

THE PATIENT AS CITIZEN

A Common-Good Approach to Medical Treatment Decisions Balances the Emphasis on Patient Desires

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Self-determination—an important principle in ethics—is a good, but one that needs to be balanced with other goods. Especially in the context of treatment decisions, we may be tempted to focus so much on the patient's own wishes that we ignore or minimize the social and communal impact of the decisions or the community's role in determining appropriate use of resources.

SELF-DETERMINATION RUN AMOK

In an article on euthanasia, Daniel Callahan describes the almost exclusive emphasis given to individual wishes in healthcare: "Self-determination runs amok."¹

Several scenarios come to mind. Self-determination runs amok when:

- Individuals are permitted to choose the criteria to be used in determining that their own death has occurred.

The state of New Jersey allows individuals to

determine which criteria of death will be applied in their case. If one does not agree with the consensus that death occurs when the entire brain irreversibly ceases functioning, then one may stipulate that his or her death be declared when cardiopulmonary functioning irreversibly ceases.

In an article in the *Journal of Clinical Ethics*, Robert Truog and James Fackler endorse the New Jersey law's recognition of conscientious objection to the brain death criterion and propose that the individual have further options for determining his or her own death. Thus, Truog and Fackler submit, individuals who hold that the permanent cessation of consciousness is a reasonable diagnosis of death should be permitted to direct that they be declared dead if they are ever in a persistent vegetative state.²

- Individuals can expect that treatment will be provided at their request regardless of their condition, their chances of survival, or the cost.

Forms available for individuals to make advance

Summary Individualism plays too strong a role in the arena of treatment decision making, frequently to the exclusion of any other consideration. Using a common-good or community-based ethic as a framework for treatment decision making may provide appropriate balance to the emphasis on patient desires.

Self-determination is a good that must be balanced with other goods. When it is not, to quote Daniel Callahan, "Self-determination runs amok." For example, in the state of New Jersey, individuals are permitted to choose the criteria to be used in determining that their own death has occurred.

Some of the principles that may lead to a reasonable understanding of the patient's rights in a "patient-as-citizen" ethical perspective are:

- Everyone has a legitimate claim to a basic

level of healthcare.

- Everyone has a legitimate claim to respect for his or her refusal of recommended treatment.

- No one has a legitimate claim to nonbeneficial or futile treatment.

- No one has a legitimate claim to treatment that is being withheld as part of a just rationing system.

- No one has a legitimate claim to the ability to determine the medical criteria to be used for the diagnosis of his or her death.

A just healthcare system is one in which individual desires for medical treatment beyond the basic level are accommodated whenever possible but not when they undermine the primary purpose of medicine to meet the basic healthcare needs of all persons.

directives regarding medical treatment often include a list of options. One statement sometimes found reads, "I desire that my life be prolonged to the greatest extent possible, without regard to my condition, the chances I have for recovery or long-term survival, or the cost of the procedures."

- What the professional judges to be good for the patient is determined by what the patient wants.

As ethics committees and ethics consultants seek to clarify the responsibility of healthcare professionals vis-à-vis the patient's wishes, it is sometimes tempting to think of the professional as a simple advocate for patient wants. Henry Perkins, for example, grounds his understanding of patient-care ethics in individualism: "A commitment to individualism allows us to define the interests that the patient would choose as those that his attending health professionals should pursue because of the fiduciary role."³

A BID FOR RESPONSIBLE DECISION MAKING

Self-determination runs amok in contemporary ethics and public policy when it is considered as the value or good that trumps all other considerations.

There is some recognition in contemporary healthcare ethics that "the sick individual is not only a patient with rights but a citizen with duties."⁴ This article explores what it means to make individual treatment decisions in recognition of the patient as citizen (as an individual-in-community). Using a common-good or community-based ethic as a framework for treatment decision making may provide appropriate balance to the emphasis on patient desires.

For a reasonable understanding of the patient's rights in a patient-as-citizen ethical perspective, I suggest the principles shown in the Box on p. 14.

RIGHTS AND WANTS

The dominant social value tradition in American society focuses on the freedoms and rights of the individual and gives much less recognition to community obligations. Without undermining the importance of individual rights, the tradition can be modified to recognize the ethical importance of solidarity, relationships, and commitment to common goals and to meeting the needs of others.

