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Quote to note

"We can't use the vocabulary that describes brain activity for psychological phenomena. It won't work."

Jerome Kagan, PhD
Boston Globe
April 24, 2006

Inside

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Free will and moral responsibility in the age of neuroscience

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Basic and clinical neurosciences have shed considerable light on the neural correlates of our thought and behavior. If our motivational states and actions have a neurobiological underpinning, then does this threaten our conviction that we act freely and can be responsible for what we do or fail to do? Are we the ultimate authors of our actions? Or does neuroscience imply that our belief in free will is an illusion? Although the brain mediates the mental states associated with our actions, this, by itself, does not mean that we have no control over our mental states and cannot be free and responsible agents.

The mind is a set of conscious and unconscious states including beliefs, desires, emotions, memories and intentions that emerge from the brain. This does not suggest a dualistic view of brain and mind, since brain and mind are linked by bi-directional pathways. Mental states are mediated by the activity of neuronal networks that enable arousal and awareness. Beliefs, emotions and other mental states, in turn, can influence the brain by the way they represent events in the natural and social environment.

The brain is subject to material analysis, but the mind is not. The essence of mind is consciousness. Attempts to explain consciousness in physical terms have failed, because consciousness cannot be reduced to physics or the organization of neural networks. The essence of mind is so unique that it cannot be described in terms of any known physical parameters. Mind, according to philosopher John Searle, is "ontologically subjective," which means that its essential features cannot be described from an external point of view. What is defined by neuroscience cannot be the essence of the mind. This position stands in contrast to cognitive science, which holds that mental phenomena can be reduced to physical terms. To borrow Searle's term, we can describe the account of mind that I have presented as "biological naturalism."[1]

One of the issues raised by neuroscience is whether brain events causally determine mental events and the actions to which they lead. This is the crux of the question of whether we are free and responsible agents. Free will pertains not to what natural laws and past events allow us to do, but to what we can do given the relation between the brain and the mind. The will is a set of cognitive, affective and conative (desire, motivation, volition) capacities. The will is free when these capacities enable us to control our behavior by guiding attention, thought and action in accord with intentions and goals. Moral responsibility for our behavior presupposes

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free will, which, in turn, presupposes the requisite control.

In the 1980s, neuroscientist Benjamin Libet conducted experiments showing that the conscious intention to act is preceded by the activity of event-related potentials in certain regions of the brain.[2] His studies indicated that our conscious intention to act lags 300 to 500 milliseconds behind the unconscious brain event that leads to the intention. If free will requires that every event in the causal pathway leading to action be under our conscious control, then Libet's experiments seem to suggest that the idea of conscious free will is an illusion.

Yet it is quite plausible to assume that we can be genuine authors of our actions if we are not impeded in consciously reasoning, choosing and acting. From the mere fact that a brain event precedes a mental event, it does not follow that the first impedes or forces the second. If our motivational states are not compelled, coerced or manipulated by factors beyond our control, and if we have the capacity to reflect on, identify with and execute these mental states in actions, then we can act freely. It is only when unconscious brain events interfere with these conscious capacities that the will might not be free. In effect, this is what Aristotle argued in *The Nicomachean Ethics*. We can assume that a person acts freely and responsibly unless there is evidence that internal or external factors forced him to act, or he was ignorant of the circumstances of action.

A person's ability to consciously form a motivational state and to restrain or execute actions is influenced by the brain. But this ability can be influenced by factors in the social environment as well. Social expectations can influence our perception of the actions that are open to us, just as lack of mobility due to physical disability can limit the available options. Brain scans showing structural or functional features, such as metabolic activity and blood flow in the brain, cannot explain the subjective experience of feeling in (or out of) control of our behavior. This feeling can influence our perception of the actions open to us when we deliberate and make decisions.

Even if functional neuroimaging could accurately measure the neural processes associated with our mental states, it would not provide simple answers to questions such as whether or to what degree people act freely and can be responsible for their behavior. Perhaps the main reason for questioning the use of brain imaging or other neuroscientific techniques to make judgments about people's ethical behavior is that it involves a move from what is true scientifically about the brain to a moral judgment. Empirical measures of brain structure and function alone will not tell us whether an individual had or lacked the capacity to control his or her mental states and actions. Mind is subjective, unique to each individual and cannot be visualized on brain scans or other imaging techniques.

We must hold persons responsible for their moral decisions and not blame their brains.

Computed tomography or functional magnetic resonance imaging of the brains of violent offenders may reveal structural and functional abnormalities that presumably would explain their behavior. Yet many people with similar brain abnormalities do not commit violent or otherwise harmful acts. Brain imaging and other neuroscientific techniques can at most show correlations between neural events and behavior but do not lead to proving that the brain determines behavior. For this same reason, there is no basis on which to claim that neuroscience implies that our belief in free will is an illusion. We must hold persons responsible for their moral decisions and not blame their brains.[3]

This does not imply that persons and brains are independent entities. We hold persons responsible on the basis of the mental states that issue in their actions, and these states depend on interacting subcortical and cortical brain functions. But the content of these mental states cannot be explained entirely by reference to their neural correlates. The reasons for holding persons responsible for their actions and omissions may be influenced, but are not determined, by what we know about the brain. Although our understanding of free will and responsibility may become better informed by neuroscience, moral decision-making is not just solely a function of neurobiology. It emanates from our conscious minds, and we cannot exculpate immoral behavior simply on the basis of the findings of neuroscience.[4]

Mapping and measuring brain structure and function alone cannot distinguish between not having the capacity to control one's behavior and having, but failing to exercise, this capacity. Neuroimaging also will not lead us to believe that we are less praiseworthy for our positive actions. Images of normal brains will not threaten our conviction that we have the capacity to control our behavior and that we are autonomous agents. Even with further advances, neuroscience will supplement, not supplant, existing criteria of free will and responsibility in moral and legal domains.

It may be some time before measures of brain structure and function become precise enough to be helpful in evaluating human behavior. When they do, they will most likely be used only to support mitigating or excusing conditions due to significant brain abnormalities that have been shown to interfere with the capacity for reasoning and impulse control. Ultimately, as a society, we will have to decide how information about the brain can or should be used in assessing whether a person acted freely and could be responsible for his or her actions. □

[1]Searle J. *The Rediscovery of the Mind*. Cambridge, MA: MIT Press, 1992.

