

Virtual Mentor

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September: The Difficult Patient-Physician Relationship
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FROM THE EDITOR

A Physician by Any Other Name

Audiey Kao, MD, PhD and Karen Geraghty

MENTAL HEALTH AND WELLNESS CENTER

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In other social relationships, such as those between patient and physician (or consumer and health care provider, or customer and mentalist in the future), the names we use to identify individuals and their roles also matter; they reflect and shape the identities, obligations, and expectations of the participants.

In medicine, terms that refer to those we seek out when we are sick changed little until very recently. The term "physician" has been around since the days of Aristotle, and derives from "physik," an ancient Greek word for "nature." Physicians were those engaged in the study of the natural world. Hippocratic physicians understood illness as part of the natural order (as contrasted with those healers who believed that illness was part of the supernatural order—punishment from the gods) and sought explanations for illness in the physical world. They constructed a system of elements (earth, air, fire, water), qualities (dry, cool, hot, wet), and seasons (fall, winter, summer, spring) and related them to constituents of the human body, known as the humors (blood, yellow bile, phlegm, black bile).

The term "doctor" came into usage in the early Middle Ages (13th - 15th centuries) when the education of physicians shifted to the university setting. "Doctor" signified a physician who had received formal university training (usually with a heavy emphasis on the teachings of Aristotle and Aristotelian logic). Thus if one wanted to be technically correct in applying the terms "physician" and "doctor," one would say that Hippocrates (who lived around 400 BCE) was not a doctor, although he was a physician.

Beyond etymology, an individual who is sick and seeks the care of a doctor has certain expectations about this interaction and the professional obligations of the physician. Patients expect their interests will be put above those of the physician. They expect their doctors to keep sensitive information private and confidential.

Patients expect their physicians to treat them with empathy and compassion, especially when that is all the physician has to offer. And patients expect their doctors to act as caregivers, and not as purveyors of a health care service.

More and more today, physicians are referred to as health care providers, a name change that is anything but benign. In our increasingly market-driven health care system, the use of such terms as "health care provider" supports the notion that the interaction between patient and doctor is no different than that of any other transaction between a buyer and seller. In this commodification model of medicine, a health care provider is guided by a market ethic, and is not bound to the professional ideals and obligations that have defined medicine for centuries. To those (presumably the young and healthy) who may say that the old model professional physician reflected in our lexicon is outdated and unnecessary, I can only say that I hope you never experience true illness and the inherent vulnerabilities that this creates. *Caveat emptor.*

Audiey Kao, MD, PhD is editor in chief of *Virtual Mentor*.
Karen Geraghty is a fellow in the *AMA Journal of Ethics*.

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CASE AND COMMENTARY

My Doctor the Researcher

Commentary by Kayhan Parsi, JD, PhD

Case

Dr. Fiddler learns about a contract research organization that matches pharmaceutical companies who are conducting clinical research trials with physicians. The company wants to test a new medication for prostate cancer and will pay Dr. Fiddler a lump sum of \$3000 for each patient of hers whom she enrolls in the clinical trial. She will follow the patients and document their responses to the trial therapy. Dr. Fiddler thinks several of her patients are suitable candidates for the study. The first one she talks to is Mr. Upinsky. During the informed consent process, Dr. Fiddler properly informs Mr. Upinsky about the risks and benefits of the trial and her role as a clinical investigator. She explains that she will continue to be his physician, that the trial is not a treatment, that he can withdraw from the trial at any time, and that he owes her no duty to participate. She does not tell Mr. Upinsky that she is being paid by the pharmaceutical company to enroll subjects in the trial.

Dr. Fiddler believes that the amount she is receiving will cover her administrative costs and produce a small profit. She has no financial investment in the pharmaceutical company that is conducting the trial. Dr. Fiddler sees no ethical conflict in enrolling her patients in the clinical trial, as long as they understand that it is not a treatment and that they are free to decide whether or not to participate.

Questions for Discussion

1. Is Dr. Fiddler's arrangement with the pharmaceutical company ethical?
2. Does disclosure or non-disclosure of Dr. Fiddler's financial arrangement to candidate clinical trial subjects make an ethical difference?

See what the AMA *Code of Medical Ethics* says about this topic in Opinion 8.13 Managed care. *Code of Medical Ethics 1998-1999 Edition*. Chicago, IL: American Medical Association; 1998.

Kayhan Parsi, JD, PhD is a fellow in the AMA Ethics Standards Group

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

Clinical Trials in Developing Countries

Sam Huber and Faith Lagay, PhD

The past year has seen much discussion on participation by physicians from developed countries in research conducted in less-developed countries. The World Medical Association revised its Declaration of Helsinki, a statement of principles for the ethical conduct of medical research, in October 2000. Earlier this year, the National Bioethics Advisory Commission (NBAC) issued a report on ethical and policy issues in international research, and the AMA passed a new recommendation on ethical considerations in international research at its 2001 Annual Meeting in June. The Council for International Organizations of Medical Sciences is currently revising its 1993 guidelines for the ethical conduct of research involving human subjects.

