

Virtual Mentor

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Putting Bioethics in Perspective

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FROM THE EDITOR

Lighten Up

Audiey Kao, MD, PhD

As we enter the month when April foolery and the bloom of spring are celebrated, it seems like an appropriate time to poke fun and laugh at ourselves with individual renewal and growth as our goals. More specifically, the bioethics enterprise that has been intently nurtured and firmly established over the past three-plus decades demands periodic examination of its roots and branches so as to promote its continued flourishing.

First, bioethics deserves worthy credit for tackling the issues and challenges brought about, in large part, by advances in science, technology, and medicine. This focus is reflected, for example, in the recognition among leaders of the human genome mapping project to dedicate public funds for examining and addressing the ethical consequences of decoding our genetic biology. Bioethicists have also played a key role in protecting respect for autonomy as it applies to clinical care and human subjects research. In an increasingly interconnected world, the social and economic implications of our decisions in these matters are so far-reaching that attention to the ethical dimensions of individual or collective choices is critical.

Given these important contributions, the bioethics enterprise is nevertheless caught, in some respects, under the weight of its success. Today, the field of bioethics and its practitioners enjoy much exposure in the mainstream discourse. Rarely does a day go by that ethical dilemmas raised by one story or another are not reported on and disseminated in print, TV, radio, and over the Internet. But like all stories that compete in the marketplace of information, the bioethics stories considered "newsworthy" are oftentimes the most dramatic, exotic, or entertaining. A scan of the morning headlines can reveal stories that feature commentary about and analysis of the fertility tourists, fashion models (or ivy league co-eds) selling their eggs, and organ snatching.

Of course, there is media coverage, like the recent *Time* cover story (February 12, 2001) that focused graphic, and much needed attention on the human suffering and devastation of the AIDS plague in Africa. With more than 17 million Africans dead from AIDS and many millions more infected with HIV, our collective response to this human suffering will define our humanity in significant ways in the new century. Therefore, the media would do better to lighten up on the load of stories that directly or indirectly affect few individuals and communities, and focus on more pressing and prevalent challenges that confront us as a global society.

While the media plays a key role in driving the public discourse, it is simply too easy and convenient to blame an insatiable appetite for sensationalistic journalism for the quality of discourse concerning matters of ethical import. As members of the bioethics enterprise, we also contribute to this trend through our over-intellectualization of issues and by focusing on one branch of a tree -- often the most remote one, at that -- rather than the forest. Moreover, philosophical critiques that border on self-righteousness can be less than helpful to those doing the work of bioethics, dealing with issues that are never black and white. As an applied field of study, the bioethics enterprise continues to contribute to positive changes in society, but bioethicists, as public intellectuals, must balance their energy and expertise carefully so that issues of greatest import and relevance get their proper due. As members of the bioethics enterprise, we can often advance our ideas and passions more effectively if we don't take ourselves too seriously, but rather lighten up on academic intensity, roll up our sleeves, and simply get to work crafting practical solutions for real-world problems.

As the *Virtual Mentor* nears its two-year anniversary, it is necessary that we constantly reexamine and turn a self-critical eye on our work, but at the same time, know when not to take ourselves so seriously; this advice will come as no surprise to the hardworking and dedicated editorial staff. To our readers and contributors, your comments and critiques about how the *Virtual Mentor* can better achieve its goal of strengthening the ethics and professionalism of tomorrow's physicians are always welcome, even if it is to tell us to lighten up now and then.

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

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CASE AND COMMENTARY

Can a Minor Be an Organ Donor?

Commentary by Kayhan Parsi, JD, PhD

Case

Amy Watson is a seventeen-year-old freshman at a large state university. During spring break, she and her friends go bungee jumping. A natural risk-taker, Amy has bungee jumped several times before. But this time, Amy's jump turns tragic; she hits her head and sustains a traumatic brain injury. The EMT team is unable to revive her, and she is pronounced dead when admitted to the emergency room. A year before when she turned sixteen and earned her driver's license, Amy had signed an organ donor card. She fervently believed in organ donation and made sure that her parents knew about her wishes when she signed her ID. Following policy on organ procurement, the surgery team has been alerted to remove her organs for transplantation. But the hospital is unsure how to proceed. Amy is a minor. Yet, her age and the fact that she has expressed her wishes to donate her organs on a legal document (her driver's license) make her situation somewhat different from that for which the policy on organ donation among minors was promulgated. Amy's parents are currently traveling throughout Southeast Asia and cannot be reached. Amy's only adult relative of age is an older brother who has no problems with organ donation in general, but feels ambivalent about his younger sister "being cut up" for donation purposes.

Questions for Discussion

1. As a minor, may Amy consent to have her organs removed upon her death?
2. If her parents are not available, may her adult brother refuse consent to have her organs removed?
3. In general, what role should family members play with regard to organ procurement?

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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. 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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IN THE LITERATURE

Is Medical Professionalism Eroding?

Keith Bauer, PhD, MSW

More ES. The remains of the profession, or what the butler knew. *Ann Intern Med.* 2001;134(3):255-259.

In [The Remains of the Profession, or What the Butler Knew](#), the author attempts to answer the above questions by reflecting on the actions of Stevens, the butler in Kazuo Ishiguro's award-winning novel, *The Remains of the Day*. By way of comparison with Ishiguro's work, the author argues that as physicians lose control over the ends of their work -- patient care and well-being -- and disclaim responsibility for the uses to which their work is applied, their professionalism erodes. As their sense of professionalism erodes, physician-employees of health care organizations may identify increasingly with their colleagues and employers, become emotionally disconnected from patients and, worst of all, fail to develop their capacity for individual moral agency. Like Ishiguro's butler, physician-employees may end up only mimicking professionalism as they work for employers who value them only as servants.

Questions for Discussion

1. The author believes that professionals must not abrogate their core duties "to make sound and ethical judgments and to acknowledge the responsibility for having made them." Is it possible for physicians to exercise these "core duties" under the conditions imposed by contracts with managed care organizations?
2. Is the recent establishment of physician unions connected in any way to the eroding of professionalism the author describes?
3. AMA policy as promulgated in its *Code of Medical Ethics* maintains that physicians' professional duties to patients should not be altered by the system of health care delivery in which they practice. How can physicians avoid conflicts between their responsibilities to patients and their responsibilities to provider organizations to whom they are under contract?

