PROTECTING PATIENT CONFIDENTIALITY IN PRIMARY CARE

Cynthia M.A. Geppert, MD, MA, and Laura Weiss Roberts, MD, MA

Whatsoever I see or hear, professionally or privately,
which ought not to be divulged, I will keep secret and tell no one.
—Hippocratic Oath

There were no computers, mandatory reporting laws, or managed care systems when the Hippocratic writers wrote the oath defining ethical conduct in medical practice 2400 years ago. Nevertheless, the duty to respect patient privacy and the responsibility to protect patient information endure in current day clinical care [1]. Adapting the principle of confidentiality to current social, legal, and political circumstances—without compromising one's professional integrity or undermining the true meaning of the principle—is a critical challenge now faced by clinicians.

There are many unprecedented challenges in protecting confidentiality. For example, some clinicians may omit important data from the medical record to protect patients who may be stigmatized or penalized if insurance companies or employers become aware of the findings [2]. Similarly, some clinicians fail to comply with mandatory reporting laws to protect their patients' identities or familial relationships [3]. Alternatively, other clinicians believe that access to an individual's medical record is so universal that they do not think through confidentiality safeguards that are feasible and ethically sound (eg, the use of confidential data codes) to help protect sensitive patient information. Clinicians may also feel pressured to omit or curtail discussions of confidentiality because they are increasingly being given less time and greater clinical responsibilities for a larger number of patients in their outpatient visits. For these reasons, we offer 8 recommendations for responding to some of the perplexing confidentiality issues arising in everyday primary care. These recommendations are summarized in Table 1.

Cynthia M.A. Geppert, MD, MA, PGY-2 Resident, Department of Psychiatry, Research Associate, Empirical Ethics Group, University of New Mexico School of Medicine, Albuquerque, NM; and Laura Weiss Roberts, MD, MA, Associate Professor and Vice Chair, Department of Psychiatry, Director, Empirical Ethics Group, University of New Mexico School of Medicine.

Patient Information

Many patients assume that physician-patient confidentiality is an absolute. Informing patients that there are limits to the confidentiality of the information they reveal may seem a strange way to inspire openness and trust in patients, but paradoxically it is. Physicians should assure patients that their privacy is respected but that limits exist regarding the extent to which the personal information they share can and should be protected. How should the physician respond in the following situation?

> A patient presents to her primary care physician for an initial visit. She is 35 years old and is the mother of 2 preschool-aged children. After she and her physician introduce each other, she says, "Doctor, I know that everything I say to you stays in this room. I need to tell you something I have never told anyone. I have a gambling problem, and my husband doesn't know."

Discussing with patients the difference between "keeping secrets" and respecting their personal information can help to establish the professional and therapeutic boundaries of the clinical relationship. The patient in the above scenario discloses a gambling problem. This "secret" does not entail mandatory reporting as would a direct admission of child abuse or a sexually transmitted disease, nor does it require immediate psychiatric referral, unless the patient should further disclose that she is suicidal or homicidal. The clinician should reassure the patient that her husband would not generally be allowed to view her medical chart without permission, although a future employer or insurance company could learn of her gambling history when reviewing her records. Because she is the mother of 2 small children, the clinician

Table 1. Eight Recommendations for Protecting Patient Confidentiality

Confidentiality Issue	Don't	Do
Patient information	Don't assure your patients that whatever they tell you is confidential.	Do provide accurate information to your patients about the "realities" of confidentiality in your clinical care situation.
Stigmatizing conditions	Don't avoid discussing difficult issues surrounding stigmatizing disorders.	Do strategize explicitly with your patients about potential confidentiality problems.
Mandatory reporting laws	Don't break the law or violate professional standards in the process of respecting confidentiality.	Do actively work to change laws and policies regarding confidentiality that you believe are unethical.
Medical records	Don't assure your patients that the medical record—whether printed or electronic—is confidential.	Do explain that the purpose of the medical record is to be read so that optimal care may be given.
Nonstandard charting	Don't use these protective practices without considering the consequences.	Do consider how to reconcile accuracy and privacy in all forms of documentation.
Speaking with significant others	Don't talk to significant others without permission from the patient.	Do remember to inquire about a patient's important personal relationships.
Consultation	Don't feel that you are on your own when confronting difficult confidentiality questions.	Do seek consultation and direction from other sources such as books, articles, CME programs, Internet sites, ethics consultants, and ethics committees.
Lifelong learning	Don't neglect your commitment to lifelong learning—including ethics.	Do continue to learn about professional aspects of medicine and share your knowledge with colleagues.

