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Upcoming Issues of *Virtual Mentor*

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FROM THE EDITOR

Commemorative Issue: Rise and Fall(s) of Professionalism

Audiey Kao, MD, PhD

During a trip to the Pacific Northwest, I had the opportunity to spend an afternoon touring the Columbia River Gorge and its spectacular waterfalls. The largest of these is Multnomah Falls, which stands at nearly 620 feet. As I stood on the bridge that spanned the upper pool of this double-tiered waterfall, I marveled at the millennia of geological activity it must have taken to create this magnificent temple of rock and water. The slow process of weathering and erosion that creates waterfalls is hardly perceivable, but there are instances where geologic change is dramatically visible. On September 4, 1995, a rock the size of a Greyhound bus broke off from the face of Multnomah Falls, and its landscape was instantaneously altered. Luckily, no one was seriously injured when the rock came tumbling down.

Driving back to the hotel after visiting the Gorge, I reflected on the notion that the creation of waterfalls symbolized to me the historical currents of professionalism that bind physicians of the present to the past and attract future physicians. The professional landscape of contemporary medicine is shaped in many respects by the ethical values and conduct of physicians who came before us, and, by virtue of our predecessors' actions and priorities, we are the beneficiaries of the trust that patients have in today's physicians. However, this public trust can be taken for granted. The erosion of trust is often difficult to perceive until a critical point is reached, and then rebuilding fallen trust may be tough if not impossible. Over the last 5 years, the number of medical school applications has fallen by one-fifth, and, while this may not seem as dramatic as the crash of a bus-size boulder, it does reflect a growing disillusionment about medicine as a calling. Thus, the actions and priorities of contemporary physicians collectively shape the professional landscape of medicine that students and residents will face, and the future of professionalism will rise or fall depending on that landscape's ethical contours.

A physician who undoubtedly contributed to creating our current professional landscape was Archibald Wright Graham. Most of you might know him better as "Moonlight" Graham, the physician who had a short-lived career as a baseball player. Portrayed by Burt Lancaster in the 1989 motion picture, *Field of Dreams*, "Moonlight" Graham made his major league debut on June 29, 1905 with the New York Giants. Because of the way the ball bounced in a single game, however, he lost his only chance to face a big league pitcher. After the 1905 season, Graham left baseball to fulfill his dream of becoming a medical doctor, eventually pursuing his life's work in Chisholm, Minnesota. "Doc" Graham spent his entire medical career

in Chisolm, where he gained national recognition for his studies on children's blood pressure and enjoyed the love and respect of the entire local community. In the film, the character played by Kevin Costner commented on the tragedy that Moonlight Graham's baseball career lasted only 5 minutes, but Doc Graham replied, "Son, if I'd only got to be a doctor for 5 minutes, now that would have been a tragedy."

With the aim of contributing to positive changes in our ethical and professional landscape, the *Virtual Mentor* was created by the AMA's Ethics Standards Group more than 2 years ago as an online forum for examining the ethical and professional issues confronting medicine. The editors and contributors of the *Virtual Mentor* have published essays and stories meant to catalyze interest, invite discussion, and broaden understanding among our readers about the challenges that confront this healing profession. We built it, and, to our delight, students and teachers have come in increasing numbers to the *Virtual Mentor*.

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

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VIEWPOINT

Commemorative Issue: It Is Good Medicine

Audiey Kao, MD, PhD

When we speak of good medicine, we typically mean the science of medicine and its clinical quality: Is the doctor providing the most appropriate diagnosis and treatment for my illness? Over the past quarter century, advances in the medical sciences and subsequent improvements in the technical ability of physicians have resulted in our increasing ability to deliver good, science-based medicine. Undoubtedly, the day will come when the details of the Krebs cycle, baptismal information that almost all first-year medical students commit to memory, will prove to be relevant to providing good medicine at the bedside.

Despite continuing scientific advances, the practice of good medicine requires more than applying the right science at the right time for a specific ailment. Good medicine demands that we practice medicine also as an art because there will always be the point at which science cannot stop the inevitable, the point at which compassion and comfort are all a physician can give to patients in need. Today, the challenge confronting the medical profession is how to educate physicians not only in the scientific but also in the artful practice of medicine. In medical school, a burgeoning number of courses that cover topics ranging from the doctor-patient relationship to the medical humanities have been developed to educate for professionalism. But while there are more ethics courses available today than when I was a medical student, the time and effort dedicated within the formal curriculum to the artful practice of medicine remain limited and, some say, ineffectual. Factors in medical school that contribute to the challenges of teaching ethics and professionalism range from competing curriculum demands, inadequate support and training for role models and mentors, student resistance to such courses, and the belief that no one can be trained to be compassionate by taking a course¹⁻⁴.

Following medical school, the barriers to educating for professionalism are even more daunting. Stress related to long work hours, lack of formal social support, and the burden of caring and treating many and diverse patient populations create a learning environment that works against the preservation and cultivation of professionalism. These cumulative experiences in the undergraduate and graduate medical settings lead to a "hardwiring" that makes professional attitudes and behavior among practicing physicians that much less modifiable. Nevertheless, I have always found the logic behind the notion that individuals cannot learn to be more compassionate or empathic somewhat flawed, when there is ample evidence

that medical students and residents learn and habituate to conduct that is the antithesis of professionalism⁵⁻⁹.

Given these educational challenges, there is a growing realization and urgency among leaders in medicine that a more systematic approach must be developed for imparting ethics competencies and then assessing whether those competencies have been attained¹⁰⁻¹². In short, it seems, paradoxically, that the art of medicine must have a more scientific basis if it is to promote the practice of good medicine. Medical school faculty are increasingly more innovative as they refine ethics curricula, both formal and informal, to address the educational needs of students. The Accreditation Council for Graduate Medical Education has adopted core competencies that doctors in accredited residency training programs must demonstrate. Among these core competencies is the ability to provide ethical care, an accreditation requirement that should lead to structural reforms of the residency workplace that will foster the practice of compassionate care. Lastly, there appears to be a growing demand for ethics CME courses, and this trend will likely accelerate further as more states require these types of lifelong learning requirements for licensure.

A not-so-famous man once said, "If you can't measure it, it's less likely to be important." In the case of good medicine, it is widely accepted that we need to measure how well physicians are providing clinical care so that we can continue to make improvements. I would argue that this logic applies not only to the science of medicine, but also in many important respects to the art of medicine—otherwise it simply becomes idealistic rhetoric. Leaders in medicine must work together to develop effective ways of imparting and evaluating the ethical skills and competencies of physicians.

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MEDICAL EDUCATION

Commemorative Issue: Professional Ethics and Instructional Success

Ken Kipnis, PhD

I shall take up 2 interwoven questions in these pages. First, what goals should medical ethics teachers be trying to achieve in their work with medical students? And second, what measures are appropriate in determining whether those sought-after outcomes have been achieved? I want to consider 6 ends-in-view that should inform the work we do with medical students and to sketch how we might gauge our success with these objectives.

I should perhaps begin by saying something about how I came to these problems. I have lived in Honolulu for more than 20 years, teaching "ethics in health care" in many different settings. Unlike most places on the planet, Hawaii has no majority population. We are all minorities here. Caucasians like myself represent only about a third of the population. The rest are Japanese Americans, Chinese, Filipinos, Hawaiians, Samoans, Koreans, Puerto Ricans, Native Americans, Portuguese, African Americans, and many others.

My students have taught me to be cautious about assuming consensus, for the moralities they bring with them into medical education are strikingly diverse. I regularly tell them about a 25-year-old Samoan patient who had a tumor in his leg. It had metastasized and death could not be prevented. It is well known in Hawaii that Samoans acknowledge a far greater deference to familial authority than most Westerners accept. So the relatives were gathered near the hospital bed for a meeting. The physician recommended amputation to prolong the young man's life for perhaps a few additional months. The father, who was also the chief, promptly approved the procedure and the young man nodded. But later on, alone now in pre-op, the patient tells the surgeon that he does not want to live out his last weeks as an amputee. Even more, he does not want his father, the chief, to know he has questioned his judgment. For the young man, the social consequences of disclosure would be worse than amputation.

I ask my students, "What should a good doctor do?" For the Samoans in my class, the question is a no-brainer. Take the leg off. Why are we talking about this? Caucasians find some way to backtrack, telling the father a story, if necessary, but absolutely not performing the surgery. Asians and Pacific Islanders are split. Some side with the Caucasians, but others honor the chief's decision either because the young man should be treated under Samoan rules or out of a sense of filial respect. It gradually becomes clear to the class that there is no consensus; that—

collectively—they do not know what a good doctor should do in that circumstance. This acknowledgment is the beginning of wisdom.

I recount this story here because what is true of Hawaii is becoming true in most places. Pluralism, as the political philosopher John Rawls tells us, has become a permanent feature of the human condition, not likely to fade away¹. The representative peoples in my medical ethics class need to be able to bracket somehow the personal moralities they bring with them into the profession. They need to open themselves to the possibility that, in becoming physicians, they may have to learn new and different ways of understanding their obligations.

As ethics teachers in medical schools, we have the advantage of working with good students who want to become good doctors. They can be shown, first, that there are troubling ethical dilemmas in medicine that they do not know how to negotiate and, second, that it is important that the profession honor some reasonable shared ethical commitment. If we are to teach professional ethics in health care, it must be our first objective to help students make room for the probability that the moral principles that have served them and their families well over the years may be inadequate to the task of providing 21st century physicians with sound ethical guidance. Vexing ethical dilemmas—like the case of the Samoan—are effective in getting students' attention. And that attention is the most dramatic evidence that this initial goal has been achieved.

It is useful to conceive the most important task of ethics teachers as, in part, the creation of an intellectual space within which persons from different cultures and backgrounds can reach responsible judgments on the obligations of physicians. One way to begin this task is to help students distinguish between their own personal values—what they happen to care about—and the core values of the profession—what a good physician ought to care about.

Dilemmas in professional ethics flow either from conflicts between core values, necessitating some kind of rule for establishing priority, or from ambiguity in a core value, necessitating what we philosophers call "disambiguation." The classical debate about medical paternalism involved the conflict between the competing values of beneficence and respect for patient choice. The problem of physician-assisted suicide illustrates ambiguity in a core value. Although we accept that physicians should never harm their patients, can there be situations in which death is a benefit rather than a harm? What should medicine mean by "harm"? The core values approach mirrors in pedagogy the creative process that can give rise to professional codes of ethics. Both medical students and the profession to which they aspire need to articulate the profession's distinctive values and, in the context of carefully chosen cases, disambiguate and prioritize these values in the process of reaching consensus about what good physicians should do. In the classroom, both the values and their prioritization are constantly in play and are the products of facilitated discussion.

The dialogue in a successful class can therefore mirror the ethical progress of the medical profession. For as the bioethics literature matures, it becomes possible to distinguish between what might be called "consensus issues," about which a broadly accepted, well-founded professional judgment has been formed, and "knife-edge issues," about which responsible professional judgments either fall on both sides or are sparse. It seems to be a fact of contemporary life that the publicity surrounding a dilemma in medical ethics is greatest at the time the troubling cases first appear and professional opinions are poorly informed. In the United States, cases of newborns with duodenal atresia and Down syndrome (e.g., the Baby Doe case) exemplify this. Now, dozens of articles and years later, there is broad and responsible consensus on the dimensions of the obligation to treat such infants. But the media do not cover the evolution of informed opinion as they publicize the first cases that precipitated the debate.

