The Timeless Debate on Ethics in Medicine
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From the emergency room to the classroom, doctors, researchers, hospital administrators and medical students at UT Southwestern face a broad range of ethical issues.

By Amanda Siegfried
Hippocrates, considered the father of medicine and perhaps the first medical ethicist, wrote in his *Aphorisms* 2,400 years ago:

> Life is short, and Art long; the crisis fleeting; experimenting dangerous, and decision difficult. The physician must not only be prepared to do what is right himself, but also to make the patient, the attendants, and externals cooperate.

While 21st-century biotechnology has far surpassed anything Hippocrates could have imagined, the basic tenets of his No. 1 aphorism still ring true for physicians and clinical scientists who grapple with far-reaching bioethical issues linked to today's cutting-edge therapies.

The University of Texas Southwestern Medical Center puts the principles of bioethics into practice every day. Ethics committees at UT Southwestern University Hospitals consult with physicians, patients and their families on treatment options and emotionally charged end-of-life issues. Medical students gain classroom and real-life experience dealing with ethical and moral dilemmas. Scientists looking to test experimental treatments on humans must first demonstrate their safety and ethical standards before a stringent review panel.

“There has been an enormous transformation of medicine to where the consciousness of ethical issues has now been built into the practice of medicine and the practice of research,” said Dr. Donald W. Seldin, professor of internal medicine and an intellectual cornerstone of UT Southwestern Medical School since the early 1950s. He also is vice president of medical center relations for Southwestern Medical Foundation.

This wasn’t always the case, however, as is demonstrated by one of America’s most notorious medical studies, the Tuskegee Syphilis Study, which began in 1932 and lasted 40 years. In that study, the U.S. Public Health Service, working with the Tuskegee Institute, enrolled nearly 400 poor black men with syphilis from Macon County, Ala. They were never told they had syphilis, nor were they ever treated for it, even after penicillin became a standard cure for the disease in 1947. The Tuskegee scientists wanted to continue to study how the disease spreads and kills. The experiments were finally made public in 1972, but it wasn’t until 1997 that the government formally apologized.

**UT SOUTHWESTERN INFORMS THE NATIONAL DEBATE**

While the Tuskegee experiments were blatantly unethical, in their wake a national commission was formed to address ethical issues in clinical research. Dr. Seldin, who was chairman of internal medicine for 35 years, was among the experts who served on the first public, national body to shape bioethics policy in the United States — the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research.

The commission was charged with identifying the basic ethical principles that should underlie the conduct of research involving human subjects and developing guidelines that should be followed to ensure that research is conducted in accordance with those principles.

For four years, from 1974 to 1978, the 11-member panel examined issues such as experiments on newborns, research in prisons and research on the mentally disabled. From those discussions the commission developed the Belmont Report, which put forward three principles — respect for persons, beneficence and justice. These principles were fleshed out later in a seminal book, *Principles of Biomedical Ethics*.

Today, those principles permeate not only research on...
human subjects, but also face-to-face encounters between doctor and patient. And those principles have stood the test of time – having been logically extended to ethical questions surrounding such broader social and public policy issues as embryonic stem cell research and the national healthcare system.

“Even though the commission was focused on the circumstances of research in various settings, the implications of the principles we developed had an enormous influence on the practice of medicine outside the research domain,” said Dr. Seldin, a UT System professor of internal medicine and holder of the William Buchanan Chair in Internal Medicine.

For example, the principle of respect for persons — which ensures that an individual’s autonomy is recognized and protected — deals with the right to allow the widest range of self expression, limited only by the duty not to harm others. The doctrine of informed consent was developed to ensure that the subject of medical research or care is appropriately informed about the dangers and benefits of a procedure and, on the basis of that information, is freely willing to allow the procedure to be done.

In research settings, institutional review boards (IRBs) were conceived to review research protocols for safety and efficacy. IRBs consist not only of specialized investigators, but also of responsible members of the lay community, in order to ensure unbiased evaluations.

The principle of beneficence — where medical professionals have a duty to confer benefits and minimize harm — found expression in risk/benefit assessments such as those routinely carried out by IRBs, which meticulously examine every aspect of proposed human trials before they are implemented. Risk/benefit assessments also help guide physicians as they deliberate about treatment options for their patients.

