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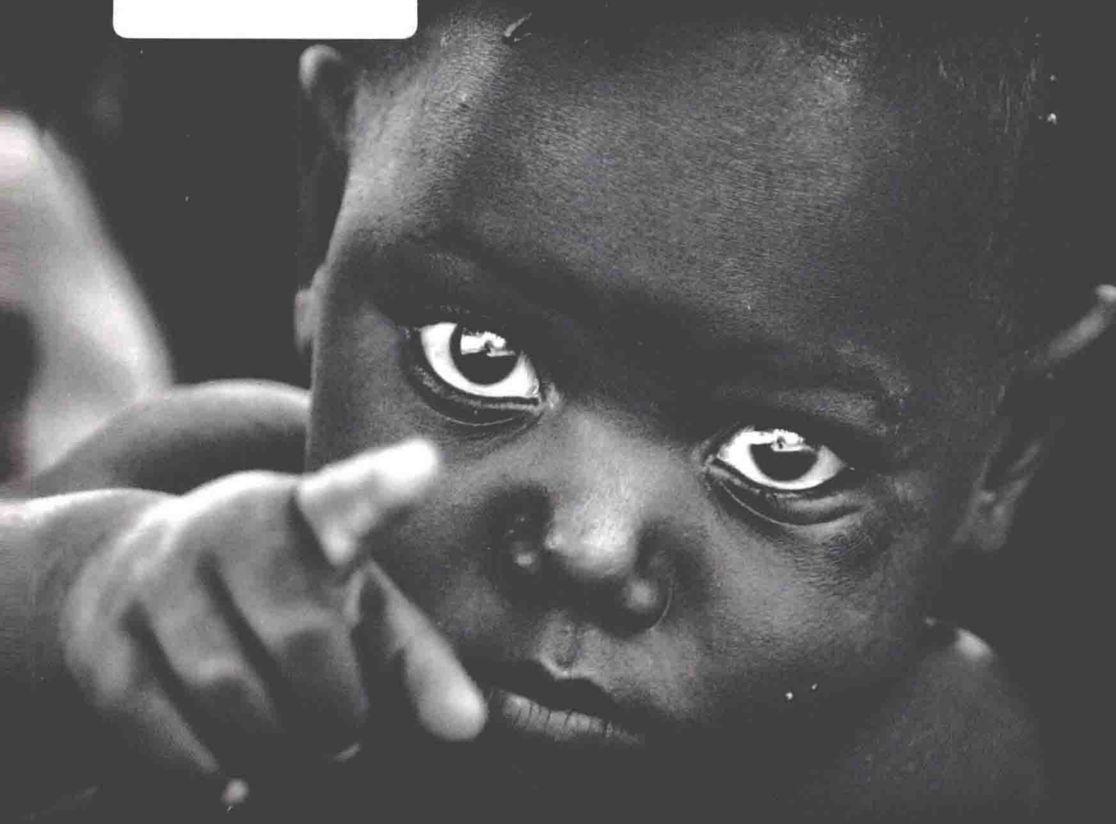

Living with HIV and Dying with AIDS

Diversity, Inequality and Human Rights in the Global Pandemic

LESLEY DOYAL WITH LEN DOYAL

Living with HIV and Dying with AIDS

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LIVING WITH HIV AND DYING WITH AIDS

Offering compelling evidence of the inadequacy of biomedical models for the AIDS response, this book provides a clear and lucid look at the inequalities that drive growing rates of HIV infection and the inadequacy of existing systems to address them. Bringing to life the old adage the 'personal is political', it provides valuable evidence of the social and economic realities faced by HIV-infected people everywhere.

Sofia Gruskin, University of Southern California, USA

A powerful combination of qualitative empirical data, sensitive sociological insights into diverse contexts of living and dying with HIV/AIDS, and a clear explication of the relevance of human rights both within nations and globally. Collaborative work between medical and social science researchers is the suggested path to deeper understanding of the profound burden of social suffering that extends beyond biomedical considerations.

Solomon Benatar, University of Cape Town, South Africa, and University of Toronto, Canada

A wide-ranging analysis of what makes HIV such a potent agent of human suffering, and why the remarkable biomedical progress of the past 30 years must be matched by advances in human rights, equity and access for there to be real progress. Here is a contextual backcloth against which clinicians can re-evaluate treatment and care for HIV.

