from a facilitated discussion. By soliciting different points of view and discussing concerns in a mutually respectful environment where all voices can be heard, they can reach a more comprehensive decision that is ethically justifiable.

It is apparent that the duty-based principles such as respect for autonomy and veracity push us very hard to disclose Mr. Dossey’s diagnosis and honor his decision if it is indeed substantially autonomous. On the other hand, the Hippocratic form of a consequence-based ethic provides the most plausible basis for overriding his decision to refuse treatment for an acute health problem that could probably be reversed. There are many cases in ethics that lead to relatively clear resolutions. At times, reasonable people can come to the same resolution but support their decision with entirely different principles or theories. Mr. Dossey’s case, however, does not lead to a definitive resolution because of the facts of the case and the individuals involved. Health professionals encounter all of these types of ethical problems from the clear-cut to the vague and messy. The decision-making model is one tool to help determine justifiable options whether the case is simple or complex.

Notes


Chapter 2
Values in Health and Illness

Learning Objectives
1. Identify moral and nonmoral evaluations in health care practice.
2. Identify value judgments in clinical cases involving a health professional and patient.
3. Describe the criteria for an evaluation to be considered an ethical evaluation.

Other Cases Involving Values in Health and Illness
Case 10-7: Biased Counseling: Teaching about Birth Control
Case 11-2: Dwarfism: When Is a Fetus Normal?
Case 12-1: Guilt over Suicidal Thoughts
Case 12-2: Obesity: Medical Problem or Lifestyle Choice?

At first it might appear that ethical and other value problems arise infrequently in medical decision-making. Although the health professional and patient are increasingly seen as confronting such issues—in decisions about abortion, euthanasia, test-tube baby cases, and genetics, for
example—most medical choices seem at first to be more technical or scientific. They seem like straightforward problems of how to best prevent or cure problems with our bodies.

While the morally conspicuous controversies in medicine are on the rise, it is important to realize that even the most routine medical choices involve a set of value judgments and that some of those value judgments involve moral choices.

Before turning to specific topics such as the ethics of abortion, genetics, informed consent, and death and dying, some preliminary work must be done. We must first be sure we can recognize ethical and other value issues when they arise. This is the focus of this second chapter. The cases are selected to help identify the value dimensions in medical choices and to distinguish moral from nonmoral value judgments.

Identifying Value Judgments in Medicine
The first task in analyzing the ethics of cases is making sure the normative judgments (or what are sometimes called value judgments) are identified when they occur. In fact, normative judgments occur constantly in all health care decisions. It is impossible to get to a clinical conclusion—to prescribe or take a drug, use an over-the-counter medication, pick between a trade name and generic medication, begin an exercise program, or enter a hospice—without making a normative judgment as well. Whenever someone decides to act (or refrain from acting), some evaluation has taken place. A decision is made that a particular course is the right one. It is better than available alternatives. It is what one ought to do.

One key to learning to recognize that evaluative judgments have taken place is to watch for value terms. Words such as right, better, and ought all signal a process of evaluation. It is the nature of all professional clinical roles—being a physician, nurse, pharmacist, dentist, or allied health professional—that one constantly makes these evaluations. Just as important, people in roles outside the professional medical realm—in the role of patient, family member, judge and legislator, or citizen—make evaluative choices in medicine as well. They decide they have a problem that needs a physician’s attention; they give their children aspirin, authorize a physician and family to withdraw life support, pass a law legalizing physician-assisted suicide, or vote for a politician who favors or opposes a new health insurance plan.

Case 2.1 does not raise a dramatic or grave ethical issue. It may not raise any ethical issue at all. It does involve a number of evaluations, however. It involves a patient confronted with a choice about how to manage his cholesterol and a physician who has to decide when to prescribe an anticholesterol medication. These are important choices, ones that patients and doctors must face daily, but they do not present obvious or dramatic ethical problems. This case helps us recognize value choices when they occur in medicine.

Case 2.1
Exercise, Diet, or Drugs to Control Cholesterol
Jake Mendiola knew he had a problem. He was 37 years old. At 5’10” and 230 pounds, he was heavier than his doctor liked. His sedentary lifestyle, as an information technology specialist at a major accounting firm, meant he did not get the exercise that his wife and his physician thought he should. His physical exams over the past several years showed a nagging increase in total cholesterol levels (237 mg/dl), the low-density lipoprotein (LDL; “bad”) was too high, and the good-high-density lipoprotein (HDL) was too low. His physician had twice recommended exercise at least three days a week and some dietary modification to get the cholesterol lower. Mr. Mendiola went part way. He cut down on eggs for breakfast. He intentionally signed up for the cheaper parking lot at work so he would be forced to walk about three blocks to his office. He knew, however, that this was not exactly what his physician had in mind.

Now at a routine trip to his HMO (health maintenance organization), his doctor nagged him again about diet and exercise. The physician continued to worry about the cholesterol, pointing out that the treatment protocol at the HMO indicated that diet and exercise should bring the cholesterol into line. If not, Mr. Mendiola was going to have to go on one of the new cholesterol-lowering medications called “statins.”

The effect on Mr. Mendiola was not what the physician had expected. A question occurred to Mr. Mendiola. He said to himself, “Do you mean I could get the same cholesterol reduction by simply taking the pill and still eat what I have been eating and not sign up for the plan at the local gym?”

Mr. Mendiola considered his options: 1) ask the doctor to put him on a statin drug right now, 2) intentionally avoid the diet and exercise regimen until his next physical exam when the physician would discover that his cholesterol was still too high and, on his own, write the prescription for the statin drug, or 3) attempt to follow more faithfully the physician’s recommendation about diet and exercise to see if the cholesterol problem will be taken care of. Of course, there was a fourth option—take his chances and continue with a high-cholesterol level, unmedicated and uncontrolled by either diet or exercise.

Commentary
At first this case may appear to raise no evaluative issues at all. The physician was giving standard medical advice and was following a treatment protocol endorsed by the HMO and widely accepted in the medical community.
Searching for the value terms, however, reveals a number of judgments that are clearly in the realm of values. They begin to appear in the very first line. Mr. Mendiola recognized he had what he called a "problem." That is already an evaluative judgment. To say that one has a problem is to say that there is something bad about the situation. In the next sentence, we see that the physician was not happy with the patient's weight. That is a judgment on the doctor's part that something is wrong. In the third sentence, the word "should" signals that both the physician and the patient's weight are making value judgments. In the next sentence, high-density and low-density lipoproteins are classified as "good" and "bad." Both his wife and his physician thought his life would be better if he got more exercise. This is followed by a recommendation from the physician that Mr. Mendiola begin a regimen of exercise and diet. Any "recommendation" conveys that the one making it evaluates the proposed course of action positively.

Mr. Mendiola's responses involved further evaluation. He changed his behavior—at least modestly. He cut down on eggs and signed up for a parking lot that would force him to walk some each day. The parking lot choice involves a rather complicated set of value judgments: he no doubt valued the money he would save but did not like the extra walking. Up until this time, he apparently believed that spending the extra money to get the more convenient parking was worth it, but with his re-evaluation taking into account the newly appreciated value of some extra walking, he apparently decided the combined benefits of the saving and the exercise outweighed the inconvenience of the extra walking.

These evaluations are all preliminary to the main focus of the case. The physician seems convinced that the cholesterol is higher than it should be; that is, that bad things are more likely to happen with continued high cholesterol levels. Moreover, he recognizes that there are at least two possible strategies to lower the cholesterol—either a combined plan of diet and exercise or the use of statin drugs. Finally, he seems to accept the value judgment of the writers of the HMO protocol that diet and exercise should be tried first, that they offer better chance of overall benefit.

