
Confidentiality — Revealing Trends in Bioethics

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Contemporary bioethics has paid considerable attention to the nature, justification, and limits of confidentiality. Examining the context in which concerns about confidentiality arise, and the methods used to address these concerns, illuminates trends and different thematic approaches within bioethics. That contemporary bioethics has developed through three phases is clear from the shifting focus of confidentiality concerns within each phase. The temporal and conceptual outlines of these phases are sometimes overlapping and fuzzy, but the confidentiality issues raised during each phase reflect recognizable trends within bioethics. We conclude by pointing out limitations in the current bioethical analysis of confidentiality and suggesting further areas of study.

Although contemporary bioethics is generally thought to have begun in the late 1960s and to span the last three decades, it obviously has roots in earlier events, for example, the Nuremberg trials. Our division of contemporary bioethics' into three phases is a conceptual analysis; it traces trends in the content and method of bioethics as they relate to issues of confidentiality, but does not seek to document specific historical events. Indeed, some authors, individuals, and institutional policies continue to conceive of bioethics in ways characteristic of its first conceptually distinct phase (i.e., as oriented primarily toward conflict-resolution and the promotion of autonomy). Other commentators lead, or have led, the way for changes in the field, often by anticipating a new phase of thought ahead of the majority. Thus, it is impossible to offer precise dates for the various phases of bioethical analysis. Instead, it is helpful to consider the trends each phase reveals and the strengths and weaknesses of its focus and methods. Such an analysis illuminates both confidentiality and bioethics generally.

Phase I — Informed Consent, Conflict, and Confidentiality

The early years of contemporary bioethics were characterized by the assertion of individual rights

of self-determination over the then prevailing ethos of medical paternalism. Within the principlist framework that came to dominate bioethics, respect for autonomy assumed a place beside the promotion of well-being and the avoidance of harm as ethical principles governing medical practice (Beauchamp and Childress 1983). Partly because the political climate promoted individual rights and partly because technological advances created treatment options about which reasonable people could disagree, judgments of relative harm and benefit came to be made with reference to patients' own values and preferences rather than those of the medical establishment (Beauchamp and McCullough 1984).

Patients' autonomous wishes were constrained primarily by liberal concern about harm to others rather than paternalistic concerns about risk to self or communitarian concerns about offense against a social ideal. The primary focus of bioethical discussion centered on the doctor-patient dyad, as the priestly model for this relationship gave way to a contractual one in which presumptively equal parties assume different role-related responsibilities (Veatch 1972). The primary function of bioethics during its first phase was to resolve ethical conflicts between doctors and

patients, between physicians and patients' families, and generally between the values of individuals and the paternalistic values of medicine and other social values.

To avail themselves of the benefits of modern medicine, patients were encouraged to tell physicians about their values and their health-related complaints, no matter how personal, painful, or shameful. Confidentiality provided an important protection for patients who did not want information about their malignancies, syphilitic conditions, or dire financial straits disclosed to the public or their loved ones. The nonabsolute but fundamental right of self-determination in medical matters was accompanied by the also nonabsolute right to confidentiality: patients were expected to seek control of their personal information as they controlled their persons.

Confidentiality limits access to information that is shared with another in confidence, in the expectation that the shared access stops there. While that which is revealed in confidence may not be secret, the presumption of confidentiality is a prerequisite for the possibility of shared secrets and thus for particular sorts of social intimacies (Bok 1983); confidentiality creates a sphere of "informational privacy" (Gostin et al. 1993). Yet what is revealed in the expectation of confidentiality may not be private information, but merely information that one wishes to keep from the awareness of others (Bok 1983).

Because bioethicists were concerned with advising physicians and establishing their own professional status in the process, phase-one bioethics emphasized confidentiality's instrumental value for assuring the quality of patient care. Confidentiality helped create trust, promoted open communication within the therapeutic relationship, and encouraged patients to seek help by entering such relationships. It helped preserve patients' privacy and social and economic status, which might have been negatively affected if particular information about them were to become more widely known (Edwards 1988). Emphasizing confidentiality's consequentialist justifications helped elucidate the limits of the

obligation by making it possible to weigh the likely outcomes of breaching confidentiality in various hypothetical circumstances (Bok 1983; Edwards 1988).

