

MEDICAL ETHICS IN THE UNITED STATES

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SUMMARY

This article provides a brief survey of medical ethics in the United States. It begins with a short sketch of issues in theoretical medical ethics, but the article's primary focus is on applied medical ethics.

The discussion of applied medical ethics begins with a review of important norms of clinical ethics which are generally accepted in the United States. These settled norms include: (1) decision - making for competent patients should be shared. (2) Competent patients have a right to refuse medical treatment, including life - sustaining treatment. (3) Decision - making for incompetent patients can be approximated by advance directives and/or surrogate decision - makers. (4) Surrogate decision - making for incompetent patients should be based on the substituted judgment and/or best interests standards.

In addition, the following areas of continuing controversy are discussed: medical futility, the moral authority of advance directives, physician assisted suicide and active euthanasia ("mercy killing"), the standard of death, living related organ donation, AIDS, reproductive technology, genetic technology, cost containment, and access to health care.

The article ends with a brief discussion of ethical issues related to research with human subjects in the United States.

Key Words :

Ethics
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 United States
 Ethical decision - making
 Advance directives
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 Medical futility
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 Genetic technology
 Cost containment
 Access to health care
 Research with human subjects

INTRODUCTION

It is extremely difficult to provide a brief and informative survey of medical ethics in the United States. To make this task somewhat more manageable, I will distinguish between *theoretical* and *applied* medical ethics, and after giving a short sketch of some issues in theoretical medical ethics, I will focus on applied medical ethics.

I. THEORETICAL MEDICAL ETHICS

Theoretical medical ethics focuses on methodological issues. It provides the conceptual and normative tools that can be used to identify and resolve ethical problems and issues associated with health care. In the United States, there are several competing methodological approaches. These include: principlism, casuistry, virtue ethics, and feminism.

Principlism

Principlism is the view that medical ethics consists primarily in applying general ethical principles and derivative rules to particular cases and issues. These principles include: *respect for autonomy*, which requires us to allow other persons to be self - governing (i.e., to make important decisions concerning their lives for themselves); *nonmaleficence*, which requires us to refrain from acting in ways that will harm or injure others; *beneficence*, which requires us to act in ways that will help others; and *justice*, which requires a fair distribution of benefits and burdens and respect for people's rights and entitlements. Derivative rules include truth-telling, confidentiality, and fidelity(1).

Casuists

Reject the idea of "applying" general principles and rules to specific cases. Instead, they advocate the use of paradigms and analogical reasoning.

Virtue ethics

Rejects the principle model's focus on discrete decisions and acts. Virtue ethics emphasizes the importance of character and social practices.

Feminists

Criticize principlism for its reliance on impersonal principles and rules. They stress the importance of personal relationships and caring (2).

II. APPLIED MEDICAL ETHICS: SETTLED NORMS OF CLINICAL ETHICS

Applied medical ethics addresses specific ethical questions and issues associated with medical research, clinical practice, and health care policy. I will present a brief survey of applied medical ethics as it is practiced in the United States, and I will focus on clinical issues. I will begin by reviewing some settled norms of clinical ethics - that is, norms which are generally accepted in the United States. I will then identify several areas of ongoing controversy and will conclude with a brief discussion of research ethics.

Shared Decision - Making

Health care decision - making is one important area in which there is general agreement. The reigning model of health care decision - making in the United States is referred to as the "shared decision - making model." According to that model, decision - making should be a collaborative activity between physicians and patients.

The shared decision making model is an anti - paternalist model of decision - making. According to the paternalist model, treatment decision should be made by *physicians* because doctors are experts and know what is best for their patients. The shared - decision - making model rejects this view (3,4).