[2]Libet B. *Mind Time: The Temporal Factor in Consciousness*. Cambridge, MA: Harvard University Press, 2004.

[3]Gazzaniga M. *The Ethical Brain*. New York: Dana Press, 2005.

[4]Rose S. *The Future of the Brain: The Promise and Perils of Tomorrow's Neuroscience*. New York: Oxford University Press, 2005.

Ask the ethicist:

Must physicians respect an incompetent patient's refusal of treatment?

Question: A 65-year-old man with longstanding untreated hypertension was admitted to the CCU for management of an acute myocardial infarct. He was anticoagulated and scheduled for cardiac catheterization the following day, but he complained that his IV tubing was restraining him and holding him against his will. He said that he did not want catheterization and demanded to be discharged. Attempts to counsel him gently about the health risks of leaving the hospital were unsuccessful. Psychiatry consultants concluded that mild dementia and paranoia, believed to be irreversible, impaired the patient's ability to test reality. They declared him incompetent to make medical decisions.

The patient lived with his daughter, who took care of him. "He intimidates me," she told the hospital attending. "I never disagree with his decisions." He had no advance directives. His primary physician of many years said that he always rejected medical advice and did not comply with recommended treatment, such as taking medicine to control his blood pressure. The attending asked the ethics consultation team to address the question: Does this decisionally incapacitated, acutely ill man have the authority to refuse necessary medical treatment?

Response: Some considerations that stem from the consult question are: Is this a medical emergency? Is the proposed intervention really obligatory? Is the patient completely lacking in decisional capacity? If so, who should decide for him? If not, is his opinion against treatment deserving of respect? What are the guidelines for the physician?

The patient has a life-threatening condition. He is being offered a test to determine the course of therapy and improve his chance of a good outcome, but he may be able to recover without the planned procedure. He is considered incapable of consenting validly to one of the choices he has been offered and incapable, therefore, of making an informed, valid refusal (by "consenting" to the always-available "choice to do nothing").

Nevertheless, he has clearly refused. To perform catheterization and subsequent stenting or angioplasty, it will be necessary to render him incapable of resisting.

Although his daughter is not his appointed surrogate, she would normally be asked for her recommendation. If she recommended going ahead with catheterization, she would not be exercising "substituted judgment" (making the choice her father would make); she knows from experience that he would refuse. She would, instead, have to decide in his best interests as she saw them—a lower standard.

This daughter, though, cannot make any decision on her father's behalf: If she supports his refusal, she may be doing so because she fears him. A coerced decision is invalid. The doctors must not try to convince her to sign for the procedure, because they might be putting her in danger.

We have no insight into the patient's reasons for refusal of treatment in the past, but we are not entitled to conclude, on that basis alone, that he was (and is) irrational. Even patients with major psychosis are not automatically deprived of the right to make their own decisions. (With the HIPAA law, the pendulum has actually swung the other way.)

The situation is urgent but not an emergency. Therefore, "presumed consent" to intervention does not exist. The term "simple consent" has been used when a patient assents to treatment without fully understanding his situation, his choices and their anticipated consequences.[1] In this case, some might use the term "simple refusal."

The validity of consent is strengthened when patients' decisions are consistent with their previously expressed values and behavior. The behavior of a demented person may change as the disease progresses. Although the idea has been advanced that a "demented self" should be fully respected and the "new person" accorded the autonomy of the old one,[2] I find that idea medically insupportable: dementing illnesses are not compatible with a new-person concept. Instead, they destabilize and relentlessly disintegrate the personality. They deprive the patient of the consistency that helps define choice as autonomous.

Whether this patient is demented or not, he has continued to behave as his long-time physician and his daughter expected. If he has a new personality, it's hard to tell it from the old one. His consistency with past behavior strengthens the idea that his refusal should be respected.

The in-between status of both the patient's dementia (not profound) and his acute condition (prognostically uncertain) may tempt his caregivers to make an end-run around the ethical issue in favor of one or another "medical" solution: He doesn't have to have the IV. Take it out; he will be more tractable. Then go ahead with catheterization. Afterwards, he probably won't even remember the intervention. OR: Don't catheterize him. He'll probably survive, as he has so often in the past, despite not going along with recommended treatment.

If, although the physicians think the best choice medically speaking is to catheterize, they don't do it *because the patient has refused the procedure,* their decision is wise from a *legal* standpoint. (Forcing a patient to undergo a procedure against his will is considered to be battery in many jurisdictions.) More important, they are being guided by *ethical* principles—as professionals should be.

A bare-bones analysis makes this case one of autonomy versus beneficence. As beneficence shades toward paternalism and respect for autonomy is fortified by the idea that the rights of those who are most vulnerable are most in need of protection, it becomes easier to recommend that the patient's wishes should be respected. Moreover, there is a *right* to *refuse* treatment, but no corresponding right to receive a specific treatment, even if a patient demands it. Ignoring a refusal may be grounds for legal action. These observations show the strength of refusal. In this case, the doctors should respect it. □

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[1]Gert B, Culver CM, Clouser KD. *Bioethics: A Return to Fundamentals.* New York: Oxford University Press, 1997:131–250.

[2]Dresser R. Missing persons: legal perceptions of incompetent patients. *Rutgers Law Review* 1994;461:609–719.

The legal column:

Choosing paternalism?

By Diane Hoffmann, JD
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Autonomy, in the context of our legal framework for patient decision-making,[1] is under siege. The attack is coming from at least two quarters. Some believe that patients have taken the autonomy model too far, demanding certain treatments that physicians would not recommend. This has occurred in legal cases like Wanglie, Gilgunn, and Baby K, where physicians believed that continued life-sustaining treatment for the patient was "futile" or medically inappropriate, and patients or their family members demanded continued treatment. But, it also occurs in other medical settings, for example, where pregnant women demand cesarean sections or assertive parents demand an antibiotic for their child's sore throat. The second onslaught comes from a wholly different perspective—patients and their surrogates, who are uncomfortable making complex medical treatment decisions, especially when their choices are fraught with uncertainty. They are often overwhelmed by the information and the responsibility.

