

12. WITHHOLDING AND WITHDRAWING TREATMENTS: ETHICS AT THE BEDSIDE

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In his treatise *The Art* Hippocrates defined the purpose of medicine this way:

... to do away with the suffering of the sick, to lessen the violence of their disease, and to refuse to treat those who are over-mastered by their diseases realising in such cases that medicine is powerless.¹

Further on in the same treatise he adds:

Whenever therefore a man suffers an illness, which is too strong for the means at the disposal of medicine, he surely must not expect that it can be overcome by medicine.²

In these words the Father of Medicine recognised the limits of medicine and gave moral sanction to decisions to refrain from treatment when it becomes futile. For many centuries in the history of medicine, health professionals followed this Hippocratic dictum. Only in the modern era, when medicine's capabilities expanded enormously, did the tendency arise to treat against all odds.

But in the last few decades it has become clear that treatment should not be prolonged indefinitely, when it has ceased to provide a benefit for the patient. Mechanical respirators, artificial hearts, dialysis machines, and resuscitation techniques can prolong the act of dying and at great financial, social, and emotional costs to individuals and society. Now the central ethical question is: When is it morally permissible or even mandatory to withhold or withdraw life-sustaining treatments? How is Hippocrates' moral dictum to be implemented amid the technical complexities of contemporary medicine?

This is the most frequent ethical dilemma in clinical medicine today. It is one which most of us will be forced to face not only in the care and treatment of patients, but in our own lives and in the lives of those for whom we act as surrogates.

In the last few decades moral sanctions for withholding and withdrawing life-sustaining treatments have come from a wide variety of sources. As a result a consensus is emerging on a moral perspective to guide these decisions. What are these moral guidelines and how are they to be applied at the bedside? Clinicians have the unique task of translating moral principles and rules into concrete decisions despite the uncertainties and uniqueness of each patient's experience of illness. This is what makes clinical ethics a more strenuous exercise than its classroom analogue.

Healthcare professionals must be able to make both technical and moral decisions to fulfill the obligation of trust inherent in the healing relationship. For this reason every clinician must understand and know how to answer the following two questions which are crucial to a sound practical decision: i) Who should decide? ii) By what criteria should decisions be taken?

The Moral Issue

The moral issue gaining acceptance today runs as follows: Is the patient competent? If so, the patient has the moral and legal right to make his or her own decisions about acceptance or rejection of treatment of all kinds. These decisions take precedence over the wishes of the doctor or family. If the patient was once competent but is now incompetent, then healthcare professionals must seek some way to come as close as possible to what the patient would have wanted were he or she able to make the decisions. The source of this judgement can be some advance directive. In the absence of

these, the decision of a valid surrogate must be sought. If the patient has never been competent, e.g. infants, the retarded or insane, a valid surrogate makes the decision.

The criteria to be used by the decision-maker are not as easily decided upon as who makes the decision. Several criteria are in common upon use: diagnosis, prognosis, benefit and effectiveness of treatment, futility or burdensomeness of treatment, brain death or permanent brain dysfunction, costs of care, quality of life, and age.

1. Who shall decide?

The question of competence

The patient's competence to make his or her own decisions is the first and perhaps the most crucial decision in the whole issue. What constitutes competence? Usually, it is defined as a capacity to make a reasoned judgement about a particular clinical choice. This involves the capacity to receive information, recognise its relevance, understand the gravity of each option, make a choice consistent with one's own value system, and communicate it. Competence is a limited capacity. It does not entail the capacity to make all decisions or handle all of one's affairs. Competence does not require that the choices be agreeable to the doctor, family or society. A person may be retarded, depressed or psychotic in other spheres and still have the capacity to choose according to personal values. Nor is competence age-linked.

The competent patient

The majority of bioethicists today argue for the autonomy of the competent patient. I think that there are few greater violations of beneficence than to over-ride the patient's moral right to decide what is in his or her own best interest. To respect autonomy is to act beneficently; to violate it is malificent.

In actual fact the strong paternalists do not treat the patient by the use of force. More usually they violate autonomy indirectly - by manipulating consent through the selective presentation or withholding of information. Even though the intent is the good of the patient, deception and coercion of this kind are morally inadmissible. Particularly reprehensible is the boast of some physicians: "I can get any decision I want by the way I present facts".

