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4

Truth Telling: Disclosure and Confidentiality

Justifications

Disclosure

Ethical obligation

Arguments for disclosing information

Conflicting obligations

Arguments for not disclosing information

Disclosure of adverse outcomes and medical error

Adverse outcomes and medical error

Scope of disclosure

Obligation of disclosure

Barriers to disclosure

Confidentiality

Justifications for protecting confidentiality

Barriers to confidentiality

Justifications for breaching confidentiality

Arguably, the most valuable health care resource is information. Clinicians depend on its accuracy in making their diagnoses and prognoses. Patients rely on its adequacy in evaluating their options and arriving at their decisions about care. Families wait for news of their loved ones' changing conditions.

But beyond lab data and examination findings, clinical information defines the very nature of the therapeutic relationship, involving notions of self-image, privacy, autonomy, power, and trust. How clinical information is elicited, protected, and shared is a matter of ethical concern for professionals, especially when their obligations conflict.

The idea that care professionals should tell their patients the truth seems self-evident and uncontroversial. Previous chapters have devoted considerable space to the discussion of the importance of *informed* decision making and the trust that is so central to the therapeutic relationship. Like most other aspects of the clinical interaction, however,

truth telling can become complicated when patient autonomy, beneficence, and non-maleficence collide.

III Mr. Nunez is a 46-year-old Hispanic man suffering from terminal esophageal cancer. He speaks no English, but his wife, who is bilingual and constantly at his bedside, translates for the care providers. This way of relating to Mr. Nunez—through his wife—is not recent. For the nine months that Mr. Nunez has been coming to the hospital for treatment, Mrs. Nunez has essentially directed his care and determined what he is to be told. Believing that she is acting in his best interest, his care providers have honored her wishes, but they are increasingly uncomfortable.

It has become clear that Mrs. Nunez is not translating everything that she is being told. In particular, she seems to be censoring information about the seriousness of Mr. Nunez's condition. When asked about this, Mrs. Nunez has made it very clear that she does not want her husband told that he is dying of cancer. He knows that he has a growth on his esophagus but not that he has cancer. Indeed, according to her, he does not even understand what cancer is. Mr. Nunez has also recently been enrolled in a phase I/II cancer research protocol, consent for which has been given by his wife.

Mrs. Nunez is adamant that her husband not be told about his diagnosis or prognosis. She seems to believe sincerely that, if he were to find out the truth, he would do violence to himself and possibly to her. When asked why she thinks this, she cites an incident in which the patient threatened to harm himself if his condition were found to be more serious than he thought. Although she has been assured that patients usually benefit from understanding their conditions, she insists that nothing can be gained for Mr. Nunez by telling him the truth. She concedes that he occasionally asks questions, but claims that she has been able to satisfy him with evasive or deceitful answers. When asked whether she would agree to have Mr. Nunez told the truth when he is finally too weak to harm himself, she emphatically replied, "No! Never! I can't imagine what it would be like for him to know that he is dying. I won't have this!" Although she describes her husband as "like a baby," there is no reason to believe that the patient could not comprehend the nature and seriousness of his condition. His cognitive status cannot be confirmed, however, because Mrs. Nunez has forbidden a psychiatric evaluation.

Members of the care team are conflicted about the limits on their ability to interact with Mr. Nunez. Several strongly believe that he is being deprived of his rights to information, while others suggest that his wife knows him better than they do. The oncology fellow notes that "in certain countries, such as Japan, patients are not routinely told the truth about their diagnoses as a way of protecting them from stress, but at least they are not tortured by being enrolled in research that is not likely to benefit them."

How and by whom should this patient's best interests be defined? Do Mr. Nunez's rights conflict with his best interest? What arguments support disclosure or nondisclosure in this case?

JUSTIFICATIONS

Honesty and trustworthiness as core interpersonal values derive from the moral imperative of veracity. Three justifications that have been advanced to support the obligation of veracity have particular relevance to the clinical setting. They are "respect owed to others . . . fidelity and promise-keeping . . . [and] relationships of trust between persons . . . necessary for fruitful interaction and cooperation" (Beauchamp and Childress, 1994, p. 396).

1. Respect for others is reflected in the ethical principle of autonomy. The capable individual's right to be self-determining imposes on clinicians the obligation to provide adequate information for informed health care decision making.
2. Fidelity and the keeping of promises are central elements in the trust-based relationship between patient and clinician. This fiduciary bond creates an implicit contract that both parties will be honest and will honor their commitments.
3. Productive therapeutic interactions rely on the truthful management of information. The effective clinician-patient relationship depends on the exchange of accurate and complete information about symptoms, diagnosis, prognosis, and treatment options, as well as confidence that care plans will be followed and patient wishes will be honored.

