

Ethics: A Primer for Non-Ethicists

By Dorothy C. Wertz, PhD

New discoveries in genetics, including those associated with the Human Genome Project, will present complicated ethical issues for consumers, for providers, and for health care policy. Meanwhile, many people are not sure exactly what the term "ethical issue" means, how to distinguish an ethical treatment from other kinds of statements, or why we need ethics. The following is a basic introduction to ethics for non-ethicists.

What is Ethics?

Ethics is a field of human inquiry ("science" according to some definitions) that examines the bases of human goals and the foundations of "right" and "wrong" human actions that further or hinder these goals.

How Does Ethics Differ from Morals?

Although the term "ethics" and "morals" are often used interchangeably, they are not identical. Morals usually refers to practices; ethics refers to the overarching rationale that may support such practices. Morals refers to actions, ethics to the reasoning behind such actions. Ethics is an examined and carefully considered structure that includes both practice and theory. Morals includes ethically examined practices, but may also include practices that have not been ethically analyzed, such as social customs (e.g., virginity at marriage), emotional responses to breaches of socially accepted practices (e.g., to single motherhood), and social prejudices. The statement that "single women on welfare should not have children (especially not children with disabilities)" reflects a belief (not necessarily our belief) that the nuclear self-sufficient family is morally superior to other family forms. Unless they are based on general principles or on statements about parent-child relationships, statements like these are not ethical statements. An ethical statement would discuss benefits, harms, individuals' rights to choose, fairness, or needs of the child. Ethical discourse operates at a different intellectual level; it is more universal and more dispassionate than morals. Some philosophers, however, do use the term "morals" to describe a publicly agreed-upon set of rules for responding to ethical problems.

What is an Ethical Question?

Ethical questions involve 1) deciding responsibilities for the welfare of others or for the human community; or 2) resolving conflicts among loyalties to different persons or groups, among responsibilities associated with one's role (e.g. as

consumer or provider), or among principles. Ethical questions include (or imply) the words "ought" or "should".

Although we frequently hear the term "ethical dilemma", many ethical problems are not dilemmas. They are even more complicated. A "dilemma", from the Greek *di* (two) and *lemma* (assumption), means a confrontation in which both alternatives have an equal likelihood of causing harm (or benefit). Many ethical problems in genetics present more than two alternatives and are therefore not dilemmas, but trilemmas or quadrilemmas.

What Is an "Ethical" Response to an Ethical Question?

Many people use non-ethical reasoning to **respond to ethical** questions. Non-ethical reasons are not necessarily "unethical" or harmful; they simply avoid the difficulty of ethical thinking.

Examples of Non-Ethical Statements

Sometimes people use technical, scientific, legal, religious, or institutional policy statements to answer the question, "What should I do?" These are not ethical statements because they do not include a rationale that transcends particular institutions. Here are some examples of non-ethical responses to ethical problems:

(1) *"Technology will eventually solve this problem."*

For example, suppose someone refuses to give blood for a DNA sample that could provide useful genetic information to other members of the family. What should the genetics services provider do?

The answer that "In the future direct DNA testing on the family members will be possible so this situation will not occur" is not an ethics based response. Many geneticists prefer technological answers because they appear to be the simplest solutions. Technology, however, will not obviate all difficult decisions. Direct DNA testing may eliminate the problem of family cooperation for some genetic testing, but may pose new problems, for example, increased requests for testing by employers or insurers. One should not look to scientific discoveries to remove or solve ethical problems.

(2) *"The law requires or prohibits this."*

Fear of lawsuits plays a role in many medical decisions. For example, in response to the question of whether to disclose fetal sex to a couple who may terminate a pregnancy solely on the basis of sex, some providers say disclosure is a legal requirement and proceed no further in their reasoning. If a pregnant woman's separated husband asks for the results of her prenatal diagnostic tests,

against her wishes, some providers also base their answers on presumed legal prohibitions or requirements. (Their legal knowledge in both cases may be faulty, but that is a subject for another paper. Laws are not as restrictive as many people think.) Although laws are often based on the collective moral experience of a community, ethics transcends law, applies to more situations, provides more guidance and more general rules. Decisions made solely on the basis of following legal regulations are not ethical decisions.

(3) "My institution, department, or supervisor requires (or forbids) this."

Authorities can be wrong. Throughout history, millions of people have been killed by employees who were simply following their employer's rules and doing their jobs. In a democratic society, institutional policies should be established by those who will use them. They also should be re-reviewed periodically to keep pace with scientific, cultural, and social developments. A decision based on policy that the decision-maker has had a hand in establishing or reviewing, or at least has carefully considered, may be an ethical decision, provided that the policy itself has underlying ethical principles. Merely following institutional policy for its own sake, however, is not an ethical response to the question "What should I do?"

