ETHICS & AIDS IN AFRICA

THE CHALLENGE TO OUR THINKING

Editors: Anton A. van Niekerk, Loretta M. Kopelman

davidphilip

We dedicate this volume to persons with HIV/AIDS
and hope this discussion of the moral issues of
their disease helps them and those who love them.

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FOREWORD

For 25 long years, we have grappled with humankind's worst pandemic since the plague cut down one-third of Europe's population nearly seven centuries ago. We have struggled to grasp the virology of AIDS, its demography, its impact on human physiology, its social and economic consequences, its responsiveness to medical treatment. But most of all we have struggled with the moral and ethical implications of so much suffering and death, first in North America and Western Europe, and now in Africa, where the epidemic's fiercest toll is being exacted.

AIDS is an economic and social challenge. But more than this, it is a moral test. For underlying the practical challenges of leadership, organisation and decision-making — themselves so critical when so many lives are at stake — are the ethical tests of our own thinking. How do we conceive an epidemic that was first diagnosed amongst the morally still-marginalised gay men of North America and Western Europe, and that now strikes hardest at the materially marginalised populations of the world's poorest continent? How do we conceive a world that has effective means to treat most people with AIDS, but in which the life-saving benefit of antiretroviral medication is still denied to most of those with the greatest need?

These challenging questions have already tested South Africa's and Africa's leadership, and that of the Western world, whose societies are more fabulously powerful and wealthy than any in human history. But they challenge us also. For in Central and Southern Africa, AIDS is not someone else's problem: it is our own. And our response to AIDS — in our own lives and households and workplaces and communities and organisations — will help determine the calibre of our future societies.

These are the questions that powerfully inform the contributions to this important collection of essays that Anton van Niekerk and Loretta Kopelman have compiled. In it, distinguished authors, including those at the forefront of the debates that most bear on life and death in the African epidemic of AIDS, discuss its central ethical issues. What are our means of knowledge in the epidemic? How do we know whether the epidemic is real (for, astonishingly, this question is still asked, and asked with aggression and righteousness by those who dispute the existence of AIDS, or its viral, mostly sexually transmitted causes)? What imperative response does the availability of life-saving medications demand of us? And how do we assess our own judgment of those who have HIV and AIDS?

Not only are these questions asked in the pages that follow, but also the contributing authors provide clarity and new moral direction in answering them. As far as I know, this is the first collection of essays dedicated to ethics and AIDS and Africa. Its appearance is most welcome. The power and clarity of its contributions is even more welcome. For far from hiding in abstraction or generalities, the authors contributing to Prof. Van Niekerk's and Prof. Kopelman's book take bold and lucid stances. Their writing adds to our understanding of the epidemic and provides suggestions for how societies should respond to this crisis. That response necessarily requires moral leadership, and this is a bold book that provides it.

Edwin Cameron
Supreme Court of Appeal
February 2005

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INTRODUCTION

A little more than 20 years ago, The Centers for Disease Control in Atlanta, USA, first reported in its *Morbidity and Mortality Weekly Report* that a few men had died of a deadly form of pneumonia. Since that 5 June 1981 publication, 23 million people have been documented as dying from what is now identified as acquired immune deficiency syndrome (AIDS). More than half, over 17 million of these people, are Africans. Currently, 39.4 million persons live with the human immunodeficiency virus (HIV) and 25.4 million (64 percent) of them reside in sub-Saharan Africa (Whiteside 2005). In Africa, the disease is mainly transmitted through heterosexual sex; whereas, in the developed world, contaminated needles of intravenous drug abusers and homosexual male sex are also major contributors to its persistent spread.

The most disturbing fact about HIV/AIDS is that, although there has been significant improvement in the management of the disease, largely brought about by the introduction of highly active antiretroviral therapies (HAART), and although progress is seemingly being made with the development of effective and safe AIDS vaccines, there is, as yet, no cure for or vaccine against this disease. HIV/AIDS has therefore become the overwhelming reality in the seemingly pervasive predicament of the African continent. Never in the history of pandemics have we seen such a persistent increase in the number of people infected over such a prolonged period of time. Epidemics are usually characterised by sharp rises in infection rates, followed by similarly sharp declines once appropriate management measures are taken. This was, for example, seen in the case of the recent SARS epidemic in the East and Canada. HIV/AIDS defies this 'law of epidemics' since its inception, in part, because of its long incubation period. It has therefore become a global catastrophe, and poses the major challenge to both health care and social stability on the African continent.