In this context, the uneasiness of the professionals caring for Mr. Nunez is understandable if they believe that withholding information undercuts his autonomy, erodes their trusting relationship, and inhibits effective clinical management. Only the strong likelihood that disclosure would be harmful to the patient can justify withholding information about his condition. This very rare therapeutic exception to the disclosure obligation is discussed below.

DISCLOSURE

Ethical Obligation

As discussed in chapter 3, collaborative decision making and informed consent depend on the reasonable disclosure of necessary or material information. Patients and their authorized surrogates are ethically and legally entitled to information that enables them to understand the likely course of the medical condition, evaluate the therapeutic options, and make choices consistent with patient goals and values.

Disclosure invokes respect for the patient's right to information that promotes effective decision making and the ethical imperatives to maximize benefits and minimize harms. Yet, as the case of Mr. Nunez illustrates, these same principles create tension

between and among professionals' obligations. The analysis weighs the benefits of disclosing information that enhances patient understanding and self-determination against the potential harms of anxiety and stress that disclosure may cause.

Because laboratory and examination findings are controlled by the care team, particularly the medical staff, disclosure of clinical information is at the discretion of the physician. Access to medical information is thus an inherently unequal process that places the patient at a potential disadvantage in decision making. This imbalance confers on doctors the disclosure obligation.

Arguments for Disclosing Information

III Ms. Kim, a 23-year-old woman, presents with an isolated case of first-bout optic neuritis. The ophthalmologist, Dr. Frank, is concerned about whether to inform her that multiple sclerosis (MS) may develop in the future. His dilemma arises because, at the time the optic neuritis presents, the likelihood of subsequent development of MS is uncertain. Until recently, it was thought that the degree of association between optic neuritis and MS was around 11 percent. Increasing evidence, however, suggests that the association may be as high as 80 percent.

The arguments in favor of disclosure are both ethical and practical. To know the truth about one's current and future medical condition is essential to a sense of self-mastery, especially as that condition changes and possibly deteriorates. Lack of information impairs decision making about health care and other life plans. Even when treatment options are limited, knowing what to expect allows patients to understand and prepare for what lies ahead.

Dr. Frank's concern is that disclosing the possibility of MS could cause Ms. Kim needless anxiety about an illness that she may never develop. Moreover, because MS cannot be prevented or cured, the information will not afford her any protection. On the other hand, it can be argued that she has the right to prepare herself for the heightened likelihood that she may develop a debilitating condition that would inevitably affect her ability to function independently. This knowledge may be an important influence in making decisions about lifestyle, career, family, and finances, as well planning treatment that could potentially delay the onset of or mitigate symptoms of MS. Finally, if Ms. Kim discovers this information independently, her trust in Dr. Frank may be eroded by the belief that he was not honest about her risks.

III Evan Barry was 17 years old when he was diagnosed last year with renal cell carcinoma. His right kidney was removed and he began several rounds of chemotherapy. Early this year, he came to the emergency room complaining of shortness of breath and chest pain. He seemed to be unaware of his diagnosis and could not explain the scar from the kidney surgery. A chest X ray showed metastases to his lungs.

Evan was transferred from the ER to the adolescent unit and given gamma interferon. The

physicians on the adolescent floor were puzzled by his apparent ignorance of his condition. When they approached his mother, Mrs. Barry was equivocal about what her son had been told. She said that she had been candid with Evan when he was first diagnosed but, when the physicians encouraged further discussions during the current admission, she adamantly refused to allow anyone to talk with him about his diagnosis and treatment. She expressed fear that he would be devastated and become suicidal, although she acknowledged that he had never attempted or threatened suicide.

Staff on the adolescent unit believed that Evan was frightened and isolated by the lack of information and communication. One of the residents carefully asked questions to probe the extent of his knowledge about his cancer. Evan said tearfully that he did not know what was wrong with him and that the doctors always spoke with his mother, not with him. He also said, "My mom is very worried about me but it makes her sad to talk about my problems and I don't want to upset her even more."

The team agreed that, although the lack of information was probably very frightening for Evan, he seemed to be protecting his mother by not asking questions. Concern was expressed that, as a capable adult who appeared to want and need information and support, he should be told the truth.

