

RETHINKING MEDICAL ETHICS: A VIEW FROM BELOW

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ABSTRACT

In this paper, we argue that lack of access to the fruits of modern medicine and the science that informs it is an important and neglected topic within bioethics and medical ethics. This is especially clear to those working in what are now termed 'resource-poor settings' – to those working, in plain language, among populations living in dire poverty. We draw on our experience with infectious diseases in some of the poorest communities in the world to interrogate the central imperatives of bioethics and medical ethics. AIDS, tuberculosis, and malaria are the three leading infectious killers of adults in the world today. Because each disease is treatable with already available therapies, the lack of access to medical care is widely perceived in heavily disease-burdened areas as constituting an ethical and moral dilemma. In settings in which research on these diseases are conducted but there is little in the way of therapy, there is much talk of first world diagnostics and third world therapeutics.

Here we call for the 'resocialising' of ethics. To resocialise medical ethics will involve using the socialising disciplines to contextualise fully ethical dilemmas in settings of poverty and, a related gambit, the systematic participation of the destitute sick. Clinical research across steep gradients also needs to be linked with the interventions that are demanded by the poor and otherwise marginalised. We conclude that medical ethics must grapple more persistently with the growing problem posed by the yawning 'outcome gap' between rich and poor.

I INTRODUCTION

Bioethics and medical ethics are necessarily a contentious enterprise. These fields have the potential to embrace not only empiric research, but also philosophical commentary, informed opinion,

and essay as well. The best scholarship in these related fields often addresses ‘unresolved issues’ of moral conflict. Some issues are unresolved because they stem from novel developments, such as xenotransplantation or the latest in stem-cell research; other issues are unresolved because too little attention has been paid to them in recent decades, in part because the discipline of medical ethics has arisen in certain social contexts and not in others. We argue here that lack of access to the fruits of modern medicine and the science that informs it is an important and neglected topic within bioethics and medical ethics. This is especially clear to those working in what are now termed ‘resource-poor settings’ – to those working, in plain language, among populations living in dire poverty.

AIDS research has been a case in point. In a recent commentary on the ethics of HIV vaccine trials, physician Joia Mukherjee voiced in print what many who do not read or write are saying about the ethics of AIDS research within settings in which AIDS is now the leading infectious cause of adult death:

When asked, ‘Have you no morals?’ Alfred Doolittle, in George Bernard Shaw’s *Pygmalion*, answered, ‘Can’t afford them, governor. Neither could you if you was as poor as me.’ The modern concept of human rights underpins a moral society and holds government responsible for fulfilling those rights. From informed consent to the right to privacy, civil and political rights have dominated the human rights focus of the HIV-1 epidemic. Yet, the economic and social rights of people with HIV-1 infection, in particular the rights to health care and to share in scientific advances, are glaringly disparate between rich and poor countries. This disparity has become the focus of debate in transnational HIV-1 vaccine research.¹

Mukherjee’s commentary will resonate with some and rankle others. But many of those who would find her views compelling are those who will never read a medical journal because they do not read; others read but do not have access to journals. These are the people whose views we seek to echo in offering a view of medical ethics ‘from below.’

First, what is meant by ‘a view from below’? What is not intended by this expression? Elsewhere, we have elaborated a critique of the scholarship of suffering from the perspective of those

¹ J.S. Mukherjee. HIV-1 Care in Resource-Poor Settings: A View from Haiti. *Lancet* 2003; 362: 994–995, at 994.

living in great poverty.² Here we will note in passing that dissymmetries of power are present in all medical exchanges: between well and sick, expert and non-expert, white and black – the list goes on. But these dissymmetries are often masked in the language of academic medicine and public health. In a 1992 book, Howard Brody notes that ‘the word *power* is essentially absent from the vocabulary that scholars of medical ethics have constructed for their discipline and that has been accepted by almost everyone who does work in the field or tries to apply medical-ethic insights to the clinical context.’³ This honest assessment serves as a stepping stone for our essay, which moves far beyond the boundaries of the world’s most affluent nations, the birthplace of professional societies of medical ethicists and bioethicists. Since the topic of medical rationing, which implies scarcity, is a staple of the medical ethics literature,⁴ we add at the outset that we refer in this essay to the world’s poor, especially the poor of the poorest countries. When the question ‘Who shall live?’ was posed, these people were not yet in the consciousness of those building a new field.

Subaltern populations within rich and middle-income countries have long been caught up in the key dramas of medical ethics: witness the Tuskegee Syphilis Study, which followed 600 African American men in Alabama from 1932 to 1972, and continues to have its echoes even today.⁵ Similar experiences have been documented in Europe, South Africa, and Brazil.⁶ But, to this day, the poorest people in the poorest countries are likely to appear only in the margins of the bioethics literature if they

² P. Farmer. On Suffering and Structural Violence: A View from Below. *Dædalus* 1995; 125: 261–283.

³ H. Brody. 1992. *The Healer’s Power*. New Haven & London. Yale University Press: 12.

⁴ V. Fuchs. 1975. *Who Shall Live? Health, Economics, and Social Choice*. New York. Basic Books.

⁵ Roughly 400 of these men had syphilis, and most lived in poverty. Despite the 1947 discovery of a cure for the disease – to this day, syphilis is treated with penicillin – subjects were never offered that very inexpensive drug, even though they had joined the study assuming that they would be treated. Nor were they informed of the study’s real purpose. (S.M. Reverby, ed. 2000. *Tuskegee Truths: Rethinking the Tuskegee Syphilis Study*. Chapel Hill. University of North Carolina Press. A.M. Brandt. 1987. *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880*. New York. Oxford University Press.)

⁶ See, for example, commentary on Norplant trials in Brazil. A.R. Dos Reis. Norplant in Brazil: Implantation Strategy in the Guise of Scientific Research. *Issues in Reproductive & Genetic Engineering: Journal of International Feminist Analysis* 1990; 3: 111–118.

appear at all. We have seen their critiques of research ethics dismissed as confused and ill-informed commentary or as ‘conspiracy theories.’ But much is to be gleaned from such critiques, as more in-depth and sympathetic explorations of them suggest.⁷ This paper is meant as a constructive critique of bioethics and medical ethics, not only from the point of view of those living in great poverty but from the perspectives advanced by the ‘socialising disciplines.’ These include anthropology, history, political economy and the sociology of knowledge; few would regard philosophy, for years the parent discipline of ethics, as a socialising discipline. It is our hope, here, to help ‘resocialise’ medical ethics as part of a broader intellectual and social project that is necessary as dominant cultures, academic and otherwise, increasingly favour psychological or individualist readings of social problems ranging from addiction to AIDS to ‘non-compliance’ with medical regimens.⁸ We will draw on our experience in Haiti and the United States in order to offer an overview of what is lacking not only in ethics but also in conventional human rights discourses, which have also influenced medical ethics and bioethics.

