Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 155-185
Request to Discontinue Treatment

From the Editor

Case and Commentary

In the Literature

State of the Art and Science

Viewpoint

Personal Narrative

Upcoming Issues of *Virtual Mentor*

July: Interpreting an Advance Directive
August: The Profession's Ethical Standards
September: Helping an Impaired Peer
October: The Clinician-Researcher

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 157-158.

FROM THE EDITOR

Duck Soup

Audiey Kao, MD, PhD

Lyrics from a song in the 1933 Marx Brothers' comedy *Duck Soup* entitled "The Country's Going to War," read as follows: "We're going to war. I think we're going to war."

Among movie experts, *Duck Soup* is considered the Marx Brothers' greatest and funniest cinematic masterpiece. This classic comedy is a short (70 minutes) but cutting satire on nationalism and dictators, diplomacy and war, international intrigue and espionage. When it was first released, the film was both a critical and commercial failure. Audiences were taken aback by such preposterous political disrespect, buffoonery, and cynicism at a time of political crisis. In fact, Fascist Italian dictator Mussolini banned the film in his country for mocking his regime. Fortunately, the film was rediscovered by the generation of 1960s college students and many others.

The film's story concerns Mrs Teasdale, a millionairess who will donate $20 million to Freedonia, a Balkan state gone bankrupt through mismanagement, if it will agree to make Rufus T. Firefly (played by Groucho Marx) its dictator. Trentino, the ambassador from neighboring Sylvania, hires the sultry Vera Marcal to seduce and distract Firefly so that Trentino can move in on Mrs Teasdale, marry her, and get control of Freedonia. To aid his chicanery, Trentino hires Chicolini (played by Chico Marx), a peanut salesman, and his friend Pinky (played by Harpo Marx) as spies. Eventually war breaks out and, after much manic double-crossing and side-switching, Freedonia emerges victorious. Zeppo Marx, the other brother in his last Marx Brothers film, had a minor role playing, Bob Rolland, Firefly's assistant.

"We're going to war. I think we're going to war." All of us have seen on television, read in the newspaper, or heard on the radio that our country is at war. Most political and military pundits claim that this war is unlike any that we have fought in the past because our enemies do not have armies or soldiers in the traditional sense. While there may not be planeloads of body bags returning our servicemen and women, there still have been casualties. But for most of us, is there really a war going on? What should our role as citizens and more specifically as health care professionals be in this war that our elected leaders and most of us would agree is a just war.

In wars past, citizens on the homefront were asked to contribute in many ways—ration our use of supplies needed by the armed forces, recycle resources, spend thriftily, buy war bonds, plant victory gardens, (wo)man the factories. For the most part, very few of us are asked to sacrifice much this time—is there really a war going on? As physicians, many of our colleagues are serving in harm's way in the US armed forces, and their efforts must be commended. Recently, there have been disturbing accounts on the threat to the principle of medical neutrality as medical personnel and facilities are being targeted while coming to the aid of the injured on both sides of conflict. As a profession, we must denounce such actions. Many experts also believe that it is not a matter of *if* but *when* the next terrorist event will occur on the homefront. And the next time, the attack may involve a biological or chemical agent. With this apparent eventuality, physicians will undoubtedly be responsible for the initial detection and provide much of the subsequent care for those harmed and injured. As a profession, we must reaffirm our duty to care for and treat the sick and injured, without prejudice, though doing so may put us at risk.

Returning somewhat belatedly to how I started my comments. For those of you who are wondering why the political spoof is titled *Duck Soup*, it is reported that Groucho Marx had the following recipe: "Take 2 turkeys, 1 goose, 4 cabbages, but no duck, and mix them together. After one taste, you'll duck soup the rest of your life."

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

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 159-163.

CASE AND COMMENTARY
Right to Discontinue Treatment, Commentary 1
Commentary by Jim Kirkpatrick, MD

Case
Jim, a retired attorney, is 70 and, for the last 15 years since receiving a pacemaker, has led a reasonably active life that includes some golf and occasionally throwing the football or baseball with his grandsons. He has always watched his diet and maintained a health-conscious lifestyle. He takes pride in his appearance and in looking younger than he is.

Both Jim and Dr. Austin, his internist, were shocked when an endoscopic biopsy confirmed that Jim had pancreatic cancer. Dr. Austin had been seeing Jim only every 18 or 20 months since his pacemaker surgery; he saw his cardiologist more frequently. He came to her to check out stomach pain that gradually had become constant and severe and a low-grade but persistent fever. Blood tests suggested that he had pancreatitis and a CT scan showed a mass obstructing the pancreatic duct. "Probably an impacted gall stone," Dr. Austin had said, hopefully. Then she ordered the endoscopy.

Dr. Austin was as honest as her knowledge and experience permitted in giving Jim a prognosis and explaining what he could anticipate. In her 20 years of practice, she said, she had followed about 7 patients with pancreatic cancer. The longest survival after diagnosis was over a year; the shortest was 3 weeks; the average was 3 to 6 months. But, she said, she hadn't treated such a patient in several years and didn't know how treatments and life expectancy had changed in that time. The best medical oncologist in the area, Dr. Austin said, was Dr. Maggio, and she would be happy to put a call into him right then while Jim was in her office.

Jim, appearing more calm than when the discussion began 20 minutes earlier, declined the referral, saying he didn't wish to spend his last 3 weeks to a year in doctors' offices and hospitals, undergoing and recovering from experimental treatments. "I watched my grandfather die from pancreatic cancer, and it was hell for him and everyone else. No," Jim said, "I'm going, as we say in both our professions, to put my affairs in order. Then, when things begin to go downhill, I'll come back and ask you to disconnect or turn off or however you do it, stop this ticker monitor in my chest," Jim patted his heart.

Another long discussion ensued, during which Dr. Austin cautioned that the disconnecting of Jim's pacemaker could very well not result in his immediate death.

He would go along until some arrhythmia or other event occurred. If such an event left him temporarily unconscious or disabled, she cautioned, someone would probably call 911, and Jim would end up in an ICU, connected to this and that monitor—just what he wanted to avoid.

Jim countered that he would spread the word to his wife, son, daughter, and friends that he was not to be resuscitated or sent to the hospital—"and I won't go to the mall by myself," he joked. He did not intend to tell anyone about his plan to "discontinue the pacemaker treatment" as he insisted on putting it.

Back and forth the discussion went. Dr. Austin assured Jim that she could control his pain from the cancer, even at the last. Jim said he didn't want to be in la-la-land. After the long and exhausting conversation, Jim left, asking, with the uncompromising frankness of a dying man, that she help him die in the least objectionable and "obscene" way. "We both know I'm gonna die," Jim said, "Help me not die by degrees, suffer, and drag everybody through hell. Will you, Dr. Austin?"

