

# ETHICS AND INFECTIOUS DISEASE<sup>1</sup>

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## ABSTRACT

*Bioethics apparently suffers from a misdistribution of research resources analogous to the '10/90' divide in medical research. Though infectious disease should be recognized as a topic of primary importance for bioethics, the general topic of infectious disease has received relatively little attention from the discipline of bioethics in comparison with things like abortion, euthanasia, genetics, cloning, stem cell research, and so on. The fact that the historical and potential future consequences of infectious diseases are almost unrivalled is one reason that the topic of infectious disease warrants more attention from bioethicists. The 'Black Death' eliminated one third of the European population during the 14<sup>th</sup> Century; the 1918 flu killed between 20 and 100 million people; and, in the 20<sup>th</sup> Century smallpox killed perhaps three times more people than all the wars of that period. In the contemporary world, epidemics (of AIDS, multi-drug resistant tuberculosis, and newly emerging infectious diseases such as SARS) continue to have dramatic consequences. A second reason why the topic of infectious disease deserves further attention is that it raises difficult ethical questions of its own. While infected individuals can threaten the health of other individuals and society as a whole, for example, public health care measures such as surveillance, isolation, and quarantine can require the infringement of widely accepted basic human rights and liberties. An important and difficult ethical question asks how to strike a balance between the utilitarian aim of promoting public health, on the one hand, and libertarian aims of protecting privacy and freedom of movement, on the other, in contexts involving diseases that are – to varying degrees – contagious, deadly, or otherwise dangerous. Third, since their burden is most heavily shouldered by the poor (in developing countries), infectious diseases deeply involve issues of justice – which should be a central concern of ethics. I conclude by providing sociological and historical explanations*

<sup>1</sup> A version of this paper was presented at the VI World Congress of Bioethics, Brasilia, Brazil, October 2002.

*of why the topic of infectious disease has not already received more attention from bioethicists.*

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## I. DISTRIBUTION OF RESEARCH RESOURCES

The '10/90 divide' is a phenomenon whereby 'less than 10 percent of [medical] research funds are spent on the diseases that account for 90% of the global burden of disease . . . [D]iseases affecting large proportions of humanity are given comparatively little attention.'<sup>2</sup> Because medical research so often aims at the promotion of profits rather than solutions to the world's most urgent medical problems, a majority of funds focus on the wants of a minority of the world's population – those who are relatively wealthy. As a result, health care is often unavailable to those who need it most.

A situation analogous to the 10/90 divide in medical research apparently holds true for research in bioethics. A quick flip through most bioethics texts and journals (or a visit to any number of websites) reveals attention on abortion, euthanasia, assisted reproduction, genetics, and doctor-patient relationships. To a large extent the issues examined one way or another involve advanced technologies or expensive interventions available primarily in wealthy developed nations. 'Distribution of resources' is a common topic; but discussion here often (at least implicitly) concerns domestic allocation rather than issues of *international* justice. Greatly lacking, in comparison, is discussion of ethical issues involving infectious disease and the (related) health care situation in the developing world. Infectious diseases (such as AIDS, tuberculosis, and a variety of other emerging and re-emerging pathogens) and the health care situation in developing countries pose some of the most serious problems of our times, but they have received relatively little attention from medical ethicists. In what follows I will (1) argue that the topic of infectious disease should be recognized as one of *the* most important topics for the discipline of bioethics, (2) briefly illustrate that it has received comparatively little attention from bioethicists,<sup>3</sup> and (3) attempt to explain why it has not received the attention it warrants.

<sup>2</sup> K. Lee, and A. Mills. Strengthening Governance for Global Health Research. *British Medical Journal* 2000; 321: 775–776, at <http://www.bmj.com/cgi/content/full/321/7264/775>.

<sup>3</sup> Although I shall not in this article discuss this point at great length, others who have worked in this area, such as Margaret Battin and Solomon Benatar,

## II. THE ETHICAL IMPORTANCE OF INFECTIOUS DISEASE

The lack of bioethics discussion of infectious disease is both odd and unfortunate. Given that infectious disease was traditionally a – if not *the* – primary focus of medicine, for example, one would expect this to be obvious territory for a discipline concerned with ‘medical ethics.’<sup>4</sup> More specific reasons why this should be recognized as one of the most relevant and important topics for bioethics are the following:

1. The historical and likely future consequences of infectious diseases are almost unrivalled,
2. Infectious diseases raise exceedingly difficult ethical questions of their own, and
3. The topic of infectious disease is closely connected to the topic of justice – which is a central concern of ethics.