Most attention in the bioethical and medical literature has focused on the former of these assaults; I want to focus on the latter. There is considerable support for the view that patients who are ill and fragile may not want to make their own treatment decisions. In his book, *The Practice of Autonomy: Patients, Doctors and Medical Decisions*,[2] law professor Carl Schneider amasses considerable data on this point. For example, he cites a study by Ende et al.,[3] who presented 312 patients in a primary care clinic with a series of vignettes representing various levels of illness severity and asked them in each scenario, on a scale from 0 to 100, to indicate their desire for making their own treatment decision. The mean score for the study population was 33.2, indicating that patient preferences for decision-making were quite weak. In addition, they found that as patients were asked to consider increasingly severe illnesses, and as they got older, their desire to make decisions declined.

Schneider also presents data that patients are willing to cede some of their autonomy when they are incompetent, even if they have expressed preferences for or against various forms of treatment. He cites the work of Sehgal and colleagues[4] who asked 150 dialysis patients "how much leeway their physician and surrogate should have to override [their] advance directive if overriding were in [their] best interests." The patients varied greatly in their responses: 39% said "no leeway;" 19% said "a little leeway;" 11% said "a lot of leeway" and 31% said "complete leeway."

Articles confirming this perspective have also appeared in the popular press. Last August, a *New York Times* article[5] described the anguish and abandonment patients feel when forced to make difficult medical decisions. The article relates the case of a 39-year-old woman with ovarian cancer that had metastasized to her liver. She was asked to decide whether to undergo a novel chemotherapy regimen about which five oncologists disagreed. When she asked her doctor what she should do, he said he didn't know, and that she would have to make the decision based on her own values. The patient, "bald, tumor-ridden and exhausted from chemotherapy, was reeling. 'I'm not a doctor!' she shouted. 'I'm a criminal defense lawyer! How am I supposed to know?'" The story illustrates the frustration, anxiety and loneliness of being a "modern patient" attempting to cope with medical uncertainty.

When patients are competent, ideally they and their physicians engage in shared decision-making, where there is give-and-take between both, and neither the autonomy nor the paternalism model dominates. However, once a patient lacks competency, the opportunity for shared decision-making is gone (at least between the patient and physician). In those circumstances, how should we respond?

If we are persuaded by the studies and anecdotes indicating that at least some portion of our population is not comfortable with the "autonomy model," should we change our legal framework for health care decision-making? In particular, should we change our framework for making decisions about life-sustaining treatmentfor patients lacking decision-making capacity?

Certainly, we cannot abandon autonomy; for many people the autonomy model is still sacrosanct. Rather, we need a model that allows for flexibility—for both autonomy and paternalism. There are, however, obstacles to choosing paternalism once a patient lacks capacity. One reaction would be to give patients an option to "undermine" their own autonomy, i.e., to autonomously choose paternalism. At least one state, Alabama, has made it easier for patients to give up some autonomy by modifying the state's advance directive form to allow patients to indicate whether they want their wishes strictly followed or prefer that their proxy do what he or she thinks is best, even if it means doing something different from what the patient has specified in the form.[6] The Maryland legislature recently made a similar change to its advance directive form.[7]

Another response would be to make it easier for patients to appoint their physician as their health care agent. Many states specifically prohibit this, arguably due to concerns about physician paternalism and possible conflicts of interest.[8] Ironically, these laws replace physician paternalism with state paternalism.[9] In New York, for example, health care proxy instructions provide that you can appoint your physician as your proxy but then he/she cannot also be your treating physician.[10] In Massachusetts, a physician can be appointed as a health care proxy but only if he/she is not the administrator, operator or employee of a health care facility where the patient is receiving care, unless the physician is also a relative of the patient.[11] Whether or not we should loosen our laws to allow for this option raises normative questions about whether physicians should be given the authority to both treat and act as agent.

Unfortunately, our current framework for health care decision-making seems to be one in which we expect that one size will fit all. In the 1960s, we rejected the paternalism model and

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In the line of duty: SARS and physician responsibility in epidemics

This is an edited transcript of a forum presented by the Harvard Medical School Division of Medical Ethics in December 2005.

***Dan W. Brock, PhD**, Moderator, Frances Glessner Lee Professor of Medical Ethics at Harvard Medical School, Director of the Division of Medical Ethics:*

Several decades ago many people thought that the era of infectious disease was behind us. HIV, SARS and avian flu have relieved us of that illusion. We invited Dr. William Ho, chief executive of the Hong Kong Hospital Authority at the time of the SARS epidemic in Hong Kong, to speak about his experience, and Dr. Walter Robinson, a member of the Divisionof Medical Ethics, to speak aboutthe physician's responsibility in an epidemic.

***William Ho, MD**, former chief executive of the Hong Kong Hospital Authority:*

Let me begin by giving you the background for this epidemic in Hong Kong. There are factors unique to Hong Kong—different health care systems, different societies, different professional cultures—which make this outbreak different than one in Boston. In our public hospitals, we don't have the luxury of individual beds and individual rooms. We have large hospitals with more than a thousand beds, which are quite crowded, and patients are nursed in bed cubicles very near to each other.

Yet we also had some advantages in dealing with this outbreak: In my position, I manage all 40 public hospitals with all 53,000 staff, and these hospitals have a unified information technology network. This single system uses common definitions for illnesses, and unique patient identifiers as well as a host of common applications for data management and transmission. We also have a very high level of professionalism from our staff. We pride ourselves in having a good partnership between managers and doctors, because almost all the CEOs in our system are doctors. Unlike some of our neighbors, we also have a high level of public transparency about our work.

In the wintertime of 2002, we began to hear rumors that there was a mysterious disease in Guangzhou, something like atypical pneumonia But how should we prepare for this? Every month we would have about a thousand patients with atypical pneumonia in our hospitals. If a new disease were present, we might not recognize it. We concentrated on the most severe cases and asked hospitals to report all cases of severe community acquired pneumonia, so that a group of experts could review the charts and X-rays. But we did not know whether we had an epidemic situation until the first hospital outbreak occurred.

> *"For us in Hong Kong, SARS was a nightmare. It's over for now, but there are still a lot of unanswered questions."*

This story evolved very rapidly. On March 10, 2003, the CEO of the Prince of Wales Hospital discovered that 10 staff members on the respiratory ward had reported in sick. For a hospital with 1,200 beds, this was not unusual. It was only through the vigilance of the hospital management that they suspected something different. They quickly called all the staff for chest X-rays. Within a matter of days, 24 staff members had been admitted with atypical pneumonia. Only five days later, the WHO coined the term SARS and the epidemic became a public emergency.

