desired service, equitable funding, and the care being predictably life prolonging.

here? It is morally reasonable to support the withdrawal of ventilators or even feeding tubes in such cases. But calling the inappropriateness "medical" tells us absolutely nothing and, in fact, perpetuates a serious philosophical mistake that has horrendous implications.

If continuing treatment is inappropriate, it is inappropriate religiously, philosophically, or morally, but medically the treatment has a definite effect. It clearly prolongs her life and is therefore efficacious.

TWO BASIC DISTINCTIONS

To understand the debate over futile care, two basic distinctions must be made:

- A critical distinction between physiologically futile care and "normatively futile care"
- A distinction between denying so-called futile care on the basis of allocating scarce resources and denying it on the grounds that it violates care givers' integrity

Physiological Versus Normative Futility Some interventions labeled futile are really without physical effect. This is what Stuart J. Youngner has called "physiologically futile treatment."³ Such treatment will not produce the effect sought by the one insisting on it. This must be distinguished from care that has the anticipated effect but is believed by someone to be of no net benefit. We will call this second kind of futility "normative futility" because it involves a value judgment that the effect is of no benefit.

Physiological futility is more or less a question of medical science. We say "more or less" because every scientific question involves some value judgments (e.g., a choice of *p* values and a choice of the concepts used to describe the effects). In rare instances, clinicians will disagree over the facts because of these hidden value disputes. Laypersons may also disagree with clinicians over such matters. To the extent that they do, it is not irrational for society to require care that physicians have deemed physiologically futile. That occurs only in unusual circumstances, however. In virtually all cases of so-called futile care, the



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To distinguish physiological from normative futility, ask the question, Is the disagreement over the science (the judgment about what the effect will be) or over the value of the agreed-on outcome? We can presume that clinicians are correct on the science, but also that they have no special claim to expertise on the value

of the outcomes.

Rationing Versus Clinician Integrity A second distinction is also important. There are two separate reasons to be concerned about patient demands for care deemed futile: issues of rationing and of care givers' integrity.

First, an obvious reason to resist providing care believed to be futile (in either sense) is that it appears to consume scarce resources and therefore burden others. Our communal resources are inevitably scarce. Surely, if a treatment's benefits are so debatable that most of us consider them to be nonexistent, that is an obvious place to cut. But that does not mean it is a clinician's role to do the cutting.

We have acknowledged the legitimacy and necessity of rationing healthcare,⁴ provided it is done equitably and with full public participation in decisions. But historically the clinician's job has been to help patients, not to act as society's cost-containment agent. This gatekeeping role must be someone else's task. Just like a defense attorney's role in the legal system is to advocate for a client, even an unworthy client, a clinician's job in the medical system is to advocate for his or her patient.

We agree that care without effect should not be funded on scientific grounds. A clinician should not be permitted to authorize treatments that he or she is convinced will not produce the effect a patient or surrogate seeks. In fact, insurers who receive requests for reimbursement for such care ought not to pay for it. However, for care that affects the dying trajectory but seems to most of us to offer no benefit, the proper course



is for society—not clinicians—to cut patients off. Subscribers to insurance should have a strong interest in limiting care that offers little or no benefit and should agree to exclude such coverage from their plans.

For example, most Americans apparently believe that providing continued, long-term life support serves no purpose for a patient who is in a PVS. Insurers or health maintenance organizations (HMOs) should ask whether subscribers want to include long-term support for PVS patients in their coverage. Insurers should be able to explain what premiums would be if coverage for PVS treatment is and is not included. Insurers should not care whether subscribers vote PVS treatment in or out as long as they set an appropriately larger premium if such treatment is included.

We believe that most subscribers would vote PVS treatment out. The minority of subscribers who have an interest in such care can decide to buy supplemental insurance (a PVS rider) or to pay for the care out of pocket. If the insured group votes to include the coverage, or if individuals self-fund or buy supplemental coverage, then there is no unfairness to society as a whole. We can call this "equitable funding."

Helga Wanglie was an HMO member. HMO administrators should have asked her and her fellow subscribers whether they wanted to fund care for PVS patients. However, the HMO was explicit in its willingness to provide the funding for the care. There was thus no economic reason why the hospital or the individual physicians responsible for Helga Wanglie's care should have felt compelled to resist on grounds of allocation or resources. Also, at the time there were no noneconomic demands—a scarcity of time or of beds—that would force a rationing decision. Had there been such scarcities, the institution would have had a moral obligation to make allocational choices.