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AMA CODE SAYS

AMA Code of Medical Ethics Available Online

Herbert Rakatansky, MD

As stewards of the process by which the 150-plus-year-old *Code* is revised and updated, the Council on Ethical and Judicial Affairs recognizes its important role in the adjudication of ethical and legal issues by professional boards and courts of law across the nation. Ironically, many members of the profession by and for whom the *Code* was developed view it as an historical artifact rather than as a living document and practical guide for day-to-day decision making. The challenge today is—as it was 100 years ago—to promote the *Code* as a viable compendium of guidelines that can help physicians recognize, analyze, and resolve ethical and professional dilemmas that arise in patient care and clinical research.

A new means for accomplishing this goal is the Internet. The entire *Code* is now publicly available online at the AMA web site. The annotated version (with legal references citing the use of the *Code* in US jurisdictions) is the accepted reference for nearly all states and licensure authorities and is available for purchase from AMA.

Since the *Code* sets the standard for professional conduct of US physicians, medical students and doctors should know how to access it and become familiar with its content. Organized medicine and academic institutions should work together to find cost effective means for increasing awareness of the *Code* by medical students and physicians.

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STATE OF THE ART AND SCIENCE

Cloning Talk Turns Serious

Faith Lagay, PhD

Parents seek to duplicate dead child! Scientists say, "It can be done!" When these banner headlines appear on the cover of the venerable *New York Times Magazine* rather than in the *National Inquirer*, cloning talk has, indeed, turned serious¹. After the initial media flurry following reports of a successfully cloned mammal (Dolly) in 1997, talk of human cloning disappeared from the front pages of serious and staid publications (replaced by back page musings about those with the money and the desire to replicate a favored and recently departed pet dog.) Now human cloning's back in the *Times*, with accounts that "a grieving family hopes to replace a lost child," and that a rich sect in Italy is prepared to help them do it¹.

Genetic science has changed in the 4 years since Dolly's birth and, with it, discussion of the ethical issues that cloning raises. One of the early specters spawned by the notion of cloning, for example, was the nightmarish vision of "flocks of enslaved clones raised for body parts"². Stem cell research has since dispelled that dark dream with the bright hope that scientists will learn to program undifferentiated (pluripotent) cells so that they develop into specified types of tissue and organs that can then be used to replace defective or diseased body parts. Such developments, of course, present their own sets of ethical issues.

If the talk is now more serious -- meaning it's more likely that cloning will happen - it is also more serious in being far less sensational. Geneticists, ethicists, fertility specialists, and health policy makers have thought calmly and carefully about cloning and its ethical and social implications, and have broken the early monolithic specter of "cloning" into at least 3 categories of practices: (1) cloning of embryos, (2) cloning one's self or one's partner to have and rear a child, (3) cloning a sick child to generate transplantable tissue for it or cloning a dying or recently deceased person to replace him or her.

Cloning Embryos

Researchers are working to unlock the secret of cell differentiation, believing that when they do, they will be able to direct pluripotent stem cells down a select path of development, ultimately producing specific types of tissue to replace, for example, dysfunctioning brain tissue in patients with Alzheimer's. Couples using in vitro fertilization (IVF) techniques might then clone the embryos that are implanted so as to have the potential for matched bone marrow or other tissue if their child should ever need it. Stem cell research, however, has been controversial in the US since its

beginning because stem cells are derived from embryos that are destroyed in the retrieval process. Current National Institutes of Health (NIH) guidelines allow funding of research only on stem cells derived from embryos created for but not used in fertility treatment. The guidelines prohibit use of federal funds to derive cells from embryos or to create embryos for research purposes. (Federal funds may be used for research on stem cells retrieved from fetal tissue.)

The NIH position against funding the destruction of embryos to retrieve stem cells is understandable. Yet one must recognize that by prohibiting creation of an embryo—either from an existing embryo (by so-called "twinning") or by somatic cell nuclear transfer (cloning), NIH commits to the destruction of more embryos created from eggs and sperms in fertility clinics. What, then, is unacceptable about embryo cloning in the laboratory³? Since the embryos created in fertility clinics are destroyed also, it is not the outcome or consequence that matters but the intent. Intent is a valid determinant in law as well as in ethics. The NIH guidelines grant, in effect, that creating embryos with the intent that they be used in engendering a child demonstrates a respect for the sanctity of life that is missing when embryos are created or cloned for the sole purpose of destroying them to retrieve stem cells for research. The difference matters to the national conscience, the guidelines suggest, regardless of the final disposition of the embryos.

Cloning One's Self or One's Partner

If a couple is unable to reproduce because of insufficient or defective gametes in one or the other partner, then cloning one parent's genes enables the couple to have a child without introducing a third party's genetic material. This use of cloning has been defended by some as no significant departure from the intent and procedures of other artificial reproduction techniques⁴. In the early post-Dolly days, ethical opposition to this practice centered on the argument that the individuality and personhood of the cloned child would be compromised. He or she, it was claimed, would not have a unique genetic makeup. It wasn't long before many pointed out that a clone was essentially a time-delayed twin, and, as Stephen J. Gould asked, "Have we ever doubted the personhood of each member of a pair of identical twins?" His answer: "Identical twins provide sturdy proof that inevitable differences of nurture (which would be far greater in cloning than in simultaneously gestated twins) guarantee the individuality and personhood of each human clone"⁵.

This assurance does not dispel another aspect of parental cloning for reproduction purposes that was seen as repugnant: the relationship of the cloned child to its parents. The cloned offspring is, in effect, the child of one parent and the sibling of the other. The ambiguous kinship could lead to psychological and emotions confusion for all family members -- the mother and her daughter -- sister (or son-brother-in-law) as well as the father and his son-brother (or daughter-sister-in-law).

