

The Case of Helga Wanglie - Futile Treatment

Summary

On December 14, 1989, Helga Wanglie, 86, fell in her Minneapolis home and broke her hip. After the fracture was successfully set at Hennepin County medical Center (HCMC), she was discharged to a nursing home. She was readmitted to HCMC on January 1, 1990, when she developed respiratory failure and was placed on a respirator. During the next five months repeated attempts to wean Mrs. Wanglie from the respirator were unsuccessful; she was conscious, aware of her surroundings, and could recognize her family.



On May 7, 1990, she was transferred to another facility that specializes in the care of respirator dependent patients. While there and still unable to be weaned from the respirator, she experienced a cardiopulmonary arrest and was taken to another acute care hospital in St. Paul. Diagnosis now showed severe and irreversible brain damage. The hospital ethics committee discussed with the family the possibility of limiting further life-sustaining treatment because of her dismal prognosis. The family resisted the idea and requested that Mrs. Wanglie be transferred back to HCMC where they felt she had received excellent care.

The family thought the suggestion of withdrawal of life-sustaining technologies reflected moral decay in our culture and hoped instead for a miracle. Mr. Wanglie said that only God can take life and that doctors should not play God.

By late 1990 repeated evaluations by neurology and pulmonary medicine services at Hennepin County Medical Center confirmed the diagnosis of permanent unconsciousness (persistent vegetative state) and permanent respirator dependency because of chronic lung disease.

The hospital staff concurred that they had erred initially on the side of continuing treatment in order to provide time for the family to come to see the futility of the treatment being offered Mrs. Wanglie; but the months passed and several conferences with the family proved to widen the rift between the medical judgment that the use of the respirator could not serve the patient's interests and the determination of the Wanglie family to do nothing which would shorten Mrs. Wanglie's life. Subsequently, in early 1991 the hospital filed papers with the Fourth Judicial District Court, Hennepin County, Minnesota, in order to ask whether medical professionals were obliged to provide what they considered to be unbeneficial and inappropriate treatment. The court ruled in favor of the husband's and family's wishes.

The hospital was unable to wean Mrs. Wanglie from the respirator, and on May 7, 1990, she was transferred to a facility that specializes in the care of respirator-dependent patients. There she experienced a cardiopulmonary arrest and died.

The following two articles (Rie and Ackerman) present opposing viewpoints on the ethical issues at stake in the Wanglie case.

Article: The Limits of a Wish

By Michael A. Rie

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In our secular, pluralist nation, health care is founded on the legal and moral presumption that the societal basis for individual care delivery is a fiduciary trust relationship between physician and patient. Physicians, being more knowledgeable than patients and families, were widely perceived to hold the upper hand regarding treatment decisions as patients and families began to seek liberation from physiologic life support and to legally and publicly assert their fundamental freedom to decline medical interventions while remaining within the trust relationships. Under the tutelage of the autonomy movement that began with *Schloendorff* in 1914, blossomed with *Quinlan* (1976) and *Brophy* (1986) and reached maturity with last year's Supreme Court decision in *Cruzan*, the medical profession has come to accept a patient's right to be left alone and to acknowledge the autonomous patient's authority in decisions to withdraw life-sustaining care.¹

The case of Helga Wanglie now seeks judicial clarification of three issues that have lurked in the background of patients' rights cases. In the first instance, it reminds us that physicians, like patients, are moral agents and are so acknowledged in law.² Further, this case calls on us to recognize that the right not to be battered by the medical profession, and to be left alone, is *not* synonymous with a positive right to make claims against the physician to dispense any medical diagnosis and treatment that he or she believes offers no medical benefit to the patient.³ Finally, it urges us to acknowledge that physicians and other health care professionals must be accorded moral and legal prerogatives akin to patients' rights to withdraw informed consent to treatment. If trust relationships are individually created by mutual consent and not by legislative or judicial mandate, then preserving balanced and fair trust relationships in our society requires that, in some measure, physicians and other health care professionals be accorded the right to withdraw their consent to provide care when they can no longer in good conscience accede to a patient's request for a particular treatment.

