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### e-Ethics, 2003 January

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## Cultural Barriers to Organ Donation

**O**rgan donation seeks to fulfill medicine's central goals of preserving life, alleviating suffering, curing disease, and restoring function. Yet a great disparity in donation rates across ethnic groups means that these goals are often unmet.

Medical experiences of minority community members—such as African Americans, Asian Americans, Hispanics, and American Indians—are unique and difficult to generalize. But there are common themes. In 2002 the LifeLink Foundation reported that common factors in reluctance to donate included:

- Lack of awareness
- Religious perceptions<sup>1</sup>
- History of racism
- Distrust of the medical community
- Fear of premature death.<sup>2</sup>

Lack of continuous access to quality health care increases minority groups' vulnerability to a host of health problems, some of which damage organs and make transplants necessary. Successful transplantation is often more likely if the donor is a member of the patient's racial or ethnic group. But when minority group members struggle to obtain necessary medical care, have fewer choices about where they receive care, and cannot access care regularly, they are less likely to have positive care experiences that would support a willingness to donate.<sup>3</sup> It is, however, possible to address the barriers to donation while working to improve

the experience of medical care.

*Lack of awareness.* There is a need for community education that focuses on minority healthcare needs in general, and in particular on organ donation and transplantation. Those who advocate donation should attend to how members of the community perceive and interpret their message. They should be well versed in the complexity of the donation process *and* familiar with the culture of prospective donors. Partnering in education efforts with respected local leadership, such as clergy and community organizations, can be helpful.

*Religious perceptions.* Beliefs about the body are often formed through one's religious tradition and its practices, texts, and teachings. In their texts or mores, many religious traditions regard the body as intact, in some form, after death. Organ procurement may raise religious concerns about the relationship of physical and spiritual realms; implications for the afterlife of donating organs, either during this life or after death; and moral imperatives regarding the body as a gift from God. In traditions that draw no clear distinction between body and soul (or body and mind), intentionally giving away part of one's gift from God may have significant ramifications. Some cultural communities also have beliefs about how specific organs relate to the soul (the person's essence), and those beliefs may discourage donation. Almost

all traditions, however, support the gift of an organ when it makes the difference between life and death. The wholeness of one's body after death becomes less important than saving another's life.

The importance of knowing the patient's or family's beliefs regarding donation cannot be overstated. Early attention to the spirituality of patients by members of the pastoral staff can help lay the groundwork for sensitive presentation of donation as an option. The presence of a representative of the spiritual care team, along with a trusted spiritual or community leader, can help a patient or family confront underlying myths, conflicts, and fears regarding donation.

*History of racism.* The ugly and persistent vestiges of slavery, segregation, and racism continue to provide a disturbing context for the delivery of health care to minorities. Examples of discrimination in medical treatment and research include the Tuskegee Syphilis Trials; the federally funded sterilization of women of color; and the sterilization of low-income, non-English speaking Hispanic women who had signed consent forms written in English. Another example is a 1980s Norplant study with Mohawk and Navajo women. Five years after the study was terminated because of safety issues, it was found that some of the women still had Norplant implants. Such incidents produce anxiety and lingering doubt about health providers' motives.<sup>4</sup> Providers must



recognize this skepticism and address it through serious efforts at reconciliation with minorities.<sup>5</sup>

**Distrust of the medical community.** Healthcare providers need to consider whether their behaviors may contribute to lower donation rates among minorities. When donation is an option, do providers approach persons of different ethnic backgrounds routinely—or only infrequently? When they suggest the possibility of donation, do they convey assurance that they believe a commitment to donate may well result? Or are they encumbered by cultural stereotypes that assume a reluctance to donate? In communicating with families, are they sensitive to those nuances of language and gesture that could create apprehension, especially among those who do not speak English or who speak English as a second language?

If members of a cultural group have suffered historically because of racism, how will the healthcare community rebuild trust when history documents that medical personnel often did not promote their best interests? Will providers explain to minority groups and their members the complicated distribution system so that a prospective minority donor understands who may receive the organs, and why?

**Fear of premature death.** Members of minority communities are more likely to believe that healthcare professionals will not do enough to save their lives, especially if they are identified as organ donors. Such fears, and cultural barriers that discourage discussion of death, can hinder acceptance of a physician's

suggestion that aggressive treatment is unwarranted.<sup>6</sup> Moreover, distrust can make wary patients less likely to complete advance directives that would limit life-saving initiatives. A trusting physician-patient/family relationship is critical to creating a safe space in which difficult decisions about care at the end of life and, when appropriate, organ donation can be openly discussed. Further, physicians and other caregivers should take time to answer the questions that organ donation raises for families.