Jane Anderson, Homerton University Hospital NHS Foundation Trust, UK

No other source provides such an insightful, integrated, broadly-focused analysis that uses an explicit conceptual framework to take context and differences into account, systematically connecting human needs, human rights and inequality. This brilliant, accessible book is essential reading for policy-makers, practitioners and academics, whether or not they are interested in the specific case of HIV and AIDs.

Pat Armstrong, York University, Toronto, Canada

Global Health

Series Editor: Professor Nana K. Poku,
University of California, Berkeley, USA

The benefits of globalisation are potentially enormous, as a result of the increased sharing of ideas, cultures, life-saving technologies and efficient production processes. Yet globalisation is under trial, partly because these benefits are not yet reaching hundreds of millions of the world's poor and partly because globalisation has introduced new kinds of international problems and conflicts. Turmoil in one part of the world now spreads rapidly to others, through terrorism, armed conflict, environmental degradation or disease.

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Introduction and Acknowledgements

This book had its origins in an invitation from Professor Jane Anderson to give a lecture on gender to health workers involved in HIV care. Having coffee afterwards she talked about how she wanted to carry out a wider sociological study involving the many African women she was helping to care for. However she was afraid she did not have the relevant skills. But I did – leading us to begin what was to be a lengthy collaboration resulting not only in several studies of African migrants living with HIV in London but also in Jane adding anthropological skills to her very considerable clinical ones. The difficulty we had in obtaining funding for this work offered an early warning of the fact that priority is usually given to biomedical research. However it also highlighted one of the central themes of this book: the value of bringing social science into the study of HIV and AIDS, especially when this is based on interdisciplinary collaboration.

Our first study of women was followed by one of men who defined themselves as heterosexual (who had hardly been studied at all in any setting) and one on men who had sex with men. This latter group had been almost totally ignored in African contexts, though they had of course been extensively studied in the USA. As our studies proceeded, my exploration of the background material raised many questions about the bias in existing studies. The most obvious was the lack of available information on the experience of living with HIV and dying of AIDS in the global south. At this early stage (2005) the global spread of the pandemic was already clear, especially in the African region. However the literature on the experiences of those infected was sparse and focussed almost entirely on what were seen as practical policy-oriented issues such as 'safe sex' and the 'proper' use of antiretroviral therapy (ART).

As I continued to review the literature, other problems began to emerge. Most importantly it seemed to be extremely fragmented, with very little connection between the different dimensions of people's lives. Moreover some very important topics were almost entirely ignored, including both paid and unpaid work and experiences of reproduction and parenting. It appeared that these were not deemed relevant to HIV-positive people despite the fact that the beneficial effects of ART were beginning to extend their lives. The key themes still appeared to be 'stigma' (used in what was often an overly simplistic way), sex and death – especially in the poorer settings where the majority of those affected by the pandemic were now to be found. They were still being treated as an undifferentiated mass whose illness was largely their own fault and whose individual experiences were of little interest or value.

From 1994 onwards I was lucky enough to spend several weeks a year in South Africa at the Women's Health Unit at the University of Cape Town. This highlighted for me the importance of understanding the different epidemics in their social, economic and cultural contexts. In the early years in particular the lack of available treatment threw the circumstances of what were now millions of HIV positive people into sharp relief. I vividly remember visiting the clinic funded by Médecins Sans Frontières (MSF) in the township of Khayelitsha, where ART was just beginning to be rolled out. This was taking place against the background of extreme reluctance on the part of the government to provide the necessary drugs, as well as dire warnings from richer parts of the world that this was an impossible challenge. On a visit to a maternity hospital the same year I sat with a 16-year-old girl who was HIV positive as she gave birth, and watched her walk away a few hours later. The baby had been treated to prevent mother to child transmission but there was no therapy for the mother: their future seemed intolerably bleak and entirely unfair.

By the time I had finally decided to write the book, circumstances were beginning to change for the fortunate ones, but for many more they remained hopeless. Researchers were gradually beginning to explore the situation in different parts of the world but their results were narrowly focussed, with little integration of different aspects of living with HIV and almost no comparison between settings. My aim was to combine these diverse and usually small-scale studies into a more holistic picture. This could then contribute to an evidence base for the implementation of broader policies as well as bearing witness to the tragedies that were continuing to engulf so many people's lives.

As the book progressed it felt like new research findings were exploding around me (as witnessed by the eventual size of the bibliography). My main concern became one of synthesising these into a form that would be accessible to activists, clinicians, other health workers and policy makers as well as social scientists and, of course, students. A key theme was the relationship between diversity and difference on the one hand and universality on the other. How did the experiences of HIV positive individuals differ across social groups and nation states? And what needs did they have in common which would have to be met if they were to realise their potential in what were often desperate circumstances?