Cloning to Replace a Deceased Person (or Provide Tissue for an Ill Person)

This part of cloning was taken, at first, as the whole, particularly by the media and its vast audience: people cloning themselves, cloning deceased others that they did

not intend to rear as children, or cloning a sick child to "grow" tissue for that child. And this is the aspect of cloning that remains most controversial. In his attempt to suggest policy for regulating rather than banning cloning, John Robertson draws a bright line of distinction between cloning a child that one intends to rear and cloning without the intent to rear. "A ban on human cloning unless the parties requesting the cloning will also rear is a much better policy than a ban on all cloning," he says. "It prevents a person from creating clones to be used as subjects or workers without regard to their own interests⁴." Even so, allowing cloning on the condition that the cloners intend to rear the child as their own does not remove a crucial ethical stumbling block, namely, that the child cloned to replace another or to provide tissue for another is being used instrumentally, rather than as an end in itself. Parents who conceive children through sexual reproduction in order to provide tissue for an existing child with an illness can be charged with the same violation. In the well-known 1991 case of Anissa Ayala, a second child was conceived to provide compatible bone marrow to treat Anissa's leukemia. The event predated embryo selection technology, but fortuitously Marissa-Eve Ayala's tissue matched Anissa's, and Anissa is now healthy. One cannot speculate on the degree of acceptance and love Marissa-Eve may have received had her marrow not been compatible with Anissa's and had she been unable to serve the purpose for which she was conceived.

Conclusion

These various categorizations and decidedly moderate ways of thinking about cloning may confirm the doubts of those who, like Leon Kass, warned from the beginning that cloning lay at the bottom of a slippery slope with artificial reproductive technologies at the top. "The burden of moral argument," Kass declared, "must fall entirely on those who want to declare the widespread repugnances of humankind [concerning cloning] to be mere timidity or superstition"⁶. While the US government guidelines for research funding currently recognize the moral repugnance of cloning, the tide seems to be shifting in the private sector. According to Richard Dawkins, a chair-holding professor in Public Understanding of Science at Oxford, the fact that one finds cloning repugnant "is not, in itself, sufficient justification for stopping others who wish to enjoy it. The onus is on the objectors to press a better objection"⁷. Cloning talk is getting really serious.

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HISTORY OF MEDICINE

The Company of Undertakers: Satire and the Medical Profession

Karen Geraghty

In Molière's famous comic drama, *Le Malade Imaginaire*, written in 1673, the character Beralde ruefully observes that "medicine is only for those who are fit enough to survive the treatment as well as the illness." Seventeenth century medical therapeutics were indeed harsh, with bleedings, purgings, and enemas liberally applied to suffering patients to correct the humoral imbalance thought to be the cause of disease or illness. Molière's biting critique of the medical profession of his day, however, concerned not so much the treatments physicians used (although his own personal experience of physicians had left him disinclined to seek their advice). Rather, Molière took aim at the blind deference to social etiquette that dictated the use of medical procedures despite the obvious harm this approach may have caused to the patient. In the 17th century, medicine practiced in the royal court was often imitated by less socially prominent physicians seeking to climb the social ladder. "Better to die according to the rules, than to escape [death] against the rules," states Macroton in another of Molière's plays (*L'Amour Medicine*, 1665) that ridiculed the medical profession. Better for whom? The physician of course, whose adherence to the rules and social etiquette assures him of professional advantage at the expense of health (and life) of the patient.

Figure. "The Company of Undertakers" by William Hogarth in 1737



In the 18th century, some of the most notable satirical portrayals of the medical profession came in the form of artistic renderings. William Hogarth skewered the profession, mockingly portraying physicians in "The Company of Undertakers" in 1737. The painting, framed with a black sash signifying a recent death, shows twelve portly physicians deep in thought, studying a flask of urine. Presiding over the consultation are three figures who turn out to be "Crazy Sally" Mapp (center), a well-known bonesetter, and two notorious quacks of the day, Joshua "Spot" Ward (left) and "Chevalier" John Taylor (right). By lumping professional physicians with the quacks and the bonesetter, Hogarth challenges the presumptions and pretensions that set the professionals and the quacks apart. Physicians in the 18th century were distinguished by their walking canes and stylish wigs—an appearance clearly appropriated by the quacks in the portrait. It is also not clear that any sort of superior education or training sets the professionals apart from the quacks—indeed in the eighteenth century, quack therapeutics were often less harmful to patients than professional therapeutics. The observer is left to conclude that consultation with either group will result in a request for the undertaker's services.

Although the 19th century brought about better education and more effective therapeutic techniques, these changes did not render the medical profession immune from the satirists' barbs. Other factors came into play that challenged the profession's commitment to the patient's interests well into the 20th century. A recent television commercial for example, portrays an emergency room filled with medical professionals, motionless with eyes fixed on a cash register, springing into action to restart the patient's heart only after his credit card has registered "approved." Clearly an eye toward the financial bottom-line weighs heavily in 21st century patient care.

Throughout the centuries, satirical portrayals of the medical profession have parodied the profession's adherence to social rules of etiquette for personal advancement, the display of false knowledge in the guise of professional training, or the quest for profit in the marketplace. Regardless of the theme however, satirical portrayals of the medical profession reiterate one common belief held by audiences everywhere: that physicians are obligated to seek the best interests of their patients and any other pursuit is a mockery of the profession.

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ART OF MEDICINE

Mona, Is That You?

Sara Taub, MA

A report on three patients with bulimia nervosa who had bled themselves was published in 1993 in the *British Journal of Psychiatry*¹. It caught the attention of the authors' local newspaper, which then carried the story, relating nothing more than information from the case report. It reiterated, for instance, the de-identified description of a 26-year-old patient, Ms. C. Still, one reader was able to see right through the anonymized facts, and recognize Ms. C. Three years later, the physician-authors appeared before the General Medical Council, the body that regulates British doctors, to answer a formal complaint by Ms. C that she had given consent for use of her case in teaching and research, but not for publication in a medical journal. She charged the doctors with serious professional misconduct for failing to adequately protect her confidentiality².

When patient information is released without the patient's consent it is usually stripped of identifiers in an effort to maintain confidentiality. This practice is justified by some when, in the contexts of teaching and publishing, it facilitates an important educational opportunity. In these circumstances, the identity of a patient is successfully concealed from strangers, but, as attendees of case conferences can attest and as the above scenario illustrates, it does not always follow that the patient remains unrecognizable to family, friends, or acquaintances. More often than not, the novelty of a case is the precise reason for its being shared with others. Accuracy in the knowledge being imparted requires that some details be highlighted rather than changed. People who know the patient can sometimes make the connection between the sum of the general information and the person it describes.

