

Harvard University
16th HIPAA Summit and Privacy Symposium
2008 August 17-21

Privacy as a Cultural Phenomenon

Susan E. Mazer
Healing HealthCare Systems
700 Smithridge Drive, Suite A102
Reno, NV 89502
smazer@healinghealth.com

1. ABSTRACT

Privacy, the power and ability to control one's own destiny, access to their person, and information about themselves, is a social construct, defined in a 'historical moment,' surrounded by social and economic factors that are changeable, using values born within a cultural context. For the most part, privacy is an ambiguous concept, self-declared and often not clear until it is breached. The individual can exercise his/her right to privacy and also waive this right in exchange for social accessibility, public acknowledgement, promotion, money, entertainment, and other considerations. Still, privacy is now defined as an inalienable right.

Thus, the difficulty of precisely defining and codifying privacy is matched only by the value with which it is protected and respected. Because the U.S. health system is a mirror of its multi-cultural, diverse population, the concept of privacy within healthcare is equally challenging to define, honor and uphold. Privacy regulations have brought unparalleled pressures on healthcare organizations to protect private and confidential information from reaching third parties. The challenge, however, is in the operational requirements of institutional healthcare where information must move freely and directly for the benefit of patients and where the same information that is required for patient safety can be used to their detriment. Further, as in the example of public health, the threat to privacy is born in a complex social system that requires information to survive and moves into the realm of what has been considered private to determine and find what is relevant. The dependency on human, social, and political systems for privacy to exist and have meaning remains its greatest challenge.

2. INTRODUCTION

Since the rapid onset of informational technologies, privacy as a cultural icon has been guarded and threatened, secured and stolen, defined and obscured. In many cultures, such as in China or India, where privacy exists on a minimal level, it is not perceived to be at risk because it is not expected. Basically, one cannot lose what one has never had. In the U.S., however, privacy is highly valued as evidence of a free society. Now interpreted to be a constitutionally guaranteed right, privacy and confidentiality have been legislated by congress and challenged in the courts. Most recently, with the Patriot Act, personal privacy has been at odds with national security. To some, national security takes precedent over individual rights; to others, protection of privacy is the very foundation of a free society.

Freedom and Privacy: Where it all began

Integral to the "pursuit of happiness," a concept based on John Locke's writings, was a fundamental belief in a right to privacy as it related to "life, liberty, and property". The right to own private property, together with the protection of privacy, was viewed as the underpinnings of a well-lived life. "Paradoxically privacy is also

described as a condition from which we should flee, promoting isolation, deprivation, and separation. It possesses the potential to entrap the powerless, eliminating their recourse to the public sphere.” (Inness, 1992, p. 7)

Bier in describing privacy in the fold of Western practice, states, "It is just as important for the individual to exercise and experience his uniqueness as it is for him to relate to the group." (Bier, 1980, p. 3) This conflict between the perceived right to privacy and support of individuation with the needs of the collective society is a tension that has existed from the onset.

The State of the Union: When the Individual meets everyone else

“Three issues which diagnose the situation of privacy in the Western world and, further, reveal some of the complexities of the notion of privacy itself: (a) the spatial-territorial conception of privacy in the Western tradition; (b) contemporary exhibitionism as an apparent voluntary cession of privacy; and (c) the technological invasion of privacy--its socio-cultural context and its significance.” (Bier, 1980, p. 4) Without question, privacy only exists and is only sought where there are two or more people. That its domain covers more than electronic records, a well-built fence, and Internet monitoring is not only fact, but also evidence of our developed world. At one time, privacy meant only the fence that surrounded a plot of land. It is because we are developed and our needs and definitions diverse, that the questions of how and what can be protected and what will and needs to remain public are so rich.

The Media Grapevine: The Ultimate Antidote to Privacy

Not to be ignored in the privacy discussion, media—print and broadcast media, Internet, cell phone users, - have each given themselves waivers on practicing the basic principles of privacy. Local newspapers publish marriage licenses, divorce decrees, birth certificates, obituaries, legal transactions, and (in some cities) traffic and criminal activities. They announce bankruptcies, thefts, traffic violations and other arrests. Freedom of the Press allows for total invasion of privacy at the risk of the reporter more than the individuals or groups being invaded. More so, media and the internet access to private information, the use of cell phone technologies and video cameras as small as a credit card, place individual privacy on hold by further challenging anonymity in public places.