### 1. *Consequences*

First, the paramount ethical importance of infectious diseases is illustrated by the fact that their consequences have been, and will likely continue to be, enormous. Epidemics have constituted some of the most catastrophic events in human history. The Black Death, for example, is famous for eliminating approximately one third of the European population between 1347 and 1350.<sup>5</sup> Another devastating epidemic occurred in 1918 when a nasty strain of influenza killed somewhere between 20 and 100 million people. According to the historian Alfred Crosby, the 1918 flu undoubtedly ‘killed more humans than any other disease in a period of similar duration in the history of the world.’<sup>6</sup> Gina Kolata writes that the 1918 flu killed ‘more Americans in a single year than died in battle in World War I, World War II, the Korean War, and the Vietnam War.’<sup>7</sup> (According to the *New York Times*, ‘[J]ust about everyone who has studied the disease says [that] a new pandemic is inevitable.’)<sup>8</sup>

have agreed that it is quite correct. A similar point is made by (especially Chapter 8 of) P. Farmer. 2003. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. Los Angeles. University of California Press.

<sup>4</sup> I shall use the expressions ‘bioethics’, ‘biomedical ethics’, and ‘medical ethics’, interchangeably.

<sup>5</sup> P. Ziegler. 1969. *The Black Death*. London. Penguin.

<sup>6</sup> A.W. Crosby. 1989. *America’s Forgotten Epidemic: The Influenza of 1918*. Cambridge, UK. Cambridge University Press: 203.

<sup>7</sup> G. Kolata. 1999. *Flu*. London. Pan Books: xii.

<sup>8</sup> B. Gewen. ‘The Great Influenza’ and ‘Microbial Threats to Health’: Virus Alert. *The New York Times* March 14, 2004, available at: <http://www.nytimes.com/2004/03/14/books/review/14GEWENT.html>.

A third major killer, which has received high-profile attention in American newspapers recently, is smallpox. Smallpox allegedly killed more people in history than any other infectious disease. In the 20<sup>th</sup> Century alone it killed somewhere between 300 and 540 million people – or ‘more than all the wars and epidemics [of that century] combined.’<sup>9</sup> Michael Oldstone claims that smallpox killed three times more people during the 20<sup>th</sup> Century than were killed by all the wars of that period.<sup>10</sup> Although the disease was declared eradicated by the World Health Organization (WHO) in 1980, fears about smallpox have resurfaced. It has recently come to light that the Soviet Union, until its fall in the early 1990s, manufactured and froze tens of tons of smallpox for military purposes. Many are worried that stocks of the Soviet supply may have fallen into the hands of ‘rogue nations’ or terrorists. Experts claim that a smallpox bioterrorist attack could spark a catastrophic global epidemic now that the world population largely lacks immunity (because routine vaccination ended 20 or 30 years ago).<sup>11</sup> Modeling has shown that a smallpox attack could cause the devastation of (perhaps a series of) nuclear attack(s).

Smallpox aside, it is important to recognize that the enormous impact of infectious diseases is not just a matter of history. Infectious diseases are currently the world’s largest ‘killer[s] of children and young adults. They account for more than 13 million deaths a year – one in two deaths in developing countries.’<sup>12</sup> The rapidly growing HIV/AIDS epidemic perhaps provides the clearest illustration that infectious diseases continue to have the power of their past. AIDS is arguably ‘the greatest health disaster in history.’<sup>13</sup> In 24 years, it has killed 20 million people<sup>14</sup> (whereas the Black Death killed only 9 to 11 million people in Europe

<sup>9</sup> J. Miller, S. Engelberg & W. Broad. 2001. *Germ: The Ultimate Weapon*. London. Simon and Schuster: 58.

<sup>10</sup> M.B.A. Oldstone. 1998. *Viruses, Plagues, and History*. New York. Oxford University Press: 3.

<sup>11</sup> For more on smallpox, see M.J. Selgelid. Smallpox Revisited? *American Journal of Bioethics* 2003; 3, 1, available at [http://www.bioethics.net/journal/j\\_articles.php?aid=91](http://www.bioethics.net/journal/j_articles.php?aid=91), accessed 1 March 2005; and M.J. Selgelid. Bioterrorism and Smallpox Planning: Information and Voluntary Vaccination. *Journal of Medical Ethics* 2004; 30, 6: 558–560; available at <http://jme.bmjournals.com/cgi/reprint/30/6/558>, accessed 1 March 2005.

<sup>12</sup> World Health Organization. 1999. Report on Infectious Diseases, Chapter 16, Removing Obstacles to Healthy Development, available at <http://www.who.int/infectious-disease-report/pages/textonly.html>, p. 2.

<sup>13</sup> C. Gilbert. AIDS Draws New Attention. *Milwaukee Journal Sentinel*, 15 April, 2002.