That judgment is so commonly held among medical professionals that many are likely to assume that somehow it is a fact of medicine that diet and exercise are a better first approach to the problem of high cholesterol. That turns out to be a category mistake. It is not a fact that diet and exercise are better than drugs. It may turn out to be a widely held value judgment, but it is a value judgment nonetheless. Diet and exercise are cheaper than drugs; they do not pose the risk of side effects that the statin drugs do; and they have some other features that appeal to many people. They are thought of as "natural" rather than as "artificial" or "chemical" interventions. All of these considerations lead many people to evaluate diet and exercise as preferable at least as a first response to high cholesterol.

Even though many people are concerned about the pharmacological risks of statin drugs (they can cause liver toxicity, for example), and they are attracted to the economic and philosophical features of interventions that they consider "natural," there are also problems with the diet and exercise approach. Mr. Mendiola is clearly among those who do not find exercise particularly enjoyable. He apparently likes foods that contribute to his cholesterol problem rather than those that would help reduce it. This leaves him in a bind. He perceives disvalue in the diet and exercise regimen. He seems to evaluate that regimen differently than the doctor and his colleagues. He may also evaluate the benefits and risks of the statin drugs differently. Surely, taking the drug is easier, perhaps much easier in Mr. Mendiola's opinion. He may also judge the pharmacological risks differently. He may not adequately appreciate the problems statin drugs can cause. On the other hand, he may fully understand and simply make the value judgment that the small risk of a serious liver problem from the statin drug is less onerous than the certain disvalue of the diet and exercise program.

It seems like this patient and physician simply have different assessments of the benefits and risks of the options that are available. They have made different value judgments. Is there any way that one could claim that the physician has made the correct evaluation? It should be clear that there is no amount of medical science that could prove whether the physician's evaluation was correct. If Mr. Mendiola were ignoring the risk of the statin drugs, if he had not been told about the liver toxicity risk, then the physician would have been working with a different set of facts. He would have failed to inform his patient. But, assuming that the doctor adequately informed the patient, there is no way that medical science can prove that the risks of the drug outweigh the negatives of the diet and exercise. Even if all physicians believed the drug's risks were more weighty, that would not constitute proof. It would merely show that doctors evaluate the options in a particular way. A double-blind, controlled study with large numbers of patients would be convincing evidence of what the effects of the two approaches would be. It could identify the intended and unintended effects of each alternative but still could not prove which set of effects would be better. That is a value choice not amenable to medical science.

Some philosophers hold that some value judgments—perhaps the one comparing the risks of drugs and of diet and exercise—can be held to some objective standard. They claim that, at least in the ideal, there are objective lists of right and wrong evaluations. In aesthetics, for example, they might hold that the soprano Renée Fleming is "objectively" a better singer than pop vocalist Miley Cyrus. People who hold this position are sometimes called "objective list theorists." Others hold that value judgments are inherently subjective, that there is no external objective standard of what is good and what is bad.

For purposes of medical ethical decisions, however, we need not settle this difficult question. Even if there is some objectively correct answer to the question of which set of risks and benefits among alternative medical treatments is preferable, this is surely not a question that medical science can answer. For evaluating such as this, increasingly patients' value judgments are seen as requiring respect. These are not a matter of ethics. These are what could be called normative value judgments. For these, either there are no objective standards of good and bad or, if there are, they are not matters of medical science. Many health professionals and, in fact, many laypeople may agree with the doctor that the risks and benefits of diet and exercise are more attractive as a first line of therapy, but, if they do, it is an evaluative judgment, not a medical fact. Unless one can develop a definitive list of objective values for such choices, it will not be possible to prove that one choice or the other is superior.
Case 2-2 presents another opportunity to identify the evaluations taking place in a conversation between a health professional and a patient. In this case, try to identify the value judgments made.

**Case 2-2**

**Treating Breast Cancer: Finding the Value Judgments**

It seemed to Mary Bachman that she had never been confronted with so many important decisions in such a short time frame in her life. Just two short weeks ago, when she went in for annual mammography, she learned that the microcalcifications in her right breast (the radiologist had been monitoring) had changed in their appearance from the last year’s film. Ms. Bachman had dense breast tissue with numerous microcalcifications, so she knew that annual mammography was in order. She had been told by her radiologist that the calcifications could be a sign of ductal carcinoma in situ (DCIS). It was still a shock to learn that the changes in the mammography films required more diagnostic tests; a breast biopsy was needed to ascertain the actual pathology.

The results from the core needle biopsy showed that the lesion was invasive cancer. There was no palpable mass in the breast, but further operation would determine the size of the tumor and whether it had invaded the lymph nodes. In a whirlwind of appointments, Ms. Bachman met with a surgeon to learn about what options were available. If no lymph nodes were involved, breast conservation therapy (BCT), also called lumpectomy, was one option, as was a simple mastectomy (excision of the breast, nipple, areola, and most of the overlying skin). Ms. Bachman also met with an oncologist who said that further treatment decisions would be based on the stage of the disease and her age. For example, if the tumor was small (2 to 5 cm) and had invaded the lymph nodes, then she would be a candidate for chemotherapy. Moreover, whether the tumor was estrogen-receptor positive or negative played a significant role in how aggressive treatment should be.

Depending on how many lymph nodes were involved, the oncologist might recommend radiation therapy, noting that some studies suggested that postmastectomy radiation therapy was indicated even for patients with T1-2 (tumor of 1-2 cm) breast cancers with 0-3 positive nodes. The chemotherapy had significant side effects such as nausea, vomiting, fatigue, cognitive changes, sleep disturbance, insomnia, and constipation. Another serious side effect was ovarian toxicity. Since Ms. Bachman was 37 years old and premenopausal, this was of concern to her. It was likely that chemotherapy would result in amenorrhea and premature menopause. The surgeon and oncologist stated that if the cancer was in an early stage, they would recommend BCT and aggressive chemotherapy and radiation for the best survival outcomes. Ms. Bachman knew, from looking at reputable sites on the Internet, that there was controversy over what was the best course of action. She felt pressured by the surgeon to choose BCT even though she thought she would feel safer with a more radical removal of breast tissue, but she was not sure. She had so little time to weigh the benefits and risks of all the different treatment options that were presented to her, she felt overwhelmed.

**Questions for Thought and Discussion**

- Choose one of the treatment options presented to Ms. Bachman and highlight the underlying values from the health professional’s and patients’ perspectives.
- What differences exist between the values of the health professional and patient?
- How might the values identified impact communication and decisions?

**Commentary**

As in Case 2-1 the issues in this case are not conspicuously matters of ethical controversy. The subject matter may be more momentous—matters potentially involving life and death—but most probably would not consider this an ethics case. Nevertheless, the account contains many evaluations. Most would agree with the judgment opening sentence that the decisions Ms. Bachman would face were important. That in itself is a value judgment, even if it is one that would be widely shared.

Further in that first paragraph we learn that annual mammography was “in order.” The value choice here may be less apparent. Presumably, Ms. Bachman “knew” this because she had been told about it by her clinicians. That was apparently the common consensus among clinicians. The phrase “in order” is a less obvious way of conveying the evaluation, but it is an evaluation nonetheless. Clinicians had considered the medical facts about the possible risks of microcalcifications that show up on mammography films, the difference between DCIS (not cancer) and cancer, the importance of detection while the tumor is at an early stage, and the potentially terrible consequences if the tumor metastasizes.