In very acute situations, there may be some justification for a weaker form of paternalism. When competence is doubtful because of reversible disturbances of the brain resulting from shock or fever, the physician has first the obligation to treat these reversible causes and restore competence. As soon as this is accomplished, the wishes of the patient should be ascertained and followed. When the patient loses competence, the last competent decision should prevail. The physician ought not to speculate that the patient may have changed his or her mind. On the other hand, competent patients should be permitted to change their minds whenever they wish and are competent mentally to do so.

The incompetent patient

If the patient is incompetent, then the decision is made through some surrogate mechanism. The moral requirement here is to come as close as possible to what the patient would wish were he or she able to decide, not what the physician or surrogate would wish if he or she were the patient. When an advance directive is at hand, it "substitutes" for the patient's will. In the absence of advance directives, the autonomy of the patient is transferred, first to his or her chosen surrogate and then to others if the patient has not made a choice.

Surrogates must meet several tests of moral validity whether they are family members, friends, or court-appointed guardians: first, they must meet the same tests of competence

already discussed for the patient's decisions; second, they must be free of conflict of interests, financial or emotional; and third, they must know the patient's values well enough to make a so-called "substitute judgement" for the patient, i.e., they should provide evidence that their decisions reflects the patient's values.

The physician has a special obligation to be the advocate for the patient's best interests. Healthcare professionals must therefore make some effort to ascertain the moral validity of surrogate decisions. The surrogate decision must be in the best interests of the patient.

In emergency situations, when there is doubt about what the patient would wish, the patient should be treated. The moral onus rests on anyone who chooses to shorten life. The supposition is that most patients would wish to live. Healthcare professionals must be especially careful to avoid decisions not to treat that are based on their own value systems or in their evaluation of the quality or burden of the patient's life or the value of the patient to society. If the treatment is medically indicated it should be instituted, at least until valid surrogates are available or the patient recovers sufficiently to act in his or her own behalf.

2. By what criteria?

Whoever makes the decision, that decision itself must be grounded in morally valid criteria. Here the clinician has grave obligations because ethical decisions depend on the judgements and clinical knowledge of the technical expert. The physician's irreplaceable expertise is in his or her knowledge of the technical facts. If they are shaky, the whole process of ethical decision-making will be distorted.

Diagnosis and prognosis

In every case diagnosis and prognosis are the first and indispensable criteria. They are essential to deciding whether a medical treatment is futile or, to use Hippocrates' phrase, "beyond the means at the disposal of medicine". It is the clinician's responsibility to make as accurate an assessment as possible of the chances for recovery. In some cases it is not easy to determine the prognostic criterion as a terminal or preterminal state. A conscientious doctor will not consider withdrawal of treatment unless he or she is morally certain that the patient is in a "terminal state".

But how is this state defined? At the one extreme, we may all be "preterminal" in that we shall all die. Some ethicists find it safer to consider a patient terminal when death, to the best of our limited prognostic abilities, is foreseeable within hours, days or weeks. This is admittedly arbitrary but some practical limit must be set if decisions are to be made.

Brain "death" criteria

From an ethical point of view one can ask: which criterion is indicative of the patient's death? This question is essential in establishing a moral foundation for terminating life-support systems, artificial feeding and hydration, removing organs for transplantation, or writing do not resuscitate orders.

Some neurologists equate death of the person with death of the brainstem. Others define the "point of no return" as death of the neocortex, in which the brainstem is spared but patients remain in a persistent vegetative state. Others disagree strongly and require "total" brain death to consider the person dead.

Effectiveness and benefit

Two criteria are the effectiveness and benefit of proposed treatments. The two are not synonymous. Effective treatments

are those which demonstrably alter the natural history of an illness or alleviate an important symptom. Beneficial treatments are those which bring some good for the patient, not simply medical benefit, but benefit in terms of his or her value system. Antibiotic treatment of pneumonia in a patient dying of metastatic malignancy is effective, but not beneficial if it merely postpones the moment of dying when neither patient nor surrogate wish to prolong the dying process. Another example is in the use of analgesics. They are effective for pain relief in terminal cancer and therefore beneficial, but not effective so far as the natural history of the disease is concerned.

