



Curriculum Units by Fellows of the Yale-New Haven Teachers Institute
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Bioethics and Effective Health Care

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Introduction

Just open a newspaper, medical journal, magazine, go on the internet or visit a medical facility or talk to family members, friends and others. You will soon discover that humanity is confronting many ethical issues as it relates to our health and welfare. The world's population at the beginning of the new millennium is over six billion, each in pursuit of life, liberty and happiness. On one hand, individuals want to have control of their own welfare. On the other hand, society wants to advance the general health and welfare without allowing any individual or any one group to benefit at the expense of another. Sometimes these needs conflict with ethics and create difficulties in crafting a sustainable and economically sound medical system. Overall, our goals should be to balance personal choice with the general goals of society. This causes a dilemma, because what makes a moral, acceptable and fundamentally right or wrong individual is not always easy to define. How do we become morally responsible? Where do we learn values, principles and reasoning skills to solve moral problems related to health and welfare of the general society? Perhaps, bioethics, is one means to ensure the pursuit of life, liberty, and happiness of society by specifying the characteristics of an ethical, rational, and economically sound system.

The purpose of developing this unit on bioethics is to make teachers aware of the characteristics and strategies used in developing a fundamentally rational, ethical, and economically sound medical system. These strategies can then be applied in resolving ethical issues in conflict. The unit will present the opportunity for teachers to engage students in moral knowledge and integrity that can and should be nurtured along with content knowledge. This will help students to become critical thinkers.

As a result, this will better help students move from a single-minded view of self towards a vision of the self in relationship to the needs of others in this world. Hopefully, this unit will raise the level of awareness in helping teachers and students face, evaluate and make hard choices now that will benefit society later. In addition, analyzing problems on ethical issues and conflict that represent life will provide a level of knowledge and comfort and make the real dilemmas less threatening.

The unit is designed for grades 5-8 and will consist of knowledge content, lesson plans, student resource list, teacher resource list and a bibliography. Science: Content Standards 5.0 and 6.0 will be used. Science Content Standard 5.0 deals with technological science which states that students will develop abilities necessary to distinguish between naturally occurring objects and those of human design, and they will develop

understanding of the roles of science and technology in contemporary society. Science Content Standard 6.0 Ecology states that students will develop an understanding of personal and community health; of the characteristics of changing populations; of the ecology of and uses of natural resources; of changes in environments; and of the use of science and technology in addressing present-day local and global challenges.

Student Performance Standards 5.1, 6.1 and 6.2: Students will develop understanding of technological designs, changing population and ecology, which problems can be solved or improved through scientific information or the development of a new product or process; (2) students will develop a proposal which solves or improves a problem through a new product design or procedure; (3) students will implement the proposed new design or procedure for the improvement or demand a higher quality of life for all; (4) students will understand that all technological solutions have trade-offs or consequences which affect our environment or quality of life, and (4) students will understand that some consequences are predictable and some are not. and improve the quality of life. All of these objectives are directly related to the Connecticut Mastery Test (CMT). Teachers using the unit can assess students by using portfolios, tests, written, and oral evaluations.

Definition

Bioethics

Bioethics is a study of moral conduct, of right and wrong in problems dealing with biology or medicine. Bioethics inquires about the rightness or wrongness of various actions, character traits, and social policies. Bioethicists ask questions such as: Can euthanasia be morally justified? And whether such practice would be good social policy. Bioethicists are interested in questions on the nature of moral justification and the kind of thinking that supports it. For example, justifiability of physician-assisted suicide must be sought in the articulation and application of various moral theories or principles. Others might claim that justification must proceed the other way around, beginning with concrete and unmistakable instances of good and bad behavior, and then gradually developing principles that seek out and capture our most fundamental moral response! It is a question of whether ethical thought should proceed from the top down or bottom up.

Narratives of Moral Dilemmas

The Constitution of this United States of America clearly expresses a desire to promote the general welfare of its citizens. It is hard to imagine that all Americans have the same availability to the health care system. Some people are born with good health and live a long happy life. Others are born unhealthy and need health care to sustain quality of life.