If those were the only considerations, however, they might recommend testing more often than once a year. They must also have considered the costs of the mammography, the risks of radiation exposure, and the inconvenience to the patient in coming up with the recommendation that yearly exams were right. It should be obvious, however, that different patients in different circumstances might make these evaluations differently. A woman who is particularly anxious about the risk of DCIS leading to invasive cancer might want the mammography more often. Someone with very good insurance or great wealth would worry less.
about costs. Those with great fear of radiation might prefer somewhat less frequent exams. Weekly mammography would pose such costs, risks, and inconvenience that virtually no woman would seriously consider it. Going without any further testing similarly poses extreme risks that most women would reject (although in some cultures mammography is beyond the economic reach of many citizens). Different patients with different evaluations would no doubt prefer somewhat more or less frequent retesting.

Once the test results show invasive cancer, the evaluations become even more conspicuous. The first issue was presented as a choice between two treatment options: BCT (lumpectomy) or a simple mastectomy. The first option would remove only a small portion of the breast; the second would remove the entire breast. Choosing between them would, of course, depend on the current scientific evidence regarding survival rates. That literature is, unfortunately, somewhat ambiguous. Some sources indicate that breast conservation should be attempted when possible and desired. If the lesion is large, a simple mastectomy may be necessary. There are differences of opinion on radiation treatment depending on the size of the tumor.2 Ms. Bachman may also feel that common sense would support the belief that, when it comes to survival, the removal of more of the breast would give her greater confidence. Thus, if she is worried about removing as much of the cancer as possible, she may prefer the more total procedure even if current medical science does not provide clear evidence of superiority. On the other hand, the more worried she is about the psychological and social aspects of preserving as much of her breast as possible, the more she might be inclined toward the lumpectomy. It would not be irrational to take some degree of risk with survival in order to gain these more psychological benefits.

At the other extreme one could choose no operation at all. While that would be more likely to have fatal consequences if in fact Ms. Bachman has invasive cancer, someone without insurance or someone with extreme fear of operative procedures might consider it. Although these options would be considered only for people with unusual values or unusual economic situations, one cannot rule them out in all circumstances, even if, for most people, they would make little sense.

Finally, we come to the postsurgical therapy. Here the options are greater and the choices more subtle. The value judgments are more complex. The case includes the provocative sentence, "the oncologist might recommend radiation therapy noting that some studies suggested that postmastectomy radiation therapy was indicated even for patients with T1-2 breast cancer with 0-3 positive nodes." Note first that the "oncologist might recommend radiation." This reveals that different oncologists might evaluate the radiation option differently even for medically identical patients with identical lymph node involvement. Even more provocative is the claim that some studies suggest radiation therapy is "indicated" for patients with T1-2 breast cancer with 0-3 positive nodes. If nodes are involved, the cancer may have spread beyond the breast, but with a small number of nodes involved, that risk is not great.

The choice is a complex one. It involves not only the estimate of the risk of cancer beyond the breast but also assumptions about how much risk to take with the radiation. To claim that radiation therapy is "indicated" begs the question of what this strange word means here. Many clinicians understand it to mean that the evidence shows that radiation ought to be used in these cases. That, of course, is something that evidence cannot show. The evidence can show that the risk of a secondary cancer is less with the combination treatment of BCT and radiation.3 Almost no one would reject radiation if the difference in expected survival with and without the radiation were great. With small numbers of nodes involved, however, the difference will be rather small (although even with radiation, survival is not absolutely guaranteed). It seems that different patients with different concerns about radiation and about secondary cancer would evaluate the radiation option differently. Certainly, studies cannot definitively tell us exactly when radiation should be provided. That is why different oncologists will see the choices differently.

Chemotherapy following operation poses similar value choices. Many of the negative effects of the chemotherapy are subjective: nausea, vomiting, fatigue, cognitive changes, alopecia, insomnia, and constipation are all unpleasant to almost everyone, but deciding how much unpleasantness is worth enduring for the potential gains from the chemotherapy requires subtle trade-offs that patients and physicians may make differently. Ms. Bachman also learns that the drugs could produce a premature menopause—an effect that women would perceive differently depending on whether they want to have future children or have unbearably menstrual cycles.

Although her physicians seem to hold values that support BCT (the lumpectomy) and radiation therapy, Ms. Bachman reveals values that seem to incline her toward the simple mastectomy. Is there any reason why Ms. Bachman would be mistaken if she chose the more invasive procedure?

Case 2-1 and Case 2-2 both pose value issues that do not seem to involve ethical questions. The choice between the lifestyle option and drugs for controlling cholesterol would not normally be seen as a moral choice, nor would the choice between lumpectomy and mastectomy. It is conceivable that someone would insist that it is immoral to use drugs when lifestyle will accomplish similar results. Some minority cultural group might believe it is unethical to choose less than the most certain strategy for preserving life but most probably would see these as nonmoral value judgments. They are usually perceived as matters of personal or cultural preference rather than as matters of morality. In the second half of this chapter we look at two cases that force us to identify clearly what makes normative judgments moral judgments.

Separating Ethical and Other Evaluations

We have seen that evaluative judgments arise constantly in medicine, not just in the ethically dramatic cases, but in routine judgments about whether an effect is good or bad, whose good or bad it is, and whether it is worth taking the risk of a procedure, diagnostic test, or medication given the alternatives available. Not all evaluations are
In order for an evaluation to be an ethical evaluation, certain criteria must be met. First, the judgment must be about a human action or character about norms generally governing actions or character. When we say that a painting is good, we do not make an ethical judgment; we make an aesthetic one. When we say a person is good, however, we can mean many things. If we say he or she is a good runner, we probably mean the person is technically proficient; we are not still making a moral judgment. We may mean, however, that the person is morally good.

In that case we are judging the person’s character or conduct. Moreover, we are judging it by what we take to be a certain standard, an ultimate or final standard from which no further appeal is possible. By contrast, a person may be good according to the standards of the local community or the culture. Or he may be good according to a legal standard. In these cases we might agree that the person is approved by the local community or culture or law, but still ask meaningfully whether the person’s or the person’s actions are ethical.

An ethical evaluation is one that is made according to the most ultimate standard. For religious people that standard may be the will of God. For secular people, it may be reason or natural law or some similar standard. Since the standard is ultimate, it is universal. We believe that everyone ought to reach the same conclusion. If there is one ultimate standard, it would be contradictory for some people to claim that the behavior conforms to the standard and others to say it does not. Of course, in the real world finite humans disagree about ethical evaluations. The point, however, is that if two people disagree about what they take to be matters of ethics, logically, at least one of them must be wrong.

This is not to suggest that moral norms have to be so rigidly applied that ethics can be reduced to simple, general rules. It is not that all mercy killings or all breaches of confidentiality or all research studies without consent of the subject are wrong no matter what the circumstances. Rather it is that if two people are debating a particular instance of mercy killing or breaching confidentiality or conducting research without consent and one of them claims that instance is unethical while the other claims it is ethical, there is an understanding that at least one of them must be wrong. They must be wrong because they agree that they are debating whether this instance conforms to some single, universal standard—the approval of a deity or reason or some set of laws of nature. The deity or reason might well approve of some breaches of confidence and disapprove of others. It cannot simultaneously approve and disapprove of a particular case in a particular circumstance. One of the chief characteristics of an ethical evaluation is the presumption that the evaluation is based not on mere personal or social or cultural standards, but some universal authority.

The following case provides an opportunity to try to separate ethical judgments from other kinds of evaluations. It deals with a couple making decisions about infertility treatment. The substantive issues of this case will be covered in the cases in Chapter 11. Here the focus should be on identifying the evaluative judgments. In reading them, try to identify the issues you consider to be ethical and those that involve nonethical evaluations.

**Case 2-3**

**Infertility Treatment: God’s Will?**

Bette Gabrielle had struggled with obesity most of her adult life. She lost and gained 100 pounds at least twice. When she finally found a healthy combination of diet and exercise, she was almost 30. A year later she met Gina, the man she would marry. For the past six years the Gabrielles have tried to conceive. Both were fully evaluated at an infertility center. Test results indicated that the Gabrielles have unexplained infertility, although Bette’s age and weight gain since her marriage were risk factors in the development of infertility.

