Chapter 1
Introduction and Overview

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In June 1981, a rare form of pneumonia, *Pneumocystis Carinii*, was diagnosed in five young homosexual men in Los Angeles in the United States. The diagnoses were reported in the Morbidity and Mortality Weekly Report (MMWR) (Gottlieb et al., 1981). Other reports began to emerge in the United States of other unusual disease presentations, and Acquired Immune Deficiency Syndrome (AIDS) was named a year later. The report in the MMWR was to be the first reported cases of AIDS in the world. In South Africa, the first two reported cases of AIDS were diagnosed in two male homosexuals and documented in 1983 in the South African Medical Journal (Ras et al., 1983). Following on these and other reported cases and the discovery of AIDS, the agent that causes AIDS was officially named in 1986 as the Human Immunodeficiency Virus (HIV).

It has been over 25 years since the first diagnoses of AIDS and HIV in the world, and the disease, reported in just a few isolated cases in the first days, has spiralled into the biggest epidemic in modern history. Since HIV and AIDS were first discovered, an estimated 65 million people worldwide have been infected with HIV and 25 million people are estimated to have died of AIDS (UNAIDS, 2006). The Joint United Nations Programme on HIV/AIDS (UNAIDS, 2008) estimated that there were a total 33 million people living with HIV in 2007, of which 2.7 million were newly infected in 2007.

HIV and AIDS have been researched, written about, discussed and even denied countless times. There are thousands of articles published dealing with a variety of aspects of HIV/AIDS; there are academic and non-academic journals which are dedicated to reporting on HIV/AIDS, and there are hundreds of books focusing on a multitude of issues relating to HIV/AIDS. So the question that is perhaps asked is, why the need for yet another book? And why focus on South Africa?

UNAIDS (2008) reports that although the HIV epidemic seems to be stabilising in many countries, this is not consistent across regions in the world, with many countries showing an increase in incidence in recent years, including "developed" countries such as China, Germany, Russian Federation and the United Kingdom. The UNAIDS (2008) cautions as to the often cyclical and unpredictable nature of infectious disease epidemics, referring to surprising new outbreaks or increases of epidemics, such as that in the Russian Federation. So, while HIV/AIDS has perhaps

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_1,

been the most researched disease in modern history, it remains a significant global issue and impediment to development, and we need to prepare for any future unpredictable developments. South Africa, located in the epicentre of the global epidemic and with its controversial history of HIV health-care policy, remains an important region for trying to understand the many social, psychological, political and medical factors that play a role in HIV/AIDS.

1.1 The HIV/AIDS Epidemic in South Africa

The emerging epidemic in South Africa in the early 1980s affected mostly the white homosexual population, as was the case in the United States and Europe. As South Africa was transforming into a democracy (in 1994) after 40 years of apartheid government, it began to emerge as the epicentre of the world's HIV/AIDS epidemic, with the predominant mode of transmission being among the majority black African heterosexual population.

Sub-Saharan Africa, and southern Africa in particular, is currently the region most affected by HIV/AIDS in the world. This is reflected by the most recent data released by the Joint United Nations Programme on HIV/AIDS (UNAIDS, 2008):

- Approximately 67% of adults and 90% of children living with HIV in the world are in sub-Saharan Africa.
- There are approximately 22 million people living with HIV in sub-Saharan Africa.
- Three-quarters (75%) of AIDS-related deaths occurred in sub-Saharan Africa in 2007.
- The epidemic has left orphaned approximately 12 million children under the age of 18 in sub-Saharan Africa.
- Thirty-five percent of people living with HIV in the world live in southern Africa.
- South Africa has an estimated 5.7 million of its citizens living with HIV, thus making it the country with the largest number of people living with HIV in the world.

The South African Department of Health conducts yearly studies surveying the prevalence of HIV infection among pregnant women attending antenatal clinics. The Department of Health (2007) estimated an HIV prevalence rate of 29.1% among pregnant women in 2006. Using this data to extrapolate an estimated prevalence of HIV infection among the general population, the Department of Health approximates that 5.41 million people are living with HIV in South Africa. A survey conducted by a consortium led by the Human Sciences Research Council and commissioned by the Nelson Mandela Foundation (Shisana et al., 2005) estimated that the prevalence of HIV infection in South Africa's general population is 10.8%. The survey further suggests that persons aged 20–40 years are the most affected and that the prevalence rate among women is higher than that of men. In addition, generalised

epidemics are also found among young children aged 2–14 years of age and the elderly aged 50 years and older.