Examples of Reasoning Based on Principles of Ethics

Autonomy

Counselors should be nondirective, support whatever decision clients make; patient requests should be respected, whether they're right or wrong; optimal choices are based upon use of medical/genetic information; patients' rights to know or not to know; honesty, obligation to tell the truth; refusal to lie; right to privacy or confidentiality; doctor-patient relationship (trust); rights to referral.

Beneficence

Removal of guilt or anxiety now, help with present problems; physician's responsibility to provide health care for family, society; the "Golden Rule" of Christian tradition: do unto others as you would have others do unto you; benefits outweigh possible harm; means of truth-telling so as to maximize good (means of telling truth, support, counseling, referrals); family planning, making informed reproductive choices; prepare patient for the future, including help cope with stresses of disease or abortion; improvement of life of future generations; health care; social planning; insurance coverage; workers' health (includes responsibility of factory to worker); working conditions; social unity; protection of persons through regulation or licensing of labs and providers; (insure proper level of service, quality control) to prevent misuse; common good, public health, public safety; population limitation, maintain balanced sex ratio; eugenic arguments cost to society (although eugenics is now associated mostly with harm, most eugenicists thought they were doing good).

Justice

Equal access; entitlement to full insurance coverage; right to medical care that is affordable; fairness or unfairness; they deserve or don't deserve the service; interests of the fetus ought to be treated equally with those of living persons; use resources wisely, don't waste resources; appropriate or inappropriate use of technology medical indication or no medical indication; this is a misuse of the service; all available services should be provided on request.

Non-Maleficence

Do no harm (the Hippocratic Oath); preserve family unity, resolve conflict through discussion truth telling to avoid harm; truth telling as a source of harm; no benefit gained from truth telling (no need to know); avoid potential misuse of information by third parties; avoid social stigmatization, discrimination in the workplace or elsewhere; avoid harm through regulations or government intervention; avoid harm to society if sex ratio upset; parent's request serves no useful purpose; don't set a precedent that will harm the moral order ("slippery slope" argument).

Strict Utilitarianism

Efficiency or utility; cost-benefit analysis; protection of economic interest of third parties; consumers have a right to whatever service they can pay for out of pocket.

(4) *"The Bible tells me so."*

Religion and ethics is closely linked. Ethics is a part of all major religions. However, ethics is not identical with religion; ethical reasoning must be understandable outside the framework of particular religious beliefs. For example, to say "I would do this because the Bible tells me so" is not an ethical answer. Over the centuries, people have interpreted the Bible differently. To make an answer based on the Bible into an ethical statement, one would have to explore the reasons why the Bible makes this statement and then explain this in terms meaningful to someone with a different interpretation of the Bible or no experience of the Bible at all. The statement that "God said this" is inherently unsatisfactory because it falls back on a legal/ policy/ authoritarian approach. It is also particularly unsuitable for providers in a multicultural society. An ethics based interpretation of religious approaches almost inevitably uses principles or relationships.

(5) *"I disapprove of this!"*

This statement appears frequently in answers to questions about sex selection. This knee-jerk response includes no ethical reflection whatsoever, merely the emotion of the moment. Although ethical principles may underlie the response, it is not an ethical statement in itself.

Examples of Ethical Statements

Ethical statements may be based on 1) principles; 2) action-rules or action guides which are informal statements based on principles; 3) relationships; or 4) a combination. The principles-based approach is most common in ethical textbooks and discussions. . The action guide approach appears to be most common in geneticists' actual reasoning, at least according to the survey responses of almost 800 U.S. geneticists and counselors.

In biomedical ethics, five general principles are commonly discussed:

Five general principles provide the foundation for most reasoning in biomedical ethics:

1. Autonomy (*Respect for Persons*): the duty to respect the self-determination and choices of autonomous persons, as well as to protect persons with diminished autonomy, e.g., young children, mentally retarded persons, and those with other mental impairments.

2. Non-maleficence: the obligation to remove or minimize harm, to persons and wherever possible to remove the causes of harm altogether.

3. Beneficence: the obligation to secure the well-being of persons by acting positively on their behalf, and moreover, to maximize the benefits that can be attained. Beneficence goes beyond non-maleficence in not only avoiding harm but purposefully trying to do good.

4. Justice: the obligation to distribute benefits and burdens fairly, to treat equals equally and to give reasons for differential treatment based upon widely accepted criteria for just ways to distribute benefits and burdens.

5. Strict Monetary Utilitarianism: economic interests or material ends have the highest priority in reasoning. Although most people think of utilitarianism as promoting "the greatest good to the greatest number," utilitarian philosophy originated from monetary theory. In the above analysis, the "beneficent" aspects of utilitarianism have been separated from the monetary or efficiency aspects. Autonomy is the most common principle underlying decisions in the U.S. and other Western nations. This view is shared by providers and consumers alike. There appears to be a trend toward providing all services requested, provided only that the consumer can pay out of pocket. Justice and equity concerns are rarely mentioned, though they should be of paramount importance in a nation debating health care reform.

