CHAPTER 4

Truth-Telling and Confidentiality

A major moral issue in patient–provider relationships is how to handle the truth—specifically, whether doctors and nurses should always tell the truth to patients and whether doctors and nurses should ever reveal the truth about their patients to others. The former question is about the presumed duty of providers not to deceive patients or withhold relevant medical information from them. The latter is about confidentiality, a provider's obligation to protect a patient's privacy. In both, the issues raised are contentious and ongoing, reverberating among patients, families, and caregivers and often forcing shifts in the policies and culture of medical practice. Though the debates are complex, they usually come down to disagreements about the limits of paternalism and the proper balance between the principles of autonomy and beneficence.

PATERNALISM AND DECEPTION

From ancient times, the principle of nonmaleficence—the duty to do no harm—has been enshrined in codes of medical ethics. But not so with the duty of truthfulness. The Hippocratic Oath does not mention an obligation of truth-telling or disclosure, and until 1980 even the professional code of the American Medical Association did not say anything about dealing honestly with patients. Many physicians have viewed the truth as something to conceal or reveal for the therapeutic good of the patient. For them, the overriding principle was beneficence (or nonmaleficence), which was best honored by delicately managing what patients knew about their own cases. The truth could be harmful, unsettling, and depressing—so why inflict it on vulnerable patients? In a famously blunt formulation of this view, an early-twentieth-century physician declared that to be compassionate and gracious, doctors "must frequently withhold the truth from their patients, which is tantamount to telling a lie. Moreover, the physician soon learns that the art of medicine consists largely in skillfully mixing falsehood and truth."[1]

Nowadays, in the age of patient autonomy and informed consent, such strong paternalistic sentiments are less common. Most physicians value truth-telling, and professional standards encourage it while counseling sensitivity in conveying vital information to patients. But the moral problem of truthfulness still presses both physicians and patients, prompting questions with which they still wrestle. Is it ever morally permissible for a physician to lie to a patient? Does a physician's duty of beneficence sometimes justify deception? Does respect for patient autonomy rule it out? If there are exceptions to a duty of truthfulness, what are they?

Consider how easily (and painfully) such questions can arise. Karen, a 30-year-old woman with two small children, is admitted to the hospital after experiencing headaches, vomiting, memory loss, and partial paralysis. Dr. Smith runs numerous tests and discovers that Karen has a malignant brain tumor. It is advanced and untreatable, leaving Karen with only weeks to live. Before the tests, she had told Dr. Smith that she was terrified of cancer because her husband died of lung cancer and her mother of breast cancer. And if she succumbed to cancer, what would happen to her children? Who would care for them?

IN DEPTH
DO PATIENTS WANT THE TRUTH? DO PHYSICIANS TELL IT?

- In 1961, a survey of physicians found that 90 percent of them would avoid telling patients of a diagnosis of cancer. But in a similar 1979 survey, 97 percent of physicians said that they would disclose a diagnosis of cancer.
- More recent research suggests that most physicians in Western cultures inform their cancer patients of their diagnosis, but fewer of them tell cancer patients about their prognosis.
- Several studies indicate that most cancer patients want to know the details of their disease, whether the news is good or bad.
- Surveys suggest that patients differ in the kinds of medical information they would like to have and how it is communicated to them.

From L. J. Fallowfield, V. A. Jenkins, and H. A. Beveridge, "Truth May Hurt but Deceit Hurts More: Communication in Palliative Care," *Palliative Medicine* 16 (2002): 297–303.

Dr. Smith considers carefully whether to tell Karen of the dire prognosis. He thinks about the misery that full disclosure would cause her, the days spent in terror before the end, the dark depression that would likely spoil her remaining time with her children.

He decides to shield her from the terrible facts, shrouding them in vague statements and irrelevant details. He tells her that she has a brain disease requiring neither surgery nor radiation, and he assures her that he has many drugs at his disposal for treating her symptoms. Karen is relieved to hear the news and does not question Dr. Smith's explanation. Sensing that disturbing details might lie behind his murky pronouncements, she presses him no further and tries to rouse a sense of optimism. She is eager to go home so things can get back to normal.

The next day she does go home. But after two weeks of trying to resume her normal routine, after enduring more headaches and vomiting, she collapses and dies.[2]

Notice that in this scenario Dr. Smith does not actually lie to Karen (that is, intentionally give her false information), but he does deliberately mislead her by withholding crucial facts and avoiding definite statements. Either way, he handles her paternalistically. Notice also that this story is about protecting a patient from a dreadful prognosis, but such paternalism can also apply to the truth about diagnoses and treatments.

