

# Exploring the Medical Futility Debate: The Case of Helga Wanglie

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*Helga Wanglie 's physicians argued that they should be allowed to discontinue her treatments since continuing to treat her was futile. Wanglie's husband disagreed. One might be tempted to think the judgment of futility should be pretty cut and dried. But this is not always the case.*

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## **BACKGROUND**

Helga Wanglie broke her hip in December 1989 after a fall in her home. She was 86. She was treated in hospital and moved to a nursing home, but a month later she was readmitted for respiratory complications and needed to be placed on a ventilator.

Attempts to wean her were unsuccessful. As a result, she was transferred to a long-term care facility that specialized in ventilated patients. While there, she suffered a cardiac arrest with anoxia that resulted in severe, irreversible brain damage. She remained in a persistent vegetative state. Meanwhile, she also remained in a state of permanent ventilator dependency.

Because of her dismal prognosis, the medical staff suggested that her family consider

termination of treatment. However, the family decided against any withdrawal of care, as she was apparently heard to have said "If anything happens to me, I want everything done". The matter went to court. In its decision, the court rejected the hospital's position and turned over full guardianship to Helga's 87 year-old husband. Helga Wanglie died of multisystem organ failure on July 4, 1991. Medical bills totaled approximately \$750,000 [1-3].

## **DISCUSSION**

If one were searching for a case to use for starting a classroom discussion on futile care theory, this case would be an excellent starting point. Few clinicians would disagree that Helga Wanglie's case was completely hopeless, and almost all would also agree that there would be no clinical value in continuing extraordinary measures such as mechanical ventilation. Yet Helga Wanglie's husband fought for continued treatment of his wife despite these facts. His conflict with the medical profession highlights many of the issues involved in futile care ethics.

### **Medical Futility Theory**

The concept of futility has had historic importance in medicine. According to Drane and Coulehan [4], for Hippocratic physicians, attempting a futile treatment was a display of ignorance. They also note that 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." Drane and Coulehan recognize, however, that patients and their families may not agree:

‘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 physician's 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 a patient's quality of life.’

Ethical principles dealing with medical futility can be developed based on the traditional bioethical principle of beneficence, as well based on traditional physician values identified above. Under the principle of beneficence, which directs physicians to apply their skill and knowledge only for the good of their patient, physicians should not provide treatment known not to produce clinical benefits. Some authors go further. For example, McGee et al. [5] state: “Withholding futile treatments supports the ethical principles of both nonmaleficence (do no harm) and beneficence (relieve suffering).” Finally, the Catholic Health Association of the United States has issued a statement of principles on the issue (see Appendix).

Modern arguments against futile care generally center on two issues. First, futile care has no possibility of achieving a good outcome and serves only to prolong death. No physical or spiritual benefit comes from such care. Futile care also prolongs the grieving process and frequently raises false hope. Also, futile care can be very difficult on caregivers, who may see themselves as forced to act against the best interests of their patient [6,7].

Secondly, in a setting of limited resources, futile care involves the expenditure of resources that could be used by other patients with a good likelihood of achieving a positive outcome. This second argument would appear to be strong in those nations with socialized health care systems.

## **Families Seeking Futile Care**

The above notwithstanding, families occasionally seek to ensure that their loved ones get heroic or extraordinary care even in the absence of any likelihood of clinical benefit.

However, in most of these cases the family eventually comes to realize that there is no possibility of a good outcome from such efforts, and end up agreeing with the clinical team. But not always.

One famous case is that of Baby K, an anencephalic infant. The infant's mother wanted the hospital to continue with advanced supportive care (primarily ventilatory support) against the wishes of the clinical team, and sought legal support for her position. Ms. H. knew of her baby's condition from the second trimester of her pregnancy, but, motivated by a strong religious conviction that "all life is precious" and that God alone should decide how long the baby would live, she remained adamant that Baby K. be kept alive as long as possible.

The hospital's position was that such care would be futile. At the trial [Matter of Baby K. 16 F.3d 590 (4th Cir. 1994), n. 9 at 598.], expert testimony was given to demonstrate that provision of ventilator support for anencephalic infants goes beyond the accepted standard of care. The legal team for Baby K's mother adhered to a religious sanctity-of-life principle as the basis for their case. In the end, in a particularly controversial decision, the U. S. District Court ruled that the hospital caring for Baby K must put her on a mechanical ventilator whenever she had trouble breathing. In particular, the court

interpreted the Emergency Medical Treatment and Active Labor Act (EMTALA) to require continued ventilation for the infant. The wording of this act requires that patients who present with a medical emergency must get "such treatment as may be required to stabilize the medical condition" before the patient is transferred to another facility. The court took the position that "it is beyond the limits of our judicial function to address the moral or ethical propriety of providing emergency stabilizing medical treatment to anencephalic infants. We are bound to interpret federal statutes in accordance with their plain language..." As a result of the decision, Baby K was kept alive much longer than most anencephalic babies, living to age 2 ½ .

