Futile Care Policy

Lessons Learned From Three Years' Experience in a Community Hospital

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After reviewing intensive and life supportive care for patients in whom it was probably inappropriate, the hospital bioethics committee established a futile care policy. The issues we encountered in the first 3 years since the policy became effective should be instructive for other hospitals, physicians, and families.

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Santa Monica-UCLA Medical Center is a nonprofit community teaching hospital. It is in an area where many homeless people use the emergency department and twenty nursing homes transfer patients to the medical center for acute care. In the past few years, as with many hospitals, its bed capacity of 367 has not been matched by its bed occupancy, which is now about 50%. Managed care contracts and discounts, Medicaid low reimbursement, and Medicare DRGs (diagnosis-related groups) have combined to make the hospital's financial state precarious.

In my position as Director of Medical Education, I have been involved not only with clinical care education but also with bioethics and cost-effective care training. While studying the clinical case records of the medical center's largest financial "losers" in 1990 and 1991, I learned that one-third of those patients (thirty) had been transferred from nursing homes. They arrived at Santa Monica-UCLA Medical Center with acute illness superimposed on multiple chronic ailments or with severe dementia and an intervening illness. We were devoting tremendous resources to these patients and subjecting some to inappropriate examinations, therapy, and unnecessary suffering, in a cause that could not produce restoration to a satisfactory quality of life or even survival. As a response to these problems, we developed the "futile care policy," which has been a subject of much curiosity since it was mentioned in the JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION.[1]

Development and Operation of the Policy

Thirty nursing home patients were studied by medical record review and outcome and by interviews with the attending doctors. On the basis of this information, a futile care policy was adopted by the hospital bioethics committee in early 1992. The bioethics committee, which has been functioning for 11 years, has 20 members including physicians, social workers, nurses, clergy, administration, a psychologist, a lawyer, and a community representative. Seven members have had formal bioethics courses, and the others are urged to read distributed material.

The policy was explained in the hospital staff bulletin and at educational conferences. Since the policy was adopted, eighteen patients have been referred to the ethics committee for "futile care" advisory consultation. We encourage the doctor, patient, and family to work out any medical ethical dilemmas themselves, without committee involvement, as has been traditional. We attempt to frame the issues and suggest ways to resolve them. We do not do formal consultations that are recorded on the chart, and our recommendations are not mandatory.

The Futile Care Policy

Futile care: Any clinical circumstance in which the doctor and his or her consultants, consistent with the available medical literature, conclude that further treatment (except comfort care) cannot, within a reasonable possibility, cure, ameliorate, improve, or restore a quality of life that would be satisfactory to the patient.

Examples:

1. An irreversible coma or persistent vegetative state;
2. Terminal illness in which the application of life-sustaining procedure would serve only to artificially delay the moment of death;
3. Permanent dependence on ICU care.

When the attending physician believes that further care (other than comfort care) is futile, but the patient or the patient's family insist on continuing the effort,

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1. The attending physician should take enough time to carefully explain to the aware patient and to the family the nature of the ailment, the options, and the prognosis. The doctor should explain that abandoning the treatment does not mean abandoning the patient in terms of comfort, dignity, and psychological support.
2. The attending physician should provide the names of appropriate consultants to provide an independent opinion concerning the futility of the situation.
3. The assistance of the nurses, chaplain, patient care representative, and Social Services should be offered to the patient's family. A joint conference with the doctor is desirable.
4. At the attending physician's request, the Bioethics Committee may be called to consider the matter and offer advice and counsel to the physician or family.
5. Adequate time should be given for the patient and family to consider this information.
6. If all of these steps are taken and the family remains unconvinced, neither the doctor nor the hospital is required to provide care that is not medically indicated, and the family may be offered a substitute physician (if one can be found) and another hospital (if available).
7. If the patient can no longer benefit from an acute hospital stay and the patient or family insists that the patient stay, the mechanism for personal payment can be invoked.

Case Reviews

Ten problem cases were resolved by a single committee consultant, and eight came to the full committee. None of these patients had advance directives (now 20% of our patients do). All the patients lacked capacity to reliably understand or communicate their wishes, so decisions were made with families or conservators. In only two situations did families oppose the medical recommendations throughout the process. In the other situations, the families and consultants agreed to stop life support; the families and consultants agreed to a time-limited trial of therapy; the patient died during deliberations; or the outcome was delayed because of indecision by the family or medical team, failure to conform to the futile policy in a timely way, or conservator appointment.