Some medical writers would agree with Dr. Smith's decision. They think there are good reasons for occasionally misleading or lying to patients. Their main argument is that truth-telling can be injurious, evoking in patients feelings of panic, hopelessness, fear, and depression—any of which can worsen the patient's condition, sap her will to live, or tempt her to suicide. Honest disclosure must be modulated to promote the patient's welfare. The physician's duty to do no harm must take precedence over the obligation of veracity.

Others reject this argument, contending that it exaggerates the harm done to patients by full disclosure (and underestimates the beneficial effects of truthfulness) and fails to recognize that misleading or lying to patients can also do damage. A common suggestion is that if patients knew the truth about their situation, they would likely live their lives very differently than if they remained ignorant. If so, not knowing the truth robs patients of informed life decisions. If they knew their prognosis was terminal, for example, they might try harder to make every remaining day meaningful, to put their financial and legal affairs in order, and to behave differently toward their family and friends.

Advocates of full disclosure (that is, honest communication of the essential facts) also insist that informed patients are better patients—that patients who know where they stand are more likely to comply with the requirements of their treatment.

Moreover, some argue that deception breeds distrust—and not just between patient and doctor:

> [T]he long-term effect of lies on the family and, perhaps most importantly, on society, is incalculable. If trust is gradually corroded, if the "wells are poisoned," progress is hard. Mistrust creates lack of communication and increased fear, and this generation has seen just such a fearful myth created around cancer.[3]

The impact of the truth on patients may also depend largely on how it's told. As one writer puts it, cases that seem to indicate that truth-telling is harmful to patients may instead

> argue, not for no telling, but for better telling, for sensitivity and care in determining how much the patient wants to know, explaining carefully in ways the patient can understand, and providing full support and "after-care" as in other treatments.[4]

Another argument against full disclosure is that patients do not want to know the truth, especially if the prognosis is grim. A common claim is that even when patients say they want all the facts, they actually do not. Many writers counter this view with data from surveys suggesting that most patients really do prefer to be told the truth about their diagnosis. In light of these findings, presuming that patients do not mean what they say seems questionable at best.

None of this implies that the truth should be forced upon patients who genuinely choose not to be informed about their medical condition. As one commentator notes, autonomy can be served by offering a patient "the opportunity to learn the truth, at whatever level of detail that patient desires."[5]

Many skeptics of full disclosure have argued that physicians have no duty to tell patients the truth because patients are incapable of understanding it anyway. The practice of medicine is technically complex—so complex that even when a physician tries to explain the relevant facts to patients, they cannot grasp them. Telling patients the whole truth, the skeptics say, is impossible.

Critics of this argument say that even if communicating the whole truth is impossible, physicians still have a duty of complete honesty—an obligation to try hard to convey to patients the essential and relevant information. What's more, some argue that conveying the "whole truth and nothing but the truth" is unnecessary:

> [T]he explanation of a complicated situation in ways a layperson can understand is not a challenge unique to physicians. The same problem is faced by lawyers, electricians, automobile mechanics, and computer help-line workers. In none of these fields, including medicine, is it necessary to provide the layperson with a complete explanation (the "complete truth") of a situation. All a patient requires is an understanding adequate to appreciate the nature and seriousness of his illness and the potential benefits and risks of the available therapies. A diabetic need not know the stages of oxidative phosphorylation to grasp the importance of insulin and the role of diet in maintaining her health.[6]

The main argument in favor of truth-telling rests on the principle of autonomy. The gist is that we must always respect people's autonomy—their rational capacity for self-determination. Autonomous persons must be allowed to freely exercise this capacity: to decide how to live their own lives and what can and cannot be done to their own bodies. To respect their autonomy is to respect their freedom to act by their own lights, as long as their actions accord with the freedom of others. When physicians deceive a patient, they fail to respect his autonomy by constraining his ability to make informed choices. They compel him to make important decisions in a fog of distorted or missing information.

Many who insist on truth-telling and respect for autonomy admit that deceiving a patient may sometimes be necessary, but they say that any deception requires strong justification and should be a last resort. Some contend that deceiving a patient is permissible only when the deception is small and the benefits to the patient are great (as when a minor lie will save the patient's life). Most who argue in this vein believe that cases of permissible deception are rare.