What are the care providers' conflicting obligations and how can they be resolved? What benefits and risks should be considered? Who should determine what Evan is told?

Truth telling goes to the core of trust-based relationships, especially those among family members and between the patient and care professionals. Shielding patients from the truth is generally an imperfect undertaking, requiring the collusion of others, including staff, family, and friends, in a conspiracy of silence. Uncertainty about what the patient knows and discomfort with the deception often result in caregivers and even family avoiding contact with the patient. It is not unusual to hear, "I was so sure that I would give it away that I just didn't want to be around him."

Yet, patients—even children and adults with a history of not wanting to know—sense when things are being kept from them and may avoid discussion as a way of accommodating those protecting them. Evan, for example, is reluctant to ask questions about his condition because he knows that talking about it upsets his mother. The result is a cycle of increasingly difficult efforts for mother and son to protect each other from acknowledging their sadness and fear. The burden of the deception itself, thus, can be a barrier to communication. Perhaps the most damaging aspect of withholding information is that the patient is isolated at precisely the time when close and supportive relationships are critical. In short, although the obligation of truth telling is not an absolute, it is something that requires a compelling reason to disregard.

Conflicting Obligations

The tension arises when clinicians feel that their obligations require them to either disclose information that the patient may not want or withhold potentially problem-

atic information, all in the name of promoting the patient's well-being. The challenge is determining what the patient should know to receive needed care without undue stress and have his autonomy respected.

As you might suspect at this point, disclosure is not simply a matter of rattling off the results of lab tests or physical examinations. Effective disclosure is a clinical skill that depends on physician judgment and communication as well as knowledge. Too much information can be as harmful as too little. The difference between truth telling and truth dumping is the difference between providing specific material information that facilitates decision making and indiscriminately overloading the patient with facts in the interests of completeness. An unbroken monologue of clinical data can be counterproductive, leaving the patient with glazed eyes and little recollection of what was said. Far more useful is breaking up the explanation every few sentences with, "Does that make sense?" or "What else can I tell you that would be helpful?" Patients often indicate what they want to know, and perceptive clinicians can be guided by their spoken or unspoken signals.

Truth dumping also occurs when information is disclosed without the accompanying explanations or guidance that frame the decisions patients or surrogates must make. "Let me tell you what all this means and then we can figure out the reasonable choices you might consider." Finally, patients need to be reassured that they are not expected to absorb everything all at once. "I know that this is a lot to take in right now and we will talk again. When you think of questions, it might be a good idea to write them down so that we can address them next time."

Patients have both the right to receive information and the right *not* to receive it. Some people, especially those who are elderly, anxious, easily confused, or from cultures that do not place a high premium on individual autonomy, find it burdensome and even frightening to learn about their conditions and be asked to make treatment decisions. For example, while persons from European American backgrounds typically value full disclosure of medical information, those from Asian and Middle Eastern cultures tend to protect patients from knowing about illness or impending death. For them, authentic decision making in the clinical setting is expressed in the capacitated request *not* to be informed and the voluntary delegation of decision-making authority to trusted others. Implicit is a long-standing or culture-based comfort with the practice of decision making by surrogates. Likewise, Mr. and Mrs. Nunez may be an example of families that have their own decision-making patterns that may be effective and comfortable, rather than paternalistic or coercive. Decision making, like other interpersonal dynamics, comes in assorted shapes and sizes entitled to respectful attention. But, as noted in chapter 3, a waiver of informed consent is something that must be explicitly confirmed, not inferred, to demonstrate respect for the patient and protect his autonomy.

Arguments for Not Disclosing Information

The more common disclosure dilemmas concern withholding information from patients who have not waived that right, usually justified by notions of shielding them from harm. Disclosure, especially of bad news, is one of the most difficult clinical tasks, and evasion or awkwardness is often the result of efforts to avoid inflicting pain. Physicians often protect themselves and—they think—their patients by resorting to euphemism. "The patient has a grim prognosis" becomes "the patient is not doing well." "The patient is dying" becomes "the patient is failing." Sometimes it sounds as though, if the patient and care team only tried harder, she would not be dying.

Rather than comfort, however, deliberate vagueness creates confusion, anxiety, and unrealistic expectations. It is not uncommon for a family to react with frustration and seemingly unreasonable demands when told that, although the patient is *not doing well*, aggressive treatments should be limited. The family argues that she could be doing *better* if only the care team were doing *more* rather than *less*. The importance of compassionate candor is emphasized in the discussion of medical futility and forgoing treatment at the end of life in chapter 6.