It occurred to Dr. Austin that she might tell Jim to ask his cardiologist for help, but she rejected that approach. If helping Jim was the right thing to do, she should have the guts to do it. If it wasn't, she shouldn't suggest that someone else do it.

Commentary 1

Dr. Austin finds herself in the unenviable position of counseling a long-time patient and friend, Jim, who has pancreatic cancer. As difficult as end-of-life issues are, her dilemma is further compounded by Jim's insistence that his pacemaker be turned off when his condition deteriorates, allowing him potentially to die via cardiac causes, instead of lingering in the painful death throes of pancreatic cancer.

Dr. Austin has her reservations, and she reasons that terminating pacemaker therapy may not be effective in preventing an "objectionable and obscene" death, since misguided resuscitative measures by bystanders may place Jim in the ICU anyway. Jim counters that he will avoid the situation by staying close to family and friends who will know he doesn't want CPR, but he states he won't tell them about his decision to turn off the pacer.

Framing this case in terms of a conflict between a patient's right to make decisions about treatment limitations and medical recommendations about what is the most beneficial course of therapy provides a helpful starting point, but there are other issues that arise.

Cardiovascular Treatments: It's Not All about Mortality

Advances in medicine have dramatically improved survival for patients with a host of cardiovascular disorders. From open-heart surgery to PTCA with stenting to cocktails of medications, doctors have arsenals loaded with weapons against

infirmities of the heart and blood vessels. Understandably, cardiovascular medicine has focused attention on patient longevity, often excluding other patient outcomes.

Successful prolongation of cardiovascular life allows patients to live long enough to die from other causes. The added years represent tremendous blessings to many patients. But for others, the added years are full of suffering. Although some cardiac conditions cause slow and uncomfortable deaths, dying from ventricular arrhythmia is relatively quick and painless. The heart stops contracting effectively, brain perfusion ceases, unconsciousness ensues, and the patient dies—quickly and painlessly.

It is easy to view a "code blue" as an invasive, degrading, and, often, futile medical treatment. But what about Automated Implantable Cardioverter/Defibrillators (AICD's), which detect lethal arrhythmias and shock the heart from the inside? Vice President Dick Cheney became a poster-child for these devices in 2001. They are routinely implanted in patients who survive cardiac arrests. A recent New England Journal article suggests that AICD's should be implanted in many more patients.[1] There is no question that these devices prolong life. However, patients may suffer from multiple shocks, which, even though appropriate, are extremely uncomfortable and often necessitate hospitalization.[2] In addition, devices sometimes malfunction and shock patients inappropriately. Some patients choose to have their devices turned off because they would rather die than undergo more shocks. Doctors often turn off the AICD's of patients suffering from terminal diseases. Although timing of death becomes less predictable, patients with terminal conditions may prefer a quick death.

So far, there has been little question about the ethical appropriateness of patients with terminal conditions deciding to turn the devices off or declining them in the first place. Since AICD may be considered analogous to CPR, the ethical resolution seems relatively straightforward: a patient with decision-making capacity may refuse both the initiation and continuation of AICD therapy.

What about Pacemakers?

In the case presented, Jim is asking to have his pacemaker turned off "when things begin to go downhill." Certainly, by accepted standards in medical ethics, Jim, as a competent adult, can refuse any treatment. But the question here turns on whether Jim is making an informed decision. In evaluating this case, Dr. Austin needs to probe further into 2 important areas.

The Clinical Scenario

Why was the pacer put in? There are many indications for pacemaker insertion.[3] If Jim has third degree heart block with an escape rhythm incompatible with effective cerebral perfusion, he may die relatively painlessly once the pacemaker is discontinued. If, however, Jim is like most patients and had his pacemaker inserted for symptomatic bradycardia, he may be quite uncomfortable if his pacemaker is turned off. He may end up feeling extremely fatigued and possibly experience air

hunger from congestive heart failure. Furthermore, disabling his pacemaker is unlikely to hasten his death.[4] Discontinuation of pacemaker therapy may very well contribute to an "obscene" death "by degrees."

Thus, I suggest that Dr. Austin and Jim consult with Jim's cardiologist who can provide the reasons for pacemaker therapy and the consequences if it is discontinued. Although Dr. Austin's display of moral courage in not relying on others to make tough choices is admirable, ethical decisions often turn on the medical facts, and the expertise of other physicians often illuminates the facts. As in the rest of medicine, multidisciplinarity in approaching ethical dilemmas can prove useful.

Jim's Reasoning

Clinicians construct a differential diagnosis while patients recount their symptoms, then ask specific questions to narrow the list. Likewise, clinicians should develop a differential diagnosis for patient rejection of proposed treatments, then ask clarifying questions. In this case, Jim's desire to discontinue his pacemaker raises the need to dialogue about larger issues. Why does Jim not want to involve his family in the decision to turn off the pacer? (Does he fear that his family will oppose his decision or does he want to avoid disturbing family members with difficult choices?)

What does he mean by his stated wish to avoid putting "everyone through hell?" (Might his family and friends "rise to the occasion" and provide comfort and support that is essential as Jim goes through the dying process? In trying to protect them, might Jim prevent their involvement in a significant process?)

Has Jim witnessed family members or friends die in "obscene" ways that he is not necessarily destined to repeat? What are the symptoms Jim most wants to avoid?

Does Jim or any of his family or friends hold religious and cultural beliefs that may inform their values?

My Recommendation

Dr. Austin should explore the issues in subsequent visits and should advise Jim to involve his cardiologist. Addressing these questions may shed further light on Jim's approach to his illness and help Dr. Austin craft a treatment plan compatible with clinical realities and Jim's values. A decision to discontinue pacemaker use is reasonable within standards of medical ethics as long as Jim understands his condition, and Jim's physicians have made an attempt to understand Jim's values.

Samuel C. Seiden is a medical student at the University of Chicago Pritzker School of Medicine.

References

1. Moss AJ, Zareba W, Hall WJ, et al. The Multicenter Automatic Defibrillator Implantation Trial II Investigators. Prophylactic implantation of a defibrillator in patients with myocardial infarction and reduced ejection fraction. *N Engl J Med*. 2002;346(12):877-883.
2. Korte T, Jung W, Ostermann G, et al. Hospital readmission after transvenous cardioverter/defibrillator implantation; a single centre study. *Eur Heart J*. 2000;21(14):1186-1191.
3. Gregoratos G, Cheitlin MD, Conill A, et al. ACC/AHA guidelines for implantation of cardiac pacemakers and antiarrhythmia devices: a report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines. *J Am Coll Cardiol*. 1998;31(5):1175-1206.
4. Braun TC, Hagen NA, Hatfield RE, Wyse DG. Cardiac pacemakers and implantable defibrillators in terminal care. *J Pain Symptom Manag*. 1999;18(2):126-131.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 164-168.