Yes, it is hard to deny that we do not all have equal availability to health care, so an analysis of our medical care system can serve to illuminate our moral theories and applied ethical practices. Some people are rich or middle class and have the money to pursue life, liberty and happiness. Other people are poor and cannot afford expensive medicines and other health care needs to pursue life, liberty and happiness. The common focus of health care is money and resources are scarce and health care is expensive. There are not enough resources to satisfy everyone's preferences and needs for health care. Even if we can reach consensus that a right to health care exists, priorities must still be assigned. The question is who should be saved, when we

cannot save all? Which group of people and which treatments and diagnostic techniques should have highest priority?

Most of us can recognize good or bad moral reasoning. However, it becomes more difficult for us to deal with real complicated situations, such as, Is assisted suicide wrong because it helps someone to kill him or herself, and killing is wrong? Or is it right because it helps someone to do what he or she reasonably wants to do, and thus promotes autonomy? To answer such questions, we need a framework to reflect on the acceptability of actions and evaluate moral judgments and character. These frameworks are called ethical theories.

Ethical Systems

For many years different ethical theories have been used to justify decisions about important health issues in society. Health care providers want to go forward with promoting the general welfare of society without allowing any one group or individuals to benefit at the expense of another. Promoting the general welfare of the society involve justice. Justice is a higher ethical value that requires treating people fairly. Theories of fairness suggest that each person should have equal opportunity. The theory of fairness has been rationalized in several ways.

Egalitarians

First, the egalitarians believe that fairness involves the distribution of goods equally among all members of society. The concept of distributive justice is based on the idea of innate merit. All people by virtue of birth and their common humanity should merit some share of the total amount of goods and services turned out by the economic system according to abilities and needs. Others think that a person's claim to economic goods ought to be limited to some minimum standard of distribution. Still others think that the distributed benefits should be limited to certain specific goods, such as medical care (1)

Libertarians

Second, the libertarians focus on social and economic rights. They believe that the government should not interfere with individual action, even to insure equal opportunity. The notion is that a just society protects the rights and freedoms of its citizens. This protection allows them to improve their circumstances through their own efforts (2).

Utilitarians

Third, the utilitarians believe in the distribution of health care and favor equality of access to needed services. The utilitarians judge the rightness and wrongness of an action by its consequences, or what will happen if the action is not performed. Utilitarianism's theory of value says that good consequences are those that produce or promote happiness or pleasure, bad consequences those that produce or promote the reverse

The strength of the utilitarianism is that it provides us with a procedure for deciding what to do: that is, whichever action produces, on balance, the greatest amount of happiness. Happiness is claimed to be

something measurable and comparable. This means that in principle, utilitarianism provides definite answers to the question of how we ought to act.

An important feature of utilitarianism is that it regards the question of whether a given course of action conforms to established social norms or ethical codes as relevant only to the extent that such conformity has a bearing on happiness or unhappiness. Anyone breaking the rule experience adverse consequences. Impartiality is another important feature of utilitarianism. It does not say that goodness of action produce happiness for me; rather, the good is determined by the overall net happiness achieved. The principle of utility is derived from the very point of morality, which is to improve the lot of human beings living together. Morality relates to the improvement of the human condition, which means alleviating suffering and increasing happiness (3).

Communitarians

Communitarians believe in communal values with traditional practices. Social goals play a major role in making decisions about health. For example, if an organ transplant were a concern, then the communitarians would ask questions about decisions relevant to acts, policies, and rules that would best respect and promote the general welfare of the society. Communitarians view principles pluralistically as to promote diverse moral communities.

In sum, regardless of the system, individual people make the analysis in all ethical systems. Every principle or policy that we develop must be a statement about the way that individuals make choices, struggle with the problems of availability or scarcity of resources in the society. Specifically, policies related to health care must be judged in terms of their impact on the welfare of individual people.

This means that ethical systems are based on the recognition that society has no importance except to serve individual people of which they are made up. Therefore, the concept of equity plays an important role in policy analysis. However, careful considerations must be given to justice or fairness to the value of distributing services or goods in society (4).