CME = continuing medical education.

should thoroughly investigate the severity of her gambling and its impact on her children's welfare. Sincerity and accurate information in this dialogue will demonstrate that trust and privacy remain the cornerstones of the physician-patient relationship.

Stigmatizing Conditions

The evaluation of psychiatric problems, the treatment of substance dependence, and the assessment of a possibly abusive relationship are situations commonly encountered in ambulatory care. In these cases, it is essential that patients reveal their concerns openly, even if their disclosures may lead to serious negative consequences. Patients with stigmatizing problems often have symptoms that heighten their fears of self-disclosure, such as self-blame and poor self-esteem [4]. Many patients also may experience indecisiveness, impaired memory, low energy, insomnia, and negative thinking, all of which hamper their efforts to seek treatment, especially from mental health professionals who may be less accessible in systems that use "gate keepers" [5]. Consequently, these individuals may have difficulty making an appointment with a mental health professional on their own. Coordinating referrals to specialist providers often is necessary to ensure that these patients receive the treatment they need. Worries about the consequences of revealing sensitive personal information may complicate already difficult patient-physician interactions [6]. What options are available to the patient and physician in the following scenario?

> A security officer at the local university comes to you for the yearly physical examination required by his company. During review of systems, he hints that he may have an alcohol abuse problem. When you ask for more history, he refuses, stating that he is afraid that the information may be disclosed to his employers.

Changes in the delivery of health care (eg, the evolution of managed health care systems that rely on utilization review procedures and information technology) and in the requirements of the law have made the protection of patient privacy complex and perplexing, especially in relation to stigmatizing disorders such as the one faced by this patient. Insurance companies and places of employment are often one and the same entity in the

present day. Many large corporations have established their own health plans; thus, the same organization that pays a patient's salary provides his or her health benefits. These overlapping relationships create a situation in which the documentation of a patient's psychiatric and psychosocial issues may unfairly affect his or her employment status or health benefits [7].

It may be helpful to anticipate the problem of discrimination and to explore the advantages of alternative routes of care that offer more privacy protections (eg, public health or community-based clinics, domestic violence programs, rape crisis centers). Self-help groups such as Alcoholics Anonymous and Narcotics Anonymous also may offer support and guidance for substance-dependent individuals and allow them some degree of confidentiality [3]. Members of these self-help groups pledge to keep personal information confidential within the group. Referral to these organizations would not need to be noted in the chart because the groups are public, free, and open to anyone. Similarly, referrals to other health care facilities could be documented but without specifically stating the reason for the referral.

Mandatory Reporting Laws

Some stigmatizing patient issues fall under the jurisdiction of mandatory reporting laws, and in these circumstances the clinician's duty to comply with the law must override the desire to protect the patient from the negative consequences of disclosing embarrassing information. Generally, 4 main categories of information are covered under mandatory reporting requirements:

1) Child abuse or abuse of an adult if he or she is not mentally competent (eg, because of dementia or mental retardation)
2) Infectious and sexually transmitted diseases that are matters of public health, such as tuberculosis, HIV (in some contexts), syphilis, and gonorrhea
3) Gunshot wounds and sexual assault
4) Threats made toward identifiable persons

It is especially important to explain the exceptions to clinician-patient confidentiality when discussing sensitive material such as substance use or sexually transmitted diseases. In some instances, mandatory reporting laws serve as a positive step toward providing resources to individuals who are having difficulty coping with their problems [8]. In situations of suspected child or elder abuse, for example, the clinician may use this legal duty therapeutically to help family members seek counseling and, with the clinician's assistance, report their own concerns about their behavior to the proper agency.

Mandatory reporting laws vary among states and jurisdictions, and it is crucial for clinicians to be aware of applicable statutes. Moreover, many patients may be unaware of the mandatory reporting requirements with which clinicians must comply to obey the law, uphold professional standards, or both. How should the physician in the following scenario proceed with his patient who tests positive for HIV?