Just as a person's anonymity can be compromised by disclosure of medical information -- even when the data has been stripped of identifiers -- so too can it be jeopardized by use of a photo -- even when black bands have been placed across the eyes. Patients' photos might accompany an article in a medical publication if their subject illustrates physical manifestations described by the authors. The instructions to authors of several widely distributed peer-reviewed medical journals reflect a full range of responses to the problem of sufficiently anonymizing material that relates directly to the patient. *Clinics of North America* instructs that "If a release [authorizing use of a photograph in which a patient is identifiable] is not submitted with the figure, the eyes will be masked so that the person(s) cannot be identified." The *British Medical Journal* states that, "Black bands across the eyes are wholly ineffective in disguising the patient." *The Journal of Forensic Sciences* suggests a

middle ground: "Masking of the eyes in photographs may not be adequate protection."

To form your own opinion on the matter, try the following experiment: place a black band across the eyes on a photo of a person you know well-- at least by sight. Chances are the face will look somewhat impersonal after this alteration -- and certainly different, but not unrecognizable. A short piece in the *New England Journal of Medicine* illustrates this point. Though pop-star Michael Jackson is featured wearing dark sunglasses, there is no mistaking who is in the photograph³.

Concealing the eyes of a person in a photo to confer anonymity is imperfect at best. Those who know the face will see right through the black bars. Likewise, photographs that narrow in on the face to depict only the eyes -- an alternative some journals use when a feature of the eyes is the object of discussion -- may not protect the patient's anonymity from the careful gaze of a person who knows "those" eyes.

The sometimes insurmountable challenge of guarding anonymity, when a person's information or photo is featured in an expose, is finally being acknowledged by key players in the publishing industry who say it's time for a change. In its publishing guidelines, the International Committee of Medical Journal Editors⁴ (also known as the Vancouver Group) makes clear that the emphasis is now on obtaining consent rather than on trying to achieve anonymity. At a time when the distribution of medical journals is greater than ever, due to both the advent of electronic publishing and a rise in the general public's interest in health-related issues, it is more important than ever to err on the side of caution when sharing a patient's private information.

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PERSONAL NARRATIVE

Physician Profiles in Africa

Robert Davidson, MD, MPH

When I came to Eastern Africa, I was not sure what to expect regarding my colleague physicians. I have been pleasantly surprised by most of the physicians I have met in Eastern Africa. Since some of you may be contemplating a career or experience in international work, I have decided to profile several of the physicians I have met.

Dr. S., an American, is an important medical consultant to Peace Corps Kenya. He went to medical school in Chicago and completed both his residency in Internal Medicine and a fellowship in Cardiology in Seattle. Now in his fifties, Dr. S. has spent most of his career practicing in Nairobi. He has developed a well-respected group of Kenyan physicians. Dr. S. seems genuinely happy with his practice and his life. Observing him in his consultations, I noted that he uses less confirmatory testing than is customary in the US, which may be a blessing since most people do not have insurance and pay out-of-pocket for their health care. Dr. S. is well known throughout the country as "the President's personal physician," a position that has embroiled him in some messy politics in the country. My impression is that he would enjoy less prestige and demand for his services were he to return to a practice in the US.

Dr. K. is a Kenyan who went to medical school at Nairobi University. He did six years of surgical training at the Medical College of Wisconsin and holds both General and Cardiothoracic Board Certifications in the US. He met his wife during his surgery training when she worked as an ICU nurse at the University hospital. She now manages his office as well as raising their children. He could return to the US to practice but prefers to stay in Kenya. The volunteers who see him are initially taken aback by this obviously Kenyan male who speaks English with a mid-western American accent. He is trying to develop a cardiac surgery program in Nairobi, but is frustrated by the lack of skilled nurses and technicians. Most people here think of South Africa as the place to go for cardiac surgery. He reminds me of some of the well-trained surgeons I met in small communities in rural northern California. They wanted to use the advanced skills they had received in their training and often resented the implication that you get better care for major surgery in the large urban hospitals.

Drs. D. and M. represent the best of the United States contribution to international health through the Centers for Disease Control. I have been surprised by the large

CDC presence in Eastern Africa. These two physicians typify the epidemiologist-researcher in international health. Their predominate focus now is on HIV / AIDS. Dr. M is a pediatrician-epidemiologist whose area of interest is maternal-child transmission of HIV. His wife is a social worker, well known for her leadership in several programs in Eastern Africa targeting HIV prevention. They have two children who have been raised around the world and are now in high school in Nairobi. Both have spent their entire careers, except for some obligatory time in Bethesda, in overseas countries, seem very happy with their career choice, and feel a sense of accomplishment from their professional lives.

Dr. H. at 64 heads a major project on reproductive health in Kenya and devotes much effort to marketing his dream to various funding agencies. He envisions an Africa-wide initiative to develop leadership in HIV / AIDS programs based on the US Peace Corps model where African volunteers would be trained, supported in their work for two years in another African country, and then returned to their own country. His enthusiasm when describing his proposal is infectious. I understand his rationale for selecting the Peace Corps model, since I am witness to the tremendous impact the US Peace Corps has had on the development of leadership. Many current employees in the State Dept. and US Agency for International Development are former Peace Corps volunteers, including three of the five US ambassadors in the countries I cover. Dr. H's wife heads a major US program in Pakistan, so the couple maintains a long-distance marriage. He has training in pediatrics, has taught international health in a US medical school, and has worked all over the world in both government positions and with many of the non-governmental agencies (NGOs) involved in health projects. I again sense a happy person who believes he has made a difference through his work, and is still excited about international health projects.

Drs. M, G, and S. are colleagues of mine working for the Peace Corps in Africa. Drs. M. and G. came to Peace Corps from the Indian Health Service. The commitment they have for under-served populations is met by both their previous and current jobs. Dr. S.'s story is a bit different. Following medical school and Internal Medicine and gastroenterology training in the US, she had a private practice for a while and then moved into increasing responsibilities in a managed care company. Becoming disillusioned with this, she came to Africa. She has some wonderful stories about her experience as a black American woman in a position of responsibility in Africa. She is married to an African man whom she met in the US, and they are raising their children in both cultures.

Drs. G. and H. are American physicians working in Kenya as part of religious missions. Dr. G. is an ophthalmologist who divides his time between a practice in Oregon and directing an eye institute near Nairobi. He is fascinated by the pathology he treats in Kenya. He plans to return full time to the US sometime in the future. Dr. H. is here on a two-year mission commitment. He is an orthopedic surgeon who acts as Chief of Surgery in a mission hospital that serves a rural, poor

population. Both of these physicians receive much personal satisfaction from using their skills in service to humanity.

