

Virtual Mentor

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FROM THE EDITOR

Pay it Forward

Audiey Kao, MD, PhD

"Think of an idea for world change, and put it into action."

In response to the above homework assignment, Trevor, the 12-year-old hero in the book-turned-movie entitled, *Pay It Forward*, comes up with an intriguing idea. He describes it to his mother and teacher this way: "You see, I do something real good for three people. And then when they ask how they can pay it back, I say they have to pay it forward to three more people each. So nine people get helped. Then those people have to do 27. Then it sort of spreads out, see. To 81. Then 243. Then 729. Then 2,187. See how big it gets?"

Trevor puts his idea into action by providing a homeless man with a place to sleep in his garage. This act ultimately leads to the first scene in the movie where a stranger, a high-powered litigation lawyer, hands over the keys of his new Jaguar to a reporter whose car was just demolished. Questioning the stranger's motivations, as many of us probably would have, the reporter is determined to get the story behind this seemingly irrational act. In the end, the reporter gets his story. But the film's ending is bittersweet—Trevor dies, although his idea lives on.

While Trevor's tale is fictional, the notion that 1 person or act can make a difference appeals and resonates with our better selves even in a time when hopelessness and destruction are not in short supply around the world. In fact, a [Pay It Forward Foundation](#) has been established to "educate and inspire young students to realize that they can change the world and provide them with opportunities to do so."

At its recent Annual Meeting in Chicago, the American Medical Association (AMA) officially launched WorldScopes, the first in a series of *Caring for Humanity* projects intended to bring the ideals of the [Declaration of Professional Responsibility](#) to life. Over the next 2 years, the AMA intends to collect 100,000 stethoscopes and then distribute them, with the help of humanitarian organizations, to health care professionals in communities where medical resources are scarce. We recognize that no single project can solve the underlying inequities and disparities in health and health care around the world, but we hope this project, with all its simplicity, will serve as a springboard for future actions from individuals and institutions of medicine.

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

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CASE AND COMMENTARY

The Letter and Spirit of a Directive, Commentary 1

Commentary by Mark G. Kuczewski, PhD

Case

An 83 year-old woman, Mrs. U, was admitted to the hospital from a personal care home due to a stroke with left-sided weakness and aphasia. She had a history of Parkinson's disease, coronary artery disease, and a prior stroke several years ago. The day after admission she was seen by a neurologist who noted dysarthria (ie, problems of speech articulation due to muscular control disturbance) and a severely diminished gag reflex. She was not ambulatory but did respond to right-sided commands. Speech and physical therapy were recommended.

A speech therapist also recommended that Mrs. U not ingest anything by mouth due to her swallowing difficulties. A Dophoff (nasogastric) tube was inserted for feedings. Mrs. U subsequently pulled out the tube twice; the neurologist's notes indicated she would need a peg tube (inserted into the stomach) to survive. At that time, Mrs. U's daughter June, who lived nearby, refused the peg tube but eventually agreed to reinsertion of the nasogastric tube as a temporary measure.

A social worker spoke at length with June, who, wanting to follow the wishes expressed in her mother's advanced directive, was reluctant to agree to any feeding tube at all. Mrs. U's advanced directive, typical of the living will forms used in Pennsylvania, stated she would not want artificial nutrition and hydration if she were in a terminal condition or permanently unconscious. The next day June, still uncertain, was advised to confer with her sister Donna, who lived out of town, in hopes that they would clarify their mother's intent. Mrs. U's family physician also spoke to June, explaining to her that a peg tube was not an "extraordinary measure."

Due to uncertainty about the patient's decision-making capacity, a psychiatrist was consulted. The psychiatrist described the patient as disoriented and lacking insight, with impaired cognition. He deemed her not competent to make decisions at that time. The social worker again talked with June, who had spoken with Donna. The daughters were in agreement in their refusal of any type of tube feeding for their mother.

During the next 2 days, the psychiatrist examined Mrs. U again, finding her mental status to have gradually improved. She appeared to understand what a peg tube was and that it was necessary to provide her nourishment. He declared her capable of decision making at that time.

The hospital's ethics review group, summoned to consider the case, determined that the living will was not applicable at this time because Mrs. U was neither terminally ill nor unconscious and was found competent by the psychiatrist. In light of this, they contacted Mrs. U's daughters and arranged a conference call for the next morning. After receiving the new information, June and Donna differed in their opinions.

In the meantime, the patient was given a barium swallow. It showed that it was still not safe for her to take nutrition orally. Due to the psychiatrist's most recent evaluation of the patient's decision-making capacity, she was referred for a surgical consultation. The patient thought she wanted a peg tube but indicated that she also wanted family agreement. Her daughters were again contacted with this information and presented with Mrs. U's 3 treatment options: (1) placing a Dophoff tube and physical restraints to prevent the patient from removing it, (2) placing a peg tube with no restraints, or (3) transfer to another facility for evaluation and treatment. Shortly thereafter June, who voiced opposition to artificial feeding in the conference call, telephoned the social worker to say she now agreed with her sister on insertion of the peg tube.

The peg tube was inserted the same day. Within a few days, the patient was stable and was transferred to a skilled nursing facility.

Commentary 1

This kind of case raises myriad questions, and there are innumerable points on which one can focus.¹ However, it is all-important to be clear on the general framework and the principles that should guide decision making in such situations. Otherwise, we run the risk of invoking legalisms as a smoke screen for one's own preferences or prejudices.