<sup>14</sup> See <http://www.redribbon.co.za/>.

between 1346 and 1350).<sup>15</sup> HIV prevalence rates commonly exceed 30% (of adults) in sub-Saharan Africa, and similar scenarios may follow in parts of Asia and the former Soviet Union. As of 1999, anyway, only 5% of those infected could afford life-extending antiretroviral therapy.<sup>16</sup> In 2004, 3 million people died from AIDS, and 5 million people were newly infected with HIV. At the end of 2004, an estimated 39 million people were living with HIV.<sup>17</sup>

A related, but less well publicized, scenario involves the re-emergent spread of tuberculosis. Previously thought to be controlled, or at least considered controllable, TB was declared a global health emergency by the World Health Organization in 1993 and currently kills more people than ever before. 'Each year, 2 to 3 million people die from tuberculosis . . . despite the fact that the disease in its most common form is entirely preventable and treatable.'<sup>18</sup> One third of the world's population is infected with the latent form of the disease; and, a tenth of these are expected to develop active illness. 'It is estimated that between 2000 and 2020, nearly one billion people will be newly infected, 200 million people will get sick, and 35 million will die from TB – if control is not further strengthened.'<sup>19</sup> Of particular concern is the rise and spread of multi-drug resistant TB, resulting from the improper use of medication (in Russian prisons, for example).

The recent emergence and spread of SARS (Severe Acute Respiratory Syndrome) is, of course, the latest indicator that the impact of infectious diseases will continue to be severe. According to studies, the 'death rate from SARS may be . . . up to 55 percent in people 60 and older, and up to 13.2 percent in younger people . . . unless the numbers fall drastically, SARS would be among the infectious diseases with the highest death rates . . . By contrast, the influenza pandemic of 1918 . . . had an estimated mortality rate, overall, of 1 percent or less.'<sup>20</sup> In the meanwhile,

<sup>15</sup> L. Garrett. 2000. *Betrayal of Trust: The Collapse of Global Public Health*. New York. Hyperion: 474.

<sup>16</sup> *Ibid.*, p. 473.

<sup>17</sup> UNAIDS: AIDS Epidemic Update, 2004. Available at [www.unaids.org](http://www.unaids.org).

<sup>18</sup> L.B. Reichman and J.H. Tanne. 2002. *Timebomb: The Global Epidemic of Multi-Drug-Resistant Tuberculosis*. New York. McGraw Hill: x–xi. See also P. Farmer. 1999. *Infections and Inequalities: The Modern Plagues*. Berkeley, CA. University of California Press.

<sup>19</sup> World Health Organization. Tuberculosis, Fact Sheet No. 104, revised April 2000, available at <http://www.who.int/inf/fs/en/fact104.html>, p. 1.

<sup>20</sup> L.K. Altman. Death Rate from SARS is Revised Upward. *International Herald Tribune* May 8, 2003.

there is no treatment, vaccine, or reliable diagnostic test for the SARS virus – which ‘can survive on surfaces [such as doorknobs] for up to four days.’<sup>21</sup> Isolation, quarantine, travel advisories, travel restrictions, and related public health measures were put into effect; and the economic impact, alone, was staggering – ‘[j]ust a few weeks after SARS was identified, WHO [calculated] that the cost of the disease [was] already close to \$30 billion.’<sup>22</sup>

It is now widely acknowledged that, in addition to posing global health and economic threats, AIDS and other infectious diseases threaten global security. Historical studies reveal that factors such as high infant mortality, low life expectancy, decreasing life expectancy, etc. – which are being severely affected in places like sub-Saharan Africa and the former Soviet Union – are among the most reliable indicators of major social upheaval. Given the serious historical and potential future consequences of infectious disease, it is no wonder that the CIA recently conducted (and published) a special investigation of ‘*The Global Infectious Disease Threat and Its Implications for the United States*.’<sup>23</sup> It is puzzling, on the other hand, that medical ethicists have not had more to say about infectious disease – compared to abortion, euthanasia, and genetics, for example, which have saturated the literature.

## 2. *Difficult ethical questions*

A second reason why infectious diseases warrant more of bioethics’ attention is that they raise serious, difficult philosophical/ethical questions of their own. Obvious examples arise from the fact that infectious diseases can be contagious. Depending on the disease in question, infected individuals can threaten the health of other individuals or society as a whole. The public health measures required to protect other individuals and society from contagion (again, depending on the disease) might sometimes involve surveillance, mandatory testing, mandatory vaccination or treatment, notification of authorities or third parties, isolation (of individuals), quarantine (of entire regions), or travel restrictions. Because such public health care measures could infringe upon

<sup>21</sup> Ibid.

<sup>22</sup> I. Kickbusch. A Wake-Up Call for Global Health. *International Herald Tribune* April 29, 2003.

<sup>23</sup> Available at <http://www.odci.gov/cia/publications/nie/report/nie99-17d.html>. One conclusion of the report is that we should perhaps worry most about new infectious diseases – more dangerous than AIDS – likely to emerge in the future.

widely accepted basic human rights and liberties, we are here confronted with conflicting values.

An extremely difficult ethical question asks how, in situations of conflict, the utilitarian aim to promote the greater good in the way of public health should be balanced against libertarian aims to protect privacy and individual rights and liberties such as freedom of movement, and so on. Most philosophers, policy makers, and ordinary citizens would (upon reflection, I imagine) deny that *either* liberty or aggregate utility should *always* be given *absolute* priority over the other regardless of the degree (in terms of likelihood and severity) to which the other is threatened. So the challenge is to find a principled way of striking a balance between these presumably legitimate, but apparently conflicting, social aims in contexts involving diseases that are – to varying degrees<sup>24</sup> – contagious, deadly, or otherwise dangerous.<sup>25</sup> I will later say more about the difficulty of ethical issues raised by infectious disease.