To justify breaches of the prima facie duty of confidentiality, the consequentialist considerations supporting confidentiality and the values they serve, must be less weighty than values served by breaching the duty. Moreover, it must be reasonably certain that the benefit expected from the breach

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will actually occur and that the person has no other reasonable means of achieving that benefit (Edwards 1988). Thus, most bioethical analysis in this phase dealt with extreme cases; for example, the physician had to weigh breaking confidentiality to prevent a car or plane accident or to inform an unsuspecting other of the risk of harm (e.g., from a violent patient or from one with a sexually transmitted disease). The arguments regarding how to weigh confidentiality versus these other values, by and large, supported the majority opinion in *Tarasoff v. Regents of University of California* (1976), which holds that when the patient of a psychotherapist makes a credible threat of harm to an identifiable third party, the therapist has a legal duty to take reasonable measures to protect that person.

The 1980 revised Code of Ethics of the American Medical Association reflects the importance that bioethics gave to confidentiality. No longer permissible were breaches of confidentiality to protect the welfare of the particular patient or society, except as prescribed by law (e.g., legal requirements to report cases of diseases in the

interest of public health, or Tarasoff-like requirements to protect specific third parties). Physician discretion gave way to social consensus about the few competing interests that were sufficiently important to outweigh confidentiality. Here, as in other areas of bioethics, physicians' personal values and the professional values informing medical paternalism gave way to values reflected in social consensus. Public health concerns or protection of life served to justify breaches of confidentiality.

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The value of confidentiality stemming from respect for persons and the inherent value of privacy received less attention than its consequentialist justifications in bioethical analysis, even though it was recognized that "having a capacity for autonomous control over certain intimate details of life in accordance with a rationally informed plan of life is an integral part of what we mean by being a moral agent" (Edwards 1988, 78). Outside bioethics, commentators theorized that "if we could keep none of our thoughts or actions private, we would avoid those that, if publicized, might subject us to censure, rejection or harm" (Gavison 1984). In this sense, what is really important is not confidentiality per se, but establishing and maintaining a sphere of informational privacy, and being able to control others' access to information about ourselves.

Confidentiality is a way to exercise control and preserve privacy, while enjoying the benefits of sharing information on a limited basis. In some cases, being able to share secret or otherwise private

information is inherently valuable. Being able to share innermost thoughts with a domestic partner or best friend is inherently valuable because this sharing constitutes a relationship that has inherent value. Such relationships allow people to nurture ideas, plans, and aspects of personality in ways that they might not without a special other who provides supportive and critical responses to what is shared.

In other contexts, sharing personal information has a strictly instrumental value, as when we share information with a lawyer or physician so that he or she can help us address legal or health-related concerns. A physician's preservation of confidentiality allows patients to seek health care they might otherwise avoid or "purchase" at great personal costs, for example, incurring embarrassment or social stigma, worrying loved ones, or risking discrimination. In these cases, confidentiality is valued because it preserves informational privacy, which can be valued for its own sake and for other benefits. Where privacy, especially informational privacy, is valued for its own sake, it is most closely connected to autonomy, self-expression, and human flourishing.

Phase II — Structural Challenges to Confidentiality and Preventive Ethics

In its first phase, contemporary bioethics was process-oriented; it identified, analyzed, and resolved ethical conflicts that arose in health care settings, much as acute care medicine treated symptomatic illness. In its second phase, bioethics adopted another process-oriented tack. Mirroring preventive medical approaches, it began to identify the epidemiology of ethical concerns, to analyze their preconditions, and to anticipate particular problems before they arose (Forrow et al. 1993).

Preventive strategies shift medicine's focus beyond the individual patient to patient populations and broader social conditions (including economics and the environment). Similarly, in Phase II, bioethics turned away from the doctor-patient dyad to the institutional and cultural contexts of health care. By adopting this preventive stance, bioethics was able to make

recommendations and draft institutional policies designed to avoid the "morbidity" of ethical conflict and promote the "ethical health" of health care itself.

In 1982, Siegler published his now classic article declaring confidentiality a decrepit concept. His analysis reflected the preventive ethics approach. Moreover, the type of confidentiality issue that Siegler identified reflected a changing structure of health care delivery in which teams of specialists now provide acute care. What the Tarasoff decision was for our understanding of confidentiality during Phase I, Siegler's analysis was for Phase II.

