

Intercultural Communication in Healthcare and the Medical Privacy Debate

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Medical Privacy and Medical Records

The history of the rise of privacy as a public issue in the United States may have started with an 1890 article by Samuel Warren and Louis Brandeis that spoke of "the right to be let alone." (Gangloff, 2007). It took decades for courts to begin articulating this right and comprehensive federal laws did not appear until the 1970s. However, it was not until the late 1990s and early 2000s that medical privacy became a right as a result of healthcare privacy legislation. Today there are stricter privacy laws in effect to regulate who has access to patients' medical records.

As stated by the U.S. Department of Health & Human Services (2003), the *Standards for Privacy of Individually Identifiable Health Information* (Privacy Rule) establishes, for the first time, a set of national standards for the protection of certain health information. The U.S. Department of Health and Human Services (HHS) issued the Privacy Rule to implement the requirement of the Health Insurance Portability and Accountability Act of 1996, known as HIPAA. The Privacy Rule standards address the use and disclosure of an individual's health information—called "protected health information" by organizations subject to the Privacy Rule—called "covered entities," as well as standards for individuals' privacy rights to understand and control how their health information is used (U.S. Department of Health & Human Services, 2003).

HIPAA and other privacy laws set rules and limits on who can look at and receive an individual's health information. According to the U.S. Department of Health & Human Services, (2003), information can be used and shared for one's treatment and care; to pay doctors and hospitals for one's health care and to help run their businesses; with one's family, relatives, friends, or others an individual identifies who are involved with their health care or health care bills, unless they previously object in writing. Completed consent forms by the patient are a critical step in ensuring patient's privacy.

Other ways an individual's medical information can be shared includes protecting the public's health, such as reporting when the flu is in an area; and when information can be shared to submit required reports to the police, such as reporting gunshot wounds. Patients' health information cannot be used or shared without their written permission unless law allows it. For example, without written authorization, a patient's provider generally cannot give one's

information to their employer; use or share one's information for marketing or advertising purposes; or share private notes about one's health care.

Since HIPAA was enacted in 1996, Congress mandates the establishment of Federal standards for the privacy of individually identifiable health information. When it comes to personal information that moves across hospitals, doctors' offices, insurers or third parties, the United States has relied on a variety of federal and state laws. Under the laws existing prior to adoption of HIPAA, personal health information could be distributed—without either notice or authorization—for reasons that had nothing to do with a patient's medical treatment or health care reimbursement. For example, unless otherwise forbidden by state or local law, patient information held by a health plan could, without the patient's permission, be passed on to a lender who could then deny the patient's application for a home mortgage or a credit card, or to an employer who could use it in personnel decisions (Garfinkel, 2001).

Health care providers have a strong tradition of safeguarding private health information. However, in today's world, the old system of paper records in locked filing cabinets is not enough. With information broadly held and transmitted electronically, the Privacy Rule provides clear standards for the protection of personal health information.

A major goal of the Privacy Rule is to assure that individuals' health information is properly protected while allowing the flow of health information needed to provide and promote high quality health care and to protect the public's health and well being (U.S. Department of Health & Human Services, 2003). A balance needs to be met that permits important uses of information, while protecting the privacy of people who seek medical treatment. The recent growth of electronic records has spurred further privacy regulations.

Electronic health records (EHRs) create conflict among several ethical principles. Electronic health records are alleged to increase access to health care, improve the quality of care and health, and decrease costs. Research, however, has not consistently demonstrated access for disadvantaged persons, the accuracy of EHRs, their positive effects on productivity, nor decreased costs (Layman, 2008). Autonomy is jeopardized when patients' health data are shared or linked without the patients' knowledge. Fidelity is breached by the exposure of thousands of patients' health data through mistakes or theft. Lack of confidence in the security of health data may induce patients to conceal sensitive information. As a consequence, their treatment may be

compromised. Justice is breached when persons, because of their culture, socioeconomic class or age, do not have equal access to health information resources and public health services. Layman (2008) suggested that health personnel, leaders, and policy makers should discuss the ethical implications of EHRs before the occurrence of conflicts among the ethical principles.