### 3. *Justice*

Third, infectious disease should be recognized as a crucial topic for bioethics because the topic of infectious disease is closely connected to the topic of justice. Pathogens primarily prey upon the poor. Bad nutrition, dirty water, crowded living conditions, poor education, lack of access to basic medicines, disempowerment of women, and a complex host of other factors combine to make the populations of developing nations especially vulnerable to infectious diseases:

Most deaths from infectious diseases occur in developing countries – the countries with the least money to spend on health care. In developing countries, about one third of the population – 1.3 billion people – live on incomes of less than \$1 a day. Almost one in three children are malnourished. One in five

<sup>24</sup> I highlight variation in severity to suggest that there is likely no simple, obvious answer to this question. I should here point out the practical importance, in addition to theoretical difficulty, of this kind of question. It is now widely acknowledged, for example, that quarantine policy is outdated and in need of revision. Biodefense planning and the emergence of SARS provide the most recent illustrations of the immediate importance of this issue.

<sup>25</sup> This topic, of course, has not been altogether ignored. For discussion in the context of AIDS see U. Schuklenk. 1998. AIDS: Individual and 'Public' Interests, in *A Companion to Bioethics*, P. Singer & H. Kuhse. eds. Oxford, UK. Blackwell: 343–354. For recent discussion of quarantine policy in light of the smallpox bioterrorist threat, see G.J. Annas. Bioterrorism, Public Health, and Civil Liberties. *The New England Journal of Medicine* 2002; 346: 1337–1342.

are not immunized by their first birthday. And over one third of the world's population lack access to essential drugs.<sup>26</sup>

Today it is widely acknowledged that ailments called 'tropical diseases' are often not peculiar to tropical regions at all. To a large extent 'tropical diseases' are those that afflict poor developing countries, rather than necessarily tropical ones.<sup>27</sup> Sanitation, hygiene, vaccination, antibiotics, other drugs, and general improvements in living conditions have, in recent decades anyway, left privileged populations relatively sheltered from the scourges of the developing world.

Relationships between poverty and disease are well illustrated by the AIDS pandemic and the health care situation in Africa at the beginning of the 21<sup>st</sup> Century. Of the (roughly) 40 million people estimated to be living with HIV/AIDS in 2002, 28 million – or 70% – lived in sub-Saharan Africa.<sup>28</sup>

[A]nd 95% [in 2001] live[d] in developing nations. Most of the infected people who live in these countries have no access to new or existing drugs for HIV/AIDS. But the problem of access to medications goes far beyond the HIV/AIDS pandemic: people in developing nations also cannot afford medications used to treat or prevent malaria, tuberculosis, cholera, dysentery, meningitis, and typhoid fever. The affordability problem also extends beyond a lack of access to new drugs designed to treat devastating, infectious diseases: 50% of people in developing nations do not have access to even basic medications, such as antibiotics, analgesics, broncho-dilators, decongestants, anti-inflammatory agents, anti-coagulants, or diuretics.<sup>29</sup>

The fact that those who are already worse-off in virtue of their poverty thus have their misfortunes compounded – as they are more likely to fall victim to disease – will strike most of us as an injustice in itself.<sup>30</sup> It seems especially unjust when the ailments that cause the already unfortunate to suffer and die are – sometimes easily and inexpensively – treatable or preventable with existing medications (that have often been developed at least

<sup>26</sup> World Health Organization, *op. cit.* note 12.

<sup>27</sup> N.L. Stepan. 2001. *Picturing Tropical Nature*. Ithaca, NY. Cornell University Press; L. Garrett. 1994. *The Coming Plague: Newly Emerging Diseases in a World Out of Balance*. New York. Penguin.

<sup>28</sup> Gilbert, *op. cit.* note 13.

<sup>29</sup> D.B. Resnik. Developing Drugs for the Developing World: An Economic, Legal, Moral, and Political Dilemma. *Developing World Bioethics* 2001; 1: 11.

<sup>30</sup> Others, to the contrary, might claim that this situation is 'unfortunate' but not necessarily 'unfair' or 'unjust'.

partly through public funding). Egalitarians and utilitarians should agree on this point.

Poverty and (consequent) illness in many cases can also be attributed to what should be considered injustices even by staunch libertarians. As (one of) the wealthiest African nation(s), for example, South Africa should have been better able than its sub-Saharan neighbors to stave off AIDS. It has, however, famously failed to do so. This country has more HIV positive persons than any other country in the world; and, its (increasing) prevalence rate is estimated (from antenatal clinic data) to be almost 25% of adults.