The glaring disparity between the prominent initial dramas and the slow and largely invisible emergence of professional consensus has perhaps led members of the public and even some scholars to opine that ethical questions are inherently resistant to responsible answers. But this is not so, and it is possible to ascertain, at any time, the conventional ethical wisdom of the profession. Several elements enter into this determination. First, there are consensus documents that regularly appear in medicine. While these are a key source, the positions found within them have to be consistent with the medical ethics literature—the second source. Where a topic has been well-explored, the relevant arguments developed and assessed, it is sometimes clear that, at least for now, the issue is settled. In the United States, for example, there is effective consensus on the nature of and need for informed consent, most cases of withdrawal and withholding of life support, and the use of patients as research subjects.

Accordingly, a second instructional objective would be to expose students systematically to the main elements of the profession's current sense of its ethical responsibility. Ideally, students would also be able to distinguish between knife-edge issues (e.g., medical futility) and consensus issues (e.g., refusals of blood by adult Jehovah's Witnesses). This objective is easy to assess: exposed to a case for which a professional consensus exists, and to practical options, students should be able to pick out the professionally favored course of action, if ethics education has succeeded.

There is an element of the profession's ethical consensus that is both critical to the student (and to the profession) but separate from understanding the favored principles that specify a physician's clearest responsibilities. For in addition to the broadly accepted ethical standards in medicine, there are the considerations and arguments that have been advanced in support of those standards. The authority of the profession's standards is not a function of bare acceptance but rather (one hopes) a function of the good reasons there are for endorsing them. For medical ethics, like all medical knowledge, must rest upon solid reasoning. An understanding of the profession's standards is incomplete unless a third objective is achieved: that

students will be able to grasp the essential relationship between the privileged status that the consensus principles should enjoy and the soundness of the arguments given in support of them. In my experience, student understanding can be assessed by means of research papers or class presentations, perhaps done as a group. The available literature is reviewed and the main arguments laid out, thoroughly and fairly. Students can explore both knife-edge and consensus issues and the task itself can mirror the social process that can give rise to a profession's distinctive ethic.

As one who teaches and works in medical ethics, however, I sometimes find myself setting out the consensus view, spelling out the arguments that have persuaded the profession, but then going on to criticize those same arguments. As a philosopher, I am trained to identify and expose arguments that are weak or flawed or inconsistent with other accepted justifications. For example, although the conventional wisdom is that physicians should breach confidentiality when necessary to protect identifiable, seriously endangered third parties, I have argued that that precept is mistaken. I talk about my reasons for challenging the consensus view and why a different position, supported by less obviously flawed arguments, should be favored. In setting out such a critique, I want students to see how medical ethics is, as it were, "in play." I want students to appreciate the possibility of change and to understand the professionally supported ways of bringing that about. My physician colleagues tell me that medicine's technical knowledge has a half-life of 7 years. Something similar is (or at least should be) true for medicine's ethical knowledge.

When we speak of technical competence in medicine, what typically springs to mind has mainly to do with the extent of the practitioner's knowledge base and his or her skills in differential diagnosis and treatment. But there is ethical competence as well. Physicians should, for example, be able to spot potential ethical problems before they become unmanageable: the doctor treating the 25-year-old Samoan should have talked with him privately before discussing options with the family. There is much to be learned about how to conduct a family case conference. We know the mistakes that clinicians make and can teach simple ways of avoiding them. Doctors should be able to retrieve information about ethics, discern and assess the arguments that are set out in those resources, and manage sensitive issues in the clinical setting.

A fourth objective would therefore be to nurture the development of practical ethical skill. An ethically competent physician doesn't merely have an open mind, a grasp of the profession's conventional ethical wisdom, and a sense of the debates that give rise to that consensus. The ethically competent physician is also capable of doing certain things. Important things. Role-playing can serve as a way of teaching and in assessment.

But now I want to consider what I think is a major oversight—even an error—in what I have just set out. In general, good teachers properly stay focused on their students. And we commonly measure our success by assessing each one of them, as if our teachings were talismans to be bestowed upon each initiate. But this attention

can blind us to a larger and much more important objective. For there is an important sense that, as teachers of medical ethics, our "student" is the medical profession as a whole. Ethics education does its job best not merely when each student acquits himself or herself respectably but, rather, when the class as a whole can model within itself the character of an ethically competent profession. Medicine is one of civilization's great traditions and, as the contemporary moral philosopher Alasdair MacIntyre has shown, to remain vital a tradition must sustain ongoing and vigorous debate about the nature of its distinctive goods and how these are to be realized in the course of practice². While one cannot and should not avoid student-centered teaching, the fifth educational objective calls upon teachers to promote the creation of what can be called an ethically competent profession. Each of the 4 preceding objectives is a prerequisite for this larger one. For unless medicine enjoys a critical mass of what we might call "statespersons," it will be unable to participate coherently in the social organization of health care, unable to chart its own course, and unable to shape its distinctive dedication. The student body needs to be prepared to play a role in the profession's ethical governance.

Though it may seem paradoxical, communities like the medical profession can be measured, in part, by the quality of their disagreements. When divergent voices are clear and cogent, when competing intellectual positions are well-informed and well-reasoned, and when open-mindedness is conjoined with respectful fairness and critical attentiveness, there is hope for progress. Ethics education in medicine can model habits of mind and discourse that can serve the abiding interests of the profession as well as individual professionals.

Success here can be seen in the political character of the profession. How does it sustain its ethical deliberations? How well do practitioners grasp the values implicit in their common work? How effectively are issues defined and settled? It is the sad fate of teachers that the ultimate effects of our work are too often lost in a jumble of concurrent causes and effects at increasing temporal and spatial distances. Nevertheless it is useful to keep our sights on the intellectual health of the profession and the character of its debates as measures of our long-term and collective success.

But there is a sixth and final objective that takes us yet to an even broader level. For the medical profession exists to serve—centrally—the health needs of its community. The relationship between the two expresses something of a social contract: benefits and resources flow directly and indirectly to the profession as its distinctive services are rendered to the community. In this arena, a community is in good order when both of the parties are reasonably satisfied with the balance between the goods they receive and the burdens they are obligated to shoulder. Accordingly, pertinent questions of justice, social values, ethical obligation and public policy will pervade aspects of that transaction and, ironically, physicians will almost inevitably find themselves on both sides of the bargaining table, as providers and, on occasion, as patients.

If, in one context, the ultimate student in a medical ethics course is the medical profession itself, in another the ultimate client is the community as a whole. For a central collective task of the profession is to reach a stable and just accommodation with its community. This has never been easy, not least because of the tendency to act out of personal interest rather than out of professional values: the boundary line between professional associations and trade associations is often blurred. Accordingly, it should be the final objective for those who teach professional ethics in health care to open up the subject of the proper place of medical care in a just society, to pay attention to the standards that should inform "the deal." As bioethicists, we have been fairly successful in moving out of the classroom and into the public sphere, making contributions that can reach broad audiences even as they address pressing social concerns. We can show how medicine can help to craft the social setting within which it is practiced even as we equip its practitioners to work responsibly within that context.

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PERSONAL NARRATIVE

Commemorative Issue: Through the Student's Eyes: Working in the Shadows

David R. Block, MD

I wondered how many others in the large laboratory had the same conflicting feelings as I: anxiety, nervousness, eagerness, and enthusiasm—all rolled into one. It was the first day of gross anatomy, the course that, arguably, defines the first year of medical school. The preceding week of orientation now completed, the 135 or so members of the Class of 2004 stood in front of our dissecting tables, awaiting the first instructions from our professor. Before opening our tables, we offered a moment of silence in deference to those deceased women and men who had given their bodies so that my classmates and I could learn from them. We were then told that the cadavers were our first patients. Then we were told to open up the tables.

During orientation week, between presentations about courses and which books to buy (and which "not" to) and exploring the social life of Buffalo (there is one), professionalism was a recurrent theme. Professionalism is a hot topic in medicine and medical education nowadays. Medical schools, charged with offering a professional education, are continually exploring how best to do so. And medicine itself is struggling to redefine itself as a profession in the 21st century amidst phenomenal scientific advancements and difficulties adjusting to a managed care model. As I stood in front of the body of a deceased 89-year-old female on my first day of med school, however, professionalism was the farthest thing from my mind. All I could think about was how intensely demanding this class was going to be both academically and physically.

On the second or third day of "gross," my dissecting partner complained that she was not getting enough light in her part of the body. "It's like I'm working in the shadows, Dave," she remarked. I'm not exactly sure why, but her comment really struck me. While she certainly could have used more illumination (especially considering we were examining the posterior cervical triangle), that's not why her words had an impact. No matter how much light we might have had, we would be spending the entire semester dissecting in the shadow of this great woman. Who knows what contributions she made during her life, but now—in her death—she was continuing to aid 8 young students in their journey towards becoming physicians. That we should consider her our first patient, however, seemed a bit strange. While we knew her age and cause of death, that was "all" that we knew. We were not told her name or her medical or social history; nor could we ask her questions. We possessed her physical being, but little of the total person.

Though I have spent barely a month in medical school, I already sense that I have learned a great deal about anatomy, cells, biochemistry, and epidemiology. In one course, histology, the student's task is to take a highly microscopic view of the body and identify the 1 or few cells on a slide. Even when such cells are aggregated, as in a smear of different bone marrow cells in various stages of development, I find it difficult to fathom that these miniscule units once were part of a very substantial human being. I am not entirely comfortable examining the body from this perspective. Much like dissecting a cadaver, I feel I am working in the shadow of something, but that something can be frustratingly elusive.

I trust these shadows will disappear as my studies progress. Every medical student knows that the scientific knowledge he or she is inundated with during the first few years will be supplemented with the artistic aspects of medicine in later years. Of course, I don't know how the essence of professionalism will be inculcated in who I am as a physician at this early stage (or even if it will be there at the end). There's a lot I don't know now about being a physician, but this doesn't stop me from being absolutely resolute that—in some way—what will enable me to become an outstanding, competent, and compassionate physician will come into focus as the years go on.

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PERSONAL NARRATIVE

Commemorative Issue: Through the Student's Eyes: Sag

Jennifer Bau

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

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CASE AND COMMENTARY

Commemorative Issue: Is It the Money? and In a Bind?

Commentary by Audiey Kao, MD, PhD

Case 1: Is It the Money?

Mr. Nelson presents to Dr. Porter's office complaining of bitemporal headaches. A medical history reveals that Mr. Nelson has been experiencing difficulties and stress in his marriage, and a complete neurological physical exam is nonfocal. Based on his evaluation, Dr. Porter believes that the headaches are stress-related and can be managed by nonsteroidal anti-inflammatory pain relievers and stress management. Mr. Nelson, however, believes his headaches may have a more serious etiology and would like a CT scan to rule out anything of greater concern. He has read that some health plans use financial incentives that reward physicians who save the plan money by ordering fewer tests. Mr. Nelson asks Dr. Porter: "Are you not ordering the CT scan because it is too expensive to get?"