As a physician-anthropologist and a specialist in health policy, our views may be regarded as suspect by some within the field of medical ethics. For this reason, we start our review by relying on certain voices from within the discipline of medical ethics. After pointing to deficiencies underlined from within the discipline, we turn to problems occurring right now in the course of efforts to respond to AIDS and tuberculosis, among other modern plagues.

II WHAT’S WRONG WITH MEDICAL ETHICS?

In the social field in which bioethics and medical ethics have emerged – affluent industrialised countries, by and large, and within the past few decades – practitioners of these disciplines are seen, by themselves and by others, as liberal reformers. Three major and overlapping groups may be discerned. Within clinical settings, ethicists are the guardians of morally sound practice and a safeguard against abuses. By the close of the last century, most major teaching hospitals had ethics committees; many boasted in-house ethicists active in addressing the quandary ethics of individual patients. As often as not, ethics consults in such hospitals

⁷ P. Farmer. 1992. *AIDS and Accusation: Haiti and the Geography of Blame*. Berkeley & Los Angeles. University of California Press.

⁸ G. Lipovetsky. 1993. *L’Ere du vide: Essais sur l’individualisme contemporain*. Paris. Gallimard.

take into consideration discord between patients' families and medical staff or withdrawal of care for those deemed unlikely to be saved by 'heroic interventions.' The salutary impact of these developments is not disputed.

A second major stream of medical ethics is constituted by the everyday practice of ethics within modern biomedical research. The research arena has been home to an explosive growth of institutional review boards (IRBs); human subjects committees abound. Disclaimers regarding potential personal gain are required in the publishing of data and it is not possible to publish even photographs or the comments of patients without 'ethical clearance.' In the university with which we are affiliated, students cannot undertake research involving human subjects without going through an ethics course and filling out an application. Again, many regard these as positive developments. But some would note that it is not easy to link the proliferation of such committees and regulations with a rise in ethical treatment of the destitute sick, especially if we take a global perspective.

It is possible to read, for example, front-page exposés of research projects conducted by first-world universities in Africa and learn that, although research subjects have signed informed-consent forms, they have no clear notion about what the research explores or about how they figure in the endeavour.⁹ Other research projects, duly blessed by multiple review boards in both the research university and the host country, are so manifestly unethical in the eyes of some leaders of modern medicine that they can be termed reminiscent of Tuskegee in the world's leading medical journals. Consider studies involving what many argue are unethical placebo controls in AZT trials attempting to develop a cheaper drug regimen to prevent mother-to-child transmission of HIV.¹⁰ Despite the fact that the US Public Health

⁹ H. French. AIDS Research in Africa: Juggling Risks and Hope. *New York Times* 9 October, 1997: A1, A14.

¹⁰ Also consider the more recent example of a randomised-control trial conducted between November 1994 and October 1998, which examined the relationship between serum viral load, concurrent sexually transmitted diseases, and other known and putative HIV risk factors. The research team screened 15 127 individuals in a rural district of Uganda, of whom 415 were identified as HIV-positive with an initially HIV-negative partner. The researchers then tracked these serodiscordant couples for thirty months, following the viral load of the infected partner and the rate of seroconversion among the previously uninfected partners. The study concludes that 'viral load is the chief predictor of the risk of heterosexual transmission of HIV-1.' (T.C. Quinn, M.J. Wawer, N. Sewankambo, D. Serwadda, C. Li, F. Wabwire-Mangen, M.O. Meehan, T. Lutalo & R.H. Gray. Viral Load and Heterosexual Transmission of Human

Service began recommending the use of zidovudine to prevent MTCT in 1994, a review by Lurie and Wolfe in 1997 counted 15 studies taking place in developing countries in which some or all of participants were not receiving antiretroviral therapy to prevent MTCT.¹¹ Editor of the *New England Journal of Medicine* Marcia Angell explicitly compared such studies to Tuskegee, and chastised the NIH and CDC for contributing funds to several projects:

The fact remains that many studies are done in the Third World that simply could not be done in the countries sponsoring the work. Clinical trials have become a big business, with many of the same imperatives. To survive, it is necessary to get the work done as quickly as possible, with a minimum of obstacles. When these considerations prevail, it seems as if we have not come very far from Tuskegee after all.¹²

The majority of such international biomedical research has inequality as its foundation, and ethical codes developed in affluent countries are quickly ditched as soon as affluent universities undertake research in poor countries. Then come a series of efforts to develop alternative (read, less stringent) codes ‘appropriate’ to settings of destitution.

A third strand of work is less closely tied to clinical care or research endeavours: teaching and scholarship on bioethics and medical ethics. Again, the explosive growth of these fields is easy

Immunodeficiency Virus Type I. *New England Journal of Medicine* 2000; 342: 921–929.) In an accompanying editorial, *New England Journal of Medicine* editor Marcia Angell voiced her hesitation about publishing the study and was quite pointed in her criticism: ‘It is important to be clear about what this study meant for the participants. It meant that for up to 30 months, several hundred people with HIV infection were observed but not treated.’ Furthermore, ‘the very condition that justified doing the study in Uganda in the first place – the lack of availability of antiretroviral treatment – will greatly limit the relevance of the results there.’ (M. Angell. Investigators’ Responsibilities for Human Subjects in Developing Countries. *New England Journal of Medicine* 2000; 342: 967–969.) Explicit comparisons to Tuskegee were made in the popular press; in the electronic magazine *Slate*, one writer asked: ‘The . . . volunteers in the sample were not offered treatment nor were their healthy sex partners informed that the research subjects were HIV positive. Excuse please, but why isn’t this like the [*New England Journal of Medicine*] supporting the Tuskegee experiments?’ (S. Shuger. Supreme Court Cover-Up. *Slate* 30 March, 2000. Available at: <http://slate.msn.com/?id=1004976>.)

¹¹ P. Lurie & S.M. Wolfe. Unethical Trials of Interventions to Reduce Perinatal Transmission of the Human Immunodeficiency Virus in Developing Countries. *New England Journal of Medicine* 1997; 337: 853–856.

