Virtual Mentor
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# Doctors and Dying

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**FROM THE EDITOR**

# Version 2.0 of the Virtual Mentor

Audiey Kao, MD, PhD

Welcome to version 2.0 of the Virtual Mentor. In addition to the new look and feel of the web site, we have introduced several new content areas to those from Virtual Mentor 1.0. We hope you enjoy this newest version and find it to be a helpful educational resource.

Produced by the Ethics Resource Center at the American Medical Association, the Virtual Mentor is an interactive, Web-based forum for analysis and discussion of ethical and professional issues that medical students, residents and young physicians encounter during their educational training. The Virtual Mentor content areas are designed to inform, awaken, and energize students and young medical professionals to engage in a learning dialogue with experts in medicine, law, humanities, and bioethics.

The owl, the Virtual Mentor's symbol, was chosen as much for its exceptional vision in dim light as for its characteristic knowing stare. The ability to discriminate within areas shaded in gray is especially useful when perusing the field and branches of ethics. Since owls, like humans, see 3-dimensionally, they are a reminder that a focused perspective lies behind that stare.

The articles and viewpoints expressed on this site are not necessarily the policy of the AMA. All submissions are subject to review and editing by the Ethics Standards editorial staff.

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

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## FROM THE EDITOR
## If You Build It, They Will Come

Audiey Kao, MD, PhD

On a recent 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 waterfalls 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 that 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 with 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. Unfortunately, this public trust can often be taken for granted. The erosion of trust may be difficult to perceive until a critical point is reached, and then rebuilding fallen trust may be difficult if not impossible. Over the last four 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 today's physicians taken collectively will shape our evolving professional landscape, and this may profoundly influence those who are considering medicine as a lifelong career.

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 five minutes, but Doc Graham replied, "Son, if I'd only got to be a doctor for five minutes, now that would have been a tragedy."

With the aim of contributing to positive changes in our ethical and professional landscape, I am proud to announce the newest version of the Virtual Mentor. To the students and teachers who have visited the Virtual Mentor in the past, I hope that you will find our new content areas informative and interesting and continue to tell your peers about this educational resource. For those who are new to the web site, I welcome your feedback and comments because Virtual Mentor's potential as an interactive forum to examine and discuss ethical and professional issues confronting medicine cannot be fully realized without your participation. Motivated by the famous line in the Field of Dreams: "If you build it, they will come," I look forward to talking with many of you on the Virtual Mentor.

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

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## CASE AND COMMENTARY

## Selling Health-Related Products from the Office or Clinic

Commentary by Kayhan Parsi, JD, PhD

### Case

Dr. Johnson practices dermatology and sees a number of patients with acne. In serious cases, she prescribes certain kinds of medications. For mild cases of acne, she sells skin cleansing products that she herself has developed. Based on personal observation, she believes that her skin cleansing products produce significant improvement in her patients' skin. Her patients are also true believers in her products and gladly pay $100 for a 3 months' supply. Prominent ads that tout the benefits of using her products are displayed in her office. Convinced that her products play a small but important role in her patients' care, Dr. Johnson sees nothing wrong with selling them directly to her patients.

### Questions for Discussion

1. Do you agree with Dr. Johnson?
2. Should she disclose her financial stake in these products to her patients?

See what the AMA *Code of Medical* Ethics says about this topic in Opinion 8.063 Sale of health-related products from physicians' office. *American Medical Association. Code of Medical Ethics 1998-1999. Edition*. Chicago, IL: American Medical Association; 1998.

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## IN THE LITERATURE
## Physicians' Attitudes about Involvement in Lethal Injection
Faith Lagay, PhD

**Farber N, Davis EB, Weiner J, Jordan J, Boyer G, Ubel PA. Physicians' attitudes about involvement in lethal injection for capital punishment. *Arch Intern Med*. 2000;160(19):1912-2916.**

Contrary to established medical society policies prohibiting physician involvement in the administration of lethal injections (see, for example, AMA Policy H-140.950 On Physician Participation in Capital Punishment), physicians do participate in such activities. In addition, a majority of physicians surveyed in this study who do not participate in such activities "condoned the actions of their colleagues in participating in cases of lethal injection for the purpose of capital punishment."

