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## Towards a Public Health Approach to Bioethics

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**ABSTRACT:** In this paper we examine the central commitments of bioethical enquiry and reasoning from a public health perspective. We argue that a core element of American national culture is individualism, which resonates in scholarly and popular debates. Our contention is that the *habitus* of bioethical debate is in large measure animated by an overriding concern with the individual, and the resulting social practice of the community has been to downplay the importance and legitimacy of group-level health care dilemmas. This paper calls for re-focusing of bioethics by employing a public health perspective, which would include a population focus, evidence-based research topics, and engagement of the ethical dilemmas that arise from decisions concerning prevention. Racial and ethnic health disparities throughout the life span of a population in central New York State are used to illustrate the need for a public health focus in bioethics.

**KEYWORDS:** Bioethics and social justice; Public health and bioethics; Individualism and bioethics; New York State, health disparities in; Infant mortality among African-Americans

In this paper we examine the central commitments of bioethical inquiry and reasoning from a public health perspective. We undertake this examination with the view that the epistemic commitments integral to bioethics are both systematic and constructed by the social practices through which they develop. To do this we draw on both anthropology and epidemiology, and examine the research questions asked by those contributing to the field of contemporary bioethics. Pierre Bourdieu (1977, 1990) directs our attention to the enactment of cultural metaphors in daily life to what he calls *habitus*. Produced by collective action and history, *habitus* creates a system of "principles which

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generate and organize practices and representations" within a community (Bourdieu 1990:53). *Habitus* can create and reinforce social structural and intellectual hierarchy.

Our goal in this paper is to be provocative in the service of renewing and refocusing bioethical inquiry on questions of social justice. In this paper we argue that *individualism*, so intrinsic to American culture, is a core principle which organizes the practices and representations—the *habitus*—of the bioethics community. The predominant focus on individual-level analyses has, we argue, privileged a narrow range of highly technological or exotic research topics and masked the enormous suffering of the medically marginalized.

We begin by assessing the cross-cultural and historical factors that led to the powerful emphasis on individualism in American culture. Then we address individualism's role in the cultural shaping of the research questions asked in bioethics. The third section of this paper sets out a template for a public health focus in bioethics that would encompass political, economic and other structural examinations of the health consequences of disadvantage. The final section illustrates the profound need for such a public health approach by looking at data on racial disparity in health and survival from Onondaga County in central New York State.

## INDIVIDUALISM

Ethnographers of many non-Western cultures document the subordination of individual desires and rights to that of larger social collectivities—family, clan, religious group, or society. Abu-Lughod describes the Bedouin's "collective identity" (1986: 44). Pellow writes about the emotional control taught to Chinese children, especially girls, so that inappropriate or excessive emotions do not mar family "solidarity" or social harmony (1996: 115–177). Meleis, in her ground-breaking work on Arab immigrants in the American medical system, cites affiliation as a core Middle Eastern value.

Ethnographers also point out that such subordination to the group may create problems for individuals. Kleinman (1980), for instance, called attention to the psychological distress, and in some cases illness, arising from the intense pressures to conform to family and social norms in Taiwan. As well, Meleis noted that Western biomedical expectations of a patient's individual agency viewed against the Arab cultural perception of the family as an integrated whole can lead to misunderstanding and mistrust.

The roots of individualism reach back into the European Enlightenment tradition, beginning in the 17th century, in which philosophers questioned both religious and feudal hegemony (Wilson 1998). Despite its transatlantic roots, scholars commonly identify the United States as the locus of individualism's full flowering. Alexis de Tocqueville, upon touring America, praised

the *individualism* that he saw occurring under democratic equality, where each person gained "sufficient education and fortune to satisfy their needs" (1945 edition:98-99). Germinal American thinkers—Henry David Thoreau (1849) in *Civil Disobedience*, Ralph Waldo Emerson (1841) in *Self-Reliance*, and Elizabeth Cady Stanton (1848) in *The Declaration of Sentiments*—argued for the right and responsibility of men, and, in Stanton's case of women, for self-determination. It would not be an exaggeration to say that individualism represents a core element of American national culture.

