# American Medical Association Journal of Ethics

February 2001, Volume 3, Number 2: 29-61 Emotions, Student Dating, and Other Valentines

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# **Upcoming Issues of Virtual Mentor**

March: Telemedicine

April: Putting Bioethics in Perspective

May: Docs Go Casual

June: Disparity in Health Care Delivery

American Medical Association Journal of Ethics February 2001, Volume 3, Number 2: 31-33.

## FROM THE EDITOR

The Almost Unknown Poet, Emily Dickinson Audiey Kao, MD, PhD

Almost unknown as a poet in her lifetime, Emily Dickinson (1830-1886) is now recognized as one of our greatest. According to biographer George Whicher, Dickinson was the "only American poet of her century who treated the great lyric theme of love with entire candor and sincerity." Although she wrote eloquently and passionately about affairs of the heart, Dickinson never married, and after age 30 she almost never saw anyone outside of her immediate family. Some believe this seclusion was her response to the patriarchal literary establishment of her time, which limited female writers to domestic and domesticated topics. Others believe that her withdrawal gave her both the space and time to write by freeing her from woman's duties. Few of her writings were published during her lifetime, and it was only after her death that 1700 poems were discovered.

For modern scholars and readers, Dickinson's poems are engaging and lyrical, but they can also be downright incomprehensible. Helping verbs and connecting words are routinely dropped, and pronouns sometimes refer to words that do not appear in the poem. Within these poetic puzzles, Dickinson's metrical mastery of English hymns results in words and sentences that are more like melodies when spoken.

Love is anterior to life, Posterior to death, Initial of creation, and The exponent of breath.

The complexities of Dickinson's poems reflect the nature of the emotions and feelings that were the subjects of her life's work. Romantic love, unconditional compassion, pure empathy, and their respective antithesis often defy rationalization, let alone full understanding of its crescendo ebbs and trickling flows. According to many scholars, Dickinson was a master in capturing the pure essence of emotionsto her, love exists before ("is anterior to") life and exists after ("is posterior to") death. But, we might want to ask Dickinson, can love really exist unaltered by the experiences of life?

Many if not nearly all of us become more cynical and jaded as we get older, and our capacity to love and show compassion diminishes over time and experience. In medicine, our ability to show compassion and empathy towards those in need also changes and matures throughout our professional careers. In some respects, this

maturation provides us with necessary protection against heartache, but unfortunately, this maturation often goes too far. What can be done to prevent and treat this ailment of the heart?

As we know, heart disease is the leading cause of death in the United States with more than a million heart attacks reported each year. Risk factors for the hardening of arteries that contribute to heart attacks include hypertension, diabetes, obesity, hyperlipidemia, and a family history of heart disease. Thus, could hardening of the arteries contribute to hardening of our compassion and empathy over time? Of course not; the cure for this heart ailment is not aspirin or an ACE inhibitor. But just as there are risk factors and remedies for heart attacks, so there are for this ailment. For physicians, one of these risk factors is the increasing level of professional dissatisfaction and stress that they experience. Common sense tells us that it is more difficult to show love and compassion if one is constantly stressed, burned out, and angry. In some cases, painting a face on a volleyball and giving it a name may be a coping strategy. However in medicine, the remedies for professional stress and burnout are not that simple.

In our mission to promote the ethical and professional development of the next generation of physicians, we have so far focused primarily on providing our readers with content and resources to achieve the former--ethical development. Throughout the rest of this year, we will introduce professional development initiatives, providing practical coping and communication skills to help students and physicians better address the stress of medical training and practice. Furthermore, we will be inviting those who are interested in advising and counseling students, residents, and new physicians to volunteer as mentors.

We expect that, as new content designed to promote the professional development of physicians is introduced, there will be cynics and skeptics out there who question and challenge the utility of our efforts. But only through frank and construct feedback from our readers, can we hope to better develop remedies to address "hardening of the arteries." If Emily Dickinson had it right,

Hope is the thing with feathers That perches in the soul, And sings the tune without the words, And never stops at all,

And sweetest in the gale is heard; And sore must be the storm That could abash the little bird That kept so many warm.

I've heard it in the chillest land And on the strangest sea; Yet, never, in extremity, It asked a crumb of me.

We hope that, in the coming months and issues of Virtual Mentor, our efforts will challenge the assumptions of our skeptics, that their responses will challenge our biases, and that interested physicians will agree to serve as volunteer online mentors. In a spirit of hope ("the thing with feathers") we trust that our call to action will play some part in promoting the professional development of the next generation of physicians.

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

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## **CASE AND COMMENTARY**

In a Bind: Use of Restraints in Disoriented Patients

Commentary by Audiey Kao, MD, PhD

### Case

Mrs. A is an 83-year-old patient hospitalized for a bowel resection for colon cancer. Her medical history includes a stroke that makes her gait unsteady and has already caused a fall which resulted in a broken hip. During the day Mrs. A is alert and oriented and enjoys the company of her family members. But at night, she "sundowns," becoming disoriented and confused and occasionally even combative with staff. During one of her disoriented episodes,

Mrs. A. wants to leave her room to buy some nachos, believing she's at a baseball game. Because of her unwillingness to stay in bed, the staff is concerned about her well-being. Her nurse believes that some kind of restraint is needed. The attending physician agrees and orders a restraint vest that wraps around Mrs. A's chest. Mrs. A does not want to be placed in the vest. The nurse's aide tells Mrs. A that the vest is actually a sweater to keep her warm and comfortable. She finally agrees to wear the vest. Most nights a family member is with her, but this night she is alone. The family learns the next day about the use of the restraint and is concerned about not being informed.

