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Confidentiality: An Expectation in Health Care

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Health care professionals have a legal and ethical duty to keep medical information private. Physicians and nurses, along with hospitals and insurers, are required by law and professional codes to practice confidentiality. The practice of confidentiality limits "the disclosure of nonpublic information within a fiduciary, professional or contractual relationship." (Majumder, 2005) Achieving confidentiality requires restricting information to persons belonging to a community of authorized recipients. The "community" authorized to receive confidential information can be smaller than a family or as large as a workforce. For example, the community of authorizer recipients of information is small where the confidence is a person's undiagnosed medical symptom secretly whispered to his spouse, but large where the confidence is the detailed medical history and insurance data needed to secure an organ for transplant. Facts, impressions, events, and data of all sorts can be deemed confidential. Confidentiality is achieved through silence, discretion and data security.

Expectations of confidentiality surround certain relationships. Both personal and professional relationships demand confidentiality. Everyday ethics treat friendships and marriages as confidential relationships of trust in which information can be safely shared. Relationships with providers of professional services are governed by written rules of confidentiality. The doctor-patient, attorney-client and clergy-penitent relationships are

apt examples. Accountants, real estate agents, pharmacists, and tax professionals are also expected to keep certain client information quiet. So are government bureaucrats with access to the personal information recorded on tax filings, census forms and social security disability claims. Revealing information learned in confidence may violate oaths, professional codes of conduct, business policies or the law. Even people in illicit criminal relationships expect confidentiality for their conspiracies and abuses.

Expectations of confidentiality surround records, no less than relationships. Personal information recorded in diaries, journals, and correspondence may be confidential. Likewise, business records, medical records, academic records, and personnel files are generally described as confidential, along with banking and financial records, library records, and motor vehicle records. Video rental records and telephone transaction logs are also deemed confidential. In the United States, dozens of federal statutes and myriad state and local laws require confidential treatment of record data. (Allen, 2007; Rotenberg 2007)

Many Americans regard information about their health as appropriately private, and medical privacy as something to which they have a moral right. In fact, health information is so sensitive and personal that some people, who know that they are ill, do not share the knowledge with anyone, leaving even their closest friends and family members in the dark. Private medical knowledge precedes the creation of a confidential provider-patient professional relationship or medical record. A smoker suddenly unable to exercise without getting short of breath knows that he has a lung disorder long before he consults his primary care doctor and lets her in on the secret. When the doctor diagnoses emphysema and creates a record of her findings for specialists and insurers,

she is expanding the community of authorized recipients of information about her patient's once-secret ailment. Of course, some medical conditions cannot be concealed. They are obvious to casual lay observers. If a man weighs 700 pounds, his eating disorder speaks for itself. Looking at jaundiced eyeballs the color of sunflowers leaves little doubt about liver disease.

Choosing to hide concealable symptoms of potentially serious health problems is a choice people make; but it can be a deadly choice. Quickly revealing blood in the stools, depression or a lump in the breast is generally the better, life-saving path. Yet, failure to widen the circle of confidence to include medical professionals may be prompted by a reluctance to confront death and decline; a fear of discrimination in insurance, employment and education; and a dread of social stigma. (Allen, 2003) Shame, embarrassment and terror of surgery or other invasive medical procedures leads even educated individuals to delay seeking treatment of treatable conditions. Lack of trust in physicians and hospitals has led some individuals to suffer privately in silence.

The Value of Confidentiality

Encounters with health care professionals convert persons confronting illness into patients with charts. Everyone and every entity participating in the delivery of health-care related services is ascribed the duty of patient confidentiality. Health care providers are ethically bound to keep charts and other medical information obtained in the context of care, confidential. Confidentiality as a clear ethical obligation of physicians: "A physician shall respect the rights of patients…and shall safeguard patient confidences and privacy within the constraints of law." (AMA, 2001) Failure to respect confidentiality

can lead to legal liability. Although health care providers may lawfully share certain otherwise confidential information with insurers, researchers, public health authorities and law enforcement, principles of confidentiality broadly pertain to health-related services and research.

American bioethicists generally agree that confidentiality is important to just and ethical health-related practices. Practicing respect for patient confidentiality benefits individuals and promotes public health. Ethicists defend confidentiality on several utilitarian grounds, each premised on the twin understandings that health is vital to human well-being and flourishing, and that a good and just society will be committed to securing public health.