A competent patient has a virtually unlimited right to refuse treatment. A patient who lacks decision-making capacity, ie, is incompetent, has the same rights as a competent one, but the manner of exercising those rights is, of necessity, different.² Usually these rights must be exercised through a written directive or through family members' attempts to determine what the patient would want if she possessed her decision-making capacities. These general principles must be kept in mind when dealing with such concepts as "ordinary treatment," the integrity of the medical profession, and the nuances of state laws. These concepts and regulations cannot trump a patient's fundamental rights. Rather, they are devices to assist in interpreting and respecting patient wishes.

There seems to have been little doubt in the minds of the health care team members that Mrs. U lacked capacity to make treatment decisions early in the process. Thus, her daughter(s) were appropriately contacted to act as surrogate decision makers. They made their initial assessments of the situation based upon their mother's advance directive. The treatment team did well to explain that the directive could not be applied in a simple deductive manner to the present case. The conditions

specified by the form did not obtain to this case. Nevertheless, the daughters are still ethically entitled to accept or refuse treatment for the patient based on what they believe their mother would or would not have wanted. We ask them what their mother would probably say to us if she could sit up and speak. Certainly, the values that caused their mother to create an advance directive are relevant to this decision-making process even if the directive is not. The health care team seemed to be unhappy with the decision that the daughters arrived at under such specifications. Thus, they directed the attention to a variety of other issues such as legalisms surrounding the living will and questions concerning "ordinary treatment."

It becomes much easier to sympathize with the health care team once Mrs. U appeared to regain partial decision-making capacity. One cannot in good conscience deny life-sustaining treatment to a patient who seems to be consenting to these measures. A presumption in favor of treatment must then govern action. However, good faith requires asking whether the patient is making a decision out of momentary fear, disorientation, or a desire to please the treatment team. That the patient gave some indication that she wanted her daughters' agreement on this decision should give the treatment team pause about their steadfast opposition to the daughters' decisions. The team probably would have done well to bring the patient and family together for a conference on treatment goals and the particular decision at hand. This might have helped further to restore the patient's decision-making capacity.

Understanding the decisions of the treatment team requires separation of motivations and reasoning. In this case the health care team seems to be motivated by a desire to provide treatment to the patient. Like many health care professionals, they find it very difficult to allow a patient to die who is at least semi-conscious. Those involved in the case seem to have a bias in favor of administration of nutrition and hydration, and, once a patient regains some consciousness, they view refusal of this treatment as "starving" the patient. Of course, it is also quite possible that placing this tube may not help the patient at all.³

Health care team members are entitled to their feelings and to some extent, to determinations of their standards of care. They are free to try to persuade the patient and/or her surrogate(s) to choose in accord with the judgments of the team. However, health care professionals have an obligation to be sure that they do not give misinformation or spread misunderstanding in an effort to persuade. This happened in regard to 2 points:

1. Ordinary treatment: Legally speaking, patients have a right to refuse all treatment. It does not matter whether one calls it "ordinary" or "extraordinary." From a legal standpoint, introducing this distinction into the process was a red herring. Ethically speaking, their use of the term was also mistaken. One cannot simply call artificial nutrition and hydration "ordinary." Whether a treatment is ordinary or extraordinary depends on whether it is a measure that is "proportionate" to the case.⁴ That is, does it

bring benefits that outweigh its burdens? In this case, the answer is not obvious. This question is exactly the point at issue between the health care team and the patient's daughters.

2. The Pennsylvania Advance Directive for Health Care Act: Like the advance directive statutes of most states in the US, this law provides immunity from liability to physicians who make a good faith effort to follow a patient's living will under specified conditions. Contrary to the inferences of the treatment team, such a law does not compel treatment under all conditions other than those it specifies.^{5,6}

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CASE AND COMMENTARY

The Letter and Spirit of a Directive, Commentary 2

Commentary by Amber Orr, JD, MPH

Case

An 83 year-old woman, Mrs. U, was admitted to the hospital from a personal care home due to a stroke with left-sided weakness and aphasia. She had a history of Parkinson's disease, coronary artery disease, and a prior stroke several years ago. The day after admission she was seen by a neurologist who noted dysarthria (ie, problems of speech articulation due to muscular control disturbance) and a severely diminished gag reflex. She was not ambulatory but did respond to right-sided commands. Speech and physical therapy were recommended.

A speech therapist also recommended that Mrs. U not ingest anything by mouth due to her swallowing difficulties. A Dophoff (nasogastric) tube was inserted for feedings. Mrs. U subsequently pulled out the tube twice; the neurologist's notes indicated she would need a peg tube (inserted into the stomach) to survive. At that time, Mrs. U's daughter June, who lived nearby, refused the peg tube but eventually agreed to reinsertion of the nasogastric tube as a temporary measure.

A social worker spoke at length with June, who, wanting to follow the wishes expressed in her mother's advanced directive, was reluctant to agree to any feeding tube at all. Mrs. U's advanced directive, typical of the living will forms used in Pennsylvania, stated she would not want artificial nutrition and hydration if she were in a terminal condition or permanently unconscious. The next day June, still uncertain, was advised to confer with her sister Donna, who lived out of town, in hopes that they would clarify their mother's intent. Mrs. U's family physician also spoke to June, explaining to her that a peg tube was not an "extraordinary measure."

Due to uncertainty about the patient's decision-making capacity, a psychiatrist was consulted. The psychiatrist described the patient as disoriented and lacking insight, with impaired cognition. He deemed her not competent to make decisions at that time. The social worker again talked with June, who had spoken with Donna. The daughters were in agreement in their refusal of any type of tube feeding for their mother.

During the next 2 days, the psychiatrist examined Mrs. U again, finding her mental status to have gradually improved. She appeared to understand what a peg tube was and that it was necessary to provide her nourishment. He declared her capable of decision making at that time.