CASE AND COMMENTARY
Right to Discontinue Treatment, Commentary 2
Commentary by Erin Egan, MD, JD and Kayhan Parsi, JD, PhD

Case
Jim, a retired attorney, is 70 and, for the last 15 years since receiving a pacemaker, has led a reasonably active life that includes some golf and occasionally throwing the football or baseball with his grandsons. He has always watched his diet and maintained a health-conscious lifestyle. He takes pride in his appearance and in looking younger than he is.

Both Jim and Dr. Austin, his internist, were shocked when an endoscopic biopsy confirmed that Jim had pancreatic cancer. Dr. Austin had been seeing Jim only every 18 or 20 months since his pacemaker surgery; he saw his cardiologist more frequently. He came to her to check out stomach pain that gradually had become constant and severe and a low-grade but persistent fever. Blood tests suggested that he had pancreatitis and a CT scan showed a mass obstructing the pancreatic duct. "Probably an impacted gall stone," Dr. Austin had said, hopefully. Then she ordered the endoscopy.

Dr. Austin was as honest as her knowledge and experience permitted in giving Jim a prognosis and explaining what he could anticipate. In her 20 years of practice, she said, she had followed about 7 patients with pancreatic cancer. The longest survival after diagnosis was over a year; the shortest was 3 weeks; the average was 3 to 6 months. But, she said, she hadn't treated such a patient in several years and didn't know how treatments and life expectancy had changed in that time. The best medical oncologist in the area, Dr. Austin said, was Dr. Maggio, and she would be happy to put a call into him right then while Jim was in her office.

Jim, appearing more calm than when the discussion began 20 minutes earlier, declined the referral, saying he didn't wish to spend his last 3 weeks to a year in doctors' offices and hospitals, undergoing and recovering from experimental treatments. "I watched my grandfather die from pancreatic cancer, and it was hell for him and everyone else. No," Jim said, "I'm going, as we say in both our professions, to put my affairs in order. Then, when things begin to go downhill, I'll come back and ask you to disconnect or turn off or however you do it, stop this ticker monitor in my chest," Jim patted his heart.

Another long discussion ensued, during which Dr. Austin cautioned that the disconnecting of Jim's pacemaker could very well not result in his immediate death.

He would go along until some arrhythmia or other event occurred. If such an event left him temporarily unconscious or disabled, she cautioned, someone would probably call 911, and Jim would end up in an ICU, connected to this and that monitor—just what he wanted to avoid.

Jim countered that he would spread the word to his wife, son, daughter, and friends that he was not to be resuscitated or sent to the hospital—"and I won't go to the mall by myself," he joked. He did not intend to tell anyone about his plan to "discontinue the pacemaker treatment" as he insisted on putting it.

Back and forth the discussion went. Dr. Austin assured Jim that she could control his pain from the cancer, even at the last. Jim said he didn't want to be in la-la-land. After the long and exhausting conversation, Jim left, asking, with the uncompromising frankness of a dying man, that she help him die in the least objectionable and "obscene" way. "We both know I'm gonna die," Jim said, "Help me not die by degrees, suffer, and drag everybody through hell. Will you, Dr. Austin?"

It occurred to Dr. Austin that she might tell Jim to ask his cardiologist for help, but she rejected that approach. If helping Jim was the right thing to do, she should have the guts to do it. If it wasn't, she shouldn't suggest that someone else do it.

Commentary 2

This is a case of a 70-year-old patient, facing a terminal illness, asking for a long-standing intervention to be discontinued. The most important fact is that Jim has the capacity to make his own health care decisions. Patients with decision-making capacity have the right to refuse any intervention or treatment, whether that treatment is believed to be life sustaining or not. Here, the fact that the patient wishes to discontinue a treatment that is unrelated to his terminal diagnosis in the hope of precipitating death is not relevant to whether this patient has the right to refuse the continued use of his pacemaker.

Autonomy is a fundamental principle of bioethics. Respect for a patient's autonomy requires that healthcare professionals honor patients' decisions and preferences, even if the professionals themselves disagree with the result. Patients with decision-making capacity are entitled to control of their bodies and deserve to make their own decisions about what care they receive. The AMA *Code of Medical Ethics* states that "[t]he principle of patient autonomy requires that physicians respect the decision to forgo life-sustaining treatment in a patient who possesses decision-making capacity."[1] The same policy statement observes that "[t]here is no ethical distinction between withdrawing and withholding life sustaining treatment.".[1]

There is no question that Jim could refuse to have the pacemaker placed now, regardless of the pancreatic cancer diagnosis. From the case description we do not know what condition led to the placement of the pacemaker. However, whether the

initial condition was life threatening or not, Jim would have the right to refuse placement of the pacemaker.

The important question to ask is, if he has the right to refuse the initiation of pacemaker treatment, then does he also have the right to have the treatment withdrawn? When medical devices are introduced into a patient's body some people believe that an ontological metamorphosis takes place. Thus, a pacemaker, like a mechanical heart valve, is part of a person in a way that a ventilator or hemodialysis is not. Turning off a pacemaker, then, is more akin to killing an individual because of this different ontological status of the technology.[2] We argue, however, that a pacemaker is a much less intrusive device than a mechanical heart valve, and is more similar to a prosthetic device that assists the patient in living their life the way they want to. Thus, the pacemaker does not become a "part" of a patient in the way that a heart valve does. So, if there is a continuum of interventions, with a heart valve on one end and a ventilator at another, the pacemaker is probably somewhere in the middle.

Therefore a patient such as Jim with a pacemaker could ethically refuse to have it maintained. Turning off the pacemaker is the only course that respects Jim's autonomy and decision-making capacity. This is a straightforward application of the principle that withdrawing and withholding treatment are ethically equivalent.

What makes this case emotionally difficult is that Jim is refusing to be evaluated for possible treatment of his cancer. Jim is suffering from abdominal pain that is reported to be constant and severe. Dr. Austin, and any responsible physician, would want to be certain that Jim's decision to withdraw treatment was not related to his pain. It would be reasonable to discuss a trial of aggressive pain management prior to discontinuing the pacemaker.

