American Medical Association Journal of Ethics

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American Medical Association Journal of Ethics August 2002, Volume 4, Number 8: 221-222.

FROM THE EDITOR
If You Don't Vote, Don't Complain
Audiey Kao, MD, PhD

For watchers of the NBC series *West Wing*, much of the show's appeal lies in the depiction of life inside the world's biggest fishbowl, a fictional presidential administration with hardworking and dedicated individuals, making daily decisions that in real life affect each of us. Yet, the growing popularity of this show belies the fact that the majority of eligible adults in the United States do not vote. This environment of civic apathy, in which so many of our fellow Americans fail to exercise their responsibilities as citizens cannot but weaken the vitality and strength of our democracy.

This depiction of working at the White House is eerily familiar to someone who has worked at the American Medical Association (AMA) for nearly 5 years. Like the characters on *West Wing*, the AMA staff includes many dedicated and hardworking individuals who oftentimes have to perform under challenging and complicated circumstances. Like the White House, decisions and positions taken by the AMA are continuously examined and scrutinized by the public. The "fishbowl" reality reflects, in part, the fact that the public considers the AMA the voice of organized medicine—many patients believe that every physician is or must be an AMA member. However, in much the same way that many of our fellow citizens do not vote, most physicians are not members of the nation's largest medical professional association. To those people who do not vote, I say, don't complain about the state of our union. Of physicians who do not belong to the AMA I ask, are you fulfilling your obligations as members of the medical profession?

In considering this question, it is important to note that physicians do have many options when choosing which professional organizations To join. As medicine became increasingly specialized during the latter half of the 20th century, physicians focused more on aspects of care in their respective specialties, and as a result identified more with their medical specialty societies. The specialization in medicine, which reflects the advances in medical science, has contributed to a dramatic decline in membership in the AMA and, in turn, created a zero sum game in the minds of some, a game in which all medical societies are competing for pieces of the same membership revenue pie.

It is in this environment that the AMA's policy making body took important steps towards the potential restructuring of the AMA. To most physician-citizens outside organized medicine's "beltway," the specifics of the restructuring plan are neither

interesting nor relevant. But what is important to every member of the medical profession, I contend, is the ultimate mission of the redesigned national, professional organization that represents physicians independent of geography and specialty. Whether they realize it or not, each physician has a critical stake in the transformation of the AMA because it will have a direct impact on whether society continues to see medicine as a trusted profession.

Democracy is resilient, but that does not give us permission to ignore our duty to vote. Society's trust in the medical profession is more fragile than democracy; physicians cannot neglect the duty to protect and strengthen that trust. Therefore, vote and voice your critique of our government; get invested in the institutions of medicine that help shape its future.

Audiey Kao, MD, PhD is the editor in chief of *Virtual Mentor*.

The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

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CASE AND COMMENTARY Organ Donor Card Effectiveness Commentary by Ben Berkman

Case

Joseph Clark is a 23 year-old unmarried, law student. One night, while riding home from the library, he loses control of his motorcycle and hits a concrete barrier. The impact of the collision throws him head first off the motorcycle. He suffers extensive head trauma.

Joseph is rushed to the emergency room, where doctors struggle to stabilize his condition. They successfully manage to stop the bleeding. Unfortunately, due to his massive brain injuries, Joseph is not capable of breathing on his own and is placed on a ventilator.

The doctors speak with his parents, explaining that Joseph has suffered serious head trauma. Although they tried to repair as much damage as they could, he is brain dead. The family is understandably overwhelmed with grief at the sudden loss of a healthy, young adult.

Upon his admission, the hospital staff had discovered from Joseph's driver's license that he wished to donate his organs. They had also found an organ donation registry card, indicating that Joseph had taken additional steps to demonstrate his willingness to serve as a donor. Fortunately for the purpose of organ donation, his significant injuries were confined to his head and neck region; all of his major organs were undamaged and healthy. The organ procurement team was consulted and determined that Joseph would make an ideal donor.

A specially trained doctor approaches Joseph's parents with this information. Even though they understand that Joseph is brain dead and had wanted to donate his organs, his parents refuse to approve the donation of his organs. The doctor gently tries to discuss their concerns and assuage their fears, but Joseph's parents refuse to change their minds.

Questions for Discussion

- 1. As the doctor in this case, would you proceed in accord with the decedent's wish to donate his organs or the family's desire not to donate?
- 2. What would your primary considerations be in making this decision? Patient autonomy and self-determination? Fear of legal repercussions? Sensitivity to the family's emotional needs?

- 3. Would explicit legal immunity from liability make this an easier or more difficult decision?
- 4. Would it be appropriate to have a statute that made doctors liable for disregarding valid organ donor cards? If this was the case, how should families be included in the post-mortem organ donation dialogue?

Analysis

The extreme shortage of transplant organs presents a medical crisis for those whose life depends upon receiving a new organ and gives rise to many legal and ethical issues. There is much controversy, for example, about the means we should adopt to procure a sufficient number of organs. Proposals include mandated choice, forcing everyone to choose whether or not they want to be a donor; presumed consent, assuming people want to be donors unless they indicate otherwise; and offering financial incentives to families. For a number of ethical reasons, none of these options has yet been adopted in the United States. Thus we continue to rely on voluntary and uncontested donations as the sole source of organs.

Donor cards have been the most common way to facilitate voluntary donation. However, the legal status of donor cards can be seen from 2 different theoretical perspectives.

- 1. Donor cards can be seen as analogous to wills, representing a gift that is binding upon the person's death. Under this reasoning, the organ donation card should be honored as an indication of the deceased's wishes.
- 2. Alternatively, donor cards could be seen as indicating a promise or intention to donate. In this framework, the promise to donate would terminate upon the person's death. Just as the family has the right and responsibility to control the disposal of the body, so too would they have the power to fulfill or not fulfill the promise to donate upon the person's death. While it might seem inherently contradictory that a promise to donate organs upon death becomes void upon death, that is the current status.