Justified Paranoia: “The Moment of Truth” as an observer sport

One of the major social forces driving our changing conception of what information should remain closed and private and, concomitantly, what information should be made open and available to the public. As our expectations of privacy decrease, our expectations for receiving more information--our expectations about what is public--increase. Everything becomes fair game for our voyeuristic viewing pleasure. "As the information age enters a new millennium, there is a widespread assumption that nothing is out of bounds," writes Marc Sandalow in a weeklong San Francisco Chronicle series on the news media published in 1999. (Calvert, 2000, p. 78)

Calvert describes the “moment of truth” as perfected in the tell-all talk shows, yellow journalism, and standard ambush techniques used by the likes of Jerry Springer and others in secrets being revealed before millions of onlookers. (Calvert, 2000, p. 22) Once exposed to the shock and awe of these reality interviews, the viewing audience includes those who want to ensure themselves that what is private in their own lives remains private. They are the ones who look for privacy policies and promise themselves it will never happen to them.

At the same time, breaking down the wall of privacy has become basic everyday entertainment, making it more difficult to fully defend it. Commercial broadcasting has now brought to the afternoon television everything from products for incontinence to vaginal deodorants to *Viva Viagra!* to tampons. What was 50 years ago sold in brown wrappers (sanitary napkins) is now sold in super markets next to the cosmetic counters and pharmacies.

Therefore, when medical information that may deal with each of these products is claimed to be private, but accessible publically, how do we really know where the boundary is?

It is within this confusing, conflicting, and complex system of people, organizations, values, and agendas that healthcare finds itself having to balance its historic respect for individual privacy with an environment that

continually contradicts its practice.

Privacy: When a Person Becomes a Patient

The Oath of Hippocrates which is taken by all physicians, states that "Whatever, in connection with my professional service, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret." Patient privacy, based on this precedent promise of doctor-patient confidentiality, is intended to be for the full and uncompromised benefit of the patient. The reality, however, in a world where healthcare is an industry, an economy, where patient care competes with other interests, patient privacy has again been bartered and redefined.

Right to Privacy vs. Public Interest

Privacy in The U.S. health system does not have a pristine history of honoring its own intent. While law now protects private health information, it has been bartered for reasons of public health. In the cases of tuberculosis and polio, which were both airborne viruses, infected individuals found to be contagious were isolated, often sent to sanatoriums, with or without their consent. Premarital blood tests with 3-day waiting periods to confirm the absence of gonorrhea and syphilis were required by law for marriage licenses. If we venture further, the right of a woman to terminate an unwanted or unhealthy pregnancy, while resolved in the courts, remains unresolved in the public sphere. The debate has challenged patient-physician confidentiality, the right of a physician to make private medical decisions without public intrusion, and the rights of a woman to control the destiny of her own body. Further legal action has moved into the actual living practice of a pregnant woman, wanting to provide separate and priority rights for the unborn fetus, again a challenge to the integrity of personal privacy as yet unresolved.

The emergence of AIDS in the 1980s caused the next great debate regarding privacy vs. public health. The threat to personal privacy and risk of public disclosure to high risk populations discouraged resulted in increased risk of spreading the virus, job discrimination, and other ramifications. The balancing of these two conflicting issues remains the ultimate threat to public health.

Verbal privacy, unlike privacy of personal documented records or communications, is in the domain of human behavior and culture, not merely a matter of information control. Speech privacy is a spontaneous, circumstantial, fleeting, and unpredictable consideration extended to and by individuals or groups. Once invaded, what was once private becomes public, with all those now privy to disclosed information complicit in its dissemination for entertainment or other uses.

3. BACKGROUND

Institutions serving individuals in public places, such as hospitals, are not private. Both verbal and aural privacy are breached because spoken words and inadvertent listeners tend to meet in midair without notice. Privacy in public places is based more on anonymity than on invisibility. Furthermore, providing for privacy in an open and highly populated culture is based on acceptance that little is private and only protected by anonymity.