Questions for Discussion

1. Some have advocated that disclosure of financial incentives be considered a part of the informed consent process. Should physicians be legally required to disclose this information?
2. If Dr. Porter's motivations are therapeutic and not financial, how might he convince Mr. Nelson that a CT scan is not indicated in this case? If Mr. Nelson remains adamant, should Dr. Porter acquiesce to his wishes? Would your opinion be different if the diagnostic procedure were a more expensive MRI scan?
3. How might the situation be different if Mr. Nelson were a physician? If Mr. Nelson were a medical student?

For more information relevant to this case, See what the AMA *Code of Medical Ethics* says about this topic in Opinion 8.054 Financial incentives and the practice of medicine. American Medical Association. *Code of Medical Ethics* Code of 1998-1999 Edition. Chicago, IL: American Medical Association; 1998.

Case 2: In a Bind?

Mrs. Albert 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 that resulted in a broken hip. During the day Mrs. Albert 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. Albert wants to leave her

room to buy some nachos, believing she's at a baseball game. Because of Mrs. Albert's unwillingness to stay in bed, the staff is concerned about her well-being and safety. Her nurse believes that some kind of restraint is needed. The attending physician agrees and orders a restraint vest that wraps around Mrs. Albert's chest. Mrs. Albert does not want to be placed in the vest. The nurse's aide tells Mrs. Albert 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.

Questions for Discussion

1. Was the violation of Mrs. Albert's autonomy justified by concern for her safety?
2. If Mrs. Albert agrees, during lucid daytime periods, to being restrained for her own safety when she is less disoriented and combative, what should care givers do in the evening when she refuses to be restrained?
3. Should the family have been notified before Mrs. Albert was placed in a restraint?
4. What is the role of Mrs. Albert's health care proxy?

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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VIEWPOINT

Commemorative Issue: The Twelve Days of Christmas

Audiey Kao, MD, PhD

On the first day of Christmas, my drug rep gave to me a partridge in a pear tree.

On the second day of Christmas, my drug rep gave to me 2 ballpoint pens and a partridge in a pear tree.

On the third day of Christmas, my drug rep gave to me 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

On the fourth day of Christmas, my drug rep gave to me a 4-volume textbook, 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

On the fifth day of Christmas, my drug rep gave to me a 5-pound ham, a 4-volume textbook, 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

On the sixth day of Christmas, my drug rep gave to me 6 baseball tickets, a 5-pound ham, a 4-volume textbook, 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

On the seventh day of Christmas, my drug rep gave to me a 7-course meal, 6 baseball tickets, a 5-pound ham, a 4-volume textbook, 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

On the eighth day of Christmas, my drug rep gave to me 8 gift certificates, a 7-course meal, 6 baseball tickets, a 5-pound ham, a 4-volume textbook, 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

On the ninth day of Christmas, my drug rep gave to me 9 holes of golf, 8 gift certificates, a 7-course meal, 6 baseball tickets, a 5-pound ham, a 4-volume textbook, 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

On the tenth day of Christmas, my drug rep gave to me 10 movie passes, 9 holes of golf, 8 gift certificates, a 7-course meal, 6 baseball tickets, a 5-pound ham, a 4-volume textbook, 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

On the eleventh day of Christmas, my drug rep gave to me 11 ounces of caviar, 10 movie passes, 9 holes of golf, 8 gift certificates, a 7-course meal, 6 baseball tickets,

a 5-pound ham, a 4-volume textbook, 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

On the twelfth day of Christmas, my drug rep gave to me 12 long-stemmed roses, 11 ounces of caviar, 10 movie passes, 9 holes of golf, 8 gift certificates, a 7-course meal, 6 baseball tickets, a 5-pound ham, a 4-volume textbook, 3 handy penlights, 2 ballpoint pens, and a partridge in a pear tree.

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PERSONAL NARRATIVE

Commemorative Issue: Through the Physician's Eyes: The Patient (Internet)-Physician Relationship

Clarence Braddock, III, MD, MPH

I smile, taking the printed pages from Mr. S then look down to see what he's found. Quickly scanning this printout from an arthritis support group Web site, I see a discussion of chondroitin and glucosamine for osteoarthritis. My mind races; do these substances work? I recall a recent Grand Rounds on osteoarthritis, the speaker suggesting a possible benefit, and breathe a mental sigh of relief. "Mr. S," I say, "there have been some studies on these 2 supplements for patients like you, and some show that they do help. But not all experts agree, and we don't know some of the possible harms. Also," I continue, "it's hard to know if the stuff you buy is the right potency, since these are not regulated by the Food and Drug Administration."

Another crisis averted. With each passing day, my anxiety about the next Internet printout rises. Next time, it may be a treatment that I know nothing about. How soon will my patients know more than I do? What will they think if I don't know the latest development? Is the information they read even accurate?

As the number of Internet-based resources for medical information rises, more patients enter the clinical encounter with unprecedented amounts of information. Ranging from diagnoses of illnesses to new and untested treatments, this information challenges the physician's traditional role as holder of all medical knowledge, and thereby potentially undermines an age-old source of medical authority. At the same time, when patients do obtain, read, and process accurate medical information in advance of the clinical encounter, it can enhance their ability to understand the clinical decisions that lie ahead, potentially solidifying their role in medical decision making and strengthening the patient-physician relationship.

Physicians can easily feel threatened by these developments. Our own medical knowledge and judgment is called into question. We may feel defensive, needing to justify our reliance on more accepted approaches to diagnosis and treatment. Our skepticism about new and untested clinical developments is questioned. Yet this need not be so. Physicians can and should use their patients' interest in medical information as an asset, allowing discussion of the sources of this information to increase the patient's knowledge and forge a stronger therapeutic alliance.

How can physicians encourage the positive side of increased patient access to information? First, we can see patient interest in learning as an invitation to discuss their conditions. The discussion will proceed more smoothly if we find parallels in the medical diagnosis that mirror the patient's own interpretation of his or her illness. It is important to make the distinction between the patient's interpretation of the illness and our diagnosis of disease and, at the same time, to understand the relationship between them. Our clinical diagnoses are translations of the patient's real life experience, and in respecting the patient's version as legitimate, we foster the therapeutic relationship.

Similarly, by demonstrating a respectful rather than scoffing attitude toward the patient's sources of information, we can convert a potentially adversarial discussion into a more collegial one. When patients share their sources of information, they are also demonstrating trust in us and giving us insight into their thinking. What do they really think of our diagnoses and treatment recommendations? These are questions for which we need answers, for the answers hold the key to fostering patient adherence to treatment regimens. We can make patients feel comfortable by acknowledging that we are aware they are not taking their medications, or that they are taking alternative treatments outside of our prescribed plan. These situations also offer opportunities to give patients advice about finding reputable sources of medical information. We can ask them about their sources, and along the way suggest sources we know to be providers of good quality information.

What should we do if the patient challenges our advice? Occasionally, patients will hold strong views on medical diagnoses or treatments that are diametrically opposed to the physician's. This can create conflict and tension. The ethical dilemma for the physician intensifies when the basis for the patient's views seems to be inaccurate information from outside sources. Such situations are not really new, but because the Internet makes such information sources increasingly ubiquitous—not to mention unregulated and potentially misleading—the physician may see strong disagreement as a way of meeting an ethical obligation to prevent harm. These situations underscore the importance of maintaining trust and open communication, even in the face of disagreement. Any chance that we might have to help the patient see that their strong views could turn out to be harmful rests on our ability to foster trust. Patients must feel confident that we know what we're talking about, can acknowledge our own uncertainty, and are acting in their interest rather than merely upholding medical authority.

Furthermore, as patients become more knowledgeable, it becomes ever important for physicians to remain up-to-date on medical developments. Critically reading the biomedical literature, attending continuing medical education conferences, and conferring with colleagues are all components of life-long learning, a core part of our obligation to maintain professional excellence.

Overall, then, Mr. S's question had a positive effect. It caused me to think more carefully about how he processes medical information and to understand the

influences, including, very obviously, the opinions of his son, on his views about his illness. I also was reminded of the importance of keeping myself current (boy, was I glad I had attended Grand Rounds that week). Finally I was grateful that Mr. S thought enough of our relationship to call me "on the carpet" for what he thought might be an omission in his medical treatment, for this afforded me the opportunity to address his concern, and in so doing lay another brick in the foundation of our therapeutic alliance.

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PERSONAL NARRATIVE

Commemorative Issue: Through the Physician's Eyes: A Racist Parent

William A. McDade, MD, PhD

The student was aghast. Pain, anger, doubt, and frustration intermingled within her. She was devastated and tearfully left the patient's room. I don't know what must have been going through the mother's mind at that time. Did she feel that she had successfully protected her child from some assault by a poorly educated black woman? Did she feel that the debased medical student would suddenly come to her senses and give up her study of medicine after such harshly delivered discouragement? Did she feel good about herself for having made another human being of a different race feel bad?

The medical student, who was a hard-working scholar and researcher, had performed wonderfully during her 4 years of medical school. Her university had historically accepted few African American students per class and there were even fewer minority faculty despite the fact that the medical center was in a predominantly minority community. Most of the hospital staff were African American as were the vast majority of the patients. In fact, the patient's mother was seeking to establish a protective circle of whiteness in a sea of cultural difference. The reality was that there was no affirmative action program in place at the medical school and that the student's scores and undergraduate performance allowed her to select from multiple offers from medical schools. She had done research as an undergraduate and spent all of her summers prior to medical school engaged in scholarly endeavor. She enjoyed her experience in pediatrics so much as a third-year medical student that she elected to do a subinternship in pediatrics during her fourth year and was ranked among the best students in her cohort. Her goal was to train to become a pediatric intensivist.

The student immediately reported the events of the early morning to her senior resident and asked what she should do for resident rounds. Her colleague suggested that she should describe the situation to the attending physician during teaching rounds and see what she recommended. Meanwhile, the remainder of the team, excluding its only African American, would examine the child during work rounds and prepare the progress note. They would also arrange for an intern to handle this patient in her place. After all, who would want to serve a patient who had so severely insulted them?

Life in a teaching hospital is often complicated by patient requests that the most senior member of the team perform the procedure or examination, but most

understand that medical students and residents are an essential part of a university health care system. History-taking and non-invasive physical exams are generally well-tolerated for the relative inconvenience they bring to the inpatient experience. Some rightly think that the more minds weighing in on their problem, the better; and many enjoy the chance to help train the nation's emerging physician workforce. The mother did not seem to have a problem with the teaching hospital concept, because she did not prevent other physicians-in-training from examining her child. It was clear that the single overriding issue was race. Cultural intolerance was afoot here. During teaching rounds the situation was detailed for the attending physician.

What were the options for the attending? If she honored the mother's wish, she would have to exclude the fourth-year medical student from the team when examining and discussing this patient. If she invited the student into the room with the team and insisted that she remain the primary contact with the parent, the attending would be negating the parent's request. A final option would be to explain the nature of the teaching hospital and the attending physician's responsibility to educate tuition-paying students and to offer to help the mother secure care at a different institution. Counterbalancing these options were the hospital's financial interest in caring for a well-insured patient, the potential disruption of the referral pattern if an unsatisfied patient were to complain to the referring physician, and the desire to comfort a fearful mother during the stressful period of her child's illness.