When, as in this case, alternate providers may not be available to accept transfer of a patient because of widespread public and professional belief that the requested care, such as ventilator support in the persistent vegetative state, should not be given, the court must either restrict the physician's freedom as a recognized moral agent or acknowledge that moral agency fully and permit the physician to exit the fiduciary relationship without risk of being held to have abandoned the patient. The third alternative is to require the doctors of Hennepin County Medical Center and the judicially appointed conservator (whoever that may be) to agree to wean Helga Wanglie from respiratory support should no other provider be willing to accept her in transfer after a reasonable period of time. If another provider can be found, the tensions of this particular case can be resolved, but such a solution sidesteps the

question of whether the medical profession is uniquely qualified to determine what constitutes medical benefit or whether that decision rests sovereignly with patients, who may then claim positive rights to health care that may violate the physician's professional integrity. Lurking behind this tension is the inescapable issue of establishing a public – and professional –

consensus as to what constitutes medical futility, and how we are to take into account the significant economic costs attendant on a decision *not* to define nonbeneficial services in a health care system of, ultimately, limited resources.

Hippocrates Meets an American Teaching Hospital

The traditional Hippocratic physician was a benign paternalist who by virtue of knowledge, skill, and training offered patients what was available and decided what could reasonably be offered in the care of the patient, with whom he enjoyed a direct, personal relationship. By contrast, the kind of serial professional responsibility that characterizes contemporary health care as delivered at a busy urban teaching hospital like Hennepin County Medical Center, where attending physicians on service rotate every six weeks, clearly poses problems in communication between the medical staff and patients and their families when moral tensions emerge around issues of deciding on appropriate medical case. In Helga Wanglie's case, the medical staff realized that they had to appoint a single responsible physician to establish a trust relationship with her family and to coordinate the day-to-day management of her care. The physicians of Hennepin County Medical Center have understood since November 1990 that they must communicate clearly and effectively with the patient's surrogates if they wish to be considered serious moral agents in the eyes of their own institution and society at large.

The Ethics of Critical Care

In December 1990 following several years of deliberation, the Society of Critical Care Medicine published its consensus report on the ethics of forgoing life-sustaining treatment in the critically ill. This statement represents a broad, mainstream consensus in critical care regarding professional morality in medicine, nursing, and other allied health care fields. The report states:

Treatments that offer no benefit and serve to prolong the dying process should not be employed. In light of a hopeless prognosis, the indefinite maintenance of patients reliably diagnosed as being in a persistent vegetative state (PVS) raises serious ethical concerns both for the dignity of the patient and for the diversion of limited medical and nursing resources from alternative applications that could offer medical and nursing benefit to others. The PVS patient should be removed from the ICU unless it is not possible otherwise to meet the patient's nursing care needs. A PVS patient should not be maintained in the ICU to the exclusion of a patient who can derive benefit from ICU care.

The report goes on to identify guidelines for caregivers when there is persistent disagreement concerning any therapy clinicians judge to be "not indicated or futile." In working with patients or their surrogates to develop a mutually satisfactory plan of care, the report indicates health care professionals may provide services which, though they offer "no reasonable medical benefit," are "meaningful to the patient." When futile therapy is requested, the physician should "reassess the goals of therapy with the patient... to clarify possible mutual misunderstandings," but is under no obligation to provide therapy that is "burdensome or has no chance of achieving benefit." This includes requested treatment that by prevailing standards of practice entails "loss of function, mutilation, or pain disproportionate to benefit." Similarly, caregivers who conscientiously object to providing a requested treatment are not obligated to do so, though they should explain their position regarding different treatment options to the patient and/or family. Finally, in such cases of conflict, the physician may transfer care to another physician of the patient's choosing.

This statement represents a publicly articulated vision of the ethical integrity of the critical care health professions and is worthy of consideration by the courts of Minnesota. The health care providers and the corporate body of Hennepin County Medical Center are expressing moral views consistent with this ethics. They remain totally committed to the humane and comfort care of Mrs. Wanglie in the hospital, while conscientiously objecting to the use of the ventilator for patients in the persistent vegetative state.

It was inevitable that we would eventually have to define the limits of individual patients' or families' autonomy claims as the unique and sovereign source of authority in decisions to limit treatment if we are to maintain trust relationships as the basis for health care in our society and to acknowledge that health care practitioners, like patients, are also moral agents. In those circumstances where providers objected to discontinuing care on moral grounds the courts usually bowed to the option to transfer the patient.⁵ In Helga Wanglie's case, the request for continued mechanical ventilation combined with her family's refusal to consider other health care options has made it necessary for the health care providers to seek judicial relief from a patient/provider trust relationship that is morally offensive to them. The issue of whether the ventilator is necessary for nonmedical benefit will require a judicial finding that Mrs. Wanglie has an unqualified right to biologic existence in the persistent vegetative state.

