

The Medical Commencement Archive

Volume 5, 2018



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NY Medical College Commencement

An Invitation To Learn

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*R*everend members of the clergy, Chairman and members of the Board of Trustees of the College; President Kadish; Chancellor Halperin; officers of the College; distinguished faculty and staff; supportive friends and family members; and most importantly graduating students:

My grandfather was an accomplished pianist and composer who, according to my mother, performed in Carnegie Hall. While I bear some physical similarities to my grandfather, I regrettably don't play the piano, and never imagined playing Carnegie Hall. Fortunately, unlike Florence Foster Jenkins as depicted in the 2016 film starring Meryl Streep and Hugh Grant, I didn't have to pay my own way to do so.

In the next few minutes, I hope to say some things that will be meaningful to you, and hopefully also memorable, but not in quite the same alarming way as those who listened to Ms. Jenkins! It's truly an honor to be asked to be giving this talk for an institution that has been devoted to diversity and inclusion since its founding.

Each of you who is graduating has been immersed primarily in the study of some type of science. What is shared among your courses of study is a relationship of science to human health and flourishing. My fields are medicine and bioethics, but you don't have to specialize in bioethics to find yourself doing bioethics. Because the health sciences and health professions are ultimately about human health and human flourishing, ethics will be inextricably intertwined with your work. Doing your work well will require thinking about the ethics of what you are doing; and being sensitive to, and respectful of, those who may be very different from yourself. Sometimes, your work will involve making ethically difficult choices.

Today, I want to share three brief stories with you that I hope provide a sense of how ethics will relate to what you will do in your careers.

Let me begin. There is currently enormous excitement among health policy makers, public health professionals, clinicians and corporations over the possibility of using "big data" and "precision medicine" to enhance understanding of a variety of diseases, conditions and their treatments. At a very basic level, this involves aggregating information from a variety of likely and unlikely sources. However, the very same tools we might exploit to learn about health and health behaviors such as Google searches, Facebook postings, and Twitter feeds, pose risks to our privacy and sometimes our well-being. (It should still be okay to put your commencement photos on Instagram, but I'm not positive about that!) Claims about fake news and about lack of transparency of governmental activities also prompt ethical concerns about such scientifically promising approaches. Are these tensions new?

In 1993, Eileen Welsome, an investigative reporter for the Albuquerque Sun revealed that a series of human radiation studies were done on US citizens without their consent during the Cold War. These included injecting people with plutonium, polonium and uranium. Other accounts surfaced about the same time, which identified experiments that included total body irradiation, feeding radioactive oatmeal to intellectually disabled institutionalized children, and releasing radiation into the atmosphere for research purposes. Ultimately it became clear that over 4000 radiation experiments were done, all supported by the US government. Why? Well, we (the US) were in the midst of a Cold War, and

among other things we wanted to know what would happen if a nuclear bomb was dropped on us, or we dropped a nuclear bomb on Russia. OK, but many of these experiments were done at academic medical institutions across the country, not in secret governmental facilities. How could practicing physicians and scientists do such things, especially after revelations of the gruesome war crimes involving so-called medical experimentation during WW II in Nazi Germany? Sorting some of this out involved the work of the Advisory Committee on Human Radiation Experiments that was chartered by President Clinton. As a young professor, I was lucky to be asked to work for this Committee (against the advice of my Chairman who thought this was all far too political, by the way). To make a long story somewhat short, after 18 months of intense work, it seems likely that individual scientists adhered to an ethic of the time that privileged minimizing risk rather than focusing on consent and they didn't realize that the government was aggregating data across these experiments to inform national security concerns. As scary as some of these experiments sound, the Committee surprisingly found little evidence that people were actually harmed, which may have been at least in part due to the compressed time frame of the task. However, it seems very clear that people in these experiments were wronged in the sense that things were done to them without their permission or consent.

The human radiation experiments underscore the importance of ethics to science. It is far too easy to be caught up in the rush to uncover the latest scientific truths. All of us, regardless of our professional careers, need to be alert to the interests of those who are subjected to science. Similarly, we all need to be vigilant regarding the temptations of big data due to the potential tradeoffs between enhanced knowledge and individual harms and wrongs, such as violating privacy. In addition, we need to be alert to what is driving the science that we do. Scientists and policy makers in particular must ask who is funding or supporting our work and for what purposes?

And now my second story. Over the past couple of years there have been repeated accounts of patients clamoring for access to experimental treatments and multiple states have recently passed "Right to Try" laws, which are intended to make this possible. Further, over the past few weeks there have been reports about the use of crowdsourcing campaigns to support the use stem cell-based interventions among people with an array of devastating diseases and conditions for which standard medical treatments are unavailable or ineffective. Unfortunately, despite years of promising research with stem cells, the treatments many patients are seeking are unproven and untested. What's driving this phenomenon?

As you may know, human embryonic stem cells were first derived about 20 years ago. These cells can turn into any cell in the human body. As such, they offer great promise to cure diseases and conditions such as spinal cord injury or

Parkinson disease in which a particular cell type is damaged or destroyed. One catch is that to derive the embryonic stem cells, embryos must be destroyed, raising important questions about the moral status of the embryo. In fact, debates about this issue reflect deep culture wars not only in the US, but also around the world.