Harold Shapiro and Eric Meslin, NBAC's chair and executive director, respectively, summarize their committee's position in *Ethical Issues in the Design and Conduct of Clinical Trials in Developing Countries*. In *Research Involving Human Subjects in Developing Countries* Greg Koski and Stuart Nightingale comment on the NBAC report and on the Declaration of Helsinki, and draw some conclusions of their own.

There is much agreement among NBAC, Helsinki, and AMA guidelines on many aspects of clinical research ethics. All subscribe to the need for fully informed consent; all require that the proposed research address a health problem within the host country, and that research protocols be approved by ethics review boards or committees. The main sticking point among various groups is over the study design—particularly the design of the trial's control arm. The authors of both articles cited here suggest that the Helsinki demand for a control that employs "the best current prophylactic, diagnostic, and therapeutic methods" available may be too rigid. Shapiro and Meslin grant that the "an experimental intervention should normally be compared with an established, effective treatment . . . whether or not that treatment is available in the host country." That, they say, is the "presumed standard." However, they can envision situations in which the condition being studied is not life threatening and the only useful research design (from the host country's point of view) may require a less effective control intervention than the current "best therapy" in developed countries. The authors stipulate that such an exception to the Helsinki Declaration would have to be approved by ethics review committees in both the host and visiting countries.

There is also disagreement over the necessity to make a successful new intervention available to research subjects after the trial is over. The Helsinki Declaration requires this, and, to the NBAC authors, it is "an especially important ethical obligation." Koski and Nightengale agree with the spirit of the requirement but believe that it will be difficult to implement for many reasons, not least of which is that "a single trial can rarely determine how best to treat or prevent a disease in all settings, or even in the setting in which it was conducted."

Questions for Discussion

1. The revised *Declaration of Helsinki* states, "The benefits, risks, burdens and effectiveness of the new method should be tested against those of the best current prophylactic, diagnostic, and therapeutic methods." Is Shapiro and Meslin's exception to this standard reasonable, or does it undermine the protection for research subjects intended in the provision?
2. Regarding the close of a trial, the *Declaration of Helsinki* reads, "At the conclusion of the study, every patient entered in the study should be assured of access to the best proven prophylactic, diagnostic and therapeutic methods identified by the study." Is there a difference between an obligation to not abandon subjects at the close of a clinical trial, and a requirement to provide the best proven methods? How is this obligation reconciled with an objective to improve health for everyone in a developing country?
3. Who should develop and enforce ethics standards in foreign countries? Is there enough of a global obligation to justify an international policy, or should standards for clinical trials be left to self-determined relativism? How does one avoid ethical imperialism in this case?

Sam Huber is a fellow in the AMA Ethics Standards Group.
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AMA CODE SAYS

Consent Needed to Perform Procedures on the Newly Deceased for Training Purposes

Faith Lagay, PhD

When medical crisis demands emergency interventions such as intubation, open-chest heart massage, or tracheotomy, skillful performance of these procedures can mean the difference between life and death. How are clinicians-in-training to acquire these necessary skills? Not in the medical crisis itself. Not by practicing the intervention on a patient who does not need it. In some medical training programs, physicians learn difficult procedures on newly deceased patients^{1, 2}. Proponents of the practice argue that endotracheal intubation, for example, simply cannot be learned properly by practicing on mannequins, animals, or even cadavers. Moreover, they say, an attempt at intubation that fails due to lack of experience or skill can damage the patient's anatomy in ways that cause future attempts to fail and, hence, could be responsible for loss of lives.

This method of teaching and learning has serious flaws—educational as well as ethical. As an educational approach, learning procedures on the newly deceased is an unsystematic, haphazard practice that depends upon events outside the educators' control rather than on organized curriculum and learner readiness. Ethically, the practice offends many by violating respect for the deceased, a closely held, widely shared cultural value in the US. Sensitive to the repugnance that violating of the body provokes, some medical student and residency programs have allowed students and physicians-in-training to practice certain procedures on newly dead without seeking consent from a spouse or next-of-kin². The main reasons given for not seeking consent are that the benefit to society of well-trained physicians overrides individual patient autonomy (particularly when the patient is no longer living) and that requesting permission from grieving family members causes them unnecessary distress³. Conducting the learning experience in this ethical netherworld of "no consent," however, compounds the conflict for students and residents who find themselves torn between demands, on the one hand, to learn as much as they can and, on the other hand, to respect patient and surrogate rights to grant or refuse consent.