### **Ouestions for Discussion**

- 1. Was Mrs. A's autonomy violated when she was placed in a vest?
- 2. Should the family have been notified before Mrs. A was placed in a restraint?
- 3. What do you think of the aide's use of deception to gain Mrs. A's consent?

See what the AMA *Code of Medical Ethics* says about this topic in Opinion 8.17 Use of restraints. American Medical Association. *Code of Medical Ethics* 1998-1999 Edition. Chicago, IL: American Medical Association; 1998.

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

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 Sources of Embryonic Stem Cells for Research Faith Lagay, PhD

Juengst E, Fossel M. The ethics of embryonic stem cells: now and forever, cells without end. *JAMA*. 2000;284(24):3180-3184.

Certain cells in the early embryo (blastocyst stage) are pluripotent; they have the ability to form almost any somatic cell in the human body. These embryonic stem cells are highly prized by researchers who envision being able to "guide" the stem cells to differentiate into specialized types of body tissue such as muscle, nerve, and blood and thus become replacements for diseased or dysfunctional body tissue [1].

Stem cells are now being collected from human embryos. In most cases, the embryos that are used have been aborted or left over from in vitro fertilization procedures. Although not technically feasible at this time, researchers expect that it is possible to clone stem cells from a patient's own somatic cells. If they could do so, and grow replacement tissue, that tissue would be compatible with the patient's own tissue and would not be rejected. Here's how the process would work. The nucleus of a patent's somatic cells would be placed into an enucleated human ovum, technically creating an embryo. Stem cells would then be collected from the embryo at the blastocyst stage, and the remainder of the embryo, dissolved. The procedure, termed "therapeutic cloning," would provide genetically compatible stem cells and, eventually, genetically compatible tissue or organs for transplant back into the patient.

In "The Ethics of Embryonic Stem Cells: Now and Forever, Cells Without End," the authors consider technical, ethical, and social policy issues associated with therapeutic cloning. They argue that embryonic stem cell research has great potential, but that it also raises profound questions about respect for human life, the moral status of embryos, and policies for public funding. (Others have examined the ethical validity of therapeutic cloning for producing tissue for transplantation.) Simply banning embryonic research will not allow society to circumvent these ethical issues. As the authors point out, there is a moral cost to be paid for not conducting research on human embryonic stem cells. Presently, many patients die because of organ rejection and a lack of transplantable organs. Many others suffer the anguish of Alzheimer's or Parkinson's disease that tissue grown from stem cells could ameliorate. Research on human embryonic stem cells could eventually change this. (See AMA opinions on fetal research: Opinion 2.10, Opinion 2.161, and on human cloning 2.147.)

## **Questions for Discussion**

- 1. Do you think that research on human embryonic stem cells collected from aborted embryos or embryos created in vitro is ethical? Should research on these human embryonic stem cells be federally funded?
- 2. Should embryos be created (therapeutic cloning) as a source of stem cells for research? Should creation of stem cells in this way be federally funded?
- 3. Does therapeutic cloning show less respect for human life than engendering a child (as has been done) to provide bone marrow for the child-to-be's sibling who has leukemia?

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## STATE OF THE ART AND SCIENCE

Gene Therapy or Genetic Enhancement: Does It Make a Difference? Faith Lagay, PhD

Asked whether genetically altering an embryo to improve the musical talent of the child-to-be is a treatment goal of medicine and, as such, should be reimbursed by health plans, most people immediately answer, "no." But suppose the human embryo (or parental gametes) could be genetically altered so that the resulting child's immune system resisted common cold and flu viruses. Would that be medical treatment? Technically, no. Should the immune system alteration—whatever it is called—be offered to everyone? Should health plans pay for it? Some would answer, "yes," and some, "no."

The point is, it's easy to recognize that extreme cases of enhancement fall outside the goals of medical treatment; not so easy to decide borderline cases like that of immune system fortification. And like so many of the questions genetic information and technology are raising, the therapy-enhancement question is neither a new one nor one that is limited to the domain of genetics. The same fuzziness has long existed between treatment and enhancement in plastic surgery and psychiatry, to name just two specialties. Developments in psychopharmacology such as personality, performance, and attention enhancers sorely test category boundaries.

## **Therapy**

A widely accepted working definition of medical "therapy" comes from Norman Daniels' formulation of the standard medical model. In the standard medical model, "therapy" is an intervention designed to maintain or restore bodily organization and functioning to states that are typical for one's species, age, and sex. According to Daniels, society has a duty to provide "treatment" only for medical need defined as departure from normal organization and functioning.

## **Enhancement**

Enhancement, on the other hand, is alteration to improve upon normal organization, appearance, health, and functioning. Taking of anabolic steroids, undergoing certain forms of rhinoplasty, and altering one's gametes to imbue one's offspring with greater than average musical talent represent attempts at enhancement.

## Prevention

Perhaps the immune system example with which this article began fits best into the category of prevention—like immunization itself. Prevention has sanction as a medical intervention because it helps achieve the medical goals of maintaining

health and obviating a later need for treatment. It is important to remember in germline genetic intervention, however, that what is being prevented is not a mere disease or symptom, not even merely the existence of a species-normal immune system (which might be prevented, for example, by gamma globulin injections, vitamin C or achinecia). What is being prevented is the existence of a human being who has a normal immune system, a human being with a certain genotype. Preventing certain genotypes from coming into existence does not fall within the traditional medical goals of prevention. The concept of genetic prevention calls for new thinking.