The hospital's ethics review group, summoned to consider the case, determined that the living will was not applicable at this time because Mrs. U was neither terminally ill nor unconscious and was found competent by the psychiatrist. In light of this, they contacted Mrs. U's daughters and arranged a conference call for the next morning. After receiving the new information, June and Donna differed in their opinions.

In the meantime, the patient was given a barium swallow. It showed that it was still not safe for her to take nutrition orally. Due to the psychiatrist's most recent evaluation of the patient's decision-making capacity, she was referred for a surgical consultation. The patient thought she wanted a peg tube but indicated that she also wanted family agreement. Her daughters were again contacted with this information and presented with Mrs. U's 3 treatment options: (1) placing a Dophoff tube and physical restraints to prevent the patient from removing it, (2) placing a peg tube with no restraints, or (3) transfer to another facility for evaluation and treatment. Shortly thereafter June, who voiced opposition to artificial feeding in the conference call, telephoned the social worker to say she now agreed with her sister on insertion of the peg tube.

The peg tube was inserted the same day. Within a few days, the patient was stable and was transferred to a skilled nursing facility.

Commentary 2

Although the commentary above is comprehensive and expert, perhaps a little more can be said on an issue that makes many cases like these especially difficult in day-to-day practice—the question of competence. Actually 2 questions arise simultaneously: how to obtain consent from a patient for a course of action and how to ensure that the patient is capable of making an informed decision. Under the law, individuals are assumed to be competent unless and until they are declared to be incompetent and in need of a surrogate decision maker. But, in the everyday practice of clinical medicine, the assumed standard may become ambiguous and can create unique problems for the health care team. In the presence of illness, the capacity to make informed decisions may swing across the spectrum of competence like a pendulum. In instances like Mrs. U's, the issue is not her general competency but her specific ability or capacity to make the medical decisions necessary for immediate intervention. This issue merits attention because it speaks not only to the decision-making autonomy of all patients, but also to the physician's ability to recommend and carry out medical interventions.

Following a complex legal history, the right of all patients to refuse even life-sustaining treatment has been established. That right is somewhat attenuated, however, where a surrogate makes decisions to withhold or withdraw life-sustaining interventions. The right is limited insofar as surrogates must provide some sort of evidence that their decisions are in line with what the patient would have chosen to do. Such evidence is often difficult to produce. For example, the advance directive, though not operable in Mrs. U's situation, does give some insight

into her preferences, albeit under different circumstances than those that came to pass. One popular and legitimate objection to advance directives is that they cannot possibly anticipate all of the scenarios in which medical decisions must be made; patients often face life-threatening situations outside of the circumstances which invoke the preferences stated in advance directive or living wills.

Although advance directives and living wills are used to achieve the same goals, living wills are more limited than advance directives, which can be expressed in many forms. One alternative that might be helpful in cases like this one is for the patient to appoint a durable power of attorney for health care. Under this agreement, Mrs. U could appoint an individual of her choice to make medical decisions that she can't make for herself or might not feel comfortable making. In states where this is an option, it allows a patient to choose someone to act as his or her surrogate, and it also creates an opportunity to exchange information on preferences and desires, information that may come into play even when an advance directive does not. Perhaps Mrs. U would have appointed one of her daughters or a friend who would have visited with her about her desires when she was lucid. Mrs. U's acceptance of the peg, conditioned on her daughters' agreement, may well have been an informal example of the durable power of attorney for health care in action. Durable power of attorney for health care may be implemented at any time, is useful anytime a patient is incapacitated (terminal or not), and may be revoked verbally at any time that the patient can indicate that revocation. In a case like Mrs. U's this type of plan for decision making is informed both by the maker's ability to understand the consequences and also by the preferences of the patient.

A note of caution pertinent to this case, ethicists and health care providers should pay close attention to referrals to psychiatry for the evaluation of competency in conscious patients. If a patient is awake and can give verbal assent, there should be a strong presumption of his or her decision-making capacity. While it is a good idea to spend as much time as possible listening to the patients desires and criteria, many ethicists are aware that patients are more often judged capable to make decisions when their decisions concur with the recommendations of the health care team than when their decisions run counter to the preferences of their providers. The case poignantly reads, "During the next two days, Mrs. U was seen again by the psychiatrist who found her mental status to have gradually improved to the point that she appeared to understand what a peg tube was *and that it was necessary to provide her nourishment. He declared her capable of decision making at that time*" [emphasis added.] Care must be taken to ensure that capacity to make decisions is not based on whether or not a patient agrees with the recommendations of the health care team. In this case, the issue of starvation is socially complex and contentious and deserves careful attention because it is likely to cause discomfort for the decision maker or health care team.

As mentioned in the first commentary, it would have been extremely helpful to those involved in care and in decision making to have had a patient care conference during a period of lucidity in the patient. This would have provided an important

opportunity to talk about the risks, benefits, and alternatives to the proposed interventions with the entire team listening and assessing the accuracy of the information presented. The issue of restraint is another controversial issue that threatens autonomy and should be discussed with the patient present and able to respond. This conversation is part of a larger process of orientation to the patient's condition. While it is unreasonable to predict the course of an illness in a patient, the experience of the medical profession provides practitioners with enough information to furnish the health care team with some "expectation management." A conversation about the best and worst outcomes, the most likely course of illness and intervention, and the risks and benefits of available interventions can provide invaluable insight to the patient and or decision maker(s) faced with difficult choices. For example, it would be appropriate to address whether the patient can expect to remain alert without the hydration-nutrition protocol in the near future or whether there is any possibility that the patient might regain the ability to swallow food orally. This kind of conference is necessary to protect the autonomy of the patient and to assure that consent is valid and informed.