The delivery of medical care is much more than the intersection of human bodies with technology, medications, and surgical interventions; rather, it relies upon communication to exchange information, beliefs, feelings, and cultural worldviews in order to make effective diagnoses and to develop treatment plans that work. Making the dimension of cultural communication more critical in medicine is the fact that today, in the United States, the diversity of the population is enormous, and growing more diverse. The fact that 23% of all doctors are educated abroad illustrates the criticality of intercultural communication in health care (Martin & Nakayama, 2008). The question therefore arises: what happens when there are cultural or language barriers between a physician, a patient and their family? When cultural communication challenges arise can medical privacy remain intact? These questions and the impact of intercultural communication barriers, and its effect on patients' proper care are explored in this paper.

Privacy is crucial to safeguard personal information against unauthorized or unjustified disclosure. It is a foundational protected right that respects personal dignity and protects patients from embarrassment, stigma, and discrimination. Scott (2000) stated that under current federal law, the records of which videos you rent are given more protection from police snooping than your medical records. Privacy also has societal value because it encourages individuals to participate in socially desirable activities, including research and public health activities.

Virginia Tech Shooting and HIPAA

Johannesen, Valde, & Whedbee (2007) discussed the media coverage of the Virginia Tech shooting that occurred April 16, 2007, which raised ethical questions about what responsible media coverage, and medical ethics questions were raised pertaining to the shooter's past medical history and mental illness. The Virginia Tech shootings brought new scrutiny to the complex and little-understood laws that govern information privacy. It was those laws that prevented anyone from getting a full picture of Seung-Hui Cho, the gunman –of his

years of behavioral and mental health problems – before he killed 32 teachers and fellow students, then shot himself – according to a Virginia state review panel that issued its report in August 2007 (Gangloff, 2007). Killing is always unethical (Johannesen, Valde, & Whedbee, 2007).

Gangloff (2007) stated that medical providers, especially mental health providers, are often cautious about sharing sensitive treatment information long before HIPAA. HIPAA is clear that information can be shared for treatment purposes. HIPAA did not, however, make any new requirements that data be shared. HIPAA and other privacy laws do not allow sensitive information to be distributed by email, since it is not secure enough, but current legislation and new healthcare reform may allow email since EHRs will soon be the norm, as paper charts become obsolete.

Importance of Communication in Health Care

A widely varying series of ethnocentric issues may arise between health care providers and their patients during the course of health care delivery. These topics, for example, might include medical issues such as mental illness, sexually transmitted diseases, abortion, flu, and end-of-life decisions, each presenting different cultural stigmas. Trust-related issues between physician and patient are another aspect that depends highly in intercultural communication in the health care setting (Martin & Nakayama, 2008). Some cultures—like high context Asian cultures—generally expect indirect, circumspect, and gentle discussion between a doctor and patient when it comes to serious medical topics. To approach it otherwise is seen as cruel and can result in the patient being removed from the care setting by the family (Kagawa-Singer & Blackhall, 2001). Other cultures, on the other hand, such as White Americans, generally expect very direct, highly informed exchanges of information. Thus, if the patient is White, or Asian, or Black, or Hispanic—and depending on the background of the physician—the differing cultural frameworks may profoundly impact the openness of the patient with the doctor, as well as the doctor's ability to treat the patient effectively.

Health care workers may view patient's records for various reasons including curiosity (e.g., about friends, neighbors, relatives, or celebrities), perversity (e.g., sexual interests), anger (e.g., an employee who is about to be or has been fired), or a desire for financial or political gain

(Scott, 2000). Unauthorized browsing of medical records effects the relationship of the “browser” to the patient which can lead to distrust, and is an abuse of privileges. Many times the viewing of patient records is not detected. As Scott (2000) explained, distinguishing between an abuse of medical privacy from a legitimate need to see a patient’s records is often a difficult question.