About 5 [million] South Africans are living with HIV and, at the current rate of infection, about half the country's teenagers under 15 can expect to contract it. By 2005 South Africa is likely to have about 1 [million] orphans.<sup>31</sup>

A recent Medical Research Council (MRC) report estimates that AIDS, which is already the leading cause of death in the country, will kill between four and seven million South Africans within a decade.<sup>32</sup>

This situation is not merely *unfortunate*. We here suffer social and political *injustice*. The facts that the current South African government (for mysterious reasons) consistently<sup>33</sup> but (apparently) illegitimately (1) challenged the causal link between HIV and AIDS (and perhaps even the very existence of HIV and AIDS), (2) challenged the safety and efficacy of antiretroviral therapy, (3) suppressed scientific research which cast doubt on its HIV/AIDS stance,<sup>34</sup> (4) failed to provide inexpensive (or, in some cases, free) antiretroviral treatment to reduce the risk of mother-to-child transmission of HIV, (5) refused to comply with court orders requiring it to do so, (6) forbid provision of prophylactic antiretroviral therapy to rape victims (some of which were *gang-raped babies*, less than a year old),<sup>35</sup> and (7) over-spent

<sup>31</sup> Fighting Back. *The Economist* May 11–17, 2002, 27.

<sup>32</sup> R. Dorrington, D. Bourne, D. Bradshaw, R. Laubscher & I.M. Timaeus. The Impact of HIV/AIDS on Adult Mortality in South Africa. Burden of Disease Research Unit, Medical Research Council of South Africa, available at: <http://www.mrc.ac.za/bod/index.htm>.

<sup>33</sup> At the time of this writing the South African Government appears to finally be changing its stance on HIV/AIDS.

<sup>34</sup> This seemed to occur with regard to the above-mentioned MRC Report, for example.

<sup>35</sup> Note that points (4)–(6), at least, appear to conflict with the South African constitution by failing to respect what are recognized as human rights here. The same thing may be said about the failure to provide antiretrovirals to HIV-positive South Africans more generally speaking.

on the military (in an apparently scandalous fashion) while under-spending on health care are only a part of what I have in mind.

The current state of AIDS in South Africa – and the government's failure to effectively deal with the situation – should also be attributed to wrongs with longer histories. The etiology of the AIDS epidemic is extremely complex; its present state is the result of a wide variety of social, political, economic, and historical factors. The new South African government's failure to ameliorate the situation is at least partly forgivable – or, in any case, explainable – by virtue of the fact that it had so many other enormous tasks to accomplish in the aftermath of apartheid. In addition to overhauling the political apparatus of the country, provision of decent education, housing, sanitation, and water to those who were victims of systematic racial oppression for decades – i.e. the vast majority of the population – posed monumental challenges for the new South African government. The shambles in which apartheid left this country is thus at least partly to blame for the health care *status quo*.<sup>36</sup> The fact that urbanization, overcrowded living conditions, migrant working conditions, poor education, fatalistic behavior, prostitution, and other ravishes of poverty (including poor nutrition, widespread infection with worms, and lack of treatment for other STDS<sup>37</sup>) each contribute to the AIDS epidemic – and are each (at least partly) the result of exploitative racist colonial oppressive practices – corroborates the point that the South African AIDS epidemic should largely be blamed on social injustice.

Similar things can be said about other developing nations where health care is compromised because of impoverishment resulting from colonialization, oppression, exploitation, protectionist trade policies, domestic corruption, failure of democracy, and so on. According to Solomon R. Benatar, for example, the poverty and consequent poor health of many in the developing world should be attributed to (militarization and) exploitative global economic activities involving irresponsible business practices of multi-national corporations in particular. The result is a

<sup>36</sup> See D. Webb. 1997. *HIV and AIDS in Africa*. London. Pluto Press; A. Whiteside & C. Sunter. 2000. *AIDS: The Challenge for South Africa*. Cape Town. Human & Rousseau; & H. Marais. 2000. *To the Edge: AIDS Review 2000*. Pretoria, South Africa. University of Pretoria, Centre for the Study of AIDS.

<sup>37</sup> Increased risk of HIV infection results, for example, in the presence of other untreated STDs or when immune systems are weakened from poor nutrition or infection with worms.

widening of the gap – in terms of both wealth and human rights protection – between the haves and have-nots.<sup>38</sup>

Pulitzer Prize-winning journalist Laurie Garrett provides an extreme example of the link between disease and injustice. In her recent book *Betrayal of Trust: The Collapse of Global Public Health*, she blames the famous 1995 Ebola (hemorrhagic fever) epidemic in Zaire (now the Democratic Republic of the Congo) on the corruption of the leader Mobutu who stole billions of dollars from public coffers, leaving public hospitals (which were primary sources of infection) in complete disarray and lacking the most basic supplies.