### Questions for Discussion
1. Should physicians engage in practices prohibited by professional guidelines?
2. If so, what does it mean to be part of a profession?
3. The practice of lethal injection is directly contrary to the medical profession's aim of serving the patient's best interest, although it serves the aim of the state and, perhaps, the best interest of the larger community. Does the medical profession have a social responsibility to be involved in lethal executions?
4. How should the medical profession define and balance its responsibilities to individuals and to society?

Faith Lagay, PhD is managing editor in of *Virtual Mentor*.

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## STATE OF THE ART AND SCIENCE

# Why Physicians Should Know the Legal and Ethical Issues Raised by Genetic Information and Technology

Faith Lagay, PhD

As a basic science, genetics is fascinating, exposing for study life's oldest, indeed, life's *defining* secret--the ability of a molecule to replicate itself. When medical students and physicians turn to more pressing concerns, people with illnesses and injuries and clinical problem-solving--the heady stuff of DNA replication soon fades into the background, as, of course, it must. One can't walk around absorbed in the mysteries of amino acid synthesis and be an attentive, effective clinician at the same time. And yet...

Putting genetics and its role in disease transmission entirely aside can come at a cost. Headlines announce a new gene for anything from risk-taking behavior to sexual preference every other week; designer babies are the topic of daily talk shows. It's easy for the public to get the impression that complex physical and personality characteristics are simply a matter of one genome trait transmission. No wonder couples expect the doctor to be able to assure them that their child will be healthy. Not surprising that, upon receiving a diagnosis of serious illness, the patient wants to find a genetic answer to the question "why me?"

These desires for genetic answers and healthy babies--and the desire to blame someone if the answers or babies are less than satisfactory--can mean legal and ethical entanglements for physicians. Three areas with legal and ethical issues of note are recognizing when prenatal testing is prudent, deducing the possibility of genetically transferred illness from a patient's family health history, and knowing when a patient's diagnosis could imply risk to present or future offspring. (There are of course many other areas where genetics intersects clinical practice, but these 3 present much to consider for starters.)

### Challenging Physician Advice on Genetic Testing

These problem areas are noteworthy because they represent instances in which physicians have been sued by parents or family members who claim they would have acted differently had the physician warned of the possibility of genetically transmitted disease.

The Munros had a child afflicted with Tay-Sachs. They sought damages from the university physician who had ordered some genetic tests but not the test for Tay-Sachs (*Munro v. Regents of the U. of Calif., 1989*). The family history had satisfied the physician that the couple had no Jewish ancestry. The court ruled in the physician's favor; the plaintiffs appealed, and the appeals court affirmed the original judgment.

Perhaps to protect itself against wrongful birth cases such as this, the California Department of Health Services, Genetic Disease Branch has an expanded alpha-fetoprotein (AFP) screening program. In association with consumer education, clinicians present pregnant women with a booklet explaining the AFP test, the meaning of results, and the conditions for which the test *does and does not* screen. The booklet contains a consent/refusal form that the woman signs and the physician retains in her file. The AFP test, of course, does not screen for Tay-Sachs, but it does constitute a first screen for many abnormal conditions, including neural tube defects, Down syndrome, and trisomy 18. And it alerts women to the potential need for other types of testing such as amniocentesis.

## Courts Disagree on the Physician's Duty to Warn

Heidi Pate's mother died of medullary thyroid cancer. Three years later, Heidi Pate was herself diagnosed with medullary thyroid cancer. She sued the physician, Dr. Threlkel, (*Pate v. Threlkel, Florida, 1995*) and other health care providers for not telling her that her mother's disease was genetically transmittable, arguing that had she been tested 3 years earlier, she would have taken preventive action. The jury decided that, in any circumstance in which the physician has a duty to warn of a genetically transferable disease, that duty is satisfied by warning the patient.