CONFIDENTIAL TRUTHS

Truth-telling, then, is about health professionals imparting relevant facts to patients. **Confidentiality** concerns patients imparting information to health professionals who promise, implicitly or explicitly, not to disclose that information to others. It is an obligation or pledge of physicians, nurses, and others to keep secret the personal health information of patients unless they consent to disclosure. Most people probably assume they have a right to confidentiality. Physicians also take seriously their duty to protect patient privacy, though they may differ on whether the duty is absolute or prima facie. Their respect for confidentiality goes back centuries, having been boldly expressed in a long line of medical codes from ancient Greece onward. The Hippocratic Oath has the physician swear that "whatever I see or hear, professionally or privately, which ought not to be divulged, I will keep secret and tell no one."

Arguments for confidentiality can take both consequentialist and nonconsequentialist forms. The consequentialist can argue that unless patients are able to rely on a physician to keep their secrets, they would be reluctant to reveal truthful information about themselves—information needed if the physician is to correctly diagnose their illnesses, devise effective treatments, and provide informed prognoses. Without respect for confidentiality, physicians would have a difficult time fulfilling their duty of beneficence. Worse, trust between physician and patient would break down, and trust is what makes the practice of medicine possible. But beyond issues of trust, the consequentialist can offer other dire consequences to consider. Disclosure of confidential medical information could expose patients to discrimination from insurance companies and employers, disrupt their personal relationships, and subject them to shame or public ridicule.

The nonconsequentialist can argue from the principle of autonomy the idea that people should be allowed to exercise their capacity for self-determination. Autonomous persons, the argument goes, have a right to determine what may or may not be done to them—not just to their bodies and to their property, but to their private lives. They therefore have a right to control access to information about themselves and to limit intrusion into their personal affairs. They have, in other words, a **right to privacy**, the authority of persons to control who may possess and use information about themselves.

A related argument is that the physician–patient relationship is based in part on the physician's implicit promise to patients to preserve confidentiality and to respect their privacy. Patients' confidentiality must therefore be protected because the physician has promised to do so. Confidentiality arises from the physician's obligation to keep promises, what some call a duty of fidelity. Others see this line as another argument from autonomy because, as Kant would have it, to break a promise is to violate autonomy.

As hinted earlier, an important issue is whether the obligation to respect confidentiality is absolute (applying in all cases) or prima facie (allowing exceptions when other duties obtain). Some argue for absolute confidentiality, insisting that *any* breach of it undermines trust between physicians and patients and amounts to impermissible deception. But many believe that exceptions are sometimes justified when confidentiality must be weighed against other duties, such as the duty to prevent serious harm to the patient and others. The law reflects this prima facie view of confidentiality. It recognizes that

LEGAL BRIEF

Confidentiality and a Duty to Warn

In the landmark 1976 case *Tarasoff v. Regents of the University of California*, the court held that duties of patient–psychotherapist confidentiality can be overridden when "a patient poses a serious danger of violence to others." In related cases:

- In 1983 people who were shot by John Hinckley as he tried to assassinate Ronald Reagan sued the psychiatrist who had been treating Hinckley. In *Brady v. Hopper*, a federal district court ruled that unless a patient makes a specific threat to a readily identifiable person, the patient's therapist cannot be held responsible for injuries inflicted on third parties by the patient.
- In *Bradley Center Inc. v. Wessner* (1982) and *Hedlund v. Superior Court of Orange County* (1983), the courts found that therapists are obligated to take reasonable steps to determine the degree of danger posed by a patient.
- In *Ewing v. Goldstein* (2004) and *Ewing v. Northridge Hospital Medical Center* (2004), the California Court of Appeal held that a therapist has a duty to warn third parties of a possible danger posed by a patient even if the threat is communicated not by the patient but by the patient's family.

communication between physicians and patients is "privileged" and should generally be safeguarded from invasion—yet requires physicians to breach confidentiality in some cases. State law, for example, may oblige physicians to reveal information about a patient if she has a serious contagious disease, suffers from gunshot wounds, or is the apparent victim of abuse or assault (whether she is a child or an adult). Thus, physicians can find themselves pulled not only between clashing moral duties but also between moral duties and legal requirements.