In this case, the attending physician chose to ask the fourth-year medical student to remain in the hallway while the rest of the team examined and discussed the patient's progress. The budding pediatric intensivist was completely devastated and sought recourse through the medical school. Fortunately, the situation was short-lived and the patient was soon discharged; however, the damage had been done. The humiliation, alienation, and pain were too intense for the student. In selecting a residency program, these events weighed heavily and caused the student to bypass her own university and complete a residency in pediatrics elsewhere. And what message was transmitted to her colleagues-in-training through their observations of the way she had been treated? Will they perpetuate the behavior exhibited by their teaching-attending physician or will they recognize the irrationality and pain associated with racism and act to confront it in the future?

Questions for Discussion

How should the attending physician have handled the situation in which a mother refused to allow an African American medical student to care for her child? What core values are in conflict here? What are appropriate expressions of and limits to patient preferences? Is it acceptable for a patient to refuse care from a physician of a particular gender or from a physician who the patient thinks is too young or too old?

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VIEWPOINT

Commemorative: Feeding Health Disparities

Kayhan Parsi, JD, PhD and Sara Taub, MA

The researchers studied 4 sitcoms that feature African American characters and are popular with African American audiences—*Moesha*, *The Parkers*, *Malcolm and Eddie*, and *The Jamie Foxx Show*. They also examined 4 sitcoms without African American stars that are popular with general audiences—*Friends*, *Frasier*, *Jesse and Stark Raving Mad*. They concluded the following:

- 27 percent of the actors on the African American-oriented shows were overweight, compared to 2 percent on the general interest shows.
- 4.78 food commercials aired per half hour during the African American-oriented shows versus 2.89 during the other shows.
- 31 percent of commercials during the African American-oriented shows were for candy and 13 percent were for soda, compared to 11 percent for candy and 2 percent for soda in the general interest shows¹.

Dr. Anjali Jain, the University of Chicago pediatrician who headed the study, commented upon the disparity: "One could say this is an accurate reflection of African American reality, but on the other hand it might also be viewed as an ideal. It might help overweight people to feel less stigmatized, but . . . it might give them the message there aren't any adverse health consequences to being overweight"². This is not to suggest that overweight people should not star in television shows. On the contrary, people of all sizes and shapes should figure in programs that claim to offer viewers a "slice of life." What is at issue is the message conveyed when people who carry excess weight are portrayed almost invariably as happy individuals who have no health complications to worry about due to their weight. A similar phenomenon occurs in film, where characters often smoke but seldom experience the health consequences associated with the habit. Nor are the concerns here different from those raised by ad campaigns that showcase emaciated women as ideals of beauty that girls will want to emulate.

Food advertising specifically tailored to certain segments of the population is nothing new. Marketers of junk food have become quite sophisticated in targeting young children. This kind of advertising has become so pervasive that critics are calling for an outright ban of junk food advertising geared toward kids. Michael Jacobson, executive director of the Center for Science in the Public Interest, and Marion Nestle, chair of the New York University's Department of Nutrition and Food Studies, both argue that the government should ban junk food advertising on

children's programs³. Although physicians have often blamed advertising for contributing to the obesity epidemic in this country, others cite a certain amount of peer pressure to gain weight. "People look at the rest of the country [and think,]: Everybody else is fat, why not me," says Michael Fumento, author of *The Fat of the Land* and senior fellow at the Hudson Institute. He states that being obese is no longer stigmatizing and is even something to be celebrated, citing the "fat and proud" movement. "You used to be proud because you did well in school, or your kids did well in school, or you earned a medal in a war," he says. "You're not supposed to be proud because you ate three sandwiches and the guy next to you ate one"⁴.

Attention to one's weight is often framed as a preoccupation with appearance, indication of poor body image, and source of social stigmatization, and these are valid considerations. It is not appropriate, however, to discuss weight only in terms of aesthetics when its implications for health are significant. The Department of Health and Human Services' *Healthy People 2010* finds overweight people at increased risk for high blood pressure; type 2 diabetes; coronary heart disease; stroke; gallbladder disease; arthritis; sleep disturbance (apnea); respiratory problems; breast, prostate, and colon cancers; and depression.

In a country where more than 100 million adults are overweight⁵ and obesity in younger children has been called an epidemic, it is time for the health consequences of obesity to be emphasized and addressed. Public education about nutrition and the importance of exercise is key to preventing and controlling problems of excess weight. To be involved in this public health initiative that has direct impact on patients' well-being, physicians need to have adequate knowledge in nutrition. Along with teachers and other community leaders, health care providers can play a significant role in helping people develop balanced diets and integrate exercise into their daily routine. As Former Surgeon General Dr. C. Everett Koop, founder of "Shape Up America!," notes, "While there are obviously some costs involved, the result in terms of reduced health care expenditures will far exceed the dollars spent"⁶.

Why has there not been more outreach in this public health area—with efforts similar to those extended in the battles against tobacco, alcohol, and violence? By using its resources to teach the principles of health-promoting lifestyles, the health sector could help reduce the number of overweight people and, in turn, reduce expenses associated with treating health complications of obesity.

Although excess weight is a problem across the population, studies report that it is more prevalent among certain groups—particularly low-income African American women who not only face financial and neighborhood safety barriers to shopping for products that promote healthy living habits but also tend to be more tolerant of obesity⁷. This observation brings us back to television programming and stereotypes. As Dr. Jain notes, "In some ways, the TV findings may just reflect

reality, but I think it also plays a role in creating that reality. The chicken-and-egg argument is definitely there"⁸.

Along with ethnicity and culture, education influences consumption patterns. Younger and less educated viewers may be more influenced by what is pitched on the airwaves. Seeing healthy and happy obese characters and commercials for junk food may undermine educational efforts to improve dietary habits. Physicians have a responsibility to educate patients about nutrition and counter the plethora of images in the culture that promote poor dietary habits. Unfortunately, these images often target the most vulnerable members of our society: children, the poor, and people of color. Medical groups should devote resources to developing programs to combat obesity based on models of existing anti-tobacco and anti-alcohol campaigns. The real challenge for physicians and physician groups lies in designing educational campaigns that promote fitness and good eating habits without further marginalizing those who are seriously overweight.

Questions for Discussion

1. Is there a danger that well-intentioned advocacy for vulnerable populations might turn into a new form of old-fashioned paternalism?
2. What can we do to encourage marginalized populations to take more active roles in their own health?

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AMA CODE SAYS

Commemorative Issue: Resuscitating Privacy in Emergency Settings

Faith Lagay, PhD

Since the trend toward reality TV in medicine took off around 1997, 30 or more emergency departments have invited film crews in for "around-the-clock taping"¹. Many physicians and administrators at participating hospitals are pleased with the results. The reality shows, they say, counteract the glamorized portrayals in dramas such as ER that create unrealistic expectations for survival and recovery from trauma. Thus, they argue, the reality shows—*Trauma*, *Paramedics*, *Hopkins 24/7*, and the like—educate the public and demystify the emergency department encounter.

Not all physicians agree. Medical ethics rests on the bedrock understanding that those who are sick are vulnerable. This fundamental truth gives rise to the ethical and professional standards governing patient privacy and confidentiality as well as to a gravity of purpose and conduct that suffuses the clinical interaction.

Some physicians believe that making an entertainment of actual clinical encounters violates these ethical and professional standards. The presence of non-medical team members, they claim, invades patient privacy, exploits the sick and dying, and could compromise clinicians' ability to work most efficiently.

One physician who felt strongly about the exploitation of critically ill or injured—and therefore especially vulnerable—individuals was Dr. Martin Fujimura, whose one-man crusade helped spearhead a movement for change in AMA policy. A family practitioner in Dayton, Ohio, Dr. Fujimura began campaigning for change in the fall of 1999. He penned letters to the Ohio State Medical Association, published an article for *In Confidence* magazine², and wrote to the AMA Council on Ethical and Judicial Affairs (CEJA) requesting that the national organization of physicians develop a policy to curtail this practice of filming. "I am particularly saddened," his letter stated, "by what I perceive as the exploitation of patients who need our care and protection the most, i.e., the severely injured and the dying. How is it permissible to allow camera crews to film half-naked, dying patients (even teenagers and children) prior to obtaining consent?" he challenged.

In response to Dr. Fujimura's request, CEJA researched the topic and, in December 2000, solicited comments from the AMA's House of Delegates on the possible need for ethical guidelines governing patient filming. CEJA compiled the comments, drafted a recommendation, and presented it to the House of Delegates reference committee at the annual meeting in June 2001. The recommendation was approved,

adopted as AMA policy by the House, and will become part of the AMA *Code of Medical Ethics*.

In essence, the recent AMA policy on filming of patients in health care settings for the purpose of commercial broadcast states that doing so without consent is a violation of the patient's privacy³. Consent, says the policy, "is an ethical requirement for both initial filming and subsequent broadcast for public viewing." The report argues that, because filming cannot confer any therapeutic benefit to the patients, it is not worth the risk to patient privacy (and possibly well being) that it entails. Therefore, the policy states, "it is appropriate to limit filming to instances where the party being filmed can explicitly consent." Many trauma patients are unconscious or in distress too great to permit their giving informed consent. In such circumstances, the temptation is to allow the next of kin or other surrogate decision maker to provide consent. The report says this is not satisfactory. Consent by a surrogate health care decision maker is not an ethically appropriate substitute for consent by the patient because the role of such surrogates is to make decisions necessary for medical treatment or refusal of treatment. Consenting to or refusing to be filmed is not a medical treatment decision.

For most of the trauma and emergency room footage that has aired on television, patients' consent was received after the filming and before the broadcast. If patients did not consent, their portion of the film was not broadcast. But the filming itself had already violated their privacy. To understand why, it is necessary to distinguish between privacy and confidentiality. Patient privacy refers to the fact that patients are entitled to have only those individuals involved in their medical care examine them or observe their examination. AMA policy dictates that "physicians are ethically and legally required to protect the personal privacy and other legal rights of patients"⁴. Confidentiality, on the other hand, refers to what happens afterward to information shared in private with the physician. Patient records and conversations fall under this protection and give sanctity to the patient-physician relationship. Information that is shared with the physician should not be disclosed to others, according to AMA policy on confidentiality, without the patient's consent or unless the disclosure can be "ethically and legally justified by overriding social considerations"⁵. Examples of overriding social considerations include patient threats of harm to self or others from physical violence or communicable disease. Protection of privacy and confidentiality go hand-in-hand. If the patient-physician encounter is not private, confidentiality is far more difficult to secure.

Thus, unless a stationary camera is used or a health professional does the filming, the privacy of the clinical encounter is violated when filming takes place. Receiving consent for distributing the film after the fact avoids breaches of confidentiality but does nothing to undo the invasion of privacy. Breach of patient privacy is permissible only through expressed informed consent before filming.

It is important to recognize that, under the new AMA policy, patients who are conscious and able to give consent may be filmed. Even here, though, the report that

paved the way for the new policy warns that the time required for informing the patient fully about what the film crew may observe and record is time perhaps better spent on diagnosis and treatment.

As stewards of the AMA *Code of Medical Ethics*, the Council on Ethical and Judicial Affairs develops opinions on a variety of ethical and professional issues that confront physicians and recommends them to the House of Delegates each year for action. Any physician, any concerned individual, can bring a matter to the Council's attention. When Dr. Fujimura did so, CEJA transformed his interest in protecting emergency patients into an opinion of the *Code*, where it stands as a guide for physicians who strive to practice ethically.