A New Jersey superior court came to the opposite conclusion in a case also involving the physician's duty to inform family members of a patient's genetically transmitted disease (*Safer v. Pack, New Jersey Superior Ct.,1996*). Donna Safer's father died of colon cancer when she was 10 years old. Her father's physician (Dr. Pack) did not tell his patient's wife (Safer's mother) of her husband's exact diagnosis or that it might have a hereditary component. Thirty-six years later, Donna Safer became ill with colon cancer. She obtained her father's medical records and, upon discovering that he had polyposis, sued the estate of the now-deceased Dr. Pack. Here, the court decided that the duty to warn may not be satisfied in all cases by informing the patient. It may be necessary at some stage to resolve a conflict between the physician's broader duty to warn and his fidelity to the expressed preference of the patient that nothing be said to family members about details of the disease.

As the decision in the Safer case indicates, recognizing that your patient has a disease that places offspring at risk is not the end of the problem. It can be the beginning, given the physician's confidential relationship with the patient. That quandary is the topic for another "Genethics" column.

Faith Lagay, PhD is managing editor in of *Virtual Mentor*.

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## HISTORY OF MEDICINE

## Rembrandt's Anatomy Lesson of Dr. Tulp

Karen Geraghty

As an introduction to the Historical Postmortem, Rembrandt's famous portrayal of the *Anatomical Lecture*, painted in 1632, seems metaphorically appropriate. Although four centuries removed from the lecture halls of 21st century medical students, it nonetheless captures the essence of medical understanding. Close observation and physical examination of the corpse are necessary in order to see beyond the obvious appearance of the human body to discover the workings and relationships of underlying organic structures and the pathologies responsible for disease and illness. The corpse, lying dead and silent, must be poked, prodded and dissected for the knowledge and answers it reveals to the living.

A closer look at the portrait reveals a text partially hidden in the shadows at the foot of the dissecting table. Representing perhaps, the assumed knowledge that guides their inquiry, the text and its contents are implicitly challenged by the actual dissection itself. The light draws your eye to the corpse and to the faces of the lecturer and students focusing intently on the partially dissected arm.

In the spirit of the *Anatomical Lecture*, Historical Postmortem will poke and prod the corpus of medical history in order to challenge and inform our assumptions about medicine and attempt to view the facts in a new light. In doing so, we may see how the seemingly "dead hand of history" continues to shape our present and future.

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## ART OF MEDICINE

# The "Serpent Cigarette"

Karen Geraghty and Sara Taub, MA

November 16th marks the American Cancer Society's twenty-fourth annual Great American Smoke Out to encourage smokers around the nation to suspend their habit for at least one day, in the hope that they will quit permanently.

As this 19th century image conveys, the ill effects from the use of tobacco products has been a concern for centuries. In the image, the young man struggles with his desire to light the cigarette while at the same time fighting to free himself from the the grip of the "Serpent Cigarette," which coils around his body, threatening to slowly squeeze from him his money, his health, and, ultimately, his life.

In 1883, around the same time as this image was published, the very first issue of the *Journal of the American Medical Association* included a brief article entitled "The Effects of Tobacco Smoking in Children." Despite mounting clinical evidence regarding the health dangers associated with smoking over the last 120 years, statistics for tobacco-usage among youth in the year 2000 remain staggering-- 90% of new smokers are children and teenagers, with over 3,000 new smokers a day (over 1 million per year). The serpent continues to move quietly and lethally, tightening its grip on increasing numbers of children and teenagers.

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**PERSONAL NARRATIVE**

# "You're Doing What?"

Robert Davidson, MD, MPH

That was the response I heard most frequently when I told my colleagues at the University of California, Davis, School of Medicine that I was leaving to go to work for the US Peace Corps in Eastern Africa. After the initial shock, and a few questions about where and how my wife and I would live, there was unanimous support for the decision. Frequently, a colleague would say, "Wow, I would love to do that." I was tempted to say, "Well, why don't you?" but realized that a decision like this was not and should not be made on the spur of the moment.

