

Facts alone won't suffice for the field of bioethics

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When you get old enough as a practitioner in any field young people seek your advice about what they should do if they want to do what you do. This has been happening to me with increasing frequency. Undergraduates, high school students, medical students, those pursuing degrees in law and nursing and even those interested in a mid-career change have been asking me how to pursue a career in bioethics.

Having thought about their question quite a bit, I realize that the answer is not the same for everyone who presents the questions. But, the core of the answer is pretty much the same; pursue masters level training in bioethics, acquire familiarity with key social science methods and tools, learn something about a particular sub-area of the health sciences or life sciences and, seek every opportunity to fine tune your analytical and rhetorical skills by working with others on projects, research, consulting, or teaching activities. At its heart bioethics is an interdisciplinary activity and knowing how to work with others who do empirical, historical, legal and normative work is a must.

I had thought that advice to be sound until I heard Zeke Emanuel's plenary address to open the most recent annual meeting of the American Society of Bioethics and the

Humanities. Zeke espoused a vision for future bioethicists that I think is narrow, misguided and wrong. I say that in the spirit that Zeke himself enjoys—vigorous debate about a matter that both of us consider of the gravest importance.

Zeke Emanuel, a physician with a degree in political science as well, is one of the best and brightest scholars in the field of bioethics. His writings are solid and exemplify how best to integrate empirical inquiry with normative analysis. And the ‘shop’ he has run at the NIH Clinical Center for many years prior to moving into the Office of Budget and Management to work on health reform has done an outstanding job training younger scholars in the ins and outs of bioethical inquiry. These facts are precisely why Zeke’s recent plenary address to the American Society of Bioethics and the Humanities was so disappointing.

Zeke began by joking that he knew much of what he had to say would annoy his audience. He then proceeded to argue that the future of bioethics and of bioethicists depended upon the field moving away from its high public profile in political, media and policy debate. What bioethics needs, he argued, is a beefing up of the shabby empirical foundation it now relies upon for its normative and policy claims.

The only way for bioethics to flourish, to paraphrase Zeke’s key contention, is if bioethicists spend less time in public places, more time mastering quantitative methods and publishing empirically grounded research on topics such as informed consent and surrogate decision-making at the

end-of-life in peer-reviewed journals. He added that he did not find any merit in masters programs or PhDs in bioethics since without a more robust empirical foundation there could be little value in such training.

A young, wanna-be bioethicist, Zeke contended, would be best served seeking training in behavioral economics, psychology, decision theory or perhaps, he grudgingly conceded, sociology. Those armed with these tools could be expected to create the rigorous empirical foundation that bioethics now sorely lacks. Moreover, Zeke predicted, those willing to enter bioethics by heading down his prescribed path can expect generous financial support in the form of a pot of gold provided by a National Institutes of Health poised and eager to provide funding for rigorous research.

Before any prospective bioethicists answer Zeke's clarion call for rigor by dusting off their applications to departments of economics and the behavioral sciences let me try to point out why Zeke's vision about what bioethics should be is severely myopic as well as inadequate.

Zeke's call for bioethics to take a sharp empirical turn has power because it is embedded in his talk of the importance of data and rigor. Both are indeed important for bioethics for a variety of reasons. But, neither will get bioethics where it needs to be if it is to serve health care providers, patients, policy makers or the public.

Bioethics, in my view, has a duty to engage the public with bioethical questions. The topics that bioethics grapples with—how to manage dying, the use of reproductive technologies, what to do to maximize the supply of transplantable organs and tissues, how best to promote clinical and animal research, what information you should expect to receive as a patient about your diagnosis and treatment—are of keen importance and legitimate interest to everyone, rich and poor; young and old around the globe. Part, albeit part, but nonetheless a crucial part of the bioethicist's role is to alert, engage and help to illuminate ethical problems and challenges both old and new in the health and life sciences. I do not say to solve them nor to be seen as an authoritative source to whom bioethical issues ought be assigned. Rather bioethics' role is both Socratic and prophetic—challenge, probe, question, warn, chastise, alert, and, as Zeke appreciates, irritate the powers that be when necessary.