The conclusion I come to is that all the physicians I have described are happy with their lives and find gratification in what they are doing. In the US, I became tired of belly aching by physicians. I too often heard comments like, "I am just putting in my time until I can get out of practice." Many seemed to look for a villain for their unhappiness and managed care seemed an easy target. They seemed to dwell on their loss of income when they were still in the top five percent of wage earners in the US. Most disturbing to me personally were comments that they did not want their sons or daughters to go into medicine.

Now my advice. If you find yourself sharing that level of frustration, do something about it. There are opportunities throughout the world where your skills are needed. Working overseas may not be the answer for everyone, but it works for the physicians I have profiled.

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PERSONAL NARRATIVE

Through the Patient's Eyes: On The Road

Gay Madsen Jervey

Bad news can be delivered in many ways at a doctor's office. Whether it is announced in an offhand careless manner by a busy practitioner or (as in my case) in hushed tones of compassion, the result is often the same. You, the patient, are pole-axed. Numb and dumb. When my GP told me I had leukemia, I sat there staring at him. His consideration was notable, but for a few days it just didn't sink in. Not me, no way. I was never sick. Never mind that my husband had taken me to the doctor for lethargy so profound I had difficulty getting out of bed.

And so my journey to a new land began.

A cruel reality of the road, so to speak, is the public perception that all serious diseases are now curable or treatable. There have been great advances in cancer treatment, to be sure, but, for many cancers, treatment is only a holding action, and, for some, treatment is more toxic than the disease. Thus, for many of us, the initial bad news is rapidly followed by an excruciatingly disappointed expectation of being cured.

Because I live in a small community I often saw people I knew, liked, or loved visibly losing their grasp on life. One acquaintance, a feisty and slightly raffish Vietnam vet, had lymphoma. He lasted quite some time, but one day he was gone. He will appear again in this story.

I go through the stages people usually do, the stages common among those grieving for lost loved ones or lost selves. The feelings I experience after the first shock recedes, fear and despair, have a sickening intensity I can share only with my husband, and he holds me as I cry for the years I am going to lose. At other times I push him away and find any human contact too abrasive.

One of my worst fears has to do with how I will die. Because I am very curious, as everyone must be in these circumstances, I inform myself from books and the Internet. Liver and kidney failure often accompany leukemia in its acute stage. Less than a year before, my father and I had nursed my mother through liver failure. It is ugly, painful, humiliating, frightening, sad. At one point during this six-month period I became convinced that life is a sadistic joke being played by a monstrous cruel deity.

The major drug I take is interferon. It is a natural substance, but people with hepatitis, AIDS, or blood cancers have to take it in nearly toxic amounts. Most folks have some trouble tolerating it in high dosages. Interferon can make you feel like you have the flu -- fever, aches, general malaise, and lethargy. But I am also taking an antidepressant, which hides all the bad feelings under a rock inside my head.

As a result of the treatment, my hair started falling out. For women and men, rapid loss of hair from head, eyelids, legs, arms, and pubis possesses far more impact than the bald fact of its absence. As you watch your body beginning to ditch its hairy cargo, you know you are in big, scary trouble. But at an even deeper gut level, like Samson, you are losing your human power. There's a good reason that prisoners, quislings or collaborators have their heads shorn (aside from lice, that is).

About 6 months into my journey, I rebelled. My joints were so painful I couldn't write or walk easily and I gained so much weight I disgusted myself. My oncologist, a caring and exceptional person, allowed me a "recess." I was glad and became quite active again, able to walk and even run.

As an aside, the varieties of "weirdness" that drugs, friends, "healers," and hospitals can offer are too numerous to mention. A kooky friend takes me to a shaman healer who pronounces that I am "cured." Please! Because I claim to be a scientist, wouldn't you think I would know better? Nah. People like this shaman can prey upon not only an individual's gullibility but the incredible human knack for self-deception. Boy, I want to be well again.

So after a month of deceptive freedom, I had another bone marrow extraction. My leukemic stem cells had shot up to 100% again from a pre-recess low of 10%. I was back where I started. On Interferon again, I rebelled against going back on the antidepressant. I feared addiction would be the next stop on my trip. I decided to go on without it, only to find a life-threatening curve in the road ahead.

A strange and important thing occurred and I have a responsibility to explain it. Oddly, the warnings about interferon causing suicidal thinking did not impress me. I was West Texas tough, thank you, and by gritting my teeth could endure anything. I started running again and my blood work showed improvement. I reported in to my oncologist and he was pleased, I was pleased.

But drugs and the mind are tricky and sly. I hoarded old tranquilizers for weeks as if I knew what I would do next. Immediately after my good checkup, a couple of squabbles set off a series of reactions in my mind that were emotional and severely sad. I drank five glasses of wine. A mistake. I was thrown into a black place with sharp cutting edges. Every thought brought terrible, terrible pain. It was time to go. I took every pill I remembered I had. By some great good fortune, my husband woke and stopped me before I downed a large bottle of Tylenol for dessert. Ironically, he saved me from death by liver damage, the thing I most feared.

We all approach serious medical conditions in ways that differ according to our personalities. Some yield, others fight, some worship their doctors, others hate their doctors. Some are like me. There is no single right way through illness, just as there is no single right way to God.

My way is to hang in there. My father, whom I am very like, wrote to me each week when I left home for school. He always closed with admonitions to "hang in there." And I do. A boss I had long ago said in reference to my work, "Gay, if you can't be smart, you'd better be lucky." I am lucky. I have a husband who loves me as I love him; I have family and friends who support me, and a church with a thoughtful congregation. I receive joy every day from people, plants, animals, all living things.

When I first drafted this article, I didn't know whether I would be accepted into a new drug trial program. The drug (formerly called STI571 and now named "Glivec") was developed by Dr. Brian Drucker of Oregon Health Sciences University and Novartis Laboratories. It was designed specifically for the kind of leukemia that I have (CML). Results to date from clinical trials have been spectacularly good and side effects are minimal. I am starting on this program April 5, and FDA approval should come late this year. Another vista appears ahead.

My friend Bob the Vietnam vet cheered everyone in the oncology waiting room with rude jokes and obnoxious, outrageous remarks. It is hard to get people to laugh in that place, but he did. He made everyone an offer: if they couldn't stand his jokes, they could buy joke insurance. Now Bob is in another place and I am taking over as Minister of Bad Jokes. If we meet some day, I will offer you joke insurance.

