‘Rock Star’ of Biomedical Ethics Tackles Cancer

By Mary Beckman

A Hollywood agent isn’t usually someone who would inspire talk of the head medical bioethicist at the National Institutes of Health. But that’s just what happened to agent Ari Emanuel.

“I was at the doctor’s getting a checkup for something, and somebody asked me if I was related to Ezekiel Emanuel,” says Ari, Emanuel’s brother. “He says, ‘Wow. That guy’s a genius, and he publishes more than anyone.’ Out of the blue, without any context to it, people in the field come up to me and tell me how intelligent and well published and insightful he is. It’s kind of remarkable.”

And his brother is not the only one who hears good things about Emanuel. The chair of NIH’s department of clinical bioethics inspires such words from colleagues, friends, and even outsiders.

“He’s this wiry, energetic fellow, and he’s never at a loss for words or opinions or intriguing questions,” says a former mentor, oncologist Bob Mayer, M.D., at the Dana-Farber Cancer Institute in Boston.

As soon as he arrived at NIH in 1998, Emanuel started building the bioethics department, motivating his staff to spend long days working with him in Bethesda. Around the same time, he started up training programs for research clinicians in developing countries.

With a CV many pages long (be warned before printing it out), he still manages to take photographs of the animal world that help him to be a leader in biomedical ethics.

“His number-one attribute is he’s brilliant. And he’s creative and an out-of-the-box thinker and provocative as all hell,” says oncologist Jane Weeks, M.D., also of Dana-Farber. As an oncologist and a bioethicist, Emanuel raised questions about what terminally ill patients experience near the end of their lives at a time when many people thought that the topic should be off-limits.

Perhaps one of his most important accomplishments, his colleagues say, is the effect he’s had on medical bioethics. “He elevated bioethics to be a respected, contributing discipline. Other people also helped, but he can be credited for a lot of that,” says his NIH coworker, philosopher Christine Grady, R.N., Ph.D. Emanuel pioneered the use of empirical data to answer ethical questions, rather than merely debating the issues in the absence of real-world information.

“He finds immense joy in helping people in this capacity. Otherwise I don’t think he would be so successful,” Ari says.

Early Years

The oldest of three sons of a pediatrician and a civil rights worker, Emanuel still shares the public eye with his two brothers—middle brother Rahm, a prominent House representative from Illinois, and youngest brother Ari, a high-powered Hollywood agent who is the real-life model for the agent in the popular HBO show *Entourage*. The younger brothers’ successes don’t interfere with their esteem for their oldest sibling. “There’s a new study out that says the oldest is the smartest,” Ari says. “I think that’s accurate.”

Emanuel’s career in medicine started in 1981, when he matriculated at Harvard Medical School; his interest in bioethics started almost immediately. “I was being groomed to be a basic researcher,” Emanuel says. “But in med school, I saw that all these ethical dilemmas were not being addressed. So I stopped med school after 3 years and went across the river” to the university.

Taking time off from medical school, he worked on a doctorate in political philosophy at Harvard University. “Zeke created a curriculum for himself,” Mayer says. “One thing about Zeke is he’s never really in doubt.”

He was already a force on ethics issues by the time he went back to medical school and into oncology. “I was a few years ahead of Zeke, and he was already publishing thoughtful pieces in the *New England Journal of Medicine*,” Weeks says. “It was hard to miss him, if you know what I mean.”

End-of-Life Research

The first issues he tackled were questions about medical care for people who were dying. “It hit you between the eyes in the mid-’80s,” Emanuel says. “All these
end-of-life core questions. How were we going to allocate resources? How much were we going to spend?” Most ethicists at the time would deliberate the issues and come up with theories, Grady says, but Emanuel wanted to supplement that approach with empirical data.

So Emanuel went out and interviewed patients with terminal illnesses. His work overturned the then-popular idea that euthanasia was the way many people wanted to go. “Most don’t want to commit suicide,” Grady says.

Emanuel’s desire to find hard, cold facts and work in the medical trenches built up his reputation as a bioethicist. “He’s not an ethicist taking potshots from the sidelines,” Weeks says. His method also changed the way many of his colleagues approach ethics research. “More and more people have begun to use empirical methodologies. And that gives us more credence with other groups that rely on empirical data. It’s a good way to bridge disciplines,” Grady says.

“He really developed the field of ethics in cancer medicine. He had the courage to tackle the thorniest, most difficult issues,” says oncologist Deborah Schrag, M.D., at Memorial Sloan-Kettering Cancer Center in New York. “He asks the questions other people know are important but don’t know how to ask.”

