Special Section:
Quo Vadis? Mapping the Future of Bioethics

Bioethics, Social Class, and the Sociological Imagination

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Last year I published a short article[1] urging bioethicists to carefully examine the question of what ought to constitute the canonical issues topics and questions driving research and teaching in bioethics. Why some subjects dominate the field whereas other topics are regarded as matters for scholars in other disciplines is a question that has intrigued me for nearly a decade. How are the boundaries of bioethics established? What factors influence research agendas and the creation of bioethics curricula? How do funding agencies, editors, and leading scholars shape the field of bioethics? These questions are increasingly receiving scrutiny from Charles Bosk, Raymond De Vries, and other researchers as they explore the sociology of bioethics and the "construction" of the "ethical enterprise."

One of the first papers I published[2] explored why particular topics are addressed or neglected by bioethicists. I wrote "Bioethics, Public Health, and Firearm-Related Violence: Missing Links between Bioethics and Public Health" during my time as a graduate student in the School of Religion and Social Ethics at the University of Southern California. When I wrote the article, I was living in one of the poorer, more socially disadvantaged neighborhoods of Los Angeles. My time in that social environment played a formative role in leading me to wonder why bioethicists pay relatively little attention to social inequalities, urban poverty, homelessness, firearm-related violence, and the disintegration of inner cities and the relationship of these topics to health, illness, and moral experience. At the time, anthropologists, sociologists, and cultural geographers were publishing detailed studies of homelessness, urban gangs and gang-related violence, and the collapse of inner city social infrastructures. Their work considered the relations among poverty, unemployment, ill health, and lack of access to basic healthcare and social services. In contrast, the literature of bioethics placed tremendous emphasis on ethical issues in end-of-life care, organ transplantation, and other topics associated with high-technology medical interventions. Bioethics, it seemed to me, was becoming fixated on an odd menagerie of dramatic, "cutting-edge" topics and neglecting the social, political, and economic contexts within which important ethical issues were unfolding. Living at the time in a low-income area, where community problems extended to the most basic social institutions, the literature of bioethics seemed dominated by middle-class preoccupations and fears. These issues were important—and remain significant today—but their dominant status pushed to the periphery of bioethics crucial aspects of health, illness, social life, and moral experience. When I was riding public transit and walking the streets of this low-income

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area, it took little effort to see how various interwoven social problems had profound ethical dimensions and were closely connected to medicine, illness, injury, and healthcare.

Unlike anthropologists and sociologists studying poverty, homelessness, structural inequalities, social suffering, and illness experiences, I cannot claim to have deliberately immersed myself in a social environment where I might explore these issues in depth. Rather, my sense that important issues were being placed too low on the agenda of bioethics emerged in a more accidental, circumstantial manner. I didn't find myself using the hopelessly inadequate public transit system or living near the intersection of 3rd and Vermont Avenue out of idealism, because I had some Marxist-inflected notion of siding with the proletariat, or because I had a cinema-mediated desire to experience Los Angeles in all its urban grittiness. To the contrary, I was there because, as a graduate student, I simply couldn't afford to live in Westwood, Brentwood, or one of the other wealthier neighborhoods of Los Angeles. I had wanted to attend graduate school in the United States; prior to arriving in Los Angeles the evening before the start of my courses I gave little thought to where I might live.

The urban landscapes through which I traveled during my time in Los Angeles were quite unlike anything I encountered during my years living a relatively stable, safe, middle-class existence in rural Manitoba. To deter criminals, jagged pieces of glass were embedded into the top of walls. Coiled razor wire made already ugly buildings resemble bunkers. The public school nearest my apartment had a play area covered in asphalt, without even a small patch of grass, and signs on the mesh wire fences indicating handguns were not allowed on school grounds. Late at night, police helicopters buzzed through the darkness, their spotlights fingering the ground and tracking individuals on streets and rooftops. The popping sound of gunfire would occasionally accompany the constant background noise of car alarms, police car and ambulance sirens, and blaring stereos. To step onto the campus at the University of Southern California (USC), a wealthy, resource-rich, private university situated amid a low-income, high-crime neighborhood, was to enter a different and much safer world.