These sorts of conflicts were drawn in high relief by the famous 1976 California Supreme Court case of *Tarasoff v. Regents of the University of California*. It concerned Prosenjit Poddar, a student at UC Berkeley who sought counseling from psychotherapists employed by the university hospital. He confided in them that he intended to kill another student, Tatiana Tarasoff, when she returned from a summer trip in Brazil. The psychotherapists told the police of Poddar's intentions but warned neither Tatiana nor her parents of the threat. Judging Poddar to be rational, the police soon released him. When Tatiana returned from Brazil, Poddar murdered her just as he said he would. Her parents sued the university for failing to warn them of the danger to Tatiana, and they won. The court recognized the importance of confidentiality but ruled that in this case the psychotherapists had a duty to breach it to warn a third party of a serious risk of harm. "We conclude," the majority opinion said, "that the public policy favoring protection of the confidential character of patient-psychotherapist communications must yield to the extent to which disclosure is essential to avert danger to others. The protective privilege ends where the public peril begins."

High-stakes collisions between the duties of confidentiality and preventing harm are more common than *Tarasoff* may suggest. Prime examples are cases involving patients who are HIV positive. Let's say a physician tells her patient that he has tested positive for HIV infection, that his wife could also become infected through sexual intercourse, and that he should inform her of the risk. But he says he will not disclose his condition to anyone and demands full physician–patient confidentiality.

Or suppose this patient has no sexual partner but will be cared for at home by people who are unaware of his HIV status (and may be exposed to his body fluids). He refuses to inform them and asks his physician to tell no one. In both cases, if the physician maintains confidentiality, there is a high risk of serious harm to people, but revealing the patient's diagnosis to others destroys confidentiality. What should the physician do?

Many physicians and ethicists say that violating confidentiality in such a case is morally permissible if there is no other way to avoid the harm to others. They assert that violations should be a last resort after exploring other alternatives, which include getting the patient to agree to notify those at risk or to cease behavior that produces the risk.

But even with such careful attention to protecting patient privacy, is complete confidentiality really feasible? According to some observers, despite the high value we put on confidentiality, it is not what it used to be. It has been eroded, they say—not by physicians and nurses, but by our computerized, bureaucratized health care systems. The number of people

IN DEPTH
TRUTH-TELLING AND CULTURAL DIVERSITY

Several studies have shown that views toward truth-telling when people are seriously ill vary dramatically by culture. Here's a partial summary of the results of one of the more recent studies:

> This study of 800 elderly subjects showed that major differences exist in the way people of different ethnicities view the issue of truth-telling. One of the core differences, around which many of the themes circled, is the question of how the truth affects the terminally ill patient. On one hand, the truth can be seen as an essential tool that allows the patient to maintain a sense of personal agency and control. Seen in this light, telling the truth, however painful, is empowering. On the other hand, the truth can be seen as traumatic and demoralizing, sapping the patient of hope and the will to live. For those who hold this view, truth-telling is an act of cruelty.
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> In fact, many, if not most, of our subjects held both views. They differed in the relative weight given to each view. In weighing the positive benefits of the truth versus its potential to harm, the deciding factor seems to be the way the self is understood. Are we mainly autonomous agents whose dignity and worth come from the individual choices we make with our lives, or is our most important characteristic the web of social relations in which we exist? If we hold the former view (as most of our African-American and European-American respondents did), then lack of access to the truth is almost dehumanizing since it strips us of our ability to make choices, without which we are something less than fully human. If, however, we tend to see ourselves not as individuals, but as a part of a larger social network (as was more common in the Mexican-American and Korean-American groups), then the notion of personal choice loses something of its force, and we may expect that those close to us will act on our behalf to protect and nurture us in our time of need.
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> Beliefs commonly held in the European-American culture about individuality, self-determination, and the importance of maintaining control too often have been treated as if they were universal ethical principles. Only by allowing diverse voices to speak, and hearing the sometimes surprising things they have to say, can we ensure that we are addressing the real concerns of the communities we serve.

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who need to know the intimate details of a patient's records—physicians, nurses, medical technicians, students, consultants, secretaries, financial officers, data managers, insurance auditors, administrators, and more—has grown beyond all expectation. And in a digitized, networked world, the opportunities for improper or unethical access to the records have multiplied at every step. Critics contend that the traditional ideal of complete confidentiality is no longer possible, if it ever was. So they suggest that we give up the traditional notion and try to salvage the features of confidentiality that matter to us most.

CLASSIC CASE FILE

Carlos R.

For many who are HIV positive, their anguish only deepens if others know about their condition. They demand medical confidentiality, and physicians are obliged to comply—but the "duty to warn" others of the risk of infection haunts both physicians and patients. Typically those thought to need warning are sexual partners and spouses, but sometimes caregivers—whether professionals or family members—are the ones of concern. This case is of the latter kind. It recounts the events that lead up to the question at issue—whether the physician's weightier duty is confidentiality or warning—then provides the opposing views of two commentators.