Nowhere is the catastrophic impact of HIV/AIDS more apparent than in the region of Southern Africa. Botswana and Swaziland have infection rates in excess of 40 percent of its population — a figure that, a few years ago, was widely regarded as inconceivable as far as epidemics go. South Africa has, in absolute numbers, the highest rate of infection in the world. More than five million South Africans are currently HIV positive. In 2004 alone, more than 311 000 people died of HIV/AIDS-related diseases in South Africa (i.e. almost 900 per day) (Benatar 2005b).

The catastrophic nature of the pandemic is well illustrated by the fact that, in the absence of effective interventions (none of which seem forthcoming), it is expected that 40 to 50 percent of South Africa's workforce will die in the next ten

years. In this coming year, there will already be 800 000 orphans under the age of 15 in South Africa (Benatar 2005b). UNICEF estimates that by 2010 an estimated 20 million children in Africa will have lost one or both parents to HIV/AIDS (Whiteside 2005). One should ask: what happens — economically and socially — to societies in which this occurs?

Much has been written about the medical, demographic, economic, political and social-psychological dimensions of the pandemic. This book, however, is the first comprehensive volume about the *ethical* dimensions and problems associated with the pandemic, and particularly so in Africa. Ethics is the discipline that deals systematically with the nature of obligation, including with the issues, judgments, theories and possible answers pertaining to the question: when are our actions right or wrong, and what things are good or bad? The HIV/AIDS pandemic has revealed a remarkable array of ethical problems that occur in the effort to identify HIV-positive people and to treat patients suffering from AIDS appropriately, and, eventually, to vaccinate the population against the disease, should a vaccine eventually be successfully developed — something that is not foreseen to occur within the current decade.

However, as will be argued in some of the contributions that follow, the ethical problems related to HIV/AIDS transcend the sphere of the day-to-day clinical practice of administering medical care to patients by health care workers. It is becoming increasingly clear that the phenomenon of HIV/AIDS reveals dramatic problems in the global interactions between countries and institutions in the developed and developing worlds. As such, HIV/AIDS has, almost more than any other health care phenomenon in recent times, revealed the necessity of the development of what can nowadays indeed be called a 'global bioethics'. The contributions to this book deal with both these dimensions of the problem.

In what follows, we shall briefly introduce the main arguments and insights of the chapters that follow:

- **Chapter 1** ('AIDS in Africa: facts, figures and the extent of the problem') is by Alan Whiteside, South Africa's leading AIDS demographer. In this chapter, the exact extent of the problem in Africa will be discussed, with emphasis on what is to be expected if current trends of (in)action regarding treatment continue, and what the effect of interventions might be. The latest and most reliable figures about the pandemic are provided, as well as remarks about the significance of apparent discrepancies that occur between data from different sources. Whiteside goes on to discuss the 'dramatic and far reaching' consequences of the pandemic, particularly their impact on the economy and on the social welfare of orphaned children, which is generally foreseen to be catastrophic in Africa. Some appropriate responses are explored in conclusion.
- In **Chapter 2**, Alan Whiteside, Tony Barnett, Gavin George and Anton A. van Niekerk ('Through a glass, darkly: data and uncertainty in the AIDS debate')

discuss the problem of unreliable statistics about the AIDS epidemic and how the moral controversies surrounding AIDS can be related to unreliable data about the pandemic. The limitations of the use of antenatal clinic surveys, which provide the bulk of our information, are discussed. While it can be claimed that there are problems with the reliability of the data from antenatal clinics, this by no means suggests that the available figures are over-inflated. On the contrary, given the fact that access to antenatal clinics is quite limited in the deep rural areas of Africa, it is safer to assume that our available figures on the pandemic are too conservative. The authors then turn to the evidence of impact of the epidemic, showing how the long incubation period for HIV infections to turn to AIDS, and for AIDS to translate into deaths has profound consequences, including orphaning, increasing poverty and changing population structures. Furthermore, it means that once the HIV prevalence has peaked, AIDS impact will take years to work through; this epidemic is a 'long-wave' event. They argue that insufficient and/or unreliable data have allowed leaderships, particularly in Africa, to deny the scope and scale of the problem and that this is unacceptable. However, it is incumbent on these leaders to accept the moral responsibility for choices and the consequences of their work, and this includes funding and supporting those who gather, interpret and use the data.