The Limits to State Authority

The state has circumscribed authority in a constitutionally limited democracy to mandate that physicians provide diagnostic and treatment regimens at variance with professionally created practices and mores. Though Mrs. Wanglie's family asserts her alleged desire for continuous biologic existence, this demand cannot compel the medical profession generally or Mrs. Wanglie's physicians specifically to offer care on a long-term basis that is professionally recognized to carry no therapeutic benefit. Should the judiciary find a constitutionally protected, unqualified right to biologic existence, it would erase a long tradition of case law concerning conscientious objection in health care, as well as assert a positive right for citizens to demand medical care for reasons other than medical necessity. Such a judicial finding would also create a claim on health insurance schemes generally to pay for medically unnecessary benefits created exclusively by a consumer's demand.

The mere existence of mechanical ventilation does not create a new standard of care within medicine, even if the judiciary should determine that Americans have an unqualified right to life in the persistent vegetative state. In the absence of public moral values and well-articulated standards of medical necessity within the Physician's Health Plan to guide resource allocation in Mrs. Wanglie's situation, the medical profession remains by public default and default of the insurance company the ultimate allocator of medical resources. Should the moral standards of the doctors of Hennepin County Medical Center and the Society of Critical Care Medicine be unacceptable to the courts of Minnesota, then the responsibility to articulate the new standards of care would be thrust on nonmedical practitioners, as the state would have created a new profession beyond the one acknowledged by the American people.

Who Pays for Autonomy

On its face, this case would appear to lack any economic concerns or conflict of interest on the part of providers. Mrs. Wanglie is covered in a health insurance program for retired lawyers and their families. Her HMO has, publicly stated that it has never intervened in the medical decisions

to provide ventilatory care in Mrs. Wanglie's case and will continue to recompense the institution and the individual providers for their services indefinitely.

Yet this type of case raises serious questions about whether there are economic conflicts of interest that would concern the patient and the patient's estate and family. Generally, health insurance will pay for hospitalization in an acute intensive care unit. But if a patient in PVS is declared to require only custodial care and is referred to a chronic care facility, most American health insurers (including Medicare) will not pay for that extended kind of ventilator support. Under such circumstances, the patient's, the family's, or other private assets - as opposed to communal health insurance assets - are used until such time as the patient spends down his or her assets and becomes eligible for Medicaid. This case raises unique questions about the duty of insurance carriers to determine whether subscribers wish to sustain massive premiums, and premium increases, on an annual basis because patients will receive insurance-subsidized ventilator support should they enter PVS. There are sparse data available to inform us of the economic consequences of mechanically ventilating the increasing number of patients in PVS, yet Mrs. Wanglie's bills of \$800,000 over some seventeen months are an eloquent reminder of our society's economic limits. How does this affect our capacity to purchase health insurance to meet a growing list of human needs and desires? As a society we visualize health insurance as an open-ended individual entitlement, which is one of the major problems confronting our ability to pay for health care generally. Such policy considerations, while not germane to this particular court proceeding, are crucial to the morality of health insurance and to our ability to set priorities among technologies acknowledged by our health care professions to be only marginally useful, or of no medically demonstrable benefit. The case of Helga Wanglie raises questions of how 'benefit' is to be determined in our society, and what role the medical profession may legitimately play in developing a definition of medical benefit. It also challenges us to assess the medical profession's role in creating public moral values to distinguish care that is recompensable under health insurance from benefits that more properly reside in the private domain of personal preferences.

And Freedom for All

The petition for judicial relief of a professionally morally oppressive request by Mrs. Wanglie's family properly belongs in a court of law. It is time to establish the limits of patients' autonomy to demand health care that the medical profession believes serves no benefit. In the case of Helga Wanglie, the providers have asserted a moral position consistent with that articulated collectively by the critical care health professions. These issues are so fundamental that the ruling in Wanglie will usher in a new chapter in our efforts to respect the individual freedom of both patients *and* their health care providers.

Article: The Significance of a Wish

By Felicia Ackerman

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The case of Helga Wanglie should be seen in the general context of conflicts that can arise over whether a patient should be maintained on life-support systems. Well-publicized conflicts of this

sort usually involve an institution seeking to prolong the life of a patient diagnosed as terminally ill and/or permanently comatose, versus a family that claims, with varying degrees of substantiation, that the patient would not have wanted to be kept alive under these circumstances. But other sorts of conflicts about prolonging life also occur. Patients who have indicated a desire to stay alive may face opposition from family or medical staff who think these patients' lives are not worth prolonging. Such cases can go badly for patients, who may have difficulty getting their preferences even believed, let alone respected.