Patient-doctor communication is essential to effective care of the patient. Scott (2000) stated that in a recent study, one in six Americans reportedly engaged in privacy-protecting behaviors, such as switching doctors, paying for health care out of pocket, asking a doctor to not write down certain information in their record or to record a less serious or embarrassing health condition. Another common practice is for a patient to not give accurate information about their medical history, or to not seek medical attention at all for a problem. Scott (2000) explained that although these tactics or “privacy-protecting behaviors” raise obvious health risks, but many Americans feel their medical privacy is jeopardized if they reveal too much information. There is an ethical intuition that an individual feels—that one is entitled to have their medical information be kept private unless an individual gives express consent.

Although physicians, nurses, and other health care professional’s ethical codes protect patient’s privacy, privacy is valued in principle but is not considered an absolute ethical right. The American Medical Association's (AMA) Medical Ethics Code begins with a clear affirmation of the privacy right and a strong prohibition against disclosures: "The patient has a right to confidentiality. The physician should not reveal confidential communications or information without the consent of the patient" However, the Code moderates this language with a qualification on the privacy principle: "... Unless provided for by law or by the need to protect the welfare of the individual or the public interest." (Scott, 2000) This exception has proven contradictory in many cases, and not always in the best interest of the patient.

Intercultural Health Care Barriers

Historically, different cultures and races have not been offered the best medical care because of cultural differences, miscommunication, or prejudice. The “Tuskegee Study of Untreated Syphilis in the Negro Male,” also known as the Tuskegee Syphilis Project, was a

clinical study conducted between 1932 and 1972 in Tuskegee, Alabama by the U.S. Public Health Service on unsuspecting African Americans who sought out medical treatment for syphilis (Martin & Nakayama, 2008). The 40-year study was controversial for reasons related to ethical standards, primarily because researchers failed to treat patients appropriately after the 1940s validation that penicillin was an effective treatment for the disease. The black patients were given placebo sugar pills, and were not told that they were part of a study. While the Centers for Disease Control received only one letter from a physician who raised ethical concerns, Senator Edward Kennedy finally stopped the study after a public denouncement was made in Congress. Because of this study and other racial discrimination, African Americans have been shown to hold greater awareness of historical discrimination in the health care system than White Americans, which has led to less trust of clinicians among black Americans (Martin & Nakayama, 2008).

Another area of health care discrimination related to the slow response to HIV/AIDS in the 1980s by the federal government because the disease first affected gays. As Martin & Nakayama (2008) explained, a disease that strikes a minority of the population (in this case gays, people of color, drug users, and poor people), did not receive the same or adequate medical attention that the rest of the population received. Likewise, this inequality in care fostered a lack of trust between minority communities and health care providers. When mistrust occurs, a patient may seek out medical help in their immediate community, or turn to alternative medicine (such as gays did in seeking help with AIDS). However, in recent years as a result of health care promotions and less discrimination, minorities are slowly regaining trust in seeking healthcare and listening to their clinicians.

It is important to realize that simply because an individual attends nursing or medical school does not purge feelings of racism, homophobia, sexism or other kinds of prejudice from these future health care providers (Martin & Nakayama, 2008). Prejudicial ideologies, or sets of ideas based on stereotypes can affect health care professionals and patients. If a patient's medical chart is in a different language or if they speak a different language, a health care professional in the U.S. cannot legally treat the patient unless a translator is present. But what if the translator is the patient's spouse and the patient is asked about a sexually transmitted disease

that the spouse could have potentially given the other? This raises ethical and legal questions regarding how the patient can be treated.

Religion and Health Care

The topic of religion and spirituality in health care is also an area that requires significant intercultural communication awareness and skills, especially when doctors encounter serious medical and end-of-life topics with patients and their families. Does the patient of other cultural orientations believe in God? Or is he or she atheist or agnostic? What is the patient's view of the role or spiritual importance of suffering in life, or the degree to which advanced life support interventions should or should not be considered? What is the religious view as it impacts choices around hospice care, and the role of family in caring for the seriously ill or dying? In these situations, health care providers must be mindful not to impart their religious views on the patient. Learning skills such as taking a religious history, encouraging other's beliefs, providing access to spiritual resources, and even seeing clergy as part of the health care team opens up significant avenues of intercultural communication and exchanges, but in a way intended to tread gently and respectfully (Martin & Nakayama, 2008). Privacy laws need to be implemented and practiced among these patient, doctor and clergy relationships.