Patient privacy is demanded but often only minimally provided. In a waiting room lined with rows of chairs facing each other in even lines, information is openly shared between family members with the assumption of anonymity. In emergency departments, the identification and use of privacy curtains are misleading given that the scope of privacy is broad and the curtain's function, greatly limited.

For patients in breast care clinics, for instance, curtains and wrap-around robes provide privacy to a degree; however, having to walk down a hall to the mammogram room can be uncomfortable. Cloth garments in a physician's office have been exchanged for paper ones and doors often open into the exam rooms, exposing scantily clad patients to the public corridor. Admitting areas look more like bank counters with multiple tellers and one

patient is overheard providing medical histories, insurance data, and other private information while sitting less than three feet from another patient. To this day, despite all the pressures to the contrary, in many outpatient clinics, names are called aloud as if in a fast food restaurant, and staff yells to the hearing-impaired elderly without regard to whom else is within earshot.

Historically, patient and family privacy was not so much of an issue, as physicians made house calls and few patients were admitted to any hospital. Today, because of the nature of institutionalized healthcare, the built environment, bureaucratic procedures of our employer-based healthcare system, and the fiduciary nature of the patient-physician relationship, privacy now requires policy declarations, legislation, and judicial review.

Furthermore, while acoustic treatment can temper the risk within healthcare settings, the nature of how we offer care provides easy pathways for information to be freely transmitted. Given that the need for privacy has not lessened, other industries have demanded solutions. The answer that came forth from engineering schools has been a second layer of acoustic engineering, the purpose of which is to ostensibly undo speech intelligibility and auditory clarity.

The question is whose task it is to ensure privacy and whose skills and technologies pose the greatest risk or provide the greatest protection.

4. WHAT IS PRIVACY IN HEALTHCARE?

Protecting a patient's privacy in a hospital requires some degree of isolation, separation, secrecy... some degree of each of these, which a patient and family may or may not want. Both are aimed at preventing unwanted penetration of the information gate and escape beyond it. Both also conflict with the objectives of institutional healthcare. Practicing efficiency, effectiveness, and fluidity of communication for the most people congregated in one location oppose the ideals of individuality, personal preference, and controlled communication.

Hospital administrators, patients, and family members are facing a similar conflict in complying with the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Among other requirements, HIPAA called for standards protecting the confidentiality and integrity of "individual identifiable health information" for the present, past, and, future. First and most obvious is the challenge of resolving the tension between keeping some third parties out of one's private health affairs while letting others in. HIPAA is intended to resolve this, but has not done so. It has caused more confusion, more cost, and more complexity to compliance efforts. In spite of good intentions, communication technologies, the lack of auditory soundproofing, visual violations (charts, monitors, and letters in plain view) are all fairly effective in breaching HIPAA regulations.

Privacy vs. Immediacy

When it comes down to the reality of health or illness, patients expect needed information to flow easily across the pathways of care giving and not be trapped by red tape. Families cringe at the idea that the right hand of the primary care physician does not know what the left hand of the surgeon is doing. Delays in information being passed between interested parties because of the new HIPAA mandates could be costly, frustrating, and possibly life-threatening.

While in the process of guarding individual privacy, in the middle of noisy corridors and waiting rooms, confidential information needs to be quickly transferred from physician to nurse to family member to others for the care of patients. Noise levels force confidential conversations to rise above the din. The common "privacy curtain" affords neither privacy nor confidentiality.

Resolving the inherent tension between accessibility and privacy are not easy or completely solved by engineering or design specifications. It is ultimately the culture of the healthcare organization that determines the "sound" of a hospital. There are proven solutions to address culture in tandem with architectural and acoustic design interventions.

So, what is realistic in evaluating the effectiveness of the well-intended and imperfect HIPAA mandates? Who is responsible for providing an environment in support of HIPAA? Does the cultural context advocate for private or public disclosures? Who or what is sacrificed?