First, confidentiality encourages individuals to seek essential medical care. Individuals will be more inclined to pursue medical attention if they believe they can do so privately and perhaps even secretly. Practicing confidentiality assures that, in most cases, a patient can choose when to disclose that she is unwell or declining. Others will not be told that she has abused illegal drugs, been unfaithful to her partner, or cosmetically enlarged her buttocks. As acknowledged in North American Memorial Hospital v. Ashcroft, a dispute over Justice Department access to abortion records, medical confidentiality enables abortion patients, and indeed all patients, to exercise constitutionally protected liberties of autonomous medical-decision making. (Bodger, 2006)

Second, confidentiality practices lay a foundation for frank disclosures in in-patient and out-patient settings. Individuals seeking care can be more open and honest if they believe the facts and impressions reported to health providers will not be broadcast

to the world at large. People are often embarrassed and humiliated by symptoms of illness. They may go to see a doctor and yet be reluctant to reveal bowel incontinence, loss of memory, or hallucinations.

Third, preventive medicine, early diagnosis and treatment save money. More people sick with more chronic illnesses means higher care costs. The cost of health care and insurance might be considerably higher if people passed on routine check-ups and prompt medical attention because confidentiality was not credibly promised.

Confidentiality is arguably an ethical mandate of respect for human dignity and individual rights. Caregivers show the concern for other befitting of their status as moral persons with rational interests and feelings when they keep information about their health and health needs private. (Starr, 1999) Individuals concerned about discrimination, shame or stigma have an interest in controlling the flow of information about their health. Some patients believe they own personal information about themselves, especially genetic information, and should control its release. Confidentiality is required by fair relations with government and businesses. Ideals of fairness embodied in "fair information practice" standards embraced in the United States and Europe provide that personal data collected about individuals should be accurate, secure and disclosed to third-parties only with consent. (Rothstein, 2005)

Openness is a Trend

In a February 29, 2004 online survey, 88% of respondents said that the confidentiality of medical records was "very important" or "somewhat important". Only 9% said confidentiality was "not too important" or "not important". (Roper Center, 2004)

However, speaking openly and publicly about health-related matters has emerged as a cultural trend, suggesting a decrease in the felt importance of medical privacy and confidentiality. Disclosures that would have been considered indelicate, embarrassing or stigmatizing thirty years ago are freely offered today. Celebrities and public officials have taken the lead, turning, for example, AIDS, erectile dysfunction, dementia, Parkinson's disease, prostate enlargement and breast cancer into topics of ordinary conversation. (Stevenson, 1991; Barron, 1998)

But the polling data and the openness trend are not inconsistent. People who speak openly about their health generally prefer to do so on their own terms. They want some control over health information, a say in who is told what. It is not unusual for patients to want health professionals to respect their medical privacy by limiting disclosures to those with a need to know. But patients can have idiosyncratic preferences. Some patients may be open with their family members but not with their friends. Or they may be open with nonjudgmental friends and coworkers, but not with critical, scolding parents. A person who shares health related information on the web with millions of strangers, may be too shy to share information over coffee with siblings they know well.

Confidentiality Remains Relevant

The United States may have entered an era of greater openness about medical matters, including cancer, HIV-AIDS and other serious illnesses. But medical and behavioral health professionals ought to respect the privacy preferences of their patients. The ethical tradition of medical confidentiality has not outlived its relevance. Many people are still particular about when and whether they share health information. With

justification, many people are still concerned that they will suffer emotional and economic harm if others learn their health status. Mental and other behavioral health-care consumers continue to face stigma and discrimination in a world in which getting what they need requires a virtual surrender of confidentiality to family members, doctors, psychiatrists, psychotherapists, neuropsychologists, social workers, teachers, school administrators, hospitals, insurers, and law enforcement.

Public concern about medical confidentiality is reflected in privacy rules promulgated under the Health Insurance Portability and Accountability Act (HIPAA). The United States Congress enacted HIPAA in 1996. HIPAA patient privacy and data security rules developed by the Department of Health and Human Services went into effect in starting in 2003. (Rothstein, 2005; Annas, 2003) HIPAA requires that new patients receive a privacy notice and consent in advance to some disclosures of health information. Under HIPAA patients do not have a private right of action to sue health care providers who do not conform to the rules. Moreover, numerous exceptions for research, law enforcement and reporting mean that patient's medical information is widely disclosed without their consent. In court challenges, including Acara v. Banks (2006), federal judges have held that HIPAA grants neither an explicit nor an implied right for individuals to sue health care providers. But complaints by individuals may be reported to regulatory bodies empowered to enforce HIPAA's rules. (Goldfein 2007)

The concern for medical confidentiality is also reflected in the special protection genetic data receives under state laws. A proposed federal statute, the Genetic Information Nondiscrimination Act (GINA), would prohibit basing employment or insurance decisions on information about a person's DNA or genetic predispositions

(Allen, 2007, p. 587; Rao 2006).

