

Clearly, family discretion is more limited than that given to competent and formerly competent patients. Family surrogates cannot go beyond reason. This notion will be explored further in Chapter 18. What is critical here is that the principle of respecting autonomy may have a place not only in requiring respect for substantially autonomous individual decisions but also in giving a family unit some space in making choices consistent with the family's beliefs and values.

There is a final question raised by this case: whether the HMO insurance staff was justified in denying coverage for those last three days. That question will be addressed in Chapter 15.

Notes

- 1 For good discussions of the principle of autonomy and related concepts see Feinberg, Joel. "Legal Paternalism." In his *Rights, Justice, and the Bounds of Liberty: Essays in Social Philosophy*. Princeton, NJ: Princeton University Press, 1980, pp. 110–129; Dworkin, Gerald. "Moral Autonomy." In *Morals, Science, and Society*. H. Tristram Engelhardt and Daniel Callahan, eds. Hastings-on-Hudson, NY: The Hastings Center, 1978, pp. 156–171; Faden, Ruth, and Tom L. Beauchamp in collaboration with Nancy N. P. King. *A History and Theory of Informed Consent*. New York: Oxford University Press, 1986; Rehbock, Theda. "Limits of Autonomy in Biomedical Ethics?: Conceptual Clarifications." *Cambridge Quarterly of Healthcare Ethics* 20 (No. 4, 2011): 524–532; Shuman, Andrew G, and Andrew R. Barnosky. "Exploring the Limits of Autonomy." *The Journal of Emergency Medicine* 40 (No. 2, 2011): 229–232; and Beauchamp, Tom L., and James F. Childress, eds. *Principles of Biomedical Ethics*, 7th ed. New York: Oxford University Press, 2013, pp. 101–149.
- 2 See the extended discussion of this approach in The Hastings Center. *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*. Briarcliff Manor, NY: The Hastings Center, 1987, pp. 20–29.
- 3 Mill, John Stuart. *On Liberty*. New York: The Liberal Arts Press, 1956.
- 4 Areen, Judith. "The Legal Status of Consent Obtained from Families of Adult Patients to Withhold or Withdraw Treatment." *Journal of the American Medical Association* 258 (No. 2, 1987): 229–235; Veatch, Robert M. "Limits of Guardian Treatment Refusal: A Reasonableness Standard." *American Journal of Law and Medicine* 9 (Winter 1984): 427–468.
- 5 Appelbaum, Paul S., Charles W. Lidz, and Alan Meisel. *Informed Consent: Legal Theory and Clinical Practice*. New York: Oxford University Press, 1987, pp. 66–69.

Chapter 7

Veracity: Honesty with Patients

Learning Objectives

1. Define the principle of veracity.
2. Describe the various ways honesty is addressed in professional codes of ethics.
3. Assess the moral soundness of the common reasons health professionals lie to patients.
4. Describe the connection between the principles of veracity and fidelity.

Other Cases Involving Veracity

- Case 1-1: Disclosure of a Terminal Diagnosis
- Case 8-7: Dishonest Colleagues: Intentionally Shorting Tablet Counts
- Case 10-6: Sterilization of an Economically Deprived Woman
- Case 17-1: Therapeutic Privilege: Scaring the Patient to Death with News about Risks

In the previous chapter, health professionals were in positions in which they had to choose between doing what they thought was best for patients and respecting the patient's autonomy. The moral principle of autonomy was in conflict with the principle of beneficence. We saw that some people believed that respect for autonomy can take precedence over doing good for the patient.

Respect for autonomy is an element of a more general moral concept of respect for persons. Respect for persons, according to this view, sometimes requires moral choices that do not maximize the patient's well-being.

Another element of respect for persons deals with honest disclosure. Traditional ethics holds that it is simply wrong morally to lie to people, even if it is expedient to do so, even if greater good will come from the lie. According to this view, lying to people is morally wrong in that it shows lack of respect for them. Expressed as a moral principle, holders of this view claim that veracity or honesty or truth-telling is a moral principle. The principle conveys that dishonesty in actions or practices is an element that makes them wrong. As with justice and autonomy, there may also be other dimensions that tend toward making actions right. For example, the fact that a lie produces good results would tend to make it right. However, holders of this view maintain that, nevertheless, the lie itself is an element that makes the action wrong. It is, according to this approach, *prima facie* wrong, that is, wrong insofar as the lying dimension is considered.

It is striking that even though many common moral systems treat lying as wrong in and of itself, traditional professional health care ethics has not. Thus the Hippocratic Oath does not require that physicians deal honestly with patients.

Many health professionals have, in fact, maintained that it is right for them to lie to a patient when doing so will spare the patient agony. In this sense, professional medical ethics has focused on the consequences of actions, not on any inherent moral elements, whether it be respecting autonomy or telling the truth.