### Remediation

There is a 4th possibility along the gene therapy-genetic enhancement continuum. Suppose an embryo's genome revealed that the child-to-be would have lower than species-normal cognitive ability or violently aggressive behavior. Molecular science knows little about the genetic components of cognitive ability and behavior at this time, but suppose, in future, genetic engineering could bring aggression or cognitive ability within normal limits. The intervention would not help maintain or restore physical health and functioning; it would not prevent illness, and would not enhance ability beyond levels that are species-normal. LeRoy Walters and Julie Gage Palmer have categorized this hypothetical intervention in cognitive ability and character traits as remediation.

# Does It Matter Whether Genetic Intervention Is Therapy, Prevention, Remediation, or Enhancement?

What does it matter whether a genetic intervention is called therapy, prevention, remediation, or enhancement? First, there is the obvious matter of equal access to the intervention. How an intervention is categorized largely determines how accessible it is to all who wish to use it. Looking into the future of germline genetic interventions, those that are labeled therapy, prevention, or remediation stand a far better chance of being available to people who cannot pay for them out-of-pocket. If an intervention is categorized as an enhancement, it will probably not be thought to satisfy the therapeutic goals of medicine and, hence, will not be a reimbursable service. Under such conditions, termed "genobility" by 2 bioethicists, the rich will not only have more money than the rest of us, they'll be taller, smarter, and better looking, too.

There is an individual therapy-enhancement matter that each physician will decide for himself and herself, and the question is not limited to genetics. Each individual physician must interpret the goals of medicine and the appropriate use of his or her education and skills in fulfilling those goals. A physician may decide not to use her skill and professional status to prescribe ritalin for normal, healthy college students; another physician, not to manipulate embryos to produce super stars in athletics or the entertainment field. Either of these physician may, on the other hand, decide to prescribe growth hormone for a young boy who does not have growth hormone deficiency, but whose parents are both short and whose adult height will place him well below normal range for his sex.

Many factors enter into the decision. Is there meaning in striving to make the most of what nature or God has given us? Do we cheat ourselves or others when we attempt to short-circuit the normal course of learning, say, or the discipline needed to excel in sport or in music? Do parents do a better job of parenting a made-to-order child? Is that what parenting is about? Is there possible harm in curtailing diversity? in systematically preventing certain genotypes from coming into existence? To what extent do we, as physicians, help people by giving them what they ask for when what they ask for is unrelated to physical, mental, or emotional health?

Some may shrug their shoulders at such weighty questions and say, "What difference does it make whether I provide services that stretch professional or ethical boundaries? If I don't do it someone else will." But therein lies the ethical boundary that must not be crossed: the boundary that separates exercise of professional judgment and integrity from shirking of responsibility. Every physician has entered into a covenant with society to apply his or her skills and judgment in the patient's best interest. The bright ethical line in the debate over therapy versus enhancement separates acting in the patient's best interest from abdicating the responsibility to determine, with the patient, what constitutes "best interest" in a given case. If the physician and patient disagree, the physician must act as professional ethics and the profession's covenant with society direct.

The specific issues are philosophical questions about which thinking people disagree. They underlie simple actions (Do I write that script?) and monumental ones (Do I participate in altering the genome of a child-to-be?). Professional judgment and integrity form the ethical framework for deliberating them.

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# HISTORY OF MEDICINE Revising the Declaration of Helsinki Audiey Kao, MD, PhD

The Declaration of Helsinki emerged in the aftermath of World War II as one of the guidelines of biomedical ethical conduct. The Nuremberg Code had been formulated as a response to the judicial condemnation of the acts of Nazi physicians, and did not specifically address human subject research in the context of the patient-physician relationship. In 1964, the World Medical Association adopted the Helsinki Declaration as a response to concerns regarding research on patient populations. The primary purpose of the accord was to assert the interests of the individual patient before those of society.

In October 2000, at the 52nd World Medical Association General Assembly in Edinburgh, Scotland, the Declaration of Helsinki underwent a controversial revision, unleashing a firestorm of criticism from many researchers, drug companies, and bioethicists who claim that the new recommendations unnecessarily restrict and impede biomedical research on human subjects. Proponents of the changes claim that it protects patients by eliminating unethical research where the populations, such as those in developing nations, are most vulnerable.

At the heart of the controversy is paragraph 29 of the <u>Helsinki Declaration</u>, which states that "the benefits, risks, burdens, and effectiveness of a new method should be tested against those of the best current prophylactic, diagnostic, and therapeutic methods. This does not exclude the use of placebo, or no treatment, in studies where no proven prophylactic, diagnostic or therapeutic method exists." In essence, the paragraph forbids the use of placebos as a control treatment in research studies unless no other proven treatment exists.

This language was adopted in order to curtail research trials in developing nations where the best care available to the local populations may fall far short of that in the industrialized world. Paragraph 29 is an attempt to set a universal standard of care for all patients, regardless of their geographic, political, or economic circumstances. Critics of this standard argue however, that it is necessary to recognize that developing countries cannot afford the same level of health care available in industrialized countries. Therefore, research trials, even those conducted with placebos in place of established therapies, are ethically permissible because they leave the patient population no worse off than before the research began. Advocates of the standard however, state that the reasoning of "better something than nothing"

basically puts the interests of society before the interest of the individual research subject, a fundamental breach in the purpose of the Helsinki Declaration.

This most recent revision in the Declaration (the document was previously revised in 1975, 1983, 1989, and 1996) is aimed at making the document relevant to today's field of medical research. As medicine becomes ever more global in its reach, the controversy regarding local or universal standards of care will continue to challenge both the interests of society and the interests of the individual patients [1-6].