It was some time afterwards that we pieced together the story of the spread of the infection. A professor from Guangzhou came to Hong Kong in late February to attend a wedding banquet. He stayed overnight in a hotel, but he never made it to the banquet because he was admitted to a neighboring hospital the next day. This one-night stay in a hotel was enough to spread the disease to many continents.

So how did the infection spread to the Prince of Wales Hospital? The professor was not admitted to Prince of Wales Hospital, but to a neighboring hospital. His wife was soon infected as was his brother-in-law, and both were admitted. The professor and his brother-in-law both died. It was only through a lot of inter-hospital collaboration that we obtained the diagnosis through a lung biopsy of the brother-in-law.

And then, one person who visited his friend in the same hotel that evening somehow picked up the virus, and he was admitted into the Prince of Wales Hospital. He was not particularly sick, so initially no one suspected he was infected. But he then spread the disease to many people.

Things were moving very fast, but the remarkable thing was that the nursing and medical staff stayed put. This dedication showed personal strength. Infected doctors divided themselves up into a "dirty team" and a "clean team." The clean team was made up of those doctors who hadn't been seeing patients in the respiratory ward and the dirty, obviously, were the ones who had been exposed. The dirty team said to the clean team, "Since you have not been exposed, don't work on this ward. We will continue to take care of this batch of patients until we find out what is happening."

We immediately wondered whether we should close the hospital to new patients or discharge patients being treated on other wards, even those who had no fever or symptoms, but who nonetheless might have been exposed and could spread the infection into the community. There would be enormous implications of closing the hospital, because there was not excess capacity to take up the slack, and this hospital served a population of more than a

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million. We knew that there had been an attempted hospital closure in Taiwan: They closed the hospital and did not let patients or health care workers leave. But people escaped from the windows and staircases. It just couldn't be done—there is no way to keep people in a hospital involuntarily.

As the infection spread, the hospitals were all very full. It was like a tornado. Suddenly we had so many patients. The stress on the workers in the hospitals was very high. We were in the difficult position of having to balance emotions and rationality in many of our decisions. For example, many of the staff wanted to wear whole-body protection gowns. We did not argue with them at first, since we knew they were afraid, but we quickly did studies to demonstrate that those who put on those gowns were putting themselves at greater risk because when they took them off, they were splashing the virus all over. But the staff was afraid, and it took a very clear head to explain all this.

And then how to ration limited supplies, such as protective gear? During this time, every country in the world was buying these masks, and 3M could not keep up with the demand. The situation was made much worse because the regular sized N95 mask did not fit the face of many nurses, so the small size was in even tighter supply.

The infection was spreading in the community. We eventually uncovered that an infected renal dialysis patient had returned home to a very densely populated high-rise housing block. Although there were different explanations of the mode of transmission, we faced an immediate ethical issue: Should we quarantine the residents of that housing block? If the answer is yes, how could we keep so many people in buildings, knowing that being there is dangerous to the uninfected? What the government did at that time was to ask all the relatives and the close contacts of patients to report to designated clinics of the department of health every day. If they did not turn up, then the police would be knocking at the door. Compliance was quite good. But we faced other questions: Should patients too afraid to seek medical treatment be charged with criminal offenses?

The government had to move in, because it was considered too dangerous to keep residents there, even though the nature of the transmission was not known. In the middle of the night, under armed forces, all the residents of that block were evacuated to a recreation camp, and they were locked in that recreation camp for a period of time until everything was clear. The whole building was washed out and cleaned. Apparently, that strategy worked, as further transmission stopped.

Complicating everything was the fact that the symptom pattern of the disease was rapidly changing from fever and respiratory symptoms to vomiting, diarrhea, rectal bleeding and, in some patients, bone fractures. This greatly complicated our ability to track the disease. It also greatly complicated our infection control measures, as it meant that patients with almost any symptom might be infectious.

We also faced hard decisions in the hospitals: how, or if, to discipline staff who were not compliant in infection control measures? Wearing these masks full time is very uncomfortable, and the infection control measures insist that anytime you touch your mask, you have to go away from your work, find a sink and wash your hands. That's very difficult. Do we wear gloves all the time? Many infection control experts advocate not wearing gloves, because by wearing gloves you have a false sense of security. So every time we touch a patient, or anything the patient has touched, we must wash our hands. How realistic was it to expect full compliance? If you know that there is not full compliance then are you putting your staff at risk? If they don't work then who will take care of the patients? Our staff members working in the SARS ward were heroic and very professional, but as the epidemic dragged on and on, the day-to-day stress was very high.

"Should patients too afraid to seek medical treatment be charged with criminal offenses?"

We had to cancel much of the non-emergency work of the hospital. And that posed another dilemma, because retrospectively, we did find increasing mortality during the epidemic due to non-SARS causes—because not only were we not admitting patients, but also they were too afraid to come to the hospital.

While the disease was spreading in the community there was a strong cry from politicians and people asking the government to release the names and addresses of all the patients so that the neighborhood could take the appropriate precautions. This would create a huge amount of discrimination against these people, and the government resisted. But the political pressure was very strong, so the government chose a creative compromise: The government just released the names of buildings with patients.

We were in an emerging infection epidemic situation, and we had to respond quickly. Even the WHO was changing the definition of a case, and the recommendation guidelines for treatment kept changing on a daily basis, sometimes two times a day. We were criticized, particularly in the United States, for using ribavirin without any proof that it was effective. Yet how can you do randomized controlled trials in an epidemic? We were desperate doctors facing desperate patients in desperate situations.

Once the crisis had passed, we still faced ethical questions. One particularly difficult issue was the one of diagnosis. Since the diagnostic definitions of the disease changed almost constantly during the outbreak, we had many instances in which patients were initially told that their relative died of SARS, and then were told that the diagnosis was not SARS, and then were contacted yet again to say that now we believe the diagnosis was indeed SARS. Normal variation in the results of some of the recommended tests, such as bone MRIs, led to many indeterminate cases. This uncertainty matters not just for epidemiologists; when the government decided to give compensation to those who were sick, making the diagnosis clearly became even more important. At every stage in this epidemic, there were cases in which patients moved in and out of the diagnostic criteria, some several times.