The cases of Baby K and Helga Wanglie vividly demonstrate how family and clinical caregivers may sometimes see matters very differently. Such differences usually reflect very different philosophical vistas, and cannot always simply be dismissed as being based on ignorance on the part of the family. For instance, some people take the "sanctity of life" argument to its extreme, arguing that all efforts to sustain life should be made wherever clinically possible, no matter how degraded that life may be. While much has been written to refute this position (see, for instance, the writings of Peter Singer [8]), such (usually always secular) counterarguments generally have little or no impact on individuals invoking such arguments based on personal religious beliefs.

Some other individuals may argue that clinical care should be a market commodity that one should be able to purchase just like cruise vacations or luxury automobiles, as long as the purchaser of the clinical services has the necessary funds and as long as other patients

are not being denied access to clinical resources as a result. In this model, Helga Wanglie should be able to get ICU care until funding vanished.

In my view, this market-oriented viewpoint is either naïve or wrong in several respects. First, in almost all such cases the funding comes from insurance carriers, who must avoid “wasting” funds to ensure that adequate funds are available for other clients. Secondly, competition for ICU resources can be intense, and providing ICU care to patients who will not benefit from them only makes access more difficult for patients for which ICU care would prove to be clinically beneficial. Finally, to view clinical care as a mere market commodity or service is to detach it from its underlying dignity and humanity.

### **The Case Against Medical Futility Theory**

Are there, then, any potential problems with futile care theory? Could it be that the issues are not as cut and dried as the clinical community would have it?

In this respect, it is helpful to consider matters from the perspective of those who disagree with the traditional clinical view regarding futile care. For Helga Wanglie and her husband, all human life - even a degraded and permanently unconscious human life – is still taken to be valuable, regardless of any considerations of quality of life. Similarly, the mother of Baby K no doubt saw her infant’s life as infinitely valuable, even if incapable of a conscious existence.

One criticism of futile care theory is that the caregivers sometimes see things only from the perspective of their training, and thus seek to be the only decision-makers in these matters. However, as noted by Weijer and Elliott [9], for clinicians to be the sole decision-makers in these situations amounts to saying to families, "Your values don't count."

Weijer and Elliott [9] go on to note that different viewpoints concerning the goals of treatment may form the basis for disagreements between families and clinicians:

“... judgments of futility make sense only in relation to a specified goal: an intervention may be futile if the aim is to cure an underlying disease but effective if the aim is to keep the patient alive. Yet in the most controversial cases in which futility is invoked the disagreement between doctors and families is not about the probability that an intervention will work but about the goals that it will serve.”

“... the concept of medical futility is a tarbaby. It cannot do what it is asked to do, and trying to force the issue won't produce a solution; it will produce a mess. When patients or families demand treatment that is unlikely to produce a good outcome doctors ought to disclose carefully the treatment options, the likely outcomes, and the probabilities of attaining those outcomes. Clearly, both the doctor's judgment and that of the patient (or family) are essential to the decision making process. ... This can be achieved only by an open and frank dialogue. Invoking futility ensures, if anything, that this will not occur.”



Another problem confronting futile care theory is that invoking the principle of futility is sometimes in direct conflict with the principle of patient autonomy. As the case of Helga Wanglie illustrates, when families make end-of-life decisions in conflict with caregivers, and the case ends up in court, the courts are often strongly influenced by concerns for patient's right to autonomy. As Weijer and Elliott note [9]: "Futility is not the ethical trump card that some would like it to be."

Another problem with futile care theory is that even defining the notion of clinical futility can be challenging. McGee et al [5] emphasize that various definitions are used in the literature:

"The term medical futility has been used to describe life-or-death situations in which proposed treatments will fail to prolong quality life, achieve the patient's key goals for medical care, achieve a critical physiologic effect on the body, or result in a therapeutic benefit for the patient. Another definition of futility states that "if a treatment merely preserves permanent unconsciousness or cannot end dependence on intensive medical care, the treatment should be considered futile." In an attempt to give a quantitative definition of futility, some have suggested that treatments with less than a 1% chance of benefiting patients should be considered futile."

The Ethics Committee of The Society of Critical Care Medicine has attempted to clarify the concept of futility with a policy statement. They emphasize, among other things, that

care that is extremely unlikely to be beneficial is not necessarily futile in nature [10].