The expectation/management/patient care conference provides an opportunity for honesty about the feelings and preferences of the treatment team. It may be helpful for a patient and family to hear why the team prefers one alternative over another. This type of meeting is also an opportunity to educate providers on the values and preferences of patients that are fundamental to the ethical practice of medicine. Finally, it may help to prevent the team from confusing the issues or presenting red herrings. Legal questions that may be pertinent can be addressed with accurate information while being placed in the proper perspective to the care of this patient. This is helpful where medical management is compromised by lapses in lucidity during which patients become incapacitated due to their condition or medical procedures. While every attempt must be made to protect the autonomy of the patient, care plans and expectation management conferences may be one of the best tools to deal with the difficulty of consent where the competence of a patient may vary.

Amber Orr, JD, MPH is a fellow in the AMA Ethics Standards Group.

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IN THE LITERATURE

Crossing the Line

Dragan Gasteovski

Peter Ubel's article¹ addresses a quandary experienced by many health care professionals: how to offer quality medical advising without falling back on a paternalistic attitude of commanding patients.

In general, people concentrate their education in a specific area, leaving them with inadequate knowledge in other areas. This is why you go to your lawyer for legal inquiries, your butcher for cooking questions, and your doctor for medical advice. Ubel points out that patients turn to doctors to answer their medical questions in a non-biased and professional manner. In the past, many doctors took a paternalistic approach to advising their patients and influencing medical decisions. That is not accepted as the best model today. Many doctors struggle to find a balance between paternalism and involving their patients in the decision-making process. The modern problem, according to Ubel, is one of accepting responsibility.

Ubel cites several situations in which people are psychologically "more averse to harms of commission than to harms of omission." In the long run, people may regret not having experienced certain things, says Ubel, but they will regret their mistakes of commission more. In his example, Ubel cites the polio vaccine of the 1970s. Some people contracted polio from the vaccine itself. The chance of getting polio from the vaccine, however, was 10-fold less than the chance of contracting it normally. But parents still chose not to vaccinate their children out of a fear of commission; they just didn't want to be responsible for the suffering of their child.

Patients do not want to assume the responsibility for their treatment decisions, but neither do docs. Ubel says that many patients are used to the paternalistic model of the medical profession so they willingly submit to their doctor's decisions. But, Ubel argues, the doctor's role is to advise, not to command. In some cases, just explaining the odds of success and the risks associated with options A and B is enough to help the patient make up his mind. A doctor hears new research findings every day. If the results are strong enough to convince him or her to favor a procedure, says Ubel, they will probably convince the patient, too.

Involving the patient in the decision-making process may also be accomplished by changing the format of the questions. Most patients are not scientists, and therefore need to hear things in their own language. An explanation of various diabetes

treatments on the biochemical and statistical level may go completely over the patient's head.

Ubel describes a case where he admitted a patient with emphysema to the hospital for a pulmonary infection. He notes that, if the patient got worse, he would have to be transferred to the ICU and intubated while antibiotics were administered. When asked if he would like to go through with this sort of treatment, the patient asked the doctor for advice. Ubel presented the situation of going on a ventilator to the patient in terms of levels of risk. "Then, rather than ask him what he wanted to do," says Ubel, "I simply asked him what kind of patient he was." The patient said, "I'm the kind of person who's willing to take a chance, even if it's only 1 percent." Ubel replied, "Then I recommend, for now, we keep open the option of ventilation." Ubel concludes, "I don't know who made that decision, but I think it was the right one at the time."

Questions for Discussion

1. If a doctor tries to convince a patient to enter into a particular method of treatment, is that doctor compromising the patient's autonomy?
2. When does a doctor cross the line between advising and deciding for patients?
3. Is it coercion if a physician tries to convince a patient to enter into a particular method of treatment by using argument and data?
4. Is it ethical to make the patient the "active decision maker" by asking if he's a risk-taker rather than asking if he wants the therapy?
5. What justifies a "correct choice"? Is it the unbiased, statistically better one? Is it the one with which the patient has the most security? Is it the one with which the physician feels most comfortable?
6. What should a patient do when his personal values conflict with a paternalistic doctor's decision?
7. Should physicians always recommend the statistically better treatment (Ubel's polio example)?
8. How does Ubel's suggested decision-making process relate to the success of the patient-physician relationship? To the physician's professionalism? To patient responsibility?

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AMA CODE SAYS

Organized Medicine Speaks with One Voice

Sam Huber

Contemporary American medicine is a fragmented mosaic of interest groups, specialty societies, and state and local medical boards and societies. Each has different goals, mission statements, and sometimes even its own code of ethics. A recent resurgence of popular interest in medical professionalism has spawned numerous professionalism projects, accreditation requirements, and position papers. A host of medical oaths and declarations from Hippocrates to Geneva are recited at medical school graduations around the country. And only about 30 percent of physicians in the United States are members of the American Medical Association (AMA).

In the midst of this individualization, contouring of particular interests, and general reluctance to join organizations, the recent support by 40 state medical societies and 65 specialty societies of a new document that calls physicians to recommit to "medicine's social contract with humanity" comes as something of a surprise. Especially since the document was developed by the AMA.