The Council on Ethical and Judicial Affairs (CEJA) took up the issue of consent for performing procedures on newly deceased patients in response to a resolution from the AMA's House of Delegates (HOD) in 2000. Speaking in the open forum that preceded the HOD vote on CEJA's recommendation, opponents voiced the fear that a consent requirement would result in inadequately skilled physicians and would

encourage the practice of unnecessary interventions on living patients. Defenders of a consent policy cited studies in which family members, when asked, had consented to allowing procedures to be performed on their recently deceased loved ones. Seventy-three percent of parents with newly deceased infants consented in one study¹, and 59 to 75 percent of those with newly deceased adult relatives consented in others^{4,5}.

After thoughtful deliberation, CEJA's recommendation requiring consent was adopted by the HOD at the 2001 annual meeting. The new policy states that "the teaching of life-saving skills should be the culmination of a structured training sequence, rather than relying on random opportunities." And the policy explicitly forbids practicing interventions on newly deceased individuals without consent: "Physicians should inquire whether the deceased individual had expressed preferences regarding handling the body or procedures performed after death." Absent advance directive preferences on the part of the patient, physicians should request permission from the family members, spouse, or a person with authority to grant permission on behalf of the newly deceased. Family members, spouse, or designated surrogates have "quasi-property rights" over the corpse; that is, the right of possession for the purpose of burial and other lawful disposition. If "reasonable efforts" to secure consent from those with quasi-property rights fail, "physicians must not perform procedures for training purposes on the newly deceased patient." The House of Delegates' consensus vote in favor of required consent reflects the medical profession's belief that society's interest in educating physicians does not override its interest in protecting individual patient rights to consent to or refuse medical intervention.

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STATE OF THE ART AND SCIENCE

Preimplantation Genetic Diagnosis

Faith Lagay, PhD

It is now possible to extract a cell from a 6- to 10-cell embryo (technically, a blastocyst) that has been fertilized *in vitro*, test the cell's DNA for any one of several thousand single-gene mutations, and then implant for gestation only those embryos that are free of the specified gene mutation. The procedure, called preimplantation genetic diagnosis (PGD), does not harm the embryo and enables those who wish to avoid having a child with a certain genetically transmitted disorder to do so without confronting the need for abortion.¹ As pediatrician and bioethicist Jeffrey Botkin says, PDG's specific advantage is that certain "couples will experience a relative psychological benefit through PGD by discarding embryos to achieve a healthy child, as compared with the abortion of an affected fetus."²

There is a trade-off, however, for circumventing the natural cycle of conceiving, undergoing more traditional forms of prenatal testing, aborting an affected fetus if necessary, then waiting for another natural pregnancy to occur, and starting the testing process again. That trade-off is the high cost in dollars, physical discomfort, and emotional stress of hormone treatment followed by invasive ova retrieval, *in vitro* fertilization, testing, and implantation. The entire process is often carried out at least twice, and, where more than 1 condition is being tested for, up to 8 attempts have been recorded³. Because PGD presupposes *in vitro* fertilization (IVF), monetary cost for PGD begins where the cost of IVF (\$11,000 and above per cycle) leaves off³. So, as Botkin summarizes the potential market for PGD, a couple must be strenuously opposed to both abortion and to raising a child with the condition PGD is employed to identify. And they must have the financial resources to realize their wishes⁴. Since Botkin's article in 1998, another indication for PGD has come on the scene: selecting a tissue-compatible sibling for a living child with a fatal disease with the intention of providing a bone marrow donor for the sick child. This particular intention or goal adds additional ethical complication to a practice that was not ethically neutral to start with.

Ethical Concerns of PGD

For all its expense and inconvenience, preimplantation genetic diagnosis does not escape the moral objections that many have to abortion. True, no fetus is destroyed, and the tested embryos are not harmed. Yet, embryos are created that the couple never intends to use, and chances are no one will "adopt" the unimplanted embryos that carry the unwanted mutation. Hence, those who think that human life, from

fertilization forward, shares the moral status of living persons view PGD and abortion in the same light: both practices disregard or at least devalue the sanctity of life. The ethical position currently expressed in US judicial decisions and health policy confers progressively greater moral status on embryos, fetuses, and newborns along a continuum demarcated by developmental milestones such as appearance of the neural streak at about 14 days, development of the nervous system, fetal viability, and so on. Individuals who share this progressive view of moral status might suffer less from discarding embryos than from destroying a fetus.

Others object to PGD for the same range of ethical reasons that they oppose [germline gene therapy and genetic engineering](#). Selective implantation prevents certain genotypes from coming into existence, thus threatening genetic diversity and discriminating against those with disabilities; it commodifies children, mocking the true meaning of parenting and jeopardizing the parent-child relationship; and it deprives people of the opportunity for personal and moral growth that can be realized from making the most of what "nature" bestowed upon them.