Action-guides

An action-guide is a practical rule for action that is principles based. Often, instead of saying "autonomy," or "obligation to tell the truth," people say, "the patient should make up her own mind" or "I should educate the patient." According to Beauchamp and Childress (1994), these informal statements that relate to principles should be called "action rules." These, rather than the more formally stated principles, are the approaches used by most U.S. medical geneticists and genetic counselors.

Relationships-Based Approaches

Relationships-based ethics incorporates the needs and deserts (special "extras" owed to certain persons or groups because of prior suffering or discrimination) of all parties concerned, as well as the more formal concepts of rights, obligations, and good of society. Relationships-based ethics are found in the psychological research of Carol Gilligan and the feminist bioethics of Susan Sherwin, Christine Overall, and others. Such an ethics appears to be an ideal framework for consumer provider interaction.

The National Society of Genetic Counselors (NSGC) has adopted a relationships based Code of Ethics that incorporates four type of relationships: 1) with self; 2) with client; 3) with colleagues; and 4) with society.

The NSGC Code includes guidelines for evaluating a potential choice of action in the light of its effect on each type of relationship. Other relationships affecting ethical decisions in genetics include relationships with the client's family, with institutions (schools, employers, insurers), and with one's own sense of professional integrity, and the client's own relationships with spouse or partner and with family members.

In responding to our current survey of geneticists, however, very few providers speak of relationships in their reasoning; they seem to prefer action guides or even formal principles over relationships. A relationships-based approach has much to offer, and should be used more frequently.

Consequentialist versus Non-consequentialist Approaches.

Classic utilitarianism (U.S. Mill, Jeremy Bentham) is based on consequences. Aristotle and Thomas Aquinas were also goal oriented ("teleological") thinkers. "Deontological" theories (Kant) are based on following rules, regardless of consequences. Many approaches combine the two (e.g., rule-utilitarianism). In a 1985 survey of 295 U.S. geneticists, 36% mentioned specific outcomes of their ethical decisions.

Why is Ethics Important?

Neither consumers nor providers can base their actions solely on technological, legal, or institutional policy grounds or on immediate emotional responses. Decisions based on external authorities, made without careful thought, lead to authoritarian societies. Technology and law will not solve ethical problems. We need a meaningful rationale behind our decisions. This rationale should be understandable to, and shared by, members of the different cultural and racial groups that make up the U.S. population. We also need consistency in our actions. Ethics enables people to think for themselves, and to consider interests of all parties concerned. Ethics is important because private decisions may lead to cultural transformations. Ethics helps us to look beyond the details of the immediate situation.

Suggested Readings:

Beauchamp, Tom L., and Childress, James F. **Principles of Biomedical Ethics**, Fourth Edition. New York: Oxford University Press, 1994.

Fletcher, John C. **Ethics and Human Genetics: A Crosscultural Perspective**. Pages 457-490 in Wertz, Dorothy C. and Fletcher, John C. (eds.) *Ethics and Human Genetics: A Crosscultural Perspective*. Heidelberg: Springer Verlag, 1989.

Gilligan, Carol. **In a Different Voice: Psychological Theory and Women's Development.** Cambridge, MA: Harvard University Press, 1982.

National Society of Genetic Counselors, Code of Ethics. **Journal of Genetic Counseling, Vol. 1, no. 1, March 1992, pp. 41-44.**

Overall, Christine. **Ethics and Human Reproduction: A Feminist Analysis.** Boston: Allen & Unwin, 1987.

Sherwin, Susan. **No Longer Patient: Feminist Ethics in Health Care.** Philadelphia: Temple University Press, 1992.

Wertz, Dorothy C., and Fletcher, John C. **Privacy and Disclosure in Medical Genetics Examined in an Ethics of Care.** *Bioethics* 5 (3); 1991: 212-232.

Some New England Ethicists Working on Issues in Genetics

George J. Annas
Health Law Section
Boston University School
Of Public Health
80 East Concord Street
Boston, MA 02118
617-638-5042

Dan Brock
Department of Philosophy
Brown University
54 College Street
Providence, RI 02912

Bernard Gert
Inst. For the Study of
Applied and Professional Ethics
Dartmouth College
Hanover, NH 03755

Helen B. Holmes
24 Berkshire Terrace
Amherst, MA 01002
413-549-1226

Thomas A. Shannon
Dept. of Humanities
Worcester Polytechnic Inst.
100 Institute Road
Worcester, MA 01609
508-831-5468

Susan P. Stafford
Dept. of Philosophy
Simmons College
300 The Fenway
Boston, MA
617-521-2210

Caroline Whitbeck
Massachusetts inst.
of Technology
Building 3, Rm 137C
Cambridge, MA 02139
617-253-1631