We also faced the question of how to use our resources after the outbreak to prepare for the future. After the epidemic we did a lot of things like building negative pressure, single isolation beds with anterooms. Now they're all empty, taking space away

from other patients, but this is the price we pay. We have been training more ICU personnel, because the bottleneck at Princess Margaret Hospital was in the ICU. We had to double the size of the ICU rapidly during the epidemic, but then half the ICU team caught SARS, so we had only half the team to care for triple the number of patients. We had to fly in experts from other centers. But even when the intensive care people arrived from other hospitals, they found that they couldn't work easily, because all the ICU's were so different: different ventilators, different protocols and so on. We have tried to remedy that problem with more standardization, but it's been a challenge.

For us in Hong Kong, SARS was a nightmare. It's over for now, but there are still a lot of unanswered questions.

Dan Brock: I appreciate your emphasis on the ethical questions, Dr. Ho. I must say it turned you into a first-rate ethicist to have to deal with this. I'll turn it over to Walter Robinson.

Walter Robinson, MD, MPH, *Assistant Professor of Pediatrics and Medical Ethics, Harvard Medical School:*

In the short time available, I couldn't possibly address one tenth of the interesting issues raised by your talk, Dr. Ho. In the grand tradition of academics, I'm going to take a small aspect of this story and analyze the heck out of it: I will consider the physician's obligation to remain to treat the sick even at personal risk of infection.

In history, the obligation to stay behind in epidemics is a mixed story. The Greek and Roman tradition emphasizes a practical injunction against taking on hopeless cases; this would suggest that you leave epidemics alone, especially if you have nothing particularly therapeutic to offer. The Hippocratic warning about hopeless cases persists in later centuries. A 14th-century physician gives this advice to his medical students, "If you're asked to treat a patient with no chance of recovery, you should state that you're leaving town shortly, and you can't take the case."

Yet this internal injunction is sometimes seen as conflicting with professional self-interest, as remaining behind in an epidemic was in some cases a way to create or maintain a reputation as a compassionate healer. If any treatments happened to be successful, the physician could generate increased prestige, and subsequent income, on technical grounds. Whatever the status of the individual physician's view, there's evidence in the 14th and 15th centuries that those responsible for the health of the public believed they couldn't depend on physicians to make the right decisions. Municipalities begin to pass legislation forbidding physicians to leave the city during an epidemic; there are examples in Venice in 1382 and again in Barcelona and Cologne well into the 15th century. By the 17th century we see, in the literature describing plagues, moral reproach of doctors who flee. Daniel Defoe's book, *A Journal of the Plague Year*, argues "great was the reproach thrown on those physicians who left their patients during the sickness. Now that they are entering the town again, no one cares to employ them. They are our deserters."

"Physicians swim in the same social ocean as their fellow citizens, and so are subject to the same set of fears as everyone else."

If we now move to the United States in the 19th century, we begin to see explicit recognition of the professional obligation to remain behind to treat the sick. In the 1847 Code of the American Medical Association, in a section entitled the "Duties of the Profession to the Public," the code states, "when pestilence prevails, it is the physician's duty to face the danger and to continue their labors for the alleviation of suffering even at the jeopardy of their own lives." The injunction to stay behind remains in the American Medical Association's code in exactly these words until the 1957 edition of the code, when it is deleted. In the decade prior to the 1957 reediting of the code, there had been increasing emphasis in medical associations on individual practitioner autonomy in the face of increasing governmental and social control of medical practice and reimbursement, so it may be that the moral injunction to treat the sick simply conflicted with an evolving professional view of autonomous medical practice in an increasingly wealthy, consumer-based medical system.

If we fast-forward to the 1980s we see heated debate over the professional obligation to treat in the face of the infectious threat of HIV. Many of you will remember accounts of physicians who refused to provide care to persons infected with HIV and who explicitly rejected any individual obligation of physicians to care for sick and possibly contagious patients. A long debate resulted in an opinion from the AMA Council on Ethical and Judicial Affairs, which concluded in 1987 that a physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence, because the patient is sero-positive for HIV. Writing almost simultaneously, the American College of Physicians was more direct: "Physicians must provide high quality non-judgmental care without regard to their own personal risks, real or perceived. Physicians and nurses alike are charged by the ethics of their healing profession to treat patients with all forms of sickness and disease."

So the historical picture was a mixed one. In summarizing, I want to point out some features of previous epidemics that I think have played a role in whether physicians have been more or less willing to stay behind. Physicians swim in the same social ocean as their fellow citizens, and so are subject to the same set of fears as everyone else. We should recognize that for physicians, just like the rest of society, the reluctance to associate with infected groups during epidemics might have more to do with the stigmatization of the infected groups than with the actual risks of contagion.

Lest we think that that sort of stigmatization with regard to illness in the United States is a relic of the past, we have only to look at the refusal to treat people with HIV. Even for the most invasive of medical work in the mid-1980s and even at the time when transmission was not well understood, the risk of HIV infection was never greater than the risk of other infections such as hepatitis B. Yet the stigma of infection to those was quite different for HIV and hepatitis B. The point is that the salient risk and the social conditions under which doctors and others are operating is the perceived

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risk, not the actual risk, and that the perception of risk itself is powerfully influenced by the relative stigma of the people who are sick. In epidemics both of ancient and recent origin, marginalized groups in any society have often been initially blamed. Examples of this abound—from Jews being blamed for the plague in medieval times, to immigrants to the US being blamed for typhus, to gay men being blamed for HIV. The list goes on and on. There is no reason to think that things will be very different in a future epidemic.

Second, I think we have to look very closely at the social conditions in which we physicians work in 21st-century America. It cannot be irrelevant to the question of whether physicians have a moral obligation to treat the sick that we live and work in a nation where health care coverage is not universal, and that many of our fellow citizens get only emergency care if they get care at all. We are a highly individualistic, market society with an emphasis on legal rights and consumer choice more than moral or social solidarity. Yet in some cases we can heroically and admirably rise above our self-interests. Will we remember the medical profession's response to the next epidemic heroically, as we remember the work of the fire fighters in New York on September 11, or indeed, as in the story Dr. Ho has just told us? That's a question that history can't answer.

William Ho: When I was listening to you, Walter, I was reflecting on also the behavior of private doctors in Hong Kong. In Hong Kong, it was an accepted practice that whenever SARS patients turned up in private hospitals, they were immediately transferred to the public hospitals. Now while none of the staff in the public hospitals ran away, there were private practitioners who closed shop. Some private practitioners continued to practice and help their patients a lot. But others closed shop, and this was accepted socially. So there was a difference in the expectations of the public and private physicians.