Gay Madsen Jervey contributed to this issue of Virtual Mentor.

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PERSONAL NARRATIVE

Through the Student's Eyes: Having a Voice in Revising The Code

Matthew Weiss

When I applied for the student position on the AMA's Council on Ethical and Judicial Affairs (CEJA) during my second year of medical school, all I knew about the group was that it discussed and promulgated AMA ethics policy. After talking to people familiar with the Council and conducting further research on my own, it seemed that serving on CEJA would be a valuable opportunity for me to discuss issues of ethical import with other physicians. I also believed that it would be interesting to have a voice in setting policy that could potentially have wide-ranging effects on American medicine.

The policy discussions required some adjustment on my part. I was used to writing and talking about bioethics in a purely academic setting -- one where incisive analysis and cogent theorizing are highly valued. On CEJA, I quickly learned that I needed to adopt a more pragmatic mindset. While an issue's complexity was understood and appreciated, arriving at a workable solution and setting forth policy that could realistically be applied were priorities. The challenge of developing practical codes of conduct, I discovered, included weighing political concerns and ethical ones so that recommendations could be implemented in the real world of medical practice.

As I settled into my term on the Council, which is composed of 7 practicing physicians, 1 resident, and 1 student, I gained a great appreciation for the members and the staff. All are dedicated, talented, and passionate people who see the importance of our work and take pride in doing it well. It is also a very warm and friendly group, which made attending meetings a pleasure.

During my brief tenure on CEJA, we discussed a range of troubling and weighty topics. Typically, each issue is addressed in a report that the Council and staff put together collaboratively. Two members of CEJA acting as "shepherds" for the report bring it before the reference committee and House of Delegates. If the report is passed, its recommendations become opinions of CEJA and go into the AMA Code of Ethics. However, if the House votes down the report, the Council and staff revise it and reintroduce the it at the next meeting of the House of Delegates.

This discussing, writing, shepherding, and rewriting process comprises the bulk of the Council's work. As a student, I have a voice and a vote equal to those of Council

members. Of course, lacking a long career in the practice of medicine but being intimately familiar with the current climate of academic medical centers, I have more insight into certain issues than into others. Because I am particularly concerned about policy relevant to training in medical school, I have consulted with the leadership of the AMA's Medical Student Section and worked to bring the concerns of the Section to the attention of the Council. CEJA has always tried to accommodate the students' viewpoint, and we have attempted (I think successfully) to strike an acceptable balance between the interests of medical education and those of ethical practice.

The other, less enjoyable though important, responsibility of the Council is its judicial function. CEJA is called upon to adjudicate certain conflicts and also to discipline AMA members who have exhibited egregious misconduct. Judicial hearings are conducted by conference call and, contrary to all other aspects of the Council's work, the student member does not vote in judicial matters unless the accused member is a medical student. I can, however, participate fully in the deliberations.

I have enjoyed my term on CEJA and am sorry to see it coming to an end. The members and staff of the Council have been a pleasure to work with, and I will miss seeing them regularly. Serving on CEJA has been a daunting responsibility, as well as a significant time commitment, but the full support of my medical school made the latter concern less onerous. Besides having the opportunity to think and talk about a number of complex ethical issues and have an impact on the practice of American medicine, I've learned a great deal about the inner workings of the AMA, a group for which CEJA is the institutional conscience.

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VIEWPOINT

The Emergency Physician and End-of-Life Care

Art Derse, MD, JD

The scene is now familiar. The dying patient is rolled into the emergency department in cardiac arrest. The emergency team rushes to the patient's side and begins medical treatment. A tube is placed in the patient's trachea, lines are started, medications are given, and a defibrillator shocks the patient. Valiantly, the medical team snatches the patient from the jaws of death back into the realm of the living. The patient has made it through the cardiac arrest and will survive.

The reason this scene is now familiar is that a number of medical shows commonly portray this course of events, getting a lot of the details right, even though they get one important thing wrong: resuscitation is usually unsuccessful, even with today's advanced technology. For every 6 patients for whom resuscitation attempts are begun, only 1 survives to be discharged from the hospital. (But there's no reason for the TV shows to be accurate; it would make for boring and depressing television to see 5 out of every 6 attempts at resuscitation fail.)

Even if the television shows don't portray the outcome of resuscitation accurately, they do convey the sense of failure that emergency physicians feel when resuscitation is not successful and the patient dies. Traditionally, emergency physicians were trained to save lives and to stave off death at all costs. The technique of cardiopulmonary resuscitation (CPR) was originally developed to treat unexpected and reversible cardiac arrest -- those cases where the patient was still relatively healthy, but the heart had stopped due to an electrical abnormality that could quickly be reversed. The technique was soon extended, however, to everyone who experienced cardiac arrest, which, of course, meant all dying patients. Nonetheless, many patients still die in the emergency department, despite our best efforts. (Emergency physicians see the second highest number of patient deaths, fewer than oncologists, but more than cardiologists.)

The Real-life ED

In general, there are two broad categories of dying patients in the ED -- those with unexpected sudden death and those who have a terminal disease and are inevitably dying. The former cases are the stuff of valiant and sometimes heroic efforts, e.g., reviving a child with hypothermia in cardiac arrest, or saving the life of a middle-aged patient with heart disease who has an arrhythmia by using the defibrillator to shock the heart back to a normal rhythm. The latter types of cases, e.g., an elderly patient who is dying from cancer because nothing more can be done, or a patient

with amyotrophic lateral sclerosis (ALS) who requests that life-sustaining medical treatment not be attempted, were not well-handled or well-taught in a field where intervention and action were the orders of the day.

Emergency physicians were reluctant to discuss these latter cases of expected death, since the emergency department was for saving lives, not letting them end. The old emergency department rules were simple: (1) when in doubt, resuscitate and (2) always doubt. That is, always err on the side of life and resuscitate. CPR was applied to almost all patients in cardiac arrest, even in cases when family members told physicians that the patient should not receive it or would not want it. Emergency physicians, though trained in resuscitation, were not trained in the care of the patient who is dying. This resulted in their attempting to resuscitate a patient who was imminently dying, whether or not it would work, or in spite the fact that this patient's own wishes may have been to forgo resuscitation. The patient was often placed on life support and admitted to the hospital, where he or she may have lingered on life support until the inevitable death occurred.