Ethical Dilemmas and Managed Health Care

Ethical issues in managed health care overlap with economics. However, leaving health care completely to market forces is not acceptable when a great portion of the population do not have access to health care. Many people who have some form of insurance are unprotected from the heavy burden of sickness. Conventional and alternative choices in health care remind us that patient autonomy is not going away, but must be brought into balance with other ethical principles.

Health care ought to be distributed equitably. People differ in their beliefs about the value of health and medical care and their use of it as a way of achieving good health. The important of health care is to cure illness, to keep people from worrying and to enable them to adjust to their situation by providing good information.

Health care enters people's lives at the beginning and continues to the end. Access to health care is essential to individual needs. Everyone should be able to receive an adequate level of care. What adequate care looks like depends upon the overall resources available resources society has to offer. However, society has a moral

obligation to insure that everyone has access to adequate care without being fiscally overburdened.

In designing a managed health care system; justice is one important principle. Autonomy and justice in the past have been treated as an item, because for one person to say and choose what he or she wants without regard to what others want is unfair if resources are coming from a common pool.

In *Fuja v. Benefit Trust Life Insurance Co.* (18F.3d 1407 7th Cir. 1994), a woman with metastatic breast cancer was referred for bone marrow transplantation. The transplant was denied because the woman's insurance contract did not cover experimental procedures. The Seventh Circuit Court supported Benefit Trust, seeing the ethical issue as one of contract interpretation. Contractual fairness is just one type of fairness. However, distributive justice: to each according to his need); egalitarian justice-to each according to what similar others receive and utilitarian Justice -to each according to what's best for all) are other types. Judging ethical issues by contract can integrate fairness and autonomy, but it is not the best way to make a decision. Employees who use contracts to make decisions about health care, are just as concerned about their budgets, as with helping their employees care for themselves or families (5).

A different way to integrating fairness with autonomy is to be as scientific as possible about medicine. In *Barnett v. Kaiser Foundation Health Plan, INC* (32 F.3d413, 9th Cir 1994), a man with e-antigen positive hepatitis was referred for transplantation. The Kaiser Foundation Health Plan Liver Transplant Advisory Board denied the procedure because, the board said, the highly infectious disease would cause the transplant to fail and was Therefore, contraindicated, Mr. Barnett paid privately for the procedure and then sued. The Ninth U.S. Circuit Court of Appeals found in Kaiser's favor. Medical criteria, it was decided, were a valid way to make medical

judgments about efficacy and benefits (6).

Physicians, ethicists and attorneys are addressing cases that deal with decisions about the responsibilities to all managed care organizations patients. fundamental questions are being asked about what level of medical care does society owe to its citizens? The good news is that they can now begin to answer.

Ethical Issues Concerning Rationing

Rationing organ transplantation has been a difficult process as it relates to justice or fairness. Rationing is a major concern because it adds a burden when allocating the already insufficient supply of organs for life-saving transplantation. However, justice is not the only issue, since allocating large resource commitments to people who are real sick, may not be efficient in producing good, because they are too sick to benefit from it. We must decide not only what is just, but also what is the right decision in producing justice, good health outcomes, and other unpredictable situations.

Some of the considerations based on other principles are deontological in character. Deontology ethics place emphasis on autonomy, justice and kind acts. This principle does not focus directly on the good consequences. In other words, you must never act wrongly in order to bring about good consequences. According to this ethics, one must treat every person as an end, and never as a means. As we deal with others we are to realize that they have their own goals, aims, and projects. We should not treat people as if they do not count, or exist to fulfill our purposes. The emphasis is on moral rules and duty. Its strength is providing a special status for humans.

In the formula for rationing, ethical resource allocation concerns who should get what kind of care when. We must consider how to get the maximum utility possible to service the general welfare of the society. Embedded in this notion is if there is enough utility to the group, the rights of individuals can always be sacrificed. In this case the right being sacrificed is an entitlement right, the right to the resources needed to have an opportunity for equality of well being as much as possible. In other cases the right may be a liberty right, for example, the right to refuse medical treatment (7).

