

## My Bioethics Journey

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The patient, an 89-year-old man—let's call him Mr. Smith—had no known relatives, friends, or advance directives. He was a bright man and served as a scientist in the Reagan administration. He was a frequent patient and was burdened with an extensive medical history. That day, he was alone in the hospital, and his organs were failing. The physicians called in the ethics committee for consultation. Mr. Smith's case presented several ethical questions:

- How should the healthcare team proceed, given his terminal and irreversible condition?
- Did Mr. Smith express his wishes for medical treatment during past visits when he might have had sufficient "capacity"?
- Which ethical principle reigns as preeminent: autonomy, justice, beneficence, or nonmaleficence?

But it is the final question that lingers with me: "Lindsay, you're the ethicist, what do *you* recommend?"

Two weeks into my summer internship at a nonprofit hospital in Georgia, where I served as the ethics committee education coordinator, I experienced this scenario—my first ethics committee consult. I am now only 23 years old, and my journey in the bioethics field has been rapid and deeply enriching.

Growing up Jewish in a socially conscious home with a close-knit family, I learned at a very young age that ethics is not what you do but who you are. The Hebrew phrase *tikun olam*, "repairing the

world," was omnipresent in my home. From volunteering in the community to always being truthful, I learned at a very young age that doing the right thing may not always be easy, but it is expected and required. As a child, I had a keen predilection, as my dad observed, "to figure things out." I enjoyed working through challenging situations and finding the best and most well-reasoned solution. I gave my bat mitzvah speech about one having to "walk the walk, to talk the talk." Little did I know, I was already favoring Aristotle's concept of virtue ethics.

Later, during my senior year in high school, I was evaluating different disciplines offered at Emory University, the college from which I subsequently graduated. I studied the alphabetical listing of the academic offerings: anthropology, art history, biology, business, educational studies, and so on, until I reached ethics. Ethics? I was intrigued. What jobs can one obtain in this field? Why have I not seen this offered at other schools? There was one question that I grappled with the most—is it possible to teach ethics?

Emory was one of very few universities that offered ethics as a field of undergraduate study. I took advantage of the opportunity to minor in the field (a major was not offered) and participated in the university's unique ethics and servant leadership (EASL) program. My experience in EASL enlightened and inspired me; I learned that everyday decisions often have an ethical dimension, and that our society needs leaders in this vital field.

Newly inspired and excited to get involved, I began a summer internship with a hospital ethics committee in Austin, Texas. This hospital happened to be at the center of the Baby Emilio controversy. Baby Emilio was on life-sustaining measures, and despite the physicians' shared conclusion that further medical care was futile, the baby's mother resisted ending all such measures. This case called into question the Texas Advance Directives Act, a policy that allows a hospital to end life-sustaining medical treatment against the wishes of the patient (or surrogate decisionmaker) if the treatment is deemed medically inappropriate (e.g., the patient has a terminal and irreversible condition). This policy—intended to reduce futile care for aged, terminally ill patients who are dependent on artificial means to remain alive—created a great deal of controversy when it was implemented in the case of newly born baby Emilio. I was fortunate to have the opportunity to observe ethics consultations, produce material for the hospital-wide ethics education day, and work with ethics administrators and physicians in the shadow of this milestone case. This was a formative summer for me personally and professionally. The firsthand experience of working through complex, abstract cases and collaborating with professionals about these important issues ignited a fire within me. I knew bioethics was the field I was destined to pursue.

During my senior year, I took advantage of EASL's summer internship, a program that placed selected undergraduate and graduate students at local, ethically charged nonprofit organizations. I was placed at the hospital where I met Mr. Smith, just two weeks into my internship. As an intern, I was responsible for reactivating the hospital's stagnant ethics committee. I created an ethics committee manual, developed educational modules, updated the hospital's ethics policies, and assisted in recruiting active,

eager members to the committee. My work in Austin had given me the background that was essential for the responsibility I assumed at this hospital. It was fascinating to observe the overlap of common ethics consultations, the glaring gaps in our current healthcare delivery, and the variation in hospital policy (e.g., Texas had a well-enacted medical futility policy, whereas Georgia did not).

Following my graduation from Emory in May 2009, I moved to Ann Arbor, where I am now working at the University of Michigan School of Public Health. I am the study coordinator for four research projects that explore ethical issues surrounding genetic testing. I also coordinate a yearlong seminar series that explores the ethical, legal, and social implications of personal genomics. Through my job, I have had the opportunity to observe the way bioethical issues are approached by different disciplines. I have been blessed to have forged relationships with bioethics academics and other professionals nationally and internationally. I am discovering that as society, medicine, and technology become more advanced, ethical issues will grow rapidly—in number and complexity. This realization excites and fuels me. I have, in this position, discovered more about myself as I learned about the wide array of ethical issues and the many avenues one can pursue to address these issues. Whether I am addressing personal genomics or end-of-life care, a strong foundation in bioethics helps me work through the challenging questions presented.

I am fortunate that by working in bioethics I have been able to merge my passion with my vocation. In bioethics, I can be hands-on in helping people confront difficult, sensitive situations, and I can be in a position to make a difference. I find myself now, however, at a crossroads. I am intent on earning my prematurely bestowed ethicist title but am unsure how best to navigate this rapidly

emerging area. I have often heard the common sentiment that a terminal degree is necessary to advance in this relatively new, evolving field, and I find the path to achieve my goal in this regard as unique as the field itself. A significant and inspirational mentor to me in this field is the director of patient rights and biomedical ethics systems for a large network of hospitals in Texas. She was not formally trained in this field and actually began her journey as an elementary school teacher. She is a profound and well-spoken “bioethicist” and exemplifies the generational differences in this still-developing field.

My sense is that, unlike my mentor, I will need an advanced degree to go further in bioethics. I appreciate that a higher-level degree may be a prerequisite, but does a master’s of bioethics suffice, or is a doctorate in bioethics required? Throughout my journey, I also continually reflect on what I can contribute to the field. Perhaps my purpose is to create a medical treatment futility policy for hospitals or even a statewide initiative, or to consult with hospital ethics committees. Maybe my path will lead me to develop bioethics education curricula for medical professionals. There is no clear-cut, direct path to reach my perceived goal. Consequently, I am relying on my experiences, insights, intuition,

exceptional mentors, and leaders in this burgeoning field to guide me in the next stage of my journey. I also hope through this process to gain clarity on issues concerning the need for ethics certification, funding, and the variety of titles applied to this field—bioethics, biomedical ethics, medical ethics, public health ethics, clinical ethics, and research ethics.

My quest to secure a career in bioethics parallels the field itself—it is thought provoking, evolving, and dynamic. Through the experiences and education I have been blessed with thus far, I understand and appreciate that ethics is about making the best decision with finite time, knowledge, and resources. Ethics entails differentiating between right and wrong and making the “most right” choice in complex situations.

As for Mr. Smith—the ethics committee reviewed his case and recommended that risk management investigate the legal and liability aspects and that a case worker pursue the possibility of having a guardian appointed. Within ten days of our consult, while still receiving standard medical treatment, Mr. Smith passed away. I know that with all the advances in society, technology, and medicine, a greater need for bioethicists will emerge, and I have every intention of rightfully earning the title of bioethicist.