Disagreements About Life Support

We originally assumed from our first experiences that conflicts arose from the families' opposition to the physician recommendation to discontinue life support. We were surprised to learn that many other scenarios are involved:

- The physician wants to continue and the family wants to stop.

An 84-year-old patient with a previous hip fracture was demented and in respiratory failure. The patient was placed in the ICU on a ventilator and given tube feeding. The patient's son wished to stop the ICU care; the doctor insisted on continued care but later agreed with the committee's recommendation.

- The physician wants to continue and is opposed by nurses, residents, or consultants.

The wife of an 84-year-old man on dialysis cared for him at home for 2 years. He did not communicate. He came to the hospital after a stroke requiring ventilator, tube feeding, and continued dialysis. After 4 weeks in this state, residents, consultants, and nurses wished to stop life support, but the attending physician considered that "too psychologically damaging for the wife." When the wife was consulted, however, she readily agreed to stop.

- The physician is concerned about legal or ethical issues if he or she stops life support.

An 82-year-old man, suffering from severe generalized atherosclerosis with heart, brain, and renal problems, developed leg gangrene. Surgery was not recommended, and enough morphine to relieve pain caused respiratory depression. The doctor worried about his legal status if he pushed morphine to the point of death. He was reassured by the ethics consultant.

- Intra-family disagreement on proper action.

A 68-year-old diabetic man was on dialysis after a stroke, an amputation, and renal failure. Three family members requested that he be allowed to die; one son, who was the most adamant, objected. The care continued for weeks.

Multidisciplinary Case Conference

When problems cannot be resolved between the doctor and the family, we have found that the multidisciplinary case conference is helpful. It is also one of the most difficult to accomplish. Assembling all concerned, including all the consultants and family, is difficult to schedule, often very time-consuming, and not financially rewarding for the doctors. Thus the meetings often do not occur or do not occur in a timely fashion. The interpersonal skills necessary to handle such a meeting well can be lacking; we have started a training process to enhance communication skills.

The Bioethics Committee

Despite our efforts, some families are reluctant to concede "futility" and to agree to limited treatment even after committee consultation.

- An 84-year-old woman with diabetes and heart failure had a stroke, leaving her in a vegetative state. After 3 months requiring dialysis for renal failure, a ventilator, and parental feeding, she had bedsores, infection, and gangrene. Two sons, one of whom is a physician, refused to stop life support because "their religion demand[ed] that they leave life and death to God" and wait for a miracle. One son had an especially dependent relationship with his mother and a suspicious attitude toward the caregivers and the hospital. He made threats against the doctor, the nurses, and the hospital. Despite the recommendations of the physicians and the ethics committee, the hospital refused to discontinue life support for fear of lawsuit. After 12 months, the patient died with all life support still in operation.
- A 67-year-old man had had a stroke, had coronary

disease, respiratory failure, and sepsis, and was quadriplegic and in a vegetative state. His wife was very devoted to life no matter how restricted. "I would never take my dog to a vet to put him to sleep," she said. "Why should I do that to my husband?" An independent consultant of her choosing convinced her to stop life support.

- A 32-year-old man had AIDS and severe fungus infection of the brain and was unresponsive to treatment. He had multiple complications. Repeated administrations of CPR restarted his heartbeat. The family refused to allow a "no CPR" order. On the tenth cardiac arrest, CPR was not successful and the patient died.
- Our first full committee futile care meeting needed to be revisited, since we were wrong in our assessment of the likely medical outcome and were probably biased against a man with a self-inflicted wound. An 85-year-old man with cancer of the prostate metastatic to the bone had severe pain. Attempting to relieve the pain, he got drunk and shot himself in the abdomen, incurring severe injury to his stomach, bowel, kidney, spleen, and pancreas. After multiple surgeries, shock, and infusion of 26 units of blood, he stabilized on a respirator, feeding tube, and dialysis. After 2 months, his doctor wanted to stop life support, expecting him to be continually ICU-dependent. His wife and daughter bombarded the ethics committee with pleas to continue. The committee agreed with the physicians. When the man was taken off the respirator, he was able to breathe on his own and came off of dialysis. He spent the last 6 months of his life in a nursing home, conversing with his family and in reasonable comfort.

Time to Consider

Guideline number 5 states: "Adequate time should be given for the patient and family to consider this information." Discussions must start early, must be gradual, and must be realistic without being cruel. When a family wishes to persist with or start a certain intervention that is unlikely to succeed, a time-limited trial (such as 2 days to 2 weeks) is encouraged.