- **Chapter 3** ('Rolling out antiretroviral treatment in South Africa: economic and ethical challenges') is by Nicoli Nattrass, an economist from the University of Cape Town who is well known for her recent book *The moral economy of AIDS in South Africa* (Nattrass 2004). In this chapter, she develops three moral-economic arguments that are all related to the issue of whether treatment with HAART is, from both a social and economic perspective, a viable option for (South) Africa at present. First, she argues, in response to some policy makers, why a rollout of HAART is likely to contribute to fewer new HIV infections. She also disputes the counterclaim that a HAART rollout will lead to less responsible lifestyles and thus increased infections. Her second argument deals specifically with the issue of cost-effectiveness. She argues: 'Once HIV-related costs are included in the calculation, the cost per HIV infection averted is lower in a treatment plus prevention intervention scenario than it is in a prevention-only scenario'. Her conclusion is that the constraints on funding a large-scale, comprehensive intervention in the current pandemic in Africa are politically and not economically driven. It is, contrary to what many policy makers seemingly accept, economically feasible to fund such a comprehensive treatment programme with HAART. Finally, Nattrass turns to an ethical issue specifically generated by the spending of tax money on AIDS. This is the phenomenon that many people living with AIDS in South Africa are increasingly becoming dependent on disability grants provided to them by the government. Given the insufficiency of other poverty relief measures in a developing country such as South Africa, these

grants are apparently becoming an incentive to either contract HIV or to fudge information when ability to go off the grant is restored. Nattrass develops an impressive argument why this phenomenon ought to provide an additional reason for considering the introduction of a Basic Income Grant for South Africa (Nattrass 2005).

- In **Chapter 4** ('Moral and social complexities of AIDS in Africa') we move from these demographic and economic issues to other moral and sociopolitical complexities of the HIV/AIDS pandemic in Africa. Anton van Niekerk discusses some of these, as well as the importance of finding responses that empower people living with HIV/AIDS in Africa. Complexities include poverty, denial, poor leadership, illiteracy, women's vulnerability and the disenchantment of intimacy as people worry about whether their partners will give them a deadly disease. Seeking long-term and comprehensive solutions to its moral, social and political problems could exacerbate the sense of hopelessness and helplessness that is engulfing the region as so many become orphans, get sick or die. Rather than wait for comprehensive solutions and warning against the disempowering consequences of tendencies to politicise the discourse about AIDS in Africa, he argues that we should focus upon what needs to be done immediately to respond to HIV/AIDS.
- In **Chapter 5** ('The HIV/AIDS pandemic: a sign of instability in a complex global system'), Solomon R. Benatar deals with the HIV/AIDS pandemic as a 'sign of instability in a complex global system'. He argues that Van Niekerk's view that we should not wait for comprehensive solutions before acting should be supplemented by conceding the role of global politics, especially the exploitation, discrimination and imperialism by first world countries of sub-Saharan Africa. For the sake of world stability and common decency, more affluent countries should realign their development aid priorities and help Africans create a better quality of life by responding to their poverty, hunger and diseases. He acknowledges that since colonial independence, some problems have resulted from 'poor governance, corruption, internal exploitation, nepotism, tribalism, authoritarianism, military rule and overpopulation through patriarchal attitudes and disempowerment of women, [but urges that] these shortcomings must be seen in the context of powerful external disruptive forces acting over several centuries to impede progress in Africa'. According to Benatar, 'a biomedical approach cannot, in isolation, sufficiently improve the health of populations. To achieve the latter will require understanding and addressing the powerful social forces that allow pandemics to emerge and spread in order to ensure that real development and empowered independence can take the place of perpetual philanthropy. Broadening the discourse on ethics to include public health ethics and the ethics of international relations could contribute to reducing the impact of the pandemic and to preventing the emergence of new infectious diseases in the future' (Benatar 2005a).