They write:

“Treatments should be defined as futile only when they will not accomplish their intended goal. Treatments that are extremely unlikely to be beneficial, are extremely costly, or are of uncertain benefit may be considered inappropriate and hence inadvisable, but should not be labeled futile. Futile treatments constitute a small fraction of medical care. Thus, employing the concept of futile care in decision-making will not primarily contribute to a reduction in resource use. Nonetheless, communities have a legitimate interest in allocating medical resources by limiting inadvisable treatments. Communities should seek to do so using a rationale that is explicit, equitable, and democratic; that does not disadvantage the disabled, poor, or uninsured; and that recognizes the diversity of individual values and goals. Policies to limit inadvisable treatment should have the following characteristics: a) be disclosed in the public record; b) reflect moral values acceptable to the community; c) not be based exclusively on prognostic scoring systems; d) articulate appellate mechanisms; and e) be recognized by the courts. Healthcare organizations that control payment have a profound influence on treatment decisions and should formally address criteria for determining when treatments are inadvisable and should share accountability for those decisions. “

Finally, futility theory may be challenged on a statistical basis. While scenarios like providing ICU care to the brain dead patient or the anencephalic patient when organ

harvesting is not possible or practical are easily identifiable as being completely futile, many other situations usually taken to be futile are far less clear. For instance, should surgeons attempt a heroic clinical rescue in a 99 year old unconscious patient with a ruptured abdominal aortic aneurysm, even though survival with a good outcome would be so very unlikely as to warrant publication of the case as a clinical case report? Various bleak clinical scenarios will vary in their degree of futility. For instance, when elderly patients sustain large third degree burns, mortality is almost guaranteed. This is similarly true for elderly patients sustaining massive trauma. But in many of these cases it can still be very difficult to accurately predict outcome [11, 12].

As Weijer and Elliott note:

“... problems will arise with any criterion that allows doctors to rely solely on their own experience. Their recollections are biased towards cases with a poor outcome. Moreover, doctors' judgments about individual cases are not accurate enough to allow them to claim reliably that a given person has (for instance) less than a 1% chance of responding to treatment. While the agreement of several colleagues about a prognosis may improve the judgment's reliability, support from the literature may be lacking. Even if empirical data exist on a particular intervention, the vast majority of "negative" clinical trials have a sample size that is too small to provide strong enough evidence to rule out a small treatment effect.”

## **Conclusion**

A case against medical futility theory can be developed based on several grounds.

First, many people have religious beliefs that invoke the notion of sanctity of life and hold to that view regardless of the quality of that life. However, to ignore the closely-held religious beliefs of a person or his family is certainly not respectful of them as persons.

Secondly, disagreements between doctors and families concerning futile care matters are often not so much about the probability that an intervention will work but about the goals that it will serve. Thus, for clinicians to be the sole decision-makers in these situations amounts to saying to families, "Your values don't count."

Another problem confronting futile care theory is that invoking the principle of futility is sometimes direct conflict with the principle of patient autonomy.

Finally, futility theory may be challenged on a statistical basis. That is, doctors are not always able to determine when there is no reasonable hope of a good outcome from a clinical intervention usually taken to be futile.

## References, Sources and Notes

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[2] <http://www.geocities.com/HotSprings/Oasis/2919/cases.html>

[3] <http://www.missouri.edu/~philwb/wanglie.html>

[4] James F. Drane, PhD, & John L. Coulehan, MD . The Concept of Futility. Patients Do Not Have a Right to Demand Medically Useless Treatment. Health Progress 1993.

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[7] For a somewhat different view from that of Perkins (above) consider the perspective of Dagi. Dagi argues against making the emotional needs of the caregiver an overriding consideration in clinical ethics, arguing that the claim of health care workers to be a professional “places legitimate constraints on the extent to which they may be permitted

to have their needs and wants influence the ethical dialectic.” T. F. Dagi, "Compassion, Consensus, and Conflict: Should Caregivers' Needs Influence the Ethical Dialectic?" *The Journal of Clinical Ethics* 3 (1992): 214-18.

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## APPENDIX

### ETHICAL GUIDELINES FOR DETERMINING FUTILITY

*Catholic Health Association of the United States.*

- A treatment is futile and the physician should not present it to a patient or surrogate as an option when, for example, the treatment:
  1. Does not alter a person's persistent vegetative state
  2. Does not alter diseases or defects that make a baby's survival beyond infancy impossible
  3. Leaves permanently unrestored a patient's neurocardiorespiratory capacity, capacity for relationship, or moral agency
  4. Will not help free a patient from permanent dependency on total intensive care support
  
- Because they require assessment of medical interventions and their relation to medical goals, decisions about futility are made by physicians, even though they involve considerations of patient benefit or patient

quality of life. Some quality-of-life judgments are linked with traditional medical goals and values and assume public standards of rationality.

- Because medicine is directed to patient benefit, not everything a doctor can do falls within the ethical goals of medicine.
- Futility always involves a failure to achieve a medical goal or a personal good. If patients do not benefit in a medical sense, even temporarily effective treatments are futile and physicians have a right (indeed a duty) based on the principles of beneficence and nonmaleficence not to offer them.

**SOURCE:**

<http://www.chausa.org/PUBS/PUBSART.ASP?ISSUE=HP9312&ARTICLE=B>