The only solution to the huge gap between the number of organs available for transplantation and the number of patient waiting is to increase the number of suitable donors. Many potential donors are victims of accidents and violent crimes, and should indicate donor status in advance. In addition, the shortage of kidneys for organ transplantation has led to some unethical ways. Organ donors are selected from prisoners, street children, and

brain damaged patients as a means of increasing the supply.

For example, it has been proposed in the form of legislation that prisoners be allowed to donate organs and or tissues. Much of the legislation targets prisoners on death row. Some states legislatures in the U.S. have investigated the possibility of condemned prisoners trading a kidney or bone their marrow for reduction in their sentence from death to life in prison (8).

In Europe, one proposal is that all reasonable compassionate persons want their organs to be used to save others' lives. Their organs would be automatically removed on their demise. However, those individuals who are not compassionate, would be allowed not to register their dissent.

In another proposal, it has been a mandatory universal declaration requiring all adults to at least register their wishes one way or another. This allows for a high degree of self-determination, but by requiring a decision, it is speculated that persons would be in favor of the donation. This is not the case in the U.S., neither presumed consent or mandatory declaration has been widely received as a solution to the critical organ scarcity, and voluntary donation remains the policy.

Ethical Dilemma of Rationing Effective But Expensive Treatments

One problem common to all health care systems is making a decision on how ethical it is to provide expensive halfway medical inventions. Managed care organization must make difficult decisions about health issues and who receive care. These decisions will affect everyone and money spent on one group or another.

Biotechnology has assisted in the creation of a variety of treatments that do not cure but allow individuals to live their lives with chronic but manageable conditions. For example, kidney dialysis is a technology that does not cure the disease, but allows a person to live by cleansing the blood of patients with a machine.

Halfway interventions are expensive. People who depend on halfway interventions live for a long time, and the cost of care increases over time. The question is should people be denied expensive halfway interventions and be confronted with possible premature death? or should they be provided with treatment knowing that it will endanger the fiscal resources for the majority (9)?

Should People Be Denied Expensive Halfway Interventions?

We must look at two sources of justice in analyzing whether or not people should be denied expensive halfway interventions. First, we must find out the effectiveness of these interventions and secondly, their ability to protect fair equality of opportunity.

First, people with chronic kidney disease are given halfway interventions. They are given kidney dialysis, a technology that cleanses the blood so that the patient can live. Although, this intervention is effective in allowing people to live longer, they may have a low quality of life. People who have kidney disease and

relevant need are not denied dialysis, regardless of limited public resources or whether they benefit or not. Managed care organizations will pay for kidney transplants, but do not pay for other major organ transplants (10).

However, this is not the case with HIV or other diseases. The drugs given to HIV patient are highly effective. In addition, there have been widespread reports of improvements in quality of life with patient who has HIV. Many have enjoyed the happiness of a normal life. It would be unjust to deny an individual life, liberty and the pursuit of happiness, if the possibility exists for better health (11).

Second, the capacity to protect fair equality of opportunity is key to understanding the demands of health care justice. Given the effectiveness of the HIV protease inhibitors, individuals would have a good case on the grounds that they should have protection of fair equality and opportunity to enjoy normal functioning and a better life. This is not to say that there is a cure for H.I.V (12).

However, several options might be available to the managed care organization

in formulating a health policy to protect fairness. These options will help ensure that diseases with a similar clinical and cost profile be rationed in an equitable way. Other drugs might become available to improve cancer and other diseases that might need to be taken on a regular basis. They too will have the option of a more general term to trade marginal expensive procedures to marginal inexpensive benefits later in life.

Option # 1: Postpone making any decision for a year. The main argument in support of this option is that we do not want to waste money on very expensive medical technology that might offer more than short-term hopes. This will give enough trial time to see if the treatment is effective, but there may still be a question about just caring (13).

Option # 2: Fund the medical technology only to the extent that competing managed care plans fund them. This may bring about corporate interest and raise moral issues. If there are large corporations that offer options with all the managed care plans in a specific location, then there would be a risk that the first managed care plan to offer coverage of the technology would attract a high percentage of individuals. This would be an unfair burden placed on the managed health care providers. In addition, the issue of right or wrong will be weighted (14)

Option #3: Let plan members themselves decide what the policy ought to be by voting or another process. This would be a democratic procedure that allows for community to make public self-imposed rationing decisions (15).