While Advocate's Mission, Values and Philosophy commits us to respect all persons—and thus to overcome ethnic prejudices—we should make the extra effort to *appreciate* each person's cultural context. Respect can be demanded; appreciation is freely given from a space within us, a space that recognizes the common ground of humanity as sacred and inspires our best efforts to improve medical care for all.

1. LifeLink Foundation, <http://lifelinkfound.org/minority.html>, 10/09/02. The source refers to religious "misperceptions," a term that may unintentionally suggest criticism of a community's or individual's beliefs.

2. Ibid.

3. Etienne Juarez Phipps and Gala True, "Women, Minorities and Organ Donation in Transplantation," in *The Ethics of Organ Transplantation*, ed. Wayne Shelton and John Balint, *Advances in Bioethics*, vol. 7 (Oxford: Elsevier Science, 2001), 318.

4. Ibid., 320.

5. Lee Ho, "Typical and Atypical Clinical Signs and Symptoms of Myocardial Infarction and Delayed Seeking of Professional Care among Blacks," *American Journal of Critical Care* 6 (1997): 7-13.

6. Phipps and True, "Women, Minorities and Organ Donation in Transplantation," 329.

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# e-Ethics

## "But You're Not in the Computer!"

**W**e can't treat you . . . you're not in the computer!" Words like these point to an emerging issue that is fraught with ethical considerations. Patient records should be accessible in a well-maintained, durable paper file system or in a well-administered, up-to-date electronic data management system that also provides confidentiality and security. When there is a failure of access—when the patient is *not* "in the computer"—the result can be substantial frustration. As more health providers move from paper files to the electronic medical record (EMR), issues of confidentiality become more complex, in part because access by appropriate parties is so obviously essential.

The growing insistence that dependable patient records, stored in remote databases, will be readily accessible through sophisticated network software poses ethical challenges for doctors, nurses, provider organizations, insurance companies, government agencies, information technologists, and patients themselves. As more patient records become "electronic," mistakes can occur at many points in the entry of patient data and its secure transfer to appropriate health professionals when treatment is required. Recent news stories portray the alarming inaccuracy of information in credit bureau databases. Add the rapid rise in identity theft by computer hackers who gain illegal access to financial or medical records that were allegedly secure, and it is no wonder that patients worry about

the quality and security of information about them.

In reality, electronic health records are normally secure and accurate, but occasionally the people handling those records make errors. In addition, those responsible for patient information may not share the patient's perspective on the importance of confidentiality and privacy, and disturbing breaches of confidentiality can result. As with credit information, many opportunities exist for highly sensitive electronic patient records to be compromised. The aggressiveness of potential employers, lenders, and insurers in accessing private records to profile credit use, life style, and health risks increases the need for laws and institutional protocols that protect the public from unscrupulous use of individual health records.<sup>1</sup>

The public's concerns about information technology often reflect personal experiences with electronic data management systems—and with the personnel who interpret the technology and its fruits to the public. Attempts to resolve computer-billing errors or understand medical reports sometimes reach a communication dead end, with responses such as "Well, that's what the computer says!"—as if the information system were infallible and therefore incapable of reporting incorrect information, regardless of human errors in programming, entering data, or specifying the content of requested reports.

In the ever-evolving information

age, we need continually to assess developing health information systems and related health policy against such key values as security, privacy, accessibility, and accuracy. Will full implementation of the privacy provisions of the Health Insurance Portability and Accountability Act (HIPAA) adequately safeguard a patient's EMR? Will information technologies used by physicians, nurses, hospitals, and emergency personnel provide sufficient access to a patient's medical record when treatment is urgently needed?<sup>2</sup> Will the use of electronic patient records, coded in the lingua franca of physicians, nurses, and pharmacists, result in fewer medical errors?<sup>3</sup> Will the expense of developing, implementing, and maintaining technologies to store, retrieve, and protect patient records drive up health care costs (or will it, perhaps, put patients at risk if their providers cannot afford the rising costs of the technology)? And who else might want or need access to a patient's medical record—the insurer, physical therapist, hospital technician, social worker, current or potential employer, government agency, or lawyer? HIPAA regulations help to clarify who has a legal right to an individual's confidential medical record. But even when such access is legitimate, will those providing or accessing the record observe the proper protocols?