Pancreatic cancer is a diagnosis with a poor prognosis. Dr. Austin has shared her limited experience with pancreatic cancer patients with Jim. Jim also has his own experience with his grandfather's pancreatic cancer (although it is unclear when his grandfather was treated and what role, if any, an oncologist played.) Jim's refusal of a referral to an oncologist with more experience in the management, treatment, and prognosis of pancreatic cancer is therefore troubling. She has admitted that she is not up to date on the newest information on pancreatic cancer. She has properly sought to involve the appropriate expert with the knowledge needed to fully inform Jim in his decision.

The AMA *Code of Medical Ethics* Opinion 8.04 states that a physician should obtain consultation whenever the physician believes that it would be medically indicated in the care of the patient.[3] However, a patient with decision-making capacity can refuse referral as well. Dr. Austin cannot force Jim to undergo an expert evaluation of his condition any more than she could force any other treatment on him against his will. Still, she has a duty to ensure that Jim is making an informed decision. Dr. Austin can update her own knowledge on treatment and

prognosis of pancreatic cancer and she can present that information to Jim before agreeing to stop the pacemaker. While an expert may have information that is more specific to Jim's condition, she can fulfill her duty to inform by learning what she needs to know to inform Jim.

Jim also needs to be aware that stopping the pacemaker may have no effect at all on his health or his life span. Pacemakers often prevent symptoms of arrhythmias but most often do not prevent death. A defibrillator would be a device that generally treats certain fatal arrhythmias. Jim's heart may not require the help of the pacemaker all the time, but only occasionally when an arrhythmia develops. Jim may be mistaken if he believes that he will die painlessly as soon as the pacemaker is turned off. He may have new symptoms of fatigue and syncope and still be facing the progression of his pancreatic cancer. Dr. Austin must be sensitive to the principle of non-maleficence, in addition to autonomy. Non-maleficence prohibits her from harming Jim, even if he requests it. Dr. Austin needs to make sure that Jim understands that he may only worsen his situation without avoiding the unpleasant course of his disease.

If Jim is fully informed and is certain of his decision, then he has a right to discontinue treatment with the pacemaker device. Dr. Austin should honor his wishes. We can glean from the case's fact pattern that Jim has a certain trust in her, despite her lack of experience with patients suffering from pancreatic cancer. If she feels that her own ethical beliefs prevent her from assisting Jim in having the device turned off, she should refer him to someone who will help. Dr. Austin should continue to care for Jim as long as he wants to be under her care, or arrange for another physician to care for him. Ultimately, she should ensure that Jim is assisted in having the pacemaker turned off if the concerns discussed here are thoroughly addressed.

References

1. Opinion 2.20 Withholding or withdrawing life-sustaining treatment. American Medical Association *Code of Medical Ethics 1998-1999 Edition.* Chicago, IL: American Medical Association; 1998.
2. Pellegrino ED. Is it ethical to withdraw low-burden interventions in chronically ill patients? *JAMA*. 2000;284(11):1380-1382.
3. Opinion 8.04 Consultation. American Medical Association *Code of Medical Ethics 1998-1999 Edition.* Chicago, IL: American Medical Association; 1998.

Erin Egan, MD, JD is a senior associate at the Neiswanger Institute for Bioethics and Health Policy at the Stritch School of Medicine at Loyola University, Chicago and a resident in the Department of Internal Medicine, Loyola University Medical Center.

Kayhan Parsi, JD, PhD is an assistant professor at the Neiswanger Institute for Bioethics and Health Policy, Loyola University, Chicago Stritch School Of Medicine and graduate program director of an online masters program in bioethics.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 169-170.

CASE AND COMMENTARY
HIV Transmission, Is it a Crime?
Commentary by Erica Ozanne Linden, JD, MPH

Case
Sarah Smith is a 19-year-old student at a state university in Illinois. As part of a blood drive at her school, she donated blood for the first time in February. In late March, Sarah learned from the Red Cross that her blood had tested positive for HIV. Shocked by the news, Sarah did not tell anyone she was HIV positive or visit her physician.

Since learning of her HIV-positive status, Sarah began several relationships, engaging in unprotected sex with male students at the university. At no time did Sarah inform any of her partners of her HIV status. One of Sarah's partners later tested positive for HIV at the university health clinic. The man then listed Sarah as one of his sexual partners to the Health Department counselors.

Following up on the case, the counselors interviewed Sarah who admitted to engaging in unprotected sex with several men without informing them of her HIV status. The Health Department then notified the police and Sarah was arrested.

Commentary
Under Illinois law, Sarah can be charged with a Class 2 felony: criminal transmission of HIV.[1] (A Class 2 felony carries a possible sentence of 3 to 7 years.) A person can be charged with criminal transmission of HIV when "he or she, knowing that he or she is infected with HIV: (1) engages in intimate contact with another; (2) transfers, donates, or provides his or her blood tissue, semen, organs, or other potentially infectious body fluids for transfusion, transplantation, insemination, or other administration to another." The statute defines "intimate contact with another" as "exposure of the body of one person to bodily fluid of another person in a manner that could result in the transmission of HIV."

The statute does not require that actual HIV infection take place in order for someone to have committed criminal transmission of HIV. In addition, under the law a person is not guilty of criminal transmission of HIV if the person exposed knew both that the infected person was HIV positive, and that he or she could be infected as a result, and consented to the action.

In this case, Sarah meets the criteria for the criminal transmission of HIV and can therefore be charged with commission of the crime. Aware of her HIV-positive

status, Sarah engaged in intimate contact with other persons without informing them of her HIV status. It cannot therefore be argued that they knowingly consented to the action.

While HIV transmission statutes are common in many states, the Illinois law has been the subject of a great deal of criticism and controversy. One major criticism is that the statute requires that the person know he or she is infected with HIV but does not define what constitutes such knowledge. It remains unclear if "knowledge" requires an actual positive test result or if symptoms of the disease would be sufficient.

The statute has also been criticized because of the unclear definition of the term "body fluid." Besides blood tissue, semen, or organs, what other, if any, body fluids qualify? Saliva, urine, tears? Does the body fluid have to have been proven to actually transmit the disease? This question is made even more ambiguous by the statute's use of the word "could" in its definition of "intimate contact"; intimate contact is "exposure of one body to the bodily fluid of another person in a manner that *could* result in the transmission of HIV." Again, it is not clear whether the bodily fluid must be a scientifically proven route of HIV transmission in order for the infected person to be guilty of criminal "intimate contact."

These criticisms have formed the basis for challenges of the statute on the grounds that it is unconstitutionally vague. However both the Appellate Court of Illinois and the Supreme Court of Illinois have concluded that the statute is not unconstitutionally vague and is therefore valid.[2]

Questions for Discussion

1. Should health officials have informed Sarah of her legal obligation to inform her partners of her HIV-positive status?
2. Does a law such as the one in Illinois discourage people from being tested or seeking treatment for HIV symptoms?