Concern about a scarcity of resources, however, is increasingly not the reason physicians want to limit care they deem futile. More commonly physicians want to protect the "integrity" of the physician who feels that it violates professional norms to deliver care that will do no good. We argue that under certain circumstances patients should have a right to receive life-prolonging care from their clinicians, provided it is equitably funded, even if the clinicians believe the care is futile and even if it violates their consciences to provide it.

This is a serious conflict, and we do not endorse such a position lightly. But clearly in some cases a physician must be obliged to violate

his or her conscience. Consider, for example, someone raised as a racist who sincerely believes that it is wrong to provide medical treatment for racial minorities. The mere fact that the prejudiced belief is held sincerely surely would not permit the physician to refuse to treat all members of minority groups.

It is similarly clear that patients cannot be allowed to receive any medical treatment that they happen to crave. Certain conditions will have to be met before the duty to provide care deemed futile will prevail. We will detail these conditions later in this article, but first we will explain the moral reasons why some patients may have a legitimate claim to care that physicians believe will do no good.

MORAL COMPLEXITIES SURROUNDING A DUTY TO TREAT

Let us return to the case of Helga Wanglie. She and her husband were members of the right-to-life movement. Previously she had told family members that she would never want anything done to shorten her life. Her husband is quoted as saying, "I'm a pro-lifer; I take the position that human life is sacred."⁵ He said that his wife of 53 years felt the same way. Their daughter agreed.

There was no dispute about the medical facts. The physicians and the Wanglie family agreed that she was permanently unconscious, that providing a ventilator and nasogastric tube would prolong her life, albeit in a vegetative state. The only question was the value of vegetative life.

A Comparison with Quinlan Compare this "futile care" case with the classic treatment refusal case of Karen Ann Quinlan, the young woman who in 1975 suffered a respiratory arrest that left her in a PVS.⁶ Her physician, Robert Morse, was absolutely convinced that a ventilator believed necessary to preserve her life was providing benefit. He considered it "medically appropriate," claiming, probably incorrectly, that letting a permanently vegetative patient die violated the professional standard of the time.

The most critical issue in the court battle was whether a clinician's judgment about benefit for a patient could take precedence over a patient's or surrogate's assessment of benefit. Karen Quinlan's family and lawyer successfully argued that a professional consensus about whether an effective treatment was beneficial was irrelevant. Her father was, in effect, given the power to decide whether his daughter would consider this treatment beneficial.

The *Quinlan* and *Wanglie* cases, despite the seemingly opposite values of the decision makers, are similar in that both involved an assessment of the value of vegetative life. This assessment is fun-

damentally not a technical medical matter. Different people with different beliefs and values can come to different conclusions about whether ventilating a permanently vegetative patient is a benefit. When a patient is competent, he or she has the right to decide. When the patient is not competent, then the designated surrogate has the responsibility to try to determine what is best.

The two types of cases differ, however, in that the moral issue confronting physicians

in futile care cases is whether patients or surrogates who make the decision that such care serves a worthwhile purpose have a right to insist that it be provided and, if so, on what basis.

Autonomy Problem Some defenders of the right to access make the mistake of claiming that the moral principle of autonomy confers that right. Autonomy gives a patient a right to refuse treatment. By extension, it even gives family members a limited right to decline treatment on a patient's behalf. But that does not imply that autonomy can give the patient a right of access. There is a lack of symmetry. Autonomy is a liberty right. A patient has a right to cancel the patient-physician relationship and at least metaphorically walk away. But in so far as autonomy is relevant, it also should give a provider the right to sever the relationship. Autonomy cannot be the basis of the claim to a right to access.

Burden of Futile Care A second complexity in the argument concerns the possibility that acting on the demand for care deemed futile might impose excessive burdens on a patient. Clinicians evaluate some care not only as providing no benefit, but as actually harming a patient. But if harm refers to pain and suffering, a patient must at least be conscious for harm to occur. It is difficult to understand how Helga Wanglie or Karen Quinlan can be burdened by continued life support. There may well be moral offense if, for example, the life support is administered against a patient's wishes, but a patient must be conscious to be burdened in any real sense.

If a patient is mentally alert, he or she could perceive burden, but if the patient is mentally



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competent, it is the patient's judgment of burdens and benefits that must prevail. The patient is the one who will suffer the burden and die if treatment is forgone. Surely, society is not in a position to override a competent patient who prefers to live even if life prolongation is burdensome. Only a monstrous society would permit a physician to impose death on a patient who wants to live because the physician believes the patient would be better off dead.

The same rationale

applies to persons who are mentally incompetent and who have expressed their wishes while competent, but what about those who have never expressed their wishes while competent? If a clinician believes treatment is actually hurting a patient significantly, he or she may appeal to a court to have it stopped.