The *Declaration of Professional Responsibility* was written by members of the Ethics Standards Group at the AMA in the aftermath of the September 11th terrorist attacks. As concerned citizens everywhere pondered what they could do to help, hundreds of physicians called the AMA to offer their medical assistance, prompting reflection on the social role of the physician in the United States and the world. The result is not a reactionary document, but an articulation of responsibility that recognizes the inter-relatedness of all humans and the integral role of health in global well-being. It is neither a Decalogue for doctors, nor a code of ethics. Rather, it is a list of specific duties that physicians must affirm in fulfilling their commitment to society. This social contract is enforced only by the integrity of those who pledge it. There is no conscripting power at work, only our professional honor.

The *Declaration* has 2 parts that fit neatly on a single sheet of paper. The first section, the preamble, frames the document in terms of current world conditions and historical physician roles. The second section is the declaration itself, nine short statements to which the "world community of physicians" commits itself. These include respecting the dignity of every individual, accepting personal risk in treating the sick, advocating for social and political change that will ameliorate suffering, contributing to research, and educating the public as well as future physicians. The

duties speak to physicians in their roles as clinicians, researchers, educators, and public citizens.

The *Declaration* was presented to the AMA House of Delegates by the Council on Ethical and Judicial Affairs and was adopted by the House at its interim meeting in December 2001. Since then, it has been formally adopted by a host of state and specialty medical societies which together represent the vast majority of American physicians. *The Declaration of Professional Responsibility* was included in the 1998-1999 edition of the *AMA Code of Medical Ethics*.

During the June 2002 Annual Meeting of the AMA, representatives from the societies that have supported the *Declaration* met to sign an official copy of the document, demonstrating a unanimity that is rare in organized medicine today.

The *Declaration* is not a panacea for a fragmented profession, and whether it will stand as a medical oath remains to be seen. While many leaders of organized medicine have agreed to its principles, it is unclear how an understanding of the *Declaration's* duties will reach practicing physicians or play a role in medical education. Nevertheless, the *Declaration of Professional Responsibility* is worth serious consideration by anyone interested in the interface between organized medicine and contemporary professionalism.

To view the text of the *Declaration of Professional Responsibility* or to order your own copy [click here](#).

Sam Huber is a research assistant in the AMA Ethics Standards Group.

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Virtual Mentor

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MEDICINE AND SOCIETY

Forced to Play Russian Roulette with Their Health

Susanna Smith

There are about 40 million people in the United States without health insurance.

I believe it.

All I have to do is glance around a table of my peers to find the faces to match with the statistics of the uninsured. Many of them are like me: college educated, in their early 20s and working. They are not numbers to me; they are friends and college roommates, my cousin and my neighbor.

We are the generation that graduated into what is called the "new millennium." We finished our high school or college education with "impeccable" timing, entering the job market just after the 1990s economic boom. Although a few years ago employment opportunities seemed limitless and almost anyone could get a job, today the market is highly competitive and flooded with more experienced, laid-off workers and thousands of other new graduates.

In the United States, health insurance is widely linked with employment, and having health coverage is "one of the best known and most common means used to obtain health care."¹ With many young adults struggling to obtain stable employment that includes health coverage benefits, too many are being left uninsured and, as a result, without health care.

There are an estimated 12 million young adults, ages 19 to 29, without health insurance in the United States, accounting for at least 1 quarter of all uninsured Americans.²

"So what," you may say? "You are young, you are healthy, you don't need to worry about health care."

And for lack of another option we, the young uninsured, often tend to agree. We brush off a sinus infection as a cold, treat a urinary tract infection with painkillers rather than the necessary antibiotics. We do not get our cholesterol or our blood pressure checked; women do not get annual exams. We do not go to dentists; they are expensive. Because we are young; and we are healthy; and we are uninsured.

But what is even scarier than the injustice of the current health insurance situation are the long-term consequences of being uninsured. Many people without health insurance don't know that they are putting themselves at serious risk for poorer health by forgoing preventive and sometimes needed medical care. A recent study, "Care Without Coverage: Too Little, Too Late," released by the Institute of Medicine, suggests that Americans with even a short interruption in health care coverage tend to have a decline in their health. Uninsured, working-age Americans are also likely to get sick more often and die sooner than those with health insurance.³

Although young adults are, on the whole, a generally healthy population, when they do need health care, it is oftentimes an acute need. According to the Centers for Disease Control (CDC), the top causes of death for people in this age group are accidents (namely traffic accidents), homicide, and suicide.⁴ Yet when admitted to the hospital for things such as trauma injuries from a car accident "the most acutely ill or seriously injured adults, when uninsured, cannot always obtain needed care."⁵

In addition to physical health care, young adults often need mental health care. This is the time in life when people are establishing their independence, starting careers, perhaps marriages, and moving to new cities. Few people make it through their twenties without experiencing depression or anxiety. But when nearly 1 in 3 young adults has no health insurance and close to half of uninsured adults ages 19-29 received no preventive care in the past year,² these patients will not pay the high fees for mental health treatment even when it may be beneficial or necessary.

The CDC recorded 5,128 suicides by young adults in 1999.⁴ Were some of those unfortunate and untimely deaths not preventable with mental health counseling?

In cases when young adults without health coverage do obtain medical care, paying for the care can become a nightmare, especially in the event of serious health crisis. Many young adults do not have the financial wherewithal to deal with quickly mounting medical bills. New to the working world and at the beginning of their careers, young adults have not accumulated the savings to fall back on in case of injury or illness. As new employees, many are not offered benefits or must wait 6 months to 1 year before becoming eligible. Our health care system is leaving uninsured adults "vulnerable to potentially catastrophic expense in the event of serious illness or injury."²

"Increasingly, the evidence points to harmful health and economic consequences related to being uninsured" which may impact not only the uninsured individual but also the community, and society as a whole.¹ Although there are numerous studies addressing and examining the population of Americans without health coverage, the group of uninsured young adults continues to grow. Why are no alternatives being offered?