Question: I'd like to raise the question of hoarding medicines. As we saw with Cipro and the anthrax scare, physicians are the first ones to grab hold of medicine and hoard it. My guess is if you go into the medicine chests of the doctors around town you will find that they all have Tamiflu, and their relatives all have Tamiflu, until the Tamiflu is gone. Is there any obligation or duty, in a time of shortage, for equitable distribution, or is it every man for himself or every woman?

Walter Robinson: It seems to me not a very far step from an obligation to treat the sick to an obligation to play fair when it comes to this issue. If we're supposed to stay behind in epidemics, we're supposed to stay behind not just to treat the people that we know and like, but to treat all the sick. I confess that I am not an optimist on this question.

Question: If the avian flu becomes a serious epidemic, what will be the response in the city of Boston or the United States to a large-scale epidemic of a disease that has an unusually high fatality rate? Shouldn't we engage hospital workers at every level and medical students in discussing now what their responsibility would be in this event? It may never happen. But if it does happen, isn't now the time to discuss it?

Walter Robinson: The Joint Center for Bioethics in Toronto has recently started this kind of discussion. They have begun with a general document exploring issues such as fairness and transparency of the planning; this effort arises from their experience with SARS. In the US, we have recently had a very dramatic example of the failure of the government to plan adequately for a predictable emergency: the loss of the levees in New Orleans. Citizens of our country were allowed to die unrescued and almost unnoticed even though the problems were in many ways less severe than ones Dr. Ho described. I have to say I am a pessimist about what would happen if we had a SARS outbreak tomorrow in a major American city.

William Ho: In any effort at planning for an epidemic there are many ethical questions to answer ahead of time. Any planning must take into account the difficult issues we faced in Hong Kong: how to keep staff as safe as possible while still treating the sick, how to manage those who are exposed, how to speed communication among the public health authorities in a time of rapidly changing information, how to respond when the disease characteristics and definitions change, how to communicate with the public at large and, most important, how to balance emotional responses and scientific rationality. Whether you can adequately plan for all these issues ahead of time is a tough question, but certainly the communication and information systems can be put into place.

References:

[1]Hong Kong Hospital Authority Avian Influenza Contingency Plan at http://www3.ha.org.hk/idctc/avianflupage

[2]Lowey EH. Duties, fears and physicians. *Soc Sci Med.* 1986;22(12):1363.

[3]Emanuel EJ. Do physicians have an obligation to treat patients with AIDS? *N Eng J Med.* 1988;318:1686.

[4]Miles SH, Zuger A. Physicians, AIDS, and Occupational Risk. *JAMA.* 1987;258(14):1924.

Ethics and the humanities:

My Sister's Keeper

By Jodi Picoult
Washington Square Press, New York, 2004

Review by James A. Russell, DO
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My Sister's Keeper is a medical ethics thriller, delivered in a chapter-by-chapter alternating first-person narrative. It offers considerable insight into the visceral and complex effects of a child's illness on her existing family, her genetically selected and yet-to-be conceived sister, and the lives of others caught up in the Fitzgerald family's kaleidoscopic existence.

The Fitzgeralds are the idyllic family of four, that is until Kate at age 2 develops acute leukemia with the loss of any future hope of familial equilibrium. Sara, the matriarch, who has put her legal career on hold to raise her family, becomes understandably preoccupied with and dedicated to the salvation of her child. She tries but does not succeed in maintaining some semblance of normalcy for herself and the other two original members of her family. Brian, the father, is a fireman admired by his men for his leadership, equanimity and courage under fire, characteristics that he displays as well at home during the long gauntlet of his daughter's illness.

Jessie, the older child, is the obvious second victim in this poignant tragedy. Portrayed in his infancy as a normal, happy child, he increasingly withdraws from his family and from life, ostensibly because of the attention now focused by his parents almost exclusively on his ailing sister and her frequent medical crises. As a teenager, he is allowed to live separately over the family garage with a "don't ask, don't tell" attitude from his parents regarding his multiple indiscretions. What better way for a teenager to gain the attention of his fireman father than by adopting arson as a hobby? Ironically, it is an act of compassion by this seemingly irreparably calloused young man that leads to his exposure.

But the nidus of the story is Anna, an intellectually precocious, emotionally ambivalent and complex 13-year-old. Although loved by her parents, it is no secret to her that she can credit or discredit her existence to the luck of the genetic draw. She was selected from the Petri dish instead of her zygotic brethren because of her future promise as a repository of spare parts for Kate. At age 13, she faces and resists the prospect of "donating" a kidney, to follow the bone marrow, red cells, white cells and platelets that have been previously harvested.

The story actually begins with Anna the prospective plaintiff/donor, entering the law offices of Campbell Alexander, a man not without his own skeletons, with the expectation of gaining her medical emancipation. The defendants are, of course, her parents. The explicit result of her suit, if successful, will be the death of her sister, a sister who is her *raison d'etre* while at the same time precluding her from having any semblance of a normal life. Adding spice to this intrigue is the somewhat unusual prospect and the potential conflict of interest of the plaintiff living with and being dependent on both the defendants and the defense lawyer.

We assume that her motives are purely selfish—but are they? As the story unfolds, Anna's complex, insightful and turmoiled reactions to her sister, whom she clearly loves, her sister's illness, and her personal and familial plight come slowly into focus.

My Sister's Keeper is occasionally guilty of taking medical license, is somewhat contrived in its story development and, depending on perspective, is enhanced or burdened by an unexpected, cataclysmic and theatrical resolution. Nevertheless, it is an entertaining read that explores a panoply of ethical dilemmas that emphasize that beneficence and non-maleficence are not synonymous, while exploring in depth the emotional reactions that this perfect storm of family tragedy engenders. □

Excerpts from *My Sister's Keeper*

Anna:

"I'm an allogeneic donor—a perfect sibling match. When Kate needs leukocytes or stem cells or bone marrow to fool her body into thinking it's healthy, I'm the one who provides them. Nearly every time Kate's hospitalized, I wind up there, too.…"

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"There is way too much to explain—my own blood seeping into my sister's veins; the nurses holding me down to stick me for white cells Kate might borrow; the doctor saying they didn't get enough the first time around. The bruises and the deep bone ache after I gave up my marrow; the shots that sparked more stem cells in me, so that there'd be extra for my sister. The fact that I'm not sick, but I might as well be. The fact that the only reason I was born was as a harvest crop for Kate. The fact that even now, a major decision about me is being made, and no one's bothered to ask the one person who most deserves it to speak her opinion."