Benevolent dishonesty by physicians was accepted (or at least not directly condemned) by organized medicine for centuries. That changed in the United States in 1980 with a major rewriting of the American Medical Association's (AMA's) *Code of Ethics*. In that code, an entirely new provision was included reading, "A physician shall deal honestly with patients and colleagues. . . ." ¹ The medical professional group, for the first time, explicitly endorsed honesty. The AMA position remained until what is generally taken to be a minor revision in 2001. At that time this provision was softened to read, "A physician shall . . . be honest in all professional interactions. . . ." Some have suggested that this made the text more ambiguous, leaving open the possibility that the injunction to honesty is only to apply to physician interaction with other health professionals. While the AMA's statement of principles has become more ambiguous, the more detailed opinions and annotation retain the earlier wording: holding that "a physician should at all times deal honestly and openly with patients." ²

The other health professions have taken somewhat different positions on veracity. The code of the American Pharmacists Association (APhA) has for many years considered truthfulness as part of the essential character of the pharmacist. The 1969 version of the APhA *Code of Ethics* states that "A Pharmacist should strive to

provide information to patients regarding professional services truthfully, accurately, and fully and should avoid misleading patients regarding the nature, cost, or value of these professional services." ³ The 1995 revised code states, "A pharmacist acts with honesty and integrity in professional relationships." This provision is followed with an interpretation that reads, "A pharmacist has a duty to tell the truth and to act with conviction of conscience." ⁴

The American Nurses Association does not speak directly of honesty among nurses but does hold that "Patients have the moral and legal right . . . to be given accurate, complete, and understandable information in a manner that facilitates an informed judgment." ⁵

Ethics that focus on consequences, such as the Hippocratic Oath, accept lies when they produce more good than harm. Classical utilitarian ethics assesses the acceptability of a lie based on the total consequences. It considers the benefits and harms for all parties. ⁶ By contrast, traditional health professional ethics looks only at the consequences for the patient. ⁷ For example, in the era when health professionals were expected to be paternalistic, if they were asked by a patient about the purpose of a medication, they might give an evasive answer trying to avoid alarming the patient. If the patient said, "Isn't it true that I am taking this because I have advanced cancer?," the physician would have at least considered telling a benevolent "white lie" or misleading reference to some other name for the tumor. Likewise, physicians sometimes prescribed placebos. If asked the ingredient in the prescription, the physician would probably have dishonestly told the patient the name of the medication that the placebo was mimicking. There is evidence that, at least in some cultures, physicians still rely on placebos, thereby misleading their patients about the nature of the therapy they prescribe. ⁸ The cases in this chapter present situations in which health professionals believe that they can benefit their patients by lying or at least withholding the truth.

While ethics that focus on consequences evaluate whether to lie by trying to determine whether a lie will produce benefit, the ethics that emphasize features other than consequences, such as respect for persons, hold that there is something simply wrong about lying. Immanuel Kant, the eighteenth-century philosopher, is most closely identified with this view. ⁹ Twentieth-century thinkers outside of medicine agreed. ¹⁰ By contrast, most physicians traditionally accepted the legitimacy of lying to patients in order to protect them. This was still the case as late as the early 1960s. ¹¹ There were some exceptions. In the middle of the nineteenth century, physician Worthington Hooker argued for honesty because he thought the consequences of failing to be truthful would be harmful, an argument also used by physician Richard Cabot in the early twentieth century. ¹² By the late 1970s there was a dramatic change in physician attitudes, a change that is reflected in more recent surveys of physicians and medical residents, suggesting that physicians are changing, giving greater emphasis to the patient's right to the truth. ¹³

The cases in this chapter begin with the special problem of what patients should be told when health professionals themselves are not yet sure what the facts are. Then a series of cases involving the problem of lying to patients in order to benefit them will be explored, followed by a case in which the health professional considers lying to the patient in order to benefit others. The chapter will then take up two

special situations involving veracity: cases in which first the patient and then the patient's family asks not to be told. Finally, a case explores disclosure to patients who ask to see their medical record.

The Condition of Doubt

Before discussing the ethics of disclosure, it is important to get some sense of exactly what it is that might be disclosed. In health care, a problem arises frequently that can be referred to as the "condition of doubt." It arises when the health care professional is in real doubt about what the facts are.

The confusion may be in regard to a diagnosis about which the health care professional has only a preliminary suspicion. The doubt may arise when innovative therapies are contemplated and the physician is not clear about what the effects of the treatment will be. He or she may not even know whether the doubt is from personal ignorance of the current literature or because even the leading authorities are unclear.

Consulting physicians and specialists as well as nurses and members of other health professions may have only limited knowledge about a patient's condition. Someone else on the health care team may be better informed. In these cases, even one who is in principle militantly committed to dealing honestly with the patient may not know exactly what should be said. The first case in this chapter raises this problem.

Case 7-1

A Routine Mole or an Early Case of Skin Cancer: The Duty to Disclose Doubtful Information

During routine physical examination, the skin of 46-year-old Betty Harris was examined by her internist, Daniel Newlander. The examination was part of Dr. Newlander's standard procedure to look for any dermatological problems. On Ms. Harris's back, Dr. Newlander saw a brown, mole-like spot that alarmed him. The color was varied; the edges ragged. He could not recall seeing it before.

Dr. Newlander's first thought was that it looked rather like it could be melanoma. Of course, he would not know without excising the tissue and getting a report from the lab. He wanted the tissue removed as soon as possible and asked Ms. Harris to schedule an appointment. Dr. Newlander suggested an opening in his schedule later in the week.

Ms. Harris asked him what the hurry was. She asked him, "Do you think it is cancer or something?" That was precisely Dr. Newlander's concern, but he did not wish to alarm her and, in fact, could not know without the lab results. He was strongly committed to dealing honestly with patients but knew that he did not know the full answer to her question. How should he respond to her question?