Helga Wanglie's case is not as clear cut. But in view of the fact that keeping her on a respirator will prolong her life, that there is more reason to believe she would have wanted this than to believe she would not have wanted it, that medical diagnoses of irreversible unconsciousness are not infallible, and that her private health insurance plan has not objected to paying for her respirator support and in fact has publicly taken the position that cost should not be a

factor in treatment decisions, I believe HCMC should continue to maintain Mrs. Wanglie on a respirator. This respirator support is medically and economically feasible, and it serves a recognized medical goal - that of prolonging life and allowing a chance at a possible, albeit highly unlikely, return to consciousness.

The Significance of Medical Expertise

Dr. Steven Miles, ethics consultant at HCMC, has argued that continued respirator support is "medically inappropriate" for Mrs. Wanglie. The argument is based on a criterion of medical appropriateness that allows doctors to prescribe respirators for any of three purposes: to allow healing, to alleviate suffering, and to enable otherwise disabled persons to continue to enjoy life. Since keeping Mrs. Wanglie on a respirator serves none of these ends, it is argued, such treatment is medically inappropriate.

But just what does "medically inappropriate" mean here? A dear case of medical inappropriateness would be an attempt to cure cancer with laetrile, since medicine has presumably shown that laetrile cannot cure cancer. Moreover, since laetrile's clinical ineffectiveness is a technical medical fact about which doctors are supposed to have professional expertise, it is professionally appropriate for doctors to refuse to grant a patient's request to have laetrile prescribed for cancer. But HCMC's disagreement with Mrs. Wanglie's family is not a technical dispute about a matter where doctors can be presumed to have greater expertise than laymen. The parties to the dispute do not disagree about whether maintaining Mrs. Wanglie on a respirator is likely to prolong her life; they disagree about whether her life is worth prolonging. This is not a medical question, but a question of values. Hence the term "medically inappropriate," with its implication of the relevance of technical, medical expertise, is itself inappropriate for doctors to suppose that their professional expertise qualifies them to know what kind of life is worth prolonging as it would be for meteorologists to suppose their professional expertise qualifies them to know what kind of destination is worth a long drive in the rain.

It has also been argued that continued respirator support does not serve Mrs. Wanglie's interests since a permanently unconscious person cannot "enjoy any realization of the quality of life"² Yet were this approach to be applied consistently, it would undermine the idea frequently advanced in other life-support cases that it is in the interests of the irreversibly comatose to be "allowed" to die "with dignity." Such people are not suffering or even conscious, so how can death benefit

them or serve their interests? The obvious reply in both cases is that there is a sense in which it is in a permanently comatose person's interests to have his or her previous wishes and values respected. And there is some evidence that Mrs. Wanglie would want to be kept alive.

But why suppose doctors are any more obliged to serve this want than they would be to help gratify some nonmedical desire such as a desire to be remembered in a certain way? An obvious answer is that prolonging life is a medical function, as is allowing a possible return to consciousness. Medical diagnoses of irreversible coma are not infallible, as the recent case of Carrie Coons clearly demonstrates. The court order to remove her feeding tube, requested by her family, was rescinded after Mrs. Coons regained consciousness following five and a half months in what was diagnosed as an irreversible vegetative state.³ Such cases cast additional light on the claim that respirator support is medically inappropriate and not in Mrs. Wanglie's interests. When the alternative is death, the question of whether going for a long-shot chance of recovering consciousness is worth it is quite obviously a question of values, rather than a technical medical question doctors are especially professionally qualified to decide.

The Significance of Quality of Life

Medical ethicists who take into account the possibility that seemingly irreversibly comatose patients might regain consciousness have offered further general arguments against maintaining such patients on life-support systems. One such argument relies on the fact that "the few patients who have recovered consciousness after a prolonged period of unconsciousness were severely disabled," with disabilities including blindness, inability to speak, permanent distortion of limbs, and paralysis. Since many blind, mute, and/or paralyzed people seem to find their lives well worth living, however, the assumption that disability is a fate worse than death seems highly questionable. Moreover, when the patient's views on the matter are unknown, maintaining him on a respirator to give him a chance to regain consciousness and then decide whether to continue his disabled existence seems preferable to denying him even the possibility of a choice by deciding in advance that he would be better off dead. Keeping alive someone who would want to die and "allowing" to die someone who would want a chance of regained consciousness are not parallel wrongs. While both obviously go against the patient's values, only the latter has the additional flaw of doing this in a way that could actually affect his conscious experience.