Recent empirical work in social science posits that societies in general and their economic and political structures in particular may be described as falling on a continuum between the two poles of individualism and collectivism (Hofstede 1980; Trindis 1995). The theme of the individual versus the collective is the basis for both more general scholarly and popular debate as well. Bellah (1985:1) and his colleagues worry that in the United States "individualism may have grown cancerous." Coontz (1997:45) traces the growing disparity in wealth since the 1970s to a "me first individualism." From the libertarian perspective, an article published online by the Ayn Rand Institute critiques affirmative action in an argument that holds individualism to be "the only cure for racism" (Locke 2000:1). Two student groups at the University of California at Berkeley (the Individualist Anarchist Society) and MIT (MIT Radicals for Capitalism) focus on the individual and the state, while a new publication, the *Journal of Individualist Studies*, provides a forum for these debates. Clearly, the concept of individualism resonates for divergent voices, which use it as a vehicle to express their admiration for or dissatisfaction with autonomy, authority, freedom, responsibility and justice.

## INDIVIDUALISM AND BIOETHICS

It is our contention that the *habitus* of bioethics is in large measure animated by an overriding concern with the individual, and that the resulting social practice of the community has been to downplay the importance and legitimacy of group-level health care dilemmas. Perhaps this bioethical fascination with the individual is due to the disciplinary roots of bioethics in medicine, theology, philosophy and law. It may also reflect the United States' cultural bias of the majority of its practitioners. Whatever the precise reasons, bioethical analyses focus predominately on the individual patient, the physician-patient relationship, or on the patient and the hospital or managed care system. The majority of recent publications in the *Hastings Center Report*, for example, address the following topics: patients' rights, genetics and the Human Genome project, privacy, death, the meaning of death, assisted suicide, end-of-life decision making, choice in managed care, managed care funding of IVF, organ transplantation, organ harvesting, organ donors and the gift of

life, informed consent, and patient decision-making. We argue for expanding this view to encompass analysis at multiple levels (Rubinstein 2000), including macro-social, structural factors leading to health disparities.

The four bioethical principles—autonomy, non-maleficence, beneficence and justice (first elaborated in the 1947 Nuremberg Code)—provide a framework for such multiple-level analysis. However, the elaboration of the four principles in the Belmont Report and contemporary bioethical literature privileges the individual-level focus on autonomy. A search of the citation database *Bioethics Line*, for articles in which one or more of the four principles was coded as a key word, demonstrates the individual focus of the field. Of the 17,594 articles reviewed, 57 percent dealt with autonomy, 24 percent with justice and 19 percent with a combination of non-maleficence and beneficence.<sup>4</sup> Moreover, bioethical scholars whose work addressed distributive justice, as in rationing of NICU/ICU care, tended to focus on access to highly technological medical treatments (Lantos *et al.* 1997). There is no small irony in this circumstance, since the Nazi human experimentation that was the impetus for the inauguration of the four principles involved no less of a macro event than genocide.

This critique of the individual-level focus in contemporary bioethics is addressed by a small number of scholars within the discipline. Jennings (1996) and Lamm (1999), both writing in the *Hastings Center Report*, called attention to the distorted individualist focus of bioethics and they suggested that a broadening of the paradigm is necessary. In the remainder of this paper we take up this recommendation by illustrating what the elements of a public health approach to bioethics might entail and by providing a more detailed case study of the value of such an approach.

### A PUBLIC HEALTH APPROACH TO BIOETHICS

In addition to a focus on the individual rather than the population, the selection of bioethics research questions overwhelmingly involves exotic or scientifically cutting-edge topics, despite the fact that the greatest ethical transgressions involve quotidian discrimination in access to primary care. The bioethics literature tends also to focus on the end-stage of problems rather than prevention. A public health approach, in contrast, would include (1) a population focus, (2) evidenced-based research topics, and (3) engagement of the ethical dilemmas that arise from decisions concerning prevention.