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Using the familiar case study approach, Siegler showed that the doctor-patient relationship no longer constituted medicine's moral universe and that third parties with competing interests were no longer the primary threat to the patient's interest in confidentiality. Instead, the structure of modern medicine and patients' own interests in its benefits make traditional approaches to confidentiality obsolete. Siegler estimated that many as 100 members of a health care team (broadly conceived) may have access to a patient's medical record. (Subsequent changes in health care financing and the advent of managed care have only magnified this problem.)

Siegler's analysis of confidentiality focused on the structural factors contributing to the problem. His remedies are directed to changing those factors, and his stance toward those that cannot be altered is borrowed from preventive medicine: forewarned

is forearmed. Access to patient information should be limited to those who have a need to know, perhaps by dividing medical records into separate sections according to who needs access to what information to provide good quality care, an admittedly difficult determination. Moreover, patients must be informed about these structural and legal limits. A company doctor, for example, should "mirandize" patients by informing them that company rules require physicians to report any drug use that may affect work performance (Forrow et al. 1993). Informing patients of environmental factors (including laws and prevailing practices) that affect the confidentiality of their information enables them to make informed choices about whether to reveal such information.

For most patients, however, "forewarned is not forearmed." There are no desirable options for the typical patient who seeks treatment and reimbursement for its cost, but who prefers not to submit a claim regarding his condition to the insurance company at which his neighbor works. More seriously, a patient may desire treatment for a potentially stigmatizing condition, like depression or human immune deficiency virus (HIV), but fear the devastating economic and social implications of the condition's becoming known. Typically in these cases, patients must choose between medical treatment and confidentiality.

Society seems to value confidentiality more in the abstract than in practice, particularly if protecting it requires changes in administrative practices. Only where such concerns are serious and involve patient populations that are particularly political, powerful, and energized have special policies or legal protections been instituted to limit the negative sequelae of learning and sharing such information about oneself. The most noticeable case is HIV. Here political and public health pressures led to anonymous and confidential testing to encourage individuals to seek information and early treatment, and research studies received special federal protections to exempt researchers from having to identify subjects in response to subpoena.

Even here the scope of such protections is

limited, however, to consequences that arise in, and can be monitored in, traditionally public spheres (e.g., civil rights and public health). It is not possible, or desirable to legislate against other negative effects of breaching confidence, such as society's unkindness, unjustified fears, or discrimination in a variety of social interactions not especially regulated by law.

During this second developmental phase, bioethics encouraged attention to preventing breaches of confidentiality within the relatively public sphere of health care institutions and their public spaces. Many of these potential breaches concerned what Siegler, at the end of his 1982 article, termed "inadvertent" breaches of confidentiality, such as hospital elevator gossip. Signs appeared, for example, in some hospital elevators reminding employees not to engage in such gossip. Since Siegler's commentary, at least two studies have documented the prevalence of such small-scale, but important threats to patients' control over their personal information (Hasman 1997; Ubel et al. 1995), and hospital ethics committees have developed policies designed to protect confidentiality and to limit access to patient information. Hospitals may, for example, require all new employees to attend in-service training sessions that emphasize the importance of confidentiality in daily practice or distribute cards reminding employees with "loose lips" to respect patient privacy.

In Phase II, bioethics recognized that structural considerations — the sheer size of health care institutions, the structure of nursing care, the computerization of hospital records, and the evolution of health care teams — affect patient confidentiality. Later bioethicists, especially feminist bioethicists, recognized that different types of patients were differently affected by these structural considerations (Roberts 1996; Tong 1996). Patients who can afford private rooms obviously have more informational and personal privacy than those in semiprivate rooms or wards; patients in teaching hospitals enjoy less privacy than those in which teams of trainees do not make rounds.

Feminists concerned with power and oppression recognize that the privacy of the doctor-patient relationship is not a reality for many patients from lower socioeconomic backgrounds who receive their primary care in public clinics or hospital emergency rooms (Roberts 1996). Feminist approaches articulate the way that microlevel issues, like confidentiality, are constrained by macrolevel structures and policies — both institutional and social — and by the social norms and attitudes that they reflect (Mahowald 1996; Tong 1996).

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Recognition of these macro-micro interactions and the way that social structures affect patients of different races, genders, and social and economic status illuminates concerns about justice in health care. As bioethics moved into the third phase, justice considerations began to receive as much attention as autonomy, perhaps more.