Sometimes, discomfort in discussing bad news with the patient persuades care professionals that disclosure would be *harmful*, when in fact it might only be *distressing*. The risk is that the therapeutic exception, noted in chapter 3, may be expanded beyond its strict definition (exception to the disclosure obligation when the information itself would cause *immediate, direct, and significant harm* to the patient) and applied to situations in which the information would be upsetting, but not dangerous. Whenever clinicians consider withholding information, especially from capable patients, they need to question who is being protected, whether the protection is truly warranted, and what the cost will be to the trust between doctor and patient. This dilemma, which requires balancing the ethical obligations of respect for autonomy, beneficence, and nonmaleficence, often triggers a bioethics consultation to explore the benefits and risks of disclosure to the patient.

Pressure also comes from families—parents of young children, grown children of aging parents, or concerned spouses like Mrs. Nunez—not to share information with the patient. The reasons are usually "The news will kill him" or "You will take away all hope." The first objection indicates the need to reassure anxious relatives that the patient will not be burdened with information that he does not want or cannot safely assimilate. The second objection speaks to expectations and the importance of hope. As further discussed in chapter 7, bad news or even a terminal diagnosis need not signal a future so bleak that deception is justified. It is frequently necessary to redefine what can be hoped for—perhaps not long life or unlimited function, but rather increased comfort or a peaceful death surrounded by loved ones.

Let us consider how these issues relate to Mr. Nunez. His caregivers are faced with conflicting obligations in determining what he should be told about his condition.

Because they have been prevented from interacting with him directly, they have no independent assessment of his capacity, emotional stability, or desire for information. All communications have been filtered through his wife, whose motives may be well meaning but overprotective, or possibly not in his best interest. The care professionals need to clarify with Mrs. Nunez that providing her husband with good care requires that they interact with him directly. She should be reassured that harmful or unwanted information will not be forced on him but that his perceptions and wishes will be skillfully assessed as part of his clinical evaluation.

When withholding information is suggested, it is necessary to determine the patient's capacity, understanding of the clinical situation, and desire for information. The first step is to use the patient's preferred language, in this case, Spanish. One approach might be, "Mr. Nunez, the examinations and tests will be giving us information about your condition and then some decisions will have to be made about your treatment. Some patients want to know all the information and some don't. What would make you comfortable? Whom would you like us to talk to? Do you want us to discuss these things with you or with someone else?" Capable patients can then elect to participate in the process or voluntarily delegate that responsibility to another person. Even if Mr. Nunez explicitly says, "I don't want to know and I want my wife to make decisions for me," he should be kept in the communication loop by being asked periodically, "Do you have any questions? Is there anything we can tell you?" A wish not to be burdened with information or decision making should not deprive patients of attention in other ways.

DISCLOSURE OF ADVERSE OUTCOMES AND MEDICAL ERROR

III Mrs. Allen, a pregnant woman with diabetes, had been encouraged to undergo amniocentesis to determine the fetus's lung development in order to plan induction of her delivery. Because there is a window of safety in delivering diabetics, this procedure is considered standard of care. During the amnio, the umbilical cord was nicked, resulting in bleeding and requiring an immediate caesarean section.

The neonatology house staff has requested an ethics consult to discuss whether the parents should be told the reason for the emergency delivery and, if so, whether the information should come from the obstetric team or the neonatologists.

Adverse Outcomes and Medical Error

Disclosure of bad news is difficult under any circumstances. Disclosure of bad news when things go wrong is a clinician's worst nightmare, but it is one that must be confronted for the sake of patients and professionals. We begin with some important definitions. *Adverse outcomes* are unintended negative results of medical care that create actual or potential harm to the patient. These untoward occurrences may be the result

of carelessness or ineptitude, or they may reflect foreseen but unavoidable risk even when standard of care was practiced. The former—*medical errors*—are considered avoidable, while the latter are generally seen as unavoidable. Distinguishing between these types of adverse outcomes may be problematic, although standard of care is sometimes used as an important criterion.

Other analyses distinguish between *system* and *individual or human* errors, attributing some adverse outcomes to problems in the health care delivery system and others to the actions of individual providers. This approach reflects the notion that "no one person [is] responsible, because it is virtually impossible for one mistake to kill a patient in the highly mechanized and backstopped world of a modern hospital" (Belkin, 1997, p. 28). The 2000 Institute of Medicine report, *To Err is Human: Building a Safer Health System*, generated considerable interest in disclosure of information as a key to managing and preventing adverse outcomes. As a result, oversight and accrediting bodies, clinicians, and institutions are adopting the concept of health care delivery as a system-wide interlocking dynamic that can either allow or prevent error. In analyzing adverse events, this perspective focuses on organization *processes* rather than individual performance.