Visiting neighborhoods such as Compton, South Central, and Watts during trips to different hospitals affiliated with USC, I passed through neighborhoods that looked as though they must be in some desolate, poverty-stricken country rather than the United States. Shattered toilets and broken sofas were strewn along city curbs. Abandoned, burned-out cars sat beside walls covered with graffiti. In some city blocks, vacant lots were all that remained following what, depending on your political leanings and reaction to the outcome of the Rodney King trial, was either the "Los Angeles Riot" or the "Los Angeles Civil Disturbance" of 1992. Visiting various medical facilities, I found that staff at hospitals such as USC/Los Angeles County Medical Center and Martin Luther King/Drew Medical Center faced incredibly challenging patients and workplace environments. Guards patrolled the hallways. Metal detectors were located at entrances. Emergency rooms were constantly overcrowded.

When I visited these institutions, it was apparent that "medical" problems typically had significant social and economic dimensions. Patients with severe psychiatric illnesses lived homeless on the streets and reached the emergency room with multiple chronic illnesses and sometimes life-threatening diseases. Lacking options, individuals without health insurance waited hours to see ER

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doctors for their primary care. NICU staff faced the challenge of providing care to infants whose mothers had used crack during pregnancy. Residents specializing in emergency care or trauma medicine learned their craft on patients arriving with gunshot wounds and stab injuries. Overwhelmed social workers juggled unmanageable caseloads.

For many individuals living in the most impoverished, devastated parts of Los Angeles and other urban centers in America, poverty, poor health, frequent encounters with both criminals and paramilitary-style police forces, lack of economic opportunities, and limited access to healthcare and basic social services are not temporary challenges. Rather, poverty, unemployment, chronic illnesses, the risk of violence, and blocked educational opportunities are pervasive features of social life and everyday experience. In many respects, to live in Bel Air or South Central is to inhabit different worlds. Concrete freeways, and not any sense of social solidarity or a common fate, constitute the main links between these worlds.

While I am writing this essay in Princeton, one of the wealthiest, most economically privileged towns in the United States, the poorest neighborhoods of Los Angeles now seem very distant. Here, the problems individuals encounter are very different. When I encounter local undergraduates discussing their future prospects, I hear them dwelling on challenging questions such as whether to go to law school or medical school or attend graduate school at Brown or Penn. Such questions are never trivial for the individuals making such decisions. Furthermore, I readily acknowledge that I am much like these students in many of my preoccupations. When considering the choices and opportunities found in middle-class or upper middle-class America, it is easy to forget that individuals in other places inhabit much different social worlds. When you are living in Princeton, the intersection at 3rd and Vermont in Los Angeles begins to seem rather distant.

I wrote that early article on missing links between bioethics and public health because I felt that firearm-related violence and all its ethical, medical, social, and economic dimensions ought to concern individuals working in bioethics. Firearm-related violence is a major topic of research in trauma medicine and public health. Firearm-related violence, medical specialists readily recognize, is not just a matter of particular individuals suffering gunshot wounds caused by weapons fired by specific assailants. Rather, firearm-related violence typically needs to be situated within a context of urban poverty, the breakdown of communities, ease of access to firearms, cultures of violence, gang-related activities, and lack of social, cultural, and economic opportunities. Firearm-related violence occurs in particular social and economic contexts; ignore the context and you have little understanding of what might be done to reduce the number of individuals suffering firearm-related wounds. Of course, in addressing this topic, I was not just attempting to draw attention to ethical and legal aspects of gun control and firearm-related violence. Rather, I was trying to encourage bioethicists to give greater consideration to many different social issues often neglected by bioethicists, yet explored by researchers in public health, medical anthropology, social medicine, and the sociology of health and illness.

What struck me when I first began to consider bioethics, public health, and firearm-related violence, as well as other social and economic issues addressed by public health specialists, was the relative lack of consideration bioethicists

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gave to questions concerning the breakdown of urban neighborhoods, radical social inequalities, poverty, and the "epidemic" of firearm-related injuries. If a patient received treatment in the ER, was transferred to the ICU, and then deteriorated, issues began to emerge that seemed to intrigue bioethicists. Should treatment be continued, withdrawn, or withheld? Was there an identifiable surrogate decision maker? Did the patient have an advance directive? How should death be defined? These topics are readily recognizable as issues bioethicists address. However, the various factors that led to the patient arriving in the ER with a gunshot wound were not matters that concerned most bioethicists. Rather, structural inequalities, urban poverty, and violence were apparently regarded as problems best left to medical sociologists, public health specialists, economists, and activist physicians.