In the U.S. medical paradigm, however, the physician is placed firmly in the position of authority: the holder of more knowledge about the patient than the patient has about him or herself, and the gatekeeper of access to treatment. This raises the topic of power imbalances between patient and physician, and represents yet another key aspect impacting intercultural communication in health care.

Power in Health Care Communication

Doctors have power over their patients. Inherently, there is an imbalance of power regarding medical knowledge and access to treatment, since patients need their doctor to write prescriptions, give referrals to specialists, order medical tests and doctors ultimately determine what kind of treatment the patient receives (Martin & Nakayama, 2008). Physician-patient communication could be challenged by the patient, but the power imbalance is built into the health care system in the United States.

When we think about our experience when visiting a doctor, many questions come to mind. How do we talk to our doctor and explain our problems? Are the doctors helpful? If we should call a doctor by his or her first name, will they see it as a challenge to the power balance? Is the doctor a staff physician or an Intern? How many patients does the health care provider see in a day? Are cultural differences or communication barriers at the doctor's office obvious? The bottom line is that a patient needs to communicate with his or her doctor, and if the patient is not getting the desired results, the individual must speak up or find another physician. Culture clearly impacts this interaction, and when intercultural communication issues are not embraced—when doctors cannot find ways to respect the cultural differences and needs of their patients—power imbalances can result in less than desired health care outcomes.

Communication in health care is essential. Effective communication is crucial between the patient and provider, because misunderstandings can lead to misdiagnosis and even death. Intercultural communication competence (ICCC) is important to understanding different cultures and how to interact on an effective level (Gibson and Zhong, 2005). Language barriers and empathy can lead to miscommunication in the health care setting.

As Martin & Nakayama (2008) explained, another important and controversial intercultural communication issue relates to whether Health Maintenance Organizations (HMOs) ration health care resources, since obtaining approvals to access care is often not easy or automatic. Patients in other countries where health care is provided by the government are confused by the private health care system in the United States. HMOs and other private practices are businesses, and patients from other cultures need to understand what kind of impact the U.S. model of “health care as business” has on their health. Privacy of patients records when many people (in HMOs and large medical facilities) have access to the records, increases risk of exposure about potentially damaging medical information to unauthorized third parties.

Ethics Committees and Decision Making

In most medical facilities, multidisciplinary ethics committees have been established to help provide informed decision making, and to help avoid malpractice suits. Such ethics committees are often used by health care organizations to help make ethical decisions in challenging medical cases. As Martin & Nakayama (2008) explained, the committees are staffed

by health care professionals, religious leaders and/or social workers. Moreover, study failures, such as the Tuskegee Syphilis Project, have led to major changes in U.S. law and regulation regarding the protection of participants in clinical studies, including the necessity for informed consent, communication of diagnosis, and accurate reporting of test results.

In many cultures, as noted earlier, the family is also very involved in the health care delivery of other family members. However, in the United States medical information is confidential and is only given to the patient, unless consent is waived by the patient, or if the patient is incapacitated or incapable of understanding, in which case other family members may then make medical decisions (Martin & Nakayama, 2008).

Argumentation

Claim

Patients should have protected private health and medical records.

Warrant

When dealing with patients, medical providers should put the patient's needs first, and maintain the patient's medical records privacy. Disregarding privacy laws is unethical.

Grounds

Privacy is crucial to safeguard personal information against unauthorized or unjustified disclosure. It is a foundational protected right that respects personal dignity and protects patients from embarrassment, stigma, and discrimination.