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VIEWPOINT

Commemorative Issue: Through the Patient's Eyes: Health Literacy - What Patients Know When They Leave Your Office or Clinic

Joanne Schwartzberg, MD and Faith Lagay, PhD

Have you ever thought that the patient in front of you, who has listened to a careful explanation of what he or she needs to do, may not understand what you have said? Some very brave patients agreed to speak with physician interviewers about this hidden and shame-causing problem¹.

Mrs. Walker: Can you imagine what it's like being sick, and you know that you have limited skills, okay, and you're talking to an intelligent doctor. And these people are using words that you really don't know because they're not speaking in layman's terms, okay? Most doctors are just presuming that everybody's as intelligent as they are. And that is just not the case. So . . . you come out of that room, that examination room, with this intelligent man or woman, thinking: God, I hope I don't make a mistake with my medicine, because I did not understand anything he or she said to me.

Mrs. Walker is well-spoken, well-dressed, and clearly competent in many aspects of her life—her work and family life—but she reads at a third-grade level, not well enough to read the front page of the newspaper, find an intersection on a street map, know from the appointment slip when her visit is scheduled, or understand the directions on the prescription.

Mr. Dallas [reading the label of one of the prescription drugs he takes regularly]:
Take one capsule.

Researcher: That's right, one capsule.

Mr. Dallas: One capsule. I don't know what that says, is that ten?

Researcher: Twice.

Mr. Dallas: Twice daily.

Researcher: Okay, so how would you take this?

Mr. Dallas: It's not on there how to take it. It says take it twice daily, but it don't say what time to take it.

Mr. Dallas is a respected community leader and church deacon. He also reads at a third-grade level. In addition to his reading problem, Mr. Dallas has pointed out that the simplest medical directions are often incomplete and confusing.

[On the desk in front of Mrs. Irwin and a researcher is a collection of pill bottles that Mrs. Irwin has brought with her, saying that she takes them all.]

Researcher: Tell you what . . . take these two and tell me which one is which and what you take them for.

Mrs. Irwin: That looks like my medicine that he gives me in the morning. I take that and the little pill that—no this is lithium. Ain't it? Yeah, that's lithium. [The label says Lipitor.]

Researcher: Okay, what do you take that medicine for?

Mrs. Irwin: Don't ask me. He puts me on that and I just take it. Anything he tells me to take, I'll take it.

Researcher: Okay. So you trust him?

Mrs. Irwin: Oh, you better believe it. With my life.

Mrs. Irwin, now retired, had a successful career as a bus driver, though she never went to school and reads at a second-grade level. She identifies her prescriptions by looking at the pills, not at the labels.

[Mrs. Stuart and a researcher sit in front of about 15 over-the-counter preparations.]

Researcher: Your 2-year-old has a high fever. Okay. What would you do?

Mrs. Stuart: Well, I would probably go and get some Tylenol.

Researcher: Okay, so which one of these things would you pick out for a 2 year old?

Mrs. Stuart: Probably this one. [Mrs. Stuart picks out a pediatric suspension form of Tylenol.]

Researcher: Okay. Let's take that. Now take a look at it, and tell me how much of that you'd give your 2-year-old?

Mrs. Stuart: Probably a teaspoon. [One teaspoon = 8 Adult Extra Strength Tylenol.]

Mrs. Stuart reads at a seventh-grade level, and is employed as a nurse's aide in a nursing home; she cannot comprehend dosage instructions.

The potential for serious medical error embedded in the 4 encounters just described cannot be overstated. Especially since research shows that as much as 50 percent of the population has difficulty understanding medical instructions. Mrs. Walker, who has lupus, leaves the office not understanding her doctor's instructions. Mr. Dallas does not know when to take his medicine. Mrs. Irwin would respond to a new doctor's inquiry about her prescription drugs by stating that she was on lithium rather than Lipitor. Mrs. Stuart would give her 2-year-old "probably a teaspoon" of Tylenol suspension, 8 times the adult dosage.

Unfortunately, no one considered the barriers posed by low health literacy in the design of the modern health care delivery system. Patients with low literacy are at greater risk for medical errors and poor outcomes than they were 30 years ago. For

example, 30 years ago a patient with an acute myocardial infarction would have been hospitalized for 5 to 6 weeks, surrounded by skilled professionals who took care of every need. With new medical knowledge, drugs, and treatments (as well as cost-containment pressures), a similar patient today is out of the hospital in less than a week. Today's patients are quickly on their own, with long lists of instructions, medications, appointments, and very little support from skilled professionals. We expect patients to learn to care for themselves. How much of their "non-compliance" arises from our failure to ensure their understanding and ability to carry out the needed care regimen? How many medical errors occur because we've based our procedures and processes on the false assumption that everyone can read at a very sophisticated level?

Mrs. Walker: When you enter a doctor's office, and you're a first-time patient there, they're going to give you a clipboard with a questionnaire, am I right? Sometimes that is very discouraging for a patient who cannot read.

Mr. Dallas: I would go to the lady, you know, that passed me the thing [clipboard], and say, "Look, I need some help with this, I can't fill it out," I'd say. "I don't have time right now," she would answer. "Can you wait a while, 'cause I don't have time; you're going to be last." You're always last when you don't know.

Handing new patients with low health literacy questionnaires that ask medical history and insurance questions is like handing them an entrance test they cannot possibly pass. Some respond like Mr. Dallas, embarrassingly seeking help from the office staff help and being treated as an annoying interruption to someone's busy schedule. Some just answer "no" to everything so they can get into the office and talk to a real person about their problems. Others avoid the uncomfortable situation altogether; they avoid routine or even symptom-related office and clinic visits and present themselves at the emergency department only when they are acutely and dangerously ill. At least there someone else holds the clipboard and asks the questions. And still others, like Mrs. Walker, bring their help with them.

Mrs. Walker: My children knew how important it was to me that people did not know that I had this problem. So any time there was business to be attended to, my daughters surrounded me like a fortress.

Fortifying oneself with health-literate family members as Mrs. Walker describes can cause physicians to feel threatened, even suspicious. One physician reported at an ethics case conference on what he saw as a "hostile" family member. The daughter, he recounted, "wrote down everything I said."

Incomplete or inaccurate information on the intake clipboard can also be interpreted as coming from hostile patients. "She checked 'No Prior Surgeries,'" one physician said, "and when I examined her, I found she had had a C-section. I guess she was testing me."

There's no "right way" for a patient with low health literacy to act. Bringing help along can be misunderstood by doctors and staff. A blank stare of incomprehension seems annoying at best, hostile at worst. Trying to please, agreeing without understanding, leads to misinformation and possible medical error. Avoiding the medical encounter altogether can ultimately lead to an emergency department visit.

Mrs. Walker: The embarrassment, the shame, I mean, it's just overwhelming, it really is. It paralyzes your every thought completely to think that you may say something or something is put before you to read, and you can't read it. I mean, you live your life like that on a daily basis.

The patient's shame creates yet another barrier between the patient and physician. Shame is ever-present for people with low literacy. One recent study found that 69 percent of people who cannot read have never told their spouses. Nineteen percent have never told anyone. As physicians, we don't want to "corner" low literacy patients; we don't want to force them to admit they cannot read. But we must make it possible for them to get the accurate information they need to care for themselves safely and effectively.

Improving health literacy is one of the AMA Foundation's signature programs². The documentary film from which these dialogue excerpts were taken offers 4 steps physicians can use in all their patient encounters to alleviate some of the problems and establish a much closer patient-physician relationship.

Create a Shame-Free Environment

Offer to help, especially with paperwork. Let patients know that many people have difficulty reading and learning new information and that you can help. If you see an incomplete form, just ask the question yourself and fill in the answer, without impatience or annoyance.

Use Simple and Direct Language

Speak slowly and cover only 2 or 3 concepts at a time. Read written material aloud to the patient and underline key points.

Use the "Teach-Back" Technique

Simply asking a patient if he or she understands is not enough. Instead say something like, "Tell me what you will do and show me how you will do it when you are at home."

Invite a Family Member or Friend

Ask the patient if he or she would like to have a family member or friend along during the counseling and planning section of the visit.

Conclusion

If, as surveys indicate, as many as 50 percent of patients do not understand the doctors' explanations and the instructions on their prescriptions, then low health

literacy is a major contributor to disparity in health outcomes. And it cuts across generational, ethnic, and racial lines.

Patients with low literacy face barriers at every step in their attempts to receive health care. Physicians can ease those problems or make them worse. If we are unaware of the problem, we may interpret the patient's self-protective behavior and coping mechanisms as inappropriate or hostile and label the patient "difficult." Our instinctive withdrawal will only add to the patient's problem. To the degree that we can aid patient's understanding and compliance, we work toward better health outcomes and fewer medical errors, and we reinforce health maintenance behavior.

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FROM THE EDITOR

Commemorative Issue: Can We Talk?

Audiey Kao, MD, PhD

Attendant: The doctor will be with you in a moment.

Elaine: [looking at her chart] "Difficult?"

Doctor: Elaine, you shouldn't be reading that. So tell me about this rash of yours.

Elaine: Well it's, it's. . . . You know I noticed that somebody wrote in my chart that I was difficult in January of '92, and I have to tell you that I remember that appointment exactly. You see this nurse asked me to put a gown on but there was a mole on my shoulder and I specifically wore a tank top so I wouldn't have to put a gown on. You know they're made of paper.

Doctor: Well that was a long time ago. How about if I just erase it. Now about that rash. . .

Elaine: But it was in pen. You fake erased.

Doctor: All right Ms. Benes. This doesn't look too serious. You'll be fine.

Elaine: What are you writing? Doctor?

In this classic *Seinfeld* episode, Elaine Benes learns that she was once labeled a "difficult" patient because she wouldn't cooperate with a nurse and change into a paper examination gown. Subsequently, Ms. Benes encounters problems getting necessary treatment for her rash and believes it is because physicians consider her to be a whiner and malingerer.

Most physicians were inspired to enter the profession by ideals of healing and caring, not by visions of patient-physician encounters like the one featured on *Seinfeld*. These essential ideals are, in large part, grounded in the virtues that define the character of a good physician; honesty, selflessness, courage, compassion, and trustworthiness. We start out committed to these ideals. Unfortunately, over time and experience, many if not most of us become more cynical and jaded. Our ability to show compassion and empathy towards each patient who seeks our help diminishes. This change can be thought of as maturation, a means of coping not only with the stress of practice but also with the everydayness that creeps into much of clinical practice. But such "maturation" can go too far, leading to an accelerated decay in the idealism among those in the profession¹⁻³.

Between the early experience of medical students conducting their first "history of present illness" and the experience of the physician who dreads seeing the name of a particular patient on his or her appointment book, lies a complex socialization and development process characterized by, among other things, a language and

discourse that is spoken by the "natives." We begin to learn the language as medical students and gain proficiency in it as we proceed into residency and practice. Replete with slang and humor, the native language emerges as a natural response of people who are constantly under stress. Physicians share their war stories with each other⁴⁻⁶, as a way to commiserate, perhaps painting their patients as laughable in order to let off steam. Who could help but laugh at Elaine's predicament with her rash and chart entries? But sometimes, especially during episodes of extreme stress, physicians characterize patients in ways that are unintentionally detrimental for both the speaker and listener(s).