As a practicing Catholic, Ms. Gabrielle spoke to her priest, who said there were no church objections to drugs to induce ovarian hyperstimulation (OH) or timed intercourse. In vitro fertilization (IVF) and intratruine insemination (IUI) were not permitted. If any treatment resulted in multiple pregnancies, reduction of the number of embryos, a common recommendation, would be forbidden as it would be seen as abortion according to Church teaching.

Ms. Gabrielle began OH treatment but did not become pregnant during her first cycle. She was discouraged because of her efforts and of the significant expense. A friend who was going through the same treatment decided to terminate further treatment after IVF failure. She told Ms. Gabrielle, “You just have to accept the reality that technology doesn’t work all the time.”

With her husband’s encouragement, Ms. Gabrielle decided to continue treatment. The next month, hope loomed on the horizon. Studies showed there were multiple mature follicles indicating a good chance of a multifetal pregnancy, thus increasing the risks to the fetuses and herself if she could all of the babies to delivery. She felt like time was running out, so she opted to proceed, saying to herself that whatever happened was God’s will.

**Commentary**

New technologies that modify the conception and birth process present many evaluative issues that are often considered to be moral. This case presents the opportunity to try to tease out the moral from the nonmoral judgments. It begins with a couple who desire to have a child. That desire clearly represents a value judgment on their part. Most people would view the desire for children to be a matter of personal preference. Some couples may prefer not to have children, but desiring to have them does not automatically raise ethical issues (at least if the couple is married and the number they desire is modest). No matter how strongly the couple or members of their family desire the birth of offspring, typically
bearing children is not considered a moral duty. Jews, Christians, and Muslims, who speak out of continuing with fertility treatments apparently did not see having a biological child as a moral duty.

In some traditions, for example, the bearing of children can be considered not merely desirable but one’s moral duty. The issue here is what the difference is between mere desires and moral duties. If bearing children is merely a matter of personal desire, then obligation of attachment is attached. Others who similarly view childbearing as a matter of personal preference might feel sorry for the childless couple, but they would not render a judgment that they have failed in their obligation. By contrast, if childbearing were perceived as obligatory, then others who share that perception would feel justified in judging them as having failed in some duty.

The source of that obligation is critical. Not all obligations are moral. We can also have obligations grounded in law, for example. A legal obligation differs from a moral one in part because the source of the legal duty is a cultural institution, such as a state legislature or court that has acted to create a duty. In the case of an ethical obligation, the perceived requiredness comes not from the act of a state legislature, that is, from a political group, but from some other ultimate source. For most ethical theories there is a single, ultimate source. For religious people, this could be the will or command of the deity. For secular people, the ultimate, universal source could be reason, intuition of moral law, or some other commonly shared source. Since there is believed to be a single, universal source for grounding moral judgment, there is a shared perception that actions can be judged right or wrong. In the case of personal preference, we might say that there is no duty to act in a particular way. It is merely a matter of taste. Our first task is to clarify whether the Gabrieles have a duty to have a child or merely a desire.

Turning to the means they consider for having this child, we learn that, as Roman Catholics, they believe that certain means of conception are morally controversial. Catholics believe that there are natural ends of beings (including humans) and of social institutions such as marriage. They believe that moral duties can be gleaned from these natural ends. Specifically, marriage and sexual relations are believed to have both “unitive” and “procreative” ends, that is, such relations should both express the union of the couple and be open to production of offspring.

Since Catholics believe that these matters of procreation are governed by universal divine moral laws of nature, such as the natural ends of marriage and of sexual relations, for the Gabrieles, how they have children is, at least in part, a moral matter. While many Catholics would consider bearing children by IVF or IUI to be a violation of these natural laws, the Gabrieles have apparently concluded some components of fertility treatment are acceptable (OH) and others not (IVF or IUI). While for many people deciding for or against IVF is merely a matter of personal preference or aesthetic judgment, for others it presents moral choice.

Having one way or another concluded that it is acceptable to manipulate the hormones in order to increase or decrease the number of egg cells and thus the number of possible embryos, they now face the possibility of a multifetal pregnancy. They have already decided that they will not selectively reduce the number of embryos. Some people would see no moral issues raised. Destroying the extra embryos would be at most a matter of preference. For others, it would be a serious moral offense, the equivalent of a homicide.

The choices throughout the events leading to technologically assisted pregnancy require evaluative judgments. For some, these will be mere expressions of preference; for others, matters of critical moral decision.

The evaluative choices in Case 2-3 present an opportunity to attempt to distinguish between personal and social preferences, on the one hand, and moral evaluations, on the other. Moral obligations involve obligations, while personal preferences do not. Not all obligations are moral, however. The next case explores the boundaries between moral and legal evaluations.

Chapter 2 Values in Health and Illness
supported the parental decision, finding that the parents, after being fully informed, "have the right to choose a medically recommended course of treatment for their child in the present circumstances." The Indiana Supreme Court refused to get involved, thus upholding the lower court's decision.

Those opposing the parents sought appeal to U.S. Supreme Court, but that appeal was made moot by death of the baby on April 15. Two weeks later, President Reagan asked the Attorney General and Secretary of Health and Human Services (HHS) to become involved, noting that federal law prohibits discrimination against the handicapped. This led to the issuing of a notice that it was illegal to discriminate against infants solely on the basis of handicap. While this notice was rejected by the courts, eventually a law was passed classifying withholding of life support in cases such as this as child abuse.

Commentary

In this case, many evaluative judgments were made. Some of them were like the judgments in the previous cases. They were expressions of matters of preference. Sometimes those judgments were presented as statements of fact, but they clearly contained value implications. They were expressed in value-laden statements, such as referring to some people with Down syndrome as "blobs" or claiming that they had a "high probability" of survival.

For our purposes, we should focus on the evaluations that go beyond these personal opinions to note the interplay in this case between the law and morality. The nurses and other hospital personnel who intervened to seek court review clearly thought that this baby's treatment was more than a matter of personal preferences. They no doubt were convinced that it was morally wrong to allow a child to die who could survive regardless of the underlying Down syndrome. They discovered, however, that regardless of their ethical judgments, the Indiana courts concluded there were no grounds for intervening. The parents, according to Judge John G. Baker, had a right to control medical decisions for their infant, by which he surely meant a legal right (not necessarily a moral one).

We thus have a situation in which allowing the infant to die from lack of surgical intervention was ethically unacceptable to many people even though doing so was deemed not to be illegal. There are many cases in which ethics and law part company. The law is the product of a political entity. It is a crude device and refrains from speaking about many behaviors that seem clearly unethical. The law permits, indeed requires, public enforcement of a normative standard enacted by a political group. Ethics normally does not have available a formal enforcement mechanism and is grounded in a more ultimate, universal standard of reference.

For example, lying to a spouse is, in the normal circumstance, a violation of the norms of morality, yet almost never would such unethical behavior be subject to legal sanctions. Explicitly in cases in which the ultimate measure for judging is controversial and hard to access, we may simultaneously recognize that a behavior is immoral but should not be made illegal. Some medical ethical decisions fall into this category. Not everything that people believe is unethical will be a violation of the law.

As this case evolved, a rather unusual reversal occurred. As the Reagan administration began a national assessment of Baby Doe decisions, it concluded that allowing infants to die from lack of potentially effective medical treatment was a violation of the law. On grounds of both discrimination against the handicapped and child abuse and neglect, arguments were made that existing law made what these parents decided illegal. New legislation eventually clarified the law so that it is now recognized in the United States that forgoing of life support for infants like Baby Doe is illegal. The only exceptions are cases in which the infant is inevitably dying regardless of treatment, will remain in a permanent coma, or in which treatment will be virtually futile in prolonging life and will be inhumane. Even in these cases, "appropriate nutrition and hydration" must be provided. Hence, what these parents did in 1982 would now almost universally be considered illegal.