The first of these objections—curtailing genetic diversity—has been voiced by advocates for those with disabilities. Spokespersons from this camp argue that elaborate, expensive, and unnatural procedures for selecting embryos without serious genetic mutations conveys the message that people with disabilities are less highly valued than those without. The majority of bioethicists, while acknowledging that this claim of prejudicial devaluing has merit, contend that the possible psychological harm done to persons with disabilities does not justify restricting the reproductive freedom of couples who wish to reduce their risk of having a child with a disability.

The technique can, at present, be used to select embryos by sex and may, in the future, be able to allow selection for certain other non-health-related traits. These real and potential applications raise a host of ethical concerns beyond the possibly prejudicial avoidance of offspring with disabilities. Sex selection because of a sex-linked disorder is generally acceptable to those who accept PGD at all, but many oppose selecting sex for "family balancing" or because parents prefer to have a son rather than a daughter, or vice versa. Trait selection for talent, personality, or non-health-related physical attributes comes under greater ethical scrutiny, even though it is not technically possible at this time. The "chosen child" faces a determinism more forceful and rigid than genes, according to David King: parental determination that the child fulfill the intention or talent or skills it was selected to embody⁵. King also worries about "opening the human gene pool to the winds of social market forces," that is, the transient, culturally influenced concepts of the ideal or perfect person⁶.

PGD To Rescue Siblings

In recent and highly publicized applications, parents of children with fatal disorders have undergone IVF and PGD to select embryos that can provide bone marrow

transplants for the sick child. This use of PGD has a less-exacting predecessor. In the 1980s, several families conceived offspring with the hope of having a child that could provide bone marrow for his or her sibling. In the famous Ayala case, the gamble paid off, and Marissa Eve Ayala rescued her older sister from leukemia. PGD improves the odds for success by ensuring that the implanted embryo is disease free and compatible. Some parents, in their endeavor to save a sick child, are willing to endure the repeated hormone injections, ova extractions, testing, and implantation that the procedure requires. But the parameters for producing a suitable embryo are twice as stringent as for those who seek a "merely" healthy child. The "sibling-saving" embryo must be, first, disease free and, second, histo-compatible. And, of course, a clock is running, ticking away the life of the sick child.

In the 2 cases recently written about for the *New York Times* by Lisa Belkin, each family had a child with Fanconi anemia, a recessive inherited disorder that causes bone marrow failure³. Together, the mothers underwent a total of 14 IVF cycles within 2 ½ years. Some ova retrieval and fertilization produced no embryos that were both healthy (no Fanconi mutation) and compatible with the existing child's tissue. Six times implantation of healthy, matching embryos, failed to result in pregnancy, and twice pregnancies resulted in miscarriages. One mother alone had 353 hormone injections over the 2 ½-year period. In the end, 1 of the PGD pregnancies resulted in a healthy, tissue-compatible embryo and in a sibling-saving child. The rescued child is confined to her home, where her teacher and ballet instructor come to deliver their lessons and where her mother feeds her through a stomach tube 4 times a day. Her anemia is under control.

Conclusion

In addition to the unimaginable distress and pain that these families endured (and sometimes manifested: 1 of the 2 sets of parents admittedly badgered the researcher, whose own wife was dying from breast cancer and who was under investigations for using federal funding for embryo research); and the ethical issues raised by any application of PGD, this application forces the question of whether it is moral to use one person as the means to save another. The answer to the question, which has been asked since the Ayala case, is usually, "We love our baby for who she is. She is not only a rescuer or an instrument. We love her dearly." But after observing the desperation of the 2 sets of parents with fatally ill children, Belkin asks,

If society gives its blessing to the use of one child to save another, then what would prevent couples . . . from aborting when the process was far enough along that the cord blood could be retrieved? Or what would prevent couples whose child needed a new kidney from waiting until the fetal kidney was large enough, then terminating the pregnancy and salvaging the organs³?

The hope PGD offers comes at a high price to all involved: to the parents; to the sick child, whose parents are constantly undergoing distressful clinical operations; to (in the case Belkin recounts) the researchers and clinicians; and to the child-savior itself. Considering these costs and the far-from-settled ethical problems PGD

poses, efforts to improve the success rate of tissue transplants from non-sibling donors may be a worthier research endeavor for the present.

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PERSONAL NARRATIVE

"You Gotta Keep a Sense of Humor"

Robert Davidson, MD, MPH

Finally, the pathologist arrived and we proceeded into the autopsy room. Because there was an ongoing police investigation into this death, 4 detectives and 2 police photographers accompanied us—too many people for the small autopsy room. The pathologist whispered in my ear, "Don't worry, they won't last long." He then chuckled and nodded for his assistant to begin. Sure enough, in a scene right out of the old television series about Dr. Quincy, medical examiner, one by one they began covering their mouths and quickly exiting the room. Soon there were only the 3 of us left. This significantly reduced the tension in the room, and I had the opportunity to talk with the pathologist about his work in Africa. He had a great sense of humor, and I realized this was his way of coping with his gruesome job. That evening, as I reflected on the day, I realized how important humor was to me in the way I dealt with the stress of the job and living in Africa. I decided to share some of the humorous things I have encountered so far in hopes that it will bring a chuckle to the readers and lighten their stress a bit.