The HIV crisis in southern Africa is significant. It has been one of the biggest obstacles to redevelopment in South Africa, as the country has tried to bring about transformation with limited resources. An already inadequate public health-care system in South Africa has been faced with the task of improving its infrastructure while having to cope with the increasing demand of the HIV/AIDS epidemic. The health crisis is also compounded by broader political issues. The official response from the South African government has been nothing but controversial, with the government being accused of AIDS denialism and being seen to be resistant to providing anti-retroviral therapy in the treatment of HIV/AIDS (see Chapter 9).

For many in South Africa, then, HIV/AIDS and the battle for effective treatment has been regarded as a "new struggle" following on from the struggle against apartheid (see Chapter 11). Although there has been an increase in access to antiretroviral(ARV) treatment across the globe, UNAIDS (2008) reports that most people in need of treatment in low- and middle-income countries are not receiving them. For many years, the South African government was seen to be actively blocking access to ARVs. A recent calculation of lives lost as a result of the restriction to ARVs on the part of the South African government (under President Thabo Mbeki) conservatively estimates that more than 330,000 people lost their lives and 35,000 babies were born with HIV due to an ARV treatment programme not being implemented timeously in South Africa (Chigwedere et al., 2008). The effect of this has been damaging to HIV prevention efforts in South Africa. It seems timely then to take stock of what has happened, what has been learnt about what works and does not work, so that we may move forward in trying to effectively address the epidemic in South Africa.

1.2 Southern Africa Within the Global HIV/AIDS Epidemic

While southern Africa may be the region most affected by HIV in the world, other regions in the world (for example countries in South and Southeast Asia and Latin America) are also faced with significantly large and, in some cases, growing epidemics.

In Europe and North America, much has been written about the rise in HIV prevalence among the heterosexual population in recent years. In the United Kingdom, for example, a recent report (UK Collaborative Group for HIV and STI Surveillance, 2007) indicates that the prevalence of HIV has increased significantly since 2000, with the number of new diagnosed HIV infections in the United Kingdom rising by almost 300% in the past decade. For many years the prevalence rate of HIV was highest for men who have sex with men. However, there has been an increasing prevalence rate among heterosexual men and women since 1997, and heterosexuals are now reported to be the predominant transmission group in the United Kingdom (UK Collaborative Group for HIV and STI Surveillance, 2007) as well as central

and western Europe (EuroHIV, 2007). In the United States, prevalence rates remain highest for men who have sex with men, but the prevalence rate among heterosexuals especially among African-Americans and indigenous populations has grown over the years (Centers for Diseases Control and Prevention, 2008). The increase in the United Kingdom and Europe has been partly attributed to immigrants (particularly African and Caribbean immigrants) with HIV, either who have arrived in the country already diagnosed HIV-positive or who have been diagnosed here after their arrival (see, for example, Hamers and Downs, 2004). Much has also been made in the UK media about the rise in HIV among the heterosexual population, with the rise in prevalence rates being attributed to African migrants and the so-called health-migrants who are perceived to be coming to the United Kingdom in order to access free HIV treatment.

With this increase in prevalence among the heterosexual population, research attention has been given to African men and women living with HIV in Europe. For example, in the United Kingdom, there have been calls for research on understanding more about the sexual behaviours and sexual relationships of African men and women living in the United Kingdom (for example, Kesby et al., 2003). The issue is complex; statistics do show that large numbers of those living with HIV in Europe are African men and women. However, there is a slippery slope to pathologising African sexuality in an effort to explain this prevalence, in a way that may fuel what can often be regarded as racist beliefs about African sexuality as different, uncivilised and potentially dangerous (Rohleder, 2007; Wellings et al., 2006). As Kesby and colleagues (2003) caution, cognizance needs to be given to factors such as poverty and racism. The epidemic in sub-Saharan Africa also needs to be viewed in the context of global inequalities to health care, and the controversies around the affordable provision of pharmaceuticals and health treatment by the richer nations of the world, or the "Third World" health dependency on "First World" wealth (MacDonald, 2005). UNAIDS (2008) reports that the HIV epidemic, which impacts on family income and ability to earn a livelihood, is likely to push an estimated 6 million households into poverty by the year 2015; a clear impediment to development.