This suggests an interesting possibility. Although withholding life support is illegal, not everyone believes it would always be unethical. It could be that we are witnessing a kind of reversal in which what once was thought to be legal but unethical is now thought by some to be illegal but ethical. For example, moral theologians as well as secular thinkers hold that it is ethically acceptable to withhold life support under certain circumstances. They hold that, as long as the death of the patient is not the direct intention, it is acceptable to withhold life support when the expected burdens exceed the expected benefits. (The details will be outlined in Chapter 15.) Sometimes this might be the case even when the patient is not comatose, inevitably dying, or even suffering from a condition in which treatment is "virtually futile" for prolonging life. A patient could be suffering terribly from a treatment even though it could prolong life. The patient could be an infant in a case governed by the Baby Doe regulations. If so, even those who hold conservative views on matters of life and death might support the ethics of a decision to forgo life support. If the patient were an infant (but oddly not if it were an older child), withholding such treatment would be deemed illegal in current American law. This could be a case in which withholding life support was illegal even though it was deemed ethical by a group normally strongly opposed to hastening death. What is ethical and what is legal are often separate issues. In analyzing cases in the remaining chapters of this book, personal preferences and desires must be distinguished from obligations, and, among obligations, the legal must be kept sharply separate from the ethical.

In Chapter 3 we turn to cases that will permit us to examine how we can know what is ethical. The role of the health professions in deciding and articulating ethical norms will be addressed as well as institutional policies, patient values, and the role of religious authorities.
Chapter 3

What Is the Source of Moral Judgments?

Learning Objectives

1. Identify sources of moral authority that can be used to ground moral judgments.

2. Describe the role of health professional codes in moral judgments.

3. Explore the relative importance of various sources of moral authority in making clinical judgments.

Other Cases Involving the Sources of Moral Judgments

Case 4-6: For the Welfare of the Profession: Should Nurses Strike?

Case 12-8: The Interrogation of Guantanamo Prisoner Mohammed al-Qahtani

Case 13-1: Warning: Premarital Sex May Be Dangerous to Your Health

Case 18-7: Demands for Futile Care

Once ethical and other evaluative judgments are identified, the next question is whether one should look to determine what is moral. Health professionals often believe the problem of what is moral to be a matter of...
alternative ways of grounding moral judgments. In each case, the important problem on which to focus is not so much what is the right thing to do, but rather what is the source of moral authority and on what authority the health professional's behavior should be shaped.

**Grounding Ethics in the Professional Code**

A health professional confronting an ethical problem that poses a significant difficulty may want to turn to the professional code of ethics to determine what it says regarding the issue at stake. Often the professional code will provide insight based on years of collective experience of the members of the professional group.

Sometimes the apparent answer from the code seems so appropriate that no further consideration is necessary. But in other cases, it may not be obvious to the individual health professional that the profession's collective wisdom is morally definitive. One problem arises because the professional group's code can change over the years. The AMA code, for example, was originally adopted in 1847 and published a year later, but it has been revised many times since then. Major changes occurred in 1903, 1912, 1947, and 1957, and then dramatic changes were adopted in 1980 and published the following year. Since then, more modest changes have been made. Some of the differences over the years have been substantial. The early versions, for example, said nothing about "informed consent." Their understanding of confidentiality was radically different from that of the most recent versions. Changes are reflected not only in the norms for right conduct but also in the character traits that the codes hold out as praiseworthy. In the most recent principles, a physician is, according to the AMA, supposed to provide medical service with compassion and respect for human dignity; in 1847, the traits of character for the physician were tenderness, steadiness, condescension, and authority.

Similar changes have occurred in the codes of the other professions. The American Pharmaceutical Association's code was first written in 1852 but was revised in 1922 and again in 1952 and 1969. Modest changes were made in 1975, 1981, and 1985. Finally, in 1994 a completely revised code was adopted. Each time the code changed, did the ethically correct behavior for pharmacists really change, or was it only what the APHA members believed was the correct behavior?

What about health professionals who are not members of their professional associations or who immigrate to the United States from other countries that may have codes that differ? Does this professional code determine what is ethically correct for those who are not members or only for those who are members? Can what is ethically correct for health professionals change depending on whether they are members of their professional association? And what about health professionals in other nations? Does the American professional code or does their own professional organization's code determine what is right for these persons? It seems odd that what is right could depend on the country in which they practice and when they practice.

Even more puzzling, students of health professional schools when they graduate often recite solemn oaths or pledges that are code-like statements. These, however, may differ in their ethical commitment from the professional association's code of
ethics, and graduates from different schools end up reciting different ethical pledges. The following case asks what role a professional code should be in determining what is ethically correct conduct for health professionals.

Case 3-1
Physician Participation in Capital Punishment

Michael Angelo Morales was convicted by the California courts for the 1981 rape and murder of 17-year-old Terri Winchell and was sentenced to death. He had boasted that he would kill Winchell and stab her in the chest with a knife. He conspired in the murder with his cousin, Nick Ortega, who had been in a homosexual relationship with another man who was concurrently dating Winchell. Ortega’s jealousy was purportedly the motive for the attack on Winchell.

For twenty-five years the conviction proceeded through the California courts until the much-postponed execution day of February 21, 2006, arrived. Mr. Morales was scheduled to be executed at 12:01 a.m. at San Quentin, U.S. District Judge Jeremy Fogel had ordered that, in order to avoid cruelty if the drugs to be used in the execution did not work properly, the prison had to have a medical professional present in the death chamber. Two anesthesiologists, whose identity has never been made public, were engaged for this purpose; but, under pressure from medical professional organizations, they withdrew two hours before the scheduled execution. The execution was indefinitely postponed. Morales expressed relief. Terri Winchell’s mother described the news as “a blow in the stomach.”

Those critical of the participation of the physicians in the execution cite the AMA’s Code of Medical Ethics, which states, “A physician, as a member of a profession dedicated to preserving life when there is hope of doing so, should not be a participant in a legally authorized execution.” According to the AMA, this precludes selecting injection sites, starting IV lines, and prescribing, preparing, administering, or supervising injection of lethal drugs. For the AMA, this does not extend about returning controversial about medical history, diagnosis, or mental state certifying death, witnessing an execution in a totally nonmedical capacity, or relieving the acute suffering of a condemned prisoner awaiting execution.

Defenders of physician participation claim that physicians, as licensed medical professionals, should be involved in order to ensure that the state’s commitment to avoiding unnecessary cruel punishment is satisfied. In California, following the postponement of the execution, competing bills were introduced into the legislature by physicians who were members of the California legislature. Senator Sam Aenestad, a general anesthesiologist, introduced legislation to protect physicians who participate in executions from punishment or professional discipline. Meanwhile, Assemblymen Alan Norenklau, an eye surgeon, and a colleague introduced a bill sponsored by the California Medical Association prohibiting physician participation. At issue is not only the general ethics of capital punishment but also the question of whether participation of physicians is compatible with their role as healers.

Questions for Thought and Discussion

Consider the various sources of moral authority, e.g., the AMA, state law, state medical association, and individual conscience, in the case of participation in capital punishment. Which one should carry the most weight in determining whether physicians should participate in capital punishment? Why?

Commentary

The substantive issues of health professional participation in capital punishment will be discussed in Chapter 9 when we examine the ethics of killing in health care. The focus here is on what the parties of this case—the physicians, legislature, courts, and general public—should rely on as their source of moral norms.