Phase III — Big and Little Confidentiality Issues

Bioethics continues to analyze significant, systemic, societywide health care issues, but it is also paying more attention to small housekeeping concerns that were often overlooked as bioethics focused on the public, institutional, and conflict-ridden aspects of medicine. Nowhere is this divide more evident than in the analysis of

confidentiality and information management. Increased attention to justice in health care and the expansion of health care access has led health care delivery systems to evolve institutional and technological structures designed to provide economies of scale. But these structures often come at the expense of individual choice and confidentiality.

At the same time, small housekeeping issues concerning confidentiality, such as gossip in elevators and cafeterias, not only persist in health care institutions, but also arise in noninstitutional settings. Managed care structures, for example, give rise to confidentiality concerns on a grand scale — often attracting the attention of bioethicists, legislators, and the media; and similar concerns arise on a smaller scale in previously unexamined contexts, such as within families, in home health care contexts, and among co-workers. Recognition of the social context of health care concerns and the interrelationship between the macro- and microlevels of these concerns characterizes current bioethical analyses.

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Reform efforts have assumed that if access to health care is to be expanded and health care costs contained, then patients' range of choice regarding physicians and their privacy within the physician-patient relationship will have to be limited. Managed care's integration of payors and providers requires that the payor have oversight of

patient care plans. Moreover, the integration of care within some managed care structures multiplies the number of providers who have access to an individual's medical records. The increased number of administrators and care providers who have access to medical information raises the confidentiality concerns that Siegler had identified in hospital-based acute care medicine.

Clinical practice guidelines, introduced to help provide a uniform standard of care and ensure efficient use of resources, along with quality assurance and economic analysis, necessitate the banking of data regarding patients, providers, and clinical outcomes. This gathering of otherwise confidential information (though well within Siegler's need-to-know parameters) is designed to benefit patients in the aggregate, not specifically the individual patients whose information is collected.

Some of these reforms have expanded access to health care for those who previously lacked primary care. For them, changes in the system enhance their access, provide some continuity in care, and assure them greater confidentiality protections than were available in emergency departments and large public clinics. For patients accustomed to a more traditional doctor-patient relationship, managed care structures, increased computerization, and more oversight have merely increased their concerns about confidentiality. The proposal to issue Health Security Cards helped guarantee the political failure of the American Health Security Act of 1993, and a similar provision in the 1996 Health Insurance Portability and Accountability Act has prompted discussion in the *New York Times* under headlines like "Hippocrates vs. Big Brother" (Healy 1998). In the trade-offs of managed care, the subtitle of another *Times* commentary provides the motto: "Forget privacy. The only issue now is access" (Powers 1998).

Even without the specters of government as big brother and computer programs powerful enough to store an individual's lifetime medical record, the growth of employer-provided health insurance has heightened concerns about confidentiality and informational privacy. While employers are not

permitted to discriminate against individuals on the basis of health information not related to job performance, co-workers' attitudes cannot be legislated. Especially in small companies where a single large claim can raise the premiums for everyone in the group plan, workers have an increased interest in the health of their co-workers.

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Even if the confidentiality of insurance claims or company medical records can be assured, subtle encroachments on informational privacy by curious co-workers may become problematic. Curiosity may stem from self-interest, as medical leaves, multiple (or complicated) pregnancies, and other signs that the company's insurance plan is reimbursing high health care expenses may prompt co-workers to feel resentment, rather than empathy, for those incurring the expense.

Other features of the current health care system raise microlevel concerns about confidentiality. Managed care's cost savings, for example, rely on providing care at the lowest level possible. Many procedures previously requiring hospitalization are now done on an out-patient basis, and patients have shorter hospital stays on average. One effect of sending patients home "quicker and sicker" is the increased role played by professional home health care workers and informal caregivers (e.g., spouses, daughters, other relatives, and close friends).

Home health care workers are privy to more private information in a month's worth of visits than most family doctors glean in a lifetime of office visits. They not only have access to medical information, but also to private information about the patient's living situation and private relationships. Many professionals involved in home health care, including physicians, nurses, and social workers, have a professional ethos of maintaining confidentiality. In addition, many home health care agencies have developed policies to help all employees maintain the confidentiality and privacy of their clients. Nevertheless, these policies are limited in scope and require interpretation.

Bioethics has not offered much guidance for interpreting such policies. How should a home health aid reply when the son of her patient asks, "So how is Mom doing today? Is she in any more pain?" In some cases, the son may be the one paying the bills. He may feel entitled to such information given his concern for his mother's health and his financial role in providing her care. His mother, however, may have requested that her reports not be disclosed to him. Home health care workers are especially vulnerable to being asked to breach confidentiality because of their relative isolation (within private homes), the intrafamilial context of the care they provide, and in some cases, gender and economic differences between themselves and their employers. More easily than other care providers, home health care workers may be intimidated or deceived by individuals seeking health information about patients, or they may believe that divulging confidential information is really in the best interests of those in their charge; yet bioethics has not considered the particular challenges that they face.