Courts routinely override parents and guardians who refuse treatment when the refusal seems to harm a patient (e.g., Jehovah's Witness parents who refuse lifesaving blood for their children).⁷ No court has yet ruled that parents or guardians can be guilty of abuse by insisting on futile care for a ward who is made to suffer by continuing treatment that is not only futile, but, on balance, gravely burdensome. Someday soon one may. But a judge, not a clinician, should determine the care to be unacceptable. Even if a clinician believes there is a burden on an incompetent patient, he or she should continue treatment until authorized to stop.⁸

Consider the case of Baby L.⁹ She had fetal hydronephrosis and oligohydramnios, leaving her blind, deaf, and quadriplegic, with a gastrostomy and recurrent pneumonia. At two years of age she had the mental status of a three-month-old and had had four cardiac arrests. But she was conscious and could feel pain. Her mother insisted on life support, but the medical staff opposed mechanical ventilation and cardiovascular support, which they thought was "futile" and "inhuman."

The treatment was clearly preserving Baby L's life. She had lived for more than two years. The real issue was whether it was normatively futile.



There are good reasons why this treatment should be considered disproportionately burdensome. Nevertheless, a clinician has no *medical* basis for deciding that the effective treatment does more harm than good. Only a public agency with due process has that authority. If a clinician believes that an incompetent patient is being harmed by futile care demanded by a surrogate, the clinician's duty is to try to get the surrogate overridden.

John J. Paris and colleagues treat the Baby L case as a paradigm futile-care case. However, this is a special case. The patient has never been competent to evaluate the burdens, and the burdens could well exceed the benefits. But even in these circumstances the clinicians cannot withdraw the life support on their own. It is appropriate and reasonable to try to get a court order to stop, but this is different from simply deciding to overrule the mother's judgment about the burdens and benefits of the life support.

FUTILE CARE FOR PATIENTS WHO ARE NOT BEING HARMED

Cases involving burden to incompetent patients are really not the essence of the futile care debate, however. The real issue is futile care for patients who are not being harmed. This is true futile care (i.e., care that produces neither benefits nor burdens for a patient). For the moment let us simplify the analysis by limiting the discussion to interventions that will predictably prolong life.

Clinicians always have the right to withdraw from a case, just as a competent patient might, provided someone else is willing to take the case. It is in neither a patient's nor a physician's interest to insist that the original physician continue. But if no colleague is willing to step forward, the treatment is life prolonging, and the treatment will not be burdensome, then a licensed professional responsible for and capable of providing the care has a duty to provide it even if he or she is morally opposed. Otherwise that clinician would have to argue that the patient is better off dead even though the patient is not being injured and even though the patient or surrogate disagrees. Effective, nonburdensome, life-prolong-



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ing care is always morally required if a patient or surrogate desires it.

But why should physician autonomy be violated in this one case when generally patient autonomy should not be violated? Two arguments can be offered: the argument from offense and the argument from contract.

Argument from Offense If a patient or surrogate is demanding life-prolonging care that his or her clinician believes is futile and a violation of his or her integrity to provide, we have a

head-on clash between a patient's or surrogate's choice for life and the provider's autonomy. A society that forces people to die against their will produces more offense than one that forces healthcare providers to provide services that violate their consciences. If society must offend, the lesser offense is preferred.

Argument from Contract The second argument rests on the notion of the social contract or covenant between medical professionals and society. Licensed professionals are the only members of society licensed to control the use of medical, life-prolonging technologies. When they accept licensure, they accept a public trust to use their monopoly on medical knowledge to preserve lives when the appropriate decision makers want them preserved.

Imagine that society is contemplating creating monopoly control over certain life-prolonging technologies. Further, imagine that there will be cases in which a minority desperately wants these technologies used while a majority does not see any value in their use. Finally, imagine that we cannot know whether we will be in the majority or the minority. We believe a rational society will extract, as a condition of licensure, a promise that the clinician will use these technologies for people who want them.

Of course, some conditions would be attached to such a promise. These might include:

1. An ongoing patient-physician relationship
2. No colleague capable and willing to take the case
3. A clinician competent to provide the desired service

4. Equitable funding

5. The care being predictably life prolonging

At least if all these conditions were met, we believe clinicians would be obliged to render the desired care. All these conditions were met in the *Wanglie* case. Once the court determined that Helga Wanglie's husband was the proper surrogate, physicians wisely acknowledged their duty to provide the care they believed was futile even though it violated their sense of professional integrity. Once one realizes that the decision to forgo effective, life-prolonging care is a moral choice rather than a technical one, it seems hard to deny the right of the minority to access. If we have created a monopoly in the use of that technology, we would be wise to insist that minority interests be protected by ensuring that holders of minority views can have their lives prolonged. The alternative is to permit physicians to decide that a patient would be better off dead even though the patient is not being burdened and even though the patient or surrogate believes the life should be preserved.