Underlying shared decision - making is the idea that physicians and patients are experts in different areas. Physicians are experts in clinical matters (e.g., diagnosing illnesses, making prognostic judgments, and identifying effective treatments). Patients are experts in values (for example, evaluating the importance *to them* of pain control, mental alertness, bodily integrity, quality of life, length of life, and so forth). There can be significant differences in the values and preferences of patients: Pain may be more of a burden to some people than it is to others; some people may prefer nausea or drowsiness to pain, and other people may have a very different set of priorities; to some people, the risk of losing sexual function may be very threatening, and to others it may not be that important; to some people, quality of life may be more important than length of life, and others may have the opposite priorities.

As experts in clinical matters, physicians should provide information and explanations that will facilitate informed choices. However, the shared decision - making model incorporates the idea that it is the patient's prerogative to evaluate the options (which always include forgoing medical interventions) and to choose among them in accordance with his or her own values and preferences.

The shared decision - making model is a patient - centered model, which reflects a commitment to the value of patient self-determination. In addition, it reflects the conviction that identifying the "best treatment plan" for a particular patient is in part a

function of that person's particular preferences, goals, and values and therefore is not exclusively a medical (clinical) judgment.

Informed Consent and the Right to Refuse Treatment

Shared decision-making is associated with a settled principle of clinical ethics in the United States, informed consent (5). The principle of informed consent requires physicians to secure the authorization of competent patients for medical interventions. Shared decision - making and informed consent imply that competent patients have a right to refuse medical treatment, including life - sustaining treatment, such as ventilators, dialysis, antibiotics, and tube feeding.

The right to refuse medical interventions is another generally accepted norm in the United States. However, this was not always the case. As recently as two or three decades ago, many physicians were reluctant to withhold or withdraw life support - even when patients were dying or seriously and irreversibly ill, and even when patients or their families asked for treatment to be forgone.

Incompetent Patients

Shared decision - making is possible only when patients are competent, that is, have the mental capacity to participate in decision - making. So, an important ethical issue is whether and if so, how, shared decision - making can be approximated in the case of incompetent patients. In the United States, there are two generally recognized means to approximate shared decision - making. One is advance directives, and the other is surrogate decision - makers.

Advance Directives

Advance directives are written or oral statements that allow people to provide guidance for health care decision - making if they were to lose their decision - making capacity in the future. There are three types of advance directives: *Instruction directives*, which provide instructions about the kinds of treatment the person wants or does not want; *proxy directives*, which specify the person who the patient wants to decide on his or her behalf; and *combination directives*, which provide instructions and designate a surrogate. One common type of instruction directive in the United States stipulates that people do not want life - sustaining treatment if they should lack decision - making capacity and they are in a persistent vegetative state or are terminally ill.

Surrogate Decision - Makers

Surrogate decision - makers are people who participate in the decision - making process on behalf of incompetent patients. To approximate shared - decision - making when incompetent patients have not executed instruction directives, surrogate decision - makers are needed. Even when patients have executed instruction directives, these directives often require interpretation, and this in turn requires a surrogate decision - maker.

To approximate shared - decision - making, surrogate decision - makers should attempt to choose as the patient would have chosen if he or she were fully informed and able to decide. This standard is referred to as the "substituted judgment" standard. When surrogates have insufficient knowledge about the patient's specific values and preferences to decide on the basis of the substituted judgment standard, it is generally agreed that they should decide on the basis of the "best interests" standard.

The best interests standard directs surrogates to consider the expected benefits and harms (burdens) to patients of each treatment option, including nontreatment, and select the option with the greatest expected net benefit, or the least expected net harm, to the patient. Insofar as there is insufficient knowledge of a patient's distinctive preferences and values to make a substituted judgment, the standard of benefits and harms associated with the best interests standard cannot be subjective (i.e., based on the patient's own preferences and values). Instead, it must be an objective standard. The objective standard that is commonly used in the United States is referred to as the "reasonable person" standard. To apply this standard, surrogates should assess the expected benefits and harms to patients of treatment options from the perspective of a "reasonable" or "average" person. From this perspective, for example, pain, suffering, and discomfort are harms; and benefits include reduction or elimination of pain, suffering, and discomfort, as well as restoration or preservation of mental and physical capacities.