What is clear is that although southern Africa, and South Africa particularly, faces context-specific issues that impact on the epidemic, concerns and issues about HIV/AIDS in South Africa are global concerns. What happens here has an impact on the rest of the world. Similarly, the local context is profoundly affected by global political issues, including the politics of gender, and the policies of neoliberalism (Susser, 2009). To look at HIV/AIDS in South Africa is also to look at aspects of ways in which a globalised world operates.

1.3 Rationale for this Book

Since the onset of HIV and AIDS, much has been researched and written on the subject internationally and in South Africa, from a variety of disciplines and points of view. As it was realised that preventing HIV infection is not as easy as just educating

people about the risk for HIV and promoting a change in risky sexual behaviours, research began to focus on the various psychosocial factors that were fuelling the growing epidemic. Psychosocial issues around HIV transmission and prevention in South Africa, and internationally, have influenced social science research in this area. Likewise, social science research has influenced how we think about and approach the HIV epidemic, and indeed other health issues. Social science research has allowed us to learn of the various cultural, social, political and psychological factors that were not always considered in biomedical research. UNAIDS (2008) argues that important for moving forward is the need to address issues such as stigma and discrimination, gender inequality and the prevention of new infections. These are all issues that social science research can help understand and address. The ethics of HIV prevention and treatment, and of research into HIV and AIDS, are complicated and highly contested, furthermore (Rennie et al., 2009; Van Niekerk and Kopelman, 2006), and social scientists have a contribution to make to ethical debates.

After over 25 years of the known epidemic in South Africa, it may be useful to consolidate what has been learnt by social science researchers about conducting research and interventions on HIV/AIDS in the context of South Africa. Much has been learnt about the epidemic during this time, about the issues of HIV in social science research, within the socio-political complexities of South Africa. The epidemic is dominating social science research in South Africa, in areas such as health research and anthropology. Furthermore, with the magnitude of the epidemic in South Africa, there has been a large amount of interdisciplinary and international collaborations in social science research in HIV/AIDS.

However, much of this research and the lessons learnt remains fragmented. Literature is published in a variety of academic and popular journals, books and other forms of media. In putting together the lessons learnt about various psychosocial aspects of the HIV epidemic into one volume, this book aims to provide a valuable resource for future researchers and academics, and those who are interested in learning more about the various psychological, social and political aspects of HIV and AIDS in South Africa.

Because South Africa is at the epicentre of the HIV/AIDS epidemic, South African concerns are global concerns, and lessons learnt in South Africa are lessons for the international community. South Africa offers a particularly useful site for consideration of the value of psychosocial approaches to HIV/AIDS, combining as it does a sophisticated research infrastructure with good international connections with all the psychosocial problems and challenges associated with widespread poverty and development challenges.

1.3.1 Overview of the Book

The book takes a look at various psychological and social issues related to the epidemic, contextualising it to the South African experience. The book focuses on what

has been learnt by social sciences, as well as lessons learnt in collaborative multi-disciplinary and international research. The book will also look at emerging areas of research in South Africa with regard to the continuing epidemic. In looking at these areas, the book also aims to try and understand and get a sense of what has worked and not worked in research and interventions.

The various chapters in the book will

- review some of the international and national literature related to specific topics, including the authors' own work;
- identify the main issues and key debates related to the various topics, in the context of South Africa;
- where relevant, chapters will identify successes and challenges and lessons learnt in conducting research in the South African context. In some cases this will also look at international or multi-disciplinary collaborations; and identify any possible areas of future research.

The book is divided into four broad sections, focusing on different aspects of the epidemic, and focus areas of research.

Part I will be concerned with psychosocial issues relating to HIV transmission in South Africa. This section starts with a chapter (Chapter 2) on the social–cultural context of the epidemic in South Africa. This provides a context in which many of the further chapters are read and highlights some of the key social–cultural issues that are discussed more in depth in future chapters. Sexual relationships are key in the ongoing transmission of HIV, and Chapters 3 and 4 will go on to look at the role that gender plays in the transmission of HIV. This is a very broad field, and the separate chapters focus on HIV and women (Chapter 3) and HIV and masculinity (Chapter 4). As reports by the UNAIDS indicate, youth and children are significantly affected by the epidemic, and Chapters 5 and 6 explore youth and infants and children, respectively. Chapter 7 looks at dynamics of poverty and HIV/AIDS, critically looking at whether poverty is a determinant or a consequence of HIV/AIDS. The final chapter in this section (Chapter 8) looks at the role that social stigma plays in maintaining the HIV epidemic, and the issues around considering stigma in research and in interventions.