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Breach of Confidentiality

American case law offers a unique window into current confidentiality practices and expectations. In Whalen v. Roe the Supreme Court stated that the Fourteenth Amendment protects the individual's interest in informational privacy. However, the Court upheld the validity of a New York state statute that required pharmacists to report the names of persons purchasing certain prescription medications prone to abuse, on the ground that the state had implemented measures to protect confidentiality. In the face of recent data breaches in retailing and health care, such promises of confidentiality carry uncertain weight with the general public. On August 22, 2007, someone broke into the offices of the Pennsylvania Department of Public Welfare in Harrisburg and stole two computers housing data concerning mental health patients receiving state services. Patients were encouraged not to unduly worry about the breach because most of information on the computers was protected by multiple security passwords, did not identify consumers by name, and contained only coded information relating to treatment.

Unauthorized disclosures of personal information are the essence of "breach of confidentiality" lawsuits. In these personal injury cases, plaintiffs seek money damages because they believe they have been injured by defendants' nonconsensual disclosure of confidential information. Interesting variants on medical breaches of confidentiality are cases in which a health care provider reveals a patient's confidences to a member of the patient's family and intends no harm by it.

In Humphers v. Interstate (1985), for example, a physician was sued after he disclosed his patient's identity to the adult daughter she had placed for adoption in infancy. In Bagent v. Blessing Care Corporation (2007), an Illinois hospital and hospital phlebotomist were sued by a patient whose sister was told of the patient's positive pregnancy test. The phlebotomist falsely assumed the patient had discussed the pregnancy with her sister. Even a spouse cannot be presumed a confidant. In Gracey v. Eaker (2002) a married couple sued their marriage counselor for breach of confidentiality. The therapist sometimes met with the spouses separately. The couple alleged that the therapist revealed sensitive and personal information that neither spouse had disclosed to the other.

Some people expect confidentiality even when they are doing wrong. In Morris v. Consolidation Coal Co. (1994) an employer videotaped an employee engaging in physical labor at his home despite claiming a serious disability for which he was receiving workers compensation benefits. The employer showed the videotape to the employee's doctor. The physician then wrote a report stating that he could no longer certify a back injury. The employee sued the physician alleging breach of physician-patient confidentiality relationship. He also sued his employer for interference with his confidential relationship with his physician.

The foregoing cases attest to the prudence of seeking consent before making informational disclosures of any sort, even disclosures to persons deemed entitled to the information or likely to already have it. In some instances a health care provider may be required to breach patient confidentiality. Psychotherapists are required by state law to report child abuse and neglect about which they learn in the course of therapy. State law

may also require that therapists warn potential victims of patients' violent intentions. Tarasoff v. Regents of the University of California (1976) imposed a duty to warn on California mental health providers. Generally speaking, however, psychotherapists are expected to keep their patients' secrets. They are not permitted to reveal infidelity, closeted sexual orientation, or ruined finances. The American Psychological Association's ethical code requires that "Psychologists respect . . . the rights of individuals to privacy, confidentiality, and self determination." (APA, 2002)

"Invasion of privacy" tort cases alleging intrusion upon seclusion or publication of private fact sometimes involve wrongful disclosure of confidential medical information. In Doe v. High-Tech Inst., a professor had one of her students secretly tested for HIV/AIDS. A medical assistant trainee, the student had informed the instructor (on the basis of an anonymous blood test) that he was HIV positive and asked that she keep the information confidential. Instead the instructor asked a lab that tested all of her students for rubella, to also test the plaintiff for HIV. The lab reported the positive test results to the Colorado Department of Health and informed the school. The student sued for invasion of privacy.

Medical information can also be acquired by witnessing medical events or procedures. A patient may wish to exclude both strangers and physicians from intimacies occurring in the hospital. In Knight v. Penobscot Bay Medical Center (1980) a physician gave the husband of a nurse permission to observe the delivery of the plaintiff's child while he was waiting for his wife to complete her shift. The plaintiff sued the hospital for invasion of privacy. In Estate of Berthiaume v. Pratt (1976) a dying man objected to being disturbed and photographed by a physician who wanted images of the man's

surgical wound for scientific purposes. A posthumous suit by the man's estate alleged invasion of privacy—the man had wanted to spend his final hours alone with his wife.

Finally, individuals' medical confidentiality expectations are protected by the rules of evidence, though not perfectly. (Denike 2003) Courts may order disclosure of medical confidences. In Ex parte Father Paul G. Zoghby (2006), a married woman accused her parish priest of sexual assault and indecencies. The woman sued only after being disappointed with the church's failure to discipline the priest. In the course of litigation the plaintiff requested that the Archdiocese produce Zoghby's psychiatric records. The church defendants objected, alleging confidentiality and the physician-patient privilege. Unfortunately for the priest, he had voluntarily signed an affidavit authorizing disclosure of his psychiatric records to a church superior charged with investigating the sexual impropriety allegations. The trial court granted the plaintiff's motion to compel production of the medical evidence, on the ground that the priest had effectively waived the physician-patient privilege by signing the affidavit.