¹² M. Angell. The Ethics of Clinical Research in the Third World. *New England Journal of Medicine* 1997; 337: 847–849.

to gauge simply by looking at journals, publications, and the number of faculty appointments within schools of medicine, nursing, and public health. Many of these scholars have formal training in both medicine and philosophy.

What is the primary purpose of these three overlapping strands of medical ethics and bioethics? An anthropologist might ask, what are the social fields in which they emerge? Whose interests are they intended to protect? What ends do they serve?

Such questions, which admit to multiple answers in multiple arenas, are not always welcome. None of the answers are facile ones, since even the quandary ethics of clinical practice are disputed terrain. But even more disputed are research ethics when projects span vertiginous social inequalities. The ethical dilemmas stemming from such research are almost invariably about the haves and the have-nots, and this is as true today as it was during the long decades in which the Tuskegee experiment was being conducted. But much professional commentary on medical ethics appears divorced from straightforward discussion of racism and the yawning gulf between researchers and subjects. Larry Churchill notes this at times absurd divorce between ethical dilemmas that arise in everyday life and the professional commentary they spawn:

Bioethical disputes – as measured by the debates in journals and conferences in the United States – often seem to be remote from the values of ordinary people and largely irrelevant to the decisions they encounter in health care. In this sense, philosophical theorizing might be considered harmless entertainment, which if taken too seriously would look ridiculous, as several Monty Python skits have successfully demonstrated.¹³

Churchill's critique of philosophical theorising is even more poignant when the 'ordinary people' in question do not have access to modern healthcare. What 'decisions' are taken by the world's poorest, who are also, by any honest accounting, the globe's sickest? One of the ways to answer this question would be to spend time interviewing the destitute sick about what they regard as their ranking problems; it is also possible, we have discovered, to interview them about the ethics of research.

We draw on our experience with infectious diseases in some of the poorest communities in the world to interrogate the central imperatives of bioethics and medical ethics. AIDS, tuberculosis,

¹³ L. Churchill. Are We Professionals? A Critical Look at the Social Role of Bioethicists. *Dædalus* 1999; 128: 253–274, at 255.

and malaria are the three leading infectious killers of adults in the world today. Because each disease is treatable with already available therapies, the lack of access to medical care is widely perceived in heavily disease-burdened areas as constituting an ethical and moral dilemma. In settings in which research on these diseases is conducted but there is little in the way of therapy, there is much talk of first world diagnostics and third world therapeutics.¹⁴ To quote a woman who had returned to central Haiti, dying of AIDS, after years in the city, 'We're good enough to study but not good enough to care for.' This woman, who later received therapy for her disease and stopped dying, was nonetheless passionate about the topic well after her own lack of care was addressed and she began to respond to antiretroviral therapy. In another interview, conducted in her home, she expounded at some length:¹⁵

I was diagnosed [with HIV infection] because of a research project that [a US research university] was doing. That was ten years ago. This was in [a slum in Port-au-Prince]. I went back a lot to have my blood drawn but I never got any treatment. And I knew from the radio that other people received treatment. These were people who could pay \$200 a month. They were people who could go and make a deposit at a bank and then they'd get their medicines for a month . . . I came home [to central Haiti] to die, but even now that I'm better I'm still angry about it. Ten years of them sucking my blood and nothing! I was a skeleton sitting on the bench waiting for them to call my name. It's when I got to be a skeleton that the nurse told me that I didn't have to come any more. It's as if poor people were animals. But we won't serve as their guinea pigs [*Men nou p'ap sevi kom kobay yo*].¹⁶

Although the expression 'first-world diagnostics and third-world therapeutics' may not be the term commonly used in Haiti, the

¹⁴ Emanuel et al. have suggested guidelines for 'what makes clinical research ethical.' Among their criteria is 'fair subject selection' – subjects should not be vulnerable individuals and must have the potential to experience the benefits of any ethical research project. (E.J. Emanuel, D. Wendler & C. Grady. What Makes Clinical Research Ethical? *Journal of the American Medical Association* 2000; 283: 2701–2711.)

¹⁵ Several patients being treated for HIV at the Clinique Bon Sauveur in rural Haiti are quoted throughout this article. These interviews are not part of a formal ethnographic study, but rather an effort to convey patient stories in their own words.

¹⁶ The research project mentioned has, by report, since been terminated.

idea behind the expression has wide currency among patients and non-patients there. This is because, with many infectious diseases, the research enterprise is fundamentally a transnational one. It is also a fundamentally inegalitarian exercise in the sense that medicine and science are expanding rapidly, but in a social context of growing global inequality, which ensures that the fruits of medicine and science are not available to many who need them most.¹⁷

Medicine, public health, and research are all caught up in a web of unequal relations. The link between research on AIDS and access to therapy for HIV has been the most scrutinised, perhaps, of this troubling aspect of modern medicine. But other startling examples abound. Organ transplantation is a disturbing case in point. This is not because the clamour for access to organs by those living with, say, renal failure and poverty has reached the ears of most who write about the ethics of the rapidly expanding practice of organ transplantation. It is rather because, globally, the poor are more likely to serve as donors, rather than recipients, of organs.

Organ transplantation is altogether unknown in countries as poor as Haiti, but is common in wealthier but inegalitarian countries and regions throughout the developing world. And almost everywhere we look, trafficking in organs occurs in predictable ways – predictable, that is, to those who look at social inequalities across borders. To quote one anthropologist who works on this topic, ‘the flow of organs follows the modern routes of capital: from South to North, from Third to First World, from poor to rich, from black and brown to white, and from female to male.’¹⁸

The seamy underbelly of organ donation in the poor world has been noted by other anthropologists and by adventurous ethicists as well; an ‘organs watch’ website has even been established.¹⁹ Although egregious violations of rights are a major problem – the literature is already rife with stories of organs, from kidneys to corneas, quite literally stolen – a far greater problem is the legal and ‘ethically approved’ transfer of organs across social gradients. In other words, the ethical codes currently in place have not prevented abuses grounded, however subtly, in growing inequalities.

¹⁷ On the growth of global inequality since 1980, see: J.K. Galbraith. *A Perfect Crime: Global Inequality*. *Daedalus* 2002; 131: 11–25.

¹⁸ N. Scheper-Hughes. *The Global Traffic in Human Organs*. *Current Anthropology* 2000; 41: 191–224, at 193.

¹⁹ *Organs Watch*. University of California, Berkeley. Available at: <http://sunsite.berkeley.edu/biotech/organswatch/>

When someone living in destitution ‘opts’ to sell a kidney and signs all informed-consent forms in front of multiple witnesses, is the term ‘informed consent’ really meaningful? Rather, what does such informed consent really mean? That the donor is a priori informed about his or her chances of survival without the money disbursed upon donation?