The other argument asserts that since long-term treatment imposes emotional and often financial burdens on the comatose patient's family and most patients, before losing consciousness, place a high value on their families' welfare, presumably these patients would rather die than be a burden to their loved ones.⁵ Though very popular nowadays, this latter sort of argument is cruel because it attributes extreme self-abnegation to those unable

to speak for themselves. It is also biased because it assumes great sacrificial love on the part of the patient, but not the family. Why not argue instead that a loving family will not want to deny a beloved member a last chance at regained consciousness and hence that it is not in the interest of the patient's loved ones to withdraw life supports? Mrs. Wanglie's family clearly wants her kept alive.⁶

The Significance of a Gesture

Mrs. Wanglie's family claims that she would want to be kept alive. Yet Dr. Cranford suggests that her family at first denied having previously discussed the matter with her, and that it was only after the HCMC committed itself to going to court that the family claimed Mrs. Wanglie had said she would want to be kept alive. Dr. Miles mentions that during the months when she was on a respirator before becoming unconscious, Mrs. Wanglie at times pulled at her respirator tubing.

I agree that Mrs. Wanglie's views are less than certain. Yet for reasons given above and also because death is irrevocable, there should be a presumption in favor of life when a patient's views are unclear or unknown. Pulling at a respirator tube is obviously insufficient evidence of even a fleeting desire to die; it may simply be a semi-automatic attempt to relieve discomfort, like pulling away in a dentist's chair even when one has an overriding desire that the dental work be performed. Basically, although the circumstances of the family's claims about Mrs. Wanglie's statement of her views make the claim questionable, it is their word against nobody's. No one claims that she ever said she would prefer not to be kept alive, despite her months of conscious existence on a respirator.

It has also been argued that we should not allow patients to demand medically inappropriate care when the costs of that care are borne by others who have not consented to do so. I have already discussed the question of medical appropriateness. And a private health plan is paying for Mrs. Wanglie's care, a plan whose officials have publicly stated that cost should not be a factor in treatment decisions. The pool of subscribers to the plan, whose premiums are what indirectly subsidize Mrs. Wanglie's care, have, by being members of this plan, committed themselves to a practice of medicine that does not take cost into account. It would be unfair to make cost a factor in

Mrs. Wanglie's treatment decision now. Public statements by health insurance plan officials are expected to be taken into account by consumers selecting health insurance and must not be renege upon. Mrs. Wanglie's insurer is not seeking to renege. Instead, it is her *doctors* who have decided that her life is not worth prolonging.

Moreover, to say it would be the underlying disease rather than the act of removing the respirator that would cause Helga Wanglie's death is not helpful. If Mrs. Wanglie is, as the HCMC staff claims, irreversibly respirator-dependent, then saying that removing the respirator would cause her death is just as logical as saying that withdrawing a rope from a drowning man would cause his death, even if his death is to be "attributed" to his drowning. If the person in either case has an interest in living, one violates his interest by withdrawing the necessary means. This is what HCMC is seeking court permission to do to Mrs. Wanglie.

Article: Futile Care – Physicians Should Not Be Allowed To Refuse to Treat

By Robert M. Veatch, PhD & Carol Mason Spicer

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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.

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 the 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* appropriate mean 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 ground 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 judgement 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 judgements (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 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.

To distinguish physiological from normative futility, ask the question, “Is the disagreement over the science (the judgement 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 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 will 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 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, 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 of 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 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 turn 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.” 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 judgement 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 fundamentally 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 offence 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 competent, it is the patient's judgement 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 “inhumane.”

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 judgement 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-prolonging 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 a 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:

- An ongoing patient-physician relationship
- No colleague capable and willing to take the case
- A clinician competent to provide the desired service
- Equitable funding
- 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 recognize 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.

Article: The Concept of Futility – *Patients Do Not Have a Right to Demand Medically Useless Treatment*

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"I will use the diata [treatment] to help the sick according to my ability and judgement, but never with a view to injury and wrong-doing." – From the Hippocratic Oath

Summary:

Traditionally, applying the principle that physicians do not provide treatments when the interventions at their disposal do not produce medical benefits has been relatively straightforward. However, with the growing importance of patient autonomy and informed consent in treatment decisions, ethicists must now balance this principle with the principle of patient self-determination.

A patient's right to choose or refuse treatment is limited by the physicians right (and duty) to practice medicine responsibly. Bizarre or destructive choices made by a patient are not sacrosanct simply because the patient made them. In some cases, physicians may choose not to act on patient decisions that appear to be unreasonably destructive.

Physicians also have a right to refuse to provide futile treatments (i.e., interventions that might be physiologically effective in some sense but cannot benefit a patient). Patients themselves have a right to provide input into what would constitute a "benefit" for them, but physicians should be able to decide when a particular treatment is futile based on their knowledge of the treatment's effects, and its likely impact on patient's quality of life.