For example, a 58-year-old woman who had had a liver transplant was in liver and respiratory failure. Her husband, who was a physician, wanted continued ICU care. He agreed to a 2-week trial after which the respirator was discontinued and the patient died.

Enforcement

Guidelines 6 and 7 state that "the family may be offered a substitute physician (if one can be found) and another hospital (if available)" and that "the mechanism for personal payment can be invoked." Neither of these articles, which were meant to bring families to our way of thinking, has been invoked. For one thing, no other physician or hospital is likely to accept a patient under these circumstances. The "pay or leave" demand is probably too coercive for the hospital or the physician's malpractice carrier or public relations advisor to accept.

Defining Futility

Our attempt to define "futile care" is clearly not as quantitative as suggested by Schneiderman et al,[2] is somewhat ambiguous, and relies on a few major examples. The definition seems to work in our hospital, however, and generally people are satisfied to leave it as is. The phrase "consistent with the medical literature" encourages doctors to search for more prognostic and therapy information than they may have at hand. "Quality of life acceptable to the patient" is an important statement. We often hear medical personnel say, "I would not want to be kept alive in that circumstance".

An article by Tomlinson and Czlonka[3] criticizes our futile care definition as giving "two different answers at once" because we allow doctors to make "value laden" judgments and also allow the patient to decide what constitutes satisfactory quality of life. After reflecting on these comments, our committee has decided that ambiguity in these situations is just right. If a patient wishes to have continued life support in a permanently vegetative state and has so indicated in an advance directive completed when he or she was competent to do so, we regard it as our obligation to provide that support. Exceptions might include the following:

- the appointed surrogate requests discontinuation of treatment;
- other complicating illnesses which produce much uncontrollable suffering intervene;
- society decides—by health care regulation or legislative action—that it will no longer financially support these type of patients;
- a court decision.

The doctors' "notorious value laden judgments regarding what will count as reasonable, cure, ameliorate, terminal"[3] are just the kind of judgments doctors are in the best position to make, and we have been doing so for many years. The system has introduced the counterbalancing influences of patient autonomy, advance directives, family conferences, health care teams, and bioethics committees. We agree that "a workable futility policy cannot be a policy that imposes a definition on practice. It must instead be a policy that creates a process for negotiating and developing, case by case, a consensus on the rightful limits of patients' demand for treatment."[3] Tong[4] compliments us for doing just that (with the exception of the "penalty" clauses).

Our policy evolved through case-by-case experience and is still evolving. With our policy as an organizing statement of principle and used only as a guideline, not a command, we have a useful definition of futility that is open to interpretation and change. The definition of futile care will depend on culture, values, religious beliefs, medical progress, and the emotional state of those involved. I hope that it will not be a strictly cost-driven definition.

But the question must be faced: who will pay to support the care of patients whose families or doctors believe that even the most diminished life must be preserved at any cost? One of our patients was on life support for 12 months at a net loss to the hospital of about $750,000. We have agreed in our ethics committee that cost is a legitimate (but not first priority) subject for ethical consideration since it involves just distribution of scarce resources. Our futile care policy was stimulated by a study of patients whose care involved large losses in a hospital with financial difficulties. We cannot say whether the policy has made a difference financially because there are so many other variables, but we are seeing earlier discussions and decisions in these cases, more staff awareness, a strategy for conflict resolution, and a general raising of consciousness. Staff doctors are also better educated regarding ethical issues and real versus imagined legal threats. It is sobering, however, that in 3 years the policy has caught the attention of only half of the medical staff, as determined by response at meetings.

Resisting the Futility Concept

Some reasons why patients or families might resist our recommendations, as stated by families of the 18 patients, are listed in Table 1. With regard to item 5, when patients are brought to the emergency room and admitted to the care of an attending doctor and his consultants, the family has not had time to establish a trusting relationship. I suspect we will see more of this problem as managed care restrictions impair the patient-doctor relationship.

In an "impasse on futility," when neither the doctor nor the family will concede, our only tools are understanding, kindness, reasoning, and time. A seminal and persuasive paper by Morreim[5] mentions "intractable conflicts of deeply held beliefs about the value of life" and practical dilemmas of how best to permit the parties to honor their own values without coercion. James Nelson[6] makes the following preliminary recommendations for clinicians faced with fundamental disagreements with patients and family: 1) Meet with family members on terms of equality seeking a respectful meeting of moral agents and 2) seek understanding, not winning, as a goal. Commenting on the values conflict between doctor and family, Lantos[7] divides the issues into power, money, trust, and hope and concludes that "futility determination must be made openly, honestly, and in a publicly accountable way. Careless, insensitive, or unaccountable use of such determination will only increase distrust."