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# **ART OF MEDICINE Patient-Centered Medicine**

Françoise G. Hultzapple

This painting is a rendering of my experience with what I call patient-centered medicine. It reveals a medical community, family and friends addressing both the body and the mind. This is the level of support my husband Denny and I would like all patients to experience. In this painting, sacred serpents like those of the Caduceus and Aesculapius' staff represent healing forces and rise from the circle of wholeness and original perfection to support my body and my mind. My body is shown scarred from a life-saving mastectomy, a TRAM-flap reconstruction, a new navel off-center, and a swollen right arm and hand due to lymphedema. My mind is focused introspectively, altered forever by the experience. These eight powerful serpents tenderly suspend my figure upon the background of an hourglass suggesting the heightened element of time. Crystal blue water fills the glass representing the conscious and unconscious. Its shape hints at the ideal shape of western woman. In the distance is the earth's horizon at sunrise - above a dark sky, below black ocean waters - the deeper recesses of my psyche.

Each sacred serpent represents a different force - individuals who focused on healing me.

### **My Medical Team**

(all within a medical cross)

- my primary surgeon (Aesculapius' staff),
- my reconstructive surgeon (two closely connected halves of a circle),
- my anesthesiologist (wave length of gamma ray),
- my radiologist/oncologist (atom),
- ...all working together to fight this cancer (crab), talking to each other as well as to Denny and me,

## My Breast Care Clinic Coordinator

(anchor within a medical cross)

- who acted as an anchor at the center of the clinic:
- directing us to resources,
- scheduling consultations with a primary surgeon and a breast reconstructive surgeon together so we could consider our option of only one major surgery,
- connecting me with a woman who had gone through the same reconstructive operation I was considering,

## My Clinic's Office Staff Assistant

(flame of knowledge over a medical cross)

- who wrote everything on a  $3 \times 5$  card when my mind could not accept another thing even directions within the hospital,
- who called me countless times to schedule me sooner during the more urgent times.
- and who told me whom I had an appointment with and why,

## My Husband

(Leo with heart)(ring)

- who took on all the gathering of current medical data and opinion so we could make decisions we could live with,
- and who loves me,

## My Mother

(pelican, symbol of parental self-denial)

- who would do anything for her children,
- who has a strong empathetic nature,
- and who raised her children to have the same,

## **My Support Group**

(ribbon within medical cross)(knot)

- whom I shunned at first for fear that I would be expected to contribute to the healing of others when I needed to concentrate on my own healing,
- but whom I still stay in touch with while we share experiences, educate each other and laugh a lot,

## My Physical Therapist

(pair of hands)

- who helped me get my arm functioning to 98% or so.
- -and who worked with my lymphedema (right arm larger),

## My Male Friends

(male symbols)

- who offered their compassion, not their personal fear,
- and who braced my self-confidence as a woman.

"Patient-Centered Medicine," 28 x 39, water color on cardboard, was painted by Francoise G. Hultzapple in October 1999.

Francoise G. Hultzapple contributed this piece for publication in *Virtual Mentor*.

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PERSONAL NARRATIVE Stopping for Death Robert Davidson, MD, MPH

Physicians are faced with death in its many varieties throughout their careers. There is an undefined socialization process which takes place during the training years in medical school and post-graduate training. This is necessary to provide the capability of continuing to function with death all around. However, we sometimes feel we are exempt from the emotional toll that death extracts from us. Several events in the past month brought this home to me and I would like to share them with you.

### 2001 Gets off to a Bad Start

The new year began on a decidedly bad note. On December 30th, a Peace Corps volunteer from one of my Eastern Africa countries was killed in an automobile accident while on holiday in a South African country. Because the death occurred in the area covered by my colleague based in Pretoria, I was spared the necessity to travel there and take charge of the death review that includes an autopsy. I began to make plans to travel to her host country to assist with grief counseling. This was the first death in my area, and I reviewed the protocol developed by the Peace Corps on what to do when a volunteer dies. Unfortunately, this review was prophetic of another tragedy that pulled me into a series of extraordinary events.

One week later, on a rainy Sunday afternoon, I got a call from another of the Eastern Africa countries I cover that a volunteer had been critically injured and was probably dead. Could I come right away? I told them I would come as soon as possible and to have the nurse in the medical office call me as soon as she knew the details. The next available flight was not until Tuesday morning. We forget the luxury of frequent flights between the major cities that we enjoy in the States. The country nurse called back that evening that the volunteer was dead and had been killed by an elephant. "What! An elephant! How did it happen?" "We do not have all the details. You will need to get these when you get here." No one else was injured but a friend observed her death. We went through the details that would need tending to since we all wanted to be able to transfer the body back to the States as soon as possible. The country nurse would arrange for the body to be brought to the capitol and arrange for a host country pathologist to perform an autopsy with me.

## The In-country Morgue and Autopsy

On Tuesday morning, we went to the morgue at the public hospital. I had been warned by more experienced medical folks in Eastern Africa that the handling of bodies in this area of the world was quite different. I felt like I had been through enough in thirty years of medical practice that I could handle anything. When I arrived at the morgue, I was surprised to see two to three hundred people arranged around the building. My driver explained that tribal customs required that the family stay with the body until burial. I thought there must be several bodies in the morgue or a very large family. The morgue building consisted of two rooms. One was a body holding area and the other a room for autopsies. The body room was completely full of stacked bodies so the overflow of bodies lined the corridor and the walls of the autopsy room. Some of the bodies were still in their clothing, but others in the clothing they were born with. There was no refrigeration or even airconditioning. The odor was predictable. All the windows in the autopsy room were wide open for ventilation. I felt like we were center stage in a theater in the round as all the relatives were sitting outside looking in through the windows.