As I exited the plane on my initial arrival in Nairobi, I was of course a bit anxious. It was about 10:00 at night, and I was scheduled to be met by a driver. As in any airport, taxi drivers, people wanting to carry my luggage, and others offering to obtain whatever I wanted, immediately accosted me. In the midst of this jumble of bodies, a voice with heavily accented English asked if I was here with the corpse. No, I replied, I was not here with the corpse. Off he went to look for someone else he was to meet. I was finally able to get across to the group that I did not want any of their services or products. I did not see anyone, however, who looked like my driver. I began formulating plans to change some money into shillings and figure out where I could spend the night. The same man came back and asked again if I was here with the corpse. Again, my reply was no. As he started away from me, I heard, "Well someone got to be here for the peace corpse." I suddenly realized that the pronunciation of corps was different in Swahili, and I was indeed here for the corpse.

The differences in English have led to several other humorous events. Early in my tour, I went to one of the major hospitals we use for volunteers. As I was given the grand tour, I was repeatedly introduced to Sister this and Sister that. I remarked to the Peace Corps nurse who was with me that I did not realize this was a church-run hospital. No, this was a private hospital she replied. Why then, I asked naively, were all the nurses nuns. When she recovered from her laugh, she began my

education in British medical jargon. Nurses are called sister and charge nurses are matrons. When I asked to see the emergency room, she looked perplexed until it dawned on her that I meant the casualty ward. But the best was yet to come. I was caring for a young volunteer with a pilonidal cyst that needed surgery. I arranged with our surgeon to do this in the outpatient surgery. I then told the volunteer to be ready, as she was booked into the theatre at 10 a.m. the next day. She got this frightened "no way" look on her face until I realized that she thought she was going to be on stage for a large audience with her bare posterior displayed for all.

Some of our best laughs have been with the workmen hired in Nairobi for various jobs. I am sure there are some very skilled workers in Kenya, but we do not seem to get them. We live in a lovely 40-year-old colonial home. It has lots of character, but, like all older homes, it has lots of problems. For instance, the roof. It seems to have a roving roof leak. After each rain, we dutifully call the landlord with the news that, yes, the roof leaks again. He sends out his trusty work foreman who inspects the house and proudly states that the roof leaks. He will schedule the men to fix it. The next day, a worker arrives to patch the inside ceiling plaster and repaint the ceiling. I try to suggest gently that he might want to fix the roof first. No, he is the painter. Another man will fix the roof. Of course it rains before the roof fixer has a chance to come. Back comes the painter with his plaster and paint. Again I suggest that the roof be fixed first. He ignores this advice and again repairs the ceiling. My wife reminds me that he gets paid to fix the ceiling and if it keeps leaking, he gets more work. Finally, the roof man comes. He proceeds to cut off some branches from trees in the area to make a ladder of sorts. After a period of loud noises on the roof, he exclaims that the roof leaks. He will come back later to fix it. In the meantime, it rains again. My wife bakes some cookies for the painter-plasterer. At last count, we have had the roof man 4 times and the plaster man 7 times. Yesterday, we had a heavy rain and of course had to get out the buckets to catch the drips through the ceiling. Actually, we are looking forward to the upcoming visit by the kindly painter- plasterer.

Perhaps the best story is the saga of the paper truck. A large truck was loaded with paper to be taken to the recycling plant. The paper was piled way too high, making the truck top heavy. As it started up the hill on a busy street near our house, it hit a deep pothole and the axle broke. It was already leaning heavily to one side with the weight of too much paper. The workers decided to try to repair the axle on site. They jacked the truck up and set it on rocks so they could work on the axle, then enlisted about 10 men to hook ropes to the uphill side of the truck and pull on them to keep it from tipping over down the hill. Meanwhile, frustrated drivers were making new pathways over adjacent lawns and winding through the men holding the ropes. We were enjoying watching this spectacle when it began to rain. Of course the paper was not covered and began acting like a sponge soaking up the rainwater. This made the truck even more top heavy and it soon began to tip. Their answer was to get more ropes and men to counterbalance the load. The crew grew to about 20 and might have worked if the rain had only gone to the paper. However, the clay dirt road soon became a slippery mud bath. I do not think even the best of

the Hollywood comedy writers could have envisioned this scene. As the day progressed, the paper continued to get heavier, the truck tipped more, the road became more slippery, and we were now up to about 30 men with ropes. Finally, the law of gravity won out and the truck slowly began to tip. As the workers and rope men realized what was happening, they all abandoned their posts and ran uphill. As if in a slow-motion film, the truck slowly tipped over and began its roll down the side of the hill. The next day, another truck arrived and the paper was hand carried up the hill to be carted away to the recycle mill. The new truck swayed from side to side with too much wet paper raising its center of gravity.