In an effort to encourage and maximize voluntary donations, federal and state legislatures have enacted a number of statutes designed to address the issue of donor cards. Unfortunately, these federal and state laws contradict each other by incorporating both of the legal theories mentioned above. This leads to a complicated legal picture and an uncertainty as to the appropriate physician role, especially in a situation where the wishes of the decedent and their family differ. The murkiness is made worse by the lack of relevant case law.

The Uniform Anatomical Gift Act (UAGA) of 1968, amended in 1987, was a national attempt to provide a standard set of guidelines for the emerging field of organ procurement and distribution. It was eventually adopted in all 50 states in the form of respective State Anatomical Gift Acts. Among other things, it provides that a signed wallet-sized, donor card is a legal instrument (like a will) that allows physicians to remove organs from the decedent. However, this law had little impact

because doctors were unwilling to rely on just a signed card, so they continued to seek the consent of family members.³

This law was followed by the Omnibus Reconciliation Act of 1986. Under this statute, Medicare/Medicaid hospitals were required to discuss organ donation with families of deceased patients who were potential donors. The majority of states copied this statute, enacting similar "required request" laws. These laws had an unexpected repercussion. By requiring doctors to always ask for familial consent to donate, these laws undermined the authority of donor cards as well as the idea of patient autonomy. This law treated donor cards as unenforceable promises, subservient to the wishes of the living family.⁴

Subsequently, the Federal Patient Self-Determination Act was passed in 1991. This statute, like the original UAGA, reinforced the concept of patient autonomy, encouraging and validating the use of advanced directives (living will, power of attorney, etc.). Unfortunately, doctors still insist on consulting the family about organ donation, even if there is a clear advanced directive or donor card.⁵

With these seemingly contradictory laws on the books, it is understandable that physicians might be unclear about how to proceed in a situation like Joseph Clark's. Doctors and hospitals have overwhelmingly insisted on honoring the wishes of the living family, even when it means ignoring the decedent's wishes. There are a number of possible reasons for this trend.

- 1. Doctors and hospitals might be afraid of negative public relations. Hospitals cannot afford to be perceived as acting against people's wishes. The public already has a tendency to distrust medical institutions. A family whose wishes are ignored will have a powerful story to tell which might fuel that distrust. By ignoring the deceased patient's donor card, however, the hospital is still acting against a patient's wishes. The only difference is that the deceased patients do not have voices to tell their stories to the public, thus they present a less immediate public relations issue.

 The public relations concern is legitimate, but ultimately reflects the ambiguous legal status of donor cards, rather than a fundamental ethical or legal consideration. If donor cards were always be honored, the hospitals would not have to worry about negative publicity, since legally mandated donor card compliance would be the legal, ethical, and societal norm.
- 2. Doctors might be unwilling to impose more conflict and grief on a reluctant family who is already in great pain.⁶
 Similar to the public relations concern, the problem of additional family grief would disappear if the legal status of donor cards were clarified. While concern for the living family is a reasonable sentiment, it ignores the express wishes of the patient. In times of grief, families might not be capable of making rational decisions. Should their judgment be substituted for that of the deceased patient, who made a deliberate, conscious decision in an presumably rational state of mind? If it were the norm for donor cards

- to be honored, physicians would present families with a positive statement of their loved one's generosity rather than a difficult, potentially painful choice.
- 3. Doctors might be concerned about potential lawsuits. The deceased's wishes take lower precedence than the family's wishes because only the family can sue.⁶

In this litigious age, such a concern is not unfounded. However, a number of states have begun to pass laws that give doctors express immunity when they comply in good faith with organ donation cards or advanced directives. It remains to be seen if this trend will spread to the entire country, but it is a positive step towards solving this problem.

However, none of this discussion gets at the root of the problem. At best, the current laws create a legally neutral environment where doctors are still free to follow the status quo of deferring to families. What is needed is a test case, but as of yet, no doctor, hospital, or organ procurement agency has been willing to step forward. If the courts made it clear that these laws did in fact protect doctors from liability and partially remove some of the moral weight from their shoulders, doctors might not be so reluctant to honor the wishes of the deceased.

Going even further in encouraging organ donation, laws could be passed to proactively pressure doctors to comply with the decedent's wishes. Maybe what is needed is a law that makes it illegal to not comply with a valid donor card, relieving the doctor of the responsibility of resolving a moral and ethical conflict between the deceased patient and their family, and legally protecting the physician.

References

- 1. Spital A. Mandated choice for organ donation: time to give it a try. *Ann Intern Med.* 1996;125(1):66-69.
- 2. Glasson J, Plows J, Tenery R, et al, for The Council on Ethical and Judicial Affairs, American Medical Association. Strategies for cadaveric organ procurement. *JAMA*. 1994;272(10):809-812.
- 3. The Uniform Anatomical Gift Act of 1968, amended 1987. National Conference Of Commissioners On Uniform State Laws. Available at: http://www.law.upenn.edu/bll/ulc/fnact99/uaga87.htm.
- 4. Omnibus Reconciliation Act of 1986. 42 U.S.C Sec 1320b-8
- 5. Federal Patient Self Determination Act of 1991. 42 U.S.C. §§ 1395cc, 42 U.S.C. 1396a.
- 6. The Lewin Group, for the Office of the Assistant Secretary for Planning and Evaluation. Analysis of state actions regarding donor registries. Available at:

https://aspe.hhs.gov/health/orgdonor/state%20organ%20donor%20registries.htm. Accessed July 8, 2002.