- In **Chapter 6**, ('Principles of global distributive justice and the HIV/AIDS pandemic: moving beyond Rawls and Buchanan'), Anton A. van Niekerk draws on some of Benatar's insights to develop the perspective of a global bioethics by specifically contributing to the debate between Allen Buchanan and John Rawls about the appropriateness and contents of principles of global distributive justice (PGDJ), as these are specifically called for in view of the HIV/AIDS pandemic. He briefly reviews the main tenets of Rawls's theory of justice, particularly as it concerns health care. In this respect, he draws on the work of Norman Daniels who has applied Rawls's theory to the issue of the provision of just health care. Secondly, he argues for the necessity of a global approach to biomedical ethics in view of the need for a more equitable provision of health care between developed and developing worlds. Thirdly, he discusses the main tenets of Rawls's *The Law of Peoples*, the book in which Rawls extrapolated the implications of his theory of justice to the sphere of just international law. Allen Buchanan's criticisms of this Rawlsian enterprise are then critically reviewed. Finally, Van Niekerk evaluates this debate, arguing that, although he largely (but not wholly) agrees with Buchanan's identification of the shortcomings in Rawls's *The Law of Peoples*, two additional principles of global distributive justice (PGDJ) ought to be added to the two formulated by Buchanan with which the author agrees. One of these additional principles shows the importance for special measures in cases of catastrophic occurrences such as the current HIV/AIDS pandemic. The other emerges from another problem the author has with Buchanan's analysis: his tendency, when formulating PGDJ, to concentrate the burden of responsibility implied by these principles entirely to the wealthy societies. Van Niekerk argues that this principle involves the responsibility of poor societies to not only be on the receiving end of aid and to bask in continuous entitlements, but to also exert responsible policies that create sustainable conditions for the meaningful redistribution of global wealth and health. This is again illustrated with reference to issues in the current debate about the global response to the AIDS pandemic.
- **Chapters 7 to 13** deal with more specific ethical issues provoked by the HIV/AIDS pandemic: the cost of drugs (Chapters 7 and 8), mother-to-child transmission (Chapter 9), ethical issues related to the development of AIDS vaccines (Chapters 10, 11 and 12) and the issue of whether HIV/AIDS can rightly be seen as 'punishment' (Chapter 13). In Chapter 7 ('Access to Affordable Medication in the Developing World: social responsibility vs. profit'), David Resnik deals with the issue of access to affordable medication in the developing world, and specifically the question as to how concerns about the profits of large multinational pharmaceutical companies weigh up against concerns of their (alleged) social responsibility. The gist of his argument is that 'large, global pharmaceutical companies have a moral obligation to develop affordable drugs for the developing world and to make these drugs

accessible, and that developing nations should cooperate with these companies in achieving these goals'. His view is that 'although pharmaceutical companies and developing nations are often in conflict they must work together to develop drugs for the developing world' (Resnik 2005). He emphasises that his view does not stem from a naïve defence of the pharmaceutical industry; pharmaceutical companies have social responsibilities that they often do not take seriously. His defence of intellectual property rights for pharmaceutical companies 'stems from a pragmatic approach to the justification of intellectual property, not from an ideological commitment to big business' (Resnik 2005).

- **Chapter 8** ('Affordable access to essential medication in developing countries: conflicts between ethical and economic imperatives') by Udo Schüklenk and Richard Ashcroft offers an alternative perspective to the views expressed by Resnik. They argue that given the public health crises, compulsory licensing of essential AIDS medications is justifiable on consequentialist grounds. Alternatives such as discounted pricing and donation schemes by drug manufacturers are, they argue, both morally and pragmatically inferior.
- In **Chapter 9** ('Mother-to-child transmission of HIV/AIDS in Africa: ethical problems and perspectives'), by Anton van Niekerk, the subject is mother-to-child transmission (MTCT) of HIV/AIDS in Africa and its concomitant ethical issues. The author first deals with the relevant facts about MTCT. This is followed by a discussion of two ethical problems, viz. the issue of the morality of placebo-controlled trials for drugs to prevent MTCT in Africa, and the issue of the lack of political leadership and responsibility to implement proven programmes that will combat MTCT. In conclusion, the author discusses a number of insights that these disputes yield for our understanding of our powers over disease in the contemporary world, the implications of these issues for our understanding of scientific methodology in medicine, the dangers of politicising a health problem such as HIV/AIDS, the need for renewed reflection on the global disparities in the provision of health care, and the need for imaginative and responsible political leadership and co-operation between the developed countries, Africa and the pharmaceutical corporations to address and combat a catastrophe of unprecedented global proportions.
- In **Chapters 10 to 12** the issue is ethical problems related to the development of AIDS vaccines in Africa. In Chapter 10 ('HIV vaccine trial participation in South Africa — an ethical assessment'), Keymanthri Moodley discusses tensions when first world countries sponsor research in sub-Saharan Africa. In order to study HIV/AIDS, especially in rural African regions, interpretations tailored to specific communities may be needed of such key notions in research ethics as informed consent, fair treatment of subjects and risk assessment. These societies, she argues, employ a moderate form of communitarianism referred to as 'Ubuntu' or 'communalism' that could help these

people understand research as an altruistic endeavour benefiting communities as a result of risks taken by individuals. The first world individualistic focus may fail to emphasise such forms of communalism, thereby thwarting the sort of approach likely to gain approval and co-operation for research needed in Africa today.