For example, talk filled with slang about "gomers" and "hits" can cause conflicting reactions among medical students on the wards and others who are less war-tested. Medical students are often caught between "two worlds"⁷, identifying with patients because they don't feel as though they know enough to be doctors, yet having just enough experience to understand the frustrations expressed by the intern, resident, or attending physician. Native discourse invariably creates an "outsider" versus "insider" dynamic; patients are considered less than whole people and the physician's job is not to heal, but to patch them up temporarily, hoping all the while to be lucky in the on-call roulette and not get this same "hit" again. Caught up in this discourse, students and doctors-in-training eventually become socialized into a world whose slang erodes their own compassion and the perceived humanity of their patients.

Finding remedies for the kind of professional stress and burnout that manifests in bad doc talk is not that simple. As physicians, we must first recognize that difficulties in the clinical encounter come with the territory, and that some challenging situations are never going to be adequately resolved. Nevertheless, some contributions to the problem can be identified and minimized if not eliminated. One growing source of professional frustration and dissatisfaction, for example, is the increasing amount of time spent on administrative paperwork and other non-direct patient care activities. Long work hours for residents remains a structural defect in graduate medical training that has not yet been fully addressed. With more time, physicians could respond more fully to patients' questions about prescribed treatments and medications, thus improving patient adherence and compliance. With more time, physicians could rejuvenate their bioelectricity through other activities inside and outside the medical profession. Whether it is more quality time with family and friends or time spent mentoring a medical student or new physician, a physician who is happier will undoubtedly be a better doc to his or her patients, and ultimately restore and sustain the ideals that continue to attract idealistic individuals into medicine.

Questions for Discussion

Dr. Kao claims that "students and doctors-in-training eventually become socialized into a world whose slang erodes their own compassion and the perceived humanity of their patients."

1. Do you believe that this is an inevitable response to the stress of medical education and training?
2. If so, are there ways to minimize or eliminate the negative effects of such coping responses?

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PERSONAL NARRATIVE

Commemorative Issue: 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 air-conditioning. 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.

Questions for Discussion

Dr. Davidson asks us to consider how treating dying patients and witnessing death affect the physician's physical health and emotional well-being.

1. How can physicians tap into social support from colleagues in a culture that expects them not to show signs of weakness or vulnerability?
2. How can physicians strike a balance between their own health and well being and that of their patients?

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. What follows 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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VIEWPOINT

Commemorative Issue: Guarding the Art, Edmund D. Pellegrino, MD

Karen Geraghty



"What you freely assert, I freely deny. Sustain your case!" Pointing his finger at the 12-year-old Edmund Pellegrino, the Jesuit priest at Manhattan's St. Francis Xavier school challenged the boy to think about his answer--to reason and to argue for his position based on logic and evidence, and not to be swayed by mere opinion. It was a lesson the Brooklyn-born son of Italian immigrants would carry with him throughout his life, using it to frame his compelling argument for the moral nature of medicine and the ethical obligations of physicians.

Today, Dr. Edmund Pellegrino is recognized throughout the world as one of the most prolific and passionate spokesmen on ethics and the medical profession. His argument is deceptively simple: medicine is at heart a moral enterprise founded on the covenant of the patient-physician relationship. He has spent a lifetime sustaining his case--in hundreds of philosophical writings, in his clinical teachings to countless students and, most importantly, in the care of his individual patients. His perspective has pitted him against those who would argue that medicine is a business and health care a commodity, subject to the caprices of the marketplace.

Dr. Pellegrino identifies 3 aspects of medicine which define it as a moral enterprise:

First is the nature of illness itself, because it is illness, as a universal human phenomenon, that makes medicine a special kind of human activity. The sick person is in a uniquely dependent, anxious, vulnerable, and exploitable state. Sick persons must bare their weaknesses, compromise their dignity, and reveal intimacies of body and mind. The predicament of illness forces them to trust the physician in a relationship that they would prefer not to enter and in which they are relatively powerless¹.

It is this fundamental vulnerability of the patient and the need for trust in the healing relationship that constitutes the moral imperative for the physician to serve the patient with the patient's best interest in mind.

Second, the physician's knowledge is not proprietary. It is acquired through the privilege of a medical education. Society sanctions certain invasions of privacy such as dissecting and performing autopsies on human bodies, participating in the care of the sick, or experimenting with human

subjects . . . to ensure that society has an uninterrupted supply of trained medical personnel. The physician's knowledge therefore is not private property. Nor is it intended primarily for personal gain, prestige, or power. Rather, the profession holds medical knowledge in trust for the good of the sick².

By accepting the privilege of medical education, physicians enter into a covenant to use their medical knowledge for the benefit of society.

Moreover, this covenant is acknowledged publicly when the physician takes an oath. . . . The oath--not the degree--symbolizes the graduate's formal entry into the profession. The oath . . . is a public promise--a "profession"--that the new physician understands the gravity of his or her calling, promises to be competent, and promises to use that competence in the interests of the sick³.

It is these 3 aspects--the nature of illness, the nonproprietary character of medical education, and the oath of fidelity to the patients' interests--that define medicine as a moral community and determine the ethical obligations of the individual physician and the profession as a whole.

According to Dr. Pellegrino however, the prevailing social milieu runs contrary to this fundamental nature of medicine. The legitimization of the profit motive has transformed the patient-physician covenant into the patient-physician contract. He argues forcefully that today's physicians must choose between doing good and pursuing profit. The profit motive is irreconcilable with the patient's best interests because when the covenant between physician and patient turns into a business contract, "the end result is a physician who is an employee whose loyalties are divided between organization and patient, and whose self-interests are pitted against the patient to curb costs or make profits"⁴.

Ironically, this elder statesman of the medical profession was almost not admitted to medical school. Despite his outstanding grades at St. John's University, where he graduated summa cum laude, he was not invited for interviews at any of the schools to which he applied. A letter from one Ivy League school complimented young Pellegrino on his grades but declined his application stating that he would be "happier with his own kind." Italians, said his academic advisor, were no more welcome than Jews in the major medical schools, and he might fare better if he changed his name. Pellegrino refused. His admission to New York University Medical School was due in part to his father's ingenuity. A salesman in wholesale foods in New York, the senior Pellegrino approached one of his customers who owned a restaurant near the campus of NYU and asked to be introduced to one of the regular customers. That customer--the dean of NYU Medical School--asked Mr. Pellegrino to send along his son's grade report. The junior Pellegrino was none the wiser and the rest, as they say, is history.

Since his graduation from medical school in 1944, Dr. Pellegrino's career has been as broad as his range of interests. He was president of Yale-New Haven Medical Center, chancellor and vice president for Health Science at the University of Tennessee, founding chief executive of the Health Science Center at SUNY Stony

Brook, founder of the Department of Medicine at the University of Kentucky, and president of the Catholic University of America.

But it is his work as a physician with which he most strongly identifies. At the age of 81, he is the John Carroll Professor of Medicine and Medical Ethics at Georgetown University and arrives at the office each morning by 6 AM to sit at his 60-year-old Olivetti typewriter and wage his crusade for the recommitment of the medical profession to its core ideals. A man of deep faith and conviction, he draws on the lesson of his schoolboy days to argue passionately--but with--for the importance of physicians' virtues, such as intellectual honesty and fidelity to the patient, as the ethical basis of the clinical encounter. For him the mandate for professional behavior is straightforward:

To be a professional is to make a promise to help, to keep that promise, and to do so in the best interests of the patient. It is to accept the trust the patient must place in us as a moral imperative, one that the ethos of the marketplace or competition does not expect us in our society to honor. The special nature of the helping and healing professions is rooted in the fact that people become ill and need to trust others to help them restore health⁵.

To Dr. Pellegrino, who has honored this trust for decades and has spent a lifetime defining and defending the core values of professionalism, your case has been sustained. QED⁶.



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FROM THE EDITOR

Commemorative Issue: Professionalism Reaffirmed

Audiey Kao, MD, PhD

A recent study assessed the effect of obesity on clinicians' approach to patients with abdominal pain¹. Investigators were concerned that stereotypic beliefs about obese people—that they "lack self-control and are lazy and poorly motivated"—might be shared by health professionals^{2, 3} and might adversely affect their diagnoses and management decisions. In the study, third- and fourth-year medical students were shown simulated video histories of patients who were experiencing identical symptoms of irritable bowel syndrome, but whose body sizes ranged from normal to obese.

Based on the video history, the medical students were asked how they would assess and manage these cases. No significant differences in diagnostic decisions and recommended management were related to patient weight, except for medically indicated differences, such as blood glucose monitoring and dietary counseling. However, the study revealed that medical students were less confident that obese patients would be able to comply with the nutritional and exercise recommendations, and they were less likely to want obese patients in their medical practice.

Despite its methodological limitations (such as convenience sampling and the hypothetical nature of the clinical encounter), this study sheds light on the complex and challenging issue of physician bias and its impact on medical decision making. More importantly, this study is part of a much larger inquiry into the seemingly intractable social, economic, legal, and political barriers that create a vicious cycle of health disparity that not only affects individuals but leads to a concretization of poor health across generations and geography⁴⁻⁸.

In the US, for example, the number of individuals and families living below the federal poverty line has decreased significantly over the past decade. Yet, over this same period, as the nation enjoyed unprecedented economic growth, the number of those without health insurance has reached epidemic proportions, with more than 16 percent of the US population unable to afford health insurance and millions more who have inadequate coverage. Inequities in health care on the global stage are staggering. More than 17 million Africans have died from AIDS and many millions more are infected with HIV. The impoverished nations of sub-Saharan Africa are crumbling under the weight of this modern plague. Without rapid and sustained

assistance from the rest of the world, some of the most threatened countries may not survive as nation-states.

In both circumstances, the primary contributor to disparity in health is not medical but social, involving poverty and inequitable distribution of whatever wealth and resources exist. Addressing the medical consequences of social conditions such as poverty demands participation and leadership from physicians in their roles as citizens of a civil society. As physician-citizens, we can give of our expertise to those in need, support charitable organizations, endorse those who advocate for effective social policy, donate blood, register in a bone marrow bank, and always vote. Of course, this level of citizenship takes time, money, and effort, but, inasmuch as we are among society's most affluent members, we must strive to live up to these obligations. How the medical profession mobilizes to address the national and global crisis of disparity in health and other challenges to the welfare of humanity will largely determine the vitality and robustness of medicine's social contract with civil society.

In many respects, the social contract between medicine and society is embodied in the codes of ethics that establish the standards for professional conduct for members of the profession. The world's first national code of professional ethics was created more than 150 years ago at the founding of the American Medical Association. At the time, the AMA's *Code of Medical Ethics* was considered comparable in its revolutionary stance to the Declaration of Independence⁹, another social contract that forever redefined the terms of our human existence by proclaiming that all men (and women) are created equal.

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ART OF MEDICINE

Commemorative Issue: "Departed, Jan 11, 1983; At Peace, Dec 26, 1990"

Sara Taub, MA

"Nancy Cruzan died January 11, 1983, when she was but 25 years old. Unfortunately for her, for those who loved her, and indeed for all of us, she died at a time and in a place that does not recognize her death. Consequently, she has never been buried or cremated, but instead kept in a hospital bed for nearly seven years. High medical technology has sustained only the most rudimentary of her biological processes"¹.