So it is with much AIDS research. If individuals living in slums in African cities, unable to read and write, are to participate in clinical trials, what sort of process must they go through in order to provide informed consent? Or is there a darker possibility: that research across such deep gradients of inequality means that the research enterprise is itself fundamentally coercive unless special measures are taken?

These questions, which are not meant as rhetorical, get at one of the oldest and most fraught debates within social theory: the reticulated relationship between structure and agency. A ‘view from below’ would ask how poverty, racism, and gender inequality come to constrain agency, the ability to make choices. If one believes in the ability of research to lessen misery and suffering – as we do – what ‘special measures’ might one envision as we seek to conduct research in settings of great poverty? How might we ensure that the measures are not in and of themselves coercive, as many incentives are deemed to be?

To answer these and related questions, we note again that it is necessary to resocialise the problems at hand – the quest for vaccines, say, or novel therapeutics or organ transplantation – in order to have a broader view of the inequalities in which such endeavours are grounded, whether researchers see them or not. Efforts to resocialise problems allow all concerned to have a more meaningful understanding of what it is the research subjects (or organ donors) hope to gain from participating in what are, often enough, their only encounters with modern biomedicine. And even a preliminary attempt to consider these topics in their broader social contexts allows us to come to a preliminary conclusion: the more desperate the poverty of subaltern populations (research subjects or organ donors who live in poverty, sick prisoners), the greater the constraint on their agency. In other words, the steeper the gradient of social inequality across which such transactions occur, the greater the risk of abuse without the ‘special measures’ we discuss below.

One of the ways of rethinking medical ethics is to place the ‘outcome gap’ front and centre as an ethical issue. The term ‘outcome gap’ admits to many meanings, but here we follow the example of paediatrician Paul Wise, who some years ago interro-

gated conventional wisdom regarding low birth weights in urban United States, where race and class are strongly associated with rates of premature delivery, with weight at birth, and with rates of infant mortality. These oft-noted disparities of outcome had led, in the last quarter of the previous century, to a movement to divert money from neonatal intensive care units to social conditions for African-American women. But Wise noted that such a diversion would not get to the heart of the matter:

Too often, those who elevate the role of social determinants indict clinical technologies as failed strategies. But devaluing clinical intervention diverts attention from the essential goal that it be provided equitably to all those in need. Belittling the role of clinical care tends to unburden policy of the requirement to provide equitable access to such care.²⁰

Arguments about resource allocation – another staple, as noted, of commentary within medical ethics – are not really ‘socialised’ since they do not include an honest accounting of how an affluent society, or even a city, chooses to spend available resources. Resocialising the problem of low birth rate would require frank discussion of racism, subsidies for the rich and shrinking resources for the poor, military expenditures, and, again, the growing gap between the rich and the poor. It would also require careful consideration of equitable access to clinical care. These topics, like the term ‘power’, are rarely encountered in professional journals devoted to medical ethics.

And so it is with each of the problems mentioned in this essay: AIDS, chronic renal failure, prison-seated epidemics of tuberculosis, and racial disparities in infant mortality. Each problem has generated debates within medical ethics, and new technologies to address them may generate debates within bioethics. But it is possible to discern in scholarly discourse what might be termed a ‘Luddite approach’ to the problem: we should halt AIDS research in resource-poor settings, we should stop performing kidney transplants, we should focus exclusively on prison reform rather than treating epidemic tuberculosis within prisons, and we should stop building NICUs. These unwelcome conclusions are reflected not only within scholarship in medical ethics but also its pious echoes in clinical medicine, medical education, and public health.

²⁰ P. Wise. Confronting Racial Disparities in Infant Mortality: Reconciling Science and Politics. *American Journal of Preventive Medicine* 1993; 9: 7–16, at 9.

We are opposed to these Luddite traps. Each of the dilemmas discussed here calls for new and better technologies, whether they are for managing renal failure or for developing a vaccine for AIDS. To argue, as we do, that the primary ethical issue of modern medicine and public health is the outcome gap, itself rooted in transnational and growing social inequalities, is not to argue for merely shuffling around research and service priorities with decisions based on primitive notions of cost-effectiveness, the latest fashion in policy making. The problem is much deeper. Indeed, we have argued elsewhere that the growing outcome gap constitutes the chief human rights challenge of the 21st century.²¹ This assertion will seem odd to many who term themselves experts in the field of human rights, accustomed, as they are, to exhorting governments to respect civil and political rights. But the importance of social and economic rights is paramount in settings of poverty, which are also settings of excess morbidity and mortality.

But what does it mean, for both bioethics and human rights, when a person living in poverty is able to vote, is protected from torture or from imprisonment without due process, but dies of untreated AIDS? What does it mean when a person with renal failure experiences no abuse of his or her civil and political rights, but dies without ever having been offered access to dialysis, to say nothing of transplant? What does it mean when an African-American neonate does not have ready access to the care only afforded in a NICU?

The world's poor do not live on another planet; nor do they live in countries in which such technologies are unavailable. Surveys have shown that in the world's poorest countries, the affluent have ready access to both antiretroviral agents and therapy for renal insufficiency; NICUs are close at hand for infants born to affluent families. At the same time, the world's poor, even those living in wealthy nations, do not have reliable access to good medical care or to the fruits of medical science. And if this is regarded as an ethical problem, then it is one that is growing rapidly and worsened by the development of new and more effective therapies. It is new because some of the diseases and all of the technologies are new: impossible to imagine the key philosophers of yesteryear pondering these technologies because they did not yet exist. Whenever more effective technologies are introduced there will be, in the absence of an equity plan, a

²¹ P. Farmer. 2003. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. Berkeley. University of California Press.

growing outcome gap – the unmentioned elephant in the room of medical ethics.

III LINKING BIOETHICS TO SOCIAL ANALYSIS: RETHINKING THE CASE OF TUBERCULOSIS IN PRISONS

We have underlined two steps that would make medical ethics more compelling in settings of great poverty: using the socialising disciplines to contextualise fully ethical dilemmas in settings of poverty and, a related gambit, the systematic participation of the destitute sick. A third step is to link research across steep gradients with the interventions that are demanded by the poor or otherwise marginalised. Examples of the fruits of linking better analysis and better interventions have been offered elsewhere. In the cases cited above, understanding the ethics of AIDS research in Africa or Haiti would rely heavily on interviewing people living with both poverty and this disease. But what is true for AIDS is true for most other maladies afflicting the poor disproportionately.