As a group, young adults would be relatively inexpensive to insure since they are largely healthy. One solution would be to develop a transitional period in health insurance plans to slowly work young adults off their parents' insurance plans, allowing parents to continue paying extra to cover their children if they so wish. Without some change in the current system, we are forcing young, uninsured adults to play Russian roulette with their health.

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HISTORY OF MEDICINE

The Legacy of Humoral Medicine

Faith Lagay, PhD

To students and beneficiaries of western biomedicine, the greatest contribution of the ages-old humoral model might seem to be the expressions it provides for describing someone's disposition: he is in good (or bad) humor; or we might even say, "he is phlegmatic." But the humoral theory left more than a linguistic legacy. The group of fourth- and third-century BC physicians known as the Hippocratics who formulated (and more importantly *wrote about*) their theories, were the first organized group to consider that illness had natural—not supernatural—causes. The significance of this change in attention cannot be overstated for reasons I will return to later. Their notion that 4 bodily fluids—blood, phlegm, yellow bile, and black bile—caused illness persisted for more than 2000 years in the West until the rise of controlled empirical science in the mid-19th century. Humoral medicine's most compelling claim on our attention, though, is its belief that health and its opposite, dis-ease, were due to complex interactions among an individual's 4 internal humors, his lifestyle and habits, and his environment.

The 4 humors corresponded in their natures to earth, air, fire, and water—the 4 elements of which all matter was composed, according to the Greek philosopher Empedocles, a contemporary of Hippocrates. As evident in the diagram above, blood was hot and wet like air; phlegm was cold and wet like water; yellow bile was hot and dry like fire; and black bile was cold and dry like earth. Health consisted in humoral equilibrium. Illness resulted when an excess or a deficiency occurred in one or more of the humors. The disturbance could result from overindulgence in food or drink, too much or too little physical exertion, or changes in the so-called "naturals," ie, the uncontrollable environment and climate. Because of the similarity of the natural elements and humors, certain humors were more likely to become excessive during given seasons of the year. Phlegm increased during the winter, bringing with it bronchitis and pneumonia because phlegm was cold and wet, like the chilly Mediterranean winters.¹ In warm, wet spring, hot, wet blood increased, causing dysentery and nose bleeds.²

The physician's task was to diagnose which humor was out of balance; treatment then focused on restoring equilibrium by diet or by reducing the offending, out-of-balance humor by evacuating it. Medicinals were not an important part of Hippocratic treatments. (It was Galen who, in the first century AD, concocted and treated with medicinal herbs and compounds. "Polypharmacy," says history-of-medicine scholar, Robert Hudson, "was Galen's legacy."³)

The all-important Hippocratic breakthrough to which I alluded earlier—the conviction that disease had natural rather than supernatural etiology—forced the Hippocratic physicians to observe their patients closely. Such observation of the patient and his or her physical condition, dietary and exercise habits, and environment were irrelevant when disease was thought to have a supernatural source. In that view, the offending curse or possession was independent of the physical characteristics of those afflicted and their environments. But, for the Hippocratics, diagnosis and treatment began with the knowledge of the patient.

The Hippocratics derived their specific theories about which imbalance caused which symptoms by observing the fluid excretions of sweat, urination, hemorrhage, vomiting, and defecation that coincided with a return to health. They then applied this empirical information to future patients. The Hippocratic *Aphorisms* attest to close and careful observation of many, many patients: "Persons who have had frequent and severe attacks of swooning, without any manifest cause die suddenly." Hudson explains that this aphorism describes Stokes-Adams syndrome characterized by insufficient cerebral blood flow, victims of which faint frequently and often die suddenly.⁴ (Today, Stokes-Adams is treated by the implantation of pacemakers.) Another aphorism, Hudson notes, anticipates present-day insurance actuarial tables: "Persons who are naturally very fat are apt to die earlier than those who are slender."⁵

Their "scientific" observation notwithstanding, the Hippocratics had it all wrong. Though they knew illness had natural causes, they believed that cause to be generalized and in the fluids of the body. The history of medical science is the story of discovering ever more localized cause of illness. That history is familiar, beginning with Vesalius's new anatomy, published in 1543 and based upon his many dissections of human cadavers. Though others had speculated on the role of anatomy in illness, the anatomical idea—that function of the body is related to its structure—took permanent hold after Vesalius. In 1761, the Italian physician Morgagni published the results of his comparisons of organs observed in autopsy with the symptoms those individuals had exhibited before their deaths. His treatise, *On the Seats and Causes of Diseases*, concluded that sickness and death resulted from changes in the organs.

From there, the localizing of disease narrowed further and further. Bichat and Virchow located disease in tissues and cells in the early and mid-1800s, respectively. Next came the discoveries, starting with Pasteur and followed by Koch, about an external cause for the pathological changes in the cells, tissues, and organs of the body—the germ. By 1900, the germ theory was indisputably established in western medicine.

Throughout the first half of the 20th century, infectious medicine was ruled by the dominance of the germ theory and the spectacular control of germs that antibiotics increasingly afforded. It is humbling, in a way, to note medicine's re-attention to lifestyle and environment in the late 20th and early 21st century. Germs and, now,

genes are indeed "master molecules," to be reckoned with in the diagnosis and treatment of illness. Yet, we are coming to realize more and more that the same germ or gene affects different people differently. As the Hippocratics turned their focus away from the supernatural and toward the individual patient, the contemporary physician, too, knows that neither germs nor genes are sacred; successful treatment begins with understanding the individual patient.