To assert that bioethics is nothing more than ethics at the bedside or ethics within the clinical setting would ignore the contributions of all those individuals who have written about the need for universal health insurance, the importance of addressing social inequalities, and the value of connecting bioethics to public health. Clearly, bioethics has long included a tradition of addressing basic issues related to social inequalities and social justice. Still, in terms of relative emphasis, I think it fair to suggest that issues at the bedside—such topics as informed consent, capacity assessment, and end-of-life care, for example—receive considerably more attention than broader explorations of ethical issues related to what are often called the "social determinants" of health and illness. Moral analysis in bioethics is now typically placed in a "social context," but all too often that context is one occupied by the relatively wealthy and the comparatively privileged.

In the 1980s and 1990s, many bioethicists directed their attention toward ethical issues related to end-of-life care. Now, much more attention is focused on ethical, legal, and social issues related to genetics. This shift in emphasis is not simply a product of individual thinkers growing tired of one set of topics and cultivating new research agendas. Rather, major funding initiatives in such countries as Canada, the United Kingdom, and the United States offer powerful professional incentives to explore ethical, legal, and social issues related to genetics and biotechnology. In my more charitable moments, I recognize the importance of these topics and appreciate that funding is available to address ethical issues related to developments in the life sciences. Such topics as embryonic stem cell research, therapeutic cloning, germ line gene therapy, genetic enhancement, and xenotransplantation all raise ethical issues worth careful exploration. However, in my less charitable moments—and I have many of them—I worry that the funding available for the study of ethical issues related to genetics and biotechnology will lead to the neglect of other important topics that ought to concern bioethicists.

Acknowledging that major changes are occurring in the life sciences, recognizing the value of careful analysis before particular technologies emerge, appreciating that the provision of funding to study ethical issues related to genetics and biotechnology is not just a calculated strategy of co-opting possible critics, I find it nonetheless plausible to suggest that many of the gravest ethical and social issues we face have rather little to do with cloning, stem cells, neutraceuticals, biotechnology, nanotechnology, and gene therapy. It is for precisely this reason that I grow concerned when I consider the issues the President's Council on Bioethics chooses to address. I would feel much more

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favorably disposed toward their study of enhancement technologies and efforts to make humans "better than normal" if I knew that this group was also engaged in addressing ways to respond to the problems facing the 42 million Americans currently lacking health insurance. In the absence of such reflection, the President's Council on Bioethics, as with many other agenda-setting groups in bioethics, is neglecting some of the most important ethical issues related to health and illness.

To criticize the tremendous contemporary emphasis on ethical issues related to biotechnology and the life sciences is not to suggest that individual bioethicists addressing these issues are doing trivial work. Rather, I wish to make a more general point that is directed at bioethics as a field rather than toward individual scholars. Bioethics, if it is to remain significant, if it is to withstand the criticisms of anthropologists, sociologists, and social activists who see it as obsessed with the concerns of middle-class, relatively wealthy, sometimes rather narcissistic individuals, needs to remain attentive to broader social issues connected to poverty, social inequalities, lack of access to healthcare, the collapse of communities and social infrastructures, and public health.

When emergency room physicians in Los Angeles addressed the "social determinants" of firearm-related violence in the 1990s, they did not take a narrow view of gunshot wounds as seen only through the lens of emergency medicine and trauma surgery. Rather, drawing upon the disciplines of public health and social medicine, they exercised what C. Wright Mills called the "sociological imagination." They rightly addressed firearm-related violence in its social and economic settings. At the time, bioethicists simply did not see such issues—and other topics related to urban poverty, violence, and the deterioration of social institutions within inner cities—as significant matters for bioethics. With the current focus on ethical issues related to genetics and biotechnology, bioethics once again risks narrowing its scope of analysis and missing important ethical, legal, and social issues that deserve careful, critical reflection. If this attitude is a consequence of recognizing the immense complexity of such issues as urban poverty, health inequalities, and homelessness, then I quite understand the sense of resignation. Understandably, many bioethicists simply feel ill equipped to address such multifaceted, complex matters. Few of us are trained in epidemiology or public health. Most of us do not have a sophisticated understanding of the economic policies and social structures that generate or mitigate social inequalities. However, if these issues are seen as matters concerning economists, public health specialists, and sociologists and are of no personal, practical, or disciplinary importance to bioethicists, then I worry that the significance and promise of bioethics has been greatly exaggerated, and we will fail to grapple with the most important ethical and social issues facing our cities, communities, and citizens.

Notes

1. Turner, L. Bioethics needs to rethink its agenda. *British Medical Journal* 2004;328:175.
2. Turner L. Bioethics, public health, and firearm-related violence: missing links between bioethics and public health. *Journal of Law, Medicine & Ethics* 1997;25:42–48.

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