Summary

In the United States, there is little dispute about the issues surveyed so far. That is, it is widely acknowledged that:

1. Decision - making for competent patients should be shared.
2. Competent patients have a right to refuse medical treatment, including life - sustaining treatment
3. Decision - making for incompetent patients can be approximated by advance directives and / or surrogate decision - makers.
4. Surrogate decision - making for incompetent patients should be based on the substituted judgment and/or best interests standard.

These and other conclusions were presented in several influential reports published in the early 1980s by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The Commission included prominent physicians, lawyers, philosophers, and social scientists appointed by the President of the United States. Their conclusions are now generally accepted in the United States. However, there are several other matters about which there is considerable controversy.

III. APPLIED MEDICAL ETHICS: AREAS OF ONGOING CONTROVERSY

Futility

One area of controversy involves possible limits on the patient - centered model of shared decision - making. In the past, patients and families in the United States invoked the right to refuse treatment to counteract a perceived reluctance on the part of physicians to withhold or withdraw life support from dying or seriously and irreversibly ill patients. Increasingly, however, physicians in the United States are expressing a reluctance to offer treatment that they consider "futile" (6, 7).

The concept of "medical futility" is often invoked by physicians when patients, or more often families, demand treatment that physicians think they should not offer. A widely publicized recent case in the United States involved a woman named Helga Wanglie, an 86 - year - old - woman in a persistent vegetative state. Whereas her husband insisted that she receive continued aggressive life-sustaining treatment, including ventilator support, her physicians wanted to withdraw ventilator support on the grounds that further treatment was "futile" (8, 7).

When it is said that a treatment is "futile", it is necessary to specify a *goal* in relation to which the treatment is futile (i.e., highly unlikely to be successful). For example, in the case of Helga Wanglie, although ventilator support may have been futile in relation to the goal of restoring her capacity to think, talk, and play chess, it was not futile in relation to the goal of keeping her alive longer in a persistent vegetative state. Thus, the key question is not whether it is "futile" to sustain patients indefinitely in persistent vegetative states. Rather, the decisive ethical question is whether such treatment is consistent with the *proper aims and goals of medicine*. More generally: When may physicians justifiably deny patient and family requests for life - extending treatment on the grounds that such treatment is inappropriate relative to the proper aims and goals of medicine? This question is an important source of continuing controversy among physicians and medical ethicists in the United States.

Advance Directives

Another area of controversy is the *moral authority* of advance directives, especially instruction directives. Some medical ethicists in the United States (e.g., Rebecca Dresser and John Robertson) have challenged the moral authority of advance directives on the grounds that when patients lose their decision-making capacity, they no longer have many of the interests that may have prompted them to execute and advance directive stating that they do not want life - sustaining treatment. For example, suppose my father executed an instruction directive that states that he does not want life - sustaining medical treatment if he has lost his capacity to recognize and communicate with me, and he develops a life - threatening illness. He executed this instruction

directive, let us suppose, because he is a proud and independent man who has a strong sense of dignity, and does not want to become a burden to me. If my father's mental status should decline to the point where he can no longer recognize and communicate with me, he will no longer understand the notions of independence and dignity, and he will no longer be aware of being a burden to me. Do my father's interests in dignity and independence cease when he can no longer understand these notions? Or do his interests in dignity and independence survive his mental decline? This question is an important point of ongoing controversy among medical ethicists in the United States.

Right to Die

Another question currently being debated in the United States is whether the right to refuse treatment should be expanded to a right to die, that is, a right to physician assisted suicide or active euthanasia. For some patients, a right to refuse treatment is not enough. In their eyes, withholding or withdrawing treatment will only mean a slow, painful, demeaning, and / or undignified death. They want physicians to help them take their own lives, or they want physicians to end their lives (9, 10).