- In **Chapter 11** ('The HIV/AIDS pandemic, African traditional values and the search for a vaccine in Africa'), Godfrey B. Tangwa also argues for the importance of traditional African values and how they should be enlisted to fight the HIV/AIDS pandemic. These values emphasise empathy and providing for people in genuine need, irrespective of their ability to pay. This contrasts with the more libertarian, market-driven, profit-oriented practices of important sectors of first world countries. Not only should these traditional African values be respected, he argues, but they could also teach others how to deal with those in need.
- In **Chapter 12** ('The dilemma of enrolling children in HIV vaccine research in South Africa: what is in 'the child's best interest'?), Melissa Stobie, Ann Strode and Cathy Slack examine whether and how to involve children in the research for HIV vaccines. Many children are infected with HIV in (South) Africa, and are entitled to benefit from the development of a vaccine. How, then, are we to think of the thorny issue of the 'child's best interest' in a situation where they will inevitably be put at risk if they participate in research to develop vaccines? The authors of this chapter argue that the 'best interest principle', so often invoked as the guiding ethical principle in moral issues regarding children, may, ironically, 'work to the long-term detriment of children if interpreted too strictly on individual grounds. This is especially so in South Africa, where the prevalence and rate of HIV infection mean that the only way to effectively stem the epidemic would be to vaccinate children against HIV infection'. Vaccinations of children, however, can only occur safely if children are included in the vaccine trials — a move which, in turn, may not be in their individual 'best interests'. The authors thus 'explore the ethical and legal framework in South Africa, and evaluate it in terms of the best interests standard'. In doing so, they 'try constantly to bear in mind not just the best interests of the individual child, but also of children as a class'. They conclude by 'suggesting some tools research ethics committees may need to use in order to determine whether the best interests of children are being respected' (Stobie et al. 2005).
- In the final chapter, **Chapter 13** ('If HIV/AIDS is punishment, who is bad?'), Loretta M. Kopelman takes as her starting point the fact that HIV/AIDS strikes with the greatest frequency in sub-Saharan Africa, a region uniquely lacking resources to deal with this epidemic. To keep millions more people from dying, wealthy countries and people must provide more help. Yet deeply ingrained biases may distance the sick from those who could provide

> far more aid. One such prejudice is viewing disease as punishment for sin. This 'punishment theory of disease' ascribes moral blame to those who get sick or those with special relations to them. Religious versions hold that God or other divine beings punish to castigate, encourage virtue, warn, rehabilitate or maintain some cosmic order. Its various religious and secular forms are untenable; they lack cogency, risk blaming people unjustly, and jeopardise compassionate care for people. These views are not only irrational but also dangerous because they influence policies and cost lives and lead people to deny the reality of the danger. We need to cooperate and respond as befits this global public-health disaster and not engage in the misguided and bad faith activity of dividing the world into the blameworthy and blameless.

The authors of this book agree that for compassionate as well as pragmatic reasons, there must be both a national and a global effort to find a solution to the HIV/AIDS pandemic. Each author discusses some of the fault lines and upheavals that this plague has exposed and the radical changes that this pandemic is likely to leave in its wake. They conclude that good solutions must be cooperative ventures amongst countries within and outside of sub-Saharan Africa, with wealthy countries making more generous contributions to help fight the world's worst plague.

This book is the outcome of a project initiated by the editors in 2002 when they were invited to edit a special edition of the *Journal of Medicine and Philosophy* (volume 27, no. 2, April 2002) on the ethical problems related to AIDS in Africa. All the articles published in that volume are republished in this book. We would like to express our sincere gratitude to the Editor-in-Chief of the *Journal of Medicine and Philosophy* (JMP), Dr H. Tristram Engelhardt, not only for the original invitation, but also and in particular for granting permission to republish edited varieties of the seven articles originally included in the JMP edition, i.e. the (considerably changed) Introduction as well as Chapters 4, 5, 8, 10, 11 and 13 of this volume.

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