When the strain and frustration of living and working in Africa (or anywhere) begins to get your down. "You gotta laugh." Those are my words of advice for the month.

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 Patient's Eyes: Once and Again

Kayhan Parsi, JD, PhD

My story here concerns a cancer I had long ago. Not a "death sentence" cancer that kills with merciless speed. No, mine was thyroid cancer, something that usually afflicts middle-aged women. Somehow, though, my cancer paid me a visit when I was only 5 years old. A true case study, probably the subject of a grand rounds presentation at my hospital. At the time, my parents were recent immigrants to America—my father an OB/GYN resident and my mother a former nurse struggling to raise 4 children. Their shock and fright about their young child having cancer was allayed only by the fact that this was a treatable cancer. Still, the cancer had spread into my lymph nodes, requiring a radical neck dissection. The experience left me with a little bit of thyroid, some surgical scars, and a strong aversion to hospitals. My follow-up consisted of a few semi-annual visits to my surgeon, who found no suspicious nodules when his warm, dry hands palpated my neck. I never needed any additional surgery nor was I even put on a regimen of synthetic thyroid hormone. My childhood may have been disrupted, but I was better off than many pediatric cancer patients.

Decades passed. My childhood cancer was one of those events that both the patient and family members put behind them. I did all of the normal things a child and, later, a young adult does—I went to school, got married, settled into a career. I became interested in bioethics issues and eventually followed this field as a career path. And then, last year, in light of my unusual history, my internist asked me to undergo some blood work. The tests suggested more work be done. I was referred to an ultrasound technician who inspected my neck. The ultrasound uncovered a few suspicious-looking nodules. The radiologist there informed me that probably half the people walking down Michigan Avenue have nodules on their thyroid. But with my history, there was some cause for concern. I was referred to yet another radiologist—this time an interventional radiologist. He numbed up my neck and proceeded with a fine needle biopsy, the "gold standard" as it's described in the medical literature. Two of the nodules were "cold." The third—a good-sized fellow—was indeterminate. I consulted with a surgeon who allayed my fears. This was nothing that required immediate attention, but it did require a surgical intervention. I read about certain celebrities—Tipper Gore and Rod Stewart—who had had thyroid surgery, an eclectic couple, I might add. I was less than eager to undergo thyroid surgery, so I put it off until the end of the year.

My surgeon wasn't just any surgeon, however, but someone who, like myself, had extensive bioethics training. What's the likelihood of that, I thought? Let's see how all of this additional training plays out in the patient-physician relationship. We in the field of bioethics often think our talk falls on deaf ears. Doctors feel they intuitively know ethics. But my exchanges with my surgeon approached the ideal of mutual decision making that we talk and write about in the field. Not much older than myself, my surgeon did not fit the paternalistic surgeon stereotype that bioethicists frequently describe. He was attentive, patient, and relaxed. Contrary to the managed care horror stories where physicians rush in and out with barely an acknowledgement, our several meetings were lengthy and unhurried. He carefully reported the risks of my surgery, which were elevated because of my childhood history. My spouse, a medical resident, accompanied me during my visits. Our numerous questions were respectfully answered, with no hint of the impatient eye roll or "let's get on with it" attitude that some patients may encounter. Paradoxically, I was reminded of the stoic oncologist who treated Reynolds Price's spinal cancer "with all the visible concern of a cheese grater," as recounted in his wonderful memoir *A Whole New Life*¹. My experience was quite happily the opposite. My surgeon removed what little I had of my thyroid and the findings were unremarkable—no cancer, just a calcified nodule.

Reflecting upon my encounters with the surgeon, I thought of how other partnerships—even marriage—have changed in the last couple of decades. Marriage has evolved from a corporate model, with the husband as the head of the household, to a companionship model, where husband and wife are partners in the matrimonial endeavor. Similarly, the old model of the patient-physician relationship characterized by a paternalistic physician and deferential patient has slowly given way to a partnership model, wherein patient and physician embark on a mutual project of health. In both relationships, the stakes are high. In marriage, a schism can lead to divorce and a broken household. The patient-physician relationship is neither as intimate nor, these days, as long-lived as a good marriage should be. Yet it may take place in the context of life-or-death circumstances, and a bad patient-physician partnership can lead to mistrust, perhaps even a lawsuit. Both relationships rely on trust as a foundational value. We can hope the new model of partnership in both relationships will lead to greater trust and respect in their individual arenas.