The "why" question was and continues to be the hardest for me to answer. I had a great job at U.C. Davis. I enjoyed teaching medical students and residents and my practice through the Family Medicine center was successful and interesting. However, I had a growing feeling that I had lost, or was losing, the desires which pushed me into medicine as a profession in the first place. I was just a bit too comfortable. I missed the feeling of commitment and job satisfaction that I had when I started my career working in an OEO (Office of Economic Opportunity) neighborhood health center in a barrio section of Los Angeles. I needed a challenge.

I need to tell you a bit about what I am doing. On February 1, 2000, I began working for the US Peace Corps as the Area Medical Officer for Eastern Africa. I am a hired employee of the US government and need to emphasize that the real heroes of the Peace Corps are the volunteers who dedicate 2 to 3 years of their lives to working in countries where they are needed.

My primary responsibility is the health of the volunteers who are working in Eastern Africa. I cover an ever-changing area that currently includes 5 countries: Kenya, Tanzania, Malawi, Madagascar, and Uganda. The area expands or contracts as the political climate changes in the nations of Eastern Africa. Ethiopia, for example, had one of the larger Peace Corps activities before the recent political unrest and destabilization resulting from its conflict with Eritrea, another previous Peace Corps country. When the safety of its volunteers can no longer be reasonably assured, the Peace Corps closes down in that country until things settle a bit.

Each Peace Corps country has a medical office as part of the core support for volunteers. For the most part, advance-trained nurses and/or physician assistants staff these. The area physician serves as consultant, mentor, and quality assurance person, and fulfills a host of other duties for the country medical staff. There are 4 area physicians in Africa, their areas roughly determined by dividing the country by the 4 points of the compass. We use regional hubs such as Johannesburg, South Africa and Nairobi, Kenya, for treating volunteers who need levels of care greater than that available in their countries. We can, and do, send volunteers back to the United States on med-evacs when they need levels of care not readily available in Africa.

A misguided and somewhat cynical colleague said before I came that all I would see would be healthy 20-year-olds with sexually transmitted diseases. He could not have been more wrong. I have seen more pathology and interesting health problems in the first 6 months than I would see in years back in the States, even at a major medical center like the U.C. Davis Medical Center. The majority of problems can be roughly divided into 3 categories: stress-related disorders, infectious diseases including tropical diseases, and trauma. I will talk more in the future about some of the tropical diseases we see and some of the inherent problems in trying to avoid them. Much time and effort are spent in preparing the volunteers to avoid health problems "in country" and stay healthy. For the most part this preparation is effective.

However, I have seen a number of unexpected health problems that are initially diagnostic dilemmas, especially without the ready availability of modern imaging techniques now standard in the United States. One such dilemma concerned a 40-year-old woman volunteer whose disorder was ultimately diagnosed at George Washington University Medical Center as a pericardial thymoma. Another case involved a 62-year-old man with cancer at the esophageal-gastric junction. In a recent case, a young volunteer complained that his "belly button" hurt and was pushing out. Examination showed a huge peri-umbilical abscess, which drained 200 cc of foul-smelling, probably anaerobic, pus. He responded well to incision, draining, and antibiotics. My impression is that the base problem is a congenital non-closure of the embryologic vitello intestinal duct that has been asymptomatic up to now. He is winging his way to Washington, and I am sure the surgery residents will enjoy and learn from caring for him.

The Peace Corps volunteers today are far different demographically from their counterparts in the early days of the Corps. The age of the volunteers in my area ranges from 24 to 74, with a large number in their 50s. They bring with them the usual diseases for their age cohort. No longer is a diagnosis of type II diabetes, asthma, or hypertension a cause for rejection from Peace Corps service. What has not changed is the wonderful sense of dedication and challenge that has always motivated volunteers to select Peace Corps service. I have enjoyed all the patients I have cared for, but the sense of dedication and commitment I find in the volunteers makes them special.