(1) *A population focus:* This would provide a corrective to the individual-level focus described above. The major health problems of uninsured individuals, for example, receive scant attention in the bioethics literature. Consid-

ering the community as the “patient,” in the manner of public health, helps to ensure that the suffering, especially of the marginalized poor, remains visible.

(2) *Evidenced-based selection of research problems:* Presently, there is a tendency among scholars in many disciplines to choose research topics that are “sexy,” in that they address hotly contested theory or the pinnacles of scientific technology. *In vitro* fertilization, cloning, and the Human Genome Project are such examples. In contrast, the use of epidemiologic studies in the selection of research questions would help to prioritize those causes of sickness and suffering that create the most harm for the greatest number of people and to direct attention to the moral and ethical problems associated with addressing those issues.

For example, the issue of traditional female genital surgeries has generated a huge bioethical literature, to which the two senior authors of the present paper have contributed (Lane and Rubinstein 1996a). Much of this literature has focused debate upon the autonomy and agency of women involved. Yet, the Arab and African women whom we interviewed about the custom of ritual cutting of genitalia admonished us to see the practice in the context of one of many types of harmful and health-lowering conditions they face. They also advised us to look at our own society with as much sensitivity to injustice as was directed towards theirs. This paper, then, represents a partial answer to their appeal.

A review of epidemiologic evidence regarding the largest causes of illness and death, both in the U.S. and abroad, reveals the root causes to be tobacco, poor nutrition, alcohol, firearms, motor vehicle accidents, inadequate primary health care, and, especially in the developing world, diarrhea and respiratory infection (Lane and Rubinstein 1996b). These issues may lack the lure of the exotic or high tech, but they also present serious ethical dilemmas.

(3) *Prevention:* Consider that 127 articles in the *Bioethics Line* dealt with kidney transplantation, but no article dealt with the prevention of renal failure. Can it be that the medical and social practices of renal failure prevention present no important bioethical issues?

Two of the most common preventable causes of renal failure—hypertension and diabetes—are untreated, or inadequately treated (Pylypchuk and Beaubien 2000, Tompkins *et al.* 1999). A look around any dialysis unit in the U.S. will reveal the disproportionate number of people of color and the poor among the patient population. This suggests that these patients have received care and treatment that is significantly different from that of other groups in our society. This tragic differential in access to preventive care surely demands bioethical consideration.

A second example is the number of bioethical studies on *in vitro* fertilization. The infertility that is solved with IVF most commonly arises from untreated sexually transmitted diseases, such as *Chlamydia trachomatis*. Yet, STD treatment for the medically uninsured is severely limited, while high-tech services for its long-term sequelae are big business (Mehta *et al.* 2000).

<sup>4</sup>*Bioethics Line* was accessed on 4/11/00 for this analysis at: <http://igm.nlm.nih.gov/egi-bin>

We want to emphasize that we are not advocating a replacement of the current bioethical concerns with this public health approach. We are urging a greater awareness of how the current *habitus* of our bioethical community mutes population-level concerns in such a way that they may be seen as peripheral to the bioethics enterprise. Yet, these issues arguably affect the largest number of people in our society. A concern with sophisticated technology and end-stage heroic treatments has its place, but it should not take such a large share of attention that it obscures the more mundane, but profoundly important suffering of the marginalized. A new balance must be reached. It is essential that bioethical analysis be deployed to address the quotidian aspects of health.

### HEALTH DISPARITIES IN CENTRAL NEW YORK

We turn now to an overview of the disparities in survival and health between African-American and white residents of Onondaga County in New York State. Located in central New York State, Onondaga County ranks as the tenth most populous county and the city of Syracuse as the fifth largest city in New York State. Containing urban, suburban, and rural areas and the Onondaga Indian Nation Territory, according to the 1990 Census 468,973 individuals reside in Onondaga County, one-third of whom live in the city of Syracuse. African-Americans constitute 8% of the County population, totaling nearly 38,000 residents. Most African-American residents (88%) live in the city of Syracuse, where they make up about 20% of the population.