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IN THE LITERATURE Who's Really Hurting? Susanna Smith

Women have been labeled the fairer sex, the weaker sex, the emotionally driven and irrational sex. Over the past century successive waves of women's rights movements have tempered these stereotypes, offering women more freedoms and opportunities. But in many ways Western society has become so conscious of being politically correct and asexual in preference that we run the risk of failing to recognize the important differences in the sexes.

Men and women are not the same. They are anatomically distinct, biologically different; and they have diverse styles of thinking and communicating. In a recent literature review, "The Girl Who Cried Pain: A Bias Against Women in the Treatment of Pain," Dianne E. Hoffman and Anita J. Tarzian highlight one significant difference in the sexes by suggesting that men and women feel and deal with pain differently. Furthermore, this study suggests that "women are more likely than men to be undertreated or inappropriately diagnosed and treated for their pain."

Pain is a subjective phenomenon that cannot be readily quantified; therefore physicians rely largely on patients' self-reporting to determine the severity of their pain. Only in the past decade has the medical research field recognized that women and men may experience illness and pain differently. In fact recent clinical pain studies found women reported more severe and frequent pain and pain of longer duration than men. Other studies suggest that women may have a varying level of pain tolerance, reflecting changes in hormone levels during their menstrual cycles.

Besides hormonal differences, structural differences between the central nervous systems and brains of men and women may affect how members of that sex feel pain. One structural difference this review cites is tissue thickness and sensory receptor density in women that may make their skin more sensitive to pain than men's. Although the disparities between men's and women's responses to pain are well documented, it is unclear whether these differences are rooted in biology or in coping strategies and pain expression, or in both.

Physiological influences and the attribution of meaning to pain may also play a part in sex-related experience and expression of pain. Studies have found that women are more likely to report and seek treatment for pain. One reason for this could be that women more frequently experience pain in the absence of illness, eg, in

childbirth and menstruation. Therefore they seek treatment for pain as a means of sorting "normal biological pain . . . from potentially pathological pain, whereas men do not need to go through this sorting process." 1 Despite higher incidence of pain reports, and their increased susceptibility to pain, women are systematically treated less aggressively than men for their pain. Women's pain complaints are often written off as emotional responses, which explains the finding that women are prescribed psychotropics more often in pain treatment whereas men are given analgesics.

The undertreatment of pain in women may also be due to the widely held but false notion that women have higher pain tolerance than men. The fact that women do undergo normal biological processes that are painful may have given rise to this generalization. Studies have also found that women have more pain coping mechanisms, such as seeking social support, relaxation, or distraction whereas men more often deny they are in pain or deal with pain through tension reducing behaviors such as consuming alcohol. But women's ability to deal with pain better should not be translated into the idea that they experience less pain when many studies point to the opposite conclusion.

Social mores also influence the way men and women report pain. In most Western societies it is more culturally acceptable for women to report pain than for men to do so; the social norm for men encourages a stoic response. One study reported that the sex of the inquiring researcher affected the way male participants responded in a laboratory setting. Although men report pain less frequently, it seems they are taken more seriously when they do seek pain treatment; women, who report pain more frequently, are often described as anxious.

Women's ability and readiness to verbalize their feelings and describe their pain may lead physicians to discredit the severity of their pain. One report suggested that women's style of communication may not fit neatly into the traditional format of the physician interview, leaving women in chronic pain vulnerable and "rebuffed by physicians in their attempts to express the multiple ways in which their pain affects the quality of their lives and their ability to function."

Hoffman and Tarzian go on to make an argument for just treatment in pain management, suggesting that a more equitable approach would be "sex-specific, gender-sensitive pain management treatments," as an acknowledgement of men and women's different pain treatment needs.

Questions for Discussion

- 1. Does the sex of your doctor affect how you report pain or how your pain is treated?
- 2. As a clinician, are you likely to think that a man who reports pain must "really be hurting," perhaps hurting more than a woman who reports pain?
- 3. What needs to be changed in medical education to make physicians more responsive to pain reports of women patients?

- 4. Why is emotional pain largely discounted as invalid pain, or pain not warranting the physician's full attention?
- 5. Should there be a different patient interview model for men and women that reflects the different communication styles of the sexes?

References

1. Hoffman DE, Tarzian AJ. The girl who cried pain: a bias against women in the treatment of pain. *J Law, Med, Ethics*. 2001;29(1):13-27.

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AMA CODE SAYS Ethical Competency and the Profession of Medicine Ken Kipnis, PhD

By training, I am a philosopher, specializing in ethics. For nearly 30 years I have been thinking and writing about the ethical dimensions of professional life. How does it happen that professionals are subject to special ethical obligations? So when the American Medical Association's Institute for Ethics opened a slot for a "Visiting Senior Scholar," I submitted an application. Now, a year later, at the end of a sabbatical, I am returning to my academic position at the University of Hawaii and reflecting on my experience. Here are some thoughts on ethics at the AMA.

Representing almost 300,000 physician-members and, arguably, the American medical profession as a whole, the AMA struggles with 3 distinct identities. In the first place, it is a corporation. It has its varied clients and a range of profit centers, and there is a relentless focus on the bottom line.

Secondly the AMA is a trade association for doctors. The vectored interests of the profession are authoritatively resolved in its House of Delegates, which meets twice a year. The House includes representatives from the state medical associations as well as from various specialty societies. Accordingly, there is some basis for the AMA's claim to be the voice of American medicine. Working through its Washington, DC offices, the AMA is a powerful advocate on behalf of medicine's interests.

In the third place, the AMA is a professional association with a selfless commitment to medicine's distinctive goods. This last claim is made completely non-ironically. Within the Chicago offices there is a broad and intense concern with the professional values that ought to inform medical practice. The staff of the Professional Standards Group, where I had my cubicle, displays knowledgeability and dedication that could credit any university. Visiting speakers offer differing ethical perspectives to the staff. The half-dozen formal presentations I gave during the year—some of them critical—were treated with nothing less than respectful interest, and a few of my suggestions found their way into policy initiatives.