The principle of justice gave rise to moral requirements that
there be fair procedures and outcomes in the selection of research subjects, ensuring that a given study did not disproportionately or unfairly exclude women or a particular racial group, for example.

“The rise of medical ethics has, in the broadest sense, been very healthy and beneficial for individual subjects as well as society at large,” Dr. Seldin said.

Advances in science and technology, along with a growing public awareness of biomedical issues, have transformed questions previously part of religious and philosophical speculation into practical concerns of everyday life, said Dr. Fred Grinnell, professor of cell biology and founder of UT Southwestern’s Ethics in Science and Medicine Program. In a book-in-progress, tentatively titled *Everyday Practice of Science*, Dr. Grinnell notes that contemporary science is increasingly under a public microscope as ethical issues in research and medical care are debated in social and legal circles.

“Incidents involving scientific misconduct and conflicts of interest have raised concerns about the integrity of scientists,” he writes. “In response to these developments, there has been a dramatic increase in the scrutiny of biomedical science. Ordinary citizens, the mass media and politicians want to know: Are scientists doing research ethically?”

For example, do large drug companies that underwrite physicians’ meetings and research compromise ethical norms and cast any shadow of doubt on the merit of scientific findings? Those considerations led major scientific journals such as *The New England Journal of Medicine* to require authors of its articles to disclose any financial or other interest they have with a company that funds their work.

The companies’ spending habits raise other societal questions as well.

“Drug companies have been scrutinized about the amount of money they pay for advertising, for example — more money than they pay for research, by some people’s accounting,” Dr. Seldin said. “Many people say that is unethical.”

High drug prices and a dearth of research on drugs that don’t have a large consumer market result in the perception that drug companies are not fulfilling certain ethical requirements to society, Dr. Seldin said. The ethical issues become even more complex when the solutions begin to involve economists, lawyers and politicians.

“If drug companies are maximizing their profits and not doing anything strictly illegal, in accord with the wishes of their stockholders, is that immoral, and in what sense?” he said.

If the pharmaceutical industry is neglecting certain vital areas of medical research, financial incentives and disincentives can be applied to reward socially desirable behavior and perhaps penalize unnecessary activities, Dr. Seldin suggested.

“Such procedures would not strangle market forces, but would encourage studies deemed worthwhile to society without compromising the financial health and solvency of the pharmaceutical companies,” he said.

Ethical questions also surround such issues as genetic screening, a developing technology that allows certain aspects of people’s DNA to be analyzed to determine whether a person carries a gene that may lead to a particular disease.

“The genetic-screening issue presents great challenges ethically because there are, for the most part, no conventional...
interventions that might be used in response to the information gained,” Dr. Grinnell said. “Compounding the problem is our healthcare system, whose restrictions for pre-existing conditions make it essential that genetic information remain secret.”

Genetic technology is also part of the debate regarding prenatal testing. A couple undergoing genetic screening before having a child, for example, may discover the genes they share could result in a baby with a deadly disease or deformity. Or early-term screening of a fetus can reveal that it has a genetic disorder.

“Ironically, genetic screening gives rise to new kinds of ‘cures,’ such as preventing a marriage, choosing not to have children or choosing which child to have,” Dr. Grinnell noted.

Embryonic stem cell research is another issue on the borderline between medical practice and social mores, and it is one of the most controversial. It elicits many questions involving philosophy and religion, and it engages legal, scientific and political agendas.

Embryonic stem cells carry the potential to turn into any kind of tissue in the body, and most scientists believe that unlocking the mystery of how they do this will result in new treatments for devastating conditions. Controversy arises because the cells must be obtained from days-old human embryos — a process that destroys the embryo.

While UT Southwestern researchers are not currently involved in human embryonic stem cell research, Dr. Seldin acknowledges the life-saving potential of such investigations.

“The discovery of stem cells from a scientific point of view is one of the most thrilling things that has happened in medicine recently,” Dr. Seldin said. “I don’t think anyone questions this. The use of stem cells for clinical purposes is in its infancy, and it’s unfortunate that the impression in certain circles amongst lay people is that tomorrow the use of stem cells will cure heart disease or diabetes. In the long run, that may be the case, but that’s a long way off and requires a great deal of research.”

