



## policy points

**A Question of Futility** Physicians, patients, and health-care ethicists often disagree about when care is futile. The AMA has proposed a process to follow in making that determination.

BY JEFF ATKINSON



Helga Wanglie, age 86, slipped on a rug at her Minneapolis home and

broke her hip. The fracture was successfully treated at Hennepin County Medical Center, and she was discharged to a nursing home. Less than three weeks later, she was readmitted to the medical center for respiratory failure for which she was placed on a respirator.

Attempts to wean her from the respirator were unsuccessful.

Subsequently, she suffered a cardio-pulmonary arrest. Mrs. Wanglie was diagnosed

as having severe, irreversible brain damage—persistent vegetative state secondary to severe hypoxic-ischemic encephalopathy. She continued to be dependent on a respirator as well as artificial feeding and antibiotics for recurrent pneumonia.

**The family insists on life support**

The staff at the Medical Center told Mrs. Wanglie's

family that her prognosis was extremely poor and that the respirator would not benefit her. Mrs. Wanglie's husband, daughter, and son, however, insisted that all forms of treatment be continued.

The story is recounted by the Hastings Center of Garrison, New York, a leading institution for the study of ethical issues in medicine. When Mrs. Wanglie's husband, Oliver Wanglie, was asked if

he understood the diagnosis and that his wife would not recover consciousness or improve in a significant way, he responded, "That may be true, but we hope for the best." Mr. Wanglie said only God can take a life and doctors should not play God. (Hastings Center Report, Vol. 21, No. 4, pp. 23-24, July-Aug. 1991).

Regarding his wife's wishes, Mr. Wanglie first said that he and his wife had not discussed issues of life support and that her views were a "black box." Later, after a conference with a representative of the hospital Ethics Committee, Mr. Wanglie said, "My wife always stated to me that if anything happened to her so that she

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could not take care of herself, she did not want anything done to shorten or prematurely take her life.”

The deadlock continued for more than five months—the hospital believing that further treatment was not appropriate and the patient’s family insisting on continued treatment for the unconscious Mrs. Wanglie. The medical director of the hospital wrote a letter to Mr. Wanglie, stating, “We do not believe that the hospital is obliged to provide inappropriate medical treatment that cannot advance a patient’s personal interests. We would continue life-sustaining treatment upon the order of a court mandating such treatment.”

### The court rules

When seven more weeks passed and the Wanglie family did not file any legal action, the hospital filed an action seeking appointment of a conservator to represent Mrs. Wanglie and to decide what treatment was appropriate. The hospital also said it was willing to transfer Mrs. Wanglie to another facility where she could receive rigorous treatment, including respiratory support. Neither the hospital nor Mrs. Wanglie’s family was able to find such a facility.

Thirteen months after Mrs. Wanglie’s second hospitalization and diagnoses of persistent vegetative state, the Minnesota state trial court ruled that decisions regarding life support for patients such as Mrs. Wanglie are best left to family members. Judge Patricia Belois said Mrs. Wanglie’s husband “is in the best position to investigate and act upon Helga Wanglie’s conscientious, religious, and moral beliefs.”

The medical center, although not pleased with the decision, decided not to appeal. Three days after the trial court’s judgment, Mrs. Wanglie

died of sepsis.

The case of Helga Wanglie raises the issues of what is futile care and who should have the power to decide when certain types of care are appropriate.

### Definitions of futility

Commentators have offered different definitions of futile care. One of the most commonly cited definitions is provided by Lawrence Schneiderman, MD, Nancy Jecker, PhD, and Albert Jonsen, PhD, who proposed that care should be considered futile “when physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of published empiric data) that in the last 100 cases, a medical treatment has been useless.” (*Annals of Internal Medicine*, 1990; 112:949-954).

Other commentators seem comfortable with setting the efficacy rate of care considered futile at a higher percent (such as five percent) while other believe treatment should not be considered futile unless there is utterly no chance the treatment would confer a benefit. The American Thoracic Society describes an intervention as futile if it is “highly unlikely to result in a *meaningful survival*.” (*Annals of Internal Medicine*, 1991; 115:478-485) (emphasis original).

In setting standards for futility, physicians have considered a variety of factors, including the number of organ system failures, the degree to which a cancer has metastasized, the patient’s mental functioning, and whether the treatment will only prolong the dying process.

When definitions of futility apply terms such as “useless,” “lacking benefit,” or “meaningful survival,” the definitions become circular. The real issue often comes down to “When is a life not

worth living?” Many (probably most) people would agree that a life in a persistent vegetative state is not worth living. Mere continuation of biological existence is not enough.

For most individuals, life derives meaning from awareness of and interaction with one’s environment—to have the opportunity to communicate with others, to do useful work, to grow in understanding of life. Dr. Schneiderman and his colleagues seemed to share this view when they wrote, “If a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive medical care, then treatment should be considered futile.”

Some people, however, disagree, apparently including the family of Helga Wanglie, who derived comfort from Mrs. Wanglie’s continued biological existence.

### Value judgments

The decision of when care is futile combines the application of medical expertise with value judgments. Physicians have expertise on whether a particular treatment is likely to cure a patient, restore a level of functioning, or have a palliative effect. But physicians do not necessarily have more expertise than the general public regarding when life is worth living and the amount of resources that should be utilized to maintain life.