Apart from these divergent orientations, the AMA is an ongoing argument about how these 3 quite different roles ought to fill out the organization's identity. In its 155-year history, the balance has constantly shifted.

I spent my year at the AMA headquarters in Chicago along with about 1000 other employees. A few feet from my eighth-floor cubicle was the office of the Council for Ethical and Judicial Affairs (CEJA), the body that now issues the AMA's ethical opinions and codes. The Council itself consists of 9 AMA members, mostly practicing physicians, who are elected to 7-year terms following nomination by incoming AMA presidents. One Council member is a medical student, another, a medical resident. CEJA's canonical ethics texts include a 1-page AMA "Principles of Medical Ethics"—a set of 9 exhortations to virtue—and a slightly longer "Fundamental Elements of the Patient-Physician Relationship"—a set of 6 fairly specific norms. There are also approximately 180 discrete CEJA "Opinions" that treat a range of questions pertaining to professional practice. Issues include the reporting of spouse abuse, genetic counseling, organ procurement, sports medicine, advertising, fee splitting, gifts from industry, caring for the poor, and so on. Finally, there are the "reports and recommendations" that lay out justifications for many of the opinions. Taken together, these 4 components—the principles, elements of the patient-physician relationship, opinions, and reports—are the AMA Code. The first 3 are easily obtained in an AMA publication entitled; Code of Medical Ethics: Current *Opinions* that is revised every 2 years.

As it happens, I have never used the *Code* in teaching medical ethics nor do I know more than a handful of professors who do. Despite much excellent analysis in these materials, there are some good reasons for passing on pedagogical use. First, the *Code* is often inconsistent. While the Council and its staff do conscientious work on the opinions, each is drafted separately. What is said this year can conflict with language drafted years ago. Second, the opinions are narrowly focused: they are not intended as a comprehensive set of norms nor are they accompanied by a background conception of the profession's responsibility to society. There is no big picture. Third, some of the opinions—especially the older ones—fail to reflect the best thinking in the current medical ethics literature. These deficits are not the result of carelessness. Rather, each is a consequence of the way CEJA and the AMA conceive the task of developing ethical standards.

Though CEJA members know much more about medical ethics than the representative physician does, it is rare for them to be "specialists" in medical ethics. While staff are knowledgeable, they can only do so much to bring the council members up to speed during their 2-day meetings every other month. In my opinion, CEJA functions, in part, as what advertisers call a "focus group." Its processes generate what may be a fairly accurate reflection of the collective moral judgments of America's better-informed physicians; judgments that are, because of CEJA's role, authoritative within medicine despite dozens of other less-prominent codes governing medical practice in the United States. (See, for example, *Medical Ethics: Analysis of the Issues Raised by the Codes, Opinions, and Statements* by Brody, Rothstein, McCullough and Bobinski.¹) What CEJA has not done is to restate and systematize the elements of its work into a single comprehensive document that could be owned by the profession as a whole.

I believe that, at the most fundamental level, the medical profession suffers from a damaging disconnect between the processes by which it articulates what authoritative ethical standards it has, and the processes by which it inculcates ethical standards in its novices and initiates. In the legal profession, for example, there are formal codes developed by the American Bar Association and mandatory courses on professional responsibility taught at every law school. Both the law professors who teach the legal ethics courses and the authors of the ABA's Model Rules of Professional Conduct are singing from the same hymnal. But in remarkable contrast, those who are teaching medical ethics in colleges and universities—who are closely following and carefully contributing to the pertinent literatures—are both distinct and distant from the CEJA members who hammer out authoritative professional guidelines for practitioners. This reflects a traditional split between the private practice doctors, who have historically guided the AMA, and the academic physicians, who have tended to take leadership roles in the specialty societies and the Association of American Medical Colleges. While the academic physicians do not take on the practical task of securing broad practitioner ownership of clear professional standards, the doctors of CEJA have not felt the need to systematize their opinions into pedagogically useful materials. This disconnect is not a problem for the AMA so much as it is a problem for the profession of medicine in the broadest sense.

It is, I believe, essential that these 2 stakeholders be brought together. The medical profession needs to generate consistent, responsible, usable ethical guidance that is incorporated into medical pedagogy even as it is authoritatively endorsed by the leading professional organizations. It is high time for those whose job it is to articulate medicine's most authoritative ethical standards To join forces with those whose job it is to inculcate a distinct sense of professional responsibility in medicine's initiates. It is a dangerous error to see the 2 tasks as so distinct that each can be assigned to separate agencies that do not pay much attention to each other. It is far better to conceive the combined task as constitutive of ethical competency in a mature profession.

If medicine's practitioners and professors are ever to sing from the same hymnal, there will have to be a hymnal.

References

1. Brody BA, Rothstein MA, McCollough LB, Bobinski MA. *Medical Ethics: Analysis of the Issues Raised by the Codes, Opinions, and Statements*. Washington DC: The Bureau of National Affairs, Inc., 2001.

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MEDICINE AND SOCIETY

Organ Donation: Altruism vs. Incentive

Akshara Meran

In a perfect world, altruism would be all that would be needed. The fact is that we're losing the battle.

Dr. Phil Berry Jr, liver transplant recipient¹

In 1954 the United States opened the door to organ transplantation with the first kidney transplant, starting a growing and controversial trend that continues to engage American society in an ethical debate today.