Commentary

Even though Dr. Newlander is committed to honesty, there are several possible honest responses. One would be simply to say that he did not know what the tissue was. Another would be to say that he did not know but that he was concerned it could be skin cancer. He could go even further and convey that the growth had many characteristics of skin cancer. Or he might say that he does not think it is cancer, but he would not know for sure until the lab results are back. All of these responses are approximately honest, yet they convey very different impressions. The last response may stretch the truth, especially if he really is quite concerned.

If the lab results had come back and had shown that the tissue either was or was not cancerous, then Dr. Newlander would have no difficulty in deciding what Ms. Harris should be told. But Dr. Newlander's situation is quite different. The real problem here seems to be that Dr. Newlander is confronted with a situation in which he really does not know what the cells are. He has a concern—in fact, a serious worry—but lacks any basis for a firm opinion.

Many people who generally believe there is a moral duty to tell the truth also recognize that there are situations in which it is too early to know what the truth is. If a physician sees a patient who is a smoker and who has a persistent cough, laryngitis, and fever, the diagnosis of lung cancer may enter her mind, but that does not mean she should blurt out to the patient immediately that she may have lung cancer. Not only is there real doubt about the diagnosis at this point, there is also doubt about who should be the one to raise the issue.

Dr. Newlander must decide what counts as truthful, meaningful communication about a preliminary concern that the growth looks like it could be cancerous. It should be clear that no one wants what could be called the "full truth." There is an infinite number of things that could be said. No reasonable patient wants to know everything: the technical names of the possible tumor, the names of the tests to be performed and how those tests were developed, the statistical probabilities of the various results, and so forth. There are many facts that most patients might not be interested in knowing.

What is usually expected is information that is "reasonably meaningful." The problem in this case is that it is not clear exactly what is reasonably meaningful. Surely some suggestions in the literature are so tenuous and the effects so trivial that patients would not consider them meaningful. In fact, supplying too much trivial, unneeded information will actually make the consent process more confusing and therefore less adequate.

Dr. Newlander's problem is compounded because he faces two different kinds of uncertainty. First, there is the uncertainty inherent in the lack of information. Even the best dermatologist in the world may lack certainty with a preliminary examination of a mole. Second, there is here doubt about whether an internist like Dr. Newlander knows adequately what the best dermatologists can know at this point. He probably does not remember the exact details of everything he has read and been taught about diagnosing a malignant skin growth. Even if he did,

he would never know for sure whether newer, more definitive studies had appeared in the literature that he simply had not seen. If he did an exhaustive search of the literature—something he cannot realistically do for the special conditions of each patient presenting in the doctor's office, he still would not know whether he had covered all the data. He will have to learn to live with the uncertainty.¹⁴ He simply responds by saying he cannot know what the growth is until the lab results are back. These are questions that arise in the consent context, which will be discussed in more detail in Chapter 17.

Lying in Order to Benefit

Resolving doubt about “what is the truth” is not all that is at stake in the ethics of truth-telling. In some cases, the health care professional may know the truth but fear that disclosing it to the patient will do the patient or someone else significant harm. Often it turns out that telling the truth is also beneficial, but the interesting moral cases are those in which honesty involves risk of hurting someone. In such cases, is there still a moral duty to tell the truth, or is it right to be honest only in those cases in which telling the truth is expected to be beneficial? The following cases are ones in which someone is worried about hurting another person by being honest.

Protecting the Patient by Lying

Often it is the patient who could be injured—psychologically or physically—if the medical professional is completely honest. Among the issues presented in the following case are: (1) Is avoiding the truth any different morally than telling an outright lie? (2) How can the physician know what the consequences will be? (3) Can the problem be avoided by referring the patient to another physician for disclosure? and (4) What is the nature of the duty to be honest?



Case 7-2

Placebos for Addiction Withdrawal

Seventy-four-year-old Mrs. Abraham had been getting the prescription filled for years. She had a malignancy of the colon four years previously. An operation had corrected the problem, but in the emotional and physical distress that followed, Mrs. Abraham had a terrible time sleeping. She had received a prescription from her internist, Dr. Raymond Siemens, for Seconal® to help her sleep and continued taking them to the point at which she could not sleep without them. Her physician, after several months, realized that he had caused her to become addicted and felt that it was his duty to help her break her habit. He had arranged with the pharmacist to take Seconal® capsules and gradually replace more and more of the active ingredient, until some months later she was on pure lactose packaged in the

distinctive Seconal® capsules. She still claimed, however, that she could not sleep without her sleeping pills.

Dr. Siemens firmly believed that it was in his patient's best interest, but he felt uncomfortable about the placebo prescription he was writing. He was concerned about potential legal implications of lack of informed consent. (He surely had not informed his patient of the treatment strategy and the risks and benefits of the “drug” he was now prescribing.) Furthermore, he was asking the pharmacist to mislabel the prescription, placing the drug name on the prescription label when, in fact, it contained nothing but inert lactose. Mislabeling was against the law. He was concerned about the fact that Mrs. Abraham was paying monthly for the prescription that contained no active ingredients. The charge was modest, barely covering the cost of the capsules' ingredients that were being discarded, surely not compensating the pharmacist for the extra time involved in emptying the capsules and refilling them. But most of all he was concerned about whether he was being dishonest.

Questions for Thought and Discussion

- Consider the positive and negative consequences, those described in the case and others not specifically mentioned, of prescribing the placebo for Mrs. Abraham. Do the positive consequences outweigh the negative ones for the patient? For all involved?
- Do placebo prescriptions such as Mrs. Abraham's involve lying, and, if so, are they morally wrong?