The inscription on Nancy Cruzan's grave marker and the message Professor Richard Momeyer conveys in a viewpoint that ran less than a year before a lower court judge ruled Cruzan's feeding tube could be removed arrive at the same conclusion: Nancy Cruzan, the person, died 7 years before her biological processes were allowed to cease and her body was let to expire. This young woman's life story was interrupted after she lost control of the vehicle she was driving on January 11, 1983. She was thrown 35 feet from the car into a water-filled ditch, where she landed face first and experienced approximately 15 minutes of anoxia. The paramedics who arrived at the scene of the accident were able to restore her heartbeat, but her cerebral cortex, seat of awareness and thought, was irrevocably damaged. Cruzan would never regain higher brain function.

Nancy, in her persistent vegetative state (PVS) could no longer experience anything of the world around her, except perhaps pain. Determined to see their daughter at peace, her parents undertook a prolonged legal struggle that led to the US Supreme Court. If they could obtain a court order to have her feeding tube removed, Nancy who was already "gone" could be put to rest. But they were confronted with the perspectives of others for whom life in any condition, sustained by whatever means, is of absolute value. To the latter, removal of the feeding tube would be morally wrong, inasmuch as it would result in the patient's death. In addition, they argued, the action would open the door to killing people who no longer seemed of use to anyone².

By the time the Cruzan case reached the Missouri Supreme Court in 1988, that court had recognized a competent person's right to refuse treatment as part of the doctrine of informed consent. For decisions to be made on behalf of an incompetent patient, however, the court required "clear and convincing" evidence that the patient would have wanted treatment terminated under such circumstances. The court decided to "err on the side of life," where what was at issue was not Nancy's "right

to die," but the right of others to take her life. Judge Edward Robertson's opinion read: "Nancy is not dead, nor is she terminally ill. This is a case in which we are asked to allow the medical profession to make Nancy die by starvation and dehydration. The debate here is thus not between life and death. It is between quality of life and death"³.

In the majority opinion of the landmark 1990 case, *Cruzan v Director, Missouri Department of Health*, the US Supreme Court broadened the ruling of the Missouri Supreme Court, though it still did not grant the Cruzans the victory they were after⁴. The Court recognized a competent person's constitutionally protected right to refuse life-prolonging treatment (including hydration and nutrition). In the case of incompetent persons, a state could adopt a standard that required "clear and convincing" proof of a person's preferences. The Court sent the case back to Missouri courts, which, later in 1990, ruled that there was sufficient evidence that Nancy would not want to be kept alive.

Beyond recognizing at the federal level that patients have the right to see their end-of-life care wishes honored, the *Cruzan* case, through the publicity it generated, brought the matter of PVS to public awareness. It asked people to give serious thought to what medical treatment, life support, and quality of life they would want should they become incapacitated. And it accelerated the development of medical and legal actions people could take to record those wishes.

In 1991, as a result of the *Cruzan* decision, the federal government enacted the Patient Self-Determination Act, which requires hospitals, nursing facilities, hospices, home health care programs, and health maintenance organizations to inform patients about their right to make forward-looking care and treatment decisions through the use of advance directives. In the years following the *Cruzan* decision, states enacted medical proxy laws, whereby individuals could designate someone to make medical decisions for them if they become incapacitated, and developed a variety of living wills, legal statements of individuals' end-of-life care wishes.

The *Cruzan* legacy was to foster the development of mechanisms for safeguarding the interests of people who become incapacitated at the end of life. Others could avert the tragedy of the Cruzans—and free themselves of some of the fear around end of life. A recent article, however, points to the fact that few people take advantage of the options the case made available to them: only 10 percent have living wills to reflect their wishes regarding end-of-life care, should they become incapacitated⁵.

Still, Nancy Cruzan is responsible for a Supreme Court decision that helped to empower people—competent and incompetent—with choices at the end of life.

"I think this is quite an accomplishment for a 25-year-old kid," her father said, "and I'm damn proud of her."

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STATE OF THE ART AND SCIENCE

Commemorative Issue: Genetic Differences - Unfair or Only Unfortunate?

Faith Lagay, PhD

When we consider health, stature, abilities, talents, and other physical and personality characteristics as integral aspects of who someone is, we seldom think seriously about whether those traits have been distributed justly or unjustly. We are accustomed to the fact that some people are more gifted than others, and unless nature has been particularly "cruel," we generally dismiss disparity with comments such as, "Lucky Alex. He's got looks and brains, and plays a mean game of (whatever)." Rarely do we apply concepts of parity and justice. But genetic information and gene therapies could change our acceptance of diversity and disparity. When we begin thinking of health, skills, and talents reductively as combinations of nitrogen bases residing on discrete segments of DNA, it is easier to think about them as "parts," assets, or even resources. And once health and other valued character traits become resources, we want to see them distributed not randomly but justly. In this light, what we once dismissed as a matter of good or not so good fortune ("lucky Alex") we now view as a matter of just or unjust, fair or unfair, distribution of traits¹.

Genetic knowledge and technology will force us to consider which inherited conditions are "normal" and which deviations from "normal" constitute a valid need for medical care. Answers to these questions form the foundation for economic decisions: To what extent does society owe "normal" health to all its citizens? To what extent should its healthier citizens be expected to subsidize care for the less healthy?

Knowledge of our genetic make-up has already begun to test existing definitions of illness and health. Is a young adult with a mutation that leads to Huntington's disease or might lead to breast cancer an entirely healthy person, a pre-symptomatically ill person, or merely, like everyone else, a potentially ill person? Does that person have a claim on medical services²? The most widely used working definition limits "medical care" to those interventions employed to prevent illness, disease, and dysfunction; treat symptoms of illness, disease, and dysfunction if they occur; and restore function that is normal for a given individual's age and sex³.

This standard medical model, as it is called, has been used to distinguish between needed medical services and optional or elective medical services. Decisions by both government and private payers about whether or not to reimburse expenses for a given medical service are generally closely tied to whether or not the intervention

is considered to be a needed medical treatment, according to the standard medical model.

Even before the Age of Genetics, some distinctions were difficult to make: the medical "need" for many psychiatric and plastic surgery procedures that could be linked, sometimes loosely, to "normal function" for one's age and sex was often disputed. Fertility clinic services are another good example. Does infertility constitute medical need? The effectiveness of a given treatment was often questioned, even though medical need was not. Could the treatment truly be considered therapy if its efficacy was still in question? Genetic information will blur these boundaries further, challenging definitions of medical need and treatment in ways that could easily create greater disparity in distribution of health care services.

In the late 1980s, when discussion of the potential for genetic intervention was still largely hypothetical, the distinction between therapy and enhancement was invoked in the hope that the standard medical model would offer a means for distributing genetic services equitably. Gene therapy should be provided and reimbursed for disorders that created medical need. Other genetic interventions—so-called enhancements—would have no claim on insurance or government coffers. Genetic enhancement would be optional and elective.

The distinction proved difficult to maintain. Borderline "hard" cases cropped up. Suppose it were possible to genetically enhance the immune system beyond what is now normal. Doing so would prevent illness and save treatment costs later on. Would that be therapy or enhancement? Would it be worthwhile for society to bear the cost of such treatment? Theorists soon recognized a more serious flaw in the therapy-enhancement distinction—the consequences its implementation would have. If enhancements were not reimbursed and only the well-off could afford it, a "genobility" would soon arise⁴. "Not only will the rich have more money than the rest of us," said philosopher Thomas Murray, "they'll be taller, healthier, better looking, and smarter"⁵. Some social intervention seems called for to prevent such an exacerbation of disparity in health-related opportunity. Can we restrict enhancement, even for those who can afford it? Should society be expected to compensate for all differences in distribution of natural assets, for each individual's good or bad luck in the natural lottery?

Recent thinking about whether and to what degree society and its individual members should bear the burden of correcting inequalities in the distribution of natural assets is summarized in *From Chance to Choice: Genetics and Justice*, published last year⁶. Its authors outline 2 positions on the question, which they call the social structural view and the brute luck view. The former view holds that society satisfies its obligation to provide equal opportunity when it compensates for defective social structures such as discrimination on the basis of race, gender, and physical disabilities. The social structural view is extended to establish a mandate for treating and preventing disease at society's expense. The argument goes like

this: Equal opportunity demands that social structures and institutions not restrict "normal" competitors in their pursuit of the goods that society has to offer. But disease can constitute just such a restriction by preventing an individual from being a normal competitor. To ensure that competitors are "normal" at the starting line, so to speak, society incurs an obligation to prevent and treat opportunity-limiting disease. That is where this view stops—at normal health for all citizens. Beyond that, the distribution of natural assets, though unequal, cannot be said to be unfair or unjust; one's bad luck in the natural lottery is just that, bad luck, and society has no obligation to provide, at its expense, remedial treatments or accommodations.

The other model—the brute luck view—maintains that people's opportunity should not be limited by circumstances over which they have no control. This view supports the notion that there can be genetically based conditions that limit people's opportunities though they may not, strictly speaking, be conditions that create the need for medical services as stipulated under the standard medical model. And society should incur the cost for correcting the unfortunate, unequal distribution of natural assets that impede one's ability to pursue opportunities. The brute luck view endorses the goal of freeing humans from opportunity-limiting effects of misfortune in general.

As is proving to be the case in so many aspects of genetic knowledge and technology, the questions being raised are not new. Rather, they give new urgency to issues that our society has not resolved. They force us to confront deeply contentious matters of individual versus social responsibility and to define what exactly our forefathers intended when they sought to guarantee citizens equal opportunity to pursue happiness, a pursuit promoted or inhibited in large part by health status.

To a large extent, philosophers and social scientists have advanced the discussion of how genetic information and technology will alter society's understanding of medical need. Physicians should want to weigh in on the discussion as well. Their specialized knowledge of human anatomy and physiology, along with their commitment to healing and human wholeness, qualifies them to speak out. The medical profession is not simply executor of society's health-related whims and wishes. Its contract requires that physicians not only apply their knowledge to the individual patient, but also help society formulate realistic concepts of health, illness, and medical need.

AMA Policy

The *Code of Medical Ethics* Opinion 2.11 states AMA policy on gene therapy. The *Code of Medical Ethics* Opinion 2.13 states AMA policy on genetic engineering.

Questions for Discussion

Genetic information is redefining what society and the medical profession consider "normal" and what departures from normal are deserving of medical intervention.

1. In a health care system with limited resources, what role should physicians play in helping to determine medical need and helping to decide which interventions make just claims on the society's health care resources?

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VIEWPOINT

Commemorative Issue: Protecting the Public: Dr. Frances Oldham Kelsey

Karen Geraghty

President John F. Kennedy, in August 1962, awarding Dr. Frances Oldham Kelsey the President's Medal for Distinguished Federal Civilian Service for her exceptional judgment in evaluating the drug Thalidomide. Dr. Kelsey was only the second woman to receive this award—the highest honor that can be bestowed upon a US civilian.

That Dr. Frances Oldham Kelsey saved countless lives and prevented numerous physical deformities of infants and children is a remarkable accomplishment in any career. More remarkable still is the fact that she accomplished this feat not through the discovery of a cure, the development of an innovative surgical procedure, or the invention of a life-saving device. Rather, it was Dr. Kelsey's professional behavior—her unwillingness to compromise the priorities of patient health and safety—that single-handedly averted an appalling tragedy nearly thrust upon an unsuspecting American public.