By 1980, the number of kidney transplants alone had gone from 1 to 3400 and with the use of cyclosporine, a drug that reduced the threat of organ rejection, successful transplantation became commonplace in the medical world. However, the success rate that accompanied the advent of cyclosporine created a demand for organs that greatly exceeded the supply. What ensued was the disorganized and inequitable allocation of organs, leading to controversy over the lack of rules on the distribution of organs.

The US Congress responded to this growing controversy by passing the National Organ Transplant Act (NOTA) in 1984, creating a system to regulate the procurement, distribution, and transplantation of scarce organs. NOTA established an organ procurement network in 1986, operated by a non-profit organization, United Network for Organ Sharing (UNOS), to maintain a national computerized list of patients waiting for organ transplants and to allocate procured organs. By late 1987 NOTA had created a registry to gather data and track service on transplant operations performed since October 1, 1987.

The system established by NOTA forbids provision of "valuable consideration" to organ donors, ruling out any form of financial incentives such as tax credits to donors.² Thus, altruism, defined as acting with the absence of any personal benefit beyond the satisfaction of giving, is the only ethically sound motivation for donation, according to UNOS. While the concept of altruism has been debated widely (eg, does altruism in fact provide benefit to the individual who is acting altruistically or to the species), it nonetheless is the central tenet of appeal for the current organ donation system. Hence, most of the methods used to encourage organ donation such as educational campaigns, voluntary donor card programs, and other motivational mechanisms have tried to appeal to a person's altruistic interest in saving lives of others.

Yet, under the current system about 6,000 patients per year with end-stage organ failure die waiting for organ transplants. Each year only 35-50 percent of potential donors (brain dead and medically suitable patients) consent to donation. The need for organs is nearly 5 times that of the actual cadaveric donations: the rate of increase in number of patients on waiting lists has averaged 14.1 percent per year, while the rate of increase of donors has averaged 2.9 percent per year.²

Addressing this issue at its annual meeting in June, the American Medical Association (AMA) adopted a report on *Cadaveric Organ Donation: Encouraging the Study of Motivation* from its Council on Ethical and Judicial Affairs. This report encourages the medical and scientific communities to re-examine donor motivation in order to better understand the central values in cadaveric organ donation and to assess the potential impact of incentives on the rate of cadaveric donation.2 These research studies, which cannot be implemented until after congressional waivers of the NOTA prohibitions are in place, will look at organs from cadavers only, not from living donors. The CEJA report does not call for any change in the current UNOS system.

The topic was intensely debated at the AMA's House of Delegates meeting, where delegates voiced concern that financial incentives could undermine donors' altruism. The delegates discussed the challenges in introducing financial incentives into the conversation with the families of newly deceased patients, expressing their apprehension that the recommended study of motivation might set off a trend that could lead to body parts being treated as commodities. Delegates also worried that linking organ donation to economics could further a negative image of the medical profession.

From the inception of the technological possibility of organ transplantation, the medical community and society as a whole have been faced with ethical questions that continue to persist. The most basic question is whether organ transplantation should be considered at all since, in a sense, it extends the natural course of life, a question also present in the end-of-life debate about whether and for how long machines should keep people alive. Some ask whether the campaign for organ donation should be replaced with a campaign that encourages people to care for their organs. For those holding this opinion, the transplant option creates a "moral hazard," one that allows people to pursue risky behaviors and unhealthy lifestyles (in this case, abusing their organs) in hopes that replacement organs will be available.

Of course, not all organ failure is the result of poor lifestyle choices, and, even when it is, our society does not deny patients effective, available treatment for ailments they had some part in creating. So we come back to the task of designing the best system for meeting the ever-increasing demand for organs. The current system is noble in intent, but research studies are needed to understand the values and factors that encourage people to donate organs. It is critical to determine the impact that financial incentives may have on the rate of donation. If 16 people must

die each day from lack of an organ transplant, we should at least be certain that there were not 16 or more available organs that we just didn't know how to ask for properly.

References

- 1. Associated Press. AMA studies payment for organ donations. *Newsday, Inc.* June 18, 2002.
- 2. Report of the Council of Ethical and Judicial Affairs. Cadaveric organ donation: encouraging the study of motivation. CEJA Report 1-A-02. AMA 2002 Annual Meeting of the House of Delegates. June 19, 2002.

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PERSONAL NARRATIVE

"Please Help Me. My Baby Is Sick and Needs Medicine!" Robert Davidson, MD, MPH

Before coming to eastern Africa, I was repeatedly warned about "culture shock." We have been fortunate to enjoy a fair amount of international travel and had lived for a time in Central America. I thought I was ready. Most of the transition has gone well. I am even learning a little Swahili. Against the advice of the Regional Security Officer for the US Embassy, we elected to not live in one of the secure compounds of clustered townhomes that house mostly Americans and personnel from other embassies. Instead, we selected a lovely older home on a 2 1/2-acre plot.

Kenyan Asians and African Kenyans

The neighborhood has very nice homes, many of which are owned and occupied by Kenyan Asians. These folks are third or fourth generation Kenyans who culturally continue to relate to India. They are the descendants from the Indian railroad workers brought into Kenya during the British colonial rule. They have prospered in Kenya financially, and "Asians" own many of the larger Kenyan companies. It seems curious that after 3 or 4 generations they still do not identify themselves as Kenyan. We have enjoyed our conversations with our neighbors and have frequently been given advice by them, particularly on how to interact with "Kenyans." It has been more difficult than we thought to relate to "African Kenyans." We have a great relationship with the Kenyan staff at work, both the professional and clerical staff. We have had some wonderful discussions about America. At our Fourth of July party we all toasted our common heritage of rebellion against British rule. However, the rest of the Kenyans with whom we have daily interaction are at such a different income level that it is difficult to be friends or even friendly.