As one of his top five priorities, Surgeon General Dr. David Satcher has called for research and intervention to eliminate disparities in health and survival related to race and minority status (2000). These disparities largely result from barriers to access and poor quality health care, lower levels of education, poor nutrition, limited economic resources, and from life patterns associated with living in poverty (David 1997, Reed 1981, The Commonwealth Fund 1997, Oberheu 1997, Friedman 1994).

Unequal health and survival for African-Americans have been United States' historical facts for as long as records have been kept (Leavitt and Numbers 1985). A major disparity and barrier to access to health care is lack of insurance; 23 percent of African-Americans in the United States lack health insurance, compared with 13 percent of white citizens (Martinez and Lille-Blanton 1996). Since Medicaid provides coverage to low-income women with children, African-American men are likely to have less health insurance than African-American women. In New York State about 16 percent of all residents lack health insurance, totaling some 80,000 individuals in Onondaga County.

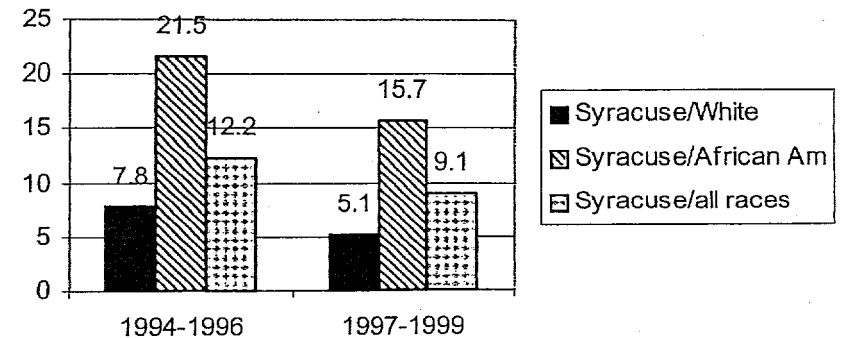


FIGURE 1. Infant mortality in the city of Syracuse: three-year averages.

### Infant Mortality

In 1985–1987, infant mortality in Syracuse averaged 15 infant deaths per 1000 live births, making it the fourth worst of 56 small United States cities surveyed by the Children's Defense Fund. The infant mortality rate (IMR) for African-Americans in Syracuse reached 30.8 per 1000 live births during 1985–1987, the highest of any of 47 U.S. cities reporting comparable data. Many intervention programs began or expanded in response to this crisis, and rates improved during the early 1990s. By 1996, however, African-American infant mortality remained at a standstill; the African-American rate for Syracuse fluctuated around 21 per 1000 from 1993 to 1996. During 1994–1996, Onondaga County experienced greater disparity in infant mortality rates between African-American and white infants than did other upstate New York counties and the nation as a whole.

Non-high-school completion is the leading population-attributable risk (24%) for infant death in the city of Syracuse (1996–1997). Parents who read poorly rarely read to their children, who are then less likely to become competent readers themselves. During 1999, 34 percent of African-American women and 23 percent of white women aged 19 or older, who gave birth in the city of Syracuse, had not graduated from high school, indicating a potential problem with low literacy.

Since 1997, an infant mortality prevention project funded by the by the Health Resources and Services Administration—*Syracuse Healthy Start*—has contributed to a 25 percent overall reduction in infant mortality in the city of Syracuse. As FIGURE 1 shows, however, the racial disparity in mortality persists. African-American infants still die at a rate about a three times greater than do white infants.