Option #4: Let plan physicians make the relevant moral and clinical decisions for individual patients on the basis of their best professional judgment. This option might bring to bear unlimited clinical autonomy as it relates to unlimited cost and unlimited inequities (16).

Option #5: Let companies that have contracts with our managed care plan decide whether or not to have coverage for their employees on the medical technology. This option will shift the moral responsibility to others whose self-interest is likely to bring about unjust results (17).

Option 6: Fund the medical technology for all patients who believe it is in their best interest that they get treatment immediately. This would be the most expensive option. Justice might be sadly compromised (18).

Option 7: Fund the medical technology for those whom best current medical evidence suggests are most likely to benefit significantly. This option is a limited, non-ideal, just-enough option (19).

A just and caring health care system should leave enough space so that the requirements of a competitive business environment could accommodate medical advancement without threatening the long-term fiscal viability of the plan. (20).

Should People Be Provided With Treatment Knowing That It Will Endanger The Fiscal Resources of the Majority?

Overall, people should be provided with treatment knowing that it will endanger the fiscal resources of the majority if there is flexibility making good rational decisions with the presumption of (1) effectiveness and (2) ability to protect equality of opportunity. Each person life is valuable, and priority should be given to saving lives. Resources will always be limited and people are forced into competing for resources.

Lesson Plan I

Science Content Standard 6.0: Ecology

Students will develop an understanding of personal and community health; of the characteristics of changing populations; of the ecology of and uses of natural resources; of changes in environments; and of the use of science and technology in addressing present-day local and global challenges.

Performance Standard 6.1

Students will develop an understanding of the value and behavior of good personal health

Objective: Students will learn personal responsibility for their own health and

safety and identify those activities which positively or negatively affect their health and safety.

Performance Standard 6.2

Students will develop an understanding of the use of science and technology and its effect on the characteristics of changing populations, ecology resources and changes in the environment.

Objective: Students will identify the characteristics of an environment and how they affect the quality of life.

Strategies:

I. Define in your own words the following terms: write complete sentences and

elaborate on your ideas. Give examples, when possible.

1. bioethics
2. ethical systems

3. egalitarians
4. libertarians
5. utilitarians
6. communitarians

II. Look at the ethical systems. Which one of these ideologies fit your way of thinking best? Remember that no system alone answers all ethical needs. What are some other factors that should be considered in solving ethical issues related to health care?

Lesson Plan II

Science Content Standard 5.0: Technology Science

Students will develop abilities necessary to distinguish between naturally occurring objects and those of human design, and they will develop understanding of the roles of science and technology in contemporary society.

Performance Standard 5.1

Students will develop understanding of technological designs, which solve problems and improve the quality of life.

Objectives:

1. Students will make a proposal to make something work better and communicate their ideas in writing.

2. Students will learn how developing solutions to problems can help people avoid new problems.

Decisions! Decisions!

Strategies

Read the following scenario and describe in writing the kind of thinking each participant (egalitarians, libertarians, and communitarians) would use in making a decision in convincing the managed health care board to accept or not to accept a policy on paying for medication for HIV patients.

Scenario 1: In a small rural town near a major city, 50% of the citizens have HIV. The disease is out of control and is spreading rapidly. Many of the citizens in the small rural town can not afford to pay for drugs to make life a little easier. In addition, to make the matter worse, some have died.

Lesson Plan III.

Science Content Standard 5.0: Technology Science

Students will develop abilities necessary to distinguish between naturally occurring objects and those of human design, and they will develop understanding of the roles of science and technology in contemporary society.

Performance Standard 5.1

Students will develop understanding of technological designs, which solve problems and improve the quality of life.

Objective: Student will discuss, write and implement the proposed new design or procedure for the improvement or demand a higher quality of life for all.

Strategies:

1. There is an insufficient supply of organs for live-saving transplantation. More donors are needed to meet the demands. In a group of 4 students, discuss and write a plan to increase the pool of organ donors.