> During an annual examination, a 29-year-old graduate student tests positive for HIV. When the patient's physician informs him of the results and asks about the patient's sexual contacts, he learns that the patient may have acquired the virus from a prostitute while he was on vacation in Mexico. The patient begs his physician not to tell his fiancée, with whom he is having unprotected sex, because it would end their relationship.

Nowhere is the intersection of law and medicine as it pertains to confidentiality more controversial or ethically problematic than in the treatment of patients who are seropositive for HIV infection or who manifest advanced HIV-related illnesses. Considerable debate exists over how clinicians can most effectively work therapeutically with patients who do not wish their sexual partners to be informed of their HIV^+ status [9]. It is important for clinicians to address this clinical problem constructively with patients. Clinicians should discuss all aspects of the disclosure, offer to be present when the partner is told, and urge patients to inform their sexual partners themselves rather than have a stranger deliver the news. Patients must understand that the law may require physicians to inform partners or report the case to public health officials who may contact sexual partners if patients refuse to do so [10].

Similarly, a physician treating a patient who is considering harming someone has several duties. First, the physician should facilitate immediate referral to a mental health professional [5]. Whenever possible, the clinician and mental health professional together should make definitive arrangements for contacting potential victims and appropriate officials in compliance with the law [8]. Patients with violent thoughts may worry that their family and friends will reject them or become afraid of them if this information is shared. Therefore, talking with patients about confidentiality safeguards may help them to feel more comfortable discussing disturbing feelings.

Many patients consider an official report to be a betrayal by the clinician. Consequently, it is the clinician's duty to ensure that patients receive support and ongoing care during the mandatory reporting process. It is helpful to explain that the report is meant to serve the well-being and interests of the patient, family, and society. Moreover, the report is not intended as a punitive action and is necessary by law. When needed, it is valuable to reassure the patient that referral to another professional is not meant to supplant—but to supplement—the existing patient-physician relationship. The patient's ability to maintain a relationship with his or her primary care provider may provide a sense of strength and continuity during a particularly vulnerable time.

These general guidelines apply to situations in which the law dominates or usurps what the physician judges to be a more appropriate ethical choice in patient care. If a physician believes that policies or laws regarding such disclosure contradict professional principles or personal conscience, he or she must voice dissent through professional medical societies and the political process. Indeed, a cardinal principle of the American Medical Association's Principles of Medical Ethics mandates such action when a physician believes that a law or policy should be changed: "A physician shall respect the law and recognize a responsibility to seek changes in those requirements which are contrary to the best interests of the patient" [11].

Medical Records

Although patients' medical records are not likely to appear on the front page of the local newspaper, many patients may not realize that their records are not sealed documents. Patients may be unaware that members of the clinical care team, clinic staff, and other health professionals (eg, consultants, laboratory personnel) typically have open access to patient charts [12]. In addition, quality assurance and insurance audits are routinely performed in most clinical settings and often require chart review. Therefore, physicians should explain to patients that allowing other parties access to their records is intended to improve their care or is necessary to secure payment for their treatment.

The sharing of clinical information may have an unavoidably negative impact on physician-patient confidentiality. Consider the implications of the following clinical scenario:

> A middle-aged male executive with a family history of prostate cancer requests a digital rectal examination and a prostate-specific antigen test. Afterward, he asks his physician not to allow the insurance company to view his medical record. The patient is afraid that the company may cancel his coverage or raise his rates if they learn about his family history or any positive test results.

In this scenario, the patient's insurance company will have access to his medical records if the patient wants the company to continue paying for his health care. In rare circumstances, such as a criminal proceeding, attorneys and family members may also obtain the right to review medical records, even without a patient's permission.

It is also helpful for clinicians to explain their institution's policy on the use of computerized medical records. Patients need to know that electronic records are managed with the same caution as the paper chart; however, despite various protections (eg, passwords, encryption codes), most clinical systems are not yet advanced enough to fully secure electronic medical records or databases [13].