Twenty-one-year-old Carlos R. entered the hospital for treatment of gunshot wounds received in gang violence. During his stay, he confided to the attending physician that he was HIV positive, and testing proved him correct. Eventually he recovered well enough to leave the hospital to have his wounds cared for at home. The attending physician advised Carlos to have daily visits from a nurse to tend to his wounds. But Carlos was uninsured, and Medicaid would not pay for the home nursing visits because his 22-year-old sister Consuela was willing and able to care for him. For 10 years since their mother died, Consuela had assumed the role of mother for both Carlos and their younger sister.

Carlos was willing to let Consuela be his nurse, but he was adamant that she not be told about his HIV status. She was unaware of his homosexual activity, and so too was his father. More than anything else he feared that his father would learn the truth . . .

The choice for Carlos's physician, then, was between preserving confidentiality and breaching it to warn Consuela of the risks involved in caring for an HIV-positive patient.

One commentator on this case argues against violating confidentiality. He contends that for a physician to have a duty to warn, there must be (1) "an imminent threat of serious and irreversible harm," (2) no other way to avert that threat except by breaching confidentiality, and (3) a situation in which the harm done by the breach is on a par with the harm avoided by the breach. In his view, none of these conditions are fully met in this case. He does not believe that the risk of Consuela becoming infected with HIV is very great—and certainly not "imminent." He also thinks that there are alternatives to breaching confidentiality—the main one being instructing Consuela in safe wound care. Moreover, he insists that the risks to Consuela from not telling her about Carlos's HIV status are far outweighed by the awful disruption of family relations that breaching confidentiality would cause.

The second commentator argues for violating confidentiality to warn Consuela. She maintains that Consuela has a right to information whether or not there is an appreciable risk to her. One reason is that if Consuela is not being told the

truth, she is being deceived. Most people in Consuela's situation would want to know the facts and would probably assume that Carlos was not HIV positive because no one said so. Furthermore, in getting Consuela to provide nursing care, "the health care system is using her to avoid providing a service it would otherwise be responsible for." If so, then the system has an obligation to give her the information she needs to decide whether to accept the responsibility.

In the end, the physician should require the patient to choose: "Carlos can decide to accept Consuela's generosity—in return for which he must tell her he is HIV-infected (or ask the doctor to tell her)—or he can decide not to tell her and do without her nursing care."[7]

APPLYING MAJOR THEORIES

In Kantian ethics, the morality of truth-telling and confidentiality seems unambiguous. Physicians who adopt the means-end formulation of the categorical imperative, for example, seem committed to an absolute duty of preserving both. In the Kantian view, treating people merely as a means to an end is impermissible, a violation of the principle of autonomy. Lying to patients and breaching confidentiality (by breaking a promise to respect privacy) are clear instances of such violations. For a strict Kantian, these prohibitions would have no exceptions; there would be no allowances made for extraordinary circumstances. Arguments that truth-telling could be injurious to patients and must therefore be done with an eye to medical consequences would carry no weight. Likewise, there would be no place for the notion that confidentiality may be set aside if there is a conflicting "duty to warn."

For an act-utilitarian, the morality of truth-telling and confidentiality must be judged case by case, the right action being the one that maximizes the good for all concerned. In each instance, physicians must decide carefully what to disclose to a patient, calculating the impact that any disclosure would have on the patient, her family, and everyone else involved. For each decision about confidentiality, physicians must weigh the effect of the choice on the patient, the physician–patient relationship, third parties who may be harmed by maintaining confidentiality, and themselves (who may have to contend with legal consequences).

Rule-utilitarianism tries to regulate actions by rules that, if generally followed, would result in the best consequences, everyone considered. A rule-utilitarian might argue that the greatest amount of good is produced by a rule stating that a physician should, with care and sensitivity, tell patients the truth about their condition. This rule would presumably not only be beneficial to patients but also help foster trust in patients for their physicians and for medicine generally. A similar case could be made for a rule mandating strict adherence to the principle of confidentiality. But a rule-utilitarian could also reason that the best rules are those that require less than full disclosure to patients and less than absolute confidentiality—that is, rules with some exceptions built in. For example, the best confidentiality rule might demand full respect for a patient's privacy—except when maintaining confidentiality could put someone's life in danger.

Virtue ethics also has something to say about veracity and confidentiality. Many who favor this moral outlook might contend that if a physician cultivates the virtues of honesty and fidelity, he will be more likely to communicate truthfully with patients, to keep his promises to them, and to maintain their confidences. Moreover, if he