I need to put our living situation in perspective. The Eastern Africa hub is Nairobi, Kenya. This is where we live. Nairobi is no longer an easy place to live. Many people who lived here in the past speak fondly of the "good old days" when Nairobi was considered a great place to live. Certainly the weather is wonderful and the scenery is spectacular. Nairobi is a cosmopolitan city with fine restaurants and modern shopping centers and supermarkets. However, the constant threat of robbery makes it difficult to relax. United States nationals live in virtual fortresses complete with iron bars on the windows, wrought iron security gates on all doors, a wrought iron security grate to isolate our sleeping quarters from the rest of the house, perimeter security lights, and 24-hour security guards at each compound. We carry a radio link to the US Embassy at all times for use in an emergency. Home invasion robberies, street muggings, and the more recent trend of car jackings detract considerably from enjoyment of the city.

More recently, the 2-year drought has produced severe water and, therefore, electricity shortages. On alternating days, we have no electricity from 6:00 a.m. to 6:00 p.m. or from noon to midnight. Water availability is variable. Most homes have plastic tanks to store water, but to be of much value these require electric pumps and electricity. One becomes so dependent on modern appliances in the US that the transition to kerosene lamps and 2-burner gas ranges for cooking seems like a hardship. But it certainly offers the opportunity to return to a simpler way of life. I have found it fun to do puzzles by lamplight, and easy to adjust to a sleep schedule from 8:30 p.m. to 4:00 a.m. so I can have a couple of hours of electricity in the morning.

I am not quite sure how my reflections on working as a physician in Africa will be received by my colleagues and medical students. My experiences are far different from those of the many US physicians who give of their time and talents in the many mission hospitals in Africa. Yet it is certainly helpful to me to reflect on this experience, and perhaps by sharing it with you I can help you contemplate why you chose medicine and what you want from your career. In future segments, I will talk more about my impressions of the health problems in the host countries and of the medical care systems and physicians in Eastern Africa. I will also try to give some personal thoughts and observations as a US physician practicing in Africa. For now, I need to sign off before the electric.i.t.y.. g.o.e.s... o.u...

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

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## PERSONAL NARRATIVE

## Through the Patient's Eyes: Alternative Healer

Faith Lagay, PhD

What is it like to experience a debilitating, potentially life-threatening illness or to encounter the health care environment, perhaps for the first time, from a position of vulnerability? In reading patients' stories, physicians can come to see themselves and the often times unsettling medical encounter through others' eyes. When patients - including physicians who have become patients - voice their most intimate thoughts, feelings, and reactions, much can be learned.

### November Patient Story

Gianakos D. Alternative healer. *Ann Intern Med*. 2000;133(7):559.

Faith Lagay, PhD is managing editor of *Virtual Mentor*.

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## PERSONAL NARRATIVE

## 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, among presentations about courses and what books to buy (and those not to) and exploring the social life of Buffalo (one exists!), professionalism was a recurrent theme. Professionalism is such a hot word in medicine and medical education nowadays, that sometimes I feel it can be overused, but not here. Medical schools offer a professional education, and medicine in the 21st century is struggling to redefine itself as a profession in the midst of phenomenal scientific advancements and difficulties adjusting to a managed care model. During our lives as med students, professionalism will likely be redefined and refined many times before a "permanent" definition is formed. In many ways, studying or practicing medicine now has the thrills and dips of a roller coaster ride.

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, her medical or social history, nor could we ask her questions: we possessed her physical being, but little of a total person.

Though I have spent barely a month in medical school, I already sense that I have learned a great deal of information about anatomy, cells, biochemistry, and epidemiology. In 1 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. Examining the body from this perspective is something I am not entirely comfortable with. 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. As the humanism so critical to the successful and professional practice of medicine is incorporated into my development as a competent physician, those integral bits of knowledge that now lie in darkness will surely come into focus.

David R. Block, MD was a 1999-2000 Fellow at the Institute for Ethics at the American Medical Association. He is currently a first year medical student at the University at Buffalo School of Medicine and Biomedical Sciences.