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VIEWPOINT

The Dangers of Summer

Colleen Danz

Swimming

- 4,000 people lose their lives each year in drowning accidents. Drowning is the 4th leading cause of accidental deaths in the United States. Approximately 1/3 of those deaths occur in children under the age of 14.¹
- In the past 10 years there have been over 10,000 reported cases of severe diarrhea, stomach aches, and other ailments from contaminated pool water.² Cryptosporidium, a bacterium that can survive several days in chlorinated pool water, accounts for 80 percent of these cases.
- From 1991 to 1996, 6,237 children aged 14 and under died from drowning. Of these deaths, 2/3 occurred in the summer. More drowning accidents occur during the month of July than in any other month.³

Fireworks

- Of all fireworks-related injuries, 70-75 percent occur during a 30-day period that surrounds the July 4th holiday (June 23-July 23).⁴
 - 7 of every 100 persons injured by fireworks are hospitalized.
 - Approximately 40 percent of those injured are children aged 14 years and under.
 - Males are injured 3 times more often than females
- 34 percent of fireworks injuries affect the hands; 12 percent, the face; and 17 percent, the eyes.⁴
- The US Consumer Product Safety Commission estimates that in the year 2000 about 11,000 people were treated in hospital emergency rooms for injuries associated with fireworks. About 55 percent of the injuries were burns.⁵

Heat Stroke and Sunburn

- From 1979 –1999, excessive heat exposure caused 8,015 deaths in the United States. During this period, more people in the US died from extreme heat exposure than from injuries related to hurricanes, lightning, tornadoes, floods, and earthquakes combined.⁶
- Exposure to the sun's ultraviolet rays appears to be the most important preventable factor in the development of skin cancer.⁷

Boating

- According to the US Coast Guard, 734 people died in recreational boating incidents in 1999.⁸
- Nearly 3/4 of boating-related deaths were due to drowning.
- 89 percent of people who drowned were not wearing personal flotation devices.

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VIEWPOINT

The Non-Entitlement Principle: Garth Graham, MD

Susanna Smith

The thousands of people who immigrate to the United States every year in search of opportunity face the hardships of navigating in a foreign culture and establishing a new life. It is the children of these immigrants who often reap the rewards, integrating themselves more readily, and benefiting from the American education system.

For Garth Graham, MD, recipient of an AMA Foundation 2002 Leadership Award, the work ethic his parents instilled in him through example drove him to succeed in the medical field.

"My parents emigrated from Jamaica," Dr. Graham explains in a gentle Caribbean accent. "They had to work very hard when they came to this country. Seeing them putting that amount of effort into sustaining our family and giving us the resources to reach our goals, inspired us to work twice as hard to reach those goals. It is the non-entitlement principle."

"Parental role models are the most practical kind of role models," Dr. Graham seems to be realizing the thought as he formulates the words. "They are not heroes, but rather real people you can actually pattern your life from."

Perhaps it was seeing the sacrifices his parents made for him while he was growing up that drove Dr. Graham into a profession that requires him to make constant self-sacrifice.

"When you are a resident you have less time to be physically active, participate in sports, educate yourself about non-medical issues. I have difficulty finding the balance between clinical and patient responsibilities and personal responsibilities like spending time with people who are not medically related."

But if you are lucky enough to be a person who is "medically related" to Dr. Graham, then you are spending time with a man who has been recognized not only for his leadership and community service but also for his innovation.

While in medical school at Yale University Dr. Graham became involved in the New Haven Mayor's Task Force on AIDS public policy committee.

"The mayor noticed that there was a significant impact on the public health system by those affected by AIDS/HIV," Graham says. "As a member of the committee of public policy I became an advocate for legislation at the state level to maintain the funding for existing programs for HIV patients."

Graham's work with HIV patients led to the establishment of a company called Medicompliance, aimed at developing a communication system to improve medical compliance through a reminder system directed at HIV/AIDS patients.

"I was taking a class where we had to develop a venture as an assignment of the class. I met two other guys in the class, one a lawyer, and another working in the pharmaceutical company; we thought this would be a good idea," Dr. Graham explains. "I had done a lot of work with HIV and AIDS patients so I knew the regimen, the 16 to 20 medications they can be required to take a day, some with food, others on an empty stomach. I knew the difficulties associated with the regimen, and the system [we designed] aimed at increasing patient compliance with their medication regimen."

In an annual Yale entrepreneurship competition Dr. Graham, along with his partners, won initial startup funding for the company, which he cites as one of his greatest accomplishments.

"I was most proud of this accomplishment as it was one of the first African-American-led companies to win a prize in this annual competition," he comments.

While at Yale, Dr. Graham also started the Yale chapter of Physicians for Human Rights (PHR), which later grew into a larger overseeing body known as the Health and Human Rights Committee.

"At Yale we organized a number of talks and speaker series from local and international experts in the field of health and human rights in an effort to educate the Yale community on the important issues occurring in the field," Graham says. "We assembled an energetic group of individuals that were committed to the cause and attempted to mobilize the student population around the many problems affecting marginalized populations around the world."

PHR's Board of Directors recognized Dr. Graham's early work in the human rights field with a nomination to the board as the student resident representative of PHR, a position that he currently holds. In this capacity, Dr. Graham was one of the youngest people to serve on the board of directors of PHR, an organization that shared the 1997 Nobel Peace Prize.

Now working in Massachusetts as a resident in internal medicine at the Massachusetts General Hospital, Dr. Graham serves on the Massachusetts Medical Society (MMS) Executive Public Health Council. He advocates for MMS's priorities at the state level.

