ARTS & HUMANITIES

2009 Society for Medical Anthropology Conference

From Race to Repositories: Bioethics in a Genomics Age

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Medical anthropologist Barbara Koenig spoke on the intersection of bioethics and genomics at the 2009 Society for Medical Anthropology Conference at Yale University in New Haven, Connecticut.

Medical anthropologist Barbara Koenig is at the forefront of numerous endeavors that seek to understand race in the age of genomics and protect human subjects with regard to DNA repositories. Through a dialogue ranging from the history and critiques of bioethics to her own research projects, Koenig brought her respect and excitement for the anthropology found in biomedicine to the 2009 Society for Medical Anthropology conference at Yale University in September.

As a whole, the space in which bioethics operates does not constitute a “field” in the traditional sense. It is an amalgam of approaches to the social, ethical, and cultural issues surrounding biology and medicine. While the prevalent medical ethic for 2,500 years has been understood to be embodied in the Hippocratic Oath [1], the modern age of biomedical research and clinical practice demands more careful inspection of ethical issues in biology and medicine. This precise space is where bioethics has found fertile ground for investigation. For Koenig, anthropological analysis and, more specifically, empirical ethnographic study are critical tools to tease apart the complexities of bioethical issues.

Recently, Koenig, a professor of medicine at the Mayo Clinic, has considered the definitions of race in light of the emerging work of genomics [2,3]. Her book, *Revisiting Race in a Genomic Age*, argues that the complex definitions of race are an interesting blend of biological differences and cultural traditions. Often in modern society, the unity assumed among a racial group is at odds with the underlying biological diversity revealed by genomics. And yet individuals in our species are much more related to one another than, for example, any two chimps are related. It is clear from the much-cited work of the Human Genome Project [4,5] and the International HapMap Consortium [6] that genomics will...
have a deeply profound impact on how we understand our ancestry and how easily individuals will be able to trace their own origins using modern genetic technologies.

Hints at new implications in personalized medicine also have come to light, showing that different patient populations, distinguished by race, can have significantly different responses to drugs [7,8]. Increasingly, race is used as a categorization to parse individuals for the purposes of biomedical research. These categories are themselves areas of contention, as they are socially constructed. Individuals may identify themselves with different racial categories depending on the context in which the identifiers are provided. Furthermore, it is unclear what implications can be drawn from the studies in which researchers are asked to conclude something about a social identity based on biological data. Research in these areas undoubtedly will provide insightful anthropological analysis in the coming years.

Much of bioethics is concerned with the issues surrounding new medical technologies and their impact on society. In this same vein, the advent of sequencing databases and direct-to-consumer genetic tests has had broad implications for the participants. At the Mayo Clinic, Koenig is working on the development of a centralized biobank. This facility will store DNA samples collected from patients with a wide range of diseases and enable easy access for clinicians and scientists interested in studying a given disease. However, as with any collection of information, there is a question of access. Who can see what information? How will this be regulated? And to what extent is informed consent required for each of the future uses of the collected sample?

There has been much public debate regarding the ethical use of forensic DNA databases [9,10] and yet less public consideration concerning the medical DNA databases. Koenig spoke of attempts to create community understanding beyond the informed consent standard. An auxiliary issue related to the social impacts of new genetic methods is the emergence of direct-to-consumer genetic testing. Currently, certain companies market to the public with the promise of assessing the customer’s genetic profile in order to identify genetic risk factors for disease. Without the intermediary of a health care provider to validate the analysis and contextualize the risk, these tests can have an alarming and bewildering effect on consumers. How should one understand an 8 percent increase in colorectal cancer risk relative to the general population? Certainly, these new technologies and the companies pushing them directly to the consumer public are of profound anthropological interest.

While some anthropologists analyze trends and conduct surveys to understand their subjects, Koenig has entrenched herself within the clinic and on advisory boards to shape the outcome of bioethical issues facing our society in a time of ever-changing technologies. She has done so with a firm foundation in the historical perspective and practical ethic of biomedicine.

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