Since Gerald Dworkin, a prominent American philosopher and medical ethicist spoke at Marmara University not too long ago on this issue, there is no need for me to discuss it. I will only point out that there are two different areas of controversy: One is whether physician assisted suicide or euthanasia is *ethically permissible* in certain cases. A second is whether either of these practices should be *legalized*. Many American medical ethicists who believe that physician assisted suicide and euthanasia are ethically permissible in certain cases remain skeptical that it is feasible to design adequate safeguards to insure that both will be performed only when it is ethically permissible to do so.

Standard of Death

Another area of controversy in the United States is the standard of death. There are two accepted standards of death in the United States: the traditional cardiopulmonary standard and the more recent whole brain standard. However, the adequacy of these standards has been challenged recently because of a concern about shortages of human organs for transplantation.

There are two contexts in which this issue arises in the United States. One involves anencephalics, infants who are born without a brain, or with most of the brain missing. Anencephalics are a potential source of organs. But unless they are still born, they do not appear to satisfy either the cardiopulmonary or whole brain standards of death. The second context involves cases in which life - sustaining treatment is withheld or with-drawn. In some of these cases, patients are potential sources of organs. When are they really dead? When life support is with-drawn and their heart stops? Or must time elapse to insure that

the cessation of vital functions is *irreversible*? If the latter answer is accepted, many organs will be unusable by the time he patient is declared dead.

An important question, then, is whether it is ethically acceptable to tailor a standard of death for the purpose of making available more organs for transplant. That is, is the fact that standard of death A will make more organs available for transplant than standard of death B a good reason for preferring A to B?

Organ Transplants

There are several other ethical issues associated with organ transplants that are currently being debated in the United States. One of these is the propriety of paying for organs, a practice that is currently prohibited in the United States. Another is the propriety of using living related donors. At the University of Pittsburgh, where I am on the Ethics Consultation Service, transplant surgeons recently began to use living related donors for lung lobe transplants. And at other medical centers in the United States, parents have donated liver lobes for their young children. In view of the psychological and social pressures that potential donors may face, some medical ethicists have questioned whether donation under such circumstances can be truly *voluntary*. Moreover, even if donation under such circumstances can be truly voluntary, it remains to be seen whether protocols can be designed that will distinguish between voluntary and nonvoluntary decisions to serve as living related donors.

AIDS

AIDS and the human immunodeficiency virus (HIV) have generated another set of important ethical questions in the United States. The following are just a few examples: Should physicians disclose that a patient is HIV - positive to people who are at risk of becoming infected by the patient? Should there be mandatory HIV testing of all hospital patients? Should there be mandatory HIV testing of physicians and other health care professionals, and should all HIV - positive health care professionals, or those in certain specialties, be prohibited from practicing? Do physicians and other health care professionals have an obligation to treat HIV - positive patients, or may they refuse to treat such patients?

There is no consensus on these questions, but I think there is a "majority view" among medical ethicists in the United States. The majority view opposes disclosure and mandatory testing of patients and physicians and holds that physicians and other health care professionals have an obligation to treat HIV-positive patients. In addition, it ascribes considerable moral importance to confidentiality and stresses the low risk of infection from patients to health care workers and from health care workers to patients. To date in the United States, there has been only one documented health care professional to patient transmission - by a Florida dentist who apparently infected at least six patients. And there have been

only about one hundred instances in which patients infected health care workers.

New Reproductive Technology

A rather long list of other important ethical questions is associated with new reproductive technology. Thanks to *in vitro* fertilization (IVF) and embryo transfer, it is possible for married women with fertility problems to have children that are genetically related to their husbands and themselves. However, it is also possible for relatives and total strangers to conceive and / or give birth to children for women who may or may not have fertility problems, and it is possible to freeze embryos for possible future use (11).