Commentary

Dr. Siemens is facing the classical ethical dilemma of the conflict between medical paternalism and the principle of veracity. According to the traditional health care ethics based on the duty to be beneficent to the patient, placebos were considered an important therapy in the armamentarium of the health care professional. Patients in situations such as Mrs. Abraham's occasionally become addicted. If the physician was convinced that the drugs were doing more harm than good and had tried other more direct methods of withdrawing his patient without success, then the graded reduction in dosage, often done without the patient's knowledge, was judged to be the best course for the patient.

In this case, when a physician reaches this conclusion and his action is to write a placebo prescription, then the pharmacist, if he fills the prescription, is willy-nilly brought into the act as well. Thus two health professionals face a moral issue. A first level of problem might arise in deciding whether a placebo for addiction withdrawal is the best course. Other treatment options, such as referral to a psychiatrist or a plan for decreasing dosage involving the full knowledge of the

patient, could be alternatives. Recent evidence suggests that placebos can sometimes be effective even after the patient is told what they contain.¹⁵ One problem with the placebo option is that there is some chance that the patient could find out what the physician has done, potentially undercutting the trust that is critical in the doctor–patient relationship. Is there any reason to assume that the physician’s judgment about the placebo being the best course should prevail?

There is a deeper level of controversy in this case. Critics may agree that the placebo is in Mrs. Abraham’s best interest but feel that the physician is still doing her wrong if he continues to prescribe an inert substance when he comes to believe that the active drug is no longer needed. The placebo prescription clearly generates costs for Mrs. Abraham, but that may not be the main concern. Some would be concerned that it is simply dishonest to imply to the patient that she is getting something that she really is not. Some, including those who reason like Immanuel Kant, believe that there is simply something unethical about telling such lies—even when everyone is better off for the lie being told. People who hold such a view believe there is a moral principle that it is wrong to lie regardless of the consequences. This principle, sometimes called the principle of veracity, identifies all knowing wrongful statements as unethical, at least in regard to the lie.

The physician, or pharmacist in this case, may see the dispensing as an implicit lie. He may consider the labeling an outright lie as well as a legally suspect practice. First, consider the distinction often drawn between lying and failing to tell the truth. Can Dr. Siemens reason that prescribing, if it did not contain directly false statements to the patient, was not lying but merely withholding the truth about the placebo? Could he say, for instance, that “This prescription will help you sleep” without explicitly saying that he is continuing to prescribe Seconal®?

Even if all outright dishonest statements are morally wrong, no one has a moral duty to say everything he knows to other people. Could Dr. Siemens solve his ethical dilemma by omitting the directly false information?

Outright lying is *different morally* from simply failing to tell the whole truth. In normal human interactions, out of courtesy we sometimes fail to tell the whole truth—for instance, about the appearance of someone who is not terribly attractive. Lying always involves failing to respect persons in a way that merely withholding part of the truth does not.

At the same time, health professionals have a duty to make sure patients are adequately informed so that they can make autonomous choices about their treatment options. Informed consent requires that patients get relevant information truthfully. A health professional is in a fiduciary relation with a patient in which truthful information is expected. Once a relationship is established, that relationship implies not merely a duty to avoid outright lies but also a duty to provide certain information. This suggests that health professionals have an obligation to disclose relevant information, even if ordinary citizens do not always have such obligations. Here the duty of veracity is interconnected with the principle of fidelity. Those who are committed to the respect-for-persons perspective would probably claim in this case that the health professionals—the physician and the pharmacist—owe to the patient, with whom there is a bond of fidelity or loyalty,

not only refraining from false statements but also providing all potentially relevant information honestly. Holders of this view might even reach that conclusion when it conflicts with the duty to do what the provider believes is best for the patient.

Protecting the Welfare of Others

In the previous case, a medical professional contemplated lying or withholding the truth because he thought it would be better for the patient not to know. Sometimes it is not the patient but someone else—a colleague or friend—whose welfare could be protected if the truth were withheld. In the following cases, health professionals are asked to lie to protect others.

Case 7-3

Confessing an Error in Judgment: Is It Necessary?

Emilia Hedges is a 68-year-old woman who saw her primary care physician, Lawrence Aleman, soon after experiencing sudden slurring of speech and brief weakness in the right upper arm. She reported that the episode lasted about thirty minutes, with clearing of all symptoms. Dr. Aleman prescribed an aspirin and asked her to report back if any similar symptoms returned.

Three days later she was hospitalized with a major left-sided cerebral vascular accident (CVA), or stroke. An ultrasound examination of the left carotid artery revealed a 98 percent narrowing (called a “pinpoint”). On the neurology service, Ms. Hedges was treated with anticoagulants (blood thinners). A month later, an operation was performed to remove the clot (a procedure called an endarterectomy). She subsequently was left with marked weakness of the right upper arm and some impairment of her speech.

Dr. Aleman was terribly distressed by this outcome. He felt guilt about missing the signs of a transient ischemic attack that indicated a severe obstruction of blood flow to the left side of the brain, affecting the right arm and the speech center. He realized there were more things he could have done during Ms. Hedges’s initial visit, such as listening to the carotid arteries with a stethoscope. Hearing a murmur suggesting blockage is clinically helpful, even if it is not definitive. Also, he could have ordered some noninvasive diagnostic tests to narrow the possibilities.