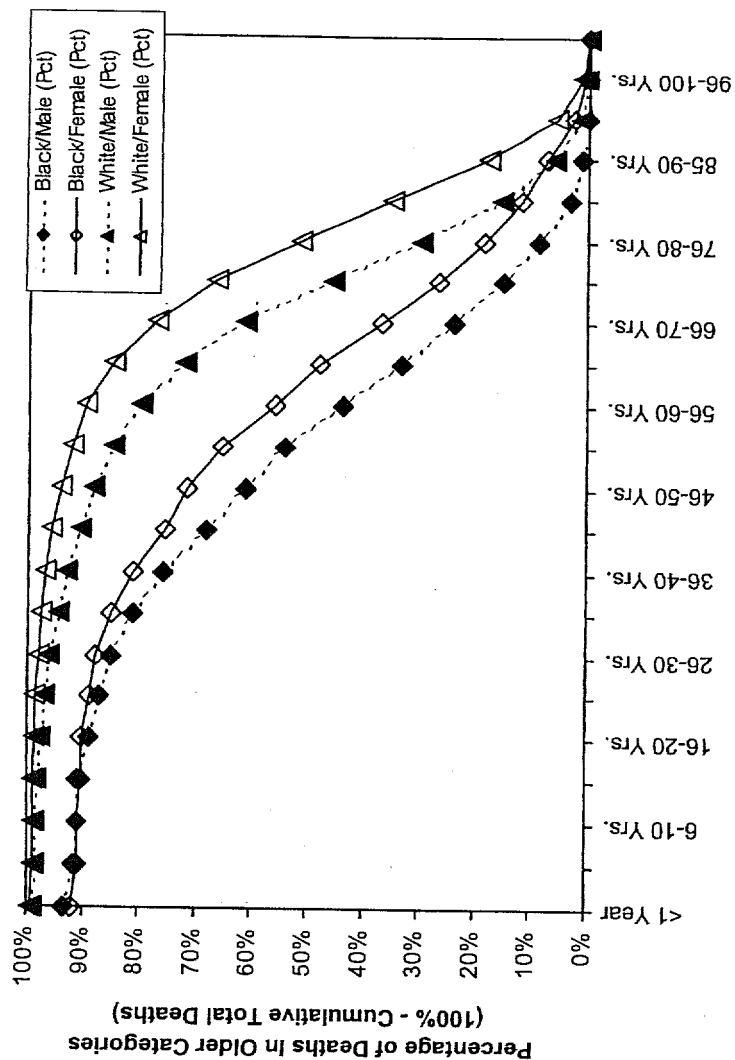


FIGURE 2. Resident deaths in Onondaga County (New York), 1994-1996 by race, sex, and age at death. (N.B.: Data for 1996 are provisional pending final review by the New York State Department of Health.

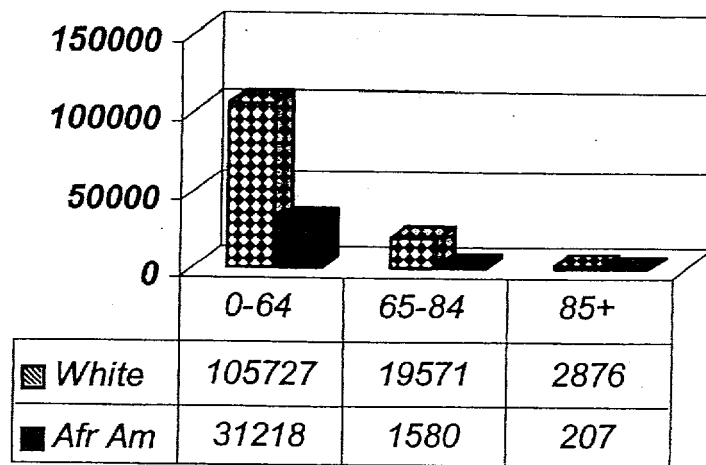


FIGURE 3. Population by age and race (1990 census) in the city of Syracuse.

*Racial Disparities at All Ages*

Racial disparities in mortality persist throughout the life span. We compared the age at death by race and gender in the Onondaga County vital records data for the three years 1994-1996. FIGURE 2 presents the age of death by race and gender for residents of Onondaga County during 1994-1996. As the graph illustrates, African-American males and females die at much younger ages than do white males and females.