For example, many people thought that patients enrolled in phase I clinical cancer trials—which often accept only those patients with the worst prognoses—didn’t know about their other options. “Why would so many put up with the side effects?” Emanuel says. So he surveyed the patients and found out. “They’re not ignorant. They know full well what their options are for palliative care. They’re not like mushrooms kept in the dark,” he says.

He also has examined the quality of cancer care. In 2005, Emanuel published results from the National Cancer Care Quality Study, which looked at medical care for breast and colon cancer patients. “We know a lot of patients are not getting optimal care. They’re not getting the right surgery, or the right treatment, or the right follow-up,” he says.

**Build It and They Will Come**

NIH hired Emanuel to lead its small bioethics department a mere 10 years after he finished school and after a stint at the Dana-Farber Cancer Institute, where he disrupted the status quo by starting things like an ethics grand rounds. There, he transformed a department of three people into a nationally renowned group with two dozen researchers.

“When he arrived, our visibility and prestige were modest at best,” says his colleague in NIH’s department of bio ethics, philosopher Dave Wendler, Ph.D. “We’re now considered one of the jewels in the biomedical crown.” Emanuel raised the department’s profile, his colleagues say, by setting high standards and bringing in good people. “He has convinced people about the importance of ethics in medicine.”

Part of his success is probably due to his style. “He goes straight for the jugular in a thoughtful and insightful way,” Schrag says. That might put some people off, until they get to know him better. “He doesn’t always play well in a traditional sandbox,” Mayer says. “And he’d be the first to say he doesn’t want to.”

“My job is to ask questions and to get answers,” Emanuel says. “And to make trouble. I look at the tough questions. I was attracted to oncology, probably because it’s fraught with major life choices and we’re always confronting mortality.” Although he can list a dozen issues that are important in health care, he says that the major issue is the quality of care that cancer patients are getting.

“In all fairness, it’s complicated,” he points out. Patients could have six different doctors or more, for example. Also, sometimes physicians give patients who are not responding a fourth- or fifth-line therapy, “just to try something. That’s not just bad medicine; it’s seriously unethical.”

His careful consideration of all sides of the issues has brought him respect in the patient advocacy arena. “I feel like we discovered a prize,” says Fran Visco, president of the National Breast Cancer Coalition. “He doesn’t have an agenda, and he doesn’t push other people’s agenda.” Visco asked Emanuel to help conduct a workshop on drug pricing. They invited industry, economists, payers, and providers—“everyone who had an interest in what cancer drugs cost,” she says. “And he had the ability to work with everyone’s agenda in a fair and balanced way.”

His advocacy doesn’t always make things easy for patients. “Often he would say things that do not make [patient advocates] happy,” Visco says. For example, he told them that a rational health care system limits care so not all people are going to get what they want. “While we don’t like that, Zeke can help us understand what’s going to look like in reality,” she says.

The president of the National Coalition for Cancer Survivorship, Ellen Stovall, says that Emanuel takes a rational, humanistic, practical approach to bioethics. “When I think about a lot of ethicists, they are just so sure what the right answer is. He answered more questions by asking questions,” she says. “He is someone who considers the human condition and how it can come into conflict with science.”

Whether talking with patients, talking with advocates, or working with other cancer researchers, Emanuel has a great sense of humor and is downright entertaining, his colleagues say. “We can be continued on page 1434...”
Zeke, continued from page 1427

talking about a difficult situation with cancer patients or a difficult person, and Zeke will just have a zinger,” Visco says. If you can get a date with him (which would be a trick—he is married to another medical ethicist, Linda Emanuel, M.D., Ph.D., at Northwestern University in Chicago), jump on it. “There’s no one more fun to go have a drink with than Zeke,” Weeks says.

What’s Next?
When asked to speculate on what Emanuel might focus on in the future, his friends and colleagues run the gamut of lofty careers—university president, head of a think tank, education reform. “We’re going to hear more about him in the years to come,” Mayer says. And the expectations aren’t small. “I’d like to see him become politically active and transform health care,” Stovall says.

Emanuel says that the cancer field is rife with big issues. One is the use of placebos in cancer drug trials. “Cancer patients are engaged in a mortal battle. When might it be reasonable to use placebos?” The health care system is also in bad straits, he says, and care for people at the end of life is still not where it could be.

His brothers might be more in the public eye. But clinical researchers, cancer patients, and medical ethicists appreciate Emanuel right where he is. “For people like me, he’s a rock star,” Stovall says.