Informal or unpaid caregivers face a different sort of challenge vis-à-vis confidentiality. First, because many informal caregivers are nonprofessionals and only unofficial members of the "health care team," physicians may be reluctant to share information about patients that they might have been willing to share with a nurse (Backlar 1996). A patient, for example, who suffers

from depression and an operable malignancy, may have requested that her physician not discuss her depression with her family. When she returns to home care, however, her spouse and daughter-in-law may be handicapped in providing appropriate care by their lack of information. Informal caregivers may be unable to understand the medications and procedures they are charged to administer, or fail to recognize drug interactions, if they are not privy to the information professional health care providers' receive on a need-to-know basis. Depending on the type and level of care being provided, the informal caregiver's lack of information could seriously compromise the quality of the patient's care.

Second, the quality of the patient's personal relationship with the informal caregiver may be compromised by her fear that confidential information will be revealed because someone in the health care hierarchy believes that her informal caregivers need to know it. Similarly, caregivers to whom information is eventually revealed may feel betrayed because the patient did not inform them earlier.

On the other hand, informal caregivers not bound by the traditions and guidelines of health care professionals may be subjected to intense pressures to reveal information shared with them in confidence. Family members who would never "bully" a physician may manipulate or pressure other family members to divulge confidences. Women, for example, who are the traditional informal caregivers, "family historians" and sources of medical information, may lack power within their households to maintain confidentiality because of their gender or economic status. Bioethics should consider the challenges faced by these intimates who learn confidential information while providing health care.

Finally, although much attention has been paid to the dangers posed by large-scale computerized databases, national registries, and health identification card systems, little attention has been paid to the relatively small-scale technological innovations that also threaten breaches of

confidentiality.

There has, however, been some discussion of the use of facsimiles (faxes) (Genesen et al. 1994). The convenience and health benefits afforded by rapid information transfer make faxing patient records and other confidential information a permanent fixture in contemporary health care. The following preventive measures should be employed to address the risks to confidentiality presented by this technology:

- use a cover sheet addressed to a specific recipient that provides legal notice of the confidentiality of the faxed material,
- telephone ahead to ensure that the authorized party will receive the fax,
- educate staff members about the confidentiality of faxed material, and
- impose sanctions for breaches of protocols designed to ensure that faxed information is treated like all confidential information (Genesen et al. 1994).

Other "low tech" innovations have not received the same attention as faxing, perhaps because they do not involve obviously confidential medical records.

Personnel who telephone patients to confirm a physician's appointment or to report test results often reach an answering machine, yet many patients would prefer not to have others, including members of their household, know that they have an appointment with an HIV specialist, a psychiatrist, or mental health counselor. Disclosure of an appointment with specialists related to less stigmatizing conditions also breaches confidentiality and may have serious consequences for patients who have not yet shared their health concerns with family members.

To protect confidentiality, patients should be asked when making an appointment or undergoing medical testing, for permission to leave messages on the machine. Alternative arrangements should be made for patients who do not authorize the use

of this technology. Test results should be disclosed directly to the patient to ensure confidentiality, to provide the patient with an opportunity to ask questions about the test, and to encourage appropriate follow-up care. Ironically, though making test results available to patients through the Internet has attracted media concern (Freudenheim 1998), personal identification codes can be employed to restrict access to the Internet. Such security measures are not available for more commonly used low-tech machines, such as answering machines.

Many of these microlevel challenges to confidentiality in health care are the indirect result of broader social changes, including cost containment measures, changing norms governing affiliation among intimates (as within families), and forced intimacies between patients and ill-prepared caregivers.

Further, just as credit card companies ask for some identifying information before disclosing account information on the telephone, so medical personnel should negotiate in advance with their patients some way of ensuring their identity on the phone. Asking that a call be returned to a specific number will not protect the patient's confidentiality if that number is answered by someone who immediately identifies the doctor or clinic.