*Survival of Elders*

The result of this disproportionate mortality in childhood and early adulthood means that end-of-life medical care, and any decisions it concerns, come earlier. As FIGURE 3 illustrates, in the 1990 census those age 65 and older represent 18% of the white population in Syracuse, but only 5% of the African-American population. In fact, of the nearly 40,000 African-American individuals in Syracuse, only a total of 207 are age 85 and older.

A Health and Human Services report on U.S. national data found that 42.3 percent of African-American deaths before the age of 70 would not have occurred if African-Americans had the same age-sex mortality rates as whites (Heckler 1985:70). While a great deal of the disparity occurs during infancy, a large part of the higher African-American mortality occurs during the productive adult years (24 to 64). Comparing African-American males and fe-

males, the report concluded that more males than females die between the ages of 25 and 44 years, whereas more females than males die between 45 and 69 years. More than 40 percent of the excess African-American male deaths, according to the report, was due to homicide and accidents, about 20 percent to infant mortality, followed by heart disease, cancer, hepatic cirrhosis, and diabetes. Many of these conditions are rooted in the cumulative risks that increase over a lifetime and are associated with poverty, poor nutrition, and stress, all of which could be addressed by effective primary health care and preventive programs.

### CONCLUSION

In this paper we have argued that the field of bioethics needs to be renewed and resensitized to the ethical questions raised by issues of social injustice. As well, we have suggested that the pursuit of fascinating yet esoteric ethical dilemmas is increasingly alienating our current bioethics practice from the concerns of the majority of our own society.

Bioethics is a field born in response to the horrors and social injustices of genocide. Its institutionalization and intensification has been propelled by the recognition that the consequences of pursuing our intellectual inquiries wherever they may lead has not infrequently redoubled social injustices, as it did in the Tuskegee syphilis experiment (James 1982).

Disciplinary histories are replete with instances of scholars pursuing increasingly esoteric and abstruse puzzles. In some instances these puzzles are pursued with such enthusiasm that not only is sight lost of the original problems that motivated the inquiry, but also intellectually portentous "products," inaccessible to those whom they are intended to assist, become the fodder of the field (Suppe 1977; Diesing 1991).

It is our view that the contemporary bioethics focus on individual-level analyses of end-stage, heroic medical technologies is bringing this discipline close to such a moment of social irrelevancy. We have argued here for renewed bioethical attention to the broader issues of social justice that helped to give the field its initial urgent force. One avenue for doing this is for the field of bioethics to integrate a public health perspective, focusing on the bioethical dilemmas presented by current population-based inequities in prevention of disease. Doing so will not only serve the development of the field, but it will lead it back to the service of social justice as well.

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## Globalization of Research and International Standards of Ethics in Anthropology

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**ABSTRACT:** Ethics and anthropology have entered the era of globalization, and professional discourse about ethics can no longer be confined to a national or domestic dialogue. Anthropology must vigorously join the international dialogue and debate over globalization and the conduct of research across cultures; indeed it is the discipline most suited to command the high ground in this discourse. American anthropology historically has been more reactive than proactive in ethics, but cannot remain so as the nature and condition of research have fundamentally changed in a postcolonial world. Indigenous peoples, Third World researchers, international development workers in government and non-government agencies, and other anthropologists outside of the U.S. are raising questions about international research that are generating new standards of conduct. Anthropology as a discipline and a profession must keep apace with these developments or it will lose ground in a crucial arena of global discourse.

**KEYWORDS:** Anthropological ethics; Globalization; International standards of research conduct; Research conduct, standards in

### GLOBALIZATION OF ETHICS AND ANTHROPOLOGY

Anthropological ethics, both as a system of moral values and as a subject of professional practice, has become a global concern rather than merely a private matter of conscience or an internal affair of professional associations. Anthropologists are increasingly held accountable to emerging international standards for the conduct of research as they have been held to U.S. federal and other national standards over the past several decades. Expectations of ethical standards are now commonly articulated by research participants, community leaders, regulatory authorities, and academic counterparts among

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