Elsewhere, we have offered the example of prisoners in Russia who are sick with drug-resistant tuberculosis in order to underline the shortcomings of current approaches to these problems.²² To summarise a complex biosocial process for the purposes of the current exercise, it is important to know that a doubling of incarceration rates occurred after the collapse of the Soviet Union. The infamous gulag came to be more than three times as full in 'democratic' Russia, with Siberian incarceration rates exceeding, at one point, 1000 per 100 000 population (only the United States rivals this ratio). Overcrowding, poor ventilation, interruption of medical supplies and salaries for overworked prison staff, and malnutrition led to explosive epidemics of tuberculosis within Russia's prisons. But this was not the sort of tuberculosis seen in Haiti or sub-Saharan Africa. In some senses, the Russian epidemics were more reminiscent of the prison-seated outbreaks documented in New York beginning in the late 1980s: although HIV was not a factor in the Russian epidemics, they were, as in New York, prison-based and involved strains of highly drug-resistant *Mycobacterium tuberculosis*, the organism that causes the disease.²³

²² P. Farmer & N. Gastineau. Rethinking Health and Human Rights: Time for a Paradigm Shift. *Journal of Law, Medicine & Ethics* 2002; 30: 655–666.

²³ For a review see: P.E. Farmer, A.S. Kononets, S.E. Borisov, A. Goldfarb, T. Healing & M. McKee. 1999. Recrudescence Tuberculosis in the Russian Federation. In *The Global Impact of Drug-Resistant Tuberculosis*. Program in Infectious

Into this dramatic and novel situation came, for the first time, non-Russian aid agencies and non-governmental organisations. To date, there have been few thorough studies of this stunning development, but such analyses are important to our understanding of what is occurring within prison walls today.²⁴ By the mid 1990s, such organisations were prominent players in post-Soviet states, all of which had seen catastrophic deterioration in their social safety nets and medical systems. The non-governmental organisations were mostly European and North American, and in the post-perestroika disarray they had something their Russian (and Azeri and Georgian and Kazakh, etc.) partners did not then have: money and clout. The ability of these aid organisations to shape responses to epidemic tuberculosis in Siberia was significant, and they insisted on what they termed the most ‘cost-effective’ approach, the one endorsed by international tuberculosis experts, including the World Health Organization: directly observed therapy with ‘first-line’ anti-tuberculous drugs. But some of the Russian prison physicians objected, as did members of Russia’s large and crumbling tuberculosis-treatment infrastructure: the prisoner-patients had drug-resistant tuberculosis and would not be cured by standard first-line regimens; some Russian specialists made other objections. These voices were drowned in an undercurrent of censorious opinion from the international experts and the non-governmental agencies, which, flush with resources and backed by international expert opinion, insisted on giving all prisoners the same doses of the same first-line drugs.

In Siberia and in other pilot sites, treatment outcomes were nothing short of catastrophic: less than half of all patients were deemed cured (expected cure rates for supervised therapy of drug-susceptible tuberculosis exceed 95%).²⁵ Worse, prisoner-patients who were not cured by therapy with first-line drugs emerged from this treatment, if they survived, with ‘amplified’

Disease and Social Change, ed. Boston. Program in Infectious Disease and Social Change: 39–83. See also: V. Stern & R. Jones. 1999. *Sentenced to Die? The Problem of TB in Prisons in East and Central Europe and Central Asia*. London. International Centre for Prison Studies, King’s College.

²⁴ For one such study, see: G. Bukhman. 2001. *Reform and Resistance in Post-Soviet Tuberculosis Control*. Doctoral Dissertation, University of Arizona. Ann Arbor. University Microfilms.

²⁵ M.E. Kimerling, H. Kluge, N. Vezhnina, T. Iacovazzi, T. Demeulenaere, F. Portaels & F. Matthys. Inadequacy of the Current WHO Re-Treatment Regimen in a Central Siberian Prison: Treatment Failure and MDRTB. *International Journal of Tuberculosis and Lung Disease* 1999; 3: 451–453.

resistance. That is, their prognosis had worsened dramatically even if they were to be afforded care with the right drugs.²⁶ But the non-Russian groups, whether international tuberculosis experts or aid groups, did not concede that they had made an error. Instead, they pressed on, delivering precisely the same medications even to prisoner-patients with documented multi-drug-resistant tuberculosis.

More delegations visited Siberia in 1998. Members of at least one delegation pointed out that drug resistance was not the *likely* cause of treatment failure, it was the cause *already documented*. Somewhat discreetly, it would seem, the lead non-governmental organisation had sent sputum samples for drug-susceptibility testing to at least two reference laboratories in Western Europe. Both laboratories confirmed that patients within Siberian prisons were sick from highly resistant strains of *M. tuberculosis* – strains resistant to precisely those drugs being administered, under direct supervision, by the non-governmental organisations who had been chastising Russian experts for their lack of knowledge of modern tuberculosis control.

Well before 2000, tuberculosis had become the leading cause of death in Russian prisons. In Siberian facilities, surviving prisoners had become less and less treatable, and those with multi-drug-resistant tuberculosis were cohorted behind barbed wire and declared altogether ‘untreatable.’ But this was not the case: multi-drug-resistant tuberculosis is treatable with other, more expensive drugs; data from a slum in Peru and rural Haiti have made it clear that such efforts can succeed in settings far poorer than Siberia.²⁷ The real debate was not about the efficacy of therapy but about its costs.

By 2001, the lead non-governmental organisation appeared to yield to growing pressure from prisoners, their guards, and expert opinion: it would work with its Russian partners to treat patients with multi-drug-resistant tuberculosis with the drugs to which their strains had been shown to be susceptible. It took

²⁶ P. Farmer. Managerial Successes, Clinical Failures. *International Journal of Tuberculosis and Lung Disease* 1999; 3: 365–367.