Ordinary treatments ought to be both effective and beneficial to warrant their use. This applies to life-support measures like respirator, artificial hearts, dialysis or cardiopulmonary resuscitation (CPR) as well. Artificial feeding and hydration are in a special category. There is substantial debate about whether they should be classified like any other medical treatment or regarded as care which would always be continued even when other life-sustaining measures can validly be withdrawn.

Futile and burdensome treatment

Most bioethicists agree that a treatment that is futile or excessively burdensome ought to be discontinued. But again the problem is how to define the terms “futile” and “burden”.

Ordinarily a treatment with little chance of altering the natural history of the primary disease can be considered futile. But how poor should those chances be? Allowances must be made for differences in values among physicians, families, or patients. The same ambiguities accompany assessment of burdensomeness. No clear-cut definition is possible. What is a burden to one is to another a challenge to be overcome.

Competent patients can make these determinations for themselves. But it is difficult to tell what is burdensome for a comatose or otherwise incompetent patient.

Opinions vary about whether patients in coma or with other manifestations of brain dysfunction suffer when food and fluids are withdrawn. Often the burden is more on the family and the medical care team who must carry out the nursing care, pass the nasogastric tube repeatedly, do the feeding, dress the bed sores, and come in day-by-day to see no palpable result to their efforts.

Quality of life

Should quality-of-life be a factor into the decision? There is no question that many clinicians, families and even courts take "quality of life" as a valid criterion for withholding or withdrawing treatment, especially in the aged or in disabled and handicapped infants. Quality-of-life is more a defensible criterion only for the competent patient. Only the competent patient can judge what quality-of-life means in terms of personal values, religious beliefs, or life plans within the limitations on autonomy. Only the patient can decide when life is so burdensome that it is not worth living.

With the incompetent patient - and especially with the never competent (the retarded, the infant, or the chronically insane) - we have no idea what constitutes a quality-of-life from the patient's point of view. It is impossible to decide what is a quality of life for anyone else. The opportunities for abuse, by imposing one's own values or by devaluating certain categories of persons are genuine.

Age as criterion

There is a growing tendency among bioethicists to suggest, either through voluntary or public policy, that limits ought to be placed on the amount and kinds of care given to the elderly.

Some suggest that when competition for some scarce resource occurs, preferences should automatically go to the young. This perspective raises serious questions. Does each human life have the same intrinsic value? Are the aged less worthy of care simply because they are aged?

Age alone is a poor indicator for moral decisions. The morally defensible way to use age as a criterion is to weigh it along with other clinical factors in deciding whether the treatment will be effective and/or beneficial.

Concluding remarks

There are still unresolved fundamental philosophical problems in the current decision-making process. We should continue to examine and clarify them even though they may seem abstract to practical people. Is there a real difference between withholding and withdrawing treatment? Is there a distinction of kind or any of degree between killing and letting die, between active and passive euthanasia? Is personal death synonymous with total, neocortical, or brainstem death? Is passive euthanasia the same as assisted suicide or homicide? Is there a difference between withholding treatments because they are burdensome and futile and doing so because of quality-of-life considerations? Is not the intent the same - hastening the death of the patient?

These questions still occur in discussions of withholding or withdrawing of life-sustaining measures? They reflect differences in our concept of the purpose, destiny and meaning of human life. While the moral perspectives emerging from the various groups are providing some answers, the deeper questions still remain for many people because of differences in deeply held religious and philosophical beliefs. These fundamental questions demand a continuing dialogue among ethicists, theologians, clinicians and policy-makers.

We can agree with Hippocrates that there should be limits to medicine. But deciding when to withhold and withdraw treatment is far more complex for us than for him. He did not face the immense power of today's medicine and the difficulty of balancing their benefits and harms.

Yet, paradoxically, we have the same tool for making our decisions that he had: the discipline of ethics, a discipline born in his era. The more technologically advanced we become, the more healthcare professionals must temper technical proficiency with ethical sensibility. "Doing" ethics has become as crucial as "doing" science for anyone who aspires to be a competent health care professional.

References

1 Hippocrates, *"The Art"*, in Hippocrates, vol. II, W.H.S. Jones (trans.) Loeb Classical Library, Harvard University Press, Cambridge, 1967, 14, p. 193

2 *Ibid.*, p. 203-205