The pathologist was very helpful. He had gone to medical school in Africa but did his post-graduate work in Great Britain. He apologized for the room and bodies but said the laws of the country required a release from the authorities before an autopsy could be done or a body released. I asked if we could drape a sheet over at least the two closest windows. He laughed and said, yes. He agreed that an autopsy on a white body would attract a lot of attention. The autopsy itself was relatively easy. There was no mystery about the cause of death. There was massive blunt trauma to the thorax and abdomen with a flail chest, ruptured left apex of the heart, bilateral hemo-thorax, a huge liver laceration and a ruptured spleen. We both agreed that microscopic examination was not necessary, and he signed off the cause of death to allow us to start the process of getting the body released for transport to the States. Meanwhile, I was charged with writing up the autopsy and getting the facts surrounding the death.

Her college roommate was visiting the volunteer. They had hired a driver and car for an animal safari in one of the National Parks. About 10:00 in the morning, they came across a herd of elephants near the road. They stopped to watch and take pictures. The driver warned them to stay in the car. After some minutes, the elephants started to move away and the two young women got out to get some better photos. After they moved about ten meters toward the elephants, a large female, probably with a young elephant ward, charged. The volunteer was knocked to the ground and the friend and driver related that the elephant then kneeled on the body and rolled back and forth. This is apparently how elephants kill. The story was consistent with the autopsy findings.

## After the Emergency, Stopping for Death

The rest of the week was taken up with government releases, securing a hermetically sealed casket for transport, and arranging for transport of the body back to the States. We had several sessions with the staff and other volunteers for

grief counseling. I was impressed with how the country personnel handled this very difficult situation. A counselor was sent out from Washington to assist the process. She was very helpful. She asked how I was holding up and of course I said I was fine. She then pushed me to describe the autopsy and surrounding events, and it all came flooding out. Tears are therapeutic, and I was getting therapy. As strong as we feel we are as physicians, situations like this extract their toll. It is ok after the emergent situation to be a human. To grieve. To cry. To be angry. If you ignore this human need, it just builds up inside. I am convinced after all these years that we in the profession do not do enough to support each other. A colleague who takes the time to listen and allow the physician to reduce their guards and talk about feelings provides a very important service.

When I got back to Nairobi, there was an e-mail awaiting me from one of my medical student sons. He is in his third year and currently assigned to the trauma surgery service at a large urban public hospital. He had just experienced his first intra-operative death that happened to be a police officer. He described how he did not even think about it during the surgery. As he left the theater after it was all over, he noticed that the lower part of his scrubs below the gown were blood soaked. He laughed that now he knew why they wore rubber boots. As he headed toward the locker room, he realized that some of the police officers were staring at his legs and the blood. The reality of what he had just been through and the impact on the lives of the officer's family came pouring over him. I felt so helpless on the other side of the world. I wanted so badly to be there to let him vent. I want him to retain his humanity. I can only hope that one of his colleagues will let him vent and provide an atmosphere that it is ok to be vulnerable as a physician.

Robert Davidson, MD, MPH is professor in the Department of Family and Community Medicine at University of California, Davis, where his interests include both rural health and the organization and financing of health care systems. In the past few years, he has served as both the Director of Rural Health and earlier as the Medical Director of Managed Care for the UC Davis Health System. *Out of Africa* is an on-line journal of his odyssey in the U.S. Peace Corps as the area Medical Officer in Eastern Africa.

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## PERSONAL NARRATIVE

Through the Student's (or Physician's) Eyes: Sag

Jennifer Bau

Sag - 1. To droop, sink, or settle from pressure or weight. 2. To lose strength, firmness, or resilience

Rumble, rumble of elevators Whir, whir of conversation Flashes of plain clothes, suits, skirts, and scrubs Weaving between beds, wheelchairs, canes. In this morning hospital hallway, Thin, gray surgeon Stops at a painting Pulling on the wall, Gleaming white coat Starched, long and flowing, Embroidered with many titles Pockets sagging with the weight Of tools, pens, papers, pager, Sipping coffee from a Styrofoam cup, Baggy eyes squint At the painting of the patient Wrapped in the healing snakes.

## He thinks

Nice contour of reconstructed breast Navel drops off to the left a bit Too bad about lymphedema in the arm

Zipping around the corner,
Medical student in jeans, T-shirt,
Back sagging from the weight of
Books, books, books
In her backpack,
Sipping coffee from a travel mug,
Stops short.
Crashing into old, important surgeons
Is frowned upon.
Baggy eyes meet baggy eyes

Thin, wan smiles of understanding Are exchanged. She looks to the painting and thinks Snakes and a lady. Not on Friday's test. Peering closer,

She wonders,
Does the new breast bounce
Like the other one?
Does that scar show
With a bikini on?

Three seconds of silence, then
The surgeon's pager screams
And the med student is reminded
To go learn the lymphatic drainage system
Of the breast.

Later, in his office, The surgeon settles in his chair Behind his great oak desk, Runs his slender fingers Over the dusty framed photos, His children's pictures from grade school All grown now, with families. He wonders how their mother Likes her new place. He thinks about the painting Pulling on the wall, The patient with the team Of helpful snakes, His shoulders sag And he whispers A verse his grandma taught him With men, things are impossible. With God, all things are possible. Yet I'm no longer God To them

Later, in the library,
The med student shifts in her chair,
Now understanding the importance
Of axillary and cutaneous lymph nodes,
She stretches, cracks her knuckles,
Notices the dent still on her finger

Where the engagement ring
Used to be.
She thinks about the painting
Pulling on the wall
Her eyelids sag
And she murmurs,
Hope all those healing snakes are standard
When my white coat
Is long enough for respect
Because it sure would be nice
To not have to do everything
All by myself

The night hospital symphony plays, Hum, hum of generators Buzz, buzz of lights Blended with the sighs Of vending machines Grateful for some rest. And as the surgeon and the med student Step home to this beat To freezer meals and cold beds. The patient in the painting Pulling on the wall Cries out to the jaded journeyers We don't want everything you have And you don't have to be everything to us Just make sure that we're surrounded By more hands Than we can hold.