References

1. § 720 ILCS 5/12-16.2 (2001).
2. People v Russell, 630 N.E.2d 794 (Ill. 1994) and People v Dempsey, 610 N.E.2d 208 (Ill. App. Ct. 1993).

Erica Ozanne Linden, JD, MPH is a fellow in the AMA Ethics Standards Group.

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 171-172.

IN THE LITERATURE

Disparities in Cancer Survival between Blacks and Whites

Faith Lagay, PhD and Rita Mitchell

Blacks in the US have poorer 5-year survival rates after diagnosis of cancer than do whites. Some large epidemiological studies have concluded that disease stage at diagnosis, socio-economic status, and level of health insurance do not account entirely for the disparity. Such findings have led some to advance the theory that cancer biology is different in blacks and whites.

Peter Bach and co-authors from the Memorial Sloan-Kettering Cancer Center conducted a meta-analysis of cancer survival studies in which they controlled for 2 different factors—quality of treatment and mortality due to other illnesses.[1] They reasoned that any remaining gap in survival rates between groups of individuals who had received the same treatment and all of whom died from the cancer itself might be attributable to differences in cancer biology.

Bach et al reviewed all English-language articles published from 1966 to January 2002 that described outcomes for black and white cancer patients. They identified 89 cohorts in 54 individual articles representing 189,877 white and 32,004 black cancer patients with 14 different cancers. The authors "identified studies relevant to the bulk of cancer types and found that, across these studies, blacks had a 16 percent increased risk of death" relative to whites. After correcting this estimate for overall higher mortality rates among blacks [that is, death from all other causes], they discovered that the "pooled estimate of cancer-specific mortality for blacks" was only 7 per cent higher.[2] Looking at specific types of cancer, the authors found that much of the excess mortality arises from increased risk of death for blacks with breast cancer, uterine cancer, and bladder cancer. No significant differences in survival rates were found between blacks and whites with lung cancer, colorectal cancer, prostate cancer, and 8 other cancers assessed in the study.[3]

Responding to hypotheses about differences in cancer biology, Bach et al claim, "We did not observe the impact of these putative biological differences consistently in cohorts of comparably treated black and white patients with cancer of similar stage once we took into account differences in underlying death rates."[4]

The authors point out that many of the studies conducted demonstrate that blacks are less likely to receive optimal care for cancer than whites and are more likely to be diagnosed at an advanced disease stage. They suggest that finding remedies for

these inequalities and addressing control of co-morbid disease should be a primary target of public health research.

Questions for Discussion

1. Do you think that these data support the authors' claim that survival after a cancer diagnosis is related to quality of treatment and other causes of death rather than to differences in cancer biology between blacks and whites?
2. What effect, if any, should the information presented by Bach et al have on a physician who has just diagnosed cancer in a black patient? Should it alter the way the physician proceeds?
3. What implications should the Bach at al findings have for further research?

References

1. Bach PB, Schrag D, Brawley OW, Galaznik A, Yakren S, Begg CB. Survival of blacks and whites after a cancer diagnosis. *JAMA*. 2002;287(16):2106-2113.
2. Bach, 2110.
3. Bach, 2110-2111.
4. Bach, 2111.

Faith Lagay, PhD is the managing editor of *Virtual Mentor*.
Rita Mitchell is a research assistant in the AMA Ethics Standards Group.

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 173-177.

STATE OF THE ART AND SCIENCE

Redefining Cloning

Faith Lagay, PhD

Picture Mr. and Mrs. Average Middle-aged American, sitting at the kitchen table, having the following discussion:

Harry: What's this stem cell research debate?[1]
Louise: A lot of people in Congress have their facts confused.
Harry: Well, I'm shocked.
Louise: One bill puts scientists in jail for working to cure our niece's diabetes.
Harry: So, cure cancer, go to jail?
Louise: Alzheimer's, heart disease, take your pick.
Harry: Why, is it cloning?
Louise: No-o-o. It uses an unfertilized egg and a skin cell.
Harry: So it's not making babies?
Louise: Just life-saving cures.
Harry: And for that, we go to jail?
Louise: We should log on and tell Congress: they can stop human cloning without stopping life-saving research.

This 30-second ad, paid for by CuresNow, appeared in selected viewer markets during an April episode of the popular weekly political drama *West Wing*. Most anyone who has followed the cloning issue, even in the popular press, since the appearance of Dolly 5 years ago, would catch what appears to be an error in Louise's emphatic, "No-o-o" to Harry's question about cloning. Many of us know by now that putting a skin cell—or other non-reproductive system cell—into an egg cell from which the nucleus has been removed is *exactly* what cloning is. The CuresNow group is not confused or just plain wrong, however. The ad is part of a larger initiative by CuresNow and others to redefine cloning so that it applies only to activities that attempt to reproduce a living, brought-to-term human being. The TV spot, nevertheless, provoked responses nearly as tangled in ethics and identity as the cloning issue itself.

The fictional characters Harry and Louise were created initially at the request of the Health Insurance Association of America (HIAA) for use in its campaign against President Clinton's health reform plan in 1994. Harry and Louise sat at their kitchen table and, with genuine concern in their voices, worried that people would lose choice of doctors under the Clinton plan and that the proposed plan would be so expensive that employers would no longer offer health insurance as a benefit.

HIAA spent $17 million on its total campaign and, as we know, the plan was defeated.[2]

HIAA brought Harry and Louise and their kitchen table back in January 2000. This time the couple hovered over a lap-top computer composing e-mails that urged their congressmen to pass universal health coverage legislation. At first, observers were startled by Harry and Louise's switch to support of "InsureUSA," but, as HIAA explained, the association has always favored universal coverage; insurance, after all, is its business. They merely opposed the Clinton plan.[2]

Harry and Louise's third appearance, the one transcribed at the top of this article, startled even HIAA, prompting them to sue CuresNow for copyright violation. A coalition of scientists, patient advocate groups, and leaders in the entertainment world, CuresNow hired Harry and Louise—the same 2 actors—to endorse Senate legislation that, while banning cloning for human reproduction, would allow the creation of embryos by somatic-cell nuclear transfer (SCNT) as sources of stem cells for research. HIAA claims in its suit that CuresNow has "hijacked its corporate identity."[3]