Computerized calling programs that are designed to confirm appointment times rely on the truthfulness of the person answering the telephone to provide a modicum of confidentiality. Such programs often ask "if you are not Mr. or Ms. X (patient's name), please hang up." These programs

cannot ensure privacy and should be used, if at all, only with the patient's prior permission and never in medical contexts where disclosure of a particular appointment may be expected to have serious negative consequences for patients (e.g., in an HIV clinic).

Similarly, patients should be asked about billing arrangements to determine whether their mail is private. Return addresses on bills should not inadvertently disclose information about the health concerns of their recipients.

With or without technological threats to confidentiality, it is impossible for health care providers to guarantee the secrecy of patients' appointments. Patients could, for example, be followed to their appointments by a worried family member. It is sufficient that providers take steps to make it difficult for others to discover confidential information about their patients, including the simple fact that a particular person is their patient.

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The Ethics of Informational Privacy — A Forgotten Nuance

During bioethics' first thirty years a great deal has been written about confidentiality. It is one of the most discussed topics in the literature, yet an important nuance has been omitted. Bioethics has focused on advising health care professionals. It has, following Tarasoff-style reasoning, focused on what is permissible and obligatory for health care professionals to do and on their exposure to legal liability. The emphasis of preventive ethics has been on what health care providers can do to decrease breaches of confidentiality. Such analyses say little about whether patients should inform their

intimates about their diagnoses, prognoses, or other health-related information.

Although it recognizes that patients have an interest in keeping information confidential, bioethics has not generally assessed the ethics of doing so, except when others' life or health is at serious risk. Other fields, like family therapy, have begun looking at questions of intrafamilial privacy (Imber-Black 1998); however, with few exceptions (Davis 1998), bioethics still ignores these issues. Bioethics' focus on the obligation of health care providers has not helped individuals decide how they can best manage the information that is important to them.

Bioethics needs to articulate these interactions and provide substantive guidance concerning confidentiality to all parties — professional and nonprofessional, intimate and nonintimate.

Challenges related to managing health-related information and maintaining spheres of informational privacy are exacerbated by changes in medicine and society. Preventive medicine attributes significance to personal information (e.g., about diet, lifestyle, and medical history) that was previously unacknowledged. Moreover, advances in genetics will increase the amount of information about individuals that is believed to have health-related significance. These developments are occurring against a backdrop that features an erosion of social regard for privacy.

To protect the values that ground concern for confidentiality, bioethics will need to address a triple threat to informational privacy — namely,

- preventive medicine's elevation of the value of health over other competing values,

- medical genetics' identification of personal information, and
- society's concern to contain health care costs.

The confluence of social norms and technological advances may be used to justify previously unwarranted incursions into informational privacy and to raise new questions, for example, whether a woman is obligated to tell her fiancé about her genetically-identified disease risk (or risk to their potential offspring), or how people should respond to well-intentioned questions about their cholesterol levels or weight. The combination of preventive medicine, genetic advance, and cost containment may lead to an ethos that sanctions a reevaluation of previously private information and decisions, and a definition of individuals as bundles of disease susceptibilities and health care costs. Although these concerns fall beyond the scope of confidentiality per se, bioethics must attend to them if only to preserve the fundamental values confidentiality is designed to protect.

Conclusion

In bioethical discussions of confidentiality, we can identify trends that mark three, roughly outlined phases of the field's development. Bioethics' initial focus was on the doctor-patient dyad; confidentiality was to strengthen and make that (presumably private) relationship productive, and the primary threats to confidentiality were constituted by the competing interests of third parties.

The focus of bioethics then shifted to the broader institutional structures of health care delivery and the threat to confidentiality presented by acute care medicine delivered by health care teams for the patient's own good. Observing these changes in health care and recognizing the advantages of both preventive and acute care medicine, bioethics adopted a preventive ethics stance to anticipate and prevent ethical problems and to promote ethically healthy practices, such as sharing information only on a need-to-know-basis.

Finally, as increased concern about access to health care caused additional changes in the

structure of health care delivery, bioethics was prompted to examine the interaction among systemic changes and macro- and microlevel challenges to confidentiality and informational privacy. Bioethics became, and must continue to be, attentive to how changing social practices and large and small technologies (ranging from genetic testing to portable phones), affect the ability of individuals to control private information about themselves.

We believe that bioethics currently needs to expand its focus from advising health care providers about protecting confidential information to helping patients think about the ethical issues associated with the acquisition of increasing amounts of medical information about ourselves and our intimates. Adoption of such an expanded focus invites bioethics to make new, substantive recommendations about how each of us, as individuals, handles an increasing amount of "private" health-related information.