2. The cost of organ transplantation is rising and in need of better ways of rationing resources. Develop a plan for allocation of the resource. (use the same group of 4 students.

3. Managed health care organizations are responsible for the health care system in the U.S. Do you feel that this is the best plan?

If not, what do you propose?

4. If your answer in #3 is no, how would you implement your new plan?

Endnotes

1 Arras, John, D. and Steinbock, Bonnie. Ethical Issues in Modern Medicine.

Mountain View. Calif: Mayfield Pub. Co., 5th ed. p. 6

2 Ibid., p.8

3 Ibid, P. 9

4 Ibid., p.25

5 LaPuma, J., M.D., "Ethics Catches Up to Law: What Is Most Fair for All ?"

Managed Care, Stezzi Communications, 1996

6 Ibid., p. 2

7 Arras, John D. and Steinbock, Bonnie, Ethical Issues in Modern Medicine,

Mountain, Calif: Mayfield Pub. Co., 5th ed. p. 624.

8 Science Museum of Virginia, Bioethics 2000 Primers, "Organ, Tissue Donation and

Transplantation, 1998, pp.3-4

9 Arras, John. D. and Steinbock, Bonnie. Ethical Issues in Modern Medicine,

Mountain, Calif: Mayfield Pub. Co., 5th ed. p. 623.

Fleck, Leon M., " Just Caring: Managed Care and Protease Inhibitors" Ethical

Issues in Modern Medicine, Mountain Calif: Mayfield Publishing Co., 5th ed.,

1999. p. 684.

11 Ibid, p. 680.

12 Ibid, p. 681.

13 Fleck, Leon M., " Just Caring: Managed Care and Protease Inhibitors", Ethical

Issues in Modern Medicine, Mountain Calif: Mayfield Publishing Co., 5th ed.,

1999. p. 680.

14 Ibid, p.681

15 Ibid, p. 681

16 Ibid, p. 682

17 Ibid, p.682

Ibid, p.982

19 Ibid, p.684

20 Ibid, p.685

Teacher Resource List

Books:

African-American Perspectives on Biomedical Ethics Guido, G. W. (1997). Legal

Issues In Nursing, 2nd ed. Appleton & Lange, Stamford, Connecticut. 361-364.

Husted, G.L. & Husted, J.H. (1995). Ethical decision making in nursing, 2nd ed.

Mosby and Company, St. Louis. 18-26.

Ethical, Legal and Policy Issues Pertaining to Solid Organ Procurement. Hastings-on

Hudson, N.Y.: Hastings Center, 1985.

Computer Resources

University of Houston Law Center

Health Law & Policy Institute

HealthPathfinder

American Society for Law, Medicine, and Ethics @Ref: Educational information concerning law, medicine and ethics, including access to monthly featured articles of the Journal of Law, Medicine, and Ethics and American Journal of Law and Medicine. <http://www.aslme.org> Bureau of National Affairs' Health Care Top Stories Daily reports of developments in health care law and policy. <http://www.bna.com/procatalog/hec/index.html> Health Care Quality Websites Links to resources relating to quality of health care services. <http://www.quality.org/html/hc-res.html> The Initiative to Eliminate Racial

and Ethnic Disparities in Health Information on the President's commitment to eliminate the disparities in health status experienced by racial and ethnic minority populations. Areas of disparity include infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV infection, and adult immunizations. <http://raceandhealth.hhs.gov>

Teacher Instructional Aid

Clouser, K. Danner. Teaching Bioethics: Strategies, Problems, and Resources.

Hastings-on-Hudson, N.Y.: Hastings Center, 1980.

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Daniels, Norman, et al. " Meeting the Challenges of Justice and Rationing." Hastings Center Report 24, no.4 (July-August 1994): 27-42. Flack, H. E. and Pellegrino, E. D. African American Perspectives on Biomedical Ethics. Washington, D.C.: Georgetown University Press, 1992. Fleck, Leon M., " Just Caring: Managed Care and Protease Inhibitors" Ethical Issues in Modern Medicine. 5th ed. Mountain Calif: Mayfield Publishing Co., 1999. pp. 679-685.

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