Does my experience suggest that all physicians should have some formal training in ethics beyond their requisite course work in medical school? Perhaps, but I'm not necessarily certain the ethical training my surgeon had enhanced an otherwise conscientious and thoughtful physician. The practice of medicine, like the practice of marriage, requires good will, integrity, and sincerity, all of which can be nourished by being attentive to ethical aspects of practice. A world-weary physician might respond that the partnership of medicine is constantly being influenced by third parties. Similarly, the dance of marriage is constantly being challenged by outside influences. Yet, becoming a better communicator and learning how to identify concerns before they become problems are the hallmarks of a good spouse

as well as a good patient and a good physician. If exposing physicians to formal ethics training improves the possibility of achieving this goal, then we're all the better for it.

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Kayhan Parsi, JD, PhD is a fellow in the AMA Ethics Standards Group.

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PERSONAL NARRATIVE

Through the Physician's Eyes: Two Poems

David Schiedermayer, MD

Fighting Bare-Handed

Last night, Saturday night
I fought death bare-handed
in and over the body
of a 61 year-old man
with liver and kidney failure
which started and worsened
after his back surgery.
I had a bad feeling at about 6 pm,
looking at his 4 pm labs,
so I went to his room and found him
barely breathing. Breathing once
or maybe twice a minute.
So I sat by his bed
and I begged him to breathe
I pinched his toes when he stopped.
Once, when he had stopped for a minute,
and I am not proud of this,
but it is just true,
I rubbed my bare knuckles right across
the staples on his abdomen
(they had operated his back from both
the back and the front to fix the bones)
and he woke up with a start
and a grimace
and said, "what do you want me to do?"
And knowing how death was possessing him,
I said "Breathe!" to him, not to death,
and he took a big breath before he
fell back to sleep.
And so I kept him alive until we could
move him down to the ICU, waited with him
for an hour in that quiet room at the very end
of the orthopedics unit, just me and him and death,
me pinching him every minute
death quietly creeping in and through

I pinched him and shook him
and used Narcan to fight the morphine
so he would have a chance to breathe
And when I went home
I laughed a little as I walked across the driveway
I skipped up the steps
because
in the ICU they were giving him all kinds of medicine
and putting in all kinds of lines
but me
I guess I really do
like a good bare-knuckled fight on a Saturday night.

Folding Both Hands

On Sunday morning
it is now clear
he is dying.
His ammonia is 800
His creatinine is 6
The dialysis is not working.
Here's the truth:
He is puffed up with fluid
and twitching.
When the liver fails
the kidneys fail too
the lungs congest
the brain swells.
And when I come back
from talking and praying with
his wife and sister and daughter
(we folded our hands
and prayed
and I asked for comfort
and healing
and also for God's Will
to cover the bases)
he is brain-dead.
His temperature
does not register despite
the heating blanket.
He is not triggering the vent.
His blood pressure is 50
on maximal pressors.
So I talk with the family again
briefly this time
- the news speaks for itself.

His wife hugs me
a familiar face in a foreign land
and I can feel her stress and grief
as she holds on.
No decisions to be made now, I tell her -
no guilt about making decisions.
Just go and see him.
Take as long as you wish.

On Monday morning I call down to the morgue.
We happen to be doing him right now,
the pathology intern says.
I find the room just as the diener is saying,
as he deftly cuts and pulls out the viscera,
the funeral director has called me three times
wanting the body. If he calls again, I'll have him here!
And I look in the body and see where the bone graft is laid
neatly into the vertebrae; the bone is clean and fresh.
No pulmonary emboli. No visible infection.
I see the enlarged spleen.
Please cut the liver
I ask the intern, and he slices through it with a long
stainless steel knife.
There is no actual liver tissue present,
no nice dark tissue, only yellow scar replacing
the organ the liver should be.
That's why they call it cirrhosis, stupid,
I say to myself:
You think you're so bright
fighting with death
and here is just one more loss
in your long series of losses.
Thanks, I say to the pathology intern
and he smiles and bows,
folding both hands around the knife.

David Schiedermayer, MD is interested in the long-term management of diabetes and hypertension and in teaching ambulatory medicine and clinical ethics. He also works at a community clinic for the underserved, and has practiced in a number of other settings including West Africa and the Navajo Indian Reservation in Arizona. He has authored several books, including *House Calls, Rounds, and Healings*, a book of poetry.