What approach to health information technologies might strike a balance between our concerns about accuracy and access and our desire



## "But You're Not in the Computer!"

for confidentiality and security?

Healthcare stakeholders—individuals and institutions—must agree on and adhere to shared ethical values, policies, and protocols that can both shape and implement emerging EMR standards. Inevitably, this approach must blend the old and the new: electronic patient records will call for new protocols, but the "old" rules for managing paper patient records will still apply.

To achieve the desired results, patients, health providers, and the general public will first need to recognize that healthcare information systems are not socially, politically, or ethically neutral. They were developed by human beings for social institutions (hospitals and other healthcare entities) to improve health care. The multiple needs and interests of societal players in health care—congregations and their representatives, governments at all levels, regulators and accrediting agencies, insurers, vendors, and the many healthcare disciplines—inform EMR development, operations, and functionality. EMR systems must be flexible enough to respond to new and evolving policies, laws, and medical procedures. Undoubtedly it will be necessary to design additional EMR standards, especially to ensure the security and confidentiality of patient record content and govern third-party use.

Second, patients—who should be the primary beneficiaries of these new technologies—must become active partners in managing their healthcare information. To create such a partnership,

providers will need to enlist patients' help. Reminding patients of their right to expect that medical records will be confidentially and securely maintained is one step in this direction. Inviting patients to notify providers when they encounter a breach of trust or a mistake in the record is another. Only if patients recognize their responsibility to initiate—even insist on—needed corrective action can a genuine partnership in information management be forged. Providers, in turn, should display genuine openness to patients' inquiries and to their suggested corrections of the medical record (which HIPAA regulations require providers to consider). A patient's request to meet with "someone in charge" to remedy a perceived problem should be not only accommodated but welcomed. When patients are active partners in establishing and maintaining the medical records that concern them, it is more likely that shared values about confidentiality, security, accuracy, and appropriate use will be consistently honored.

1. See: Doupnik, AM (2002). "An overview of electronic document management system product offerings." *Topics in Health Information Management*. 23(1): 62-73. Rindfleisch, TC (1997). "Privacy, information technology, and health care." *Communications of the ACM*. 40(8): 92-100. Laing, K (2002). "The benefits and challenges of the computerized electronic medical record." *Gastroenterology Nursing*. 25(2): 41-45.

2. Melton, LJ (2000). "Medical privacy." *Issues in Science and Technology*. 17(1): 12-13.

3. Lee, T (1999). "Too much privacy is a health hazard." *Newsweek*. 134(7): 71.

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### Culturally and Religiously Competent Health Care for America's Diverse Muslim Population

**M**uslims may now be the second largest religious group in the U.S. Good health care for patients who are Muslim means culturally aware and religiously sensitive care. Such care requires commitment, the willingness to honor differences, and openness to exploring diversity—even within America's Muslim population. When, for example, a Muslim woman visits a Western-trained, white, male doctor, she may be uneasy with practices taken for granted in that setting. Depending on the individual and the circumstances, different cultural and religious issues come into play.

Consider Mrs. A, a 50-year-old Bosnian refugee who emigrated to the U.S. in 1997 to escape the war in her country and to live with her eldest daughter. Over the past two months she has become sleepless, irritable, unfocused, and anxious, distancing herself from friends at her suburban mosque; she now attends only midday Friday prayer services. Repeatedly she hears sermons about the attacks of September 11, 2001, and about threatening messages left on the mosque's answering machine. After one Friday service Mrs. A was so distraught that her daughter brought her to Dr. Albert for medical attention. A thoughtful family physician, Dr. Albert was able to learn,

despite the language barriers and her agitation, that the hostility some Americans now feel toward Muslims has rekindled Mrs. A's horrible experiences in Bosnia.

Dr. Albert sees Mrs. A as manifesting classic symptoms of post-traumatic stress disorder.<sup>1</sup> Before referring her to a colleague in psychiatry, Dr. Albert performs a physical exam. He does so cautiously because he is aware that in many Muslim countries men and women relate differently than they do in America. Knowing this, he asks for guidance from Mrs. A's daughter. He learns of the Islamic conventions about modesty and standards for interaction between unrelated males and females. Thus, he learns it is not rude when Mrs. A and her daughter decline to shake his hand, not a cause for offense when they request a female doctor, and not unusual when they insist that parts of Mrs. A's body, such as her head and arms, be covered.