The authorship of the book has been somewhat unusual, as evidenced by the names on the front cover. It began life as a solo project but ended up as a much more collaborative venture. As I advanced further into the text I became aware that it would be much better if some of the more conceptual/philosophical debates underlying it were made more explicit. Expanded discussions of the universality of basic human needs, inequality, disadvantage, human rights and global injustice were clearly central to any understanding of life and death in the context of the pandemic. But there had so far been relatively few attempts to make these connections in any systematic way.

Fortunately issues such as these are one of my husband Len Doyal's areas of expertise as a philosopher and medical ethicist. Hence we agreed that he would help me extend the scope of the book to include a number of topics that had been referred to only briefly in early drafts. I cannot thank him enough for his huge contribution in this and in so many other ways. His love, moral support, technical skills and continued enthusiasm for helping me tease out the many intellectual puzzles that inevitably arise in a project of this kind were invaluable. Indeed they made it all possible. We hope that this work together will further highlight the importance of moral and political philosophy in current debates concerning HIV/AIDS policy in this time of crisis.

Throughout the writing of the book Sara Paparini has played a major role as a researcher, confidante, supplier of references I might have missed and all-round supporter and friend. Despite the fact that her first language is not English she was especially good at 'vetting' the political correctness (or not) of my own language in a field that is notoriously full of pitfalls. My visits to South Africa were made more fun as well as more enlightening by the advice, help and hospitality of many friends, including Margaret Hoffman, David Coetzee, Solly and Evie Benatar, Toni and Ivan Strasburg, Helen Schneider, Lucy Gilson, Paul and Belinda Roux and Naeema Abrahams.

During the writing of the book I needed more than my fair share of complex medical and dental care and most of this was delivered not just with expertise and professionalism but also with real humanity. For that I want to thank Dougie Clark, Habib Ellamushi, Fazeela Khan-Osborne, David Osborne, Leigh Stephens, Adella Shapiro, Mike Swash, David Vasserman and Lloyd Williams. My son Daniel Wilsher was a huge source of support throughout this period, pushing my wheelchair, sitting in doctors' waiting rooms, sharing snatched lunches and providing essential advice on international law.

When the going got tough, eating, drinking, laughing and loving with others was always a special treat, and for that I especially want to thank in London Evi Campetella, Reno and Soraya Cerio, Joel Gladstone, Peter and Sue Kopelman, Ania Korszun and Ian ('Chef') McKenzie, Lucy Parham, Sara Paparini and Chris Passeroti, Jane Smith and Sybil Williams. The same applies in Perugia to Elisa Ascione, Pierluigi Buratta and Sonia Bittoni, Laura Formeniti, Luigi ('Gigio') Montelione and Barbara Belfiori Montelione, Margherita Taticchi, Marcella Giogliali and at Faula, Paul Mackay and Luca Colautti.

Over the last three years so many other people have given me helpful and critical advice and support that there is not enough space to name them all. You know who you are and I thank you for your help. I want to thank Jane Anderson and Vin-Khim Nguyen for their valuable comments on the manuscript. Peter Aggleton was especially helpful in sending important and detailed suggestions, while Sofia Gruskin went out of her way to help at what was a difficult time for her. Thanks also to an anonymous reviewer for encouragement to turn a 'good' book into an 'excellent' one. Special mention also to Gary Morgan for support and technical assistance above and beyond the call of duty.

I owe everyone a huge debt of gratitude.

As series editor, Nana Poku's enthusiasm for the book has never wavered, despite huge pressures on his own time. I am also immensely grateful for the speed, professionalism, patience and personal support of all those at Ashgate Publishing. Thanks especially to Margaret Younger, Kirstin Howgate, Elaine Couper, Maria Anson, and Michael Drapper. What a team!

Finally, I am very grateful to Andy Clark for allowing me to use his amazing photograph which is on the cover of the book. It perfectly captures the reasons for writing it and points toward the urgency of resolving the problems of all of the adults and children who live with HIV or die of AIDS. Whenever I wavered in my work, the young man in the photograph appeared to be telling me to get on with it. I hope that he has the same effect on all who see him and read this book.