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**VIEWPOINT**

## What Is Advance Care Planning?

Faith Lagay, PhD

Advance care planning is a process, not an event. It is the process of planning for future medical care in the event that the patient is unable to make his or her own decisions. During this process patients explore, discuss, articulate, and document their preferences. The process helps patients identify and clarify their personal values and goals about health and medical treatment. They identify the care they would like, or not like, to receive in various situations. Patients also determine whom they would like to make health care decisions on their behalf in the event they cannot make decisions for themselves.

Ideally, advanced care planning is a process of structured discussion and documentation woven into the regular process of care that is reviewed and updated on a regular basis. It is designed to ensure that a patient's wishes will be respected in the event that the patient is unable to participate in decision making.

The physician plays an important role in initiating and guiding advance care planning. He or she needs to be involved in some, but not all, stages of advance care planning in order to understand the patient and establish a trustworthy shared decision-making process.

The patient, proxy, and family can do most of the work without the physician if they are given a worksheet and background materials.

Some physicians choose to have other members of the health care team assist them with advance care planning (eg, a nurse, physician assistant, or social worker). Once the patient's ideas have been gathered, the physician can focus on the core discussions in direct meetings with the patient, proxy, and family. Preparatory work will permit these discussions to be to the point and effective. Once the core discussion has taken place, invite the patient to reflect on things and then return at a subsequent visit with decisions to review.

Terms used in advance care planning can be confusing.

- *Advance directives* are prior directives by the patient for his or her health care. Advance directives fall into two categories, those that have to do with instructions for medical care and those that have to do with designating a proxy for the patient.

- *Instructional directives* for care can be re-corded in a number of types of documents.
- *living will* is usually a simple statement asking for no heroic care in case of poor prognosis. A personal letter may also be used.
- *values history* is a statement of values regarding health care in life-threatening illness situations.
- *medical directive* is a set of instructions based on likely scenarios of illness, goals for care, and specific treatments, combined with a general values statement. It is also combined with a proxy designation section.
- A person who is empowered to make decisions in the place of the patient is sometimes termed *health care proxy* or *durable power of attorney for health care*.

### Steps for Successful Advance Care Planning

Five steps are identified for successful advance care planning. These steps are explained in greater detail in the handbook for the project to Educate Physicians on End-of-life Care (EPEC).

**Step 1:** Introduce the topic
**Step 2:** Engage in structured discussions
**Step 3:** Document patient preferences
**Step 4:** Review and update the directive
**Step 5**: Apply directives to actual circumstances

### Common Pitfalls of Advance Care Planning

Anticipating and avoiding the common pitfalls is essential to a successful advance care planning process. There are several.

**Failure to plan:** Do not avoid advance care planning. Too often, situations occur and decisions are made without the benefit of advance care planning. Be proactive. It is easy to forget the central role of the patient, and easy to forget the importance of the proxy. Involve both early and often.

**Proxy not present for discussions:** Do not leave the proxy decision maker(s) out of the initial discussions with the patient.

**Unclear patient preferences:** Vague statements can be dangerously misleading. Be sure to clarify patient preferences if they do not seem clear to you or to the proxy. For instance, patients who make statements such as "I never want to be kept alive on a machine." should be asked to clarify whether their wishes would change if their condition were readily reversible, or if their prognosis were unclear.

**Discussion focused too narrowly:** Avoid isolated do-not-resuscitate (DNR) discussions; they often create chaotic emotions and thoughts in patients who have to imagine imminent death to make the decision. A DNR discussion is usually an indication that other palliative goals and measures should be considered in the context of a range of scenarios.

**Communicative patients are ignored:** Sometimes people assume that what a patient wants in the present is what he or she indicated for future possible scenarios. As long as the patient is competent, talk to him or her. An impaired patient may still be able to express wishes at some level. In such cases, both the advance directive and tangible evidence of the patient's current wishes should be taken into account.

**Always read advance directives:** Sometimes physicians assume that they know what is stated in an advance directive. This is a mistake. Advance directives can be for aggressive intervention, comfort care, or a wide range of specific views and must be read and understood.