References

- Backlar, Patricia. 1996. "Ethics in Community Mental Health Care: Confidentiality and Common Sense." *Community Mental Health Journal* 32(6): 513-518.
- Beauchamp, Tom L., and James F. Childress. 1983. *Principles of Biomedical Ethics*. 2d ed. New York: Oxford University Press.
- Beauchamp, Tom L., and Laurence B. McCullough. 1984. "Two Models of Moral Responsibility in Medicine in *Medical Ethics: The Moral Responsibilities of Physicians*. New Jersey: Prentice-Hall, Inc., pp. 22-51.
- Bok, Sissela. 1983. "The Limits of Confidentiality." *The Hastings Center Report* 13(1): 24-31.
- Davis, Dena. 1998. Privacy, Property and Family in the Age of Genetic Testing. Harvard Journal of Law and Technology Symposium. Harvard Law School, Cambridge, MA. May 2.
- Edwards, Rem B. 1988. "Confidentiality and the Professions" in *Bioethics*, ed. R.B. Edwards and G.C. Graber. San Diego: Harcourt Brace Jovanovich, pp. 72-81.
- Freudenheim, Milt. 1998. "Medicine at the Click of a Mouse: On Line Health Files Are Convenient. Are They Private?" *The New York Times*. August 12, C1.
- Forrow, Lachlan, Robert M. Arnold, and Lisa S. Parker. 1993. "Preventive Ethics: Expanding the Horizons of Clinical Ethics." *The Journal of Clinical Ethics* 4(4): 287-294.
- Gavison, Ruth. 1984. "Privacy and the Limits of Law" in *Philosophical Dimensions of Privacy: An Anthology*, ed. Ferdinand Schoeman. Cambridge: Cambridge University Press, pp. 346-402.
- Genesen, L., H.M. Sharp, and M.C. Genesen. 1994. Letter: "Faxing Medical Records: Another Threat to Confidentiality in Medicine." *JAMA* 271: 1401-1402.
- Gostin, Lawrence O., Joan Turek-Brezina, Madison Powers, Rene Kozloff, Ruth Faden and Dennis D. Steinauer. 1993. "Privacy and Security of Personal Information in a New Health Care System." *JAMA* 270(20): 2487-2493.
- Hasman A., Hansen N.R., Lassen A., Rabol R. and S. Holm. 1997. What do people talk about in Danish hospital elevators? [In Danish.] *Ugeskrift for Laeger* 159(46): 6819-6821.
- Healy, Bernadine. 1998. "Hippocrates vs. Big Brother." *The New York Times*. July 24, p. A19.
- Imber-Black, Evan. 1998. *The Secret Life of Families: Truth-telling, Privacy, and Reconciliation in a Tell All Society*. New York: Bantam Books.
- Mahowald, Mary B. 1996. "On Treatment of Myopia: Feminist Standpoint Theory and Bioethics" in *Feminism & Bioethics: Beyond Reproduction*, ed. Susan M. Wolf. New York: Oxford University Press, pp. 95-115.
- Powers, Richard. 1998. "Losing Our Souls, Bit by Bit: Forget Privacy. The Only Issue Now is Access." *The New York Times*. July 15: A19.
- Roberts, Dorothy E. 1996. "Reconstructing the Patient: Starting with Women of Color" in *Feminism and Bioethics: Beyond Reproduction*, ed. Susan M. Wolf. New York: Oxford University Press: 116-143.
- Siegler, Mark. 1982. "Confidentiality in Medicine—A Decrepit Concept." *New England Journal of Medicine* 307:1518-1521.
- Tarasoff v. Regents of University of California*, 551 P.2d 334 (1976).
- Tong, Rosemarie. 1996. "The Relationship of Feminism and Bioethics: Feminist Approaches to Bioethics" in *Feminism and Bioethics: Beyond Reproduction*, ed. Susan M. Wolf. New York: Oxford University Press: 67-94.
- Ubel, Peter A., Margaret M. Zell, David J. Miller, Gary S. Fischer, Darien Peters-Stefani, and Robert M. Arnold. 1995. "Elevator Talk: Observational Study of Inappropriate Comments in a Public Space." *The American Journal of Medicine* 99:190-194.
- Veatch, Robert M. 1972. "Models for Ethical Medicine in a Revolutionary Age." *Hastings Center Report* 2(June): 5-7.