In American thought generally and in ethics specifically, the fundamental commitment to the dignity of the individual leads to efforts to clarify and defend human rights. Too often, however, our cultural use of "rights talk" has confused rather than clarified the meaning of respect for human dignity. It has often tended to be too inclusive, to

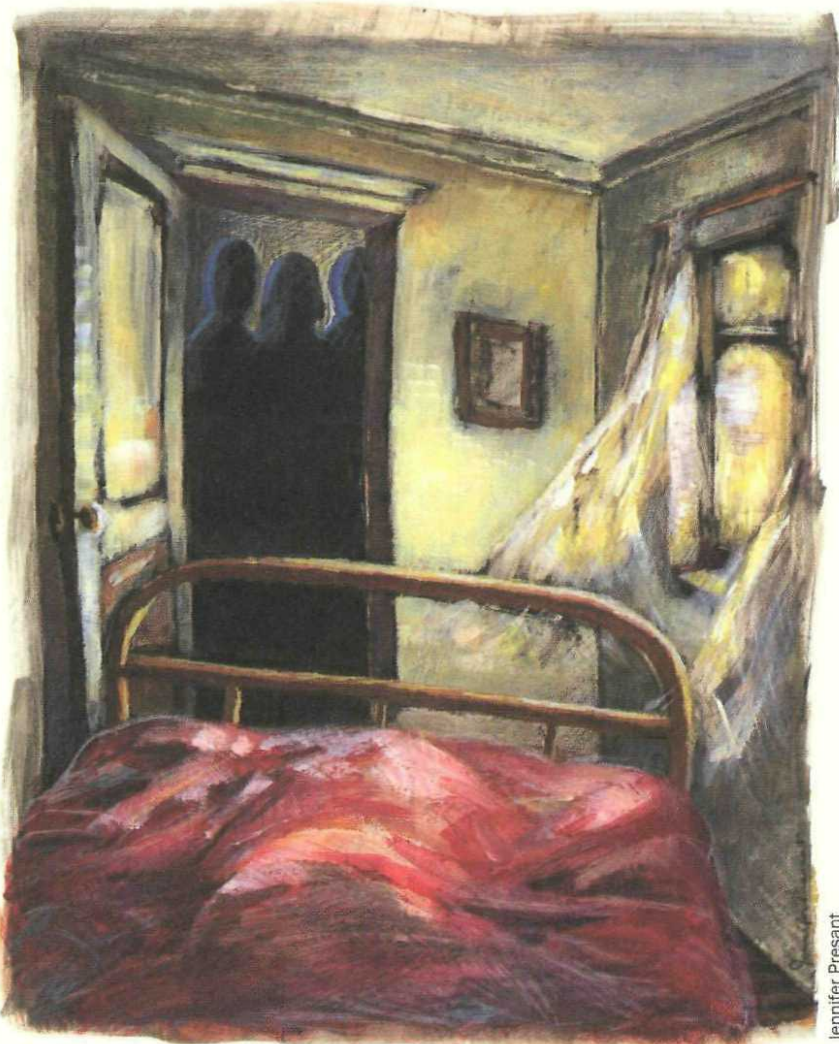
identify too many personal interests as "rights."

The use of rights language is important but should be restricted, for the most part, to basic or fundamental rights. These fundamental rights, which are the "prerequisites for dignified life in community,"⁵ include both individual freedoms and the right to fulfillment of material needs.

Basic rights include both civil and political human rights (such as freedom of speech, religion, and assembly) and economic and social human rights (such as right to food, healthcare, and education). Human dignity requires that civil freedoms be protected and economic necessities guaranteed. Individual freedoms and access to common resources are two sides of the same human dignity.

Human dignity can be achieved and protected only in solidarity with others. The essence of a common-good approach to ethics is that the individual is never seen as existing separate from the

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community. The individual has freedoms, rights, and privacy that must be respected, but he or she also has responsibilities to others. Even when we pursue the good life as defined for ourselves, we must still be aware that we are part of a community, that we still have the responsibilities of citizenship.

There is a difference between basic human rights and basic needs, on the one hand, and individual wants or preferences, on the other. Respect for human dignity requires that essential freedoms be recognized and that fundamental needs be met. The good of society as a whole—the common good—can be realized only through concern for the dignity and needs of individuals.

The common good also requires, however, that individual wants be satisfied only to the extent possible within the context of concern for the needs and essential freedoms of others. Catholic social ethics has clearly made this point when discussing property rights: We are not justified in claiming for our exclusive use more than we need when others lack necessities.⁶ Individual claims that go beyond meeting basic needs and protecting basic rights are to be subordinated to society's obligation to meet the basic needs and protect the basic rights of all.

TREATMENT DECISIONS, INDIVIDUAL CLAIMS

Those discussing treatment decisions often do not make the necessary distinction between rights and

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wants. Society and healthcare providers often mistake the patient's desire for the patient's legitimate claim. An ethical approach that recognizes the patient as citizen will not make that mistake. Nor will it deny, on the other hand, that the patient's refusal of treatment should ordinarily be decisive. It is important to distinguish between appropriate and inappropriate patient claims.

Everyone Has a Legitimate Claim to Respect for His or Her Refusal of Recommended Treatment (Except in Unusual Circumstances) Patient self-determination should be understood as the right to informed consent and informed withholding of consent. We should respect individual's competent and informed decisions to refuse proposed treatment (except in rare cases where that decision would result in unacceptable harm to others). Even when the person's decision to refuse treatment seems to threaten his or her health, respect for individual self-determination should mean that the patient will not be forced to accept unwanted treatment.