ADVISING THE PRESIDENT

Questions concerning the ethics of embryonic stem cell research were the impetus behind the formation of the President’s Council on Bioethics, a panel of experts selected in 2002 by President George W. Bush to apprise him of new developments and provide a forum for discussion and evaluation of profound ethical issues related to advances in biomedical science and technology.

“At the initial meeting in the White House, where President Bush met with us, embryonic stem cell research was the issue he wanted to talk about,” said Dr. Daniel Foster, professor of internal medicine at UT Southwestern and also a former longtime chairman of internal medicine.

The panel of distinguished scientists, ethicists, sociologists, lawyers and theologians — now numbering 17 — meets on a regular basis to discuss and produce reports on a wide range of topics, from human cloning and assisted reproduction to care-giving in an aging society.

“The initial council was absolutely dazzling,” said Dr. Foster, who will continue on the panel for at least another two years. “The level of discussions has been out of this world. It has been one of the most exciting experiences of my life.”

A presidential council is the highest level of advisory panel in the federal government, and as such, all of the bioethics panel’s meetings are transcribed, with the text available on the Internet.

Dr. Foster, holder of the John Denis McGarry, Ph.D., Distinguished Chair in Diabetes and Metabolic Research, said that since he has been on the council, people are more interested in talking with him about its proceedings than about his research in metabolism and endocrinology. While he generously shares his panel experiences with students and colleagues on campus and across the country, he has been taught a thing or two as well.

“I have learned by being on the council that despite very fervently held opinions, rational people can have discussions about controversial topics without rancor,” he said.
QUESTIONS OF CARE

Ethical questions surrounding stem cell research and the choices associated with genetic screening center on such personal views as when life begins, what the status of a fetus should be, when “personhood” begins, and quality-of-life issues. Similar uncertainties about what constitutes “life” can also come into play for physicians as they encounter difficult ethical questions regarding patients who are near death.

To help guide doctors, along with patients and their families, through some of the toughest of life decisions, UT Southwestern University Hospitals and affiliated hospitals have in place ethics committees that offer consultation services when a dispute arises among the people involved in a particular medical case. Such panels may include legal, medical, psychiatric, religious and policy experts as well as lay members of the local community. The committees also meet regularly to review and discuss past cases to learn what might have been done better, or to examine issues that may require the adjustment of hospital policies.

“In an ideal world, ethics consultations would be unnecessary, but that hasn’t happened yet,” said Dr. John Sadler, professor of psychiatry at UT Southwestern and co-chair of Parkland Memorial Hospital’s ethics committee.

At Parkland, he said, many times basic questions about what to do with a dying loved one are first brought to the attending physician or the nursing staff, and the discussion starts there. For example, physicians may think a patient is going to have a significant recovery, while family members request that the patient be allowed to die. Or the physician will want to withdraw care while family members, in their desire to hold on to their loved one, desperately want care to continue. Also, there may be questions about the legality of certain procedures, or the status of legal documents such as living wills and advance directives.

In many instances, differences can be reconciled simply by sharing information and communicating in lay terms. When that fails, the role of the ethics committee is to help re-establish the lines of communication in a way that results in agreement. If necessary, the medical team and family sit down together at a roundtable discussion, which may also include staff representing pastoral care, patient advocacy and palliative care, plus a translator if needed.

“At Parkland, the style of a consult is fairly simple,” Dr. Sadler said. “It starts with everybody getting together in a room and sitting at a round table so there is not one person in charge.”

The doctors present their case in ordinary language, which often is sufficient to clarify misunderstandings. Then the discussion opens so that all participants have a chance to share their thoughts and feelings. The goal is to build consensus, develop an action plan and follow through.

“Often times, the ethics endeavor is seen in a negative way — that we are in a sense herding people to their graves,” Dr. Sadler said. “What we really do is address how to ensure a dignified dying process.

“Another thing the ethics consultations can do is save lives by preventing rash decisions based on misinformation. It’s important to see us as a vital life-giving effort as well as a stewardship to the next world.”