"We pick a few issues of public health, such as this year, obesity, violence, and bioterrorism, and then bring them to the General Council for MSS to focus funding on," Dr. Graham explains.

Even with all his work in the public policy side of medicine, Dr. Graham still recognizes the need for compassionate and individualized patient care.

"You have to take each patient as a single patient with a pathology," Dr. Graham suggests. "When I see Mr. Jones, he is not a diabetic patient, he is Mr. Jones who has diabetes. Medical students learn a lot about pathology and physiology but they have to develop their own method of seeing patients as people by interviewing each patient."

When asked how someone like himself, who has accomplished so much, can be a realistic role model for other students and health professionals, Dr. Graham responds, "Personally I don't believe I have accomplished a lot as yet; there are still so many things I would like to do. But as far as the work I have done so far, I would say anyone is capable of reaching their goals as long as they are willing to put the time and the energy behind what they believe in, and be able to think outside of the box."

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PERSONAL NARRATIVE

Through the Patient's Eyes: Paying Interest on Borrowed Time

Stephen Foster, MD

So, the question is: "Why?"

Why would someone volunteer for a study that virtually guarantees no clinical benefit, may exclude him from receiving therapeutic doses of the drug when it is approved, may actually make his condition worse, and has 3 pages of possible side effects that begin with liver cancer and get worse from there?

I was recently presented the opportunity to participate in a research project to investigate the safety of gene transfer as a potential treatment for hemophilia. The study involves injecting a genetically modified adeno-associated virus directly into the liver. This virus will transfer a normal gene for human clotting factor IX into the liver, where it will begin producing the factor missing in people with hemophilia B. As a safety study, the dosage administered is purposefully low to minimize any side effects. The researchers expect the body's immune system to develop antibodies to this virus, so it is likely the subjects can receive it only once.

I'm a 48-year-old factor IX hemophiliac with a history that includes HIV, HepC, lymphoma, and bilateral knee and elbow replacements. As evident from this list, the medical community has done a great deal for me, and perhaps, by implication, to me. When I turned 40, I foolishly researched the life expectancy of those with hemophilia. I found it to be 34. As HIV takes its toll, I'm sure that number decreases; I just haven't had the nerve to look. A big part of the reason I enrolled in this study is what I refer to as "paying interest on all that borrowed time."

Looking back at this decision has been fascinating for me. Being an engineer by both training and disposition, I prefer decisions based, at least remotely, on facts. Here, there aren't many, and I made a decision based almost entirely on emotion. Decisions in either medicine or engineering typically affect other people, so each has a strict set of ethical and legal guidelines. There are years of research indicating that the proposed procedure can be done safely, but nobody knows for sure until it's been done.

I've been around medical research all my life and acutely understand its importance. Some of my pre-teen urine was used in early clinical investigations of Urokinase, a clot buster still in use nearly 40 years later. More recently, I was involved in clinical trials of some early anti-HIV cocktails. I credit those trials with my survival. And

so, there's the rather vague "making the world a better place" reason. Logically, however, there's got to be an easier way; one that doesn't involve such personal risk. The procedure is uncomfortable and provides no benefit to me. The follow-up is long, tedious, takes 28 days away from home over the course of a year, involves sitting in the waiting room and hearing the size of your semen sample discussed, and trying to get containers of bodily fluids through airport security. It's not a matter of informed consent. I'm not sure how much better informed I could have been. All the facts were revealed in the consent process. It's the implications that were missing, and, as far as I can tell, they are impossible to write.

It all boils down to a leap of faith in the medical community, faith that may or may not be deserved. The medical community has done a great deal to keep me alive all these years. I have no doubt that I'm better off now than I would be if I had received less aggressive care. But, I also realize the possibility of human error (at best) or incompetence (at worst). I've been exposed to both, and am alive today, in part, through dumb luck. Knowing that I was participating in cutting edge research actually helped reassure me. I assumed that every move the researchers made would be watched and evaluated by review boards and others with no vested interest in the project. This layer of oversight added some security that, I felt, greatly reduced the chances of error or incompetence. This feeling of security was shaken severely when I heard a research nurse complaining that all these regulations were getting in the way of the science. My unspoken response was that if researchers weren't interested in cutting corners, there wouldn't be so many regulations.

Regardless of the mistakes I've witnessed, I still basically trust these people. Many of them have dedicated their lives to helping people like me, and, in a very real sense, I owe them my life. Maybe it's just my turn.

Stephen Foster, MD (a pseudonym) lives with his wife and teenage daughter near Austin, Texas, with 3 dogs and 3 cats. His work involves racing airplanes and fast cars. In his spare time he's learning aerobatics, flying in a cross-country race, and reading W.G. Sebald and Edward Tufte.

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PERSONAL NARRATIVE

Through the Student's Eyes: On Pimping

Marc Libman

Umm...
I don't know.
Hmm... No, I don't know.
Don't know.

little stabbing hints...

...flop sweat.

Feeling their eyes boring into the back of my skull,
My ignorance bolstering their also battered egos.

I don't know.

The indignity. Four years my junior but R1 to my cc3.

OK, my turn:

How old was Mendelssohn when he composed A Midsummer Night's Dream?

What was Harpo's real name?

List for me the signs of an Auspicious Buddha?

What's my favorite color?

"You're lucky you make me laugh, Libman.

Otherwise,
you'd be
worthless."

Marc Libman is a 4th year medical student at the University of Rochester School of Medicine and Dentistry. In addition to writing poetry, Marc is a jazz aficionado and recently became a father.

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