Ethical rules covering futility can be developed based on socially sanctioned standards of rationality and traditional physician-based values. Clarifying the concept of futility and establishing defensible ethical policies covering futility are important steps toward eliminating unhelpful, medically inappropriate practices.

The norm of beneficence, which directs physicians to apply their insights and techniques for patients' good, has been a basic principle of medical ethics for 2,500 years. Under this principle, physicians do not provide treatments when the interventions at their disposal do not produce medical benefits.

Traditionally, when medical treatment was provided in a paternalistic style (i.e., when physicians made treatment choices without asking their patients' permission), the application of the norm of beneficence was relatively straightforward. Today, however, an ethic of patient autonomy and informed consent has replaced the traditional paternalistic approach that gave maximum authority (as well as responsibility) to the physician. Thus, the principle of beneficence must not be balanced with the principle of patient self-determination.

The question we address here is whether the patient self-determination requirement can compel physicians to make futile interventions – treatments they know provide no benefits and therefore violate the beneficence principle. The futility issue can be a key ethical consideration in cases in which the principles of physician beneficence and patient autonomy appear to conflict.

Physician Beneficence and Patient Autonomy

Patient autonomy, or self-determination is first a right to refuse treatment and then a right to choose from among medically justifiable options. It is *not* a right to demand treatment. Put differently, a patient's right to choose or refuse treatment is limited by the physician's right (and duty) to practice medicine responsibly. The belief that medical professionals ought to respect informed choices of patients, or their surrogates arises, first, out of respect for autonomy. But it is also a consequence of the realization that beneficence is ordinarily best served when patients can judge for themselves the impact of various treatment options on their life plans and personal goals.

Although patients ordinarily choose a course of action they judge to be in their best interests, sometimes they make bizarre and destructive choices. Such irrational choices are not sacrosanct simply because the patient made them. Commitment to beneficence demands at least that physicians try to understand patients' intent and motivation and to influence them to make a rational decision. In some cases, physicians may choose not to act on patient decisions that appear to be unreasonably destructive.

Professional discretion and judgement are always part of the clinical decision-making process. Physicians should communicate with patients throughout the treatment process and must monitor patient participation in medical decision making. Physicians, in effect, make judgements about the nature and relevance of patient values, in addition to making value judgements about medical issues. They evaluate patient competency based on patients' responses to medical interventions, their thoughts about their medical situations, and their reasons for deciding one way or the other.

To suggest that doctors abandon all such judgements and then ignore the personal harm resulting from a risky or useless intervention “because the patient asked for it” is to subvert the core of medical professionalism.² Medical judgements are never value free. However, physicians should be aware of the value components of their decisions and be able to justify them.³

Value commitments (e.g., relieve suffering, do not assist in suicide, do not harm patients, do not cause suffering without proportionate benefit) inform most physician decisions. These professional standards reflect medical values and guide judgments about the appropriateness of a medical intervention for a particular patient. Among these standards should be the following: Do not offer futile treatments as medical options.⁴

The Concept of Futility

The concept of futility has had historic importance in medicine. For Hippocratic physicians, attempting a futile treatment was a display of ignorance.⁵ Contemporary ethical standards published by the Council on Ethical and Judicial Affairs of the American Medical Association (AMA) show continuity with this tradition: “Physicians should not provide or seek compensation for services that are known to be unnecessary or worthless.”⁶

Because the concept of futility has been consistently confused with other concepts and categories, some distinctions are in order. A futile intervention is different from one that is *harmful* (e.g., poison), *ineffective* (like cough drops for a lymphoma), or *impossible* (like a self-administered coronary bypass). Nor is a futile intervention the same as a treatment whose goal is to achieve *uncommon* or *unusual* outcomes, like the long-term survival of a patient with metastatic pancreatic cancer. The issue of whether a situation is deemed *hopeless* is also irrelevant to the issue of futility, since hope is a subjective disposition that can be maintained even in the face of impossible situations. Finally, while certain treatments in certain situations are simply too expensive for a family or society, it does not help to refer to these as economically futile.⁷ Much of the confusion about futility arises when authors claim to be talking about this concept but are actually addressing very different issues.