The Most Difficult Cultural Adjustment We Have Faced

The level of poverty and unemployment in Nairobi is so high that we are constantly made aware of the disparity of resources. "Please help me. My baby is sick and needs medicine." This plea came from a woman in rags sitting on the street outside our home with a baby asleep on the dirt. Perhaps the easiest thing to do would be to give her some shillings, which might make me at least feel a little less guilty. However, we are repeatedly warned by other expatriates and our Asian Kenyan neighbors to give nothing to beggars. They will return 10-fold the next day, we are told, if the word gets out that the "daktari" gives money. Perhaps some examples will help portray the dilemma.

We interviewed for a man to help with housework and driving. "Lucas" was selected. He had a pleasant personality and came with good references. However, very soon problems began to arise. Lucas was repeatedly absent for several days at a time due to illness. He came to see me at home on a weekend and asked me to get him some medicine to cure him. I asked if he had seen a doctor. Of course, the answer was that he could not afford it. He then proceeded to take off his shirt to show me a rash that was bothering him. As I gazed at an emaciated body with a typical Herpes Zoster rash, I suspected immediately the problem. This man was in the latter stages of AIDS. The physician part of me began to race through options. How could I help? I knew I could not be his physician. I did not even have a Kenyan medical license. He could never afford retro-viral drugs nor even lab tests and preventive therapy such as Sulfamethoxa-zole/trimethoprim. I began to worry that his cough might be more than a simple problem. Could he be spewing mycobacterium? My mind returned to an incident the previous week when he had presumably fallen asleep while driving and almost went off the road. I knew he could no longer work for us. I was not worried about his infectivity, but rather his capacity to do the job. We sat on the porch and talked for a long time. He seemed to understand that he could not work anymore for me but began bargaining for some money so he could go to the doctor, get cured and find another job. I simply could not say no. I gave him one month's salary as terminal pay and some extra money to go see a doctor. We left on good terms.

The next day he was back with his daughter in her school uniform. "Please, I need some money to pay my daughter's school tuition or they will kick her out. She wants to be a doctor like you." As hard as it was, I held the line on what I had already given him and assumed this ended the saga. The next day his wife showed up toting a small baby. "Please daktari, Lucas is very sick and will die if you do not give him some money for medicine." My heart went out to this woman. Was she also HIV+? Was the baby? How could I justify sitting on the porch of this beautiful home saying no to her? On the other hand, where would it stop? This is one of the dilemmas of "giving" in Kenya.

Institutional Need

Recently, I visited a mission hospital outside of Nairobi, staffed by rotating American physicians under the auspices of their church. The chief surgeon, an orthopod from Atlanta, immediately took hold of me and urged, "Come with me. You have to see something." He led me to the bedside of a precious 10-year-old Kenyan girl. She had been brought to the hospital following snakebite. He had operated to remove necrotic tissue from the area of the bite and relieve the tremendous pressure from swelling. However, she was showing increasing systemic manifestations of the venom. In his opinion, if she did not receive anti-toxin within the next 24 hours, she would probably die. Did the Peace Corps have any? How about the US Embassy? Could I help him? My mind began to race. Yes, I knew that we stocked a shared supply of anti-venom with the US Embassy medical office. It was for use on Embassy personnel or dependents or Peace Corps volunteers. The words from my orientation sessions came ringing back. "Under *no* circumstances

are you to treat or give medicine to any person other than authorized US personnel." This was the General Counsel for the Peace Corps speaking. My boss, the director of clinical services for Peace Corps and a general surgeon, leaned over and whispered, "You better listen to this as you will be tempted." The speaker went on to outline the dire consequences which could ensue if we "misused" US property. OK! I can handle this, I mused. However, standing in a mission hospital a world away from Washington, looking at a little girl that I could probably help from dying, was not part of the bargain. The US spent millions in aid to Kenya. How could I justify not "giving" to this little girl and this caring and dedicated physician?

The Harambe

The harambe is a long-standing cultural custom in Eastern Africa. It has been explained to me that it comes from the tribal custom of helping other members of the tribe in times of need. During my first week in Nairobi, one of the staff said there was a harambe for one of the secretaries and I was invited. Great, I thought. It is nice to be included. It turned out that it was not a gathering at all. Rather, it was a memo to all participants telling them how much they "owed." I have always been supportive of the graduated income tax, but wow, this was a pretty hefty bill. I paid the money, mainly because I was new in country and did not know what else to do. I did not have a very good feeling about it. Sure enough, the next week I was invited to another harambe. Was this the spirit of giving I wanted? Where would it end? Was I being selfish for wanting a bit more personal involvement and control over my gifts? Would I be culturally insensitive if I did not join in this "long standing Kenyan tradition"?

I could cite more examples, but I think these give a good picture of the dilemmas faced by an American physician in Eastern Africa. I purposely did not say how I decided to respond in these situations. The issues are more important than my responses. I do not view my working here as a "gift" to anyone. I am supported well by the US Government through the Peace Corps, and I am gaining much more than I am able to give through my work as a physician. I do feel a desire to "give" in the face of the huge need I see in this country. We are slowly finding what works for us, but if you are faced with the same situation, expect the decisions to be harder than you think.