Two things are clear: Ebola spread in Kikwit because the most basic, essential elements of public health were nonexistent. And those exigencies were lacking in Kikwit – indeed, throughout Zaire – because Mobutu Sese Seko and his cronies had for three decades looted the national treasuries. Ebola haunted Zaire because of corruption and political repression . . . [Ebola's] emergence into human populations required the special assistance of humanity's greatest vices: greed, corruption, arrogance, tyranny, and callousness. What unfolded in Zaire in 1995 was not so much the rain forest terror widely depicted then in popular media worldwide as an inevitable outcome of disgraceful disconcert – even disdain – for the health of the Zairois public.<sup>39</sup>

Garrett implicates American meddling in the affair, insofar as the U.S. government backed Mobutu and propped him into power. She insinuates CIA involvement with the murder of his predecessor Patrice Lumumba, unfavored because of supposedly socialist sympathies. In her earlier book *The Coming Plague: Newly Emerging Diseases in a World Out of Balance*, Garrett suggests that the AIDS epidemic in Africa was at least partly fueled by the fact that under-equipped hospitals in places like Congo sometimes had no choice but to use the same unsterilized syringes over and over and over again.

### III. WHY THE NEGLECT?

Based on what I have said so far, one would expect that infectious disease would already be a typical topic of dedicated discussion in a discipline called 'medical ethics.' One would expect that

<sup>38</sup> S.R. Benatar. Global Disparities in Health and Human Rights: A Critical Commentary. *American Journal of Public Health* 1998; 88: 295–300.

<sup>39</sup> Garrett, *op. cit.* note 15, p. 59.

there would be books on ethics and infectious disease and that articles and sections specifically devoted to ethical aspects of infectious diseases would be regular fare in bioethics journals and anthologies. In reality, however, 'infectious disease' is hardly found even in indexes of standard bioethics texts; and I have never seen a book on this general topic. An October 2002 *Google* (internet) search of the phrase 'ethics and infectious disease' yielded only 11 entries.<sup>40</sup> Six of these referred to a single project (of Margaret Battin), and some of the others were false positives. In March 2005 a similar search yielded 35 entries<sup>41</sup> – while a search of 'ethics and genetics' led to 5,100 entries.

### 1. *High tech medicine*

Why, then, has the topic been neglected by bioethics? It is likely that part of the explanation relates to the origins of the discipline of medical ethics itself. Although the roots of bioethics extend twenty-five hundred years back to the world of Hippocrates, bioethics' birth as an autonomous discipline is a relatively recent phenomenon. Medical ethics really came into its own during the last four or five decades, largely as a result of advancements in biological science and technology. With revolutionary developments in medical technology came unprecedented moral and policy dilemmas, and hence an academic discipline was born.<sup>42</sup> If

<sup>40</sup> Search conducted on October 30, 2002 at [www.google.com](http://www.google.com).

<sup>41</sup> Many of these referred to a more recent work of Ronald Bayer. There have of course been books and anthology sections on ethical issues associated with AIDS in particular. And Internet searches of 'Ethics and AIDS', as was pointed out by Peter Singer in discussion, will yield more results – i.e. 408 results on 1 March 2005. The fact remains, however, that discussion of infectious diseases in general (which would likely inform discussion of particular diseases such as AIDS) is lacking. In my opinion even AIDS – with the exception of doctor-patient relationship issues (especially the 'duty to treat') and AIDS-related international research ethics (especially the debate over 'standards of care') – has not received adequate attention in mainstream bioethics literature, given the magnitude of the problem. On 1 March 2005, in any case, a Google search of 'ethics and tuberculosis' yielded only 42 results (though tuberculosis kills two or three million persons per year) and 'ethics and malaria' yielded zero (though malaria kills one million per year). On the same date, 'ethics and stem cells' yielded 440 results – despite the newness of stem cell research (in comparison with AIDS).

<sup>42</sup> The development of elaborate life-sustaining technologies made the question of euthanasia, for example, more urgent. I should note that – in addition to technological advance – the birth of bioethics was also importantly related to the civil rights movement of the 1960s. See H. Kuhse and P. Singer. 1998. What is Bioethics? A Historical Introduction, in *A Companion to Bioethics*, P. Singer and H. Kuhse eds. Oxford, UK. Blackwell: 3–11.

this rough sketch of the birth of bioethics captures much truth, then there should be less surprise that there has been a high-tech, wealthy-world slant to discussion within the discipline.

## 2. *Optimism in medicine*

A second probable reason why infectious disease has not received more attention of medical ethicists similarly relates to the timing of the birth of the discipline. The rise of bioethics coincided with a period of tremendous optimism in medicine. The development of antibiotics in the 1940's and the hugely successful Salk Polio vaccination program in the 1950's, and other developments such as the discovery of DDT, led the medical community to believe that infectious disease would soon be defeated through medical progress.<sup>43</sup> As early as

1948 U.S. Secretary of State George C. Marshall declared at the Washington, D.C., gathering of the Fourth International Congress on Tropical Medicine and Malaria that the conquest of all infectious diseases was imminent. Through a combination of enhanced crop yields to provide adequate food for humanity and scientific breakthroughs in microbe control, Marshall predicted, all the earth's microscopic scourges would be eliminated.<sup>44</sup>

In 1955 the World Health Organization decided to 'eliminate all malaria on the planet' via the eradication of mosquitoes with DDT. 'Few doubted that such a lofty goal was possible: nobody at the time could imagine a trend of worsening disease conditions; the arrow of history always pointed towards progress.'<sup>45</sup> 'By 1965, more than 25,000 different antibiotic products had been developed; physicians and scientists felt that bacterial diseases, and the microbes responsible, were no longer of great concern or of research interest.'<sup>46</sup> In 1967 U.S. Surgeon General William H. Stewart was so convinced of success that he told a White House gathering of health officers 'that it was time to close the book on

<sup>43</sup> See Garrett, *op. cit.* note 27, pp. 30–52, esp. pp. 30–31.