Nonstandard Charting

Shadow Charts

Some clinicians attempt to protect patient data by using parallel medical records that contain potentially stigmatizing health information that is omitted from the regular chart. These records are referred to as *shadow charts*, and access to them is more restricted than access to standard medical records. Using shadow charts enables a physician to keep careful notes about potentially stigmatizing diagnoses while allowing more control over authorization to view this sensitive information. What problems may arise from the following situation?

> A primary care physician sees one of her partner's patients. The patient had come in because he noticed his blood pressure was elevated when he checked it as his health club. He understood from a previous physician that cocaine use could cause high blood pressure. The patient, a successful attorney, begins discussing his 10-year struggle with cocaine abuse. The physician can find no notes regarding this problem in the patient's chart, but later her partner informs her that his notes about the substance abuse are in a shadow chart that is locked in a file cabinet in his office.

The use of a shadow chart in this situation did not adversely affect the outcome of the patient's visit. However, in some situations, such as clinical emergencies, patient care may be compromised if the treating clinician does not know about or have access to information

contained in a shadow chart. For example, if this patient had a myocardial infarction—a not uncommon consequence of cocaine abuse—it would be important for the emergency room physicians to be aware of this history when determining the management of the patient. Even in nonemergent clinical situations (eg, transfer of care, referral for specialty care), key omissions in the principal medical record may interfere with optimal health care [14]. Therefore, clinicians should use shadow charts cautiously and should always make a formal notation in the standard medical record regarding the existence of the shadow chart. In addition, because no established consensus exists regarding the legality of shadow charts, physicians should consult the legal counsel representing their institution before using shadow charts.

Gaming the System

Physicians may modify pertinent data regarding diagnosis, prognosis, or the course of a patient's illness to meet the criteria for obtaining third party authorization of diagnostic or therapeutic modalities that are indicated but that may be denied under current utilization parameters. These practices are referred to as *tailoring the chart* or *gaming the system* [15]. For example, a clinician treating a middle-aged patient with new onset headache may be fairly certain the patient is suffering from migraines. To rule out a brain tumor, however, the physician may wish to obtain approval for magnetic resonance imaging by exaggerating the intensity of the patient's symptoms or adding associated symptoms (eg, vertigo, morning vomiting) that suggest a more serious pathology. An even more prevalent variant on tailoring the chart is altering diagnostic codes to obtain payment from insurance companies. For example, a physician seeing a construction worker with an upper respiratory infection might code for bronchitis or even pneumonia to guarantee coverage for necessary medications or even the visit itself.

From an ethical perspective, these are questionable practices, even if performed with the best of intentions. In a recent study, Freeman et al [16] reported that 74.5% of physicians surveyed responded that their primary professional responsibility was to "practice as [their] patients' advocate working within the rules/restrictions of third party payers as long as those rules do not significantly compromise [their] patients' interests." The results of this study and similar research indicate that these practices may be widespread, especially in managed care settings.

Speaking with Significant Others

Speaking with family members is a delicate endeavor. It seems natural to share concerns about patients with the individuals closest to them, and patients often wish to share the details of their diagnosis and therapy with their families. However, certain dynamics or sensitivities within a family that are unknown to clinicians may become significant problems if caregivers disclose personal information without patient approval. Therefore, clinicians should clarify their patients' wishes regarding confidentiality and familial relationships early in the course of care. If patients ask for assistance, it may be useful to discuss their reservations about involving family members in clinical decisions.

Finding the appropriate balance among gathering data, offering support, and providing information can be especially challenging when patients have stigmatizing conditions such as alcohol abuse, depression, or posttraumatic stress disorder. For example, communication is critical to treating substance abuse and psychiatric disorders, but forcing the issue may undermine a patient's trust if he or she is not ready or willing to discuss the problems with family members. Listening to the concerns of family members, however, is not an infringement of patient confidentiality and is often a vital source of collateral information. Offering to mediate family meetings or to involve third parties with special expertise (eg, social workers, substance dependence counselors, clergy) may facilitate discussions of embarrassing or sensitive conditions with family members.