Daktari Bob

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VIEWPOINT Water, Water Everywhere

Colleen Danz

- 66 percent of the human body and 75 percent of the human brain are made up of water.¹
- A person must consume 2.5 quarts of water per day through food and drink to maintain health.¹
- On average, Americans consume 17.6 eight-ounce servings of beverages each day—6.1 servings are water; 5.6 servings are beverages like milk and juice that don't contain caffeine; and 5.9 servings are beverages that contain caffeine or alcohol, which are diuretics that can cause the body to lose water. In fact, 33 percent of what Americans drink every day can cause dehydration.²
- Americans drink more than 1 billion glasses of tap water a day. 1
- Americans are drinking bottled water in record numbers—5 billion gallons in 2001, according to the International Bottled Water Association (IBWA), an industry trade group. That's about the same amount of water that falls from the American Falls at Niagara Falls in 2 hours.³
- Fluoride is usually added to tap water to promote dental health. The EPA has set a limit to how much fluoride can be added because an excess amount over years can cause bone disease and tenderness in the bones.³
- Many water suppliers add a disinfectant, such as chlorine, to drinking water to kill germs like E coli. After heavy rainstorms water systems may add more disinfectant to guarantee that these germs are killed.¹
- 1.2 billion people worldwide do not have access to clean water.⁴
- Every hour more than 600 people die because their water supplies are contaminated, inadequate, or non-existent.⁴
- More than 2.7 billion people will face severe water shortages by the year 2025 if the world continues consuming water at the same rate.⁵

<u>Learn more</u> about how you can conserve water within your home or get in touch with your <u>regional EPA</u>.

References

1. EPA Water Facts. http://www.epa.gov/safewater/sdwa/30th/factsheets/pdfs/fs_30ann_waterfacts web.pdf. July 19, 2002.

- 2. International Bottled Water Association. http://www.bottledwater.org/public/BWFactsHome_main.htm. July 22, 2002.
- 3. Bullers AC. Bottled water: better than the tap? http://www.fda.gov/fdac/features/2002/402 h2o.html. July 22, 2002.
- 4. Kirby A. A fight to the last drop. http://news.bbc.co.uk/2/hi/science/nature/245363.stm.
- 5. UN warns of looming water crisis. http://news.bbc.co.uk/2/hi/1887451.stm.

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VIEWPOINT

A Better Perspective: Dr. Alan Heins and the CATCH Program Susanna Smith

Dr. Alan Heins, a resident physician in the University of Maryland Emergency Medicine Residency Program, is president of the House Staff Association of the University of Maryland Medical System. He was recognized as one of the 2002 AMA Foundation Leadership Awardees primarily for his role in founding the *Community Action to Check Hypertension* (CATCH) Health Fairs during his first year in medical school.

The CATCH program was created to deal with the disproportionate problems in health and hypertension in African Americans of inner-city Tampa. The CATCH Health Fairs, held each year as part of the American Medical Association's Medical Students' Section activities at the University of South Florida medical school, offer information on hypertension and regular screening for underserved populations in the Tampa area. Dr. Heins has also served on the Academic Affairs Committee of the American College of Emergency Physicians for the past 2 years.

Dr. Heins did not enter medicine in the traditional way. He had always dreamed of becoming a doctor, but, by the time he got to college, his commitment and motivation to enter medical school flagged. He dropped out of school and took a job, working for some time as manager of restaurant that was open 24 hours a day. Many years later, this experience at an all-night restaurant would contribute to his interest in the issue of residency work hours.

"I had to schedule people to work 24 hours a day, but no one ever had to work a 30-hour shift," Dr. Heins explains. "It baffles me why the medical community thinks that is a good idea."

At 33, Dr. Heins decided to return to school, at first working days and taking classes in the evenings. Eventually he was able to flip this schedule, attending classes during the day and working in the evenings. Dr. Heins suggests that going to medical school a little later in life, rather than right out of college, can offer a better perspective.

"I had learned some good organizational and time management skills. In addition, I seemed to be able to identify what was important in the mass of material presented in medical school," he says. "This last was essential because if you can't decide

what is important to know, you attempt to learn it all, which I would venture to say is an impossible task."

Dr. Heins suggests that all medical students should make it a point to decide each day what is important in their lives and take action on those decisions.

Read Dr. Heins' thoughts on residency work hours in <u>Through the Physician's Eyes</u> in this issue.

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PERSONAL NARRATIVE

Through the Patient's Eyes: Baby Picture

Colleen Lennon

"We're just going to let him lie there for about 20 minutes," the X-ray technician says, hanging up her lead robe. "Maybe he'll sleep the whole time."

I nod vacantly, realizing that she does this all day, every day. Our hell is just her job.

"You can stay in here with him," she says, walking out.

I look down at Ryan asleep on a wooden board that turns like a rotisserie. His arms are taped together over his head. He clutches his beloved and tattered T-shirt in his hands. His head is taped down and there's a washcloth underneath the tape to protect his skin. He is covered with hospital-issue baby blankets and taped across his midsection and ankles.

"The first moment I saw you was the best moment of my life, Ryan," I whisper to him. The gentle hum of the machinery in the room soothes me, but the swiveling stool I'm sitting on hurts my back. I've been sleeping on a vinyl recliner in a hospital room for 9 days--everything hurts. I look up at the TV screen above our heads. On it is a picture, an image frozen in time. The title of the picture, decorating the top left corner of the screen, is:

Poirier, Ryan 03/29/01 UGI Illeal 11:27 Duke Children's Hospital

The image captured on March 29th at 11:27 is the convoluted, loopy maze of Ryan's small intestine. I stare hard at the screen, once again amazed at the opportunity to look voyeuristically into someone's body, as I felt when Ryan was the size of a peanut and the ultrasound confirmed his existence. I can see where the barium has moved through his stomach and I can see the thin trickle as it struggles to move past the duodenal restriction. It's still moving through him as I look back and forth from the screen to his sleeping face, but the picture has frozen that moment of labored digestion.

Ryan will be 2 years old in 4 days. I have cancelled the birthday party that we planned because I don't know if he'll be out of the hospital. I stare at the TV screen and imagine that the picture is Ryan at his birthday party, surrounded by green grass and smiling in the sun. There are balloons too. Ryan and I breathe quietly in the colorless, odorless room that is so far away from grass, balloons, and birthday cake. It's just us, left alone with our photographic souvenir of what hurts Ryan. I stare up at the screen and initiate a telepathic dialogue with the inflamed and troublesome duodenum. "Why are you so angry?" I whisper to the swollen mass that is both on the screen and in my son. I imagine myself crawling inside of his stomach, sliding gently down into the area of inflammation and soothing it with pacifying words.