Hearing and Listening: The Public Conduit

For all the reasons stated and circumstances described, the greatest ambiguity regarding privacy occurs in the auditory environment. Absolute auditory confidentiality does not exist or is rare at best. Regardless of acoustic treatment, closed doors, and barriers of the highest quality, hearing acuity is uncontrollable and immeasurable. A child, who seemingly hears sounds and words that adults fear most, knows no confidentiality. Adults, whose hearing is impaired most of the time, hear words and inflections and translate them into whole news stories with varying degrees of accuracy. Likewise, nurses and physicians appropriately exchange critical information at the right time and in what is now labeled as the wrong place. Patients whose rights have been violated may be either grateful or resentful, depending on the news and their situation.

Charles Fried of Yale Law School stated that “privacy is not simply an absence of information about us in the minds of others, it is the *control* we have over information about ourselves. It is not simply control over the quantity of information abroad; it is the ability to modulate the quality of the knowledge as well. We may not mind that a person knows a general fact about us, and yet we feel our privacy invaded if he knows the details.” Furthermore, we are far more comfortable if the “knowing of us” does not include our name, address, and phone number. In common practice, extending “respect” for another’s privacy refers to not intruding or interfering. It does not refer to not overhearing, not trying to overhear, not having an opinion about what is overheard, or not telling others what was overheard.

Under other circumstances, overheard information is information stolen without notice, similar to seeing what one should not see. It is auditory voyeurism, enjoyed for the same reasons, with far more opportunities.

5. THE ONSET OF HIPAA

HIPAA was, in part, passed because confidential information was being transmitted through various uncontrolled conduits and could be accessed by unknown third parties. While HIPAA does address verbal confidentiality, it uses a soft standard of “reasonableness” and “good judgment” in practice. These standards are far from quantifiable. Hospitals and other providers are implementing specific protocols to protect written and electronic records and, as yet, have not been able to harness the massive amounts of information exchanged verbally. Communication technologies such as internal cell phones and pagers are perhaps the most efficient methods of transmitting information and reaching persons critical to patient care. However, they also present one of the greatest challenges to confidentiality and privacy.

Where communication and its technologies meet is in the auditory environment. While acting as a tether between critical patient needs and those who care for them, the cell phones and pagers that have brought staff together for the intention of expediting patient care decisions, these technologies are now an ongoing challenge to privacy and confidentiality. Furthermore, their use wherever the person in question is standing contributes to the noise factors that need to be controlled.

Perhaps over simplified, *who*, *what*, *where*, *why* and *when* are the major tests of HIPAA’s regulatory triggers, which are only evaluated when a claim of violation is filed. In the HIPAA standards, compliance is voluntary and so are complaints. The ambiguity is so apparent that even HIPAA authors made it the task of patients to insist on enforcement, dealing with the standards on a reactive basis. The Privacy Rule published by the Department of Health and Human Services, which summarizes and explains HIPAA is laced with exceptions, ambiguities, and suggestions for practicing an intention to keep private even when it is not possible. That said, enforcement of HIPAA is complaint driven. HIPAA is ultimately being verified in practice with the standards set forth to contain what seems uncontrollable have yet to be fully tested in all of its aspects.

Inside the healthcare arena, HIPAA has determined that *who* —patients’ identity—and *what* —their diagnosis or condition or other information— are to be assumed confidential (inside the privacy fence) unless otherwise indicated. *Why* information is exchanged is perhaps the most critical place where definition and protection is needed. The Privacy Rule clearly states that privacy is not to take precedence over patient safety or medical communications requisite for patient care. Nonetheless, motives behind information seeking and management are perhaps the major fear to the patient. However, *where* information is exchanged and *when* the information should be accessible are also more questionable and leave much room for dispute, delay, and confusion.

6. RESEARCH: HOW PRIVACY IS PERCEIVED AND ITS OUTCOMES

In a report titled “The Role of the Physical Environment in the Hospital of the 21st Century,” Ulrich and Zimring cite research showing that physicians and nurses very frequently breach patient confidentiality and privacy by talking in spaces where they are overhead by other patients or persons (Ubel, Zell, & Miller 1995). They also further mention a study of an emergency department at a university hospital that showed 100 percent of physicians and other clinical personnel committed confidentiality and privacy breaches (Mlinek & Pierce 1997).