<sup>44</sup> *Ibid.*, pp. 30–31.

<sup>45</sup> *Ibid.*, p. 31. Not only did it fail, but this program was somewhat counter-productive. DDT-resistant mosquitoes returned in higher numbers than before; and misuse of medication promoted drug-resistant strains of malaria. By '1975 the worldwide incidence of malaria was about 2.5 times what it had been in 1961 . . . A new global iatrogenic form of malaria was emerging – "iatrogenic" meaning created as a result of medical treatment. In its well-meaning zeal to treat the world's malaria scourge, humanity had created a new epidemic' (p. 52).

<sup>46</sup> *Ibid.*, p. 36.

infectious diseases and shift all national attention (and dollars) to what he termed “the New Dimensions” of health: chronic diseases.<sup>47</sup> ‘In 1972, the Nobel laureate Macfarlane Burnet concluded that “the most likely forecast about the future of infectious disease is that it will be very dull.”<sup>48</sup> Fields such as bacteriology and parasitology appeared less important and subsequently fell out of vogue in the medical scientific community. The rise of medical ethics thus occurred at a time when it was popular – though perhaps hubristic – to think that infectious disease would no longer be a central concern of medicine. This presumably explains at least part of the neglect on the part of those concerned with medical ethics.

### 3. ‘The other’

AIDS, of course, has been on the scene for more than twenty years already – and thus overlaps with roughly half the lifespan of bioethics proper. And it has been clear for quite some time that malaria, TB, and other infectious diseases would not just disappear as planned. To the contrary, plenty of pathogens have developed more dangerous drug-resistant strains. And many morbid microbes – such as SARS and Ebola – have newly emerged during the last few decades.

A third reason why infectious diseases receive sparse discussion by academic ethicists is that they have likely been relegated as problems of ‘the other.’<sup>49</sup> AIDS, for example, for a long time was, and perhaps still is, considered a problem for homosexuals, IV drug users, and poor black people in Africa. AIDS and other infectious diseases are, as has already been said, by far more prevalent in the developing world. Given that the vast majority of professional medical ethicists are straight, non-drug-injecting, relatively well-to-do whites who reside and work in wealthy developed nations, it should not be entirely unexpected that they have focused most on matters of more obvious central domestic concern, rather than problems of ‘strangers’ on the fringe of society and foreigners in faraway places. This third explanation involves both psychological and practical elements. Regarding the latter, (relatively conservative) university employers (and research funders) likely expect academic ethicists to focus most on

<sup>47</sup> *Ibid.*, p. 33.

<sup>48</sup> Gewen, *op. cit.* note 8.

<sup>49</sup> See H. Joffe. 1999. *Risk and the Other*. Cambridge, U.K. Cambridge University Press; & N.L. Stepan, *op. cit.* note. 27, for discussions of how AIDS and tropical diseases, respectively, are regularly understood and portrayed as problems of others.

pressing local issues rather than (radically) concentrating on international justice.<sup>50</sup> This has *explanatory* power, but I doubt it makes the failure of medical ethicists to further discuss one of world's most consequential topics *excusable*. Ethics and morality essentially involve elements of impartiality; and, *tenured* professors, in any case, have substantial freedom to choose their topics.

#### 4. Complexity

A fourth explanation of neglect by bioethicists relates to the complexity of the issues in question.<sup>51</sup> Traditional topics in medical ethics already require difficult interdisciplinary study. Expertise in both ethics and science are required to do bioethics well. Though many scholars have expertise in the discipline of ethics and many scholars expertise in scientific and technological aspects of biology and medicine, it is rare to find both kinds of expertise embodied in single individuals. One result is the relatively weak reputation of medical ethics within philosophical circles. Philosophers commonly complain about a 'low level' of discussion in medical ethics. This is attributed to the fact that (1) contributors with philosophical mastery in ethics often fail to get the science right and are thus unrealistic while (2) contributors with scientific backgrounds too often lack sufficient training in rigorous philosophical argumentation to get the ethics right, and (3) too few contributors are skilled enough in both areas to generate a consistently high level of discussion.

I have been discussing the challenging nature of the interdisciplinarity of medical ethics scholarship because I believe this difficulty is greatly exacerbated with discussion of infectious disease and the health care situation in the developing world. In addition to grounding in ethics and science/medicine (the latter of which is itself complicated by entry into the realm of epidemiology and drug-resistant pathogen emergence), we here need a greater grip on complex social, political, historic, and economic dynamics in order to *explain* – and thus comment upon the justice of – the current global healthcare situation.<sup>52</sup> A similarly

<sup>50</sup> Udo Schuklenk suggested this point in conversation.