Scope of Disclosure

Disclosure includes but is not limited to the requirements of informed consent, which permit *prospective* analysis of proposed interventions. Armed with adequate information, the patient can proceed to make decisions about future care. Full disclosure that promotes patient self-determination and protection also includes *retrospective* analysis of unintended consequences. This aspect of disclosure suggests that, in addition to patients' need for information to enhance care planning and decision making, there is also a desire just to understand what did or will happen to them. Taken together, the *preview* and *review* aspects of the disclosure obligation can be seen in the patient's need to *act* and to *know*.

Obligation of Disclosure

The obligation to disclose adverse outcomes rests on both ethical and legal foundations. Recognizing the need to ensure the provision of adequate information, courts have imposed fiduciary obligations of disclosure on physicians. Judicial reasoning is that these obligations exist when "one party is dependent on another for information or knowledge that only the first party possesses" (Vogel and Delgado, 1980, pp. 66–67). In the clinical setting, the physician is the person most likely to have and control information about an untoward event or medical error, heightening the professional obligation of disclosure. The patient who has suffered an undisclosed adverse event is doubly vulnerable—not only is she unaware of the actual or potential harms she faces and how to prevent or mitigate them, she may not know the nature of the event or even that it has occurred. Her reliance on the physician for information that will minimize

harm and/or help her cope with the consequences creates an ethical imperative for timely and full disclosure of the adverse event. This obligation has received explicit attention in the various codes and opinions that provide ethical guidance and analysis for physicians.

A related basis for the disclosure obligation can be found in the values underlying informed consent. This analysis views informed consent as a compact entered into by physician and patient. The doctor says, in effect, "Here is the information you need, including the possible risks." The patient says, in effect, "I understand what you have said and I consent to the test or treatment *because I trust that you have told me everything I need to know* in order to make a decision." Implicit in the patient's response is, "I trust that you will exercise all due care in treating me. *I further trust that, if any foreseen or unforeseen harms should occur, you will disclose that information so that I can understand and manage the negative consequences.*"

Seen in this light, the values underlying informed consent support the disclosure obligation. The patient is able to balance the benefits, burdens, and risks in advance of treatment, and also mitigate potential harms and protect herself from further harms after an untoward event has occurred. Rather than a passive recipient of treatment, the patient becomes a fully equal partner in planning for and managing the outcomes of care.

Barriers to Disclosure

Given the ethical and legal justifications, it seems hard to argue with the notion that information about untoward occurrences should be made available to patients or their surrogates. It will not be surprising, however, that physicians are very reluctant to discuss negative outcomes with patients and families. Reasons for avoiding disclosure include the difficulty of determining whether the event was medical error, the belief that the information will only be upsetting, and the omnipresent fear of legal action.

Liability to medical malpractice suits is cited by physicians as the chief barrier to disclosure of unintended occurrences. Doctors' understandable risk aversion makes them uneasy about admitting error or other behavior that might have contributed to patient harm. That said, you should know that legal action does not inevitably follow adverse events, including those caused by negligence. Instead, whether litigation is instituted appears closely related to how physicians handle discussions with patients about untoward outcomes, including disclosure of information about actual or potential harm (Liebman and Hyman, 2004; Gallagher et al., 2003; Goldberg et al., 2002). Concerns about who assumes the duty of disclosure and bears responsibility are especially difficult in an academic medical center, with its multiple levels of interdisciplinary staff and different authority structures.

Perhaps even more threatening to physicians than the specter of malpractice litigation is the personal devaluation that accompanies acknowledging adverse events. This may include "a loss of personal confidence and self-esteem, diminished professional

authority and reputation, as well as a loss of referrals and income" (Baylis, 1997, p. 338). The inability to cope with untoward outcomes appears to stem less from blatant physician callousness or dishonesty than from belief in the widespread myth of infallibility and total control that define the perfect healer. This image, born in medical schools, nurtured throughout medical careers, and sold to the public, is shared by physicians and their patients, leading to unrealistic expectations, unreasonable disappointments, and unbridgeable gaps in communication.