The American Medical Association, the national professional organization for American physicians, has adopted the view that participation in capital punishment is inconsistent with the physician’s professional role as a healer. Its code requires that physicians not participate. The AMA takes no position on the general ethics of capital punishment. Apparently it would not protest if the state used some method that did not involve a physician.

In contrast to the AMA’s position, the California courts and presumably the people of California who have established the laws of the state not only accept capital punishment but insist that, on grounds of humaneness, a physician be present at executions. At least two physicians in the state are also members of the legislature, and one of them, state senator Sam Aenestad, seems to accept the view that capital punishment is ethical and that physicians may participate. He has introduced legislation to protect his fellow physicians who do participate from discipline by the medical association.

The state medical association is essentially a private organization that has a limited right to discipline its members. The most severe discipline would be expulsion from the organization. There was a day when expulsion meant the loss of hospital privileges and perhaps even the loss of the right to practice medicine. In recent times, however, the right to practice medicine is controlled by state licensing boards. Those boards have the right to discipline physicians up to the point of suspending a license to practice medicine.
The issue at stake here is whether the medical association or some other group (such as the state licensing board—accountable to the state government) should have control over determining what is ethical for physician.

There is no reason why the public board would need to adopt the view that any licensed physician must participate in executions, but it plausibly can determine (in fact, has determined) that a licensed physician willing to participate has done no wrong. That would leave the medical association in a position to condemn the state’s position but with no power to discipline the physician who chose to participate except possibly censure or expulsion from its membership. As long as the expelled physician retained the license to practice medicine, expulsion would have limited significance.

Should the people of the state or the professional association have control over decisions about what is ethical physician behavior?

The problem raised here is whether the professional association code is necessarily the definitive authority for determining what is ethical for physicians or other health professionals. It seems to make sense to consult the code in difficult cases, but is that because the code defines what is right for the health professional or is it because the code simply summarizes the judgment of the health professional’s colleagues who have faced somewhat similar situations? If the professional role is created and controlled by the broader society (as implied in the licensing process), then the ethical duties of those in the role would seem to be the responsibility of society. If, on the other hand, the professional role is controlled by the members of the profession itself, then the code of the professional association has claims to authority.

Grounding Ethics in the Physician’s Orders

In some instances, patients and caregivers are presented with ethical decisions that seem to be grounded not so much in either public policy or professional codes, but in the beliefs of practicing physicians. Of course, the physician in reaching his or her moral conclusion may have to decide how important the physician’s professional code is, but by the time the physician has decided on a course of action, others involved may be presented with only the doctor’s order. The following case raises the question of whether the implicit moral judgments incorporated into the physician’s instructions provide a grounding of moral positions taken in the practice of medicine.

Questions for Thought and Discussion

- Can either Dr. Simweiler or Rev. Kerman claim authority to establish the moral norms for Mrs. Patterson’s care?
- If not, how should Rev. Kerman bring Mrs. Patterson into a more active role in choosing a pain-management approach?

Commentary

This case leaves the clergyman having to evaluate the moral judgments of a physician. Rev. Kerman recognizes that Dr. Simweiler’s choice of pain medication and his decision that appears to minimize the patient’s involvement in the treatment decisions involve moral choices. At the same time, Rev. Kerman is aware that he is in an awkward position. He is on the doctor’s turf and has not even been invited into the case by Mrs. Patterson.
Rev. Kerman is also aware that traditional medical ethics has long assumed that the physician has the right and the responsibility to formulate a treatment plan including making judgments about what is morally right conduct in a doctor-patient relationship. The Hippocratic Oath, for example, has the physician promise to “benefit the sick according to my ability and judgment.” This Hippocratic foundation has evolved into a presumption that a doctor’s orders should prevail in the clinic.

At the same time, Rev. Kerman knows that he is a member of a profession that has historically often assumed moral decision-making authority for parishioners. At least the clergy have traditionally provided moral advice and interpretation of church teachings. Thus we have a case of members of two professions colliding in which both are accustomed to acting on behalf of laypeople, rendering judgments about their welfare and what is morally appropriate for them.

What is at stake here is not only a choice of treatment options but also a question of the proper style for doing one’s dying. Rev. Kerman, no doubt, accepts that legally physicians are the only ones with legal authority to authorize medications. What he questions is the physician’s moral authority to pick the approach to her care. One strategy attempts to spare the patient the burden of direct confrontation with some technically complex and psychologically difficult choices. The other holds that the patient has not only the right but also the duty to confront them.

We might ask whether either of these professional actors has any legitimate claim to make moral choices for this patient. Is there any skill or status inherent in the roles that would authorize either Dr. Simweiler or Rev. Kerman to decide how Mrs. Patterson should deal with her pain and eventual death? While physicians are sometimes placed in a position in which it is assumed that they are the medical experts and therefore have authority to make choices in the doctor-patient relationship, that assumption is now being examined more closely.

Surely, on technical matters, the physician has a special expertise. While Dr. Simweiler might not be a world authority on pain-management options for his patients, he surely is in a position of relative expertise. He is the authority among all the players on the scene.

The issue here, however, is not primarily the technical matters of Mrs. Patterson’s pain management. Rather the issues here involve moral questions: how much Mrs. Patterson should be told about her options and how active a role she should play in choosing a pain-management regimen. Choices must be made about steps to be taken to prepare for what is likely to be a long and difficult process that could eventually lead to her death.

Rev. Kerman also is in a profession that has traditionally claimed expertise in dealing with these normative issues. Moreover, as a clergyman, he is in a profession that has assumed responsibility for teaching and guidance on matters moral. While Dr. Simweiler’s expertise seems to prepare him poorly for providing moral and spiritual counsel to Mrs. Patterson, clergy are often assumed to be uniquely prepared for that role, especially for those parishioners who have voluntarily chosen to be members of their congregations. Thus, the clergy are recognized by members of their congregations to have a role in expounding on moral norms within their communities.

Rev. Kerman is within a church that has not emphasized the teaching and moral guidance role of the clergy as much as some other traditions. Roman Catholic and Jewish traditions, for example, explicitly recognize the teaching authority of their clerical professionals. Nevertheless, Rev. Kerman seems to be standing in a relation to Mrs. Patterson that is different from that of Dr. Simweiler. At the same time, although Mrs. Patterson is a member of Rev. Kerman’s church, she has not asked him to become involved.

Grounding Ethics in Institutional Policy

If we cannot automatically ground ethical judgments in a physician’s moral views, societal opinion, or professional beliefs about what is ethically correct, can the institution in which health professionals work provide that grounding? Many health professionals work in hospitals or other health care institutions that may have codes of ethics of their own. These codes may come from large public or private organizations that sponsor the hospital or the local institution that, through its board of trustees or its medical board, may have formally adopted a statement or code of conduct about what is believed to be ethical. To what extent should health professionals working within such institutions feel bound by such statements? To what extent is the institution the “source” of the ethical obligation?

Case 3-2

Providing Less-than-Optimal Services

The number of clients referred to the out-patient rehabilitation clinic of Centerview Medical Center seemed to increase every week. Occupational therapist Mark Petty, OT/B/1, (licensed occupational therapist), enjoyed the busy pace and the variety of clients he saw in the clinic. Mr. Petty was assigned a new client, Lee Tung, a 28-year-old automobile manufacturing worker, who had sustained a severe crush injury of his hand on the job. Mr. Petty noted that there were orders to evaluate and begin treatment. As he read further in Mr. Tung’s medical record, he saw that the physician specifically requested a certified hand therapist’s (CHT) services. Mr. Petty was not a CHT, so he approached his supervisor, Vivian Cunningham, to discuss the problem. Mr. Petty explained that the physician’s orders specified a CHT.