Jennifer Bau is a poet and first-year medical student at Penn State University College of Medicine with an interest in family practice. Her medical poetry has won recognition in the Delta Epsilon Sigma Undergraduate Writing Competition. Bau is the first-year editor for *Wild Onions*, an annual publication of poetry, prose works, photography and artwork created by members of the whole Hershey Medical Center community and funded by The Doctors Kienle Center for Humanistic Medicine. In October, 2000 Bau participated in the poetry reading The Voices of Breast Cancer organized to coincide with the art exhibit *Breast Cancer: Moments In Time*.

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## PERSONAL NARRATIVE

Through the Patient's Eyes: Artist's Statement on Patient-Centered Medicine Françoise G. Hultzapple

I was diagnosed with breast cancer at age 38. I underwent a modified radical mastectomy and TRAM-flap breast reconstruction. And later I was treated with radiation. After the crisis was over and I had time to reflect, I realized that the support I received from my husband, family, friends, other patients and the medical community was not only heart-warming but essential to my complete recovery.

During our own struggle with breast cancer, my husband Denny and I learned that our generally positive experience was not the experience of many breast cancer patients. Many newly diagnosed women found themselves without a cushion of support medically or mentally thereby diminishing their probability of a full healthy recovery. This prompted me to become an advocate of what I call "patient-centered medicine."

For me, a crucial element to my patient-centered medical experience was a course of action which I took for granted at the time the seamless referral. From the time I called for an appointment requesting a second opinion in 1990 until today, as I continue to manage my lymphedema, my medical community provided me with priceless and timely, seamless referrals. In my case, these referrals were managed by one person the breast care clinic coordinator. However, this could not have occurred without the compassionate cooperation of a whole host of medical professionals. Immediately after my phone call to the clinic, I began to reap the benefits. I received guidance on how to gather my medical records necessary for a second opinion. I was scheduled for a consultation with both a surgeon and a reconstructive surgeon simultaneously at our request. I was put in contact with a patient who had undergone a similar procedure to the one I was considering. I was scheduled for consultations with an anesthesiologist, a radiologist/oncologist and a physical therapist as needed. And, as time went on, both my husband and I were referred to support groups which in turn provided us with information on advocacy groups, current literature, medical research and clinical trials. I want to stress that this experience did not feel like riding on a medical assembly line but more like being supported by a medical team focusing on my medical care and recovery.

My husband and I have heard accounts of women lost in a medical abyss desperately attempting to manage their own medical course of action not knowing there are physicians who practice patient-centered medicine by closely associating themselves with like-minded hospitals, clinics, medical professionals and even support groups. Thus creating an atmosphere conducive to seamless referrals.

Pennsylvania's Hershey Medical Center where I was treated is a teaching hospital associated with Penn State University's College of Medicine. I decided to share my positive experience as a patient with the medical students there in hopes that they might better understand the value of patient-centered medicine and adopt the view of participation in the team approach necessary to achieve it.

Having had absolutely no connection with the hospital prior to my diagnosis, I was surprised and delighted that the Humanities Department faculty was so receptive to my proposal. I was invited to share my patient experience with the medical students and have done so for the last 8 years using poetry, artwork, and narration through venues such as a class course called Cancer: The Patient's Experience, student assemblies conducted by the Humanities Department, and presentations to the student chapter of the American Medical Women's Association.

When I first attempted to draft a speech explaining the importance of each person's contribution to my own healing process including my husband, family and friends, the explanation became a litany of names and personal anecdotes which took far too much time to tell time-starved medical students. Instead I created the painting Patient-Centered Medicine.

For the last 2 years I have organized (as a volunteer and patient) an art exhibit featuring 50 works by breast cancer patients and their families for display in the college's art gallery. Patient Centered-Medicine was included in that exhibit and inspired first-year medical student Jennifer Bau to write a poem entitled Sag about her reaction to the painting (see "Through the Student's Eyes"). I was deeply gratified by the eloquence and insight of Jennifer's poem. It is clear to me that this future physician is as concerned as I am about the further expansion of patient-centered medicine with so many medical establishments and physician ns struggling to survive our changing times.

Françoise G. Hultzapple contributed to this piece for publication in *Virtual Mentor*.

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## **VIEWPOINT**

# Addressing End-of-Life Treatment Conflicts through Improved Communication

Audiey Kao, MD, PhD

One of the more challenging situations in clinical medicine occurs when patients and their physicians have differing opinions on the utility of life-sustaining treatments. Such conflicts over the use or futility of treatment often present in the following manner:

A 75-year old man with stage IV colon cancer is admitted to the hospital for a sudden change in mental status. An evaluation which included a head CT and sepsis work up revealed that the cause for his mental status changes is uremia secondary to acute renal failure. After considering hemodialysis as an option, the attending physician recommends against it, given the patient's poor prognosis and the potential downsides of long-term hemodialysis. After the patient's wife hears the facts, she wants "everything done" and demands that the physician proceed with hemodialysis immediately.

In this case, the wife's demand for hemodialysis is driven, understandably, by her emotional response to the situation more than by her true grasp of the prognosis. The ensuing discussions will proceed more smoothly if the attending physician can bear in mind that the current hospitalization is one chapter in a long story for the patient and his family. Some chapters in this ordeal have been punctuated with hope and optimism that the patient's battle with cancer would conclude happily.