Growing recognition of these issues has prompted six states (Florida, Nevada, New Jersey, Oregon [voluntary participation], Pennsylvania, and Washington) to enact disclosure laws requiring that patients or their surrogates be notified of adverse events, typically according to specified procedures and within specified time limits (Liebman and Hyman, 2006). One response to these statutory requirements and the potential that other states may enact similar legislation has been the Project on Medical Liability in Pennsylvania, using trained mediators to strengthen physicians' skills in communicating difficult news and establishing mediation as an alternative to proposed litigation (Liebman and Hyman, 2004).

CONFIDENTIALITY

III Mr. Miller is a 42-year-old man who came to the emergency room with iritis and whose work-up was positive for syphilis. When Dr. David discussed the diagnosis with Mr. Miller, the patient requested that Dr. David not disclose the infection to his wife or report it to the state department of health. He said that he must have contracted the condition during a one-time extramarital encounter on a recent business trip. He also stated that he has not had sexual contact with his wife since that time and that he will undergo treatment before doing so.

Another aspect of information management central to the therapeutic relationship is the ethical obligation of confidentiality, which also derives in part from the moral imperatives of veracity and privacy. "Confidentiality is present when one person discloses information to another, whether through words or an examination, and the person to whom the information is disclosed pledges not to divulge that information to a third party without the confider's permission" (Beauchamp and Childress, 2001, pp. 305–6). In that sense, confidentiality, like truth telling, invokes the patient's trust in and reliance on the health care professional's integrity. Although the common perception is that confidentiality binds only the patient and physician, the professional obligation also covers other clinicians, including chiropractors, clinical social workers, dentists, nurses, podiatrists, and psychologists.

Justifications for Protecting Confidentiality

III Mr. Gordon, a 43-year-old man, is picked up by the police on Saturday evening and rushed to the nearest emergency room after passing out on a mid-town sidewalk. ER physicians

detect a high level of alcohol in his blood and a urine toxicology screen reveals opiates. Upon regaining consciousness, Mr. Gordon provides his past medical history, which is unremarkable, and says that his occupation is city sanitation truck driver. He acknowledges that he used alcohol and cocaine earlier in the evening, and reminds the physicians that they have a duty not to disclose to others confidential patient information.

What obligations do physicians have to Mr. Gordon and others, and how can they be reconciled? What ethical principles and additional factors should be considered?

The notion that the therapeutic interaction creates a zone of protected information can be supported by the three justifications for veracity discussed earlier.

Respect for persons underlies patients' right to control who has access to their health care information and requires that medical records and communications in the clinical setting be protected from unwarranted disclosure. If personal information can be seen as a reflection of the most intimate aspects of an individual's life, then control of that information can be seen as a form of self-determination that requires provider respect. Protecting confidentiality also prevents the harms that result from unauthorized disclosure of sensitive information, such as HIV status or psychiatric history.

Fidelity and promise keeping are reflected in the bond of trust that requires professionals to hold in confidence information learned in the clinical interaction. This justification is based on the moral imperative to honor a duty or promise regardless of the results. It holds that, without explicit patient waiver, the clinician is bound by the confidentiality inherent in the relationship. The argument also encompasses the notion of secrets, those pieces of our private selves we give in trust to others with the implicit or explicit understanding that they will be held in confidence.

The effectiveness of the clinical relationship and the resulting quality of the health care provided depend on an atmosphere of trust that promotes the candid and complete exchange of information. This justification rests on the need to encourage patients to provide all relevant facts about their medical history and symptoms, no matter how private or potentially embarrassing, to facilitate accurate diagnosis and effective treatment. This utilitarian rationale argues that, without an obligation of strict non-disclosure, patients would avoid seeking or fully cooperating in treatment.

Barriers to Confidentiality

It would seem that nothing could be more ethically compelling than the promise to protect what patients reveal about themselves. Like truth telling, confidentiality seems a clear and simple duty that professionals owe their patients. But, like other ethical imperatives, the confidentiality obligation is neither absolute nor always easy to honor.

So what gets in the way of protecting patient confidences? Medical information is generated in the health care setting as a product of the therapeutic interaction between clinician and patient; it is also generated in the pharmacy, the research lab, the autopsy

room, the insurance office, the medical classroom, and the hospital elevator. It goes into reports, books, lectures, legal briefs, and computers, from which it is accessed by countless people for countless valid and not-so-valid reasons.