TEACHING STUDENTS TO DECIDE

Even as medical ethics experts debate standards of practice and broad social policy, UT Southwestern Medical School is training the next generation of medical professionals by including ethics in the curriculum. But how do you teach doctors in training and junior research faculty to make the tough calls?

Two programs provide a good start. First, there’s the Clinical Research Ethics course, directed by Dr. Robert Bash, assistant professor of pediatrics. The class aids junior faculty
and fellows in the ethical conduct of human-subjects research. Each week a rotating panel of faculty members presents seminars on research cases in a variety of topical areas.

Beginning in September, this and similar initiatives will be organized under a new Division of Ethics, which will be part of the Department of Clinical Sciences at UT Southwestern. The department -- the first one of its kind in the country -- was established this year to train physician-scientists in methods to carry out exceptional clinical research. Dr. Sadler will head the ethics division.

On the patient-care side, the Clinical Ethics in Medicine (CEM) course, also led by Dr. Sadler, is required for first-year medical students.

“The CEM course allows students with different agendas, value systems and religious beliefs to come to the table to discuss life-and-death decisions and perhaps discover some convictions they didn’t even know they had until they have to make a decision in class,” Dr. Sadler said.

Ethics education is not strictly the teaching of what is right and what is wrong, but rather it occurs within the larger context of socializing students into the physician’s or the researcher’s role. For example, first-year students in the CEM course don’t come in grappling with ethical dilemmas and come out as mature clinicians who will be facile in dealing with anything that comes up in their practice.

What students often don’t realize is that they have a sort of idealized image of themselves, and they tend to approach the material in an idealized way, Dr. Sadler said.

“Of course, I’m always going to be nice to my patients,” they think, but they haven’t yet experienced what it’s like to be at the end of a shift and have a provocative, angry patient who, underneath it all, is a needy, scared person,” Dr. Sadler said. “That post-call young doctor is going to respond more to the anger and provocation than the neediness and vulnerability, but that’s really hard to capture until you’re in the nitty-gritty.”

One of the highlights of the CEM course is a mock meeting of a hospital ethics committee, at which students role-play as physicians, patient advocates and other panel members. Last December, the ethical dilemma facing 25 such groups was determining which individual among several candidates would receive a liver transplant.

The case illustrated one of the major ethical issues facing hospitals worldwide — allocation of scarce resources.

On one such mock panel, seven medical students assessed five transplant candidates. The patients were a 21-year-old woman who had attempted suicide, damaging her liver in the process; a financially strapped middle-aged widow with three children; a wealthy recovering alcoholic; a successful architect who had done drugs as a teenager; and a man with mental illness.

The students analyzed each patient’s case and used various criteria and principles to guide their decisions, such as: Who is in danger of dying the soonest? Who could afford the operation and the expensive anti-rejection medicine that must be taken for the rest of his or her life? Who has a support network to ensure those medicines would be taken? Who has the most to live for, the most to contribute to society, and the best chance at long-term survival?

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“What if the person who least deserves the transplant needs it most?” asked Matthew Simon, who led the discussion and portrayed a liver-disease expert.

“We were given eight criteria to look at to determine whether someone should get a liver,” said Blake Staub, who played a liver-transplant surgeon. “For the most part, everyone on this list has multiple issues with our criteria, so I don’t know whether I’d give it to anybody on the list — maybe give it to someone else.”

Hana Tartibi, also a “transplant surgeon,” offered her view of why liver transplants are performed: “The two biggest reasons are to prolong life and to improve the quality of life.”

Dr. John Vanatta, an adjunct professor of physiology and one of the physician-facilitators of the meeting, has taught students of every medical class at UT Southwestern since 1947. “On the basis of all that information, have you decided which criteria you are going to use?” he asked the group. “The ethical principle, the survival principle, support principle, financial interests they have that may be important to society?”

Much of the debate went back and forth between the merits of the 21-year-old, who had caused her illness herself but needed the liver most urgently to survive, and the widowed mother of three — a former math teacher on disability because of an illness she did not bring on herself.