About a dozen years ago I watched a short promotional film showing the first use of deep-brain stimulation to treat a patient with Parkinson disease at Johns Hopkins. In the film, the patient, John Kellermann, is initially shown having tremors and difficulty walking as is typical of patients with the disease. He next undergoes a surgical procedure in which electrodes are placed in his brain. In the final scene we see John playing lacrosse with his sons, scoring a goal no less. The film is very powerful and I was proud to be working at Hopkins!

A few months later, I was appointed to the Maryland Stem Cell Research Commission. One of my fellow commissioners was none other than John Kellermann. It turns out that he had been instrumental in passing the legislation to form the Commission that was charged with making grants for stem cell research in the state. In one televised add for a Democrat running for election as a state representative, John states, "I'm a Republican, and I trust Jim Brochin, with my life." What he also didn't say is that he was Catholic. I asked John soon after he met why he was invested in stem cell research given that he now seemed to be the best lacrosse player I knew. He pointed to the device that operated his brain stimulator and mentioned that if he turned it off, he would be unable to move well. More critically, he wanted to be cured of ALL the problems associated with Parkinson disease, not just be treated for some of the symptoms. Stem cells offered him hope. Moreover, this hope took priority over his personal political and religious beliefs. Illness is a powerful force. Sadly, John died in 2010, never having his hopes realized.

John's story emphasizes the importance of being balanced as we explain our scientific findings so as to not inflate the very natural hopes of people who are sick. An experimental approach that helps cure a mouse and be scientifically fascinating may never help cure a human. As I heard one scientist say, 'it's a great time to be a mouse, but not a great time to be a human.' John's story also reminds us to recognize the distinctions between treatment and cure. These differences matter. Anyone who is in anyway involved with the care of patients needs to be sensitive to them. Finally, the contemporary practice of delivering untested and unproven interventions that exploit this hope for cure are unethical and don't in any way comport with the ethical obligations of beneficence inherent to the health professions.

Now finally, my third story. Near the end of my residency in internal medicine, much to my parent's chagrin I did a rotation in Dar es Salaam, Tanzania. I worked on an all-male, "adult" ward, about age 7 and up. There were 50 beds and usually around 70 patients. AIDS and TB were widespread. We had no treatments for HIV at the time, but we could treat TB. These were some of the stark realities of public health problems writ large. At a clinical practice level, on the ward, the local attending doctor often held my hand (literally) for a long time as we made ward rounds. Handholding is commonplace among friends and colleagues in parts of East Africa, but it was unusual for an American!

One morning as we arrived at the hospital some of the boys on the ward rushed to our truck and brought us to the bedside of a patient who was very sick. His lips were blue. I listened to his lungs and they were fine. I tried to listen to his heart but couldn't hear it. I wondered whether there was fluid around his heart that could be causing his problem. I had been trained that the test of choice is an echocardiogram, which is basically an ultrasound for the heart and mentioned this aloud. The nurse promptly informed me that the hospital didn't have one. My next idea was to take an x-ray. If the heart looked big, then this would be consistent with my diagnosis. Unfortunately, there was a shortage of film so this wasn't possible. The patient was getting noticeably worse, so the only thing left to do was to attempt to place a needle into his pericardium, the lining of his heart. I had done this before, but only with an ultrasound guiding me. And this is a dangerous procedure regardless because it can cause the heart to stop, a lung can collapse and infection can follow. We had a needle, some gloves, and soap and water, but no local anesthetic. I did my best to explain to the patient what I thought was happening and the risks of the procedure as well as not doing it. I asked if he had questions and he did not. He nodded agreement to proceed. That was the consent process. I inserted the needle and was able to extract a large amount of fluid. He was immediately able to breathe and his lips miraculously changed from blue to pink. He looked up at me and said in Swahili, which the nurse helped translate because I didn't know one of the key words he had spoken: "You are the most skilled of laborers" he said. A laborer I thought? After all my education and training was I a laborer? I soon realized this was the highest honor he could pay.

While this story has a good ending, it could have gone terribly wrong. Practicing in resource limited settings is risky and raises many ethical issues that ought to be recognized and managed. This is essential for those doing short-term rotations in global health of any form including medicine, public health and even similarly fashioned mission trips. We ought not to do more harm than good.

Working in Tanzania taught me many things that are of importance for your careers, regardless of whether you will be engaged with public health practice, a

clinical role, or policy making. First, we respect one another by honoring appropriate cultural norms. For example, in the US we shake hands firmly and quickly; in Tanzania we hold hands gently and for long periods of time; in other cultures we kiss or bow or wai. Second, it is possible to engage patients in their care, even in desperate circumstances. Third, for clinicians, medicine is not only about knowledge but also about laboring. Aristotle considered medicine a techne, a skill or an art. And a skill needs to be practiced to be perfected.

So those are my three stories for today. Please realize your degree is an invitation to learn. Stay alert for the lessons that will accompany your work. Welcome unlikely experiences. Welcome unlikely teachers. And welcome the ethical challenges in your work. Congratulations and all the best in the future.