²⁷ P. Farmer, J. Bayona, S. Shin, L. Alvarez, M. Becerra, E. Nardell, C. Nuñez, E. Sanchez, R. Timperi & J.Y. Kim. Preliminary Results of Community-Based MDRTB Treatment in Lima, Peru. *International Journal of Tuberculosis and Lung Disease* 1998; 2 (Suppl. 2): S371. C. Mitnick, J. Bayona, E. Palacios, S. Shin, J. Furin, F. Alcantara, E. Sanchez, M. Sarria, M. Becerra, M.C. Fawzi, S. Kapiga, D. Neuberg, J.H. Maguire, J.Y. Kim & P. Farmer. Community-Based Therapy for Multidrug-Resistant Tuberculosis in Lima, Peru. *New England Journal of Medicine* 2003; 348: 119–128.

the organisation well over a year to procure the drugs, but early in 2002 it announced the programme was to commence treatment right away. The need was great: in a single oblast in Western Siberia, an estimated 2000 prisoner-patients were warehoused with active multi-drug-resistant tuberculosis. But although the drugs began to arrive in Siberia, no treatment occurred in the ensuing year. In September 2003, the lead organisation issued a press release: they were pulling out of Siberia. As of today, not a single prisoner has been treated, by non-governmental organisations based in Siberia for a decade, for multi-drug-resistant tuberculosis, although thousands, perhaps more, have died of this disease. The press release blames Russian officials, particularly those in the Ministry of Health, for their intransigence, but it is likely that careful study of what occurred will come to a somewhat different conclusion.²⁸

The story is a sad one, but it will become sadder: circulating strains of multi-drug-resistant *M. tuberculosis* will mean that prisoner detainees are exposed to epidemic strains of highly drug-resistant tuberculosis and then do not receive care when they need it. But that will not change the fact that the initial approach of the non-governmental organisations was incorrect: multi-drug-resistant tuberculosis cannot be cured with regimens based on the very drugs to which infecting strains are resistant, but these patients' prognosis can be worsened by such practices, even if proper therapy later becomes available. Since international authorities had endorsed these practices they should have been the first to acknowledge the error and to make pledges to help correct it. But no *mea culpa* has been issued from any interested party.

All interested parties, including those willing to underline the ethical lapses involved, must be part of a broader movement not merely to point to such lapses, masked or acknowledged, but also to address them. In the case of multi-drug-resistant tuberculosis in Russian prisons, that means staying and seeing these patients through treatment that is effective, not 'cost-effective.' The fact that prisoners with drug-resistant tuberculosis were given drugs that were wholly ineffective is a reminder that concepts such as 'cost-effectiveness' are in fact ideological constructs. The example is one of many and serves, too, as a reminder of the most pressing questions for modern medical ethics.

²⁸ MSF Ends Tuberculosis Treatment in Kemerovo Region, Russia. 30 September, 2003. Available at: <http://www.msf.org/countries/page.cfm?articleid=D657393B-C8E6-4CD7-9835259FD4F8AFEF>

IV ALTERNATIVE AND COMPLEMENTARY FRAMEWORKS: PRAXIS MAKES PERFECT?

The examples offered above have received scant attention in the medical ethics literature and much of that attention has been inaccurate. To blame a lack of HIV care on beleaguered and cash-poor African governments is similar to blaming tuberculosis outbreaks in Siberia on prolonged pre-trial detention or the malfeasance of local prison officials. Such observations are superficial and also convenient, since they deflect attention from the truly powerful forces and actors that, respectively, shape epidemics and declare which interventions are cost-effective and which are not. These actors are more likely to be found in New York, Washington, Geneva or London than they are to be found in Siberia, Port-au-Prince, or Pretoria. It is also superficial to spend time underlining the shortcomings of any one particular field, and we add that our goal here is not to denigrate what constitutes a robust enough intellectual enterprise, but rather to point to ways in which the medical and bioethics communities might illuminate complex and transnational ethical problems. Such analysis would prove useful across steep gradients of social inequality, the context and driving force of the world's great epidemics.²⁹ One cautionary lesson of Tuskegee is that it may take decades for ethics to catch up with observations that come quite naturally to those marginalised by poverty, racism, and other forces that are not often the subject of polite conversation within medical ethics.

One reason for this selective silence is that ethics in general has until recently relied heavily on philosophy, its parent discipline, and very little on the social sciences relevant to medicine. Bioethics is fundamentally socially constructed. To resocialise medical ethics – as part of a broader project, which includes critique of dominant modes of thinking in a broad variety of fields – would mean a turn towards disciplines such as anthropology, history, and political economy. But even within philosophy, John Rawls has laid out a framework that might be applied fruitfully to problems such as those now gathering force within Siberian prisons and African slums. Rawls is, of course, famous for his difference principle, which requires preferential treatment for the most disadvantaged, regardless of the social costs this principle

²⁹ P. Farmer. 1999. *Infections and Inequalities*. Berkeley. University of California Press.

can entail.³⁰ Critics have rightly noted the principle's under-emphasis on health,³¹ but one can read Rawls as making a broader point about how we should view social practices. For if we take Rawls seriously, we have to ask ourselves if we truly care about the most disadvantaged when we give prisoners ineffective therapy that is declared 'cost-effective.'³²

Sociologists of knowledge will one day point to the competing paradigms that have led important ethical dilemmas to remain invisible or little noted, but in the short term much more could be said simply by restoring to these problems more of the social and historical complexities inherent in each of them. A certain humility is warranted, as philosopher Caputo wryly suggests:

Far be it from me to make ethics tremble. I tremble even at the prospect that I will be found guilty of spreading the word that the pants of the great man are split. For that I have already prepared a defense aimed at exonerating me of all responsibility . . . The result is that it will be very hard to identify the guilty party, to find anyone who is singularly responsible, if we are all rounded up by the police and charged with inciting a riot against ethics.³³

³⁰ J. Rawls. 1999. *A Theory of Justice*. Revised edition. Cambridge, MA. Harvard University Press: § 26, pp. 130–139; § 13, pp. 65–73. Rawls's more precise definition of the difference, or maximin principle, is that society must choose the scheme of institutions that most advantages the least advantaged persons in society. In practice, this emphasis on the absolute position of the most disadvantaged in society may force society to forgo schemes that produce lesser aggregate wealth or utility. Other scholars have cited the tensions between distributive 'injustice' and over-consumption by the wealthy, which may lead to such harms as environmental degradation and exploitation of the poor. See: A. Jameton & J. Pierce. Environment and Health: Sustainable Health Care and Emerging Ethical Responsibilities. *Canadian Medical Association Journal* 2001; 164: 365–369.

³¹ D. Brock. Broadening the Bioethics Agenda. *Kennedy Institute of Ethics Journal* 2000; 10: 21–38. Philosopher Norman Daniels has also contributed significantly to bioethical literature by applying Rawlsian principles to justify the right to health (see, for example: N. Daniels. 2002. Justice, Health, and Health Care. In *Medicine and Social Justice*. R. Rhodes, M. Battin & A. Silvers, eds. Oxford. Oxford University Press: 6–23). Both Brock and Daniels discuss resource prioritisation for the worst off.