In the United States a woman served as a gestational surrogate for an embryo that was produced by means of IVF from her daughter's egg and the sperm of her daughter's husband. I was recently involved in a case at a Pittsburgh women's hospital in which a divorced woman in her late forties wanted to have a child with her younger second husband. The woman wanted her daughter to serve as an egg donor. She requested *in vitro* fertilization of her daughter's egg with her new husband's sperm and wanted the embryo implanted in her uterus. Some of the medical staff questioned whether the daughter's consent was truly voluntary. In a recent court case in the state of Tennessee, a divorced couple was involved in a legal battle over the disposition of embryos that had been produced by means of IVF and had been frozen. At first the woman wanted the embryos to be implanted in her uterus, but she later requested that they be donated to other women. For his part, the man wanted the embryos destroyed.

An ethical assessment of the various possible uses of reproductive technologies has and will continue to be an important area of inquiry for medical ethicists in the United States.

Genetics and Genetic Technology

Two other areas of growing interest to medical ethicists in the United States are genetic mapping and genetic engineering. The Human Genome Project is a major genetic mapping project. As more and more genetically based diseases are identified, it will become increasingly urgent to develop guidelines for genetic testing and disclosure of test results. For example, should test results be disclosed to insurance companies or employers?

Genetic engineering is the process of manufacturing genetically altered substances. An earlier concern about genetic engineering was the risk of accidents. A more recent concern in the United States is cost. For example, there are two drugs that prevent clotting and further damage after heart attacks. One is Streptokinase and the other is TPA. Some studies suggest that TPA, the biogenetically engineered drug is somewhat more effective. But it costs about 10 times more. Is a slight increase in effectiveness worth the cost? As the ability to produce genetically altered substances increases so too will the ethical questions associated with this technology (12).

Cost and Access

Another important set of ethical issues related to health care in the United States is associated with the dual problems of cost and access. Last year in the United States, health care expenditures were more than 14 percent of the gross domestic product (GDP), significantly higher than in any other country. It is estimated that spending on health care will exceed \$1 trillion for the first time this year--about 15 percent of the GDP. Projections indicate that spending on health care may reach 20 percent of the GDP by the year 2000.

Despite all the money that is spent on health care in the United States, it is estimated that between 35 and 40 million Americans do not have health insurance. Millions more have insufficient insurance. A recent study reported that 25 percent of Americans lacked health insurance for at least one month during a two and one half year period from February 1990 to September 1992. Thus, despite all of the money that is spent on health care, many Americans lack *secure access* to it.

Recently, there was a major effort to restructure the health care system in the United States to control costs and increase access, but this effort failed. The failure may be due less to a lack of good ideas than to a lack of political will. It was reported that an unprecedented amount of money was spent by a variety of interest groups, including insurance companies, corporations, hospital associations, and physicians' organizations, to defeat health care reform in the United States. Currently, the prospects for meaningful health care reform in the United States seem very poor.

IV. RESEARCH ETHICS

I will conclude with a few brief comments about ethics and research with human subjects. An interest in the ethics of research with human subjects following the Second World War contributed to the birth of contemporary medical ethics in the United States. Revulsion at the horrors that were committed in the name of medical science by Nazi doctors and researchers during World War II gave rise to a heightened interest in medical ethics in the United States.

It is now an axiom of research ethics in the United States that investigators must secure the informed consent of competent human subjects or the informed consent of proxies of incompetent subjects. This commitment to informed consent reflects two values: individual autonomy and the principle that it is unwarranted to use people to benefit others without their consent.(13).

Recent revelations that many United States citizens were deliberately exposed to high levels of radiation without their consent during the height of the Cold War in the 1950s and 1960s has generated renewed interest in the ethics of research with human subjects

and the informed consent requirement. There is now a Presidential Commission in the United States investigating these episodes. More recently, earlier last year a trial of tamoxifen to prevent breast cancer was temporarily halted because of a concern that subjects were not adequately informed of the risks. The trial was resumed after a new informed consent protocol was implemented.

V. CONCLUSION

In such a brief sketch as this, it is not possible to do justice to a very complex topic. However, I hope I have at least presented an informative broad overview of many of the settled issues and current controversies in medical ethics in the United States today.

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