A Decision-Making Model for Bioethical Issues

Introduction to Bioethics

Since the middle of the 20th century, rapid improvements in technology have changed the practice of medicine profoundly. The technology often allows physicians to restore or supplant basic bodily functions. Mechanical ventilators, heart pacemakers, kidney dialysis machines, exotic drugs, organ transplantation, and artificial nutrition and hydration are some of the life-extending tools available to the modern practitioner.

Initially, the use of these techniques was seen as altogether positive, a must-do choice for the physician. It was not long, however, before difficult questions surfaced. Just because we can maintain a person with artificial ventilation and nutrition, should we? Who should answer such a question: the patient, physician, family, nurse, social worker, hospital administrator, insurance company, ethicist, politician?

Since the 1960s, questions like this one have provided us with an entirely new discipline or, more accurately, interdisciplinary: bioethics. Bioethics, or biomedical ethics, has become an immensely important topic. Few major hospitals are without an ethics committee to assist patients or health care providers when they need help. Colleges offer courses of study in medical humanities or bioethics.

Paralleling the medical developments described above were striking advances in our understanding of genetics and molecular biology. Genetic knowledge has only recently been applied to specific diseases or patients, but the ethical questions that plague us about any medical technology apply also to medical biotechnology.

How do we decide what is right or wrong, what is better or worse, as medical biotechnology offers us ever more choices? Should everyone be screened to determine who the carriers of recessive alleles for genetic diseases are? Should genetically engineered products be available to everyone, or should we sometimes screen requests for them (such as requests for human growth hormone)? Who should (and who actually will) have access to a person's DNA fingerprint? Are we on the road to employment and insurance discrimination based on genetic profiles? These are but a few of the ethical questions that can be posed.

The Bioethics Decision-Making Model

In attempting to answer difficult ethical questions, it is helpful to focus on specific cases and follow a step-by-step procedure. Below, you will be presented with specific case studies to analyze and a decision-making model to be used in these analyses. Part of the decision-making process will be to gather any additional background facts you need for evaluating the situation and to find out what sort of ethical standards that apply to your case have been established. Finally, you will make a decision as to the best course of action and justify it in terms of basic ethical principles.

Identifying a dilemma

The case studies we have provided raise bioethical dilemmas. A dilemma exists when there is no "right" course of action in a certain situation but, instead, several options, none of which is wholly acceptable. Ethical dilemmas revolve around trying to find the best solution when no solution is completely good. Not every situation presents a dilemma; many times, the possible courses of action are clearly right or wrong. The following example may clarify what does and does not constitute a dilemma.

Assume that a patient with a certain condition would be an appropriate candidate for a drug research study. The patient's physician places her on this drug without getting her permission. This situation is not a dilemma. It is just plain wrong. Even if the doctor believes the drug will benefit the patient, by all modern
medical standards, the physician has the obligation to get the patient’s informed consent to include her in the study. (The Nuremberg Code and the Declaration of Helsinki, two internationally recognized codes of ethics, specifically address the ethics of research using human beings.)

On the other hand, assume that the patient has been given all the information she needs for making a decision. She is told that the drug has the potential to help her but might also have harmful side effects. She sees benefits and costs regardless of which decision she makes. Now we have a dilemma. A dilemma exists when no choice is ideal but all options have benefits and risks that must be carefully assessed.

Once a dilemma has been identified, the next step is to pose the dilemma in the form of a question about a specific case. Often, more than one question can be formulated. You will need to choose one question at a time for analysis, although you may consider several questions, one after the other, about a single case. It is also helpful to categorize the kind of issue being discussed. In the example given previously, the issue might be human research and the question posed could be, “Should the patient agree to be part of the study or not?” Since these discussions are usually very interesting and emotional, it is easy to get off track. The decision-making model presented here reduces that risk.

**Basic ethical principles**

In order to make ethical decisions, we must agree on some basic guidelines about what constitutes moral conduct. In the field of biomedical ethics, certain guides are well established. The moral-action guides or principles can be divided into four major principles and several secondary ones. These principles are listed below. The terms in parentheses are those used in bioethical literature. You may encounter them in your library work.

**Major Ethical Principles**
1. Do no harm (nonmaleficence).
2. Do good (beneficence).
3. Do not violate individual freedom (autonomy).
4. Be fair (justice).

**Secondary Ethical Principles**
1. Tell the truth (truth-telling).
2. Keep your promise (fidelity and promise keeping).
3. Respect confidences (confidentiality).
4. Use the principle of proportionality: risk-benefit ratio (how much harm can be justifiably risked to effect good).

5. Attempt to avoid undesirable exceptions, also known as the wedge principle, the slippery slope, or the camel’s nose.

Although these rules are simple, they represent fundamental values associated with respect for human dignity that most people agree to. These are the principles to which you should refer when making and justifying decisions.

**Basic steps of the decision-making model**

Here is a summary of the steps in the decision-making model. Each step will be explained more fully later on. Begin with a case study.

1. Identify the question you want to address. Usually, for any given case, many questions could be considered. Choose the one you want to explore.

2. Identify the issue you are exploring (i.e., genetic screening, confidentiality, gene therapy, human research subjects, etc.). Naming the issue will help in the search for relevant literature.

3. State the facts in the case. Be sure to avoid inferences.

4. Think of as many possible decisions in the case as you can.

5. Gather additional information as needed.

6. Pick the decision you want to support.

7. State the ethical principle that supports your decision (your claim).

8. Identify an authority that supports your decision. Quote the authority, if possible.

9. Formulate a rebuttal. Under what circumstances would you abandon your claim?

10. How strongly do you believe your claim? What is your level of confidence, the qualifier?

11. “Box up” the case for reporting your decision.

12. Write a prose argument describing the case and your decision.
Case Study: Bobby K.

Bobby K. is a healthy 10-year-old boy. He is very agile and quick and loves sports. The coach of his city league basketball team has told Bobby's parents that their son's skills on the court are astounding for a child of his age.

Bobby's father, Mr. K., is a healthy man who is 5'3" tall. Bobby's mother is also short, only 5'0". Bobby's pediatrician has predicted that Bobby will attain an adult height of about 5'3" but has emphasized to his parents that he is a normal, healthy boy. Mr. K. remembers being teased constantly about his size and recalls that his lack of height kept him off all the varsity sports teams at his high school. He has often wondered if his shortness is a disadvantage to him in business dealings, too. Mr. and Mrs. K. both anticipate that their son will be the recipient of more and more pointed teasing as he reaches his teenage years. They also fear that he will not be selected for the basketball team when he reaches junior high or high school.

Bobby's coach has heard of a program at the local university in which gene therapy is being conducted on children who have a disease that results in the inadequate production of growth hormone. The children are being given working copies of the gene for human growth hormone, and the levels of growth hormone in their bodies have increased. These children's growth rates have also increased.

Bobby's coach tells the K. family about what he has heard. Bobby is thrilled, because he might be able to keep playing basketball, maybe even on a professional level. Bobby's parents are more cautious but would like their son to be spared the pain of being much smaller than his classmates.

The K.'s go to Bobby's pediatrician and request that Bobby be given the growth hormone gene therapy.

Using the decision-making model

This case obviously presents many possible questions for consideration. For example,

- Should Bobby's doctor allow him to have the gene therapy?
- Should Bobby's parents let him have the therapy?
- Should Bobby's coach have told the K.'s about the program?

There are probably many background questions you will need to investigate. For example,

- Have there been any studies to determine whether it is safe to give additional growth hormone to normal children?
- What height range is considered normal? How can you tell whether a short person is normal?

Choose a dilemma question for analysis, and use the model to generate a solution.