In September 1960, Dr. Kelsey was a newly appointed member of the Food and Drug Administration (FDA). Her very first assignment was to review the application for the drug Kevadon. Synthesized in 1954 and introduced to the market on October 1, 1957 in West Germany, the drug—known there by the name Thalidomide—was hailed as a wonder cure for insomnia¹. Non-addictive and non-toxic, Thalidomide induced sleep and was prescribed as a sedative that promised no side effects. As its popularity grew, it soon became the drug of choice prescribed to pregnant women combating symptoms associated with morning sickness. By 1960, Thalidomide was popularly prescribed throughout the world, including Europe and Canada.

The application by the Richardson-Merrell pharmaceutical company of Cincinnati to introduce Thalidomide under the brand name Kevadon to the US market reached the desk of Dr. Kelsey less than 1 month after her appointment to the FDA. Richardson-Merrell expected a routine approval for the drug. To Dr. Kelsey, the evaluation process for which she was responsible was anything but routine. Alarmed by the paucity of clinical evidence to support the drug's safety claims, she rejected the application with the request for more clinical evidence of its safety.

Of particular concern to Dr. Kelsey and her staff was one of the drug's major selling points: unlike barbiturates, which induced sleep but also induced death if taken in

large quantities, Thalidomide could be ingested in large quantities, seemingly without toxic side effects. However, Dr. Kelsey recalled a study she conducted on rabbits as a young post-doctoral pharmacologist at the University of Chicago in 1942. As a member of a team seeking to create a synthetic cure for malaria, Dr. Kelsey had noted that, although adult rabbits metabolized quinine rapidly, pregnant rabbits were less able to metabolize the drug and embryonic rabbits had no ability to metabolize the drug. Furthermore, Dr. Kelsey noted that the drug did indeed pass through the placental barrier between mother and developing fetus. Recalling those observations in reviewing the Thalidomide application, Dr. Kelsey was concerned that physiological changes such as pregnancy might change the absorption of Thalidomide, leading to harmful consequences².

Responding to Dr. Kelsey's requests for more clinical proof of the drug's safety, Richardson-Merrell submitted additional evidence, but she again rejected the application on the grounds that the reports were testimonial—not clinical—in nature. As autumn closed in on the Christmas holiday season—the most lucrative time of the year for the sale of sedatives—the pharmaceutical company, frustrated by the repeated—and in their view, unnecessary—delays, began to pressure Dr. Kelsey with visits and phone calls to her superiors. Despite the increasing pressure, Dr. Kelsey remained steadfast in her demand for thorough clinical studies demonstrating the drug's safety.

In December 1960, Dr. Kelsey read a letter published by the *British Medical Journal*³ that strengthened her skepticism regarding the safety claims of the drug. The letter was from a physician whose patients had taken Thalidomide over long periods of time and were now experiencing pain in their extremities. Concerned that this report was the first indication of toxicity effects, Dr. Kelsey continued to refuse to grant permission for marketing the drug in the US.

In the meantime, physicians throughout the world were beginning to report an unusual increase in births of severely deformed infants, particularly of infants born with the unusual condition of phocomelia. Although the first known casualty of Thalidomide—a child with severely deformed ears—was born on December 25, 1956, well before the mass marketing of the drug, the medical community was slow to recognize the link between Thalidomide and birth defects⁴. It was not until November 1961 that a German pediatrician determined that 50 percent of mothers with deformed children had ingested Thalidomide in the first trimester of pregnancy. German health authorities pulled the drug from the market, and other countries followed its lead⁴. Faced with growing evidence against the use of Thalidomide, Richardson-Merrell Pharmaceutical company withdrew its application from the FDA in March 1962⁵.

In the few years that the drug was on the world market, thousands of children were born with Thalidomide-related deformities⁶. Many did not survive their first year. Countless more miscarriages were traced to the use of Thalidomide. The damage in the United States, due to the work of Dr. Kelsey, was small by comparison, with 17

children documented to have Thalidomide-associated deformities. These children were affected during clinical trials of the drug, prior to its approval. During this investigational period, Richardson-Merrell distributed more than 2.5 million Thalidomide tablets to more than 1,000 doctors who, in turn, gave the tablets to nearly 20,000 patients—several hundred of whom were pregnant women.

By refusing to compromise her exacting standards for patient safety, Dr. Frances Oldham Kelsey prevented what could have been a tragic outcome for thousands of children in the US. For her vigilance Dr. Kelsey received the highest honor that can be bestowed upon a US civilian: the medal for Distinguished Federal Civilian Service, presented to her by President John F. Kennedy, on Aug. 17, 1962. Dr. Frances Oldham Kelsey's commitment to the primacy of patient health and safety serves as a model of professional behavior for all physicians.

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HISTORY OF MEDICINE

Commemorative Issue: AMA President's Inaugural Address, 1943

James E. Paulin, MD

Those of us whose privilege it was to serve our country during the first world war and to observe in the past few years the gradual destruction of principles for which we fought now face a new world conflict. Those of us who have an opportunity now to participate in the defense of our nation must turn our attention to a study of medical needs during the present emergency and to planning for the postwar world. Such planning should consider the rehabilitation of mankind and the establishment of a permanent peace which will assure to every man, woman, and child freedom of thought, freedom of action, and liberty. Hate, despotism, and tyranny should have no place in a postwar world dedicated to humanity. Medicine has a fundamental role and will assume an integral part in the establishment of enduring world peace. Without healthy minds and bodies, no nation of civilized men can survive or prosper. The government of the United States was founded on certain principles which establish our present mode of living, thinking, and acting. These principles were written into our Constitution by Thomas Jefferson, the anniversary of whose 200th birthday we recently celebrated¹.

The dedication of a memorial to him, in the city of Washington, pays tribute to a great man who wrote, "We hold these truths to be self evident: that all men are created equal, that they are endowed by their Creator with certain inalienable rights; among these are life, liberty, and the pursuit of happiness." He also gave expression to a guiding principle, on which a sound program of medical planning is based, when he said, "I have sworn upon the altar of God eternal hostility against every form of tyranny over the mind of man." The achievements of the medical profession in our country are an example of the wisdom of such freedom. By scientific progress in the control of infectious diseases, including the almost complete eradication of a few diseases by prophylactic inoculations, prevention of accidents, establishment of adequate public health measures, and development of better curative treatments, many years have been added to the span of life.

The present global war, with its far-flung battle fronts, has created many new and unexpected problems and has placed heavy demands on the medical resources of our country. As the war progresses in duration and in intensity, these demands will be greatly multiplied. We must be prepared to meet medical problems as they arise, to supply the immediate needs, and to formulate plans for effective service under changing conditions. In formulating such plans the American Medical Association is not an isolated unit. For the greatest good, the combined and cooperative efforts

of all organizations interested in medical care must be enlisted as participants in the program. The American Medical Association, the American College of Surgeons, the American College of Physicians, the American Dental Association, the American Nurses Association, the Association of American Medical Colleges, the United States Public Health Service, the Medical Corps of the Army and Navy, the Procurement and Assignment Service are vitally interested in the perfection of plans which will furnish better and more evenly distributed medical service for our people². I know of no time in the history of American medicine when such an undertaking could be more effectively or usefully initiated than now!

The American Medical Association has a continuing interest in every physician who has joined the military forces. Our obligation to keep physicians informed concerning matters of military importance is the publication in each issue of *The Journal [JAMA]*, under the special heading "Medicine and the War," of the activities of various agencies in national defense. Scientific achievements, as related to war, are published in *The Journal* as well as in *War Medicine*.

With the approval of the Surgeon Generals of the Army, the Navy, and the United States Public Health Service, the American Medical Association, in cooperation with the American College of Surgeons and the American College of Physicians, is now offering a series of "Wartime Graduate Medical Meetings" to all service hospitals of the Army and Navy over the entire United States. The committee in charge of this program has the help of a large group of consultants in special medical fields, as well as the aid of most medical schools. The organization of a faculty for graduate medical training contemplates making available to military organizations various types of medical instruction conducted in the form of lectures, clinics, round table discussions, and ward rounds. The program consists of 30 or more different subjects, from which each organization may choose 6 or 8 for presentation by experts. Thus medical leadership again proves itself alert to the needs of the hour.

After the cessation of hostilities, the American Medical Association, with its 123,000 members, faces the obligation of directing the intelligent planning and continuation of procedures which can be utilized in the rehabilitation of the health and medical needs of our people and, through other agencies, made available to the countries of our allies. Problems will arise in this country that will need serious consideration. During the last 2 years, through my connection with the American Medical Association, the American College of Physicians, and the Procurement and Assignment [Service], it has been clearly shown that many communities, particularly those in rural districts, have suffered because of an uneven distribution of public health facilities, hospital beds, and medical personnel. We should now be planning methods for overcoming these inequalities. Our present system for the education and training of medical students necessitates some provision which will enable them to go to rural communities and to practice there the type of medicine for which they have been trained. Arrangements may be developed whereby such communities can establish medical centers through which necessary hospital and

laboratory facilities for the diagnosis and treatment of disease will be available for all civilian needs. The Beveridge [P]lan and the report of the National Resources Planning Board indicate that the trend of medical practice inclines toward the establishment of the hospital and the medical center as the sources for distribution of medical care^{3,4}. The present emergency has accentuated the needs for such an arrangement. Even now, in areas of great distress, the local profession, in cooperation with the United States Public Health Service and other federal agencies, can arrange for the establishment of such facilities for the use of these communities.

Just now most research is concerned with problems directly related to national defense. The results of some of this can be utilized in civilian life, such as the advancement in chemotherapy and the study of virus diseases and tropical medicine. The development of new drugs for the treatment of disease and particularly the results of research in aviation, are only a few of these benefits. There is, and will be for the duration, a diminution in investigation concerning many diseases which are constantly with us, such as arteriosclerosis, heart disease, arthritis, cancer, and mental disease. Facilities and personnel must be provided to institutions and laboratories for the resumption of studies on these and other unsolved problems directly affecting the health of our people. Stimulation to undertake such work must be furnished by the medical profession to many of those returning from military service war weary and exhausted. The time is not too soon for those who are far sighted to survey the field and to lay the lines of attack on these unsolved problems.

A committee on Postwar Medical Planning of the American Medical Association working in cooperation with similar committees from the American College of Surgeons, the American College of Physicians, and other well recognized organizations should now begin to formulate plans whereby the facilities of all groups who occupy a vital part in the rendering of medical care can be most efficiently applied. When the war is over there can be offered to the people a carefully designed technic [*sic*] for the medical rehabilitation of a war sick people. There are many agencies useful in preparing such a program which undoubtedly will help in an undertaking of this nature.

Poverty, hunger, and disease know no bounds. Let us recognize our humanitarian obligation and duty, as representatives of a nation which possesses medical and other resources superior to those of any other nation in the world, to make our talents available in this emergency. Let us cooperate with all related organizations and governmental agencies interested in postwar rehabilitation to help in achieving the restoration of health and hope to a world suffering the devastating effects of a ruthless war. Such an undertaking is one of the essentials of an abiding peace. To this end the medical profession dedicates itself until the world shall again be progressing peacefully on the paths of human advancement.

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James E. Paulin, MD was an AMA President in 1943.

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