Dialogue:
How much suffering is enough?

In his article "Euthanasia for Existential Reasons," Gerrit Kimsma, a physician, philosopher and end-of-life activist from the Netherlands, addresses the question of whether voluntary active euthanasia (VAE) or physician-assisted suicide (PAS) might ever be justified on the basis of pure existential suffering. As a philosopher, he can make a strong argument for its justification, but as a physician he is inclined to draw a line and say that such assessments are beyond his province and expertise, and therefore, he could not justify his participation and assistance.

Just how bright are the lines between physical, psychological and existential suffering? Callahan has argued that physicians should restrict themselves to physical suffering and that psychological, spiritual and/or existential suffering should be left to others with more expertise.[1] On the other hand, Cassel persuasively suggests that suffering is an inherently integrated experience that cannot be so easily objectified or dissected, and can only be understood by exploring the inherently human experience of the patient.[2] For some patients, there is a direct easily comprehensible connection between physical symptoms, debility and suffering. Others, however, with seemingly overwhelming symptoms and debility are able to adapt and experience relatively low levels of suffering. And still others experience overwhelming suffering with seemingly little physical discomfort or debility. Frankel has taught us that suffering has as much or more to do with the meaning attached to one's experience than to its physical dimensions.[3]

Thus, understanding an individual's suffering requires full exploration of both its physical and nonphysical dimensions. In fact, this exploration is at the core of the humanistic practice of medicine. To reduce the physician's role exclusively to the physical realm would reduce them to technocrats, not humanists, and would ultimately deprive them and their patients of many opportunities to address and potentially alleviate nonphysical suffering. On the other hand, considering only the psychological and existential dimensions of suffering without contextualizing them within the physical concomitants would severely restrict our potential understanding of the totality of a person's experience. Furthermore, without the centrality of a disease process, it would not make sense to have physicians involved in assessing or responding.

So how should a physician address a patient's suffering that he reports to be "unbearable"? What if the ante is upped by the patient sharing that he is considering ending his life and asking for the physician's assistance?[4] (If you want to take the VAE or PAS controversy out of this discussion, consider a patient with chronic renal failure who wants to discuss stopping dialysis.) The first step in this inquiry would be to fully explore with the patient what makes his situation so "unbearable" and to make sure the underlying issues are fully understood. Before any decisions are made about how to respond, use a patient-centered interview that includes a: 1) bio- *(Are you having any pain, shortness of breath, nausea…?)*, 2) psycho- *(Are you depressed, anxious, terrified…?)*, 3) social *(How are things going at home? Have you talked with your family about this?)*, 4) spiritual- *(Do you have a sense of why this is happening? Are there any religious parts of this decision in your tradition?)* and 5) existential *(Are there things that still make life worth living for you?)* exploration.

Restricting this exploration to the physical domains would lead to an incomplete understanding of the underlying issues beneath such requests and would also severely restrict the physician's opportunity to be responsive. We know from both Dutch data on VAE and PAS[5] as well as the Oregon data on PAS[6] that the main reasons patients give for requesting PAS/VAE are often a mix of physical, psychological and existential dimensions. The recently reported 2005 data from Oregon, for example, cites that terminally ill patients report psychological, existential and physical reasons that cannot be easily dissected, including loss of autonomy (79%), loss of dignity (89%), unable to engage in enjoyable activities (89%), losing control of bodily functions (45%), burden on family/ caregivers (42%), inadequate pain control (24%).

Existential issues are often central to such descriptions of suffering. But there must be a direct relationship between the degree of disease-related physical suffering and the existential distress as well as a reasonable effort to find acceptable alternative approaches before considering any last-resort response by a physician (be it stopping a life support or PAS).[7] The request for a hastened death by a patient who is already near death from lung cancer and whose severe shortness of breath cannot be adequately relieved is relatively easy to understand, and may require a relatively fast-paced, but nonetheless thorough, exploration before there is a response. The patient with ALS who is dependent on a respirator, who feels his life has lost meaning and wants to stop the respirator and die, should receive a multidimensional exploration of potentially reversible aspects of his suffering, but should ultimately be listened to and assisted if no acceptable alternatives can be found. Philosophical and ethical issues that justify such actions include respect for patient autonomy, the right to bodily integrity, compassion, mercy and nonabandonment.[8]

The bereaved patient cited in Dr. Kimsma's article who no longer finds life worth living would be much more problematic. The patient's suffering is certainly severe, but the wish to die can be a central feature of severe depression, which clearly warrants aggressive, multidimensional assessment and treatment before being assisted in this manner. The elderly patient who is simply tired of living also would be problematic, in part because the desire to die may be part of an underlying depression, but also because there is no physical illness to anchor a physician's involvement.

In Oregon, the presence of a terminal illness is an absolute requirement to receive legalized physician assisted suicide (along with a voluntary request, an evaluation by a second physician and a mandatory two-week waiting period). There have been no reported cases of PAS for pure existential suffering, and, in fact, such patients would not qualify for PAS under the law. The numbers of cases of PAS in Oregon has remained very low and stable over the first 8 years, accounting for under 0.1% of deaths

each year. But 1 out of 50 patients talk to their physicians about PAS, and 1 out of 6 talk to their families, so the main impact of legalization has probably been more open conversation between terminally patients and their doctors and families about these challenging issues.[9]

In the Netherlands, where both PAS and voluntary active euthanasia are openly practiced, there is no absolute requirement for a terminal prognosis.[10] Instead, a patient who requests such assistance must be experiencing unbearable suffering with no prospect for improvement, and that situation must be verified by two physicians. The Netherlands only recently legalized the practices of PAS and VAE, but they had studied the extra-legal practice for over 20 years before making this public policy decision. (Previously, physicians would predictably not be prosecuted for breaking the law provided they met agreed upon criteria prior to this time). The Netherlands is a much more legally permissive and socially tolerant society than the United States, and they wanted to have data about the practice's safety before legalization. In the Netherlands, there have been a few well-publicized cases of euthanasia for existential reasons, and such cases remain very controversial both legally and in public opinion because of the absence of an incurable terminal disease. The overall number of PAS and VAE cases have remained remarkably stable in the Netherlands over the last 15 years. The Dutch seem to rely heavily on the good clinical judgment of their physicians to work with patients to decide how much suffering is too much. (Unlike the United States, the Netherlands has universal health care and a stable corps of family physicians who have long-standing relationships with their patients and their families, creating a much more conducive context for these difficult decisions.)