Privacy, Space, and Time

The environment of care is spatial and temporal. It is a place and a time so undefined as to imply everywhere and all the time. Nonetheless, there are very effective means of designing privacy and confidentiality into the environment in ways that support the ethics and practices of providers while providing the intended protections for patients and families. Visual barriers, conditioned sound environments, and ongoing monitoring of the density of people provide clues as to whether patient privacy (and dignity) are being tended to adequately.

A study that looked at patient’s perception of privacy and related outcomes (Barlas et al. 2001) showed that patients withheld medical information when they only had a curtain barrier as opposed to walls. Clearly this implies that auditory privacy -- as it is perceived and experienced -- impacts patient safety. It also implies that patients who overhear confidential information from their own bed or gurney believe that they are being overheard. In this study, some patients refused parts of their physical exam because they felt that they had no privacy.

The nature of noise and its impact on communication adds one more threat to auditory privacy. The “Lombard Effect,” which causes people to raise their voices above the noise floor, increases the chances of information penetrating the privacy walls (Atushi, et al). In their review of the impact of the Lombard effect on speech recognition, Atushi found that the louder the noise, the less accurate was speech recognition. The implication is that errors could be made in a noisy setting and, as well, perception of privacy is threatened. The louder it is, the louder it gets. The louder it gets, the greater chance the one voice will rise above the others, and with the voice comes misunderstanding or inaccuracies of communication as well as breaches of privacy.

By balancing the use of opaque visual barriers with transparent sound baffles, such as acrylic walls, providers and patients alike can better learn to trust what surrounds them. Nursing stations that are accessible but not exposed, controlled paperwork (as long as it exists), and computer monitors that are placed with cautions regarding use and misuse are not difficult to implement, if thought through carefully.

Nonetheless, the question remains of the role and responsibility of providers. Does responsibility for control of oral information fall within the scope of work of acoustic/noise control engineers, caregivers, patients themselves, or their families? Once made public in any form, does the confidentiality veil still hold?

6. CONCLUSIONS

Privacy is a social construct and is defined as contextual, void of absolute definition. A paradox, it

contradicts the nature of social order while preserving it. That said, privacy has been held and valued as a vital evidence of a free society, allowing individuals the right to control their own destiny, access to their person, and information about themselves.

Where private and public interests collide is in the arena of healthcare. Safety for patients and effective care requires a healthcare environment that is not a militarized zone of secrecy where needed information is put into unintended isolation. A new standard and practice of information management is needed that will allow information to flow freely between interested parties and secure the same information from disinterested parties. Ultimately, time and practice will reveal what is best and practical for the optimal outcomes for everyone involved. However, for HIPAA to be an effective policy and not a liability, the environment in which patients are cared for must no longer be considered just a regulation or a good idea, but must be acknowledged as the custodian, if not the guardian, of privacy, confidentiality, and, currently, HIPAA compliance.

The dictates of HIPAA and the right to privacy are easier spoken, said, and demanded than accomplished. Within the auditory environment lie the keys to privacy as well as confidentiality. However, when using the paradigm of the noise society vs. the surveillance society, it is clear that the most difficult task is to remain an “anyone” and only to become “someone” by choice and intent.

Current solutions or efforts at protecting privacy directly impact communication, audibility, and primary information containment. However, none of the solutions, on their own, can guarantee or effectively control the auditory privacy. Moving the sounds out of the generic wash of random noises into the specific experience of a patient, family, and caregiver are a cultural task and, with HIPAA, a professional obligation. Bringing together organizational ethics of privacy with acoustic treatment offers the strongest and most effective strategy for protecting individual privacy.

Privacy is a perception, a courtesy, a practice, a right, and a promise. It is realized through a dynamic partnership between substantive and evidence-based design and function, between the built environment and those who use it that will best improve the chances of protecting information and individuals.

Susan E. Mazer is the President and CEO of Healing HealthCare Systems in Reno, Nevada. Her principal areas of service are noise management strategies for hospitals, design and implementation of healing environments, and patient privacy.