I wonder if I can speak the right language. Will it respond to medical language? Religious or philosophical language? Will it understand the shameless pleading of a frightened mother? I look away from the screen, defeated and exhausted from the effort of trying to convince a duodenum to heal itself. I fall back on the familiar lamentations of self-pity. Why do I even have to do this? Why can't I be a mother who never thinks about the intricacies of her child's duodenum? Why am I not looking at a photograph in an album?

Because it's Ryan.

Ryan will always face medical challenges like this one. His one in a million diagnosis of chronic granulomatous disease will bring us to the hospital often, pondering massy collections of cells that follow an infection. For the rest of his life, he will be subjected to intravenous antibiotic and antifungal medication to kill opportunistic infections. Ryan's immunologist has assured me that many CGD patients enjoy long stretches of good health—that they can go several years without a major infection. I try to see past the walls of the cold room to those better times, I hold onto her words for hope. I have developed a deep and lasting affection for the global medical community. I am personally grateful for their continued efforts to improve procedures and medications, and I have come to think of them as distant family. Even the X-ray tech, who is probably enjoying lunch in the cafeteria right now—maybe a chicken sandwich, maybe meatloaf.

Still, I want to sleep in my own bed and point a camera at the smiling face of my two-year-old boy. I want to think about God and life and love in less urgent ways. I want to feel safe. When I was young, I laughed at the idea of safety, wishing instead for unpredictability and adventure. Unpredictability seemed so much easier then and everything was hypothetical. Then, I couldn't see through people and love was just an idea and not a tiny body strapped to a wooden board. I want to get out of this room and go back to our familiar hospital room where at least there is a window to remind me of sun and sky, green grass and red birthday balloons.

Colleen Lennon is a student at North Carolina State University, pursing an MA in English, with a concentration in creative writing. Her son, Ryan, is now 3 years old and has enjoyed good health for the past year, with the exception of a few minor infections. She hopes to write a memoir soon, chronicling her experiences with Ryan's illness and the unique perspective on life that it has afforded her.

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PERSONAL NARRATIVE

Through the Physician's Eyes: Rational Work Scheduling for Residents Alan Heims, MD

Systematic sleep deprivation is a dangerous anachronism in graduate medical education. Continuous work periods of 30+ hours every 3rd or 4th night for months at a time are scheduled in most residency programs and are most frequent in general surgery, surgical subspecialties, OB/GYN, pediatrics, and internal medicine residencies. Rigorous evidence from prospective, controlled trials and well-designed observational studies has documented harm to residents and patients from this practice, and has been reviewed and synthesized in the articles cited below.^{1,2} No such high-quality evidence demonstrates a benefit for patients or residents from sleep deprivation. Other evidence from aviation, trucking, and the nuclear power industries supports shift length limits as a proven safety measure for employees and the public.

Recent policy pronouncements by the American Medical Association (AMA), the Accreditation Council for Graduate Medical Education (ACGME), and legislation introduced in the U.S. Congress seek to address this issue by limiting weekly work hours and prescribing elimination of the most egregious scheduling practices. The 3 proposals are similar in recommending a maximum 80-hour work week (in line with existing limits in New York state), requiring one day off per week, and limiting overnight call to no more frequently than every third night. In addition, all three plans permit continuous work periods of 24 hours, and in the case of the AMA and ACGME up to 30 hours of work with no protected time for sleep. This is where all of these policies fail to protect the health and welfare of the employed resident physicians and their patients.

Patient care and medical education cannot be accomplished safely, efficiently or effectively by sleep-deprived residents. Resident physicians and the public must demand rational work scheduling to maximize patient safety and improve the quality of medical training. The model of the lone practitioner providing continuous care for patients has outlived its usefulness. Teamwork is the paradigm for medicine in 2002 and the future. Most other industries have embraced teamwork because of long experience with the higher quality and greater efficiency of teams compared to individuals working alone.

Medical educators and attending physicians who are responsible for resident physician training and supervision must seize this new paradigm and lead interdisciplinary teams in providing optimum patient care and promoting wellness and professionalism in practitioners. Rational shift length limits within this new model are 16 hours for most physician work and 12 hours in high intensity areas such as emergency departments, critical care units, operating rooms, and labor-and-delivery suites. Of course, exceptions may be permitted in the event of a disaster or other unexpected event, but not allowed to occur on a regular basis. These limits provide for daily, protected sleep, the opportunity for interaction with family and friends, and other health promoting activities. This scheduling will also raise resident productivity and learning, eliminating any need to increase resident numbers or residency length, as suggested by defenders of the status quo.

Now is the time to cast off out-dated thinking about medical education and resident physician work scheduling. Traditional professional organizations, such as the AMA and ACGME, are still allowing irrational, harmful practices, and the federal government is following their lead. New leaders must step forward to take on the challenge of designing the medical profession of the future, a profession where quality, safety, and health are paramount. Much of the recent work to change scheduling practices has been done by medical students and residents. As these people advance in their careers they are the natural candidates for such leadership. However, established academic and community physicians must also join this effort for reform to occur.

References

- 1. Green MJ. What (if anything) is wrong with residency overwork? *Ann Intern Med.* 1995;123(7):512-517.
- 2. Heins A, Euerle B. Application of chronobiology to resident physician work scheduling. *Ann Emerg Med.* 2002;39(4):444-447.

Alan Heims, MD is a resident physician in the University of Maryland Emergency Medicine Residency Program, is president of the House Staff Association of the University of Maryland Medical System. Read Dr. Heins' full profile in this issue.

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