With regard to hastened death for existential suffering, I personally draw a line close to where Dr. Kimsma does. There needs to be some direct relationship between the severity of unrelievable, illness-related physical distress and the existential suffering for me to potentially provide any last-resort option as a physician. The more uncertain the relationship between the two, the more I would require involvement of others with more expertise in the non-physical domains. Sometimes that might be a psychiatrist or other psychological counselor with experience with seriously ill patients, other times, a spiritual counselor or a family therapist. Although I would empathize with, explore and do my best to help alleviate pure existential suffering, without the anchor of proportionate physical suffering, it would be beyond my expertise (and comfort level) to assist as a physician.

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[1]Callahan D. *The Troubled Dream of Life: In Search of a Peaceful Death.* Washington DC: Georgetown University Press, 2000.

[2]Cassell EJ. *The Nature of Suffering and the Goals of Medicine.* New York: Oxford University Press, 1991.

[3]Frankl VE. *Man's Search for Meaning.* Boston: Beacon Press, 1959.

[4]Quill TE. Doctor, I want to die. Will you help me? *JAMA.* 1993; 270:870–873.

[5]van der Maas PJ, van der Wal G, Haverkate I, de Graaff CL, Kester JG, Onwuteaka-Philipsen BD et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med.* 1996; 335:1699–1705.

[6]http:www.oregon.gov/DHS/ph/pas/index.shtml

[7]Quill TE, Lo B, Brock DW. Palliative options of last resort: A comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted suicide, and voluntary active euthanasia. *JAMA.* 1997; 278:1099–2104.

[8]Quill TE, Cassel CK. Nonabandonment: A central obligation for physicians. *Ann Intern Med.* 1995; 122:368-374.

[9]Tolle SW, Tilden VP, Drach LL, Frojje EK, Perrin NA, Hedberg K. Characteristics and proportion of dying Oregonians who personally consider physician-assisted suicide. *J Clin Ethics.* 2004; 15:111–118.

[10]Kimsma GK, vanLeeuwen E. Assisted death in the Netherlands: physicians at the bedside when help is requested. In: Quill TE, Battin MP, eds. *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice.* Baltimore, Md: Johns Hopkins University Press; 2004:221–244.

Response: There is still much confusion, both in theory and practice, on the relationship between palliative care, including terminal sedation, voluntary active euthanasia and the justification of medical professional involvement. A request to die in a permissive climate changes the roles of all participants and current conceptions of professional duties and their limits.

The imperialistic WHO definition[1] of palliative medicine implies a duty to help terminal patients in almost every aspect of their needs and suffering, *not* excluding existential and spiritual. In that scenario, the patient really is the receiver and *a passive object of near total care:* physical, psychological and existential. There is no difference of opinion on whether physicians have a vested interest and a duty to participate in that sort of care, because the needs and suffering have their "roots" in a medically qualified disease.

When someone wants to die because of suffering without a medical cause, that person becomes an active participant. Then the question is, what intensity of suffering is enough for a physician to have a "duty" to actively help a patient die. This entails a need to assess suffering and define the conditions that allow voluntary active euthanasia. This means a redefinition of authentic medical professional participation.

A medical professional duty can only be justified in a medical relationship based on the presence of a disease. A problem arises when patients suffer existentially without a defined disease. The key issue is that helping to address existential suffering in general is a physician's assignment. But whether this type of suffering is enough to help a patient die is a personal or group assessment. This assessment may be a professional rational reconstruction of an individual physician, but it is always outside the boundaries of shared professional norms. □

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[1]World Health Organization Expert Committee Report. Cancer pain relief and palliative care. Geneva: WHO, 1990:11.

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Letter to the Editor

Advocating public policy through research

In **"The Politicization of Science"** (Medical Ethics Forum from Harvard Medical School, *Lahey Clinic Medical Ethics*, Winter 2006), Mr. Mooney describes "the current crisis over the political misuse of science." Researchers ask for and accept federal funding of their research with tax dollars while claiming that, in the name of ethics, any political content in publicly funded scientific research should be unchallengeable. While understandable, this desire of the research community, to arrogate to itself sole power for deciding which policies federal research or regulatory monies will support, smacks of an anti-democratic elitism. □

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adopted autonomy. Perhaps in the context of decision-making for patients who lack capacity, we need a scheme that allows for both—permitting the patient to choose autonomy *or* paternalism. □

[1]The bioethical concept of patient autonomy is reflected in the law through the common law doctrine of informed consent.

[2]Schneider CE. *The Practice of Autonomy: Patients, Doctors, and Medical Decisions.* New York: Oxford University Press; 1998.

[3]Ibid., 36 (citing Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients, *J Gen Intern Med.* 1989;4(1):23–30.)

[4]Ibid., 42 (citing Sehgal A, Galbraith A, Chesney M, Schoenfeld P, Charles G, Lo B. How strictly do dialysis patients want their advance directives followed? *JAMA.* 1992;267:59–63.)

[5]Hoffman J. Awash in information, patients face a lonely, uncertain road. *New York Times.* August 14, 2005:A1(L)

[6]Ala. Code §22-8A-4(h) (LexisNexis Supp. 2005).

[7]S. 369, 2006 Leg. 421st Sess. (Md. 2006).

[8]See Rai AK, Siegler M, Lantos J. The physician as a health care proxy. *Hastings Center Rep.* 1999;29(5):14–19.

[9]Ibid.,16.

[10]NY Pub Health Law §2980(3)(c) (McKinney 2002).

[11]Mass Gen Laws Ann ch 201D, §3 (West 2004).

Medical Ethics

Lahey Clinic Medical Ethics **encourages reader participation. We welcome comments for our "Dialogue" column and invite submission of ethical dilemmas for "Ask the ethicist." Send correspondence and requests for complimentary subscriptions to David Steinberg, MD.**

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