Some clarity can be achieved by distinguishing futility from ineffectiveness. In contemporary medicine, ineffectiveness is determined statistically on the basis of accepted scientific standards. A 0 percent success rate in 1,000 trials, for example, would constitute an ineffective treatment. Categorizing a treatment as ineffective, however, does not imply 100 percent certainty about its outcome, because the next trial might reveal an effect not evident in the previous 1,000. Another closely related category is highly improbable. In this case, a given treatment may have been successful on a few occasions, but its success can neither be scientifically explained nor reliably predicted.

A futile treatment differs from an ineffective or highly improbable treatment in that it is always somewhat effective (e.g., a temperature is lowered or raised, lung function is sustained). However, futile treatments are fruitless because they do not achieve “worth” in the sense of meeting a patient’s medical goal or providing a true personal benefit.⁸ Doctor-patient communication is sometimes required to know that personal patient benefit cannot be attained, but at other times it is obvious (with the permanently unconscious or dying).

In light of the above distinctions, a medically futile treatment can be more accurately defined as an action, intervention, or procedure that might be physiologically effective in a given case, but cannot benefit the patient, no matter how often it is repeated. A futile treatment is not ineffective, but it is worthless, either because the medical action itself is futile (no matter what the patient's condition) or the condition of the patient makes it futile.⁹

Futility and Patient Consent

Attempts to determine personal patient benefit or acceptable quality of life ordinarily depend on patient input. Should all futility questions then be left up to patients or surrogates? Do futility decisions fall outside physician discretion?

Some medical ethicists think so.¹⁰ We take the opposite position. Determining futility entails evaluations of a medical intervention and a patient's medical status that only a physician can make. Physicians know, for example, that cardiopulmonary resuscitation (CPR) can do no good for terminal patients whose cardiac arrest relates to the natural progression of their disease.¹¹ Even if the patient is incompetent and no family is available to provide input about his or her preferences, physicians in consultation with other team members can decide that a particular treatment cannot achieve medical goals, values, or objectives.

The discussion of futile treatments with patients and family is altogether appropriate,¹² except when such a discussion would cause added and unbearable burden to an already difficult situation. The objective of such discussions is to help patients and families understand the clinical situation and why a particular intervention is not an option. The physician should be as responsive as possible to the patient's physical, emotional, and spiritual needs, but neither consent nor refusal should be requested.

The AMA's Council on Ethical and Judicial Affairs upheld this view in deciding that physicians need not seek consent for a do-not-resuscitate order when CPR is deemed futile.¹³ Informed consent is a process by which competent patients make judgements about real options and, as such,

supposes socially sanctioned standards of rationality. Although some individuals may operate outside these rational limits (e.g., by demanding what is useless or futile), they cannot insist that professional standards and public policies support their preferences.

Beneficence requires that doctors do only what is medically helpful. Individual autonomy cannot be so inflated in importance as to destroy the principle of beneficence. The key to the futility debate is identifying what constitutes legitimate medical help, like most contemporary medical ethics problems, determining futility requires balancing the values and goals of medicine with the goals and values of patients, taking into consideration the uncertainty inherent in making predictive medical judgments.¹⁴ Inevitably there will be some differences among physicians in judging uncertainty and the helpfulness of specific treatments.¹⁵

Ethical Rules, Rationality, and Beneficence

Ethical rules covering futility can be developed based on socially sanctioned standards of rationality and on traditional physician-based values. Several such rules are suggested in the **box**.

Some ethicists argue that allowing physicians to not offer futile treatment to patients would constitute an unacceptable return to paternalistic medical practice. They hold, in effect, that physician assessments of benefit are always suspect, and that benefit is so inherently subjective that even the most idiosyncratic choices must be honored.

Obviously, a physician's decision will reflect his or her values. A professional physician's value judgement, however, will be neither random nor individualistic. If doubt is raised about an instance of physician decision making, the decision can be reviewed by an ethics committee to make sure that beneficence and not some selfish value is operating.

An extreme autonomy position ignores the fact that a well-established "best interest" standard assumes both a connectedness of the patient to family and physician and a communication process that allows surrogates to decide based on objective, community-based best interest standards.¹⁶ The existence of such standards and their relevance to medical decision making can be seen from the fact that five state courts recently permitted forgoing life supports for incompetent patients who had never expressed a previous preference.¹⁷ Without available subjective preference, the decisions were made on physicians' and families' objective evaluations of a patient's best interest.

The current situation, in which patients or their surrogates are commonly (but falsely) led to believe that futile treatments are medically acceptable, actually does violence to the principle of autonomy, as well as to beneficence. It creates a sphere of decision making where (traditionally) none exists and, thus, seems intrinsically deceptive.