Corporate identity's just the beginning. In its outrage, HIAA charges that by employing the same actors to play the same characters, the CuresNow ad is confusing the public and affecting the association's image. This line of argument implies that the TV characters have *characters*, that is, personalities, world views, and political leanings, the integrity of which is being violated by the CuresNow ad. [Surely a persuasive anti-anti-cloning caution about equating appearance with identity lurks herein.] Lest anyone miss the irony in it all, a group known as Americans To Ban Cloning, chaired by William Kristol, playfully responded with the following radio ad starring, not Harry and Louise but, Harriet and Louis:

Harriet: Louis, did you see that ad on TV about cloning?[4]
Louis: The one with the couple who look just like us.
Harriet: Spooky, huh?
Louis: You don't suppose they're really clones, do you?
Harriet: Who knows? It seems like some biotech companies will do just about anything to make a buck. Did you know they want to get patents on human clones, just like they do on lab animals?
Louis: But their ad says they're only using a human egg and a skin cell.
Harriet: Well, that's how you make a clone!
Louis: But they also say cloning is needed to cure terrible diseases.
Harriet: Look, if they were really interested in cures, they'd be talking about adult stem cell research, which shows far more promise—not creating embryos to destroy them for medical experiments.
Louis: What can we do to stop them?
Harriet: Well, there is a Senate bill that bans all human cloning.
Louis: But not lifesaving research?

Harriet: Of course not. It's the bill President Bush supports. We need to call Senator [whoever represents the viewing area] at [telephone number].
[Doorbell rings]
Louis: Harriet, your sister is here.
Harriet: Sister? I don't have a sister.

What's It All About, Harry?

Those who read Harry and Louise's opening exchange carefully noticed just what Harriet points out and probably responded the same way Harriet did, "that's how you make a clone [Duh deleted]." The ads are working from 2 definitions of "cloning." Harry and Louise are departing from the more widely used definition that understands cloning to include all somatic-cell nuclear transfer. That's how Dolly was created and how any other cloned organism is created. The defining difference between cloning and sexual reproduction is that the cloned organism, rather than getting ½ of its genetic material from each parent, gets its full complement of nuclear genetic material from only one source—the person whose DNA is inserted into the enucleated egg.[5]

Harry and Louise, scripted by CuresNow, are following the lead of democratic Senators Edward Kennedy, Dianne Feinstein, and Thomas Harkin and their supporters in subdividing SCNT into 2 separate activities: (1) SCNT intended to reproduce human beings—which they call "cloning," and (2) SCNT for the purpose of creating embryos from which stem cells can be retrieved by researchers, with the embryo destroyed in the process. The latter, they do not call cloning.

The Senate has been attempting to pass anti-cloning legislation since shortly after Dolly's appearance in 1997; it last came close in 1998. An event of that same year, however, complicated the task of passing anti-cloning legislation. Researcher James Thompson, working at the University of Wisconsin and funded by the biotech industry's Geron Corporation, isolated stem cells from human embryos for the first time in that year. Embryonic stem cells give rise to every other type of cell in the human body, and cell biologists are confident that, by studying these cells, they will learn how to direct them down specific paths of differentiation. If they succeed, they will be able to grow tissue to replace diseased or damaged tissue in the nervous system, blood, cartilage, pancreas and other organs, even the heart. Such capability might then allow physicians to combat Parkinson's and Alzheimer's diseases, diabetes, cancer, spinal cord injury, and many other conditions. Cloning embryos would make many more embryonic stem cells available and hasten the day when treatment is possible. Moreover, if the embryo is created using the somatic DNA of the person with the disease or damaged tissue, the resulting tissue can be transplanted without fear of its being rejected.

Because of the promise of embryonic stem cell research, the authors and supporters of 2 Senate bills want to distinguish between SCNT to create another human being—which they want to prohibit and penalize—and use of SCNT to create embryos for research purposes which would be destroyed after 10 to 12 days.

Opponents object to both reproductive cloning *and* creating embryos that will be destroyed in the interest of research. They call the latter practice "therapeutic cloning" or "research cloning," but Kennedy, Feinstein, Harkin, Harry, and Louise don't want the C-word in there at all.

The Feinstein-Kennedy Bill (SB 1758) defines the cloning it wants to outlaw as, "asexual reproduction by implanting or attempting to implant the product of nuclear transplantation into a uterus.6 The Harkin Bill (SB 1893), called the Human Cloning Ban and Stem Cell Research Protection Act of 2002, similarly limits the definition of cloning to asexual human reproduction achieved by "implanting or attempting to implant the product of nuclear transplantation into a woman's uterus or a substitute for a woman's uterus."[6]

Both bills are alternatives to the Human Cloning Prohibition Act of 2001 (SB 790), authored by Sam Brownback and supported by Louis and Harriet, the Americans To Ban Cloning, and others, including anti-abortion and many religious groups. The Brownback bill defines human cloning as "human asexual reproduction accomplished by introducing nuclear material from one or more somatic cells into a fertilized or unfertilized oocyte whose nuclear material has been removed or inactivated so as to produce a living organism (at any stage of development) that is genetically virtually identical to an existing or previously existing human organism."[6] By inserting "at any stage of development," the bill includes as "clones" embryos that will be destroyed after giving up their stem cells to researchers and will not be implanted into a uterus or uterus substitute.

All 3 bills differ from earlier fetal tissue, embryo, and stem cell regulation by outlawing the practices they define (differently) as cloning rather than merely withholding federal funding from such operations. All 3 stipulate a $1 million fine and up to 10 years imprisonment for those who (1) conduct or attempt to conduct human cloning, (2) ship the product of nuclear transfer for the purpose of human cloning within the US or elsewhere, or (3) use federal funds in support of the activities proscribed in (1) and (2).

The Feinstein-Kennedy Bill, in adopting the same name as the Brownback Bill—the Human Cloning Prohibition Act of 2001—is forcing its definitional distinction. Passing that legislation would mean that senators opposed "cloning" as more narrowly defined by the Feinstein-Kennedy and Harkin bills. The bill is far from becoming law. Even if passed by the Senate, the bill is so different from the bill passed by the House of Representatives in July 2001 that it would have to go to a conference committee for compromise legislation. As bioethicist George Annas put it in a recent *New England Journal of Medicine* article, "if the link between research and reproduction cloning cannot be severed, efforts at [legislative] compromise will likely prove futile and the effort to outlaw reproductive cloning will die in the Senate again as it did in 1998."[6] But if legislation similar to Feinstein-Kennedy or Harkin were enacted into law, all subsequent enforcing regulation would restrict the

definition of cloning to "cloning with the intent to reproduce," and we would be witness to language in lexical transition.