Dedicated to Hannah Doyal and Daniel Wilsher

For your love, support and understanding

Contents

Chapter 1

Posing the Problems

As we pass into the fourth decade of the global pandemic of HIV and AIDS, much progress has been made in understanding it. The retrovirus responsible for HIV has been identified, enabling biomedical therapies to ameliorate the symptoms and extend the lives of many of those who have been infected. However, millions more remain uncared for and uncared about. At the same time the resources available to meet their needs are shrinking as financial storms break over much of the world. If this challenge is to be met we will need to know much more about the economic, social and cultural contexts within which HIV epidemics continue to spread.[1] A broader global policy agenda can then be developed to tackle the preventable inequalities and disadvantages that still constrain the lives of so many HIV positive individuals whether or not they go on to develop AIDS.

Where Are We Now in the Pandemic?

The early history of HIV and AIDS has been well documented (Shilts 1987). It was first identified among gay men in the US and it was quickly linked to what were seen as 'lifestyle factors.[2] The disease became emblematic of a stigmatised sexual identity, with many of those infected being blamed for their own misfortune. No treatment was available and many died extremely painful deaths as the illness ravaged relatively small and close-knit groups. However these experiences did engender high levels of political advocacy by and on behalf of those affected. And, as we shall see, this has continued in various forms as the infection has spread.

The late 1980s brought major changes, with positive developments in the therapeutic arena – but also huge increases in the numbers of those affected around the world. The introduction of antiretroviral therapy (ART) in the form of Zidovudine (AZT) in 1987, followed 10 years later by highly active antiretroviral therapy (HAART), allowed those already infected to 'cheat death'.[3] Though life

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[1] The use of the term 'HIV epidemic' is recommended by UNAIDS as the most inclusive formulation to include both HIV and AIDS (UNAIDS 2011).

[2] Of course it is likely that others were already affected in different parts of the world but they remained almost entirely invisible.

[3] Unless there is a need to be more specific, the general term antiretroviral therapy (ART) will be used throughout the book to refer to the various drugs used for treating HIV.

expectancy remained uncertain, HIV and AIDS could now be treated as potentially separable entities rather than the inevitable continuum implied by the use of the term HIV/AIDS. Thus those who were able to access these new drugs began to rebuild their lives on a reasonably firm basis.

But over the same period the shape and size of the original epidemic had changed dramatically. By the beginning of the new millennium it had been transformed from what was frequently referred to as a 'gay plague' into what more closely resembled a 'disease of the poor'. The vast majority of the 27 million who were now HIV positive were living in middle or low income countries, with sub-Saharan Africa at the heart of what could now be defined as a 'pandemic'. And most were unable to access the drugs that were creating new hope among those infected in the 'global north'.[4]

The significance of this inequity was reflected in the Millennium Development Strategy, which called for universal access to ART by 2010 and a halt to the spread of HIV and AIDS by 2015. Over the following decade this aspirational approach encouraged the creation of many new prevention and treatment developments. This included, among others the WHO's '3 by 5' initiative which focussed on treating 3 million with HIV by 2005 (WHO 2003). However these targets can now be seen as unrealistic. Access to treatment did increase dramatically, with the numbers on ART rising to around 6.2 million in middle and low income countries by 2010. The annual number of new infections declined from a peak of 3.4 million in 1997 to 2.7 million in 2009, while deaths from AIDS-related illnesses also dropped from 2.2 million in 2005 to an estimated 1.8 million in 2010 (WHO, UNICEF and UNAIDS 2011).

However serious challenges remain. Despite the 'roll out' of ART more than half of those in need are still not able to access it. By 2010 around 34 million people were estimated to be HIV positive and 1.8 million died from AIDS during that year (WHO, UNICEF and UNAIDS 2011). But, most importantly, the total number of people living with HIV is continuing to rise as a result of new infections as well as the greater longevity associated with ART (UNAIDS 2012c). For every two individuals currently starting HIV treatment five more are newly infected. This situation poses two major challenges: how to prevent the further spread of HIV and how to support those who are (knowingly or unknowingly) already infected.

The need to slow down the numbers infected has received increasing attention as the gap between available resources and projected needs has widened. However there appears to be no simple solution, and the different types of biomedical, behavioural

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[4] There are now many challenges to be faced in distinguishing between the geopolitical statuses of different countries. The terms 'developed' and 'developing', for example, no longer stand up to critical scrutiny, while 'rich' and 'poor' are often too simplistic. Where collective terms are needed we will therefore use 'global north' and 'global south' where appropriate or high, middle and low income countries as the alternative found in most official documents.