NON-LIFE-PROLONGING FUNDAMENTAL CARE

What we have said thus far is limited to care that can be expected to prolong life effectively, at least for a length of time that a patient or surrogate considers worthwhile. The argument for the duty to provide care deemed futile clearly does not extend to all non-life-prolonging treatments that may be of interest to the patient. Some patients' demands are too offensive or too trivial to make them part of the contract between professionals and society. For example, a patient's demand that a surgeon amputate a healthy limb would not have to be honored.

On the other hand, some care that does not prolong life may still be considered so fundamental that physicians would have a duty to provide it. Consider, for example, medication to relieve severe chronic pain. Some physicians may sincerely believe that providing such medication is wrong, for instance, because it may shorten a patient's life. A physician may consider the use of such risky medication immoral, even though Catholic moral theology and much secular thought acknowledges the legitimacy of risking the indirect side effects in such cases. Even if a physician is sincerely opposed, however, he or she may well be expected by society to administer the pain relief, provided no other physician will take the case.

The key is that some interests of patients and surrogates may be recognized as fundamental. Even if a majority would not consider the treatment worth pursuing, that majority might recog-

nize the importance of the minority's claim. Life-prolonging care is fundamental in this way; certain non-life-prolonging care may be as well. If the care is perceived as fundamental, then it should be part of the social covenant between society and the profession. In such cases, as in ones involving life-prolonging treatment, if (1) there is an ongoing patient-physician relationship, (2) no other physician will take the case, (3) the clinician is competent to provide the care, and (4) the funding is equitable, the licensed professional who is given a monopoly over the control of life should be expected to promise to use that technology when patients or surrogates ask for it. □

NOTES

1. Nancy S. Jecker and Robert A. Pearlman, "Medical Futility: Who Decides?" *Archives of Internal Medicine*, June 1992, pp. 1,140-1,144; Lawrence J. Schneiderman, Nancy S. Jecker, and Albert R. Jonsen, "Medical Futility: Its Meaning and Ethical Implications," *Annals of Internal Medicine*, vol. 112, 1990, pp. 949-954; Donald J. Murphy, "Do-Not-Resuscitate Orders: Time for Reappraisal in Long-Term-Care Institutions," *JAMA*, vol. 250, 1988, pp. 2,098, 2,101; Tom Tomlinson and Howard Brody, "Futility and the Ethics of Resuscitation," *JAMA*, vol. 264, 1990, p. 1,277; Steven H. Miles, "Informed Demand for 'Nonbeneficial' Medical Treatment," *New England Journal of Medicine*, August 15, 1991, pp. 512-515; Michael Coogan, "Medical Futility in Resuscitation: Value Judgement and Clinical Judgement," *Cambridge Quarterly for Healthcare Ethics*, vol. 2, 1993, pp. 197-217; John J. Paris, "Pipes, Colanders, and Leaky Buckets: Reflections on the Futility Debate," *Cambridge Quarterly for Healthcare Ethics*, vol. 2, 1993, pp. 147-149.
2. Miles.
3. Stuart J. Youngner, "Who Defines Futility?" *JAMA*, vol. 260, 1988, pp. 2,094-2,095.
4. Robert M. Veatch and Carol Mason Spicer, "Medically Futile Care: The Role of the Physician in Setting Limits," *American Journal of Law and Medicine*, vol. 18, nos. 1 and 2, 1992, pp. 15-36; Robert M. Veatch, "DRGs and the Ethical Reallocation of Resources," *Hastings Center Report*, June 1986, pp. 32-40.
5. B. D. Colen, "Fight over Life," *Newsday*, January 29, 1991, p. S64.
6. *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976), cert. denied sub nom.; *Garger v. New Jersey*, 429 U.S. 922 (1976), overruled in part; *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).
7. Maureen L. Moore, "Their Life Is in the Blood: Jehovah's Witnesses, Blood Transfusions and the Courts," *Northern Kentucky Law Review*, vol. 10, no. 2, 1983, pp. 281-304.
8. Hastings Center, *Guidelines on the Termination of Life-sustaining Treatment and the Care of the Dying*, Hastings-on-Hudson, NY, 1987, p. 32.
9. John J. Paris, Robert K. Crone, and Frank Reardon, "Physicians' Refusal of Requested Treatment," *New England Journal of Medicine*, vol. 322, 1990, pp. 1,012-1,115.