**Note:** This information on advance care planning is excerpted from Module 1 of the Participant's Handbook for the project to Educate Physicians on End-of-life Care (EPEC). The complete text is available online.

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**Advance Care Planning**
EPEC Project, The Robert Wood Johnson Foundation, 1999.

Faith Lagay, PhD is managing editor of *Virtual Mentor*.

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## VIEWPOINT

## Health and Mental Competency of Presidents

Audiey Kao, MD, PhD

- Until 1967 there was no procedure in place for assessing the physical or mental capability of the President to carry out the duties of office? Indeed, when President Woodrow Wilson suffered a paralytic stroke in 1919, his inner circle, consisting of personal physician, private secretary, the first lady, and the Secretary of State, kept the President's condition a secret until his presidency ended in 1921.
- The possibility that such a presidential secret could be kept again diminished with the adoption of the 25th Amendment to the US Constitution in 1967. The Amendment states that "whenever the Vice President and a majority of either the principal officers of the executive departments or of such other body as Congress may by law provide, transmit to the President pro tempore of the Senate and the Speaker of the House of Representatives their written declaration that the President is unable to discharge the powers and duties of his office, the Vice President shall immediately assume the powers and duties of the office as Acting President." The Amendment, however, did not explicitly define the relevant types and degrees of "disability," nor did it designate who should make the medical determination that might ultimately lead to a political decision to relieve the President of his Constitutional authority.
- Lt. Colonel Richard Tubb, Air Force Academy Class of 1981 and a graduate of the University of Wisconsin Medical School specializing in family practice, currently serves as a White House physician. It would seem that the White House physician would be the person best equipped to make an informed medical determination concerning the President's ability to dispense the duties of his office. But many argue that an independent panel should make this critical medical determination.
- Maintaining the proper balance between medical privacy and the public's right to know can be tricky when the patient is the President. Over time, privacy has given ground to right-to-know, and the expectation has evolved for more and fuller disclosure concerning the health of both the President and those running for the office. Some claim, though, that there must be limits on medical disclosure, arguing that the President and candidates for president deserve a reasonable degree of privacy when it comes to their medical records [1].

## References

1. Annas G. The health of the President and presidential candidates: the public's right to know. *NEJM.* 1995;333(14):945-949.

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## VIEWPOINT

## Death and Dying Come to Primetime TV

Sara Taub, MA

Bill Moyers' PBS series "On Our Own Terms" looked in on real people facing end-of-life decisions. The 4 part, 6 hour program, had an implicit question for viewers to contemplate: "What kind of care do *you* want at the end of your life?

Part II of the program reflected on the importance of that question by introducing viewers to the dying process of several patients; some determined to make their last moments more tolerable, others unable to speak for themselves. The patients' experiences illustrated how, even in the absence of effective medical treatment, choices about how to care for a dying person remain. Health care teams, hospice, and loved ones try to address physical, emotional, and psychological needs in an effort to make people who are dying more comfortable. Direct feedback or prior input from the patient about end-of-life care preferences certainly helps in this attempt to allow individuals to die on their own terms. The following vignettes, taken from the program, contrast 3 individuals' involvement in end-of-life planning.

### "It' s her life. She' s going to lead it."

Ms. Curr is dying from late-stage ovarian cancer. The viewer meets her after she has decided to stop chemotherapy and to receive comfort care measures only. Homebound, she will lead the remainder of her life as she sees fit, with her family and her garden. Dr. Sean Morrisson, one of her physicians and a pain management specialist, has helped her plan the process that lies ahead in a way that reflects her wishes. Hospice will visit Ms. Curr at home regularly to assess whether she can be made more comfortable. Dr. Morrisson will continue to care for her if she needs a doctor or if she changes her mind about wanting to be at home. "There is no right way to do this," we hear him tell her. Still, there is a sense that with the support of all her caregivers, she is achieving the dying process that is right for her.