³² This attitude toward prisoners is also hard to square with an equally important, though largely forgotten, aspect of Rawls's theory of justice – the inviolability of each person. As Rawls himself elegantly states, '[e]ach person possesses an inviolability founded on justice that even the welfare of society as a whole cannot override.' Rawls, *op. cit.* note 26, § 1, p. 3.

³³ J.D. Caputo. 1993. *Against Ethics: Contributions to a Poetics of Obligation with Constant Reference to Deconstruction*. Bloomington. Indiana University Press.

The sociology of knowledge is another field full of promise in the broader project to resocialise medical ethics.³⁴ Our understanding of science, for example, is given a significant boost when the non-rational procedures that lead to paradigm shifts come into clear relief. ‘Given a paradigm, interpretation of data is central to the enterprise that explores it’, writes Thomas Kuhn. ‘Paradigms are not corrigible by normal science at all.’³⁵ Most would argue that medical ethics and philosophy are not the sorts of science that Kuhn had in mind; many practitioners of anthropology and, to a lesser extent, sociology, are willing to admit that the term ‘social science’ may be a bit grand. And although economists are unwilling, often, to point to the ideological frameworks that undergird their work, they are at least willing to call theirs ‘the dismal science.’

In addition to the invaluable insights of sound epidemiology, which suggests the mechanisms by which social inequalities serve as the leading risk for both falling ill with infectious disease and then being denied access to adequate care, there is a special role for ethnography and for detailed case studies. If ethicists were to interview patients and sick *non*-patients – for many of the destitute sick never become patients and are never offered the chance to confront ethical dilemmas – as often as they interrogate philosophical treatises, the resocialisation of medical ethics would be well underway. Here we quote another Haitian woman, whose commentary easily spans the gulf from access to AIDS therapies to the right to employment. She made these comments in 2001 after gaining more than 20 pounds on antiretroviral medications:

We’re always sick here. If we’re not dying of AIDS, we’re dying of hunger, or both. Now that I am better, it’s not as if my problems have disappeared. It’s that I can wake up and fight them again. For two years I lay in bed, my children watching me die,

³⁴ Berger and Luckmann note that ‘The sociology of knowledge must concern itself with whatever passes for “knowledge” in a society, regardless of the ultimate validity or invalidity (by whatever criteria) of such “knowledge”. And in so far as all human “knowledge” is developed, transmitted and maintained in social situations, the sociology of knowledge must seek to understand the processes by which this is done in such a way that a taken-for-granted “reality” congeals for the man in the street. In other words, we contend that the sociology of knowledge is concerned with the analysis of the social construction of reality.’ (P. Berger & T. Luckmann. 1966. *The Social Construction of Reality: A Treatise on the Sociology of Knowledge*. Garden City, NY, Anchor Books.)

³⁵ T. Kuhn. 1970. *The Structure of Scientific Revolutions*. Second edition. Chicago. University of Chicago Press: 122.

bringing me sips of water . . . [Their father] is gone – my sister has seven children of her own. All I could think about was what will happen to my children when I die? My sister had already purchased my coffin but then [the clinic] gave me these [antiretroviral] medicines. Someone comes to see me every day, to make sure I take them. The first thing that hit me was hunger. The medicines started killing the virus and then I became hungry. But we had no food in the house – how would that be possible, if [the father of her children] were gone and I was dying? Charity food does not allow you to regain your strength and to feed your children at the same time. That's why we always reach the same conclusions in our [support-group meetings]. If you want to prevent AIDS among poor women, give them jobs . . . I'm happy I'm better, and I'd rather be alive than dead. But all I do every day, still, is worry about how I'm going to feed my children. I don't want to become a thief.

In our own writing on these topics we have sought to echo and amplify such commentaries, writing about the need to re-mediate inequalities of access to healthcare as a fundamental human right. Are such calls – for the right to healthcare and to jobs – merely grandstanding when echoed by academics, broadsides dressed in scholarly guise? We would answer by insisting that both bioethics and medical ethics have a long way to go on this score before scholars in these fields can object that the views of the destitute sick receive too much emphasis in the literature.

Listening to the afflicted is not merely moral praxis, although it is that. It affords us rich insights into the sorts of problems that we have outlined in this essay. Because the poor quite literally *embody* many of the ethical dilemmas stemming from injustices within medicine and public health, they add insights that cannot be obtained through reference to philosophy. For ethical reflection is part of everyday life, and when the stakes are high – in a squatter settlement in Haiti, say, or a prison in Western Siberia – soliciting these views are central to the quest for understanding. With the exception of sociopaths, as Churchill notes, '[the capacity to think critically about moral values and direct our actions in terms of such values] is common to all of us.'³⁶ The same is not true of particle physics or evidence-based medicine, which do not figure prominently in everyday discourse and reasoning. But

³⁶ Churchill, *op. cit.* note 13, p. 259.

herein lies the great promise of a resocialised ethics: seeking the views of the destitute sick will breathe new life into medical ethics.

The call to rely more heavily on the views of the afflicted is not a call to turn our backs on philosophy but rather a call to turn our attention to those who suffer most. It is also a call to turn towards the disciplines that can illuminate the social production, and maintenance, of that suffering. Just as history and political economy can show us how science and medicine have grown but not in tandem with ethical approaches to global health equity, so too can history and political economy in turn illuminate ethnography and other 'experience-near' disciplines.

Each of the problems mentioned above is an obvious example. The distribution of HIV infection is as surely sculpted by social inequalities as is access to both HIV care and to what might be called prevention equity. To engage in ethical debate about vaccine trials or ethically sound clinical research in 'resource-poor settings', as many have done in recent years, it is necessary to understand the social inequalities that sculpt both the AIDS epidemic and social responses to it. Indeed, it is these very inequalities of risk and access that make it attractive to conduct research on diseases endemic among the world's poor. As for organ transplants, there can be no honest understanding of international movement of organs without acknowledging the steep social gradients across which they move. Such observations, even when undergirded by robust research, cause those involved in the enterprise to bristle, but that makes these observations no less true.

There are other paradigms and bodies of knowledge that can help to resocialise bioethics. Within the human rights movement is a small but growing effort to underline the importance of social and economic rights, which are the rights commonly demanded by the poorest populations. These include the right to healthcare, schooling, housing, and clean water. Some have attempted to listen to the poorest and restore these rights to their proper place in the hierarchy of rights, and also to underscore the impossibility of understanding current debates in global medical ethics without understanding the extreme disparities that underpin the 'ethical' dilemmas of the destitute sick.³⁷

³⁷ P. Farmer. *Pathologies of Power: Rethinking Health and Human Rights*. *American Journal of Public Health* 1999; 89: 1486–1496.