Frequently, physicians believe they have done their duty when they allow patients or families to make difficult treatment decisions, even when they have not explained sufficiently the medical and human consequences of the options. In such cases the focus on patient choice diminishes the physician's commitment to professional duty and patient well-being. Thus, we believe that respect for autonomy and beneficence is impaired by allowing patients to choose futile treatments or by claiming that the concept of futility is so inherently subjective that it is useless.

Weakening futility as a workable category has other ill effects. Aggressive treatments that override considerations of futility are frequently justified by standards requiring absolute certainty and by fear of malpractice. Clarifying the concept of futility and establishing defensible ethical policies covering futility are important steps toward eliminating unhelpful, medically inappropriate practices. Even the famous Baby Doe regulations of the Reagan administration, which advocated aggressive medical interventions for infants in almost all situations, recognized an exception for futility and virtual futility, when medical goals could not be achieved, and quality of life had slipped below what is considered acceptably human.¹⁸

The Helga Wanglie Case

The Helga Wanglie case did for the futility issue what the Nancy Cruzan case did for the question of medical alimentation.¹⁹ Wanglie, an 85-year-old nursing home resident, was transferred to a hospital after suffering a heart attack. She had been resuscitated but remained unconscious and on a respirator. Physicians at that hospital considered continued technological life-sustaining support to be futile and wanted to withdraw it. Wanglie's husband refused and had her transferred to another medical center, where she was diagnosed as being in a persistent vegetative state. Again, doctors recommended withdrawal of the ventilator because no medical goals for the patient could be realized.

The family thought the suggestion of withdrawal of life-sustaining technologies reflected moral decay in our culture and hoped instead for a miracle. Ultimately, the hospital went to court to ask whether medical professionals were obliged to provide what they considered to be unbeneficial and inappropriate treatment. The husband (a lawyer) then cross-filed, asking that he be appointed conservator. The court decided in favor of the husband's petition. More than a year after the initial hospitalization, and three days after the court decision in favor of Mr. Wanglie, Helga Wanglie died of multisystem organ failure and septicemia.

Once the Helga Wanglie case was taken to court, we could have expected that the values of the courts would inform its judgment. The judge did not address the issue of medical values or physician discretion in medical practice. Rather, he ruled that the husband was the proper surrogate and that the surrogate's claims about the patient wishes were reliable. In a culture ruled by individual rights and a purely subjective view of autonomy, the surrogate's freedom to decide about treatment held priority over physician or professional judgment about the treatment's futility.

If Helga Wanglie had actually wanted her treatment, it could be argued that she was getting some "benefit" from continuing it in the face of futility. (There is good reason to believe she did not want it.) But this kind of "benefit" is not what is meant by benefit in the history of medical ethics. Personal medical benefit consists of such advantages as restoration of health, cure, pain relief, comfort, alleviation of suffering, and improved well-being or quality of life. The principle of beneficence calls on physicians to help patients achieve those particular goals, not just any goals or any interests.

For Traditional Standards

Futility and physician discretion arguments will increasingly be crowded out by another influence on physician discretion—cost. The need to control medical costs will require that strict statistical measures of effectiveness be used to limit the options physicians can offer.

But independent of limitations on treatment options that might be imposed by considerations of justice and public policy, we have shown that an analysis based on beneficence allows physicians to refuse to offer—in fact, makes it their duty not to offer—futile or ineffective treatments. Futile and ineffective treatments are not acceptable or advisable even if they can be afforded.

The idea that a right exists to futile treatments is absurd, especially when there is not enough money for basic care for millions. Physicians and healthcare institutions need to make a stand for traditional medical rights and professional standards.

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Wanglie: Discussion Questions

1. Who defines "futile" treatment?
2. How is "futile" treatment defined?
3. Might the question of when treatment becomes futile present a conflict between a personal and a social ethic (i.e., between what is good for the individual and what is good for an institution or a larger part of society)? Give an example.
4. Ackerman's article raises the case of the comatose woman who regained consciousness after five and a half months. How are such cases to be handled in the futility debate?
5. Arguing from analogies or examples can be helpful and 'can, at the same time, be immensely unhelpful. At the end of Ackerman's article, she attempts to show that there is no moral distinction between killing and permitting to die. She does so by means of an example of withdrawing a rope from a drowning man. What is the difference between removing a respirator and removing a rope from a drowning man?
6. Has the use of advance directives affected the problem of futile treatment? What if Helga Wanglie had expressed her desire to "have everything done"?
7. Writers in the field of bioethics offer good arguments both for a policy defining futile treatment and against the formulation of such a policy. Where do the members of your ethics committee stand?

Further Readings

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