Medical Providers are governed by state and federal laws, and by their ethics codes. The American Medical Association's (AMA) Code of Medical Ethics begins with a clear affirmation of the privacy right and a strong prohibition against disclosures: "The patient has a right to confidentiality. The physician should not reveal confidential communications or information without the consent of the patient."

Patients cite privacy, together with security, as their issues of greatest concern about their medical records, particularly now that the shift is towards electronic records.

Data from several recent surveys indicate that privacy protection remains highly important to patients, particularly among patients who are diagnosed with illnesses, and minority groups who face intercultural communication challenges in healthcare, as discussed in this paper.

Backing

Medical providers should put the patient's needs first, and maintain their privacy as mandated by law. A balance needs to be met that permits important uses of information, while protecting the privacy of people who seek medical treatment.

Rebuttal

Others have argued that patients should not have such strictly regulated protected medical records; that too much privacy can be bad for your health. Americans feel a strong sense of entitlement to health care privacy, even though most are unaware how often and to how many parties their information is routinely disclosed.

My answer to that would be state and federal laws are in effect to protect patient's medical rights, regardless of culture, religion or economic status. Patients are faced with intercultural communication challenges at the doctor's office, as well as financial challenges with insurance. The last thing patients should be worrying about is whether or not their medical information is secure and not being distributed to unauthorized parties.

Conclusion and Implications

The practice of health communication has contributed to health promotion and disease prevention in several areas. One is the improvement of interpersonal and group interactions in clinical situations. The quality of provider-patient communication can affect numerous outcomes, including patient adherence to recommendations, public health laws, and the patient's health status. Health care professionals continue to need more and better training in effective communication skills to address both increasing cultural and language differences, and to better communicate medical terms, treatment issues, and their implications among all stakeholders.

Rather than seeing privacy and research as conflicting values, policy and law makers can improve both. To do so, they must move beyond formalistic rules toward fair information

practices and uniform ethical oversight. They must also remove barriers to high-quality research, thereby attaining the societal benefits of scientific knowledge, medical advances, and protection of the public's health.

Scholars describe the use of health records to discern discrimination, socioeconomic, racial, and geographic, in the delivery of proper health care. Electronic health records present conflict among the ethical principles of autonomy, fidelity, and justice (Layman, 2008). Health personnel, health leaders, health policy makers, and ethicists should continue to examine EHRs and the ramifications of their implementation to ensure proper patient care. Layman (2008) suggested that continued discussions need to occur to best use this technology to the benefit of patients and clients and support management and operations.

Ultimately, as the American culture becomes increasingly diverse, the importance of intercultural communication, and adherence to patient privacy laws, will continue to increase as a critical issue in the delivery of medical care, impacting health care outcomes and resource utilization. While cultural competence is growing in awareness, a wide range of historical and cultural barriers to effective intercultural communication remain. Given the inherent power imbalances that exist in U.S. healthcare between provider and patient/family, the need to identify and openly address the dimension of intercultural communication will only grow in importance in the future.

Your privacy is a lot like your reputation-once you lose it, it is very difficult to get it back. Both the ethical tensions and the legal debates have entailed considerable balancing of an individual's interest in privacy against other larger concerns of the community (Scott, 2000). We should be wary when someone (especially government) tells us that they are doing something for our benefit that "it's for our own good" that we are being asked to give up something that was ours, be it our liberty, our property, or our privacy (Scott, 2000).

Scott (2000) stated that medical researchers, HMOs, law enforcement officers, public health officials, and others all strenuously argue that it is just too much trouble to get the patient's voluntary and informed consent before they look at the patients' records. The potential problem with this argument is that we have heard it before, in contexts that now we look back on and think how wrong it was not to have gotten the patient's consent.

Assurances of privacy may be the most important foundational element for promoting good health. Assuring privacy within the doctor-patient relationship encourages full and open dialogue, which is essential to appropriate diagnosis and treatment. The medical privacy debate will continue, but open communication among patients and providers, regardless of culture, and adherence to privacy laws, will give a patient the best medical care possible.

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