Life, of course, involves a continuum of levels of functioning. People may differ on the appropriateness of maintaining life for themselves or a family member in a variety of circumstances, including: chronic vegetative state; partial consciousness with significant pain or heavy sedation because of a cancer that will soon take the patient’s life; terminal cancer at an earlier stage; progressive

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respiratory failure; severe dementia; moderate dementia; and varying levels of developmental disability.

The laws in the United States favor letting patients and their family members make health-care decisions rather than leaving treatment to the complete discretion of physicians. Competent patients have a right to accept or decline treatment, including treatment that generally would be considered beneficial.

In addition, federal and state laws encourage patients to sign advance directives, such as living wills and powers of attorney for health care, to specify what they want done in the event they were not able to communicate their wishes to health-care providers. If a patient has not made an advance directive, family members generally have the power to make decisions on the patient's behalf.

When a physician declares that treatment is "futile" based on her own perception of when life is not worth living, there is concern that the autonomy of patients and their families has been undermined. In such cases it may seem that the practice of medicine has returned to the days of paternalism in which doctors did not adequately consult with patients and provide informed consent in order for patients and their families to make decisions about their care.

In the words of Susan Wolf, "futility" should not become a "powerful tool for relieving physicians of the requirement to talk with their patients." (*Law, Medicine, and Health Care*, Winter 1988, 16:199).

### Different from rationing

Futility in health care should not be confused with rationing of health care or determining health care's cost-effec-

tiveness. If health care is considered futile, the determination has been made that the treatment or procedure will not benefit the patient (or that the likelihood of benefit is very low). Care which is withheld because of rationing or because it is not considered cost-effective, on the other hand, usually would provide benefit to the patient, but the benefit is not considered worth the price.

Thus, for example, in cases of rationing, a person over a certain age (such as 85) or a person with terminal cancer is unlikely to receive an organ transplant, even if the treatment would provide some benefit to the patient. The frequency with which expensive diagnostic tests are conducted also might be controlled—not because the test would not benefit the patient, but because the payer wants to control costs.

If health care is to be explicitly rationed, one method of rationing could be to come up with a dollar amount which society (or its insurers) is willing to spend to provide a person with an additional year of life. If the amount were \$25,000, for example, a liver transplant (which might cost about \$500,000) would be considered appropriate for a person who was 30, but probably would be considered inappropriate for a person who was 85 or whose life would be substantially shortened by another disease. Appendectomies presumably would be covered for all ages, as would comfort care.

In the case of Helga Wanglie, the cost of her care during the one-year period from the time of her diagnosis of persistent vegetative state to the first court hearing was approximately \$800,000. That amount was reimbursed by Medicare and her supplemental insurance.

### AMA proposes a solution

Last spring, the American Medical Association's Council on Ethical and Judicial Affairs proposed a process for making determinations of futility. (*JAMA*, Mar. 10, 1999; 281:937-941). The proposal begins by respecting "the reality that objectivity is unattainable." In circumstances in which absolute rules and definitions cannot solve a problem, the council proposes "a fair process for resolution."

The Council suggests that general parameters for determining futility should be set by regulatory bodies or health-care institutions within a community. Persons developing the parameters should include not only health-care professionals and other experts, but also representatives of patients and the public. Through open participation and publication of the parameters, the parameters will have more legitimacy and the community will have more "ownership" of them.

For individual cases, the Council encourages the physician, the patient, and the patient's proxy to negotiate an understanding of what constitutes futile care. It is best if this can be done before a critical illness occurs. If a serious disagreement cannot be resolved, transfer of care can be arranged, with the transfer taking place immediately or at a later time as the parties agree.

Further joint decision-making would take place at the patient's bedside as the illness unfolds. Decisions would be based on outcomes data, when possible, and on the patient's goals. As part of this process, a consultant or patient's representative might be brought in, not only to give a second opinion, but also to facilitate discussion.

If a dispute continues, despite assistance from a consultant or patient's rep-

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representative, the institution's ethics committee could become involved. The committee's involvement, whether by the full committee or an ad hoc sub-committee, should be structured to insure that the patient or the patient's proxy has a full voice in the process.

If the ethics committee agrees with the patient, but not with the physician, and the physician remains unpersuaded, arrangements could be made to transfer the patient to the care of another physician in the institution.

If, on the other hand, the ethics committee agrees with the physician and disagrees with the patient, the patient could be transferred to another institution. If transfer is not possible, the service requested by the patient or the patient's proxy need not be provided, presumably because the service is considered contrary to medical standards or ethics. The council notes

that the legal consequences of not providing a service are uncertain.

### Religious beliefs vs. resources

Views about the meaning of life and what constitutes futile treatment can be compared to, and indeed overlap with, views about religious beliefs. Each person has a right to his own beliefs, but that does not mean an individual has the right to insist that society actively or economically support these beliefs.

On the issue of providing care that many people would consider futile, a person has a right to obtain that care as long as they can find a willing provider, pay for it themselves, and no one else is hurt by the actions. When it comes to spending society's money (either by government payments or through insurance companies), society has a right, after using a reasonable process, to decide what it will pay

for and what it will not pay for.

Daniel Callahan, PhD, a leading writer on medical ethics and co-founder of the Hastings Center, has observed, "Life was easier when we thought 'medical necessity' and 'futility' were scientifically discoverable." (*Hastings Center Report*, Vol. 21, No. 4, p. 35, July-Aug. 1991).

In cases such as that of Helga Wanglie, our society may never develop a complete consensus on the definition of futility and where the line should be drawn in deciding when to provide health care and when not to provide it. Nonetheless, increased dialog on these issues will help guide physicians and patients in making such decisions. ■

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