Now he faces the dilemma of whether he should say something to Ms. Hedges about the fact that he realizes he could have, probably should have, done more for her. Primary care physicians are frequently placed in a position in which they are not sure whether they ought to refer a patient to a specialist. That comes with the territory of being a general internist or primary care doctor. Dr. Aleman’s question is whether, when he realizes he made the wrong judgment, he should say something to his patient about it.

At this point there is really nothing that can be done to reverse his error in judgment. Telling Ms. Hedges could seriously damage the trust and confidence that she has in him. It will be an embarrassing and unpleasant experience for him and arguably will not do anything to help Ms. Hedges correct the effects of Dr. Aleman's error.

Questions for Thought and Discussion

- ❑ Should Dr. Aleman inform Ms. Hedges about his error in judgment? Why or why not?
- ❑ The error in this case is one of omission in that Dr. Aleman didn't go far enough in his diagnostic work-up to catch the early warning signs of a possible stroke. Would you view the case differently regarding truth-telling if the error was one of commission, i.e., Dr. Aleman did something to Ms. Hedges that resulted in harm?

Commentary

Like the previous cases, this situation poses a conflict between following the principles of beneficence and nonmaleficence on the one hand and the principle of veracity on the other. The difference here is that there is little reason to believe that the patient, Ms. Hedges, will benefit from the disclosure of Dr. Aleman's bad judgment. In fact, she could plausibly be harmed in the sense that she will experience a strain in her relation with her physician. It is possible that with the information about his error, she might take action to protect herself in the future—by changing primary care doctors, for example. Nevertheless, if the case were to be decided on Hippocratic grounds of patient benefit, an argument could be made that having Dr. Aleman keep his mistake to himself does Ms. Hedges more good than harm.

The real issue is whether that is the ground on which this case should be decided. There are two other grounds. Still working within the framework of beneficence and nonmaleficence, there are benefits and harms to other parties that some consequentialist ethics would take into account. Utilitarianism differs from Hippocratic ethics in that it considers potential benefits and harms to all parties impacted by an action.

There are two other elements of benefit and harm that one might want to consider. First, the disclosure of errors in judgment by health care professionals potentially could affect future patients. The disclosure might lead to corrective action—further education or development of checks on decision-making that could eventually benefit patients down the road. Hippocratic ethics would not necessarily take these effects into account, at least if that tradition is interpreted as requiring that only benefits and harms to the present patient count morally. Still, a utilitarian would consider these less direct consequences to be morally relevant.

The other party who could be affected is Dr. Aleman himself. He has interests at stake. He surely will feel more comfortable if he can avoid disclosing to his patient that he has failed to perform tests and make a referral and that these judgments are directly related to Ms. Hedges's present medical problems. If a utilitarian would take into account all parties affected by a decision about whether to disclose, then presumably Dr. Aleman can add into the calculation the benefits and harms not only for Ms. Hedges and future patients but also for himself, his family, and anyone else who will be influenced by his disclosure decision.

Many analysts of this case will call into question whether consequences alone should be the basis for settling the issue. The principle of veracity holds that actions are morally right in so far as they involve speaking truthfully to patients. This includes admitting to patients one's lack of competency to respond to a given problem and to see that such expertise is obtained. When serious errors of judgment occur, this at minimum would require answering a patient's questions about the error truthfully. In the previous commentary, we saw that the structure of some relationships requires not only speaking truthfully but also disclosing information, even embarrassing and painful information, when the relationship is a fiduciary one in which such communication is expected. Do benefits for Ms. Hedges or for Dr. Aleman justify withholding what he knows about Ms. Hedges's medical problems?

Special Cases of Truth-Telling

Although the usual cases of truth-telling involve situations in which the physician contemplates lying or withholding the truth in order to benefit the patient or benefit someone else, some special cases occur in which lies, deceptions, or withholding of information are motivated by other concerns such as respect for someone who is believed to have authority to decide that the truth should be withheld. These include cases in which the patient or some member of the family requests that the truth be withheld.

Patients Who Do Not Want to Be Told

Sometimes a patient is said to fear bad news or, for other reasons, desires not to know some of the aspects of his or her condition. When being seen for a diagnosis of a potentially fatal disease, the patient himself or herself may explicitly ask the provider to avoid disclosing the bad news. A physician may, as in the following case, contemplate a plan of care, including informing the patient of his diagnosis, only to discover that the patient does not want the information.

Case 7-4

Refusing to Learn about Cancer

Wesley Crossman was a 43-year-old real estate broker who had just been hospitalized for persistent pain in the bone of his right hip. At first he thought he must have pulled a muscle, but the pain gradually became more severe. About six months ago, after he had endured the pain for

almost a month, he went to his family physician, who made a tentative diagnosis of arthritis. After several months of treatment with indomethacin, an antiarthritic drug, during which time the pain became unbearable, referral was made to an orthopedic specialist for further tests.

Mr. Crossman was the proprietor of a small agency in a suburb of Phoenix, Arizona, in the path of urban growth. Although only marginally successful, he earned enough to support his wife and three children, who were now 18, 14, and 12. The rapid development of the area gave him new hope for some promising real estate speculation. After overcoming his wife's concerns about the financial risks, he invested \$20,000 from their savings account in a development project. It would take a few years to pay off, but he was tired of making fortunes on land for everyone else while he and his family made so little.