Under the best circumstances, a dying patient's primary physician might arrange that the ambulance or family transporting the patient bypass the emergency department and admit the patient to a bed in the hospital where compassionate care could be administered and life-sustaining medical treatments withheld. But more often, family members who experienced the distress of their loved one dying called the emergency medical system, and paramedics, by standard protocol, transported the patient to the nearest emergency department where the cascade of interventions began. Some emergency physicians were even known to admonish families with, "if you didn't want an emergency response, you shouldn't have dialed 911."

Sometimes patients were allowed to die in the emergency department without attempts at resuscitation, but emergency physicians often did not understand how to provide appropriate comfort care to those patients. Maren Monsen, an emergency physician, produced a documentary called "The Vanishing Line," which portrayed, among other things, her distress when a patient who was dying (and was not going to be resuscitated) was brought to the emergency department and placed in a room alone to die without any comfort measures. Her distress motivated her to consider how physicians should treat patients at the end of life.

Emergency physicians were also reluctant to prescribe and administer narcotic pain medication to patients who were dying. They had not been trained to distinguish those for whom large doses of pain medication were appropriate because of their suffering at the end of life from those not facing death who were merely addicted to pain medications and using the emergency department to obtain the drugs. They were also afraid that if they gave enough medication to relieve the patient's pain, they might also inadvertently hasten the patient's death.

Important Changes in ED Customs

Two important developments have changed these customs. The first was the development of do-not-resuscitate (DNR) orders and pre-hospital DNR orders. DNR orders recognize that some patients -- whether because of the uselessness of attempting resuscitation or because of the patient's wishes to forgo resuscitation -- should not receive CPR. DNR orders were also developed which apply beyond the hospital, to the pre-hospital arena of the emergency medical system.

Patients are now able to express their wishes to forgo resuscitation and other life-sustaining medical treatment, either verbally, or in written directives to their physicians before they become incapacitated and can not communicate. The most common types of these "advance directives" are the living will (a direction to the physician to forgo life-sustaining medical treatment if the patient has a terminal condition or is in a persistent vegetative state) and the power of attorney for health care (an appointment of an agent to act as health care decision maker when the patient is incapacitated).

The second important development was the emergence of palliative care as a field of special expertise. With its emphasis on care rather than cure, this field has changed the way medicine and emergency physicians approach end-of-life care. Palliative care principles identify methods of comfort care and means for conferring adequate pain relief, including the principle of double effect, which recognizes that appropriate pain relief in end-of-life care (which may, on occasion, inadvertently hasten a patient's death), can and should be differentiated medically, ethically, and legally from intentionally hastening a patient's death.

Educating Emergency Physicians to End-of-life Care Needs

Important outreach efforts have been made, such as the [Education for Physicians on End-of-Life Care \(EPEC\) Project](#), originated at the American Medical Association, funded by the Robert Wood Johnson Foundation and now sponsored by Northwestern University Medical School. This 16-module program has been educating physicians, including emergency physicians, on medical, legal, and ethical aspects of end-of-life care around the country.

With training, emergency physicians can now identify those for whom comfort care is more appropriate than attempts to resuscitate or other life-sustaining measures. And they now have the ability to care for these patients and to consult and collaborate in their treatment with their colleagues in palliative care. Emergency physicians are also learning that expected death is not necessarily an impending failure but rather an opportunity to successfully care for the patient at the end of life.

Emergency physicians' treatment of patients at the end of life has thus broadened. Trained in the past to work exclusively toward saving lives, they are now being trained to care with comfort and compassion for those who face expected death.

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VIEWPOINT

Origami and Paper Airplanes

Audiey Kao, MD, PhD

- In Japanese, "oru" means "to fold" and "kami" means "paper." Origami, the art of folding objects out of paper without cutting, pasting, or decorating, has its documented origins as far back as 12th century Japan. There are 2 categories of origami: one is [ceremonial](#) in nature (folded decorations attached to gifts), and the other is for recreational purposes (birds, flowers, animals, and other objects that are more familiar to most of us).
- Pediatric hospitals are designed to look and feel less like traditional adult hospitals because hospitalized children (and their parents) when confronted with potentially serious or life-threatening illnesses are less equipped to deal with these stressors than adults. Thus, many hospitals design interior spaces using warm colors¹, provide common areas for patients to play and interact^{2, 3, 4}, and develop programs specifically designed to reduce the stress and anxiety associated with diagnostic and therapeutic procedures^{5, 6}. Pediatricians also rarely wear their long white coats because it has the potential effect of increasing a child's anxiety and stress. Many pediatricians have little stuffed animals attached to their stethoscopes so as to occupy the child with something familiar during a physical exam. Try your hand at making a paper [hummingbird](#) with a pediatric patient -- it may be a good way to relate to your young patients.
- While the origins of origami are fairly well-established, the history of paper airplanes is less certain. The origins of flying paper objects probably date back to when the first pages of papyrus were thrown at the first "trash cans," but the first flying devices to use paper were kites made in China about 2000 years ago. Early hot air balloons, such as those fashioned by the Montgolfier Brothers in France in the late 1700s, also used paper in their construction. Try your hand at making a [paper airplane](#) with a young patient.
- More than 100 people die while traveling in airplanes each year in the United States. Causes of death are usually myocardial infarction or pulmonary embolus. The lower atmospheric pressure in the airplane cabin that results in lower blood oxygen levels is seen as a predisposing factor for heart attacks. In addition, passengers are sitting down for extended periods of time, which may predispose individuals to develop blood clots in their legs. Therefore, recommendations have been developed for airline passengers who may be at risk for MIs and DVTs: stay well hydrated, avoid alcohol, and take a walk up and down the aisle every couple of hours.

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VIEWPOINT

Think It's Information? It Could Be a Sales Pitch

Kayhan Parsi, JD, PhD and Sara Taub, MA

Once upon a time (the early 90s) most prescription drug ads resided safely within the pages of medical journals read largely by physicians. Their color contrasted sharply with the black and white text that surrounded them. Like other kinds of advertising, they were there to grab physicians' short attention spans. Accompanying the ad, however, was vital prescription information that described potentially harmful side effects and contraindications. Until a few years ago, the FDA required pharmaceutical manufacturers to include these extensive consumer warnings in their sales pitches to physicians.