In this role of moral diagnostician bioethicists must be responsible and strive for clarity in provoking public attention and debate. However, in this role data is often absent, in dispute or woefully poor. In addition questions loom large and pressing, passions run deep and fear and ignorance are omnipresent companions to doing bioethics with an eye toward helping the public understand issues and options. To engage in the public role that bioethics has and should enthusiastically continue to play in the media, policy, education, legislation and the law more tools are needed than empirical data no matter how rigorous or precise that data and the means used to generate it may be.

One must be able to present a cogent argument, know the areas of consensus that have been established about ethical issues over the history of medical ethics and bioethics, have a familiarity with health law, the infrastructure of policy and a grasp of political, cultural, literary, historical and social dimensions of what makes morality tick in various cultures. In the absence of these skills and knowledge data is completely and utterly blind, even useless. That is why it is precisely this skill set that the aspiring bioethicist should expect a masters program or a PhD program in bioethics to provide in order to gain the analytical and argumentative skills to competently and responsibly carry out the crucial public role bioethics has.

At the end of the day bioethics is a public activity which uses empirical inquiry and information as a tool. Admittedly empirical data are the most important of the tools in the bioethicist's toolbox but still they are only one of the types of tools that are used.

Zeke's vision of bioethics completely confuses the instrument—compiling reliable empirical information relating to normative issues—with the job—informing the public about problems, options and suggesting possible avenues for their resolution.

Zeke's vision makes a bit more sense if one focuses on the role that bioethics plays within health care for professionals and institutions. There bioethicists often act as consultants or help formulate policy in ethically contentious areas

working with providers and administrators and sometimes even payers. But even in this setting, while data is often essential it is never sufficient. What occurs in doing an ethics consultation, for example, has as much to do with knowing how to mediate a dispute as it does a recitation of the facts of a case or having at hand well-supported information about the consequences of various courses of action. In many other situations the ‘facts’ are not known and won’t be known—ever because the human interactions are too complex. Bioethics at the bedside is very much an ethical, social and personal activity and while data has a part to play it has about as much a part to play as it does in our everyday lives and decisions which is to say—sometimes it matters, often it does not.

Before the young bioethicist is told to follow Zeke’s path of empirical positivism consider one other fact. We will not in our lifetime or that of our children ever achieve the kind of empirical certitude about much of anything of the sort that Zeke suggests will help future generations of bioethicists do their work. For every ethical problem for which sufficient data exists to point toward an answer a hundred blossom for which the data don’t. For every ethical problem for which sufficient data have been assembled to make an answer rational, sensible, or even self-evident there are many where behavior, policy and practice do not and cannot be made to conform to that data. Sometimes data alone can point toward an answer. Almost always, however, it is a prior moral argument that points toward the use to which data will, could and ought be put whether that be in medical practice or in medical ethics.

And more often than not moral and value arguments simply moot data and that situation cannot be rectified by appeals to more data.

Zeke ended his remarks that day by acknowledging he was not really trying to end the public role or policy dimension of bioethics. Rather he was just trying to reorient the field's priorities. I suggest Zeke be heeded but only half-heartedly.

More data is needed in bioethics. More scholars with empirical quantitative skills are needed. That said, if the goal of bioethics is not simply to produce every-increasing amounts of NIH funded empirical data but rather to make a difference for the better in the lives of patients, their health care providers, scientists, and the general public then what we need and will continue to need are bioethicists who know their history, understand the power of cases, stories and analogical reasoning, can mount cogent, coherent arguments based on the best information at hand, are comfortable talking with a state legislator, an NIH institute director, a TV talking-head, an athletic coach, a small town family doctor and a minister. Aspiring bioethicists would be well served to develop that full skill set and to seek bioethics programs that can teach them to meet all of those needs.