“How soon can Mr. Tung see the CHT?” he asked his supervisor.

“She’s just too busy to take any new clients,” Mr. Cunningham responded.

“I’ll tell you what to do. I would hate to lose this case. It looks like it will take at least a year of service to rehabilitate Mr. Tung. It is part of our hospital’s officially adopted code of ethics that we must work always for the good of the...
Commentary

In this case, the rehabilitation clinic’s policy seems controversial. One could easily suggest it is grounded in self-interest. It could be in serious legal trouble if the patient learned of the substitution of a lesser skilled professional than indicated in the clinical record. Assume, however, for purposes of discussion, that Mr. Petty is convinced that the clinic’s policy is believed by his supervisor and the administrators to be justified as the best way to get the patient high-quality therapy—that they really are concerned that patient would have to wait for the CHT to provide treatment and that delaying therapy would jeopardize Mr. Tung’s well-being. This, after all, is a long-standing interpretation of the Hippocratic Oath’s imperative to do whatever is believed to benefit that patient. (A link to the text of the Hippocratic Oath is included as an appendix to this volume.)

If the clinic’s position is intended to have a moral purpose, then there is a real conflict between the holders of two ethical perspectives. One focuses on the dishonesty or deception in having the CHT sign off on treatment she did not provide; the other, on the traditional moral imperative to do what is best for the patient. Here the issue is whether an occupational therapist should treat the clinic and its supervisory staff as the legitimate source of morality for choosing between these two options. Presumably, Mr. Petty made at least an implied commitment to the clinic to abide by its norms when he accepted employment there. To what extent does that commitment imply agreeing to accept clinic policy as a source of moral authority?

In some ways, the problem is similar to the conflict in Case 3-1, in which physicians and parents have to factor into their reasoning the moral obligation to obey the Baby Doe regulations. In this case, however, Mr. Petty has real reason to believe the clinic’s policy is unacceptable and to question whether what amounts to fraud is moral just because it is incorporated into clinic policy (or the interpretations of that policy) by the supervisory staff. Can

Mr. Petty, at the same time, acknowledge his general obligation to conform to clinic policy and still claim that there is a source of moral obligation beyond the clinic where he works?

Grounding Ethics in the Patient’s Values

The patient is another possibility for the source of the ethical and other evaluations that are incorporated into the medical practice. It is sometimes believed that, since there are so many different ethical positions possible on controversial issues, everyone person should have the right to choose his or her own ethics. A slightly different view, referred to by philosophers as personal relativism, is that to say something is ethical literally means nothing more than that it is the position approved by the speaker. According to this view, if one believes an action is morally right, it literally is right; that is, the final standard. However, someone else may have a quite different perspective. For the other person, the same action could, for him or her, be wrong. There is no further appeal beyond the individual. When medical choices are made by people outside the context of relationship with a medical professional, no direct conflict with the ethics of the professional will arise. Nevertheless, many find it implausible to claim that ethics is literally nothing more than one’s personally chosen standards. In relations with a physician or other health professional, personal relativism presents an even more difficult problem. A physician–patient relationship could exist in which a patient holds that a certain treatment course (e.g., actively ending a patient’s life for mercy) is ethical while the physician holds it to be unethical. The following case poses the problem of whether a physician–researcher and an institutional review board (IRB) regulating human subjects research should treat the patient as the source of moral standards.

Case 3-4

The Eager Research Subject: Justifying External Moral Standards

Dr. Leauro Bollinger was a 52-year-old former college professor of biology who had taken early retirement when she developed macular degeneration, taking her sight was deteriorating, she began researching the causes and potential therapies for blindness. She had been a patient in the National Institutes of Health’s (NIH) Age-Related Eye Disease Study and had developed a friendship with NIH scientists at the National Eye Institute. In particular, she came to know and became friends with Dr. Anton Hohoka, one of the leading researchers in the vision restoration lab.

From that friendship, she learned of some avant-garde research that was around the interest of the research ophthalmology community. With the development of microelectronics, some scientists believed that...
eventually the technology would be developed that could produce an artificial eye. In effect, it would be a miniature camera that converted images into electrical impulses that could be fed directly into the occipital lobe of the brain, thus bypassing a damaged eye. At the point Dr. Bollinger heard about these ideas, the research was in its earliest stages. Very few animal studies had been completed. She knew that eventually researchers would want to attempt the development of this technology in humans, who could give much more precise feedback on the placing of the electrodes into the brain.

After extensive research on the safety and potential effectiveness of this line of research, Dr. Bollinger gradually came to the conclusion that she would be the ideal research subject. She was blind, had a deep interest in developing such technology, and had the scientific capacity to understand the risks and to cooperate with the investigators. She also had large amounts of time available. She offered her services to Dr. Hakola.

At first, he was skeptical. Dr. Bollinger understood exactly what she was doing and could, in fact, be a significant contributor to the research. She understood that the research would involve cutting a half-dollar-sized hole in her skull, through which researchers could pass electrodes. Similar work had been done over the years to map the location of motor and sensory areas of the brain, but these experiments were often done on patients who needed to have their skulls opened for some therapeutic purpose. This project would involve a much larger hole, and it would be undertaken solely for research purposes.

A protocol was developed and presented to an institutional review board (IRB), a hospital board responsible for reviewing research to assure that subjects are protected. Several members of that board questioned the research on the grounds that it posed risks that were too great and that the research must first be developed in lower animal species before being tried in humans. After extensive debate, the IRB refused to approve the proposal until further animal studies were completed. These could take two to three years.

Dr. Bollinger was disturbed, indeed annoyed, at the IRB decision. She understood that she was very unlikely to benefit from the study. Surely the first results would produce nothing more than a crude visual image of light and dark patterns, and that could take many years. She was unlikely to live long enough for the technology to be perfected. On the other hand, she felt a close identification with the community of the visually impaired and felt she had a moral right to make her unique contribution, as long as scientists were willing to accept her as a research subject. She was willing to sign any legal release from liability that seemed necessary. If Dr. Bollinger and Dr. Hakola both find this research at this time to be moral and the informed consent is impeccable, are there moral standards to which the IRB can appeal that would justify delaying the research?

Commentary

The question raised by Dr. Bollinger's offer to volunteer for avant-garde research deals with the substantive questions of the ethics of human subjects research as well as the ethics of informed consent. These will be explored further in the cases in Chapters 16 and 17, respectively. Here, the problem needing attention is where the parties should turn to find the source of his moral obligation in this case.

The patient is making a moral claim. She feels a moral right and perhaps even an obligation to contribute to a community of people with whom she shares a special interest in therapies to overcome blindness. Dr. Hakola is probably similarly motivated by compassion for those who could benefit from his research. The IRB seems to have concluded that, even with impeccable consent from an ideally informed subject who is a member of the class of patients who will eventually benefit from the research, it has a duty to impose moral standards on the research.

In some cases, committees such as IRBs may feel obliged to impose restrictions on research to protect the institution from lawsuits or negative stories that could damage the institution's reputation. If this was what was driving the IRB, their appeal would not be a moral one. Moral appeals require a more ultimate grounding, not merely to the legal or financial interests of the institution. In this case, the IRB seems to believe that it is immoral, not merely imprudent, to permit a human subject to undertake risky research unrelated to therapy before adequate laboratory and nonhuman animal studies have been done.

Two counterpositions seem possible. One is that ethics is merely a matter of personal judgment about what is right or wrong, so that if Dr. Bollinger and Dr. Hakola both find moving directly to human studies acceptable, there is no basis for objecting, provided they have an adequate understanding of their decision. Since the potential subject and the investigator are both well-trained scientists with considerable experience in this line of research, there can, in principle, be no moral objection to their proceeding.