The treating relationship is only one context in which medical confidentiality is raised. The dramatic change in health care delivery has altered what used to be a confidential relationship between patient and family doctor. Medical treatment has moved from the home to the institutional setting; multiple disciplines and subspecialties, legal and government bureaucracies, and third-party payers now converge on each case; and computers connect all parties to the clinical interaction. The result is that the number of people with legitimate and nonlegitimate access to medical information has increased geometrically. A 1982 article reported that medical information about a patient, whose case was not unusual or complex, was necessarily available to at least seventy-five people who provided direct or support health care services (Siegler, 1982). We can safely assume that access to patient information and the parties who want it have expanded significantly since then. The contemporary clinical setting has greatly enhanced the efficiency and efficacy of communication among care providers, while compromising the privacy of patients' medical information. Concerns about the security of patient information prompted the inclusion of stringent regulations in the 1996 federal Health Insurance Portability and Accountability Act (HIPAA).

Consent to care with a loss of some measure of privacy is either explicitly obtained, through signed releases upon entering the hospital, or presumed, but the consent is never to be considered unlimited. For example, although it should be explained upon admission, it is generally understood that treatment in a teaching hospital includes having one's records, examinations, and therapies available for observation and study by students and house staff. Most patients expect that their cases will be discussed formally and even informally to obtain the benefit of other opinions and to provide teaching examples. They neither expect nor deserve to have their personal or medical information shared in public hospital areas or social situations. Likewise, patients should have control over who has access to their medical information through updates in their clinical condition. As a precaution against inadvertent unwanted disclosure, it may be helpful to say early in the patient's hospital stay, "You seem to have a lot of family and friends who are concerned about you. Please know that we will not be discussing your medical condition with anyone unless you specifically request that we do so."

In addition to those who use medical information for treatment purposes, such data are routinely used by medical researchers, law enforcement agencies, attorneys (requesting their own clients' records or those of other patients in connection with medical malpractice or personal injury), insurers (life, health, disability, and liability), employers, and creditors. Although these secondary users are routinely required to access information through formal requests for patient record releases, they may not always

follow procedure. Finally, there are potential users of medical information who have nothing to do with the patient's health care, including those with commercial, political, and media interests.

So, are confidentiality and privacy obsolete or decrepit, as some commentators (e.g., Siegler, 1982) suggest? Given the formidable barriers and incentives in the current health care setting, is it possible or even desirable to manage the flow of information? The goal of providing state-of-the-art care increasingly requires quick access to medical data by multiple parties. The protection of third-party interests is receiving heightened attention. The obligation of confidentiality is being reshaped by its exceptions and its boundaries are increasingly porous. Yet, the ethical core remains intact and worth preserving. The contours may be redrawn, but the central values deserve protection through policies and regulations that respond to current clinical and legal imperatives.

Justifications for Breaching Confidentiality

Even people with little experience in the health care setting know and rely on the sanctity of clinician-patient confidentiality. Based on well-established ethical and legal justifications, this obligation normally precludes professionals from disclosing information learned in the course of diagnosis or treatment. Precisely because this ethical mandate is so central to the clinical relationship, exceptions are justified only when disclosure of confidential information is essential to preventing significant harm to other vulnerable individuals, especially those at unsuspected risk. In these select instances, the patient's right to confidentiality is considered to be outweighed by the obligation to protect those who are not in a position to protect themselves.

The following two situations that justify breaching confidentiality illustrate the conflicting ethical obligations when competing claims are made for physician fidelity. In both circumstances, the needs of the nonpatients are elevated because their vulnerability is heightened by their very ignorance of the risks they face.

1. Providing information that prevents harm to *identified* third parties at risk (e.g., partner notification). This exception reflects the opinion in *Tarasoff v. Regents of University of California*, a 1976 case in which the court held that a psychotherapist who had prior knowledge of a patient's intention to kill his unsuspecting girlfriend had a duty to warn her. This reasoning has been incorporated into the laws of many states in addressing the needs of those who have been unwittingly exposed to HIV/AIDS or sexually transmitted disease. When the infected patient refuses to inform sexual or needle-sharing partners, notification is considered essential to enable those known to be at risk to be tested and treated.
2. Providing information that prevents harm to *unidentified* others at risk (e.g., public health or public safety reporting). In some instances, the potential danger is to the general population, rather than to specified individuals. To protect the

public health and safety, state laws commonly require that health care providers report certain findings, including suspected cases of child abuse and neglect; wounds that are the result of gun shots, knives, or other pointed instruments; burn injuries of specified severity; and cases of reportable communicable diseases specified in state health laws.