Medical ethics also stands to gain from insights from liberation theology, as noted by Marcos Fabri dos Anjos. Although ethics and philosophy have long been entangled in religious reflection, there is thus far very little synergy between medical ethics and the one branch of theology that concerns itself chiefly with the problem of poverty in the modern world. The conclusions of dos Anjos are worth citing here:

First, to what level of quality can medical ethics aspire, if it ignores callous discrimination in medical practice against large populations of the innocent poor? Second, how effective can such theories be in addressing the critical issues of medical and clinical ethics if they are unable to contribute to the closing of the gap of socio-medical disparity?³⁸

Regardless of which or how many of the socialising disciplines are used, modern medical ethics would stand to benefit from another dramatic change. We argue here that those who study ethical dilemmas will be called increasingly to have a hand in remediating them. These calls will come from ‘below’, from the afflicted themselves. The concept of ‘pragmatic solidarity’ is instructive as medicine, science, and public health stumble and fall in the very regions most in need of them. AIDS in Africa and tuberculosis in prisons are cases in point. Pragmatic solidarity is a cumbersome term, perhaps, and one that makes many academics uncomfortable. Anthropologists, for example, have long argued that their task is to observe rather than intervene, but this claim is undermined by the arguments that anthropology’s supposed neutrality was in fact perceived by others, including those studied, as a small but at times integral part of the colonial project.³⁹

The social sciences, if that is what we are to term them, cannot claim neutrality. There is no social variant of Heisenberg’s principle, and it is possible to argue that no field of inquiry can span such dizzying social inequalities and not influence the very topic it proposes to study. Researchers from the modern university are invariably actors in a social field and medical ethicists who work across steep gradients of inequality are, all objections to the contrary notwithstanding, powerful actors when compared to those they study.

³⁸ M. dos Anjos. Medical Ethics in the Developing World: A Liberation Theology Perspective. *Journal of Medicine and Philosophy* 1996; 21: 629–637.

³⁹ T. Asad, ed. 1975. *Anthropology and the Colonial Encounter*. London. Ithaca Press & Humanities.

Listening to the poorest will lead us back, inevitably, to the outcome gap. The 'special measures' mentioned above will vary from place to place and from problem to problem, but medical ethicists should expect to become part of teams seeking to lessen the outcome gap by remediating access to effective medical care. And once that step is taken, we will have the option of trying to ignore what we are being told by the afflicted, or to take seriously the challenge of linking the struggle for social and economic rights – the right to food, housing, clean water, education, and jobs – to scholarly inquiry that breaches the frighteningly deep gap between the haves and the have-nots.

V CONCLUSIONS OR NEW DIRECTIONS?

Like any established fields of scholarly inquiry, bioethics and medical ethics are broad and large enough to contain their own internal critics. And like many practitioners of an academic discipline, ethicists are not always eager to embrace critiques from beyond the field. But this essay is meant merely to complement ongoing research and reflection within bioethics and medical ethics.

Writing of AIDS, historian Allan Brandt astutely notes that, 'In the years ahead we will, no doubt, learn a great deal more about AIDS and how to control it. We will also learn a great deal about the nature of our society from the manner in which we address the disease. AIDS will be a standard by which we may measure not only our medical and scientific skill but also our capacity for justice and compassion.'⁴⁰ When Brandt writes of 'our society', he refers to the global village through which HIV has raced. Access to AIDS care has yet to follow. Surely this constitutes a daunting ethical problem.

Research in medical ethics has thus far been conducted largely in affluent and industrialised nations. Yet these 'resource-rich' settings are tied, and intimately so, to the poorest parts of the world. Haiti, the Western Hemisphere's most HIV-burdened nation, is the classic case in point: born of late 15th-century European expansion, Haiti was, by the 18th century, the world's most profitable slave colony. It is now commonly termed the poorest country in the Western Hemisphere. But the creation of this

⁴⁰ A. Brandt. 1988. AIDS: From Social History to Social Policy. In *AIDS: The Burdens of History*. E. Fee & D.M. Fox, eds. Berkeley. University of California Press: 147–171, at 168.

poverty over time is seen within Haiti as a result of the historical processes that created one of the most brutal slave colonies on record. The key events in Haitian history, from the slave revolt that led to the founding of Latin America's oldest republic to the 20th-century US military occupation of Haiti and subsequent generous support of military dictators, are as familiar to Haitians as they are forgotten by French and US citizens. So too was Tuskegee all but forgotten by modern medicine and yet remembered by African Americans. Indeed, historians and medical ethicists are to be thanked for having kept this issue alive until a formal presidential apology was obtained in 1997, 50 years after penicillin was found to be effective therapy for syphilis, and 25 years after the cessation of the experiment. Research in South Africa, similarly, is necessarily fraught, in part because the scars of apartheid are forgotten by newly arrived AIDS researchers but not by those who endured apartheid and now see their communities attacked by yet another foe. The Haitians have a saying, '*bay kou bilye, pote mak chonje*': he who delivers the blow forgets; he who bears the scar remembers.

Injustices of one sort or another are very often central to the modern ethical problems in medicine, public health, and science. Rawls was correct to underline the centrality of justice in considerations of ethical problems, and the process of resocialising medical ethics and bioethics is in part a process of restoring the historically deep and geographically broad analysis that comes naturally to the world's destitute sick, who bear the scars of history.

Another way of putting this is best saved for the end of this essay: medical ethics must grapple more persistently with the growing problem posed by the yawning gap between rich and poor. The central topics of bioethics and medical ethics need to be linked to questions of social justice and to consideration of how inequalities of all sorts are linked to the inequalities studied by sociologists, anthropologists, and epidemiologists. In almost all countries in which medical ethics and bioethics have taken root – which is to say in most countries, at this writing – access to care, even access to informed participation in clinical trials, is determined as much by social standing as by disease process. This basic epidemiological and social fact emboldens us to close with a warning: if social inequalities persist and grow, we will no longer be welcome to conduct research or even to comment on it. To cite Joia Mukherjee again, 'If the medical community is to use data generated in high-burden and vulnerable

populations to develop an HIV-1 vaccine, we must ensure that the global community will help governments fulfill the right to health and share the fruits of research with the world's poorest communities.'⁴¹

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⁴¹ Mukherjee, *op. cit.* note 1, p. 995.