### "It would be nice to know if he wanted this."

Upon arrival to the emergency room for an episode of acute illness, Mr. Gentry went into respiratory arrest. With no information immediately available about possible advance directives or family contacts, the decision was made to intubate him though he could not provide consent. In the words of one of his physicians, "treat the acute problems first, ask questions later." We first meet the unconscious patient in the intensive care unit. According to the hospital team, his prognosis is dismal; life support, as they see it, is prolonging his dying. Mr. Gentry' s brother and niece have been convened for a family planning meeting, at which they are presented with the question about whether to withdraw care. They are asked to provide substituted judgment for their incompetent relative or to anticipate what course of action the patient would want if he could comment on his situation. Uncertain as to what the patient would do in this instance, the providers and the family can only guess how he would have chosen to orchestrate his dying.

**"Comfortable and pain free"**

In a nursing home room, 3 daughters introduce us to their mother, Ms. Lane, a woman with late-stage Alzheimer's who has suffered 3 strokes. They describe how, despite the impossibility of communicating with her coherently, they come to visit her daily: to talk to her, feed her, and make certain that she is being cared for respectfully. What they want for their mother is that she be made comfortable and pain free. Given her advanced disease status, they oppose the future use of tubes or machinery, which they consider dehumanizing. Ms. Lane's dying process reflects the values of her daughters who want to promote what they think is in their mother's best interest.

Where Ms. Curr actively participated in determining how she would spend the rest of her life, the 2 other patients lacked decision-making capacity and advance directives. No one felt able to infer what choices Mr. Gentry would have made if he could have commented on his current situation or what values he would have used in the process. Family and members of the health care team had to reach decisions for the patient based on what they consider to be in his best interest. Ms. Lane's daughters directed their mother's care according to their notion of what was acceptable, partly informed by values the patient once held.

According to a Gallup poll a majority of Americans would like to die at home, free of pain, and surrounded by loved ones. The discrepancy between this stated preference and reality--most people continue to die alone in the hospital, experiencing discomfort--is regrettable. The program made a good-faith effort at laying out different approaches to end-of-life care and at generating a discussion with the general public about end-of-life planning--, a first step toward reducing the gap between how we would like to die and how we do.

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## VIEWPOINT

## Gary LeRoy, MD

Audiey Kao, MD, PhD

As an African-American, Dr. Gary LeRoy grew up in Dayton, Ohio, at a time when people were segregated based on the color of their skin. "It was an unspoken law that if you were African-American, you stayed on the west side. I was told never to go on the east side of Dayton. I couldn't live with that. There are poor people on this side of town and that side of town, and my challenge is to bridge that gap and dispel those rumors that cross the river." In many respects, Dr. LeRoy's career is marked by his tenacity to overcome barriers and make positive changes in his community.

As a young man, Dr. LeRoy never thought about attending college, let alone becoming a physician. Instead, he intended to find an assembly line job after high school. But, his guidance counselor convinced him to go to college, and he eventually enrolled in and graduated from Wright State University. He credits his success to the guidance that he received from his professors and other "angels" who ultimately inspired him to apply to medical school. Dr. LeRoy graduated from Wright State School of Medicine, after which he completed a residency in family practice.

As the medical director of the East Dayton Health Center, Dr. LeRoy cares for a poor community in Appalachia, many of whom are white. "At first, they didn't feel comfortable with a black man taking care of them. But patience is like little drops of water that gradually wear away the stones of misconception. Now, I have patients that will tell family members [that they refuse to see any other doctor]." In addition to his clinical work, Dr. LeRoy chairs the Ohio Academy of Family Physicians Minority Health Affairs Committee offering his experience and guidance to minority physicians, residents, and students. He also sits on the Board of Directors for the Wright State University Alumni Association and is the Chair of the Ethical Standards Committee at Wright State's School of Medicine

For his many contributions, Dr. LeRoy was named one of *The 50 Most Positive Doctors in America* (ed. Mike Magee, MD). Adding to this well-deserved honor, we are proud to present the Virtual Mentor Award to Dr. Gary LeRoy for his commitment to the physical and social health of his community.

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