References

1. Transcript of TV ad paid for by CuresNow. Available at: http://curenow.iwarp.com/transcript.html. Accessed May 3, 2002.
2. Bunis D. The Harry and Louise show. Salon. Available at: http://archive.salon.com/health/log/2000/01/20/harry_and_louise/. Accessed May 3, 2002.
3. Faler B. New "Harry and Louise" ads spur lawsuit. *Wash Post*. May 3, 2002.
4. Americans To Ban Cloning. Harriet and Louis set the record straight on human cloning. Available at: http://www.cloninginformation.org/audio/shc_commercial_script.htm. Accessed May 3, 2002.
5. As a general description, this is accurate. To be scientifically precise, it must be qualified. The product of SCNT will have some non-nuclear DNA from the mitochondria in the egg cell's cytoplasm that will pass to the embryo. The greatest portion by far of encoding genetic material for the new organism's structure and function will come from the nuclear DNA.
6. Annas GJ. Cloning and the US Congress. *N Engl J Med*. Available at: http://content.nejm.org/cgi/content/full/346/20/1599. Accessed May 24, 2002.

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

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 178-179.

VIEWPOINT
Medical Errors
Rita Mitchell

- In 1999, the Institute of Medicine reported that there are an estimated 44,000 to 98,000 deaths among Americans each year due to medical error.[1]
- A *JAMA* article in 2000 categorized medical error deaths as follows:[2]
- 12,000 deaths/year from unnecessary surgery.
- 7,000 deaths/year from medication errors in hospitals.
- 20,000 deaths/year from other errors in hospitals.
- Patients with some serious medical conditions are more likely to die in the hospital if they are admitted on a weekend than if they are admitted on a weekday.[3]
- More than half of the surgical errors occur in either a hospital-based ambulatory surgery unit or freestanding ambulatory setting.[4]
- According to the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), the most common reported surgical errors involve surgery on the wrong body part or site (76 percent), surgery on the wrong patient (13 percent), the wrong surgical procedure (11 percent).[4]
- Of the surgical errors reported to JCAHO, 41 percent related to orthopedic/podiatric surgery; 20 percent related to general surgery; 14 percent to neurosurgery; 11 percent to urologic surgery; and the remaining to dental/oral maxillofacial, cardiovascular-thoracic, ear-nose-throat, and ophthalmologic surgery.[4]
- Factors contributing to the increased risk of surgical errors included: emergency cases (19 percent); unusual physical characteristics, including morbid obesity or physical deformity (16 percent); unusual time pressures to start or complete the procedure (13 percent); unusual equipment or set-up in the operating room (13 percent); multiple surgeons involved in the case (13 percent); and multiple procedures being performed during a single surgical visit (10 percent).

References

1. Kohn L, Corrigan J, Donaldson M; Institute of medicine, eds. *To Err Is Human: Building a Safer Health System*. Washington, DC: National Academy Press; 1999.
2. Starfield B. Is US health really the best in the world? *JAMA*. 2000;284(4):483-485.

3. Bell CM, Redelmeir DA. Mortality among patients admitted to hospitals on weekends as compared with weekdays. *N Engl J Med*. 2001;345(9):663-668.
4. Joint Commission on Accreditation of Healthcare Organizations. Sentinel Event Alert. 2001;24. Available at: http://wwwjointcommission.org/sentinelevents/sentineleventalert/sea_24.htm.

Rita Mitchell is a research assistant in the AMA Ethics Standards Group.

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 180-181.

PERSONAL NARRATIVE

Through the Patient's Eyes: A Maddeningly Complex Disorder

Ellen Painter Dollar

Though I don't remember his name, I will never forget his face. I was 9 years old, in the emergency room with two broken femurs. My parents—well-versed in fracture care, given that I had already had about 30 fractures—suggested that the doctor wait until I was sedated to remove my long leg braces. The braces were helping to stabilize the fractures, and minimize my pain. The doctor's response? "I'm the doctor here."

My whole family remembers this doctor. In the dozens of other trips we made to the emergency room, there were no doubt many more gentle, more compassionate doctors and nurses. But we don't remember any of them. We remember the one who was arrogant and insensitive to a child's pain and her parents' hard-earned wisdom.

I have osteogenesis imperfecta (OI)—a genetic disorder of type 1 collagen that causes fragile bones and a host of other problems. OI occupies an unfortunate place in the medical glossary of most physicians. It is common enough to merit some attention in textbooks. Most doctors I've met have heard of it. They ask to see my eyes (the sclera are blue—a telltale sign of OI). But it is rare enough that most physicians, even orthopedists, have never treated anyone with OI. Their knowledge is limited to a paragraph or two in a medical textbook, perhaps accompanied by a photo of a severely affected child.

OI is a maddeningly complex, variable disorder. It can be so mild it is never diagnosed, and so severe that newborns die within hours. I have a 30-month-old daughter who inherited OI from me. She has had one fracture. She has significant delays in physical development and just started walking this week. By the time I was her age, I had had seven fractures—six femurs and one radius. But I walked at 18 months. I spoke to a new mother earlier this week whose infant daughter has had as many fractures in her 6 months of life as I have had in my 34 years. I, my daughter, and that little girl all have OI. But for everything we have in common (fragile bones, blue sclera, loose joints) there are innumerable ways we are different.

Perhaps the most unpredictable facet of OI is the fractures themselves. My older brother accidentally tipped me out of my baby carriage when I was 2 weeks old. I was fine. One day when I was about 4, I sat on the floor and broke my femur. I've seen pictures of a teenage boy with OI snowboarding. This week, I heard about a

little girl whose arm broke while she was sitting—yes, just sitting there—in a grocery cart.

Few physicians have enough contact with the disorder to understand these variabilities. They tell parents whose babies are prenatally diagnosed with OI that they should prepare for their baby's death. Never mind that the most severe form, in which neonatal death *is* quite possible, is the least common of several types of OI, and that it is difficult to prenatally distinguish this type from the other severe but nonlethal types. Other doctors report parents whose baby has repeated unexplained fractures to social services, refusing to consider an OI diagnosis because they have that textbook picture in their mind of a severely affected infant with c-shaped femurs, a large head, and a tiny body. They can't believe that a child who looks completely "normal" (except for that funny blue tint in her eyes) could possibly have OI.

My family has been fortunate not to have either of these all-too-common, horrifying experiences. We have, by and large, been blessed with gentle and kind physicians who, although they are not OI experts, understand that we are, in our own never-been-to-med-school way. They understand that, though we can't explain the intricacies of OI genetics or the properties of type 1 collagen, we can tell when an injury requires an X-ray and when it just requires an Ace wrap. We know when our children have reached the limit of their endurance—when they need a sedative to calm them before the umpteenth IV stick, when they need mom or dad to position them on the x-ray table instead of an inexperienced X-ray tech, and when they need to keep their braces on bilateral femur fractures until anesthesia takes away the pain.