Mr. Crossman felt tense when he went to the appointment with Dr. Marvin Greenblatt, the orthopedic specialist. He had not said anything explicit to his wife, but they were both thinking about the neighbor who had succumbed to bone cancer. During the examination, Mr. Crossman remarked that he was a busy man and mentioned his real estate deal to Dr. Greenblatt when he was asked what he did for a living. Then Mr. Crossman got down to business and stated, "Doctor, you do what you have to do to get rid of this pain," he said. "Put me in the hospital if you have to, but don't trouble me with all the details. Do what you think is best. Even if it's awful, I'd just as soon not know." Both Mr. Crossman and Dr. Greenblatt knew that "cancer" was the word he would not or could not say.

Dr. Greenblatt had seen patients like Mr. Crossman before. Some patients give signals, just as clear as can be, that a diagnosis of a terminal illness would be more than they could handle psychologically. Dr. Greenblatt asked himself, however, "Does he have a right not to know the truth?"

Commentary

This case leads to conclusions that are not typical of most truth-telling cases. Whereas, in most cases, the principle of patient self-determination would lead to a decision to disclose a diagnosis or prognosis and the consideration of consequences for the patient would support nondisclosure, in this case these arguments seem to lead to the reverse conclusions. If patient freedom and self-determination are dominant, then the clearly expressed wishes of the patient not to be bothered with the details certainly support nondisclosure, even if the physician feels Mr. Crossman would be better off knowing.

On the contrary, if Dr. Greenblatt considers the consequences, he might conclude that Mr. Crossman ought to be told. If he limits the relevant consequences to those related to the patient, he might consider the therapeutic advantages as well as psychological adjustment that can be made over the next

few months if the patient knows his condition. These consequences alone, however, probably will not be decisive in a decision to disclose because of the consequences. If, however, Dr. Greenblatt considers the consequences for Mr. Crossman's three teenage children of having a father speculate with the family's modest savings in a venture that will not pay off for several years, he might well conclude that the total consequences will be better if he tells Mr. Crossman of his condition. Even if he limits his concern only to patient-related consequences, this might be relevant. If Mr. Crossman will later be disturbed at the realization that he has squandered the resources his children need, then the consequences for Mr. Crossman himself might more decisively justify the disclosure.

The case can be approached from another perspective. Instead of asking what Dr. Greenblatt ought to do, one can ask what Mr. Crossman ought to have done. While the principle of patient self-determination might well justify the physician's agreement with the request of the patient not to disclose, it is irrelevant to the patient-centered question. Assuming that Mr. Crossman has the freedom to request nondisclosure, ought he to do so? While the consequences for the family must be excluded from the physician's judgment if he follows the principle of doing what he thinks will benefit his patient, those familial consequences certainly are not irrelevant to Mr. Crossman's own moral decision-making. He has an obligation to provide for his family and presumably an interest in their welfare as well. From the standpoint of consequences it seems that he has a strong obligation to have the important information about his future.

What, however, if there were no family members in the picture? Would there then be any obligation to accept the information if he would rather not be troubled with it? While the freedom of choice of the competent patient might justify his right to refuse the information, some would nevertheless hold that such refusal is still not ethically the best course. According to this view, a mature adult has an obligation as well as a right to make decisions about his own medical care. The fact that avoiding unpleasant information makes life more comfortable would not necessarily make it right. Some would make the case that Mr. Crossman ought not to have requested the nondisclosure even if the interests of his children were excluded from the case.

Family Members Who Insist the Patient Not Be Told

A second kind of special case involves a patient whose family insists the patient should not be told or that the consequences of telling would be so bad that the physician should refrain. Now it is the family member who is claiming the authority to waive the right to know. In some cases, such as the two that follow, it can be argued that the patient would be hurt, psychologically or physically, if he or she knew the threatening information. Some families might also be concerned that the patient could not understand the information, that he or she might really not want to know, or that the patient would be better off not knowing. Nevertheless, the question persists whether there is anyone who has the authority to overturn the patient's claim on the information. The first of the cases in this section involves a patient from a

culture where nondisclosure is the norm. In this case there is no reason to believe that the patient is mentally impaired, and, in the United States, nondisclosure would appear to constitute treating without consent. In the second case the patient may well not be mentally competent, in which case the next-of-kin is normally the presumed surrogate. The issue becomes one of whether the valid surrogate can decide that the patient should not be informed.

Case 7-5

A Clash of Cultures: A Japanese Family Asks That Their Father Not Be Told of Cancer

The surgeon, Dr. Phyllis Rollins, had just examined the patient after referral from an internist. Dr. Rollins was part of a large oncology practice in a large, West Coast American city. Mr. Nikki previously had endoscopy and biopsy of the stomach confirming a very large cancer. Since Mr. Nikki spoke little English, his son came into the room to help. The patient's wife took the patient into another room beyond hearing distance. Then the surgeon fully explained the nature of the malignancy, that an operation was clearly indicated, and that the father must be given that information, including the process of preparation, the prognosis, the risks, probable outcomes, and other details so that truly informed consent may be obtained.

Abruptly, the son replied that if his father were told the diagnosis, "he will wither up and die." Dr. Rollins replied that she could not proceed with surgical care of Mr. Nikki without his understanding of and agreement to a major operation. "You just don't understand 'the Japanese way'—in Japan, the word 'cancer' cannot be mentioned to the person who is ill," said the son. He proposed that Dr. Rollins tell Mr. Nikki nothing and prepare for surgical treatment secretly. Dr. Rollins withdrew from the case, providing some other surgeons' names to the family. Later, she learned that the patient had been operated upon at another hospital, presumably without being told of his diagnosis.