Exceptions to the Nondisclosure Rule

In some situations, it may be necessary to disclose information to family members without a patient's prior consent. For example, when a patient's wishes are unknown or impossible to assess (eg, if the patient is unconscious or cannot make his or her own decisions), a clinician may assume that the patient would like his or her privacy to be respected to the extent feasible under the circumstances. In other situations, such as a family's formal, planned intervention with a very sick and impaired patient, the confidentiality "rules" differ. In these situations, the family group itself "becomes" the patient (ie, assumes responsibility for making decisions on the patient's behalf); explicit conversations about what should and should not be discussed are important to the success of the intervention.

When mandatory reporting laws affect the management of the case, it may also be critical to disclose uncomfortable, private information to family members and officials. In such situations, it is essential to reveal only the amount of sensitive data necessary to comply with legal mandates while the patient's preferences about disclosure are being assessed. For example, when a person is the victim of physical or sexual assault, it

may be necessary to disclose certain private information to the patient's significant others to build a network of support for the patient's recovery. However, the detailed circumstances of the assault, such as the presence of alcohol in the situation, should not be revealed because this may further victimize the patient.

Confidentiality and Adolescent Patients

Treating adolescents raises unique and particularly sensitive questions regarding confidentiality and how the concerns of parents and children are balanced as children mature and assume more responsibility for making their own health care decisions. Nevertheless, clinicians should not make false or unrealistic promises to adolescents regarding confidentiality [17]. Clinicians should explain to adolescent patients that information that does not involve direct harm to themselves or to other people generally will not need to be discussed with their parents against their wishes. Furthermore, in many states information regarding the sexual identity and sexual behavior of adolescent patients is specifically protected. Such discussions may help adolescent patients feel comfortable enough to talk about sexual activity or drug use without creating an unrealistic assumption that the information will be absolutely confidential.

Similarly, clinicians should not promise parents that everything their child discusses during a visit will be disclosed to them. For example, a mother whose daughter sees her family practitioner for a sore throat may demand to know whether the "real reason" was to obtain a pregnancy test. In this situation, the physician is not required to comply with the mother's request; instead, he or she may encourage the mother to discuss the visit with her daughter directly, in a way that respects her privacy. Clinicians may serve as moderators or family counselors in the process. Clinicians can facilitate a healthy parent-child balance by encouraging communication between adolescent patients and their parents, providing education, and offering timely referrals to deal with pregnancy, drug use, sexually transmitted diseases, depression, violence, and the myriad other teen crises with which many families are confronted [18].

Consultation

When confronted with a challenging clinical case, it is common practice for physicians to seek the advice of a colleague or specialist. The same practices should be followed when dealing with ethical dilemmas, particularly issues of confidentiality that may have repercussions for patients and institutions. Consider the following situation:

> A 60-year-old truck driver with a history of diabetes asks his family practitioner to complete a form from the local motor vehicles department certifying that it is safe for him to continue driving. However, the patient divulges that he has recently experienced several "spells" while driving.

How should the physician proceed? A good first step would be to obtain the advice of an expert. Most hospitals have ethics committees and hospital attorneys that may provide information and guidance, and most academic medical centers have ethicists on staff who are available for consultation. In addition, local, state, and national medical societies have legal and ethical experts who can be consulted regarding applicable statutes and rulings.

Formal consultation through such avenues is a highly effective method of gathering information about ethical and professional standards and obligations and for identifying one's blind spots relative to a specific patient case. A trusted colleague or former clinical supervisor may also serve as a good sounding board. In addition, Table 2 lists recent books, articles, and Internet sites that can be consulted by the interested clinician.

Lifelong Learning

All physicians face significant stresses and time pressures, and many feel that they do not have sufficient time to read, reflect upon, and share new or useful information with colleagues. Transitions in the health care system over the past 2 decades, such as the shift from fee-for-service to managed care systems and the movement from hospital-based to ambulatory care, have contributed to this challenge to medical practice for individual clinicians [19]. For example, a physician who is preparing to leave residency considers signing a contract with a large health maintenance organization (HMO). However, she has read and heard about disturbing instances of breaches of confidentiality in some HMOs. Given the stresses and time demands of residency training, this young physician finds that she does not have ample time to educate and prepare herself to make an informed decision.