<sup>51</sup> This was (independently) suggested by Mary Tjiattas. Peter Singer concurred in conversation.

<sup>52</sup> I do not mean to imply that other issues in bioethics do not require appreciation of social, political, historical, and economic phenomena. My point is one of degree: assessment of the health care situation in the developing world *often* requires substantially *more* contact with these other disciplines. Others who have worked in this area will agree.

broadened understanding is needed to realistically assess – and base moral/policy prescriptions upon – *predictions of impact*. Exploring the issues I have in mind requires more *empirical* work than most (medical) ethicists are likely to be trained for or accustomed to.<sup>53</sup> With regard to distribution of resource questions, confrontation with issues of international (rather than merely domestic) justice is an additional obvious way in which *theoretical* discussion is complicated.<sup>54</sup> The fact that infectious diseases do not respect international borders is just one of the ways in which the topic is inherently international. My fourth explanation, thus, is that questions concerning infectious disease and the healthcare situation in the developing world have been neglected by biomedical ethicists at least partly because of the *difficulty* of working on them.

### 5. *Apparent ease*

My fifth explanation, ironically, is that this area has been ignored because of a *misperception* that the questions raised are all-too-easy. The injustice of the situation, which has received substantial *media* attention at least, whereby AIDS medications are unavailable because they are unaffordable – at least partly because of prices set by profit-driven pharmaceutical companies – to populations in sub-Saharan Africa where they are by far needed most will strike many as a clear and blatant injustice. ‘Of course this is wrong. Of course more should be done to make medication available to AIDS victims in Africa,’ many might say, ‘and you don’t need to be a philosopher – or priest – to figure that out.’ Questions about the justice of the health care situation in the developing world, where the innocent poor are sick and suffering, at first glance anyway, *appear* to lack the deep philosophical significance of questions upon which medical ethicists usually focus their attention.<sup>55</sup> Topics such as euthanasia and abortion, for example, raise what might look like deeper and more intellectually challenging issues: When is it morally permissible to kill another human being? What is a person? Upon what is the moral status of human beings based? What does quality of life consist in? Notice that emerging bioethical debates surrounding genetics and embryo/stem cell

<sup>53</sup> For further illustration of what I here have in mind see M.J. Selgelid. Ethics, Economics, and AIDS in Africa. *Developing World Bioethics* 2004; 4, 1: 96–105.

<sup>54</sup> See D. Moellendorf. 2002. *Cosmopolitan Justice*. Boulder, Colorado. Westview Press.

<sup>55</sup> This objection was (independently) raised by Julian Savulescu in discussion.

research often revolve around these same sorts of questions. In comparison with these more theoretical (or perhaps *metaphysical*) questions, the injustice of a situation where tens of millions of (relatively innocent) people will soon suffer and die because they are too poor to buy medications might look like a no-brainer.

#### 6. *Religious hijacking*

My final explanation of why infectious disease has not received more attention from bioethicists refers to the fact that bioethicists have been kept so occupied by discussion of *religious objections* to things like abortion, euthanasia, cloning, stem cell research, and so on. Contrary to Paul Farmer,<sup>56</sup> my own belief is that most bioethicists *are* (at heart, anyway) genuinely concerned about issues of justice. Liberal-minded bioethicists presumably would have focused much more attention on the topic of infectious disease and the injustice of the health care situation in the developing world if they hadn't been kept so busy battling the illiberal policy agenda (regarding abortion, euthanasia, cloning, stem cell research, etc.) advocated by the church.<sup>57</sup> Debate in bioethics has thus, to a large extent, been hijacked by religion.

### CONCLUSION

I have offered six explanations of why ethical issues associated with infectious disease (and the related health care situation in the developing world) have not been more prominent in medical ethics literature. I have suggested that this is the case roughly because (1) bioethics was born (as an autonomous discipline) with advances in medical technology and thus has largely focused on these, (2) bioethics' birth and initial development (as an autonomous discipline) came at a time when it was believed that infectious disease would be conquered by medicine, (3) infectious diseases are often seen as problems of others, (4) bioethical research on infectious disease in the developing world is especially difficult because so empirical and interdisciplinary, (5) ethical questions about infectious disease (in the developing world) might not *appear* to pose the kinds of deep philosophical questions that academic ethicists are interested in, and (6) bioethics debate has been hijacked by the church. These are just

<sup>56</sup> In discussion.

<sup>57</sup> James William Ley, philosophy Ph.D. student at the University of Sydney, encouraged explicit inclusion of this point.

suggestions; and this list is not meant to be exhaustive. Rather than choosing between these alternative explanations, I believe that they each likely capture *parts* of the story we are after. In any case, as argued above, it would be entirely wrong to explain the lack of discussion of infectious diseases by denying their central importance and/or relevance to the discipline of bioethics.

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