Questions for Thought and Discussion

- Did Dr. Rollins do the morally correct thing by refusing to operate on Mr. Nikki? What other options might she have pursued?

Commentary

Given the facts as presented, the initial surgeon felt bound by important ethical principles and the law requiring that patients be told truthfully of their condition as part of the consent process. Failure to disclose would mean that consent is not

adequately informed, which would constitute an assault against the patient. In this case, Dr. Rollins withdrew from the care of the patient by referral. The net result was that, as far as Dr. Rollins knew, the patient was treated without being fully informed.

It could be claimed that Mr. Nikki delegated decision-making authority to his family members, who aggressively acted for him in their understanding of his best interest. He could have done so explicitly (although there is no evidence of this). Some patients, particularly those in stressful medical situations, may explicitly acknowledge that they do not feel capable of handling decision-making and may waive their right to be informed. That was the issue in the previous case.

This case presents a more complicated problem. Assuming that Mr. Nikki did not explicitly waive his right to be informed and consent to his medical treatment, could it be argued that he was part of the traditional Japanese culture in which disclosure to the family rather than to the patient was the usual custom?¹⁶

There are problems with the presumption that Mr. Nikki would consent to having his family take over decision-making. Even in Japan there are people who reject the traditional view. They insist that they would want to be informed of their diagnosis and retain decision-making authority. Since there is no way to determine whether a specific patient is in this group who would want to retain his or her decision-making authority (and patients cannot be asked without raising suspicion of some serious medical problem), showing respect for the unidentified group who are not willing to let their family play this role is a serious problem in Japan. From the point of view of those who believe there is a moral right to truthful disclosure, this right cannot be waived by majority vote even if it can be shown that the patient is from a culture that generally follows a pattern of nondisclosure.

In the United States, the issue is even more complicated. There is an increasing moral consensus in favor of truthful disclosure of diagnosis. The duty of honesty is even incorporated into the *AMA Code of Ethics*. Hence, in the United States, where Mr. Nikki is being treated, both law and ethical principle support a duty of disclosure. Although that duty might be overridden in the case in which a competent patient explicitly authorizes nondisclosure, it is hard to imagine the justification based solely on the instruction of the family.

The physician who accepted the case under the reported "don't tell" stipulations of the Japanese culture did so even though there was no evidence that the patient was incompetent. Postoperative care might well be compromised by complications, need for reoperation and/or intensive care, and so on.

The issue of familial request for nondisclosure is even more complex in the case in which there is doubt about the mental competency of the patient. That is the situation in the next case.

Disclosing Cancer to a Mentally Compromised Patient

A 64-year-old man, David Younis, was brought to the emergency room (ER) after his wife found him suddenly disoriented and incoherent. Mr. Younis was known at the hospital for alcohol dependence, with cirrhosis of the liver. Examination revealed liver enlargement including a mass that was confirmed with a computed tomography (CT) scan. He was admitted to the hospital, and a biopsy of the mass was scheduled. Mr. Younis's mental status improved; his wife requested that he not be told if the diagnosis was malignant. Mrs. Younis said that if he learns he has cancer, he will kill himself. Dr. Andre Caldaroni, the hepatologist (liver specialist), then canceled the biopsy procedure.

Commentary

This case resembles Case 7-5 in many ways. Both cases involve family requesting that a patient not be told of a diagnosis on the grounds that it would be contrary to the best interest of the patient to disclose. The present case differs, however, not only because the potential harm to the patient appears more severe—a purported risk of suicide—but also because that patient has been disoriented and incoherent. The moral principle of veracity and its related notion of informed consent clearly applies to patients who are mentally competent. Whether it also applies to mentally compromised patients is difficult to determine.

If Mr. Younis is not mentally competent, the doctrine of informed consent does not apply directly. Consent is usually related to the rights derived from the principle of respect for autonomy. As such it only applies to substantially autonomous persons. If Mr. Younis is incompetent, his wife is his presumed surrogate. She would retain the right to determine how much he should be told based on her assessment of his best interest. This is the same approach used in informing young children, who are also mentally not competent to consent to medical treatment.

Not all mentally compromised patients are sufficiently lacking in autonomy that they should be treated as incompetent. Thus the first problem for Dr. Caldaroni is a determination of Mr. Younis's competence. This could involve a psychiatric consultation and, especially if the matter is in dispute, potentially a judicial determination of whether the patient is competent, and, if not, who should be his surrogate or guardian.

If Mr. Younis is found to be incompetent, his wife would plausibly become the moral and legal surrogate. The obligation to benefit the patient clinically would prevail, unless she knows his wishes about how he would want to be treated. A good utilitarian argument could be made that the greatest good is preservation of life, which calls for proper clinical diagnosis and treatment of a

potential life-threatening illness as well as avoiding the threatened suicide. This could lead to a biopsy diagnosis and then truth-telling in careful but honest terms, with promise of and support/care of the patient afterward. The attending physician will require virtues of interpersonal skills, professional skills of evaluation and decision-making, and great sensitivity in truly caring for this patient.