In the case of Mr. Miller, Dr. David is in a difficult position. He knows that confidentiality is the bedrock of the patient-physician relationship, assuring the patient that he can share accurate and sensitive information with the doctor without fear of disclosure. Not only does the assurance of confidentiality promote trust, it facilitates full and candid communication that is vital to successful diagnosis and treatment. Fear that sensitive or embarrassing information, such as a diagnosis of sexually transmitted disease (STD), will be disclosed may dissuade Mr. Miller from providing critical facts or even seeking necessary treatment.

Sometimes, however, withholding information poses risks to others outside the physician-patient relationship. In this case, Mr. Miller's wife is at risk of contracting syphilis and she is especially vulnerable because she has no reason to suspect that she is at risk. By taking action early through testing and, if necessary, treatment, she may be able to avoid the dire consequences of syphilis and perhaps other STDs. To protect vulnerable persons, public health has traditionally intervened by contact tracing and partner notification. Clinicians are required by law to report most STDs by patient name to public health officials so that they can trace and notify partners at risk. Public officials try to maintain the anonymity of the index case as much as possible. But if Mrs. Miller's only sexual partner has been her husband, it may be difficult or impossible to prevent her from figuring out how she was exposed.

Despite pressure from Mr. Miller, it is ethically and legally unacceptable for Dr. David to cooperate with the request to withhold information that can prevent harm to an identified person at risk. Dr. David should counsel Mr. Miller about the importance of disclosure, including the legal requirements and the risks of nondisclosure, and encourage him to tell his wife. It may be helpful if he offers support in the disclosure process.

Mr. Gordon's case raises somewhat different issues. Here, the concern is whether the physicians have a responsibility to report the fact that a person who drives a sanitation truck for the city is known to have used alcohol and illegal drugs. In this analysis, the justifications underlying the confidentiality obligation would be weighed against the possible harms to unidentified persons—the public—who have no reason to believe that they are at risk. Relevant factors would include the potential for harm, the likelihood that it could be prevented, alternatives to breaching confidentiality, and the legal requirements of the state in which the situation occurs.

While no one would encourage Mr. Gordon to abuse alcohol or drugs, it can be argued that his behavior on this occasion does not place others at immediate or inevitable risk. In this case, the patient's substance-related loss of consciousness occurred on

a weekend evening, not during work hours, and not while he was driving a truck or any other vehicle. It would be important to know whether his use of alcohol and drugs is substantial or minimal, and whether it occurs daily or only occasionally. This information, which is relevant to his health care as well as the safety of others, is much more likely to be revealed to his caregivers if Mr. Gordon is assured that it will be kept confidential.

In terms of state law, the patient's only illegal behavior is his use of narcotics. Health care professionals should not be expected to compromise their obligations to their patients by functioning as agents of the law enforcement or judicial systems. Accordingly, all states presume a general rule of patient confidentiality, carving out selected specific instances when that obligation must be breached to protect others from harm.

If Mr. Gordon suffered from epilepsy, he would be required by all states to report his condition to the motor vehicle bureau and, if he worked as a school bus driver, his physicians would have a heightened incentive to discourage his driving. The argument might also be made that, if Mr. Gordon did not report his epilepsy, his doctors would have an ethical obligation to do so. None of those conditions apply here, however, and his care professionals are likely to respect his confidentiality, while counseling him about responsible behaviors.

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5

Special Decision-making Concerns of Minors

Decisional capacity and minors

Children

Adolescents

Consent for minors

Newborns

Children

Adolescents

Confidentiality and disclosure

Special problems of the adolescent alone

DECISIONAL CAPACITY AND MINORS

If you think that assessing adults' ability to make and take responsibility for decisions is challenging, keep reading. Children and adolescents present a whole other set of issues related to their emerging cognitive abilities, self-awareness, and moral authority. Because minors are usually considered incapable of assuming responsibility for their health care, conflicts about treating this vulnerable population will likely come before your ethics committee.

As discussed in chapter 2, the concept of decision-making capacity involves notions of autonomy and moral responsibility. Autonomy refers to self-governance, which requires that, at the very least, the individual has a *self* to govern. In this sense, autonomy implies a more or less integrated set of personal values and preferences that are recognizable and generally well-established. Moral responsibility refers to a person's capacity to be accountable for his actions and suggests qualities of stability, consistency, and foresight. These qualities develop as part of the maturation process that begins in young childhood and continues through adolescence into adulthood.