The other possibility is to concede that morality is not merely a matter of personal judgment; it rests in some definitive, objective external standard. It could be, however, that in cases like this, the general moral rule against moving to risky research on human subjects before animal studies have been completed needs a sophisticated qualifier that takes into account the moral perspectives of the potential subject, her moral commitment to her group, and her unusual level of knowledge and understanding. It could be that a carefully crafted moral rule would allow for this particular subject to volunteer, perhaps even acknowledge that she is morally obligated to volunteer. That is a conclusion quite different from the claim that morality can be reduced to personal preference or judgment.

Grounding Ethics in Religious or Philosophical Perspectives

Health professionals sometimes find that they, or the people with whom they are interacting, claim they are grounding their ethical positions not in professional codes, public policy, or the opinions of physicians, hospitals, or patients but see
Abortion in a Catholic Hospital

Natasha Jones was a 34-year-old, single, African American woman pregnant for the fourth time. She was being seen in the prenatal clinic at the community's only tertiary care Catholic hospital because she had a history of three previous episodes of ruptured uterus that had resulted in the death of her previous fetuses. She was currently in her twenty-fourth week of pregnancy. She was a member of a local Baptist church.

Dr. Lashonda Nevitt, her attending physician, was very concerned because ultrasound revealed that a portion of Ms. Jones's uterine wall was no more than a millimeter in thickness. She was convinced that it would soon rupture, ending the life of the fetus and posing a serious risk to Ms. Jones's life. It was her opinion that, with virtual certainty, the uterus would rupture before the fetus could reach full term.

Dr. Nevitt knew that, since the hospital had a Roman Catholic affiliation, abortion could not be performed there. Even though Dr. Nevitt was herself not Catholic, she accepted this stance when she wanted to work at this hospital. Even if an exception could be made in this case to preserve the life of the mother, no one in the hospital's obstetrics department had enough experience with abortion to perform one safely. The real issue was whether they should advise Ms. Jones of the seriousness of her situation and recommend that she be transferred to a hospital in an earlier stage of pregnancy. Dr. Nevitt asked for a hospital ethics committee meeting to try to sort out the options. There was a quick consensus among the medical people on the committee that this was a life-threatening situation and that Ms. Jones's uterus would almost certainly rupture well before a full-term birth. The ethics committee included two Catholic chaplains, both of whom emphasized that since they were in a Catholic institution, they must begin with the presumption that all life, including fetal life, is sacred and cannot be intentionally terminated. The Ethical and Religious Directives for Catholic Health Care Services was cited, which states categorically, “Abortion (that is, the directly intended termination of pregnancy before viability or the directly intended destruction of a viable fetus) is never permitted.”

One of the committee members raised the question of whether an exception could be made for preserving the life of the mother. He pointed out that it seems tragic to condemn the death of both mother and fetus when at least the mother could be saved. Since this was an extremely rare case, there was virtual certainty that the mother could not survive the rupture and that, if this occurred, the fetus would die as well. He urged making an exception by informing the woman that their committee recommended that she be transferred to a secular hospital such as City Hospital.

One of the chaplains responded, pointing out that the prohibition was exceptionless. The only possibility would be to interpret the intervention as an “indirect” killing of the fetus, which would be acceptable for proportionally good reasons. This, he indicated, was the reasoning used in cases in which a pregnant woman has cancer of the uterus. In such cases, a hysterectomy is permitted to remove the cancer even though the fetus would die in the process. He suggested that perhaps a hysterectomy could be acceptable in this case as well since the weakness in the uterine wall would pose a threat to the woman not only in this pregnancy but in any future pregnancies as well. He acknowledged that this reasoning was controversial but thought it would justify a recommendation from the committee that the patient be directed to the City Hospital. He noted that legally the hospital was not required to have staff to perform abortions, but that they were required to inform the patient of treatment options— including transferring to another hospital that would offer abortion services.

The committee members recognized that, if this case had arisen in any other hospital without an institutional commitment opposing all direct abortions, a recommendation for terminating this pregnancy would be reached by easy consensus.

The dilemma here is how the moral stance of the sponsors of the hospital should shape the way medicine is practiced in this institution.

Commentary

The substantive issues of abortion will be taken up in the cases of Chapter 10. Here the problem is what role the hospital ethical committee and the moral framework of a religious community should play in deciding how to handle a controversial case. In almost all hospitals this patient would receive a strong recommendation to terminate the pregnancy in order to save the patient's life. This seems to be the rare case in which medical science can present no good alternatives, or if the risk to the woman is to be avoided.

That the Catholic Church has a well-developed position on abortion is widely known. When the church operates hospitals, it insists on its right to rely on its moral stance in operating an obstetrics department. Most people understand this and accept it if they do not agree substantively with the church's stance. The problem here is to what extent that stance can shape the behavior of the staff including presentation of options to patients.
Those who developed and run this hospital presumably accept the main tenets of the church’s teachings. This includes the metaethics, that is, the general theory of how one can know what is morally right and wrong. In the case of the Catholic Church, its teachings hold that morality can be known by reason aided by revelation, by reflection on the moral laws of nature. Moral authority resides with the scripture, tradition, the Pope, and church councils, all of which aid reason in discerning the content of the natural law. Those in the Catholic tradition acknowledge these sources of moral knowledge, which are reflected in teachings from the Vatican as well as national bodies such as the United States Conference of Catholic Bishops, the group responsible for the Ethical and Religious Directives for Catholic Health Care Services, the source cited in the ethics committee meeting. Since those committed to the moral tradition around which this hospital is organized accept this metaethical view, there is reason why it would be reflected in the policies of the hospital and its ethics committee.

The professional staff of the hospital, including Dr. Nevitt, should be made aware when they accept employment at a hospital that it is committed to a particular medical ethical tradition. This seems rather different from entering a profession such as medicine. When one chooses to go to medical school and become a physician, one usually does not think of these choices as committing to a particular metaethical theory about where ethical norms are grounded. Committing to a religious tradition, in contrast, seems to imply a general acceptance of that tradition’s views about the foundation of ethics (even if individuals may conscientiously depart from those views on some occasions). Working or receiving care in a religiously sponsored institution carries with it some implication that one is willing, to some extent, to accept that view of moral norms. In this particular case, the religiously sponsored institution may confront some legal requirements—the requirement of adequately informed consent including presentation of reasonable alternatives for treatment—that conflict with the institutional understanding of what is morally required.

The patient may be left in an awkward position. In this case, Ms. Jones became a patient at this hospital for prenatal care. When patients become involved with a hospital they may or may not understand that they are committing to an institution that operates based on a moral tradition of its sponsors. In fact, there was some conflict between the institution and Ms. Jones, but also some agreement as this follow-up to the case indicates.

Ms. Jones was informed by Dr. Nevitt that her pregnancy posed a very serious threat to her life. She was informed that this hospital was sponsored by the Catholic Church and therefore could not endorse an abortion even though her condition was life threatening. In conformity with legal requirements, she was told that abortion services were available at City Hospital and that she was free to transfer to that institution.

When she learned of this, Ms. Jones appeared deeply disturbed. She told them she had no principled objections to abortion, but that she had chosen a Catholic hospital because she knew this was her last chance to have a baby. She was going to carry this child through to a live birth or die trying.

Once the clinical team understood the strength of her commitment, they redirected to the task of providing carefully monitored support for her as an in-patient. On the basis of careful review, they determined that she could probably carry the pregnancy until between thirty and thirty-two weeks, at which time they could deliver the baby by cesarean section. They explained to her that the longer they waited, the better it would be for the baby but the greater the risk to the mother. They eventually agreed to attempt to wait until the 30- to 32-week period before intervening.

Notes

Ethical Principles in Medical Ethics