The abrupt canceling of the biopsy raises additional moral issues. While it is true that a physician cannot legally operate without a valid consent, either consent from the next-of-kin under the presumption that the patient was not competent or a further discussion with the wife if the patient is determined to be competent would seem to be in order.

The Right of Access to Medical Records

Closely related to the ethics of truth-telling is the question of the right of access of a patient to his or her medical records. This is a problem for medical records administrators and also for all other health care professionals, especially those in a hospital setting. If the patient has the right to be told all that is potentially meaningful about his or her medical condition and treatment, does that also imply a right to see his or her medical records or at least to know what they contain?

Traditional medical ethics and law presumed that patients had no right of access to their medical records. They were presumed to be the property of the treating health professional. Concern was expressed based on Hippocratic concern for patient well-being that if patients saw their records, they could learn things that would be upsetting. Moreover, they might misunderstand the content of the record causing psychological distress and confusion.

More recently, as medical ethics has shifted from more paternalistic consequentialism to a more rights-oriented ethic, patients are seen as having a right of access as part of their more general right to be truthfully informed of their medical condition.¹⁷

A Psychiatric Patient's Right to See Her Medical Record

Claire Mowry was a 38-year-old, single woman who had worked intermittently over the past ten years as a secretary. She had had difficulty keeping jobs because she would regularly engage in disputes with fellow employees, accusing them of not carrying their load of the office work, criticizing their work, and in one case reporting a fellow worker to the supervisor for consistently showing up late for work.

Currently out of work, she was seeing Martin Gaskell, a psychiatrist working with the mental health clinic of the health maintenance organization (HMO) of her previous employer. Ms. Mowry was currently paying out-of-pocket so her HMO coverage could continue.

Dr. Gaskell had now had four appointments with Ms. Mowry. He had identified patterns of what appeared to be paranoid thinking and had generally come to find her an unpleasant, difficult patient. She clearly did not have a major psychiatric disorder. She was not psychotic—a paranoid schizophrenic—but she had personality traits that were causing her problems.

By the end of her fourth visit with Dr. Gaskell, Ms. Mowry had become convinced that Dr. Gaskell did not like her. She thought he seemed to be implying that her employment problems were her own fault and that she needed further therapy to address these issues. Ms. Mowry suspected that Dr. Gaskell was keeping notes on her that would reflect his poor opinion of her. She asked to see her medical record.

When Dr. Gaskell hesitated, Ms. Mowry indicated that she would report him to the management of the HMO. Patients in the United States have the right to review their medical records. However, some moral uncertainty still exists. In particular, many physicians, especially psychiatrists, are concerned that granting patients the right to see their records may harm patients as well as violate the privacy rights of the provider. Regardless of the law, what is an ethically appropriate decision by Dr. Gaskell?

Commentary

In the era of Hippocratic medicine, it was assumed that medical records were not for the patient to see. They were the property of the physician. A patient would not be able to understand the physician's documentation and could be harmed by any misunderstanding. Psychiatric records were particularly subject to the claim that disclosing of contents could do more harm than good. If the patient were mentally incompetent—a child, an adult adjudicated to be incompetent, or perhaps even an adult who has not formally been found incompetent but is deemed to lack sufficient mental capacity for autonomous medical decision-making—there is good reason why records might not be disclosed, but cases of mentally competent adults, including those who have some psychiatric problems, pose the question of whether they ought to be given access to their records, whether the information in some sense belongs to them.

In more recent times, the assumption that patient access to medical records will cause harm to the patient has been called into question. Some claim that seeing the record will actually help the patient understand his or her condition and clarify matters not adequately presented by the physician. In fact, preliminary studies have shown that provision of psychiatric records has been met with positive responses on the part of patients.¹⁸ Seeing the record of the physician or the hospital is considered an additional source of information to help the patient understand the diagnosis and treatment as well as clarify any miscommunication from the provider. In addition, the patient is

sometimes believed to have a right to information about the physician's views of the patient's problem.

Those concerned that the record could be misunderstood have suggested that the patient who asks to see his or her record should have access with the professional present to clarify any issues that are not clear. With the advent of electronic medical records, patient access could be instantaneous with the option of electronic messaging within a secure Internet system so that the patient and physician can communicate and clarify issues at a distance and at times that fit their schedules. Ms. Mowry has revealed sufficient signs of paranoid thought that she probably would not be satisfied with anything less than access to her medical record. A traditional consequentialist would ask whether the information would, on balance, be beneficial to the patient. The answer in this case is not obvious. There is information at stake that is potentially important to her current health care and peace of mind. On the other hand, the physician or other members of the health care team may have entered notes about the patient's mental state or other potentially embarrassing information they did not expect the patient to see. Basing an assessment just on the consequences, it may not be clear whether the patient will, on balance, be helped or hurt by seeing her record.

Now look at the case from the point of view of the rights of the patient. Assuming she has the right to information that is potentially meaningful in making medical decisions, from this point of view she would have a right to the information even if it is, on balance, likely to harm her.

In recent studies, patients and physicians alike indicate satisfaction with all sorts of electronic medical/health records and messaging options.¹⁹ Patients also believe they could understand the information that is in their medical records and have concerns about accuracy and completeness that access could help correct.²⁰

This completes the exploration of the cases dealing with the ethical principle of veracity. Autonomy and veracity, the issues of the previous chapter and this one, were the first two principles related to respect for persons. We now turn to the third such principle: fidelity.

Notes

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