Fast forward to 2001. Colorful print ads still populate the pages of journals. And they're still mostly read by doctors. But turn on the television at any given prime-time hour and you can see the color ads for prescription drugs that vied for space in the medical journals transported to the small screen. Along with their new home, the ads have a new audience of millions of consumers, many of whom have not heard of the drugs -- or the disorders -- until recently.

Some ads, such as a recent one for a medication to treat premenstrual dysphoric disorder (PMDD), are cryptic. A woman wrestles with a shopping cart trying to dislodge it from its stack to no avail. We watch her frustration mount while a voice in the background recites the symptoms of premenstrual syndrome. "Think it's PMS?" the voice asks. "Think again. It could be PMDD." Mention of this new condition is followed by mention of a new drug (actually the old drug fluoxetine). The focus shifts to a different woman. Her confident demeanor and immediate success in releasing a cart from the stack leave little doubt: she's taking the old drug for the new condition.

You may remember seeing this advertisement at the beginning of the year, before it was pulled for modification. The Food and Drug Administration (FDA) objected that the televised spot failed to distinguish PMDD from the more familiar PMS. The FDA's chief complaint was that the overall message broadened the indication for the drug and trivialized the seriousness of the condition it treats.

The FDA's issuing of warnings like these has been on the rise ever since relaxed rules for pharmaceutical advertising in 1997 made it easier for drug companies to market their products on television. While most companies respond to FDA warnings by altering the problematic content of their ads, they are under no

obligation to comply with the agency's recommendations. This may surprise many, who view the FDA as a regulatory agency with teeth. In fact, the agency's watchdog role in advertising is limited to embarrassing drug manufacturers rather than fining or punishing them.

It wasn't long before a new ad for treating PMDD was on the air: one that captured the significant impairments that accompany PMDD. Several women are portrayed as they go through bouts of depression, anger, or moodiness that interfere with their daily routines and relationships. The tone of the ad is darker, the disorder more serious, than those of its predecessor.

Most ads, however, are cheerful and upbeat. Rather than focusing on the drug itself, the ad creates the mood its marketers want consumers to associate with the drug. In this way, the ads are quite similar to more conventional advertising. They differ in that the bright and sunny images are accompanied by a voiceover that quickly lists some of the side effects of the drug; an 800 number or Web site where consumers can obtain more information is flashed on the screen. If the sound on your set were muted, you would be hard pressed to tell what the images were trying to sell.

The juxtaposition of upbeat images alongside dour warnings creates a strange mixture that is unique to this genre of advertising -- one that reflects the delicate balancing act that advertisements for prescription drugs have to perform. Through their ads, pharmaceutical companies deliver information that is meant, on the one hand, to make the public more knowledgeable about a condition and its corresponding treatment and, on the other hand, to plug a given product. The line between empowering people to become better-educated consumers and manipulating them to buy drugs of a particular brand is easily crossed. That is why controversy surrounds the upsurge in marketing prescription pharmaceuticals directly to general audiences -- especially when there are less-expensive alternatives that are thought to be as effective as, or better than, the one advertised.

Direct-to-consumer advertising, with its pros and cons, is probably here to stay. With this in mind, some guidelines have been written that apply to physicians. The *AMA's Code of Medical Ethics*, for instance, admonishes that "Although physicians should not be biased against drugs that are advertised, physicians should resist commercially induced pressure to prescribe drugs that may not be indicated. Physicians should deny requests for inappropriate prescriptions and educate patients as to why certain advertised drugs may not be suitable treatment options providing, when available, information on the cost effectiveness of different options."

Although the ads reach consumers directly, interested consumers cannot obtain the advertised drug without a physician's prescription. Thus, the burden for delivering pharmaceuticals to patients responsibly still rests with the medical profession. Physicians are the only professionals who can legally prescribe all drugs and with this authority comes a concomitant duty to better educate their patients. Whether or

not drug companies advertise their products properly, physicians are ultimately responsible for the quality of patient care.

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VIEWPOINT

Do What You Believe In

Kayhan Parsi, JD, PhD

The stigma surrounding AIDS has declined substantially in the last 15 years. Many of the myths of the disease have been successfully debunked, and patients with HIV are no longer looked upon as pariahs. The changes have come about through the dedication of those who offered care and compassion when it took some courage to do so. One of those heroes is Dr. Kristen Ries of Salt Lake City, Utah.

Trained in infectious diseases, Dr. Ries has been a full-time faculty member at the University of Utah since 1994. Before then she treated hundreds of patients with HIV. For "an old-fashioned doctor," as she calls herself, leaving her practice to join the University was a tough decision. But she felt it was the right move. "It's time to teach what we do," she told the local newspaper upon her arrival on campus in 1994. "The university wants us to be role models for the young trainees. I take that as a positive"¹. In addition to directly mentoring students and residents, Dr. Ries works closely with colleagues in ethics, chairing the ethics committee in her hospital.

When I spoke to Dr. Ries about being profiled here as a role model, she joked about being numbered among the "really important people" that Virtual Mentor has recognized. Despite this self-effacing sense of humor, Dr. Ries's dedication to mentoring students and residents is strictly serious. "I can take care of patients anywhere, but to make a difference in future generations of physicians, that's why I'm here at the medical school," she says. "It's the most important thing."

Dr. Ries graduated from Pennsylvania State University and received her medical degree from Women's Medical College of Pennsylvania. From Philadelphia originally, with a six-year stopover in South Dakota, she thought she could play a bigger role in treating patients with HIV in Utah. She finds the local culture to be much more open about HIV and AIDS than it was when she first arrived. "Nurses with HIV work openly here," she points out.

As a testament to her caring and compassion, Dr. Ries and her physician assistant Maggie Snyder are often thanked in the obituaries of patients for whom they cared. "She's not the typical doctor," Snyder says. "She's a person first, everything else comes second. People are important to her"¹.

Dr. Ries has been honored with numerous accolades, designated one of Newsweek's "unsung heroes" in 1988 and named Physician of the Year in 1999 by the Utah Medical Association.

For her commitment to mentoring students, her devotion to patients, and her courage to do what she believed in, "even if it doesn't seem to be what everyone else is doing," we are proud to name Dr. Kristen Ries a role model in medicine.

References

1. Forsberg H. Thank you Dr. Kristen Ries and Maggie: Utah doesn't realize how lucky it is to have AIDS doctor Kristen Ries. *Salt Lake City Tribune*. Oct. 2, 1994;E1.

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