Mazer's accomplishments include bringing the issue of hospital noise to the forefront of hospital concern through designing accredited educational programs for nurses and presenting at national conferences. She has spoken at The Healthcare Forum, The Association for the Care of Children's Health, The Clinical Lab Manager's Association, Annual U.S. Department of Education Safe and Drug Free Schools conference, the National Symposium on Healthcare Design, Environments for Aging '08, and presented two white papers on speech privacy and HIPAA for the Institute of Noise Control Engineers and American Acoustic Society. In December of 2007, she was acknowledged as an industry leader in the "Who's Who" of FacilityCare for her work in hospital noise control. She is the co-author of Sound Choices: Using Music to Design the Environments in which You Live, Work, and Heal, published in 1999 by Hay House.

Healing HealthCare Systems produces the C.A.R.E. Channel, 24-hour relaxation programming for patient television, and is currently working with over 400 hospitals nationally, including 72 magnet hospitals. She is also an internationally known jazz harpist, composer and recording artist. Susan can be reached at smazer@healinghealth.com, www.healinghealth.com

REFERENCES

- Atsushi WAKAO, Kazuya TAKEDA and Fumitada, "Variability Of Lombard Effects Under Different Noise Conditions," ITAKURA Graduate School of Engineering,
- Bier, William C. S. J. (1980). Privacy in the Tradition of the Western World. In *Privacy: A Vanishing Value?*, Bier, W. C. (Ed.) (pp. 3-19). New York: Fordham University Press.
- Barlas, D., Sama, A. E., Ward, M. F., and Lesser, M. L. 2001. "Comparison of the auditory and visual privacy of emergency department treatment areas with curtains versus those with solid walls." *Annals of Emergency Medicine*, 38(2):135-139.
- Brin, D. (1998). *The Transparent Society: Will Technology Force Us to Choose between Privacy and Freedom?*. Reading, MA: Perseus Books.
- Calvert, C. (2000). *Voyeur Nation: Media, Privacy, and Peering in Modern Culture*. Boulder, CO: Westview Press. Retrieved July 15, 2008, from Questia database:
<http://www.questia.com/PM.qst?a=o&d=55110585>
- Etzioni, A. (1999). *The Limits of Privacy*. New York: Basic Books
- Fry, B. R. (1989). *Mastering Public Administration: From Max Weber to Dwight Waldo*. Chatham, NJ: Chatham House Publishers.
- Furrow, D. (2004, May/June). The Privacy Paradox: In Keeping with the Policy of the Humanist to Accommodate the Diverse Cultural, Social, Political, and Philosophical Viewpoints of Its Readers, *The Humanist*, 64, 25+.
- Inness, J. C. (1992). *Privacy, Intimacy, and Isolation*. New York: Oxford University Press.
- Jacoby L., A. Bishara, S. Hessels, and J.P. Toth, 2005. " Aging, subjective experience, and cognitive control: dramatic false remembering by older adults," *Journal of Experimental Psychology*, 134(2):
- Mlinek, E. J., & Pierce, J. (1997). "Confidentiality and privacy breaches in a university hospital emergency department." *Academy of Emergency Medicine*, 4(12), 1142-1146.
- Nagoya University Furo-cho 1, *Chikusa-ku, Nagoya, 464-01 JAPAN* takeda@nuee.nagoya-u.ac.jp
- Ulrich, R., and Zimring, C. 2004. "The role of the physical environment in the hospital of the 21st century." The Center for Health Design. Berghofer G., Lang A., Henkel H., et al. 2001. "Satisfaction of inpatients and outpatients with staff, environment, and other patients." *Psychiatric Services*, 52(1): 104-6
- United States Department of Health and Human Services, *The Privacy Rule and HIPAA Standards*.
www.hhs.gov
- U.S. Congress, Office of Technology Assessment, *Protecting Privacy in Computerized Medical Information* , , OTA-TCT-576 (Washington, DC: U.S. Government Printing Office, September 1993).
http://www.csu.edu.au/learning/ncgr/gpi/odyssey/privacy/ota_pc.html