Confusion about the medical facts of the current incident can contribute to conflict between, in this case, the patient's wife and the physician. In helping the patient's wife understand her husband's present condition, the physician should avoid using jargon and technical language such as "vegetative state" or "hemodialysis" that confuse patients and their families. Because the use of medical terms and technical language is difficult to avoid completely, physicians and other members of the health care team should assess their patients' (or patients' surrogates') understanding of the information they provide. At the same time, information from sources such as television, magazines, and the Internet can foster unrealistic expectations concerning a given situation. In these situations, the ability to communicate a patient's prognosis clearly and accurately is critical. This is neither comfortable nor easy, especially given that physicians' prognostication skills are generally not on a par with their diagnostic and treatment skills [1-6].

Because none of his prior hospitalizations was terminal, the patient's wife may expect that, given proper treatment, her husband will go home again this time. Thus, she may not be psychologically prepared to hear and act on the facts of her husband's current prognosis and the physician's recommendations. Commands to "do everything" can be motivated by, in addition to denial, a wish to avoid guilt, a common emotional response to the death of a close relative. Statements such as "I cannot do this" or "I will not be able to live with myself" signal that a patient's decision maker is avoiding being party to decisions that could hasten the patient's death.

When talking with patients' relatives or decision makers who may be either confused about the true prognosis, in psychological denial, trying to avoid guilt, otherwise emotionally unprepared, or any combination of these, it is important that physicians be responsive listeners and clear communicators. Communication techniques that can help in these difficult conversations include active listening (repeating the speaker's thought or sentiment in your own words), simple silence, and open-ended questions. For example, physicians may initiate the discussion using opening statements such as, "It must be very hard for you to see your husband so ill," and, "You've been a wonderful caregiver for your husband during all this time that he has been sick." Avoiding language such as "withdrawing care" and "comfort measures only" may lessen the potential for future guilt. Instead actions that set positive objectives (e.g. maximizing comfort) should be the subject of these discussions.

Conflicts over the use or futility of treatment are unlikely to be resolved in a single conversation, and will likely require follow-up discussions. The first step is to identify, through responsive listening and communication, the multiple causes of the conflict; then to begin, with further careful and unambiguous language, the process of resolving the conflict. A mutually agreeable decision, while never guaranteed, is more likely attainable when physicians take adequate time for proper communication.

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## **VIEWPOINT**

The Long Shadow of Educational Debt

Audiey Kao, MD, PhD

- between 1981 and 1999, average medical school tuition and fees increased 418% at public schools (from \$2,761/year to \$11, 375/year) and 320% at private schools (from \$8,962/year to \$28,733/year)?
- medical school tuition accounted for an average of 2.8% of the total revenue of public medical schools and 5.1% of the revenue of private schools in 1997-1998? This percentage has remained relatively constant for public schools and reached a peak of 8.2% during the late 1970s for private schools.
- corrected to 1985 constant dollars, the average debt among the 83% of medical graduates with educational debt increased 99% between 1985 and 2000? (Public school graduates' debt increased 99% and private school graduates' debt increased 102%.) The average debt per medical student who graduated with debt in 2000 was \$93,000 (about \$80,000 for graduates of public medical schools and \$115,000 for graduates of private schools).
- the power of compounding is something that we should all be aware of. For example, if you invested \$100.00 each month starting at the age 25 (assuming an annual return of 10%) then by the time you retire at age 65, you will have 1 million dollars in your portfolio. But if you wait just ten years to begin investing, your portfolio at retirement will be less than \$400,000.

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## **VIEWPOINT**

A Doctor Looks at His Profession in Film Kayhan Parsi, JD, PhD

Doctors in the Movies: Boil the Water and Just Say Aah by Peter Dans, MD (Medi-Ed Press, 2000)

"Scratch almost any lawyer and you'll find a movie buff," states the first sentence in the Foreword of *Reel Justice: The Courtroom Goes to the Movies*. The same could probably said of physicians. Cinema has had an irresistible attraction to these two professions, showcasing them in various lights of grandeur and depravity. Who can forget the immortal lines of Al Pacino's character in ... *And Justice For All* (which incidentally received a poor review by the authors of *Reel Justice*). Or the brilliance of Charles Laughton's performance in *Witness for the Prosecution*? Similarly, who could forget the transformation of William Hurt's character in *The Doctor*? Or the mawkish manipulation of Robin Williams' title character in *Patch Adams*? Although Hollywood often gets some of the details wrong about these two professions, its mythmaking has had an undeniable impact on the way millions of people view both lawyers and physicians. As Peter Dans, MD, writes in his new book, "Myth, like denial, is central to human existence. History may tell us what may have been, but myths tell us what we could have been and still might be, as well as what others think we are."

In the tradition of *Reel Justice, Doctors in the Movies* is a welcome contribution by a physician critiquing and interpreting the way films depict his profession. Dans's book is a compilation of reviews of 73 films that either focus on physicians or have a medical theme. Rather than taking an historical approach, Dans groups his films into broad themes, such as "Hollywood Goes to Medical School," "Benevolent Institutions," "The Dark Side of Doctors," and "The Institutions Turn Evil." He also spends a couple of chapters looking at films that have female or African-American physicians. Unfortunately, there is a dearth of such films, as reflected in his chapter titles—"Where are All the Women Doctors?" and "Blacks, the Invisible Doctors."

The tone of the book is casual yet informative. Dans confesses in his Introduction that "I have not been schooled in film technique or filmography and in this respect I feel more kinship with everyday moviegoers." He eschews any highfalutin theorizing about film, focusing instead on the aspects of movies that draw most people into dark theaters for a couple of hours: character development, plot, and pacing. Moreover, he is deeply interested in how the film showcases physicians. Does the film offer us old, tired stereotypes of the kindly country doctor? Or does it

accurately portray how physicians actually go about caring for their patients? (The book has a wonderful appendix where Dans recounts the myriad cliches and stereotypes in doctor movies. These range from old standbys such as "boil the water!" to recurrent scenes such as students fainting at the sight of blood. Another favorite of filmmakers, of course, is the physician as arrogant and godlike).