Many new physicians may find themselves in similar situations. Nevertheless, all physicians must dedicate themselves to ongoing personal growth and education, not only in their area of scientific expertise but also in areas of ethics and professionalism. The collective knowledge and values of medical practitioners provide the skills necessary to interpret and apply scientific discoveries in the best interests of patients. Professional

Table 2. Useful Resources Regarding Patient Confidentiality and Medical Ethics

Books
American Medical Association. Council on Ethical and Judicial Affairs. Code of ethics. Reports of the Council on Ethical and Judicial Affairs of the American Medical Association. Chicago (IL): The Association; 1998.
Beauchamp TL, Childress JF. Principles of biomedical ethics. 4th ed. New York (NY): Oxford University Press; 1994.
Jonsen AR, Siegler M, Winslade WJ. Clinical ethics: a practical approach to ethical decisions in clinical medicine. 4th ed. New York (NY): McGraw Hill, Health Professions Division; 1998.
Junkerman C, Schiedermayer DL. Practical ethics for students, interns, and residents: a short reference manual. Frederick (MD): University Publishing Group; 1998.
Simon RI. Clinical psychiatry and the law. 2nd ed. Washington (DC): American Psychiatric Press; 1992.
Internet resources
The Doctor's Dilemma: Essentials of Medical Ethics (interactive role-playing program): www.expomed.com / ethics.htm
Bioethics Discussion Pages: www-hsc.usc.edu / ~mbernste
Bioethics.net: www.med.upenn.edu / ~bioethic
The AMA's Principles of Medical Ethics: www.ama-assn.org / ethic / ceja / pome.htm
Online Resources in Medical Ethics: aristotle.philosophy.msstate.edu / MedEth / resources.htm
Ethical Issues in Professional Life (video programs and telecourse): gpn.unl.edu / welcome.htm

AMA = American Medical Association.

meetings, editorials, legislative bulletins from professional societies, and continuing medical education programs all offer ways to keep current on significant developments in ethics and professionalism. Confidentiality in particular is one of the most complex and rapidly advancing medicolegal issues. A constructive and rewarding means of staying aware of new developments is to share clinical experiences and the results of individual research with colleagues through informal conversation or in more structured settings such as journal clubs. This dialogue helps to clarify ethical questions and offers the opportunity for consultation on especially problematic cases involving confidentiality.

Conclusion

Primary care providers see patients posing ethical dilemmas, subtle and not so subtle, every day of their professional lives. Too often, philosophical discussions of confidentiality are difficult to translate into the realities of clinical practice. Furthermore, legal interpretations of confidentiality obligations unfortunately define what clinicians *must* do rather than help clinicians evaluate what they *should* do to provide conscientious and compassionate care. The 8 recommendations presented here offer a pragmatic approach to applying the principle of confidentiality within the clinician-patient relationship as it exists in today's challenging practice climate. Protecting patient confidentiality need not add an extra burden to the already heavy clinical schedules of primary care physicians. Discussions of key confidentiality issues can be integrated into routine clinical practice as demonstrated in the cases presented here. Indeed, such discussions may actually prevent difficulties and misunderstandings and optimize the efficiency and quality of care delivered.

The Hippocratic writers' dictum on confidentiality was intended to accomplish a singular purpose: to encourage patients to trust the physician with their intimate personal history in the hope that it might help the physician to heal their suffering. In the present day, this purpose persists. Dedicated physicians who faithfully adapt traditional principles of confidentiality to demands of modern medicine will continue to observe the essence of the oath.

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Discussion Questions

The following questions may be useful in discussing confidentiality issues in journal clubs or postgraduate medical education forums. Case presentations such as those described in this paper or relevant articles may also help to illuminate key discussion points.

1. Confidentiality is often called a "privilege." Discuss whether confidentiality in health care should be a privilege or a right. What difference does this distinction make for clinical care?
2. Mandatory reporting of patients who test positive for HIV is highly controversial and the topic of political debate. Discuss some of the benefits, risks, and ramifications of mandatory reporting.
3. The explosion of information technology has revolutionized medical care. How may advances in information systems affect the protection of patient confidentiality?
4. You are a senior resident, and a new intern comes to you with questions about when and how to report a suspicion of domestic violence without breaching patient confidentiality. What resources would you recommend to help the intern learn about the issue? What advice would you give?