Part II will be concerned with HIV/AIDS prevention and treatment issues and projects in South Africa – what has been done, what has been learnt and some new directions in these fields. South Africa provides an interesting context in this regard, having a controversial political history in its governmental response to the epidemic. Some of this context is explored in different chapters. Chapter 9 is a critical analysis of AIDS denialism on the part of the South African government under the leadership of Thabo Mbeki. This chapter is complemented by Chapter 10, which looks at local-level responses to HIV/AIDS, focusing on the organisation, coordination and effectiveness of local-level responses, and a chapter on the history of social movements in HIV (Chapter 11). Chapter 11 looks at various social movements developed to address various crises of HIV/AIDS, for example, the combating of stigma and the provision of support for those affected. This chapter also looks at

the development of social movements in response to the politics of HIV treatment and the South African government's reluctance for many years in providing of antiretroviral (ARV) treatment to HIV-positive individuals. Chapter 12 focuses on voluntary counselling and testing (VCT) in the care and treatment of HIV and uses a case study to explore the scaling up of VCT services. A large focus of the prevention of HIV infection has been around preventing the vertical transmission of HIV from mother to child, which is discussed in Chapter 13, looking at various psychological factors as well as particular issues involved in mother-to-child transmission (MTCT) programmes. In Chapter 14, structural interventions for HIV are discussed, looking particularly at the important issue of nutrition and food security and its link to HIV/AIDS. The last two chapters in this section look at community-level responses to managing HIV/AIDS, looking particularly at how communities can be supported in responding to the epidemic (Chapter 15) and the role of religion and spirituality, and religious-institution-based responses to the epidemic (Chapter 16).

Part III is a short section but has as its focus persons living with HIV/AIDS. In the first chapter (Chapter 17), a narrative voice is given to the experience of living with HIV, using words of HIV-positive persons themselves. This provides an important personal voice to people who are otherwise objects of research. In Chapter 18, consideration is given to the importance of positive prevention – prevention interventions for persons living with HIV.

Part IV, the final section to the book, will explore some of the new agendas for research that are being developed in South Africa on issues relating to HIV/AIDS. These might not be exactly "new" concerns, but are areas that have been identified as possibly under-researched or as emerging issues for research. Chapter 19 is from a collaboration of international authors looking at how HIV/AIDS affects persons with disabilities, a population vulnerable to HIV infection that has been largely overlooked. Chapter 20 looks at the issue of HIV/AIDS and prisons in South Africa. Prisons have been identified as having higher HIV-positive populations than the general population, yet, in South Africa, there is little known or researched about HIV/AIDS in prisons. The next two chapters provide a social science perspective on new and future biomedical interventions. In Chapter 21, the authors look at the issue of male circumcision and recent findings that suggest circumcision helps prevent the transmission of HIV. As in many other areas of HIV research, the issue of male circumcision is complex for social scientists, and the chapter in this book forms part of a broader debate about how we should act on this new and important evidence (Connolly et al., 2008; Eaton and Kalichman, 2007; Kalichman et al., 2007). Chapter 22 focuses on the development of an HIV/AIDS vaccine, and issues around recruitment and participation in HIV vaccine and microbicides trials. In the final chapter of the book, Chapter 23, the authors look at HIV and mental health, looking both at mental disorders as possible risk factors for HIV and at the mental health consequences of having HIV/AIDS.

The book has attempted to reflect the diversity of perspectives, by including authors from various disciplines, such as psychology, anthropology, economics, social work, public health and medicine. We have also invited authors from different parts of the world, in the hope of capturing some of the collaborations between

international and local researchers and voices from the social sciences. While the book is wide in scope, it can never cover everything, and important issues, while touched on in some cases, cannot be fully explored. Much still needs to be learnt, and we hope that this book can serve as a starting point for the development of future research and interventions.

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