“You know, we put a lot of value on people who bring a paycheck home, but some people who don’t bring home a paycheck have value that is just as high — taking care of and raising good kids,” said another facilitator, Dr. Robert Rege, chairman of surgery and holder of the Hall and Mary Lucile Shannon Distinguished Chair in Surgery. “A transplant team would think about who is going to take care of her [the mother], who is going to take care of those kids.”

Ms. Tartibi said: “I think this is the hardest one, because of all of them, she’s the one I’d want to help the most. Her problem isn’t because of mistakes she has made; this is nature.”

“Patient advocate” Greg Steward said: “Even if the liver transplant lasted long enough for her kids to get old enough to take care of themselves, that would be a really big benefit.”

In the end, after considering a number of factors and
weighting each factor with a numerical value for each patient, the patient with the highest total score — the architect — was chosen to receive the liver.

Interestingly, this group was the only one to choose the architect. Using similar analyses, the other 24 student groups ultimately chose different recipients. Fourteen panels chose the young woman who had attempted suicide, based in part on her dire need and good chances for survival. Nine groups sided with the widowed teacher, citing her dependents and her considerable contributions to society as mitigating factors. The tally of factors by the final group came out in favor of the wealthy alcoholic.

THE STRUGGLE GOES ON

At UT Southwestern, as at other medical schools, ethics education also takes place outside the formal classroom; it’s found in bedside teaching as well.

“Just as we discuss the diagnosis and physical treatment of the patient, we also talk about the patient’s reaction to illness, the physician’s reaction to the patient’s dying, and how we will behave in a way that may or may not be morally ideal,” Dr. Sadler said. “Students here learn not only about clinical medicine and about particular diseases, but also about the ethical issues involved.

“Ethics education is really skill-oriented. There is a certain amount of facts that you have to master, in terms of the law and what proper procedures are. But ultimately, you need a certain repertoire of moral encounters with patients or research subjects to develop a sensitivity to ethical issues.”

Along with formal training, an informal effort called the Ethics in Science and Medicine Program promotes ethics awareness, interest and discourse on a continuing basis. The program—founded by Drs. Grinnell and Sadler in 1998 and now led by Dr. Sadler—provides a way for the UT Southwestern community to interact with other ethics programs in North Texas and beyond.

Each month during the academic year, an Ethics Grand Rounds lecture is offered, bringing to campus some of the leading thinkers in ethics from across the country. Everyone is welcome, and faculty can receive continuing medical education credit for attending.

For example, a recent Ethics Grand Rounds lecture was titled “Doing What . . . and for Whom? Navigating End-of-Life Decision-Making.” The speakers were Dr. Sadler; Dr. Kathleen Delaney, professor of emergency medicine at UT Southwestern; and Dr. Thomas Mayo, director of the Maguire Center for Ethics and Public Responsibility at Southern Methodist University and an adjunct associate professor of internal medicine at UT Southwestern.

To a packed auditorium, the panel examined five medical case studies through three “lenses”—strict ethics, professional finesse (bedside manner) and the law. The ethics questions might involve deciding when a medical procedure such as CPR is futile. Professional finesse comes into play when a physician must tell family members that all that can be done has been done, and it’s time to turn off the machines. Legal issues come to bear when a patient has a “do not resuscitate” order on file.

Faculty members involved with the Ethics in Science and Medicine Program help coordinate teaching and develop and promote ethics educational activities in conjunction with other North Texas institutions, such as UT Dallas’ newly formed Center for Values in Medicine, Science and Technology, which Dr. Sadler directs.

As for the future of ethics education and social debate, efforts such as those at UT Southwestern and UT Dallas have much to offer, but Dr. Seldin suggests that many medical schools could benefit from a formal department of medical humanities housing economists, philosophers and historians, all of whom focus on medicine.

“The problem of ethics in medicine is not just counseling a patient in relation to a physician, but it centers on issues that fall back and forth between economics, law and purely ethical, philosophical problems,” Dr. Seldin said. “It’s a good idea for these to be studied in context.”

Advances in technology and changes in society have thrown even more considerations into the mix for professionals and students as they wrestle the myriad variables, striving to build consensus and take action.

At UT Southwestern, in the noble tradition of Hippocrates, the struggle goes on.