Conclusion

Confidentiality has value. It confers autonomy and control over information; prevents shame and violations of modesty; and, perhaps most importantly, frees individuals from the burdens of stigma, inequality and discrimination. The practice of confidentiality has continued in an era of increased, voluntary openness about medical information in everyday life. Indeed, the number and variety of state and federal laws mandating confidentiality by medical professionals has increased in the last dozen years. Moreover, personal injury suits alleging breach of confidentiality or invasion of privacy,

along with suits asserting evidentiary privileges, reflect the reality that expectations of confidentiality of medical records and relationships remain strong.

References

American Medical Association. (2001). Principles of medical ethics. Retrieved on August 13, 2007, from http://www.ama-assn.org/ama/pub/category/2512.html

American Psychological Association. (2002). Ethical principles of psychologists and code of conduct. Retrieved August 13, 2007, from http://www.apa.org/ethics/code2002.html#principle_e

Allen, Anita L. (2007). Privacy Law and Society (Minneapolis: West Publishing Co. 2007).

Allen, Anita L. (2003). Why Privacy Isn't Everything (Lanham, MD.: Rowman and Littlefield, 2003).

Annas, G. (2003). HIPAA regulations — a new era of medical-record privacy? New England Journal of Medicine. 348(15), 1486-1490.

Barrad, C. (1993). Comment, Genetic information and property theory, Northwestern University Law Review, 87, 1037-1086, 1040.

Barron, J. (1998, Nov. 26). Public lives. New York Times, p. B2. "Actor Michael J Fox reveals that he is suffering from Parkinson's Disease."

Bodger, J. A. (2006). Taking the sting out of reporting requirements: Reproductive health clinics and the constitutional right to informational privacy. Duke Law Journal, 56, 583-609, 585.

Cohen, B. (2006). Reconciling the HIPAA privacy rule with state laws regulating ex parte interviews of plaintiffs' treating physicians: A guide to performing HIPAA preemption analysis. Houston Law Review, 43, 1091.

Denbo, S. (2006). What your genes know affects them: Should patient confidentiality prevent disclosure of genetic test results to a patient's biological relatives? American Business Law Journal, 43, 561-607, 563-565.

Denike, M. (2003). "Sexual inequality and the crisis of confidentiality: The myth and the law on personal records." In C. M. Koggel (Ed.), Confidential relationships: Psychoanalytic, ethical, and legal contexts. New York: Rodopi.

Goldfein, R. (n.d.). Comparison of Pennsylvania Confidentiality of HIV-Related Information Act (Act 148) and federal Health Insurance Portability and Accountability Act. Retrieved August 13, 2007, from http://www.aidslawpa.org/comparativechart.pdf

Majumder, M. (2005). Cyberbanks and other virtual research repositories. Journal of Law, Medicine & Ethics. 33, 31.

Rao, Radhika. (2006). A Veil of Genetic Ignorance? Protecting Genetic Privacy to Ensure Equality, Villanova Law Review, vol. 51, pp. 827-840.

Rotenberg, Marc, 2007. Sourcebook on Privacy Law (Washington. D.C., Electronic Privacy Information Center, 2007)

Rothstein, M. A. (2005). Currents in contemporary ethics: Research privacy under HIPAA and the common rule. Journal of Law, Medicine & Ethics, 33, 154-158, 155.

Roper Center at University of Connecticut. (2004, Feb.) Public Opinion Online.

Stevenson, R. (1991, Nov. 8). Magic Johnson ends his career, saying he has AIDS infection. New York Times. Retrieved July 17, 2007

Cases Cited

Acara v. Banks, 470 F.3d 569 (5th Cir. 2006).

Bagent v. Blessing Care Corporation , 2007 WL 121319 (Ill. 2007)

Doe v. High-Tech Inst., Inc., 972 P.2d 1060 (Colo. Ct. App. 1998)

Gracey v. Eaker, 837 So. 2d 348 (Fla. 2002)

Humphers v. First Interstate Bank, 298 Ore. 706 (Or. 1985)

In Ex parte Father Paul G. Zoghby, 2006 WL 3239971 (Ala. 2006)

Knight v. Penobscot Bay Medical Center, 420 A.2d 915 (Me. 1980)

North American Memorial Hospital v. Ashcroft, 362 F.3rd 923 (7th Cir. 2004)

Tarasoff v. Regents of the University of California, 17 Cal.3d 425 (1976)

Whalen v. Roe, 429 U.S. 589 (1977)