Respect for competent refusal of treatment is analogous to respect for freedom of religion. Respect for human dignity requires that we be permitted to express and live out our own beliefs (as long as others are not seriously harmed). Even though some may think our beliefs are harmful to ourselves, we have a right to live our lives and our own faith. So, too, our personal decisions regarding acceptable medical treatment must be respected (as long as others are not seriously harmed) even if others think we are harming ourselves unnecessarily.

The right to exercise informed consent and to refuse medical treatment is a fundamental right, similar to the right to religious freedom and free speech.

No One Has a Legitimate Claim to Nonbeneficial or Futile Treatment The right to accept or refuse is not the right to demand, however. Patients are not their own physicians, determining for themselves what is needed or medically appropriate. Nor are individual patients the appropriate persons to determine how resources should be allocated. When we understand patient self-determination in the framework of informed consent, the difference

PATIENT RIGHTS: A PATIENT-AS-CITIZEN PERSPECTIVE

- Everyone has a legitimate claim to a basic level of healthcare.
- Everyone has a legitimate claim to respect for her or his refusal of recommended treatment (except in unusual circumstances).
- No one has a legitimate claim to nonbeneficial or futile treatment.
- No one has a legitimate claim to treatment that is being withheld as part of a just rationing system.
- No one has a legitimate claim to the ability to determine the medical criteria to be used for the diagnosis of his or her death.

between accepting or refusing, on the one hand, and demanding, on the other, becomes clear.

Healthcare and the economic resources devoted to healthcare are community resources; they should be used to meet the basic healthcare needs of all. Society—not individuals acting at their own behest—is responsible for determining the appropriate purpose for healthcare interven-

tions and the appropriate allocation of healthcare resources. Although the judgment of medical futility is not value free, individual understandings of reasonable goals of therapy should be subordinated to the community's understanding.

A community-based ethical perspective also makes it clear that more is at stake than the individual patient's wishes. What an individual wants is never as decisive as what he or she does not want done. The latter hinges on the claim to be left free to live according to one's own values and beliefs—very different from the claim to the use of resources to pursue one's personal goals. Self-determination runs amok when this difference is forgotten.

No One Has a Legitimate Claim to Treatment That Is Being Withheld as Part of a Just Rationing System An individual has a legitimate claim only to a fair share of healthcare resources, not to every treatment that might well be beneficial. As long as a basic level of healthcare is being provided to all, it is not unjust for society to choose to put more resources into certain types of treatment or care than into others.

No One Has a Legitimate Claim to the Ability to Determine the Medical Criteria to be Used for the Diagnosis of His or Her Death Having individual patients determine the criteria of death exemplifies a totally misplaced emphasis on the individual's role in healthcare decision making; it makes the individual's personal beliefs, not the public good, the criterion for determining the purpose of medical care in society and for the use of resources.

THE FINAL ANALYSIS

Ethical analysis can often assist in identifying an appropriate and clarifying perspective to bring to a particular issue. Ethical analysis can also assist in establishing priorities among different values at

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stake. The process of determining what should be done (in individual situations or in policy) depends in large part on how the community defines the issue and how it identifies the most important values to be protected.

The perspective proposed here in regard to medical treatment decision making is that society should not consider such decisions as simply private decisions but as decisions made

by and for persons-in-community. This perspective would guard against an individualism of the sort that makes patient's wishes the determiner of good healthcare.

A just healthcare system is one in which individual desires for treatment beyond the basic level are accommodated when possible but not when they undermine or threaten medicine's primary purpose to meet the healthcare needs of all. Respecting human rights does mean, however, that individuals not be treated without their consent.

Catholic social ethics, reflecting as it does on the meaning of individual human rights in the context of community responsibility, may be instructive as we continue to clarify public and institutional policy regarding the patient's role in medical treatment decisions. □

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NOTES

1. Daniel Callahan, "When Self-Determination Runs Amok," *Hastings Center Report*, March-April 1992, pp. 52-55.
2. Robert Truog and James Fackler, "It Is Reasonable to Reject the Diagnosis of Brain Death," *Journal of Ethics*, Spring 1992, p. 81.
3. Henry Perkins, "Another Ethics Consultant Looks at Mr. B's Case: Commentary on 'An Ethical Dilemma,'" *Journal of Clinical Ethics*, Summer 1990, p. 127.
4. Marion Danis and Larry Churchill, "Autonomy and the Common Weal," *Hastings Center Report*, January-February 1991, p. 27.
5. U.S. Catholic Bishops, *Economic Justice for All*, 1986, no. 79.
6. See Pope Paul VI, *Populorum Progressio*, 1967, no. 23.