Table 2 lists why doctors are reluctant to invoke the futile care policy, as determined by interviews or statements to the ethics committee. The most common reason is the attitude that death is the enemy, that we are "clinical warriors" against death as described by Nuland,[8] and that modern medicine is so advanced that application of yet another new technology or trial will surely lead to the rescue of life. Fear of missing something, a compulsion to be thorough and to leave no possibility untried, is a style acquired in medical school that sometimes goes beyond reason. Another common reason is fear of a lawsuit, even though an advance directive may exist or the patient and family may have indicated they want nothing more than comfort care or consultants agree that the time has come to forgo treatment. The public and other professions underestimate the profound discomfort doctors feel about being named in a lawsuit whether the lawsuit has any merit or not. Emotional distress, time demands, and bad publicity drive some of us to irrationally prolonging life support at the expense of the suffering patient and family.

We have tried by organizing meetings, disseminating handouts, publishing in the medical staff bulletin, and making personal contact, to dispel the uncertainties concerning competing ethical issues, policies, and the law. The articles by Meisel[9] and Kapp[10] have helped regarding legal matters. As more doctors understand these principles, they may recognize that their life-sustaining efforts cannot meet the patient's goal and that they should concentrate on relieving pain and suffering of all kinds. The paper of Gregory and Cotler[11] is recommended for these issues. In its conclusion the authors state: "Pronouncements of futility can hide uncertainty, can cloak fear or lack of knowledge and skill, can mask paternalism or prejudice, can excuse bedside rationing, can veil frustration and hostility, and can absolve or excuse the temptation to give up on a particular patient."

Table 1.—*Reasons Patients and Families Insist on Continuing Futile Care*

- Hope that new therapy will come along in time.
- Religious or cultural traditions; strong belief in prayers being answered.
- Person of unusual courage and optimism—or denial.
- Needs time to see loved one, say good-bye, make the decision, financial considerations.
- Inadequate explanation by trusted physician.
- Family disagreement.
- Sense of heavy responsibility or guilt.
- Time to accept sad reality.
- Too grief-stricken to consider carefully what the patient would want or what is in the patient's best interest.
- Suspicion of hospital system plot to relieve financial burden.

Table 2.—*Reasons Doctors are Reluctant to Stop or Not Begin Futile Care*

- Uncertainty regarding hospital policies, legal issues, or selecting among conflicting values.
- The stand-in or "covering" doctor takes a "holding position."
- A consultant recommends technology or therapy in which he or she has expertise even though it has a very slim chance of providing any real help.
- Death is the enemy.
- Religious or cultural convictions.
- Desire to please the patient's family.
- Fear of lawsuit.
- Self-induced or peer-induced pressure to be thorough.

Table 3.—*Issues masquerading as futility*

- It costs too much money.
- The patient is too troublesome.
- This person is "not worth treating." The patient is too old.
- The patient brought this on himself or herself, doesn't deserve saving, will do it again.
- The patient has no strong family or friend to be an advocate.
- If I were in this situation, I wouldn't want to continue living.

Issues Masquerading as Futility

Table 3 lists other issues we encountered in our discussions of futile care, ones that turned out not to be futile care issues at all, but rather hidden agendas for other matters. Loewy and Carlson[12] discuss some of these, pointing out that many of our activities may be considered futile but have value as symbols that comfort and reassure us. They remind us that futility decisions may be reserved for the poor, the old, and the powerless. They remind us that the real question in some cases is the terrible expense and not the impossibility of medical benefit. Recognizing these nuances requires people on the ethics committee to be alert.

Lessons Learned

In addition to the many examples mentioned above, we have learned these lessons:

- Commitment by the doctor to treat pain and other distress goes a long way in relieving families of their fears.
- Incidental benefits of this policy have been a study of the adequacy of pain relief in our hospital and a formal course on pain control, ongoing development of a policy on "Humane Care of the Dying," and recognition of cultural differences in futility questions.
- A family conference with the entire ethics committee is cumbersome and sometimes intimidating; a smaller group of ethics committee members should represent the committee.
- Care providers other than the attending physician need to have access to the bioethics committee. Communication skills in those circumstances need to be tough.

The cost of futile care is an ethical and a practical issue and one which the public, through its legislature and courts, will have to consider and resolve. To that end a collaboration has been formed by three major hospitals to engage the community in discussion of these issues. We call it BEN (Bioethics Education Network), and our work has just begun.

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