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VIEWPOINT

Race, Ethnicity, and the Patient-Physician Relationship

Audiey Kao, MD, PhD

- At the time of this web posting, the estimated US population was 284,721,575. The US Constitution states that "the actual enumeration [of the US population] shall be made within three years after the first Meeting of the Congress of the United States, and within every subsequent term of ten years, in such manner as they shall by law direct." Based on the actual enumeration by the 2000 US Census, the racial/ethnic breakdown of the US population was as follows: White (72%), Black (12%), Hispanic (11.8%), Asian or Pacific Islander (4.1%), and American Indian (1.2%).
- Of the 17,538 applicants accepted to US medical schools in 2000, 11,112 were White (63.4%), 1,168 were Black (7.6%), 1,082 were Hispanic (6.2%), 3,457 were Asian or Pacific Islander (19.7%), and 126 were American Indian (0.7%). In the year 2000, medical school acceptance rates for applicants of various racial/ethnic backgrounds were as follows: White (49%), Black (39.8%), Hispanic (47%), Asian or Pacific Islander (46.9%) and Native American (46.2%).
- Studies have found that minority patients are much more likely to select physicians of similar racial and ethnic backgrounds. For example, an Hispanic patient is 19 times more likely to identify an Hispanic physician as his or her regular doctor than non-minority patient is¹. Minority patients seek care from physicians of their own race because of personal preference and language, not solely based on geographic accessibility². In addition, patients report receiving higher quality care from physicians of a similar race or ethnicity³, as well as being more involved in medical decision making⁴.
- Efforts to increase the number of those from underrepresented minority groups who enter the US physician workforce may partly address some of the issues raised by race and ethnicity in the patient-physician relationship. However, given the growing differences between the racial mix of the US population and the composition of the physician workforce, strategies other than changes in medical school admissions policies must be pursued. Greater emphasis on teaching those skills and competencies such as improved communication that will neutralize the consequences of racial/ethnic discordance will likely have more immediate, broader, and more permanent impact on strengthening patient-physician relationships.

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VIEWPOINT

"Better, Cheaper and Faster" Yeongchi Wu, MD

Kayhan Parsi, JD, PhD

Contrary to popular thinking, most limb amputations in the US are not due to accidents. Seventy percent of amputations are attributable to diseases such as diabetes. Eight percent are due to tumors and congenital defects. Only the remaining 22 percent are due to accidents. This month's physician role model, Dr. Yeongchi Wu believes that nearly all amputations are eminently preventable. According to Dr. Wu, "If we could get people to eat low-fat, low-cholesterol diets, stop smoking, and take care of their feet by keeping them clean and wearing properly fitted shoes, we could prevent many amputations"¹.

Barring prevention, however, the best friend a person with an amputated limb may have is Dr. Wu. Over the last 30 years, Dr. Wu has become a giant in the field of physical and rehabilitation medicine. Dr. Elliot Roth, medical director of the prestigious Rehabilitation Institute of Chicago (RIC) put it simply: "Dr. Wu is a very special guy. He has a natural affection and affinity for people . . . and has an absolute brilliance for simplicity and parsimony in developing assistance technology."

Dr. Wu has successfully combined 2 of his life passions: sculpting and helping people with disabilities. Before going into medicine, Dr. Wu studied under famed Taiwanese sculptor Yu Yu Yang. He continued sculpting as a medical student, but had to set his art aside when he started working as a psychiatrist. Dr. Wu received his medical training at Kaohsiung University in Taiwan in 1968 and then completed a 3-year residency in orthopedics. When asked why he entered physical medicine, Dr. Wu replied, "There were a lot of accidents in Taiwan, and there wasn't much I could do [for patients] as an orthopedic surgery resident." So Dr. Wu came to the US in 1971, and, after a 1-year internship at Cook County Hospital, he took a 3-year residency in rehabilitation medicine at Northwestern. He joined the staff at the Rehabilitation Institute of Chicago in 1975 and stayed on for 2 decades.

During his career as a full-time psychiatrist, Dr. Wu focused his efforts on making things "faster, cheaper and better." He invented many devices to make life simpler for those with dysfunction and disability during his tenure at RIC, including a convenient personal catheter for women, a below-the-knee bandaging system that helps wounds heal faster and better after amputation, and a simplified alphabetic board that allows non-vocal quadriplegic patients to communicate more easily².

Now semi-retired, Dr. Wu devotes half his time to the sculpting he has loved since his youth and the other half to research at the Center for International Rehabilitation (CIR). Headed by William Kennedy Smith, MD, CIR designs, develops, and delivers techniques and technologies that improve the lives of people with disabilities in low-income countries. "We have a responsibility to look at undeveloped countries," Dr. Wu said. His most recent innovation for those with missing limbs builds on a low-tech procedure developed 50 years ago. Drawing on the idea of vacuum sealing, Dr. Wu has developed a new innovation called the CIR Dilatancy System for Transtibial Sockets to create positive and negative molds for fitting individuals with prosthetic limbs.

When asked what advice he would give to a medical student, Dr. Wu states that one has to enjoy helping people. "Try to listen to the patient," he said. "You can learn a lot from listening." He believes in treating the whole person, which means attending to the range of psychosocial issues that helps define each patient. He also recommends being open-minded, and developing a hobby. His hobby, sculpture, has "complemented and supplemented" his medical work.



For his commitment to the art and science of physical medicine and his contribution to cultural enrichment through his art, we proudly name Dr. Yeongchi Wu this month's Virtual Mentor physician role model.

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