Unlike the authors of *Reel Justice*, Dans does not give ratings to the movies he has reviewed. But his feelings on certain movies come through loud and clear. For instance, he condemns *Patch Adams* as a "preachy, self-indulgent, vulgar film, starring an out of control Robin Williams, [which] elevates one doctor while demeaning the profession as a whole." On the other hand, his favorite film for use in "a seminar on movies and medicine" would be the cryptically titled *Not as a Stranger* starring Robert Mitchum, Olivia DeHaviland, and Frank Sinatra.

Trained as an internist, Dans also has an interest in ethics that surfaces occasionally. He devotes an entire chapter to the role oaths such as the Hippocratic Oath have played in films such as *The Green Light* (1937). Dans expresses concern about the dilution not only of the Oath, but also "the uncoupling of medicine from its ancient codes and any religious associations." Compared to films such as The Green Light, more recent films seem ambivalent about morality and medicine. For instance, he sees films such as Critical Care and Extreme Measures as reflecting medicine's moral confusion over many important matters. Dans argues that the physicians in such films, severed from traditional Hippocratic and Judeo-Christian values, are adrift from the traditions that anchored medicine for centuries. (I confess I have not seen Extreme Measures, despite Dans's view that it is "a veritable medical ethics textbook." I take issue, however, with his characterization of Critical Care as a "profane, unrelievedly angry and caustic film." I found the film to be a compelling story of moral redemption as told through the eyes of a beleaguered medical resident. Darkly funny at times, the film captures the new institutional pressures placed on young physicians these days.)

Despite the differences of opinion some readers may have with Dans's reviews, he does a service by showcasing older films that probably rarely see the light of day (save on such networks as AMC and TCM). Such films as *Men in White, The Citadel* and *People Will Talk* are all worth viewing and even integrating into a class on medical ethics. As Dans would attest, movies have the power to shape peoples' views and change their hearts. Many a lawyer watched Atticus Finch in *To Kill a Mockingbird* as a young person and decided that was the career path for him or her. Perhaps there is no single film about medicine that extols the profession in such a way, but the plethora of new television shows certainly attempts to capture the special nature of medicine: its urgency, its immediacy and its intimacy. Dans's book is a fine contribution in helping us think about how these celluloid images capture the specialness of being a doctor.

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VIEWPOINT Matthew Lukwiya, MD Audiey Kao, MD, PhD

The honorific title of "hero" falls easily from our lips these days. We call multimillion-dollar sports celebrities heroes for playing children's games. Yet the true title of hero should be hard-won. It should capture the sacrifice of self-interest for the benefit of others. It should describe those whose actions surpass by far what duty demands. One such hero was physician Matthew Lukwiya of Uganda.

Dr. Matthew Lukwiya was a leader in the fight against the deadly Ebola virus that plagues parts of Africa. He worked for years as superintendent of Lacor Hospital in Gulu, Uganda. A dedicated physician, his commitment to his community marked him as a role model for all health care professionals. Dr. Lukwiya saved many lives in his fight against Ebola; and in doing so, he paid the ultimate price. The disease that claimed so many lives in Uganda also claimed his.

The bright young Ugandan doctor, one of the best medical students in Uganda, was awarded medical scholarships and prizes. He had received a master's degree from the prestigious Liverpool School of Tropical Medicine in England. Qualified and invited to serve in more affluent communities, he chose instead to go where the need was greatest, an Italian missionary hospital outside Gulu. Most well-qualified Ugandan physicians leave the country in search of better opportunities. But Dr. Lukwiya stayed home. As his widow Margaret Lukwiya states, 'He felt that holding a position meant having responsibility . . . . Matthew was not for worldly desires . . . . He was just devoted to his patients. It was never business. It was just his patients. That was it.'

In honor of his humanitarianism, the Italian government offered 10 scholarships for young Ugandan doctors, while the United States Agency for International Development gave Lacor Hospital a grant of \$100,000.

Although Lacor is considered one of the best hospitals in sub-Saharan Africa, Gulu is one of its poorest regions. This northern part of Uganda is pocked by skirmishes with its neighbor to the north, Sudan. For years, Dr. Lukwiya's biggest challenge was caring for the thousands of patients who were the casualties of the bloody fighting with the Lord's Resistance Group, a rebel group. Moreover, he played a significant role in the peace movement, a role that he refused to publicize.

Because they give their all, the lives of heroes are often short. Dr. Lukwiya was struck down in his early 40s. He was the first to recognize that people were contracting the Ebola virus and is credited for the relatively low death toll, which reached 162 last December. Once he identified the virus, he organized his staff and international bodies such as the WHO to combat the deadly contagion. Amidst a climate of hysteria regarding the outbreak, Dr. Lukwiya's death only fanned the flames of fear. But his work was instrumental in preventing the spread of the virus.

For his valiant effort at combating a deadly epidemic, and his resolute commitment to his patients, we humbly name Dr. Matthew Lukwiya a role model in the field of medicine.

There is a further dimension to heroism. Heroes and their actions inspire those who follow; they challenge us to match our efforts against those of the hero and see how we measure up. The value and meaning of Dr. Lukwiya's heroism will be fully realized only when physicians accept the challenge to measure up by dedicating their professional efforts to eradicating the global catastrophe of AIDS. As earlier plagues such as smallpox and polio have elicited their heroes, AIDS demands its own acts of heroism. Dr. Lukwiya and others like him have shown us an example and thrown the gauntlet in front of us.

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

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