He also learns that the decision-making unit among immigrant Muslim groups is usually the family, not the individual. Thus, Mrs. A's husband and their extended family may wish to have a say in planning her treatment for post-traumatic stress. Dr. Albert may extend his efforts to learn how to give culturally and religiously attuned care by conferring—with Mrs. A's permis-

sion—with her *imam* (religious leader) or a lay leader of her mosque regarding religious and other community resources.

Another Muslim patient—Mrs. B, a 26-year-old African-American Muslim, six months pregnant, and suffering from bronchitis—calls for different sensitivities. She explains her understanding of the fasting obligations of Ramadan, which concern Dr. Albert because of her pregnancy and her illness. Turning to a respected Muslim leader he seeks information about treatment in general, and more particularly during Ramadan. He learns that in prescribing medication for Mrs. B's cough and congestion, he must be sensitive to Islamic prohibitions against the intake of pig products and alcohol. The gelatin coating on some pills contains pork extract, and cough medicines often include alcohol. Finally, the exemption of pregnant women from the Ramadan fasting requirement has important implications in this case.

In the "new religious America" recent immigration has created a "complex religious reality of encyclopedic dimensions."<sup>2</sup> Islam is the largest and, given current events, arguably the most significant of America's "new" religions, although Muslims have actually been part of America throughout our history. Scholars suggest that many African



# e-Ethics

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slaves who were brought to this country practiced Islam in their homelands. African-American Muslim movements founded in the U.S. date back to the early 1900s. Arab and Bosnian Muslims began their immigration around the turn of the 20th century. Many other Muslim immigrants, including Asian Indians, Pakistanis, and African national groups, have arrived since the 1960s. Many theological distinctions can also be found within the American Muslim community, such as the broad branches of Sunnis, Shi'ites, and Sufis, plus subgroups within each branch.

The U.S. Muslim population numbers perhaps 7 million and is steadily increasing. Thus healthcare professionals can expect to treat more patients like Mrs. A and Mrs. B. While it is impossible to become expert in all the ethnic and theological differences within the American Muslim community, it is important to start with the awareness that Muslims' beliefs and traditions may be quite different from those of Christians and Jews. The examples of Mrs. A and Mrs. B suggest some key

points, while the list below offers general guidelines about how Muslim beliefs and practices can touch upon medical practices.

These guidelines are important starting points for developing a keen attentiveness to difference. In addition to these actions, however, the physician and the patient will need to teach one another what it means to be sick, what treatments are culturally sanctioned, who makes decisions, and how those decisions are to be made. Physicians and other providers can sharpen their ability to ask respectful questions that will facilitate greater sensitivity to and understanding of cultural and religious beliefs and practices among Muslim patients. Quality health care committed to the whole person demands no less.

1. *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed. (Washington, D.C.: American Psychiatric Association, 1994), 424-429.
2. Diana L. Eck, *A New Religious America: How A "Christian Country" Has Become the World's Most Religiously Diverse Nation* (Harper San Francisco, 2001), 4.

### What Health Care Providers Can Do for Their Muslim Patients\*

- Respect their modesty and privacy. Some examinations can be done over a gown.
- Provide *halal* (acceptable) meals.
- Allow them to pray.
- Inform them of their rights as patients and encourage a living will.
- Take time to explain tests, procedures, and treatments. Many Muslims are new immigrants and may have language problem.
- Allow the family to bring food if there are no medically necessary restrictions.
- Do not insist on autopsy or organ donation.
- Always examine a female patient in the presence of another female.
- Provide same-sex physicians and nurses if possible.
- Allow their *imam* to visit them.
- Allow the family and *imam* to follow the Islamic guidelines for preparing the dead body for an Islamic funeral. The female body should be given the same respect and privacy as when the deceased was living.
- Identify Muslim patients with word "Muslim" in the chart, or on a nametag or bracelet.
- Allow no male in the delivery room except the husband if possible.

\* Adapted from Shahid Athar, *25 Most Frequently Asked Questions About Islam* (Indianapolis, Ind.: Dawa Information Group); Shahid Athar, *Health Concerns for the Believers* (Chicago: Kazi Publications).

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