So we've been lucky. Our worst doctor-patient encounters have been like the one with Mr. "I'm the Doctor Here" in the ER 25 years ago. I wonder, did that doctor enter the profession hoping to be the kind of doctor his patients remember the rest of their lives? He has succeeded in that, though I'm sure not as he intended.

Ellen Painter Dollar is a freelance writer and former director of public relations and events for the OI Foundation. She edited *Growing Up with OI: A Guide for Families and Caregivers* and wrote *Growing Up with OI: A Guide for Children*, both published in 2001.

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 182-183.

PERSONAL NARRATIVE

Through the Student's Eyes: Fighting Medical School Tuition Hikes in New York

Albert Hsu

Last May, the State University of New York (SUNY) Board of Trustees proposed to increase annual public medical school tuition from $10,840 to $18,840 by 2004-05, outraging and creating hardships for many medical students statewide.[1, 2] First-year students at the 4 SUNY schools were not informed until late fall; thus, they did not learn of this increase until after they had made their choices of career and school. Their mid-year and retroactive tuition hike of 20 percent at the end of that semester thus came as an unpleasant surprise. Medical students at SUNY-Upstate were not even granted extra loans, so they had to pay that extra $2,000 out-of-pocket. A second installment of these tuition increases was also approved by the Board this spring.

Tuition hikes are not just a New York issue. Faced with the current economic downturn, many state legislatures are cutting their education budgets; this often forces public medical schools to impose dramatic increases. Last December, the state medical program in Indiana enacted a mid-year tuition hike of $500. Tuition increases of 8 percent or more have also been proposed at public medical schools in Minnesota, South Carolina, Wisconsin, and Arizona.

How can medical students fight this? Here in New York, students first built a coalition of both public and private medical schools, the SUNY Medical Student Executive Council. After all, medical schools closely monitor each other's tuition—so if SUNY drastically increases its tuition, private medical schools are not likely to be far behind. Our strategy has been to underline the impact on the general public. We have focused on two issues in our argument against these tuition hikes: access to a public medical education and future access to healthcare in New York.

Under the aegis of the Medical Society of the State of New York (MSSNY), we medical students visited legislators in our state capitol this March to express our concerns, then we followed up with a letter-writing campaign. Physicians in both our AMA and MSSNY have been very receptive to our concerns, establishing new policy in support of our efforts.[3] We also obtained prominent media coverage in a large daily newspaper, which publicized the impact of these tuition hikes.

Since this is an election year for the governor and the entire New York State legislature, it is an excellent environment for our on-going lobbying efforts. This

summer, we plan to meet with individual members of the SUNY Board of Trustees, asking them to spread these tuition increases out over a more gradual time frame. Finally, we wish to develop state legislation that would freeze tuition to the levels when each student first enters medical school, similar to policies already in place at the Mayo Medical School, Johns Hopkins, and Washington University School of Medicine.

Before we can stress additional arguments nationally, we need more data to quantify the impact of educational debt on specialty choice and on practicing in underserved communities – as well as the impact of increased tuition on student decisions to choose a medical career. If you are concerned about tuition increases and student debt at your medical school, the first step is to determine who establishes your tuition. For many state medical programs state legislatures or a Board of Regents sets tuition. To join our coalition or to hear more about our efforts in New York, please contact. It is critical for medical students working on this issue to share experiences and strategies. Only by working together can we hope to restrain escalating medical school tuition and educational debt.

References

1. Winslow O. A bitter pill for students; med school tuition hike a shock. *Newsday*. April 1, 2002:A6.
2. Winslow O. SUNY hikes med school tuition–students fear effect of higher loan debt. *Newsday*. April 25, 2002:A24.
3. State medical society policy established April 14, 2002 by the Medical State Society of New York (MSSNY). AMA policy established December 2001.

Albert Hsu is a student in the MD/PhD program at the Albert Einstein College of Medicine. He is former chair of the Legislative Awareness Committee of the MSSNY-MSS.

Virtual Mentor
American Medical Association Journal of Ethics
June 2002, Volume 4, Number 6: 184-185.

PERSONAL NARRATIVE

Through the Student's Eyes: Tuition Hikes Hurt Students and the Public

Josh Cohen

In the fall of this year, students at the State University of New York (SUNY) public medical schools received unsettling news. The SUNY Board of Trustees decided to enact mid-year and retroactive 20 percent tuition increases at the SUNY public medical schools. What was particularly troubling about this was the further indication that this is only the first installment in a proposed series of similar annual tuition hikes for each of the next three years.

A few weeks ago, a further tuition hike was approved for New York public medical schools next year. This raises tuition for students at the Brooklyn, Buffalo, Stony Brook, and Syracuse campuses from $10,840 to $14,840 in less than 12 months. SUNY Chancellor Robert L. King has cited rising costs in medical education, a decline in federal and state funds for graduate medical education and the need to maintain quality as reasons for an increase.

Similarly, we're told that New York state medical school tuition will stay 'competitive' with other state schools even after two further increases. Average tuition and fees for first-years at public medical schools has already increased by over 300 percent between 1981 and 1999, and it shows no signs of stopping.

On its website, SUNY indicates that it has "gone to great lengths to ensure the broadest possible access to its institutions for students of all income and ethnic groups, and from all the state's regions." However, this series of medical school tuition increases will raise a barrier to access to a public medical education, preventing some from entering the medical profession altogether. This barrier to students seeking access to a public medical education will readily translate into barriers to patients seeking healthcare in underserved rural and urban communities.

Physicians from economically disadvantaged and medically underserved communities often return to provide health care in those communities after their training. Medical students from such areas, who are already straining themselves financially to attend medical school, would be the most adversely affected by this relentless series of coercive tuition hikes. Many of these students chose to remain close to home for medical school as a way of serving their communities and decreasing their potential debt burden on graduation from medical school. Increased debt burdens may deter these students from considering careers in primary care and

returning to practice in their communities, as they struggle to repay much more in educational loans than expected.

Students at private medical schools are also starting to get very concerned. Private medical schools often set tuition to "whatever the market can bear" -- and if SUNY medical school tuition goes up drastically, private medical schools may soon experience similar increases to balance out the market. The result could be a medical school market which prices out the economically disadvantaged students and trains the richest rather than the brightest students.

While raising SUNY medical school tuition may be a convenient short-term solution to a budget shortfall, the long-term consequences of this action will impact future physicians, as well as access to health care for the citizens of New York State.

Josh Cohen is in the NYU Medical School class of 2003 and is national chair-elect of the AMA-Medical Student Section.